GENETIC NORMALCY AND THE NORMALCY OF DIFFERENCE. GENETIC DEAFNESS RESEARCH IN 20TH CENTURY AMERICA

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ABSTRACT

Is deafness a defect to be prevented by genetic technology or merely a non-pathological variation that has given rise to a sociocultural minority? Is it ethical to prevent the birth of a child with deafness? Are deaf parents acting immoral if consciously choosing a deaf child? Over the last 100 years, geneticists' attitudes on these questions have shifted from a clearly medical-pathological definition to acknowledging Deaf culture and the Deaf community, conscious of the potential 'genocidal' impact of reproductive technology.

To understand why, by the end of the 20th century, geneticists and associated professions have “gone native” and identified with Deaf culture while neurologists or audiologists continue to consider deafness a grave neurological disability, this thesis analyzes how different professional paradigms have shaped perceptions of deafness, and how different scientific communities have – or have not – interacted with deaf individuals and deaf communities. From the late 19th century triumph of oralism – the practice of teaching lip-reading and speech at the exclusion of sign language –, with its strong ties to medical and eugenic prevention, this thesis explores the emergence of alternative perceptions of deafness among geneticists and other professionals concerned with hereditary deafness. Particularly important is the influence of psychologists and (genetic) psychiatrists in defining the abilities and pathologies of deaf people, as well as in shaping practices of family and genetic counseling.

Research of and attempts to prevent hereditary deafness reflect changing ethical and cultural norms that define who is considered normal, disabled or different, a good citizen or a burden to society. Negotiations over deafness as disability or difference are an integral part of 20th century debates over citizenship, national
identity, and overcoming otherness. Tying together the history of disability, psychology, psychiatry, eugenics and genetics, this thesis deconstruct the norms and paradigms that have and continue to shape the ethics of genetic research and reproductive counseling.

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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>v</td>
</tr>
<tr>
<td>I. Introduction</td>
<td>1</td>
</tr>
<tr>
<td>II. Progressive Science, eugenics and educational reform:</td>
<td>24</td>
</tr>
<tr>
<td>(Hereditary) Deafness research in early 20\textsuperscript{th} century America</td>
<td></td>
</tr>
<tr>
<td>III. Educational perfection and hereditary prevention. Research and</td>
<td>112</td>
</tr>
<tr>
<td>counseling at the Clarke School in the 1930s and 40s</td>
<td></td>
</tr>
<tr>
<td>IV. Big Science; a small school. The expansion and diversification</td>
<td>154</td>
</tr>
<tr>
<td>of genetic deafness research in the 1950s and 1960s</td>
<td></td>
</tr>
<tr>
<td>V. Between pathology and particularity. Genetics and deafness</td>
<td>233</td>
</tr>
<tr>
<td>at the New York State Psychiatric Institute, 1955 to 1969</td>
<td></td>
</tr>
<tr>
<td>VI. Genetic and emotional risk; self-finding and self-surveillance.</td>
<td>317</td>
</tr>
<tr>
<td>The case of Usher Syndrome</td>
<td></td>
</tr>
<tr>
<td>VII. Genetic awareness, neutrality and empowerment. The rise of</td>
<td>410</td>
</tr>
<tr>
<td>culturally sensitive counseling 1960-1990</td>
<td></td>
</tr>
<tr>
<td>VIII. Conclusion</td>
<td>507</td>
</tr>
<tr>
<td>IX. Bibliography</td>
<td>528</td>
</tr>
<tr>
<td>Curriculum Vitae</td>
<td>555</td>
</tr>
</tbody>
</table>
I. Introduction

In 1883, Alexander Graham Bell presented a speech to the U. S. National Academy of Sciences titled *Memoir upon the Foundation of a Deaf Variety of the Human Race*. Bell is most famous for his invention of the telephone, yet he was also active in the eugenic movement and probably the most influential figure in deaf education during the late 19th and early 20th century America. He combined these interests in his study of the marriage patterns of deaf people and of the hearing status of their children. Deaf people, he noted, tended to marry each other. This habit not only separated the deaf and the hearing socially, but had potential biological consequences too. Bell believed deafness to be hereditary in many cases; deaf intermarriages thus passed on hearing loss to the next generation. In the long term, it might even lead to the creation of a deaf subspecies. Such a “defective race of human beings,” Bell believed, “would be a great calamity to the world.”¹

In deaf education, Bell pursued a policy called oralism, the teaching of speech and lip-reading. In the late 19th century, oralism seemed to be the method of the future, employing scientific methods to achieve the modern miracle of teaching speech to the deaf. Advocates of oralism wanted it to replace manualism, or the use of sign language that had been considered the most effective educational tool by an older generation of teachers. Sign language also was one of the main traits of the deaf community that had formed since mid-century, organized in a myriad of clubs, churches, professional and recreative organizations. They were one of many American minorities that saw no contradictions in being US citizens while being part of a specific subculture. By the late 19th century, nativist sentiments and evolutionary

thought cast suspicion on sign language and deaf culture, and contributed to the acceptance of oralism as an assimilatory and curative technique. The fervent debate over the right methods in deaf education mirrored larger changes in understanding the nature of thought and language, the meaning of being human, of minorities maintaining their independent identities or assimilating into larger society. It also had an explicitly eugenic dimension. For Bell, oralism was not only an educational tool, but also a eugenic solution. Enabling the deaf to speak would end their separatism and integrate them into hearing society. It would discourage deaf intermarriage and thus avert the danger of a deaf race. Bell's combination of oralist principles and eugenics shaped both the course of deaf education and heredity research into the mid 20th century, instilling in professionals a long-lasting fear that deaf people’s marriage habits would lead to an increase in deafness.²

Over a century after Bell's Memoir, in 2003, geneticist Walter Nance confirmed Bell's fears, in a modernized way. By then, geneticists had identified several hundred forms of genetic deafness. Yet there was one form of recessive deafness – caused by a deficiency in the protein connexin 26 – that was responsible for half of all genetic cases in the US. This had not always been the case. Nance's analysis of population data had shown that deaf people's endogamous marriage patterns apparently had increased the frequency of connexin 26 deafness over the course of the last 200 years. Indeed, the establishment of residential deaf education in the early 19th century, and, in turn, the development of deaf communities and

identities seemed to have played a role in this process, providing a marriage pool of people from the same sociocultural and linguistic background.³

Yet for Nance, this development was no calamity. “[U]nless we are also prepared to abolish racial and ethnic homogamy,” the practice of marrying within one’s social or ethnic group, he wrote, “there would appear to be no rational genetic basis for prohibiting marriages among the deaf.” Moreover, where Bell had feared the creation of a deaf race, Nance feared the effects of modern genetic technology on the deaf community. He asked, “[w]ill future critics view this [development] as one of the medical triumphs of the 21st Century, or as an egregious example of cultural genocide?” Yet as much as the unreflected use of genetic technology posed a threat to the Deaf community, he believed that it had also the potential to “provide empowering knowledge to the deaf community.” Namely, it could provide deaf couples with information whether their unborn child would be deaf or hearing.⁴ Thus, where Bell envisioned eugenics as a tool for preventing deafness and integrating the deaf into hearing society, Nance imagined geneticists as allies in the preservation of Deaf culture and community.

Deafness remains a highly polarizing trait. Roughly, opinions fall into the two camps I just sketched out: Deafness as a severe and disabling pathology, to be prevented and cured (the medical-pathological model), or deafness as the valued trait of a cultural and linguistic community worth preserving (the sociocultural minority

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⁴ Nance, Genetics of deafness, 109, 116.
model). The latter is often denoted with a capital D.\(^5\) How American heredity researchers have come from considering deafness a grave pathology and deaf people's reproductive habits a threat, to considering genetic technology a threat to Deaf culture will be the theme of this dissertation. To explore this question, I will track changing beliefs on the meaning of deafness, the nature, abilities and social position of deaf people, the changing meaning of genetic knowledge, and the circumstances of its research and application in the US from the late 19\(^{th}\) to the late 20\(^{th}\) century.

My analysis rests on a variety of published and archival sources, including a vast literature on deafness and heredity, including articles and monographs, conference reports, memoirs, journals and institutional reports. While I focus on developments in the US, research of genetic deafness was an international phenomenon and wherever possible and useful, I included non-American sources, perspectives and approaches, in particular where research was influenced by European emigrants. Next to some smaller archival holdings at the University of Kansas, the Rochester Institute of Technology and Vanderbilt University, the archives of the Clarke School for the Deaf in Northampton, MA, and Gallaudet University in Washington, DC, have been particularly useful resources, as together they represent the range and extent of deaf history in 20\(^{th}\) century America. Finally, I have also been able to conduct a small number of focused interviews with geneticists, counselors and

\(^5\) This is a recent convention, suggested in 1972 by linguist James Woodward, that has become widely used since. I will use Deaf for the time period in the later 20\(^{th}\) century when actors used it themselves, and when the identities in question are sufficiently clear and unambiguous. Deaf Studies established itself as an academic field in the 1980s, with the goal to explore the range and variety of Deaf culture. For some of the first monographs see Padden, Carol and Tom Hummphries. 1988. *Deaf in America: voices from a culture*. Cambridge, Mass: Harvard University Press. In the 2000s, the field has proliferated. See e.g. Deaf Studies Think Tank, and H-Dirksen L. Bauman (ed.). 2008. *Open your eyes deaf studies talking*. Minneapolis: University of Minnesota Press; Ladd, Paddy. 2009. *Understanding deaf culture: in search of deafhood*. Clevedon: Multilingual Matters. Most recently, a volume on Deaf Gain explores the various traits that Deaf culture contributes to human diversity. See Bauman, H-Dirksen L., Joseph J. Murray et al. (eds.). 2014. *Deaf gain: raising the stakes for human diversity*. Minneapolis: University of Minnesota Press. Also see the work of (hearing) psychologist Harlan Lane. Lane, Harlan. 2002. “Do Deaf People Have a Disability?” *Sign Language Studies* 2 (4): 356-79.
psychiatrists. As interesting and necessary interviews with d/Deaf professionals and objects of research and counseling would have been, they are beyond the scope of this thesis, and better left to someone more fluent in American Deaf culture.

Questions of heredity, pathology and reproductive autonomy were negotiated between deafness professionals and their objects of research or education. The division between hearing professionals and deaf patients or service recipients was almost absolute in the first half of the century, and dissolved in the second half. I will show that the reasons for this dissolution were complex: they included the demands of deaf people for inclusion, access and autonomy; a general cultural shift toward acknowledging and valuing differences in sex, gender, race, ethnicity, and ability; the rising influence of the psycho-sciences in defining self, society, illness and health; an ever more refined understanding of the mechanisms of genetics; and the evolution of values and identities within the professional communities of genetic research, counseling, and education. A history of genetic deafness thus also is a cultural history of identities and ideals of citizenship, political ideologies and social movements, and not the least of the development of health and disability activism as a form of social and professional identity. What, I ask, could professionals gain from aligning themselves with a medical-pathological or sociocultural definition of deafness, and what do their positions and alliances tell us about the role of science in society, in defining disability, disease, and suffering, ethnic, cultural and genetic diversity?

A history of genetic deafness research and counseling, of the (ab)normalcy of genetic difference is necessarily and profoundly interdisciplinary. I draw from the history and sociology of science and medicine, of childhood and education, disability and Deaf history and studies. Not all of these fields have been equally in conversation with each other, yet they all share an interest in the role of science in society, of the
authority of scientists versus the autonomy of the individual, and the meaning of
difference, disease and disability.

Heredity research will receive the main, although not exclusive attention of
the sciences covered in this thesis. That deafness had a hereditary component had
long been clear. Deaf children born to deaf parents, or multi-generationally deaf
families were visible proof that hearing loss was passed on inter-generationally. At
least since the middle of the 19th century, and certainly since Bell's Memoir,
hereditary deafness was cause for anxiety and scientific inquiry. Deaf people
themselves appear to have been less concerned than educators, school administrators,
physicians, eugenicists or population scientists. These concerns often concentrated on
schools for the deaf. As the place where (applied) heredity research intersected with
other educational or scientific approaches to deafness, they will take a prominent role
in my story.

The history of eugenics and genetics has expanded enormously in the last 30
years. It is a field between traditional history of science, unfolding among scientists
in laboratories and research institutions, and social and cultural history, exploring the
sociocultural determinants and values of applied heredity research. While I trace the

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6 For some of the early historiography that focuses on scientists as its main actors, and is a cross
between intellectual history and classical history of science see Ludmerer, Kenneth M. 1972.
*Genetics and American society: A historical appraisal.* Baltimore: Johns Hopkins University Press;
Kevles, Daniel J. 1997. *In the name of eugenics: genetics and the uses of human heredity: with a*
Press. More recent work has focused on women, gender and reproduction, social and ethnic
minorities, medicine and public health, or, most recently, disability. See e. g. Stern, Alexandra
Minna. 2005. *Eugenic nation: faults and frontiers of better breeding in modern America.* Berkeley,
*Sterilization, and Abortion in Public Health and Welfare.* Chapel Hill: University of North Carolina
Press; Comfort, Nathaniel C. 2012. *The science of human perfection: how genes became the heart*
Pushful Days: Time and Disability in the Age of Eugenics.” *Health and History* 13 (2): 43-64. The
work of Adam Turner at the University of Oregon is exploring the role of parent of disabled
children and genetic counselors. For an impression of the variety of eugenic thought, and breadth of
scholarship see Bashford, Alison, and Philippa Levine (ed.). 2010. *The Oxford Handbook of the*
expanding knowledge and practices of hereditary deafness research throughout the century, my approach nevertheless is closer to the sociocultural strand. I thus use changing thought and knowledge about deafness and heredity as a proxy for understanding changing notions of citizenship and the meaning and value of (pathological?) difference and normalcy.

The relationship between eugenics and human genetics, the (degree of) continuity of eugenic thought in current genetic technology, and the possibility of a “home-made” eugenics remains a much-discussed topic among historians, geneticists, bioethicists and, not the least, those with a genetic condition. Among deaf people, certainly, the work of Alexander Graham Bell, and the eugenic campaigns of the early 20th century have left a lasting impression of being the target of restrictive biopolitics. While an older generation of historians drew a clear line between eugenic pseudoscience and (medical) genetics – the one biased in its targeting of social minorities, the other intent to reduce suffering – more recently historians have blurred this line. Not the least, they have pointed to how widespread, varied and long-lasting eugenic thought was beyond those professionals strictly considered eugenicists. Dissolving the clear division between scientists and objects of eugenic policies, this more recent historiography has explored the variety of groups and populations targeted by eugenic policies and engaging with eugenic thought.\footnote{For the older position see e.g. Ludmerer, Genetics; Cowan, Ruth Schwartz. 2008. Heredity and hope: The case for genetic screening. Cambridge, Mass.: Harvard University Press. Kevles also takes this position, yet also warns about the possibility of individualized and consumerist eugenics in the present. See Kevles, Eugenics. Comfort has traced the ties between eugenics, medical genetics and public health throughout the 20th century, and Schoen made visible the long history of sterilization practice, yet also the vast variety in its application. See Comfort, Perfection; Schoen, Choice.}

Although it will contribute to these historiographies on the variation of eugenic thought and practices, it is not the goal of this thesis to arrive at a definite definition of eugenics, of where or whether it ended. Rather, I'm interested in debates
on heredity and deafness to explore the motives and goals of those involved, to trace how they drew the lines between pathological and normal states, defined disability, suffering and disease, and how exchange with other disciplines, or with the objects of research influenced definitions. I thus pursue a history of ideas and cultures as much as of scientific practices. In the history of medicine, the work of George Canguilhem has been particularly influential in addressing these questions. In particular, his explorations on norms and average from different professional angles, and later reflections on more recent developments in science and medicine have provided important insights. Disability studies and bioethics have also contributed to deepening our understanding of normalcy, pathology and suffering, albeit in often conflicting ways. While bioethicist try to find generally valid principles as guidelines for medical practice, disability studies is concerned with deconstructing such apparently eternal, natural or universal definitions. Thus, debates over reproductive autonomy and genetic technology have produced a large body of scholarship, although one that is far from coming to any conclusion on what and what not is ethical or normal. Rather than taking a bioethics approach, I side with historians of medicine and disability in exploring the sociocultural determinants of what is considered suffering, pathology or normalcy in the first place.

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To understand changes in our understanding of these categories, we also have to address the meaning genetic knowledge took in different times and places, among different scientists and, as far as sources allow, their objects of research. Looking at the different contexts, institutions and individuals discussing heredity reveals a rich pattern of overlapping beliefs regarding capability, agency and malleability. Yet often, histories of heredity have focused on questions of heredity and environment, or of genetic determinism vs. the theories that emphasize the influence of culture. Thus, focusing on debates over racism and feeble-mindedness, historians have pointed to the genetic or biological determinism dominant in the first half of the century and how it was challenged by more sociocultural explanations of identity and behaviors in the 1950s, after the atrocities of World War II. Yet the history of genetic deafness research does not fit this narrative. In this, I would argue, it is exemplary rather than exceptional. The sociocultural and psychosocial models emerging in the 1950s and ’60s tempered yet also reinforced biologistic thought. They imbued genetic knowledge with a new sense of identity and selfhood that relativized definitions of pathology and worth, yet reinforced the notion that genetic awareness is a crucial life skill and part of our identity.

The impact of psychology and psychiatry in developing such notions of identity, citizenship and heredity has been only partly explored. Looking at the links

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between heredity research, eugenics, psychology and psychiatry, historians have mainly focused on defining mental deficiency and the feeble-minded, on the institutions that treated or contained the individuals labeled as such, and the social policies that restricted their rights. I go beyond these narratives, pointing to the role of psychology in defining the social position and abilities of deaf people, and simultaneously, in shaping the development of genetic counseling and in circumscribing the meaning of genetic knowledge. In the early 20th century, the young science of psychology, rooted in older philosophical thought, shaped ideas about the relationship between thought, language and perception so important for perceptions of deafness, and more generally for definitions of citizenship, intelligence and psychopathology picked up in eugenic discourse. In the second half of the century, psychology was influential not only in reconfiguring notions of genetic counseling as a form of psychotherapy, but also as a science at the core of redefining disability as a condition shaped by social dynamics as much as by innate defect.

Historians and sociologists of 20th century medicine, but also of education and childhood have used the concept of medicalization to describe the phenomenon of bringing into the realm of medicine conditions and behaviors previously not considered a medical problem. Deafness at once fits and challenges this narrative. Before the 19th century, deafness (and more generally disability) was mainly a matter of charity, and an educational, moral or religious problem. Indeed, in some places and communities, deaf people were not considered remarkably different at all. Certainly,

attempts to cure or alleviate hearing loss are not peculiar to modernity, but it was only with the development of secularized, industrialized societies during the 19th century that disability came to be considered a backward condition to be fixed by scientific progress.\textsuperscript{12}

By the late 19th century, an ever-growing number of disciplines had made deafness the topic of systematic scientific study. Scientists, physicians, educators and other professionals concerned with deafness could agree that deafness was a pathological condition and a grave disability, yet with increasing specialization could not find a consensus on what exactly its disabling and pathological effects were. Thus, I argue, by the early 20th century, there had developed professional clusters with different, potentially conflicting paradigms about how to best cure, alleviate, or prevent deafness, and to improve the individual and social position of deaf people. These clusters can be understood as thought collectives developing specific styles of thought, as suggested by physician-historian Ludwig Fleck and other historians of science since. Such thought collectives, Fleck argued, shaped how its members perceived new information and how it was incorporated in an existing corpus of knowledge. Beliefs about deafness moved within such thought collectives that were

\textsuperscript{12} Medicalization theory has been advanced in particular by philosopher Ivan Illich and sociologist Peter Conrad. See Illich, Ivan. 1976. \textit{Medical nemesis: the expropriation of health}. New York: Pantheon Books; Conrad, Peter, and Joseph W. Schneider. 1980. \textit{Deviance and medicalization: from badness to sickness}. St. Louis: Mosby; Conrad, Peter. 2007. \textit{The medicalization of society: on the transformation of human conditions into treatable disorders}. Baltimore: Johns Hopkins University Press. Historians of disability and deafness have – implicitly or explicitly – used medicalization theory. Douglas Baynton, for example, has explored the transformation of notions of disability under the impact of industrialization and evolutionary thought. See e. g. Baynton, Douglas C. 1992. “‘A silent exile on this earth’: The metaphorical construction of deafness in the 19th century.” \textit{American Quarterly}. 44: 216-243. Branson and Miller have argued that the normalizing force of science and medicine turned deafness into a disability in first place. See Branson, Jan, and Don Miller. 2002. \textit{Damned For their Difference: The Cultural Construction of Deaf People as Disabled : A Sociological History}. Washington, D.C.: Gallaudet. Although her source material is somewhat unreliable, Nora Groce argues that deafness was not considered a disability on the Island of Martha's Vineyard, where during the 19th century there was an unusually high number of deaf people, and was only medicalized later, See Groce, Nora Ellen. 2003. \textit{Everyone here spoke sign language: hereditary deafness on Martha's Vineyard}. Cambridge, Mass: Harvard University Press.
highly selective in integrating scientific results, sociocultural influences, and, indeed, perspectives from deaf individuals and communities itself.\textsuperscript{13}

In doing so, professionals not only formed alliances with those in other disciplines, but also with parents, patients and objects of research, disability, deaf or health activists. Such alliances offered different ways of portraying and establishing professional authority as a form social engineering, neutral science, curative medicine, or, particularly in the last third of the century, as part of a larger movement for health justice and minority rights. Professionals contributed to and drew from a growing body of knowledge of deafness, although this was not a uniform set of facts and beliefs. As, during the 20\textsuperscript{th} century, knowledge about (genetic) deafness expanded immensely, so did interpretations of this knowledge, relativizing any consensus about the meaning of deafness, of what to do with the results of research.

I tie the history of science and medicine to disability and Deaf history and studies. Although concerned with similar questions and topics, these fields have not necessarily had a close or harmonious relationship. Disability and deaf studies are closely tied to the social movements that engendered them.\textsuperscript{14} This has three important

\textsuperscript{13} Fleck, Ludwik. 1979. \textit{Genesis and development of a scientific fact}. Chicago: University of Chicago Press. Harwood, for example, has demonstrated such thought collectives for German genetics. See Harwood, Jonathan. 1993. \textit{Styles of scientific thought: the German genetics community, 1900-1933}. Chicago: University of Chicago Press. As I trace coexisting thought collectives Fleck's theories are more fitting than the work of Thomas Kuhn who has suggested a progressively dynamic theory of scientific revolutions. See Kuhn, Thomas S. 1970. \textit{The structure of scientific revolutions.}

consequences: The first is a lingering suspicion of medical and scientific establishment as institution that have engendered and are perpetuating pathological definitions of disability, and restrict the abilities and autonomy of disabled people. This suspicion often expands to the history of science and medicine and is exacerbated by the desire to establish disability and Deaf history / studies as independent academic fields. Nevertheless, there has also been fruitful collaboration blurring disciplinary boundaries, especially in a younger generation of scholars, with whom I identify.¹⁵ The second consequence is a strong focus on two periods, namely that of eugenics in the first third of the 20th century, and of activism in the last. These works have added much to our understanding of these periods, yet they have neglected changes in mid-century America that were crucial for redefining the meaning of disability, difference and normalcy, and for reshaping the role of disabled or deaf individuals in society.¹⁶


The third consequence of the close ties between disability and Deaf activism and scholarship is that Deaf and disability studies / history have largely developed as separate fields. The former has been concerned with exploring the history, culture, and language of a minority that predominantly rejects the label “disability; the latter with actively embracing and transforming this identity. Yet in exploring the history of genetic deafness with its variety of actors' perspectives, these rather presentist divisions are hard to maintain. I thus place myself with more recent scholarship that has explored the overlap between deafness and disability, and more generally the intersectionality between ethnic, racial, social, and gender identities. Not the least, this approach allows a more nuanced understanding of the overlap of activist, reformer and professional identities.17

One thing that both Deaf and disability history have in common is a strong emphasis on exploring the lives, opinions and perspectives of deaf and disabled individual as populations neglected by other schools of historiography. This scholarship has produced much-needed insight in how disability and deafness has been hidden, obscured and made invisible, and of who, in first place, was considered disabled. While I am too interested in these questions, I deviate somewhat from a classical deaf or disability history approach. Rather than providing an inside look at the beliefs of American deaf people on heredity, eugenics and reproduction – a position for which I am ill-qualified as a hearing German – I focus on the sciences and professions who defined (and restricted) deaf people's autonomy and identity in relation to these topics in the US. Yet as much as possible, I trace the disappearance, absence and reintroduction of deaf professionals and perspectives, of points of contact

and encounters between hearing professionals and deaf people, and of the dissolution of this division.\textsuperscript{18}

Thus, at least for the first part of the 20\textsuperscript{th} century, this is a story in which deaf people appear mostly as idealized citizens, innocent children, or deviant individuals, as defined by hearing professionals. In professional discourse, the very existence of a vibrant deaf community was at best a non-topic, if not cause for anxiety. The perspectives, input or opinions of deaf people themselves are mostly absent, mirroring their position in society and respective of hearing professionals. And yet, historians of deafness have shown that throughout the century deaf people were an exceptionally well-organized minority. They built an effective local and national network of self-help and advocacy for protecting the rights and interests of deaf individuals. These claims for the autonomy and independence of Deaf culture and community met with various degrees of success and acceptance in hearing society at different times and places. Often, historians have assumed a direct correlation between the degree of activism and social acceptance.\textsuperscript{19} Yet this is a simplistic assumption.

A history of genetic deafness research and adjacent professions can help explain some determinants of success for social movements in American society. While historians of deafness have mainly focused on inside accounts of Deaf consciousness and activism, I will analyze scientific and professional discourse on deafness and deaf people to address why at certain places and times, certain forms of identity, certain minorities and cultures find larger societal and / or scientific support.


\textsuperscript{19} For this position see e. g. Jankowski, Katherine. 2013. \textit{Deaf empowerment: emergence, struggle, and rhetoric}. Washington, D.C.: Gallaudet University Press.
Thus I hope to provide explanations of why some professions align with a medical-pathological, others with a sociocultural minority approach to deafness – and how we have come to draw a stark dividing line between these models in first place. Moreover, addressing the role of social activism among scientists, I offer an analysis of different models of professional authority vis à vis targets of research. Family, marriage and reproduction have been highly emotional and controversial arenas in this regard and make excellent topics for exploring the agency and insight that professionals were willing to grant, or which deaf individuals were able to claim.

This dissertation tracks the emergence of more varied, and less pathological perceptions of deafness and deaf people, and of more interactive relationship between hearing professionals and deaf constituents. It is structured as a series of connected case studies of different institutions that realized hereditary deafness research throughout the 20th century. Chapters are organized roughly chronologically, moving from the the first third of the century, with its Progressive-era reform projects, oppression of deaf culture and identities, and of state-enforced, population-oriented eugenics to the diversification of opinions in midcentury America, and to the individualized genetic services and visibility, if not acceptance of Deaf culture at its end.

I begin my analysis in chapter 2 with a survey of the background of deafness research and education in late 19th and early 20th century America, pointing to the intersection of eugenic thought and progressive reform. Oralism was part of this endeavor, defining deaf students' pathology in order to normalize them through the promising new sciences of psychology and childhood studies, eugenics or audiology. Here, I also set up the ties between evolutionary and eugenic thought, notions of citizenship, language and the meaning of being human as they played out in debates
over the targets of eugenic and educational measures. Unlike many other such populations – such, as, foremost, “the feeble-minded” – the deaf were not usually considered beyond salvation through education and social reform, or incapable of insight into regulating their reproductive behavior. Not the least, this public image was due to the success of deaf individuals and organizations in portraying themselves as rational, productive citizens embracing the ideals of progressive reform.

Chapter 2 also introduces the Clarke School for the Deaf in Northampton, Massachusetts as a leading institution in oralist education – and as the leading institution pursuing hereditary deafness research in the first half of the century. Its research department, established in 1928 with divisions for psychology, phonetics and heredity, operated in the spirit of progressive reform movements that aimed to standardize childhood development, increase the efficiency of education and bring public health measures to schools to cure and prevent disease and disability. For this goal, the school employed outside researchers, who shared their belief in progressive science. Yet there were also significant dissonances between the approaches and beliefs of the Clarke School and those outside scientists employed in their research department. Psychology research in particular undermined basic oralist assumptions, as it defined the deaf as a minority living in their own social and phenomenological world. These were the origins for professionals engaging with a sociocultural minority model of deafness during the 1950s and 60s; and the fact that they developed at an oralist school is unexpected, even ironic. After all, it was the declared goal of the Clarke School to counteract the formation of a separate deaf community, and to assimilate the deaf into hearing society as completely as possible. Yet this
development also demonstrates the variety of beliefs and approaches outside of the oralist framework that has been the focus of historians.

Education and eugenics have often been portrayed as antagonistic. Mass education is at the core of liberal democracies; it is to uplift and transform the individual into good citizen, and have a democratizing and equalizing effect. Eugenics, on the other hand, is often associated with an elitist biological determinism that condemns large parts of the population as unfit for improvement and civic participation. Yet the Clarke School, chapter 3 demonstrates, combined a vision of transforming the deaf child into a full citizen, and of preventing deafness in the following generation. Heredity research, counseling and education were part of the school's educational, paternalistic mission to normalize deaf students, and by eugenic intervention, their offspring. Yet daily interaction with students and the strong belief in deaf people's educability and inherent normalcy counteracted the biological determinism that often characterized eugenic intervention.

By looking at the unfolding of heredity research and counseling in a school setting, I thus offer a comparison to more established accounts of eugenics in institutions for the mentally ill or disabled, or in the emerging heredity clinics of the 1940s. The school’s holistic combination of eugenic and oralist thought rested heavily on Alexander Graham Bell’s approach, and it conflicted with more reductionist approaches to heredity. Thus, although there was a seemingly harmonious alliance between eugenics and oralism, based on the shared goal of preventing deafness in future generations, a closer look at the goals of school staff and outside scientists also reveals significant differences in methods and beliefs.

The 1950s and ’60s were a watershed moment in genetic deafness research. The introduction of computerized data analysis and more sophisticated approaches to
population genetics finally allowed for a better understanding of the data that had seemed so puzzling only a decade before. Yet this very development also brought a weakening of the alliance between oralist educators and geneticists. In chapter 4, I will show the erosion of this relationship by example of a new research project the Clarke School undertook with the NIH. Whereas before both educators and geneticists had agreed that two deaf people were best not to marry and procreate, now geneticists could offer a more sophisticated prognosis. Focused on reproduction rather than oralist assimilation, they were keen on presenting genetics as an enabling rather than as a restricting profession – a narrative that echoed with contemporary changes in mid-century genetics at large.

Chapter 4 is the first of three that examine the 1950s and 60s as a crucial period in changing perceptions of disability, deafness, and minorities alongside changing goals and paradigms in genetics and genetic counseling. In this, I corroborate narratives in the history of genetics that describe these changes and deviate from those established in the history of deafness and disability. Historians of genetics have pointed to the ambivalent reorientation of genetics during the 1940s and 50s when older eugenic institutions ceased to exist and were replaced by new institution like heredity clinics with closer ties to medicine. In pronatalist Cold War America, the earlier focus on population improvement through state-enforced measures gradually morphed into a more individualistic stance that placed greater emphasis on the prevention of disease, disability and suffering. These themes had long been strong in hereditary deafness research, and in eugenic rhetoric on disability in general.20

20 Comfort, for example, has pointed the incorporation of genetics into medicine and public health, and the ambivalent meaning of eugenics, Stern has traced the fitful birth of genetic counseling with its roots in eugenics, and Kline has pointed to the role of eugenics in creating the pronatalist
In disability and Deaf history, mid-century America is still mainly uncharted territory, a gap between the focus on the eugenic era and the rise of disability activism in the late 1960s. Yet historians acknowledge that this activism received important impulses from mid-century developments that have not yet been explored. In particular, these are the influences of sociological and anthropological research on defining behavior, identity and the relationship of individual, group and society. This growing interest in interpersonal relations and social dynamics was fueled by decolonization abroad, and the struggles of minorities – including the disabled – at home.

Once more, psychiatry and psychology played a crucial role in this development, and (hereditary) deafness research was an important field in which these new developments were picked up. Thus, chapter 5 explores the establishment of the first specialized psychiatric and genetic services for deaf people in the US at the New York State Psychiatric Institute (NYSPI). The project was a collaboration between the NYSPI’s department for psychiatric genetics and the New York State deaf community, an unusual realization of community psychiatry in a time when deaf people remained objects of research, but not partners in it. This cooperation was crucial for shifting perceptions of deafness. Engaging with deaf adults, psychiatrists came to ambiguous and multilayered definitions of deaf people's particular normalcy and pathology. Redefining deafness as a “stress-inducing” psychological condition, and the deaf as a disadvantaged social minority, the project introduced the logic and rhetoric of minority-specific research and counseling to genetic deafness research. This move allowed psychiatrists to fashion themselves as social activist supporting the struggle of minorities. Employing psychiatrists, psychologists and geneticists, and,

atmosphere of the postwar era. See Comfort, Perfection, 97-163; Stern, Genes; Kline, Race, 124-158.
increasingly, deaf people themselves; and merging eugenic goals with psychodynamic and sociological approaches, the project established an important professional cluster that will feature prominently in the following chapters.

By the late 1960s, then, approaches to deafness and deaf people had diversified. The older oralist, medical-pathological model of prevention and assimilation was complimented by a newer approach that considered the deaf one of America's oppressed minorities. While today these models often are considered irreconcilable, at the time hearing hearing professionals often combined advocacy for Deaf culture and identity with delineating the pathological effects of hearing loss. Likewise, they saw little contradiction between the ideal of the scientist pursuing objective truths, and of the social activist, battling against a biased establishment for more justice and better access to health care. Chapter 6 picks up on the tension and overlap between these models, looking at the debates over Usher Syndrome, a form of congenital deafness and progressive vision loss. Until the 1960s, this had been an obscure and hardly known condition that could come into the focus of professionals only because of recent advances in differentiating types of genetic deafness.

A single man, psychologist, McCay Vernon, drove the 1970 campaign to spread awareness of Usher Syndrome. Vernon was influenced by the NYSPI psychosocial approach to deafness as well as older eugenic motives. Borrowing the rhetoric of the Civil Rights Movement, he condemned the effects of minority discrimination and cultural deprivation on deaf and deaf-blind people. Yet as a psychiatrics professional, he, like the NSYPI psychiatrists, struggled to define deaf particularity and pathology. Aiming to prevent Usher Syndrome yet embracing Deaf culture, Vernon engaged with Usher Syndrome patients whose emerging patient and activist networks provided a platform for negotiating the meaning of disease,
disability and genetic risk, and their identities as patients and members of the Deaf or emerging deaf-blind community. Here, the psychologization of genetic knowledge could be used by professionals to argue for prevention and intervention, yet also by activists to define disability as an existential part of human experiences. Both approaches, however, turned genetics into an essential part of self-knowledge, and thus prepared the establishment of genetic services for the deaf I will explore in chapter 7.

In 1984, the Gallaudet Genetic Service Center (GSC) opened its doors, offering American Sign Language-based and Deaf-culture specific genetic counseling and evaluation. Chapter 7 traces the origins of the GSC in the work of a professional cluster that included psychologist McCay Vernon, geneticist Walter Nance and their students. Nance's belief in non-directive genetic counseling in the 1970s combined with McCay Vernon's psychosocial approach to genetics and deafness to offer a culturally sensitive version of genetic services attuned to individual beliefs rather than eugenic goals. Taking advantage of federal funds allocated to “underserved minorities” such as Hispanics or African Americans, the GSC defined deaf people as an ethnocultural minority cut off from genetic services. In the 1980s, when the Deaf Power movement gained national visibility, the GSC thus successfully portrayed itself as a part of Deaf culture and community. Redefining the “risk” for a deaf child as a “chance,” GSC geneticists depathologized deafness, yet at the same time propagated genetic knowledge as an integral part of self-knowledge and health management, as an instrument of political empowerment for the Deaf community, yet also a potential threat.

Covering a wide range of institutions and professions providing medical, educational, rehabilitation and genetic research and services, I trace professional
identities and alliances, the impact of encounters and moments of exchange between professionals and deaf people. With deaf people's influence growing, I follow throughout the century an apparent reversal of the goals of genetics deafness research, from perceiving deaf people's reproductive habits as a threat to the welfare of their offspring or the population at large, to portraying vice versa, genetics as a threat to the deaf community.
Chapter II: Progressive Science, eugenics and educational reform:

(Hereditary) Deafness research in early 20th century America.

In 1928, the Clarke School for the Deaf established a small research department. With its subdivisions for heredity, psychology and phonetics, the department was to reign in the powers of progressive science to make more efficient the education of deaf children. To the school, the latter had always been a holistic enterprise, not only aiming at imparting knowledge, but at forming well-rounded, successful, productive citizens abiding to the norms of hearing society. Eugenics, for the school, was one means in this larger enterprise of normalizing the deaf and for preventing future cases of deafness.

To understand why heredity research became part of the school’s mission, and how it became intertwined with education, evolutionary thought and progressive science, this chapter will survey contemporary discourse of disability, education and childhood, eugenics, medicine and science. By the early decades of the 20th century, teachers and administrators, physicians of various specializations, social workers, hygienists, reformers of various creeds, and eugenicists (such as they were professional eugenicists rather than professionals with eugenic inclinations) considered deaf people, and in particular deaf children, the target of their sciences. These disciplines, historians have argued, contributed to the medicalization and standardization of childhood and disability. This process has often been portrayed as being uniform; and indeed, certain themes unified different professions: In particular, their progressive belief in the power of science to understand, control and prevent disability guided reformers, educators and scientists at the beginning of the century. Building on older paradigms of charity, of social and personal reform, these
professionals portrayed disability as something to be overcome – yet also labeled as deviant those who seemed unwilling or unable to comply with these social norms and narratives of uplift. Thus, scholars in disability and deaf studies have emphasized the oppressive nature of this medicalization as a process that pathologized alternative identities, disenfranchised the deaf community and restricted individual agency in favor of the fortification of professional and scientific expertise.\textsuperscript{21}

Yet as much as these different professions agreed on the pathological nature of deafness and disability, they often had quite different assumptions about the very nature and meaning of these categories, and about the best means and methods to restore or protect normalcy, citizenship or eugenic ideals. The nature and extent of personal connections to deaf people as students, objects of research or targets of social reform greatly influenced such professional positions. Covering the history of deaf education, heredity research and eugenics at the Clarke School and beyond, this chapter will trace alliances and dissonances between different disciplines in their respective positions on deafness and deaf people. As such, this chapter serves to set up the various social, cultural and scientific constellations explored in later chapters, in particular the important alliance between eugenics and education so important in the first half of the 20\textsuperscript{th} century. Yet this very example also makes clear that such alliances were always rife with tensions and dissonances. What eugenics meant for heredity researchers, anthropologists or teachers could vary immensely and changed

over time. Just as, at various points in time, different professions could move closer together in their approach to deafness and deaf people, they also moved apart again with new insights, results or social constellations.

To understand the guiding ideologies of the Clarke School, this chapter will first go back to the 19th century, when the first American schools for the deaf were founded as part of the larger push for mass education. As other contemporary reformers, teachers for the deaf believed in the transforming powers of education, often portraying this transformation from disability to (partially) restored ability and productivity as a spectacle drawing in public support and charity. Residential schools for the deaf also became the center and origin of a flourishing deaf culture and community that considered itself one of the countries many socio-linguistic minorities. By the end of the century, however, as oralism became the new leading educational paradigm, this community and their language came to be seen as pathological, deviant or defective. In explaining these transformations, historians of deafness have pointed to developments that are also intimately connected to the history of eugenics: the impact of evolutionary thought on defining humanity, language and disability; nativist tendencies in defining and defending American citizenship, and the appeal of science to solve social problems. When they set out to establish first permanent oralist school in the US, the founders of the Clarke School skillfully employed these motives of scientific expertise and paternalism, citizenship and charity. In outlining the early history of the school and its vision
of transforming the deaf child into a full citizen and human being, I will also outline the omnipresent discourse of normalization, difference and deviance.22

In the person of Alexander Graham Bell, oralist pedagogy, progressive science and eugenic thought united. I will trace his work on hereditary deafness, fears of deaf procreation, rejection of deaf culture, community and language, and advocacy for oralism as a means of eugenic betterment. Bell’s work had a profound and lasting impact on the application of eugenic measures, and the on relationship of deaf people to eugenic thought, science and education. Treating eugenics as a social movement and ideology that could mean many things to many people, I will show how deaf people and professionals working in the field of deafness appropriated or rejected different aspects of eugenic thought. These groups employed and reacted to two different, but connected motives in eugenic thought: as a part of Progressive reform to improve mankind and society; and as a form of exclusionary rhetoric and policies against social and moral, physical and mental deviants that were beyond such improvement.

The first motive has often been portrayed as a form of biological determinism, of applying biological solution to social problems. Certainly, this has been the case for many eugenic publications and projects, foremost, but not solely coercive sterilization during the first half of the century. Yet various forms of eugenic thought were part of a much larger and varied landscape of reform. When early 20th century researchers talked about eugenics, heredity and deafness, they did so in a framework concerned with the passing on of deafness,

but also the standardization and efficiency of education, with mental or social hygiene, childhood studies or the mental testing movement. In their verdict about various groups of “defectives,” eugenicists drew heavily from the standards these new disciplines established regarding intellectual and physical development and moral norms.

Second, eugenic thought and policies targeted the (supposedly) morally, mentally and physically degenerate as a social underclass that was innately beyond saving by the valiant, yet failed attempts of social reform. In this sense, eugenics was a means for defending racial, social and gender privilege in an age of rapid social change. In general discourse, deaf people were often included in the group of defective and degenerate, and, as I will lay out below, threatened by politics that restricted civil and reproductive rights. This threat forced professionals and deaf people alike into a defensive position. Both insisted that (good) deaf people did not belong to this group of irresponsible and unproductive defectives. Teachers for the deaf strongly believed in educational redemption. Educating the deaf proved that they were not “dumb,” liberated them from isolation and formed successful, responsible and well-integrated citizens. This strong belief in deaf people's intellectual normalcy also influenced the eugenic policies both deaf people and professionals supported. Rather than coercive measures, the Clarke School and others supported a pedagogic-persuasive approach to heredity education and counseling that was to instill in deaf people what historian Wendy Kline has called 'reproductive morality,' a sense that one's reproductive decisions should “be based not on individual
desire but on racial duty.” As malleable eugenic thought was, then, underlying assumption of social, moral and physical worth were omnipresent in early 20th century conversations about social, medical and scientific solutions. The success of eugenic thought thus depended on a much longer tradition of portraying deaf, disabled or sick people, and other marginalized groups in regard to their social worth and contribution to society, moral virtues or lack thereof. Comparing the lobbying power of professionals and deaf people with that of other groups targeted by eugenics, I offer a relational history of eugenics, disability and the normalization and exclusion of those labeled as different or deviant.

With this framework of progressive science, reform and eugenics in place, I will turn back to Clarke School, which in the mid 1920s mobilized their influential contacts, this time to raise funds for a research department. In a period in which disability was often conflated with dangerous degeneracy, they convinced prominent donors of the value of the deaf as a population worth saving by progressive form. Envisioned as center of interdisciplinary science, the research department was to delineate the psychological, phonetic and hereditary aspects of deafness in order to normalize deaf people.

In staffing their research department, the school profited from their excellent connections. In particular, the faculty at Smith College, also located in Northampton, often engaged in research at the school. This efficient set-up introduced a variety of professionals from diverse backgrounds to deafness research. Here, the tensions between outside researchers and school staff provide insights into the convergence and divergence of professional paradigms.

Thus, at the same time as the school projected a unified and holistic vision within school reports and oralist publications, outside scientists often came to different conclusion. In the last part of the chapter, the work of the psychology division will provide an example for this development, and serve as comparison for heredity research. Thus, I argue, that even within the medicalizing framework of early 20th century approaches we can discover the germs for later, more diverse (and less pathologizing) perceptions of deafness and deaf people manifesting in different sciences.

Deaf education, deaf community, deaf culture: a 19th century world

Of the different professions concerned with deafness and deaf people, education is probably the oldest. Attempts to educate deaf individuals can be found throughout history, yet for the most part, these were isolated endeavors that reached privileged individuals rather than all deaf children of school age. More often than not, educators were priests or monks who hoped to bring the word of God to the deaf by teaching them language. In more or less secularized varieties, this motive of salvation would remain important in deaf education throughout the 19th and into the 20th century.24

The advent of state-mandated mass education in the 19th century also reached deaf children. In the US, the first permanent school for the deaf, the Connecticut Asylum for the Education of Deaf and Dumb Persons, was established in Hartford in 1817. As a tax-supported boarding school, the Asylum set the model for the institutions that sprang up all over the country in the

following decades. By 1857, 19 schools offered free education to deaf children. For the most part, these schools prepared students for vocational trades, following the general model in special education that aimed at economic independence rather than intellectual achievement. Deaf people, however, also were considered capable of receiving higher education, and the US was the first country to establish a college just for them. In 1864, Congress granted the right to confer college degrees to the Collegiate Department of the Columbia Institution for the Deaf and Dumb. Located in Northeastern Washington DC, the school was lead by Edward Miner Gallaudet, son of distinguished educator and co-founder of the Hartford school Thomas Hopkins Gallaudet. In the latter’s honor, the institution was renamed Gallaudet College in 1898. From its inception, it served and formed an elite of young deaf men – and, from 1886 onward – women, who often went on to become the leaders of their community.\footnote{Van Cleve; Crouch, \textit{Place}, 29-46; Edwards, R. A. R. 2014. \textit{Words made flesh: nineteenth-century deaf education and the growth of deaf culture}. New York: New York University Press, 11-31. For the establishment of Gallaudet see Van Cleve, Crouch, \textit{Place}, 71-86; Armstrong, David. F. 2014. \textit{The history of Gallaudet University: 150 years of a deaf American institution}. Washington D. C.: Gallaudet University Press, 1-36.}

For most of the 19th century, schools used the so-called manualist approach that considered sign languages the most efficient tool of bringing knowledge – and the word of God – to deaf children. Educators believed that when students came to residential schools and began communicating with each other, they used what they called natural signs, a form of gestural communication not exclusive to deaf people, but also used by hearing individuals in situation were speech was impracticable. At school, with the help and direction of teachers (deaf and hearing) and older students this simple system
was refined and cultivated into more grammatical, uniform and developed form. Natural sign then became the “natural language of signs.” With this transformation, contemporaries thought, sign language followed a natural development just like any spoken language.26

To the first generation of teachers – often signers and / or deaf themselves – sign language was a beautiful and respectable language. In an era that searched for mankind’s natural, long-lost language, it evoked romantic associations. Signers could take pride in employing a language that was considered more antique and thus closer to creation. For early 20th century teachers, Baynton points out, the problem of deaf people was not primarily their difference, but that their deafness cut them off from receiving the word of God. Acknowledging that deaf people had different communicative needs, teachers considered sign language the best solution for bringing the deaf within the reach of education and religious salvation. Their goal was for their students to achieve a bilingual mastery of both sign language and (written) English. For this purpose, teachers also sometimes employed a system called methodological sign that, unlike sign language with its distinct grammar, followed English linguistic structures.27

Sign language also became a main characteristic of the emerging deaf community. For pragmatic reasons, schools for the deaf had been set up as


boarding institution. Since deafness was a relatively rare condition, it made sense to bring together to one location all deaf children of a region or state. These residential schools soon became the core of a flourishing deaf community and culture. Here, deaf children met deaf adults and deaf peers who shared their experiences. They were initiated to sign language, made friends, received an education, moved on, and yet stayed in contact with and often married former schoolmates. By the 1850s, the deaf community organized regular social events; had clubs, churches and associations. The National Association of the Deaf (NAD), established in 1880, served as an umbrella organization and successfully lobbied for the interests of its members.28

Mass print culture had an important role in creating a sense of community and cohesion for the geographically dispersed community of the adult deaf. Printing was often taught in schools for the deaf, offering male students a way into a well-respected trade. Students soon began putting together bulletins informing community members about marriages, deaths, and other community happenings. By the 1870s, these had become a set of regular journals and periodicals known as the Little Papers Family, offering a commentary on cultural, political and social events. One of the most long-lasting of these publications, the Silent Worker, was established in 1896 by students and faculty at the New Jersey School for the Deaf.29

28 Van Cleve; Crouch, Place, 29, 47, 87-93. For the role of residential schools and the development of the deaf community also see Edwards, Words, ch. 3 and 4.
By the late 19th century, then, deaf people had formed a subculture and community similar to that of the many immigrant groups populating the US. Among some deaf people, the sense of a separate community and culture was so strong that they rallied for the establishment of a self-governed commonwealth in the west where the deaf would not be expected to conform to the values and beliefs of hearing society. Such a vision of excluding oneself from bias and discrimination makes clear that deaf culture and community was far from universally accepted. By the last third of the 19th century, it came under close public and scientific scrutiny. As beliefs about mankind and language, disability and medicine, American society and its minorities changed, so did perceptions of deafness, deaf people and deaf community.\(^{30}\)

**The rise of oralism: science, deaf education and “a modern miracle”**

From the 1860s on, a new paradigm came to pervade deaf education and would change how a deaf person had to act and communicate: oralism, the teaching of speech and lip-reading. This was not an entirely new enterprise. Yet in its claims to scientific progress, unique ability to kindle deaf people’s humanity, and fearful rejection of sign languages the oralism of the late 19th century was very much a product of a time that hoped to normalize the disabled. Physical and sociocultural normalcy – or at least the appearance thereof – would become the new, elusive ideal against which deaf people were measured.

The debate over the respective superiority of oralism vs. manualism is probably the most extensively covered topic in Deaf history and Deaf studies. It

\(^{30}\) For ethno-linguistic characteristics of the deaf and the visions of a Deaf commonwealth see Van Cleve; Crouch, *Place*, 60, 169.
was and is an antagonizing issue that often determines someone’s position on deafness. A lot is at stake: How do we think and communicate, what, in first place, is a language and how does it facilitate learning? Is language a means to initiate the deaf to a community of their own, or a tool to integrate them into larger society? Should they overcome their otherness and strive to appear “normal”? The answers to these questions were rapidly changing in the late 19th century. Social and linguistic Darwinism, nativist sentiment and anti-immigrant policies, professional claims of curing disability (and ethnic otherness) through progress and science, and the American belief in personal reform and betterment all influenced perceptions of what it meant to be deaf.31

While some authors have cast the rise of oralism as a simple tale of oppression and resistance, others have explained this development as an expression of changing perception of deafness and deaf people within American society. The “fight over sign language,” historian Douglas Baynton writes, “was a play in miniature of the late nineteenth-century fight between the upholders of an older romantic, genteel, and pastoral vision of live and the proponents of an efficient and rational modernity.” It was the reaction of an anxious hearing majority to the apparently pitiful – and remediable – difference and inferiority of deaf people. Oralism, with its strong philanthropic and paternalistic undertones, was to help deaf people overcome their physical and cultural otherness, unlike manualism, which seemed to encourage it. Thus, Baynton notes, the predominance of the one or other method had less to do with what deaf people

31 More or less lengthy and passionate accounts of this manualism – oralism debate can be found in most works on deafness, deaf history and culture. For some thorough and rigorous accounts see Burch, Susan. 2002. Signs of Resistance: American Deaf Cultural History, 1900 to World War II. New York: New York University Press, 3; Van Cleve; Crouch. Place, 27, 30; Baynton, Savages; Baynton, Signs; Edwards, Word, chapters 5-7.
wanted or needed than with the paternalistic mission and beliefs of hearing educators. Deaf people, nevertheless, embraced manualism and claimed sign languages as their own because it allowed for some degree of autonomy and a positive definition of deaf life.\textsuperscript{32}

Post Civil War America came to emphasize the white Anglo-Saxon male as the ideal citizen, and watched the many ethnic and linguistic minorities within its borders with suspicion. A new wave of mass immigration from Asia and southeastern Europe triggered anxious calls for Americanization. There were some important similarities in how immigrants, Native Americans and deaf people were perceived. Not quite considered full citizens yet, they were to leave behind their foreign habits and language, and be civilized and uplifted by American values and the English language.\textsuperscript{33}

The spread of evolutionary thought was a second crucial factor in the success of oralism. Once nature was no longer a God-given state, but the savage precursor to civilization, sign languages were no longer an inherent, natural, and efficient tool, but a sign of savagery that limited deaf children’s intellectual growth. Destroying the God-given division between man and beast, Darwinism triggered an anxious reshaping of human distinctiveness. To many, spoken language came to be this distinguishing feature; a reconceptualization with far-reaching consequences for deaf education. Educators of the deaf now placed

\textsuperscript{32} Baynton, \textit{Signs}, 7-8, 150.

their mission in a larger framework of humanizing and civilizing the deaf by giving them language, the mark of the human race.  

In this framework, language was no longer a God-given asset, as it had been to an earlier generation of teachers, but an evolutionary and developmental achievement. As linguists studied gestural communication among animals and 'savage' people, they associated sign language with a lower stage of evolution in which man had just barely risen above his primate predecessors. The reinterpretation of facial and bodily expressions, so important in sign languages, was telling for this change. Where pre-Darwinist thought had considered emotions an exclusively human quality, Darwin's study of emotions – and, significantly, of their facial and bodily expression – placed them in a continuum from animal to savage to human. Thus, the civilized person was to control any savage and animalistic expressions and refrain from employing a linguistic system in opposition to contemporary notions of propriety and outward emotional control.

In the oralist-evolutionary mindset, then, failing to master speech signified something almost sinister: The inability to overcome the primitive – even savage – state of childhood in order to mature into a fully civilized being. Such evolutionary-informed educational policies and beliefs could have strong racial undertones. African American children – often educated in separated

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34 Baynton, Savages, 94-103.
schools – were more likely to be taught in sign language as they were considered less capable of being civilized.36

Oralism did not win over deaf educators easily, yet for the younger generation, it seemed to be the more reasonable, scientific and progressive choice. In 1880 in Milan, the second International Congress for the Improvement of the Condition of Deaf-Mutes decreed the superiority of oral methods, and for almost a century remained a point of reference in deaf education. By the turn of the century, forty percent of American deaf students were taught by the oralist method; by 1918, it was 80 percent.37 Sign language, however, never disappeared completely. In many institutions, it was used to teach those who “failed” to learn speech and lip-reading. More importantly, deaf parents passed it on to their children who then taught other students; and students perpetuated it among themselves. Beyond schools, a well-organized and active deaf community fervently and publicly resisted what they considered a violation of their right to their own language. In evoking their distinctness, yet equality, they employed, as Baynton pointed out, a similar strategy as did branches of the 19th century woman’s movement. Deaf people, however, had little influence over educational policies and administration and their influence waned even more as with the rise of oralism, deaf teachers and administrators became rare.38


37 Baynton, *Savages*, 94; Van Cleve; Crouch, *Place*, 103.

A pioneer in oralist education: The Clarke Institution for Deaf Mutes

The Clarke School, in Northampton, Massachusetts, sited across the street from Smith College, was a leader in the establishment of oralist schooling in the US. It was, in fact, the first lasting oralist school for the deaf in the US and to this day claims a leading role in deaf education. The school's self-image and founding myth are telling for the appeal of oralism among educators and the general public alike. Clarke offered an inspirational story of overcoming disability and becoming fully human through hard work, personal reform, and, not the least, through scientific progress.

In the school's own, much repeated founding myth, the history of the school starts in 1863 with little Mabel Hubbard who lost her hearing after a bout of scarlet fever at age five. Her father, the wealthy Boston lawyer and philanthropist Gardiner Greene Hubbard sought out a method of education that would save his daughter from the mannerisms, gesticulation and peculiarities of the deaf and retain her ability to use and understand spoken language. Disappointed with the methodology of the Hartford Asylum, he engaged a private tutor and became an advocate (and wealthy supporter) of oralist education in Massachusetts. For Hubbard, oralism was a marker of social status and ability. It was, he believed, for the smart child of wealthy parents while manualism sufficed for the less fortunate, less intelligent or socially deviant. He thus employed a pattern much evoked in deaf education into the present.39

Hubbard's advocacy brought him into contact with other influential Massachusetts reformers and advocates for oralism. Among them were the

politician and reformer Horace Mann, and the educator and reformer Samuel Gridley Howe. The latter, husband of abolitionist and women’s right activist Julia Ward Howe, had advocated for the oralist method since the 1840s. Howe played an important role in the history of special education of Massachusetts. In 1832, after returning to the US from his involvement in the Greek revolution and in providing relief to refuges of the Polish revolt, he became head of Massachusetts’ first state school for the blind. Starting out with a class of six students, the school grew quickly under Howe’s leadership and soon was renamed the Perkins Institute for the Blind.40

During his 44 years as head of Perkins, Howe undertook a task many had considered impossible. He was the first person to educate a deaf-blind child, Laura Bridgeman. In doing so, as a 1930s biography put it, he “awakened” her “to communication with others, educating her to usefulness and happiness – at that time an astounding achievement which, done in the face of general disbelief, became of vast importance to human psychology, education, and hopefulness.”41 Historians since have been more critical of Howe’s endeavor, pointing out that he had chosen Bridgeman carefully for her appealing looks and outward physical normalcy. Contrary to Howe’s ideals, Bridgeman would have little agency over her life and would spend her life at the Perkins Institute, often displayed to the visiting (and donating) public as proof of Howe’s educational skills and methods.42

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40 For the political background of Howe and Mann, and their involvement in the campaign oralism and other reform attempts see Edwards, Words, ch. 5 and 7.
42 For Howe’s life as a reformer and educator, and for his work and relationship with Bridgeman see Gitter, Elisabeth. 2001. The imprisoned guest: Samuel Howe and Laura Bridgman, the original deaf-blind girl. New York: Farrar, Straus and Giroux.
Howe’s mission to save, civilize and normalize also extended to deafness. Deafness, Howe believed, separated the child from the rest of mankind and had the potential to produce morbid habits and retardation. Associating with other deaf children and communicating in a language of their own would merely strengthen these tendencies toward pathological habits and isolation. Rather than to isolate, education should aim to restore the deaf to social normalcy and communality. Speech was the humanizing agent to achieve this, the means for the deaf to stop being the other and become part of the hearing community. In this vein, he advised the Hubbards’ to refrain from using or accepting any gestural communication with their daughter.\textsuperscript{43}

With extensive fundraising and influential connections, Hubbard, Howe (now chairman of the Massachusetts Board of State charities), and their co-reformers finally succeed in establishing a state-supported oralist school for the deaf in Massachusetts. In 1867, the residential Clarke Institution for Deaf Mutes was established in Northampton with Hubbard as president of the school’s corporation. It was named after Northampton businessman John Clarke, who, hard of hearing himself, had donated $50,000. When he died two years later, Clarke made the school a beneficiary in his will, bringing his total donation up to the significant sum of $306,000 – more than any school for the deaf had ever received.\textsuperscript{44}

In 1870, the school board acquired an estate with two houses on Northampton’s Round Hill, an idyllic, small town location suitable to the school’s goal of providing as much “as humanly possible, the warmth of relationship and

\textsuperscript{44} Numbers, \textit{Word}, 17-19.
the natural home atmosphere surrounding the hearing child." The school, Schlesinger has pointed out, successfully combined the homely image of a family-like community with that of a daringly progressive institution that challenged traditional beliefs and in doing so, was able offer a more hopeful trajectory for deaf children. With this framework, they soon attracted attention from other schools, which, in the changing atmosphere of the late 19th century, considered Clarke a pioneering example. This, certainly, was how the school wanted to be perceived, and an image they reinforced by emphasizing their close association with the newest scientific developments in the field of deafness.

Toward this goal the school had from the beginning the support of influential and wealthy New England reformers and donors to whom the philosophy of saving and normalizing the disabled child appealed greatly. The speaking deaf child was a symbol of scientific progress and social reform. As a Clarke School brochure later put it, in the late 19th century teaching speech to deaf children seemed "literally" like "a modern miracle," an achievement "generally deemed impossible." Proving these presumptions wrong implied far more than merely a communicative achievement. "It was demonstrated past all doubting," the brochure asserted, "that the deaf need not be 'dumb'. They could be taught to speak." Speech and lip-reading, educators hoped, would eventually render their charges "full and active" members of society. This goal, the Clarke School believed, could only be reached by treating deaf children as much as possible as if they were hearing. Sign language, on the other hand, supposedly

restricted the deaf child to the company of those who, like him, did not fit in. Moreover, it “necessarily involve[s] conspicuous gestures which accentuate the already gaping chasm between the totally deaf and those of normal hearing.”

**Alexander Graham Bell: The sciences of speech and hearing**

The triad of linguistics, oralism and evolutionary thought was most famously embodied in the person of Alexander Graham Bell. As the inventor of the telephone and other, less successful scientific enterprises (such as his later forays into aviation), Bell is often portrayed as the embodiment of American entrepreneurship, a self-made man and philanthropist. Among the Deaf community, however, Bell’s reputation remains more ambivalent. To many, Bell is still a symbol for the restriction of scientific oralism on deaf culture and marriages.

Bell was born in Edinburgh, Scotland in 1847, into a family occupied with the science – and business – of sound and speech. His grandfather Alexander Bell was a London professor of elocution; his father Alexander Melville Bell was a scientist occupied with the physiology of speech. He developed ‘Visible Speech’, a phonetic system for teaching deaf children spoken language by connecting each sound to a specific, visualized mouth position. Hearing loss also had a personal dimension in the Bell family. Bell’s mother Eliza, the daughter of a Navy surgeon, was hard-of-hearing. A painter and musician, she avoided socializing with other deaf people and preferred oral communication.

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Bell was educated at the University of Edinburgh and at University College, London, where he took classes in physiology and anatomy. During this period in the late 1860s, he also became his father's assistant, and followed him when the family moved to Canada in 1870. In this position, his father first sent him to schools for the deaf to introduce Visible Speech as a modern, scientific and efficient tool. In 1871, Bell taught this method at the newly established Boston Day School for Deaf Mutes, the first of its kind in the US. (Bell would later become a fervent supporter of day schools in deaf education) He also tutored a young deaf boy, Thomas Sanders, in whose home he lived from 1873 to 1876.49

In 1872, on this mission to spread Visible Speech, Bell first visited the Clarke School. There, his ideas found a receptive audience. The Clarke School staff used Visible Speech to develop an adapted phonetic chart as a crucial instrument in their oralist endeavor.50 Bell would remain connected to the school for the rest of his life. In the last years of his life, he served as president of the school board. In this function and because of his advocacy for oralism, he became the school's revered founding figure.51 At Clarke, Bell also met his future wife, Mabel Hubbard. Gardiner Hubbard was interested in Bell's teaching methods for his daughter, and, engaged him to work with her. While working together, teacher and student fell in love. The couple married in 1877, after a lengthy period of courtship due to Gardiner Hubbard's concern about the eleven-

49 Ibid., 56-58.
50 Numbers, Word, 33.
51 Bell's influence is evident in school publications, in particular the school's annual report.
year age difference between his daughter and future son in law, who had (as yet) no financial means.\textsuperscript{52}

Bell's interest in the physiology of hearing, and his career as a scientist and inventor unfolded alongside his teaching activities. Boston, with its host of scientific institutions, provided intellectual stimulation and some level of institutional achievement. In 1873, he became professor of Vocal Physiology and Elocution at Boston University. Moreover, the Boston parents of his students, including Gardiner Greene Hubbard, invested heavily in Bell's inventing enterprises. In this environment, he began experimenting with human ears and with the conduction of sound, investigations that led to the invention of the telephone in 1876. With his business partners, including Hubbard and Thomas Sanders, he established the Bell Telephone Company, which quickly became immensely successful and profitable. He also promoted his invention in Europe, and in 1880 received the 50,000 Francs Volta Price from the French Government. With this money, he established, in 1887, the Volta Bureau in Washington, D.C., an information center for deafness that later became the seat of the Alexander Graham Bell Association. Throughout his life, Bell dedicated much of his time to the research on deafness and became the most prominent proponent of oralism in the US.\textsuperscript{53}

\textsuperscript{52} Mackenzie, Catherine Dunlop. 1928. \textit{Alexander Graham Bell, the man who contracted space.} Boston: Houghton Mifflin Company, 54-56; Greenwald, Bell, 61-63.
\textsuperscript{53} Greenwald, \textit{Bell}, 23, 62-66.
Oralism, heredity and marriage: The Memoir upon the Formation of a Deaf Variety of the Human Race.

Like many of his contemporaries, Bell was interested in questions of heredity and evolution and its applications to better breeding, be it humans or animals. In the 1880s, he began studying the marriage pattern of deaf people. He studied pedigrees on Martha’s Vineyard, which had an unusually high incidence of deafness. In 1883, Bell presented a talk to the U. S. National Academy of Sciences, to which he had been elected the previous year. Rather than talking about the recently invented telephone, Bell chose a topic that fascinated him and many of his contemporaries: the mechanism of heredity as governed by selection and variation. His Memoir upon the formation of a deaf variety of the human race, published a year later, would become one of the most (in)famous documents in deaf history.

In animals, Bell began, breeding offered an easy way to observe the effect of selection on race. In humans, whose random marriages were beyond the control of breeders, such close observation seemed impossible. Yet one group and their peculiar marriage pattern seemed to offer insight into this very problem. In “this country,” he pointed out, “deaf-mutes marry deaf-mutes.” Investigating their marriages and the resulting offspring would answer the question of whether “the human race” was “susceptible of variation by selection.” Thus setting up deaf marriages as a natural experiment in human heredity provided Bell with self-reinforcing, if rather circular rhetorical advantages: He turned the issue of deaf intermarriage into a general scientific question and by

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answering his premise in the affirmative – deaf people’s intermarriage increased the occurrence of deafness, thus humans were susceptible to selective variation – provided proof for the dangers of this practice: “the intermarriage of congenital deaf-mutes through a number of successive generations,” he claimed, “should result in the formation of a deaf variety of the human race.” Such a “defective race of human beings,” he warned, “would be a great calamity to the world.”

What was the cause of this “case of continuous selection”? What could be done to prevent it? Deaf peoples’ tendency for intermarriage Bell argued, was the misguided result of the noble humanitarian efforts of providing education to deaf children. Involuntarily, he lamented, the current educational system had installed a number of incentives that encouraged deaf people to seek out one another rather than to choose hearing partners: Deaf children were separated from their families and society at large in residential schools, which in turn had become sociocultural centers promoting the socializing of deaf adults in the form of reunions, societies and conventions, newspapers and periodicals. This segregation, Bell asserted, had supported the most powerful instrument of preventing interaction with hearing society: “the evolution of a special language adapted for the use of such a race.” Couching his argument in the language of natural history, he argued for a set of mutually reinforcing influences that linguistically, physically and racially removed deaf people from hearing mankind. Tapping into contemporary concerns over the divisive and destructive effects of civilization, Bell could portray late 19th century deaf culture


56 Ibid., 47
and community as an unintended and tragic biological aberration with dire consequences. His alarm over racial separation and “class-feeling among the deaf and dumb” mirrored fears of an American society increasingly divided by class, culture and race in an era of rapid social change, mass immigration and industrialization.57

When it came to preventing the formation of such a deaf race, Bell preferred educational reform and oralist assimilation over legal action. “We cannot dictate to men and women whom they shall marry,” he declared, and added that with the current state of knowledge marriage restrictions would prove impractical anyway. He believed that integrating deaf people into day schools and society at and discouraging them from associating with each other would automatically decrease the incidence of harmful deaf intermarriages. Here, Brian Greenwald argues that it was Bell’s personal and professional acquaintance with deaf people – his mother and wife, former students and business partners – that made him favor a moderate stance, yet also made oralism his prime eugenic tool. Unlike many contemporaries, who perceived deaf people as defective and deficient, he believed in their basic humanity and ability.58

As the most widely known expert on deafness of his time, Bell yielded much influence. His politics of assimilation and education would prove the dominant eugenic strategy to prevent hereditary deafness in the following decades. Bell, Greenwald argues, acted as a buffer between the deaf and more radical eugenicists who favored harsher methods. His changing relationship with

57Ibid., 42.
58Ibid., 4, 46. Greenwald, Bell, 15, 50, 80, 91.
leading figures of the eugenic movements is telling for his stance on the politics of reproduction. In the early 1890s, his sheep breeding experiments on his new estate in Nova Scotia brought Bell into contact with others interested in questions of heredity and reproduction. In particular, he began corresponding with Charles Davenport, the most influential American eugenicist of his time. In the US, the early eugenic movement had a strong orientation in zoology, agriculture and animal breeding, as witnessed by the fact that the nation's first eugenic association was founded in 1906 as the Eugenics Committee of the American Breeders' Association. These close ties favored the development of research programs anchored in biology and cytology, yet also an idealization of rural life unspoiled by the degeneration of the industrialized city.

Davenport and Bell corresponded about Bell's experiments, their shared passion for statistical observation of hereditary phenomenon and Bell's attempts to breed four or six-nippled sheep to increase milk production. He also reported on a deaf breed of white cats, and in such observations of traits in pets saw himself following Darwin's example. As a sign of their friendship, he donated three six-nippled rams to Davenport in 1904. Bell soon became active in the

59 Greenwald, Bell, 13, 72-74, 199.
emergent eugenic movement, and a charter member of the Eugenics Committee of the American Breeders’ Association. Deaf-mutism was the subject of one of the Committees ten subcommittees, along with feeble-mindedness, epilepsy, and sterilization. In 1908, Bell presented a paper to the ABA encouraging better breeding among human, and in 1910, he helped Davenport solicit funds for his Eugenics Record Office. He later served as chairman of the Eugenics Record Office’s Board of Scientific Directors, presiding over other distinguished members such as economist Irving Fisher and Johns Hopkins’ William H. Welch.62

Many of the ERO’s causes seemed worth supporting to Bell, for example their call on stricter immigration legislation. The ERO’s methods, on the other hand, and its focus on negative eugenics, did not win his approval. Where ERO representatives wanted to restrict bad marriages, if needed by legislation, Bell believed in encouraging positive eugenics as the main instrument of the movement. In 1916, he withdrew from his chairmanship, increasingly disappointed with direction eugenic policies had taken there. In particular, he disagreed with the ERO’s advocacy for sterilization legislation, a matter pushed strongly by the its new director Harry Laughlin. To Bell, such a policy was a violation of personal liberties.63

While Bell’s eugenics may seem rather mild, his advocacy for a change in educational policies has earned him a notorious reputation in the memory of the deaf community, in Deaf studies and history. Deaf scholars have charged him

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62 Greenwald, Bell, 73, 159-160. For Bell’s later position on eugenics see Bell, Alexander Graham. 1908. A few thoughts concerning eugenics. Washington, D.C.: Judd & Detweiler.

with trying to eliminate two of the pillars of Deaf culture: sign language and residential schools. “The Memoir,” Greenwald writes, “was a call – in disguise – for the eradication of deaf culture through oralism.” These measures, Van Cleve and Crouch have pointed out, had the advantage of being “well within the American tradition of using the schools to achieve social goals that could not be reached through coercion.”

Some have even drawn a direct line between Bell’s late 19th century research, the eugenics of the first third of the 20th century, and contemporary genetic research as part of a “hearing agenda” of “Eradicating the DEAF-WORLD.” Often, such portrayals draw a clear line between oppressive science and deaf people rejecting eugenics altogether. Only more recently have historians of deafness began to looked at different strands of eugenics and their reception among deaf people. Greenwald for example has shown that as eugenic thought became more widespread in the early decades of the century, deaf people, too, came to consider it as a useful tool for addressing social ills and as a means to prove their social worth as defined by eugenic ideals.

64 Greenwald, Bell, 92; Van Cleve & Grouch, Place, 148.
65 Lane; Hoffmeister; Bahan., Journey, 381. Harlan Lane, a hearing psychologist, has been a fervent advocate of rejecting the medical model of deafness as a form of discriminatory genocide of a minority characterized by genetic, phenotypical, and sociocultural traits.
To understand why and how deaf people became the targets of eugenic policies and what agency they possessed in negotiating their eugenic selves, I will now turn to the history of eugenics, disability, progressive science, and education in early 20th century America. Focusing on eugenics as a matter of social reform, policies and identities, this chapter will serve as a set-up for the more narrow discussion of the the science and locations of heredity research in chapter 3.

**Eugenic thought and policy in early 20th century America: Variations of defect and agency**

In early 20th century America, eugenics was attractive to a wide range of professional and social groups. In an age that believed in progress through science, social and self-reform, very few groups or individuals rejected eugenic goals and methods totally. Yet what exactly eugenics meant and how it should be pursued varied considerably depending on one's social, political and professional position. It could be cast as a scientific quest for the biological laws governing nature, society and heredity; as a branch of medicine or public health; and as part of progressive reform, a moral guidance for modern life, even as a religion. More often than not, eugenic thought was employed to defend one's

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own social standing and privileges against the unchecked threat posed by
supposedly inferior groups who triggered fears of miscegenation and social
unrest: immigrants and the racially other, the disabled or the morally, socially or
sexually deviant. Yet the target populations of eugenic reform were not sharply
defined. Who was granted reproductive responsibility or claimed eugenics as a
form of self-improvement, and self-evolution; and who, in contrary, was a
menace to society was matter or perspective and negotiation. Often, these two
positions have been subsumed under the terms positive and negative eugenics,
encouraging the passing on of good traits or restricting that of negative
characteristics. However, such a binary opposition obscures that positive and
negative traits could reside in the same person, making the application of
eugenic measures a complex affair.⁶⁸

Most historians of eugenics have focused on the campaigns against the
feebleminded, who, as Alison Carey noted, had “emerged as one of the principal
enemies in the nation's war against population degeneracy and 'race suicide.'”⁶⁹
When professionals, politicians and others wrote about the mentally
“degenerate” and “defective,” it was with fear, contempt and the urgency of
impending doom. Filling up asylums, hospitals, and prisons, and taxing public

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⁶⁸ Historians have long pointed to the connections between eugenic and progressive thought, see
e. g. Freeden, Michael. 1979. "Eugenics and progressive thought: A study in ideological
affinity." Historical Journal. 22: 645-671; Pickens, Donald K. 1968. Eugenics and the
progressives. Nashville: Vanderbilt University Press. Disability historians have pointed to
changes in perceiving difference and defining normalcy while historians of gender and
reproduction have demonstrated eugenic influences on definitions of family life and
reproduction. See e.g. Baynton, Douglas. 2011. “‘These Pushful Days’: Time and Disability in
the Age of Eugenics.” Health and History. 13 (2): 43-64; Kline, Race; Schoen, J. 2005. Choice &
coercion: Birth control, sterilization, and abortion in public health and welfare. Chapel Hill:
University of North Carolina Press; Lovett, Laura L. 2007. "‘Fitter Families for Future
Johnson, Russel L. 2008. "Clara Bow in 'Free to Love' (1925): Feature Film and eugenics in the

⁶⁹ Carey, Allison C. 2009. On the Margins of Citizenship Intellectual Disability and Civil Rights in
welfare and bourgeois good will, socially deviant paupers seemed to have evolved into a race of their own, one that was biologically doomed to moral, physical and mental degeneracy. Worse still, this group threatened to overpower society with their unpressed sexuality.\textsuperscript{70}

Institutionalization and sterilization were two principal measures to combat the threat of the feebleminded masses. In 1907, Indiana was the first state to pass legislation that allowed the compulsory sterilization of any “incurable” criminal or mentally retarded inmate of a state institution. By 1912, fourteen more states had passed such laws, including California, Connecticut, New Jersey, New York, Michigan and Wisconsin. In the mid 1920s, encouraged by the favorable Supreme Court decision in Buck vs. Bell, a second wave of legislation followed, so that by the end of the decade most states in the US had passed such laws. An estimated 60,000 individuals were sterilized under these laws, predominantly in the 1930s, 40s and 50s. Most sterilizations – about 20,000 – occurred in California where the first sterilization law was passed in 1909 and modified in 1913 and 1917, adapting against charges of being unconstitutional, and including ever larger population groups and more explicitly eugenic goals. Feeble-mindedness and potentially hereditary mental disease, yet also syphilitic insanity all were brought into the reach of eugenic sterilization.\textsuperscript{71}

\textsuperscript{70} See e.g. Kline, \textit{Race}, ch. 1. One of the most influential examples of this attitude is Henry Herbert Goddard’s The Kallikak Family, first published in 1912, yet the fear of the uncontrolled reproduction of the feebleminded was widespread even earlier in the century. See e.g. Risley, S. D. 1905. “Is Asexualization Ever Justifiable In The Case Of Imbecile Children.” \textit{Journal of Psycho-Asthenics} 9 (4): 92-98.

Eugenics, however, influenced a much broader range of social policies, including reproduction and family, education, welfare or immigration. Defined as an ideology aiming for the “best possible” individual and population, the reach of eugenics went beyond the ill-defined group of the degenerate feeble-minded. They only stood at the far end of a spectrum of population targeted for conditions considered hereditary to some degree. Whereas physicians and the public agreed that the feebleminded and degenerate should not reproduce (and if they did so, only once controlled by responsible professionals), this directive was less easily made with other groups, whose conditions presumably had a hereditary component, but who were thought to contribute valuable – and hereditary – traits to society. Contemporary thought on the heredity of genius and insanity – two traits that seemed to be closely allied – make clear that notions of eugenic worth were not set in stone. Similarly, Historian Arleen Tuchman has shown how early 20th century notions of diabetes shaped the debate over the benefits and disadvantages of sterilizing diabetics. Perceiving diabetes-sufferers as predominantly white, educated and middle class, Tuchman argues, made coercive eugenic measures seem unnecessary. Some physicians even asserted that diabetics’ intellectual capabilities and need for extraordinary


72 A. G. Bell, for example, supported the work of the Immigration Restriction League that lobbied for curtaining the immigration of certain supposedly inferior groups and individuals. For Bell and the IRL see Greenwald 2005, 175-185. For the history of eugenic influences on immigration policy more in general see e.g. Stern, Nation, ch. 2; Douglas Baynton has given a thoughtful analysis and striking examples of how disability influenced the immigration process. See Baynton, Defectives.
self-control outweighed the negative diabetes trait when it came to procreation.73

To understand how eugenic worth was negotiated and why restrictions affected some groups more than others, it is necessary to take into account longer-standing, established policies, social relations and institutions. Carey has demonstrated how eugenicists employed this relational network for restricting the rights of “feeble-minded” people. In early 20th century America, individuals with intellectual disabilities were embedded in families, communities or institutions where they were considered child-like wardens in need of guardianship. Eugenic measures could be easily incorporated into these systems that framed the restriction of individual rights as a matter of paternalistic charity, scientific objectivity or the social good. Especially in institutional care, power and agency were concentrated on the side of professionals and administrators, while those labeled feebleminded usually lacked the social resources, economic commodities, influential advocates and not the least the sense of coherence or community to develop an effective lobby.74 Deaf education, research of deafness and eugenic measures similarly operated in a framework preconceived assumptions and institutional settings, although deaf people had a more effective lobby.

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Fragile normalcy: Deafness and deaf people as a target of eugenics

On the range of eugenic preconceptions, the deaf stood precariously somewhere in the middle, considered physically (and sometimes mentally) defective, yet also imbued with the potential for rational thought and productive citizenship. While coercive measures were usually dismissed, deaf people’s positive traits were not enough to outweigh their negative eugenic impact on the nation’s hereditary make-up. Moreover, in an era that equated the ability for speech and lip-reading with intelligence, especially those stigmatized as ‘oral failures’ easily found themselves labeled as feebleminded, retarded or criminal. Although deaf people were not explicitly included in various state sterilization laws, individuals thus might have found themselves within the reach of sterilization legislation. As in the first third of the 20th century eugenic thought combined with older presumptions about able-bodied (white and male) civic fitness, the civil rights of deaf people were challenged in a multitude of ways. Marriage and reproduction, eligibility for acquiring a driver’s license or for partaking in New Deal programs where only some of the contested topics. Debates over deaf intermarriage and reproduction in particular intensified again in the 1920s, as eugenic publications indiscriminately included the deaf into the class of defectives, and discussed the need for health certificates prior to marriage.75

75 Burch gives the fullest account of right restrictions during the progressive and eugenic era. See Burch 2002, Resistance, ch 5. There is scarce evidence on how many deaf people were sterilized on eugenic grounds and how eugenic propaganda affected marriage patterns. Lane, Hoffmeister and Bahan claim that eugenics’ “well-publicized pursuits let untold numbers of Deaf people to abandon plans for marriage and reproduction or to submit to voluntary sterilization, and untold numbers of hearing parents to have their Deaf children sterilized,” yet do not provide evidence. See Lane; Hoffmeister; Bahan, Journey, 381.
Unlike the ill-defined and heterogeneous group of the feeble-minded, deaf people, with their local and national organizations, newspapers and sense of community possessed a certain amount of lobbying power and social standing. Organizations of deaf people advocated – with at least partial success – against being included into the biosocial categories of 'defectives.' Extensive campaigns portrayed them as productive, educated and patriotic citizens. These campaigns, Susan Burch and Octavian Robinson pointed out, came at the cost of excluding deaf people who, supposedly, did not fit these criteria. Perpetuating contemporary notions of civic fitness, capitalist productivity and bodily normalcy, the National Association of the Deaf (NAD) carefully policed the public image of deaf people. Publications increasingly emphasized the healthy deaf family that adhered to middle class standards and – importantly – produced healthy, hearing children. Such politics were revealing for the power structures within the Deaf community. Its leaders usually were white middle-class males, often adventitiously deaf, who could safely distance themselves from charges of being a pauper, defective or degenerate. In doing so, this elite distanced themselves, as Robinson put it, from "people dangerously classified as 'other'" – the congenitally deaf, racially other and multiply disabled. These tensions, which historians have only recently given attention, challenge the idealized notion of a unified and uniform deaf community.

Eager to prove their own normalcy and worth, deaf people rejected the labels of disability and eugenic defect for themselves, but did not deny the existence of these categories when applied to others – a strategy found among

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76 Robinson, Class, 7. Robinson also produced a poignant critique of the capitalist ideology underlying these assumptions.
77 Burch, Resistance, 149-152.
many groups targeted by eugenic rhetoric. Such ableist assumptions found their expression in diverse NAD policies throughout the first third of the century. In 1907, for example, NAD president George Veditz suggested the establishment of a committee tasked with lobbying against any insinuation that the deaf should be grouped with the proper targets of eugenic measures. Similarly, schools of the deaf increasingly excluded or segregated “feeble-minded” students. Terminology was another concern of NAD activism, and one where the interests of the culturally deaf community overlapped with those of advocates of oralism. Both camps advocated the use of ‘deaf’ to instead of the older ‘deaf and dumb’ due to its unfavorable associations with mental deficiency. Finally, in 1920, the NAD passed a resolution that spoke out against marriages of two congenitally deaf persons. The NAD thus pursued, as Susan Burch put it, a policy of “personal persuasion over litigation.” The deaf, so went the message, did not need outside interference to comply with the ideals of (eugenic) citizenship. To many deaf people, as to their hearing contemporaries, eugenics was an attractive means of social reform. If such scientific reform required some people to relinquish some of their rights and freedoms, this was taken as an unfortunate yet necessary sacrifice for the bigger good – as long as oneself was not affected.78

Alice Terry: Healthy motherhood, women’s rights and the right kind of eugenics

A 1918 article in the Silent Worker, the main newspaper for and by deaf people between the 1880s and 1920s, tried to accomplish this balancing act between embracing eugenics as a science and system of moral guidance, yet

rejecting the inclusion of deaf people within the category of “defectives” and “degenerates.” Featured prominently on the first two pages of the March edition, the article showcased a photo of the author, Alice T. Terry (born 1878), a deaf writer living in California. Underlining Terry’s claim to educated opinion, the picture shows a well-dressed woman looking confidently into the camera, an open book in her hands. Deafened at age nine, Terry had visited the Missouri School for the Deaf and later continued her education at Gallaudet and Marionville College in her home state of Missouri. A member of several Deaf clubs and organizations, Terry wrote for a number of their publications, including more than 50 articles for the *Silent Worker* where she covered topics as diverse as education and women’s rights, art, literature and entertainment and the history and state of the deaf community.

A defense of the right kind of eugenics rather than an outright rejection, Terry’s article demonstrates a deeper engagement with the scientific underpinnings and value system of different national and international strands of the eugenic movement. She opened with a theme familiar to many readers: the unfair inclusion of deaf people in recent debates over marriage restrictions, sterilization, and fitness for parenthood. She chastised such “sensational” accounts as the outpourings of “men poorly informed, ambitions, unscrupulous who substitute prejudice and second hand information for first hand knowledge and actual experience as much as they dare.” Determined to repudiate such “wholesale abuse hurled against us,” Terry had turned her “attention to biology

79 Terry, Alice. T. 1918. “Eugenics.” In *The Silent Worker* 30 (6): 2-3. The complete volumes of the *Silent Worker*, including Terry’s articles, have been made available online by the Gallaudet University Archive at http://www.aladin0.wrlc.org/gsdl/collect/gasw/gasw.shtml.

80 Burch, *Resistance*, 67-70. For the history of the Silent Worker see e.g. Easton, *Silent Worker*. 
and eugenics, and for two years this special branch of science has been my devoted study.” Her reaction to eugenic literature – “a world of interesting and astonishing facts” that was “beautiful and touching in the extreme” – reveals something of the contemporary fascination with heredity and biology.\textsuperscript{81}

To defend deaf people from the “wrong” kind of eugenics, Terry skillfully contrasted the supposedly misguided American eugenics with its unspoiled variant in England, the motherland of eugenics. This was, at best, an idealized reading, that turned eugenics’ founding father Francis Galton himself, deafness expert Dr. Love Kerr and, foremost, British scientist Dr. Caleb Williams Saleeby into proponents of a purer and more just eugenics. With Saleeby (1878-1940), one of the main protagonists of early English eugenics and founding member of the English Eugenic Society, Terry introduced her readers to a form of eugenics that emphasized social hygiene and environmental reform, and rejected “class eugenics.”\textsuperscript{82}

Along with Saleeby, Terry sided with a branch of eugenics that was committed to progressive reform, women’s rights, temperance and education, public health and social reform. Like many of her contemporaries, Terry considered alcoholics, the feebleminded and insane a “dependent, irresponsible class of people.” Yet only the “sham eugenist” would ever commit the “unpardonable insult and injury” to include the “educated, self-supporting, tax-paying, responsible deaf or deaf-mute citizen” in his calls for indiscriminate

\textsuperscript{81} Terry, \textit{Eugenics}, 2-3.
sterilization of all undesirables. Denouncing this “cry for wicked, mutilative surgical operations upon any class of unfortunate people,” Terry carefully set up a distinction between the true eugenicist pursuing his “noble subject” and “the pseudoist, the quack and the impostor” who is “infinitely a greater menace to society than are any of the unfortunate whom he seeks to further crush or destroy.” She embraced Saleeby’s notion of preventive eugenics that protected the unborn from the “racial poisons” of alcohol, venereal disease and harmful environment, a move that enabled her to refute the common claim that heredity was the main cause for the “alarming increase of deaf-mutism.” Scientifically, this could not be true, Terry explained to her readers. Because Mendel’s law of variation rearranged the defective or normal units of germ cells by chance, the defect would “sooner or later crop out.” Rather, “unnatural” living conditions were to blame, causing degenerative conditions such as hearing loss, tuberculosis, nervous disease, and premature birth.  

Yet not all forms of deafness could be thus explained and prevented; some cases must be hereditary. Reconciling the eugenic “desire that every child be well-born” with deaf people’s right to marry required an often uneasy stratification of reproductive rights. Not only should deaf people marry, Terry was convinced, it was “natural” for them to intermarry and form a “love marriage.” When it came to childbearing, however, it became “necessary to discriminate.” If a couple’s family history indicated a likelihood for passing on deafness, the couple “should refrain from parenthood.” To justify this distinction, Terry once more relied on Saleeby, who had dedicated several pages to negative eugenics and deafness. Only if deafness was truly “mendelian or genetic,” Saleeby

wrote, deaf people should refrain – voluntarily – from parenthood. This, Terry believed, was “good and sensible advice, it constitutes real negative eugenics that is to discourage the bringing of possibly more defectives into the world.” The best means to achieve this end, Terry was convinced, were education and persuasion. “All that the deaf need,” she appealed to her audience’s sense of civic responsibility, “is enlightenment. Ever desirous of being a useful asset to society” deaf people would – and should – embrace eugenics. Many, she believed, already had some awareness of the laws of heredity. Most deaf parents resented their deaf child marrying another deaf person, “instinctively” afraid of thus passing on deafness. “When they can grasp true eugenics in like spirit,” she asserted, “then they, the congenitally deaf, can better realize their responsibility to the race, to posterity.”

Oscillating between sympathy for the individual and eugenic demands for the population, Terry struggled with portraying the hereditary deaf as socially worthy, yet somewhat eugenically defective, a voiceless “they” who, for the sake of a better future, needed to curb their desire for parenthood. By embracing Saleeby’s voluntary eugenics, his “appeal to the conscience, the eugenic sense of these persons,” she deflected eugenic restriction and coercion to the level of the married couple’s personal responsibility. The motivations for such restraint, she inadvertently admitted, were as much due to social misconception as eugenic truth:

Once they fully realize that they as a class are not properly appreciated or understood, that instead they are classed with the unfit, the insane, the

84 Saleeby, Progress, 203-209.
85 Terry, Eugenics, 2-3.
86 Saleeby, Progress, 183.
feeble-minded, the diseased, the criminal etc., they will naturally wish to avoid bringing into the world possibly more deaf children to share the same unkind fate.

Redirecting social prejudice to a subsection of the deaf population, Terry could safely distance herself and her family from the strata of defectives. “My own children,” she assured, “have escaped, they are entirely normal, there being no trace of hearing loss in either our immediate or remote ancestry.” Yet some unease remained. “Somehow,” she admitted, “I am writing these plain facts with reluctance, knowing as I do what a fine mother is the average deaf-mute mother.” It was exactly eugenicists’ exaltation of the “divine right of motherhood” that made abstaining from it seem so “unjust or cruel.” Yet, she reminded her audience, such sacrifices in the name of race betterment would only affect a minority. “[R]emember we are discussing only hereditary deafness,” Terry buffered the impact of maternal restraint. For the unaffected rest, for women like her, she could promise partaking in the eugenic cult of the healthy woman destined for motherhood.87

Eugenics as a means of progressive reform and public health:

Professional approaches

Professionals working with deaf people, too, pursued a policy that distanced their charges from any association with the defective and degenerate, without questioning the validity of the underlying assumptions of social deviance and bodily worth. There was, sociologist Harry Best remarked in his seminal 1914 survey of the American deaf, no need to treat deaf people in any

87 Ibid., 3. For a discussion of motherhood and eugenic rhetoric see Kline, Race, 7-31.
special manner. The “exertion of moral suasion” was far preferable to
generalizing legislative action. Pointing to the success of deaf people in achieving
civil rights, Best advised that apart from providing education, “the state may
practically let the deaf alone.”

Like educators more generally in the first decades of the century, teachers
for the deaf discussed the inheritance of mental traits, the respective importance
of nature vs. nature, and the most efficient organization of the educational
system in sorting, developing and deploying individual abilities. A 1919 report
on Standardization Efficiency, Heredity at schools for the deaf, prepared by the
Standardization and Efficiency Committee of the Conference of Superintendents
and Principals of American Schools for the Deaf, speaks to the contemporary
fascination with progressive school reform, and the role of eugenics in this vision
of streamlined education. The report addressed the role of schools for the deaf
and students’ position in society, warning that “today we are facing the greatest
question ever presented to our social life – that of abnormal mentality and
feeblemindedness [...] which are filling our public schools, our custodial
institutions, and our general life, with socially unfit and defective classes.” The
deaf, however, the report insisted repeatedly, did not generally belong to this
group. On the contrary, schools for the deaf graduated their charges into the very
classes that through their hard work and high morals were America’s “bulwark
of liberty.” Classing the deaf with the intellectually and morally deficient

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88 Best, Harry. 1914. The deaf; their position in society and the provision for their education in the
United States. New York: T.Y. Crowell Co, 57, 323. Best’s 1914 survey was the first large-scale
sociological study of the American deaf population.
defectives was “ridiculous” and inflicted “upon the deaf of an unnecessary brand.”

To refute “such wild assertions as ‘sterilize the deaf’ – ‘make it illegal for them to marry’ – ‘shut them up in asylums’ – fine and imprison them for having children,’” the report, too, mobilized popularized knowledge of hereditary mechanisms. If sterilization was to be effective in preventing deafness, it should not only affect deaf people, but also the “‘hearing-carriers’ of a latent defect,” including those in which one suspected a hereditary disposition. In Indiana alone, the report remarked, there were 12,960 such carriers that would have to be sterilized “if heroic measures are to be adopted to stamp out deafness.” Such a move was neither advisable nor manageable. It was outright “ridiculous.” Emphasizing that the defect of deafness resided not only in deaf bodies, but to a much greater number in hearing ones, Johnson depathologized the deaf and moved them closer to normalcy.

The report ended with a resolution of protest, signed by the superintendents and principals that attended the association’s 1919 meeting in Columbus, Ohio. They severely condemn[ed]” the fact that schools for the deaf remained listed as “charitable and benevolent institutions,” supervised by boards of charities who referred to the students as “wards” and “defectives.” Rather, schools for the deaf belonged among “normal” educational institutions. The Clarke School, too, offered “no charity,” but regular education. In 1896 already, it had changed its name from “Clarke Institution for Deaf Mutes” to

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90 Ibid., 197-198.
91 Ibid., 256.
“Clarke School for the Deaf,” a move that in declaring oralism’s triumph over muteness and the associated condition of dumbness, distanced the school from institutions for the subnormal and defective.92

In the 1920s and '30s, educators for the deaf continued to observe developments in eugenics, and, by and large, excluded their students from coercive measures. At the 1935 Conference of the American Society for the Hard of Hearing in Cincinnati, Elbert A. Gruver, an Ohio educator and director of Bell’s Volta Association, commented on the developments in Germany. There, the 1933 Law for the Prevention of Hereditarily Diseased Offspring included the deaf along with the blind, the mentally disabled, and others deemed defective. Although so far “about 60,000 defectives have been subjected to sterilization,” Gruver remained unsure of the law’s effect. Yet, he amended, “[s]everal generations may bring a different story.” Watching this large-scale scientific experiment from afar, Gruver did not see its applicability to the American deaf. He could imagine “no person who has lost his hearing who would willingly bring a child into the world to suffer the same experience.” Generally, deaf intermarriages were not a sign of deaf people’s selfishness, he assured his audience: “I do not believe that the young people who are contracting these marriages are selfish; I think they are merely uninformed.” Acting with the same sense of educational mission that characterized the Clarke School, Gruver asked: “Is it not our duty to teach them?”93


Such idealized standards point to the increasing stratification within different branches of special education. Both schools for the deaf and for the “feeble-minded” had been founded in the mid to late 19th century with a shared belief in the power of education to reform the individual, and to restore the disabled to social participation and economic usefulness. By the 1910s and 1920s, however, educators and researchers in the field of intellectual disability increasingly talked about their charges using the eugenic language of hopeless. Psychologist Henry Herbert Goddard’s famous research on the Kallikak Family is just one notorious example for the close connection between contemporary discourse on psychology, eugenics and education (or, in other words, the malleability of intellect and behavior). Goddard had played a crucial role in introducing and promoting intelligence tests in the US, and was well respected in the fields of psychology and special education. As head of research of the Vineland Training School for Feebleminded Boys and Girls, he had traced the pedigree of one of the students, “Deborah Kallikak” and had come to the conclusion that feeble-mindedness was a recessive trait that predisposed its carriers to a life in amoral misery and stupor. Social deviance and intellectual inferiority thus was really a matter of biology, a trait of a hopelessly defective class of people that could not be elevated by social or educational reform.94

Driven by financial, pedagogic and eugenic motivations, institutions for the feebleminded thus began turning from improving and educating their charges to merely providing more cost-efficient custodial care and behavioral training. The directors of such institutions often shared the more widespread concern over the social burden caused by feeble-mindedness and considered institutionalization a eugenic as much as a pedagogic instrument. Similarly, sterilization could be cast as a means to protect society and to suppress individual social, moral and sexual deviance. Educators at other institutions – including those for the deaf – increasingly tried to rid themselves of those mentally and physically defective individuals that were considered lost to pedagogical efforts.95 “Admission into schools for the deaf has become more and more like that in the regular schools,” Harry Best explained in 1914. They generally “are open [...] only to those able and fitted to be educated, and the mentally and physically disqualified are often rejected.”96

Comparing how notions of invisibility, normalcy and disability played out in perceptions of feeblemindedness and deafness provides an interesting contrast. The most dangerous feebleminded, Goddard claimed, were not those whose defects were clearly visible. The real danger, he asserted, came from the high grade feeble-minded, who could pass as normal to the untrained eye and – unless eugenicists intervened – would perpetuate their moral and intellectual


96Best, Deaf, 252.
deficiencies in their progeny. Whereas with the deaf, invisibility was coded with hidden suffering and the potential for normalcy, the invisibility and apparent normalcy of the feeble-minded signified a threat to future of healthy society. These judgments were closely connected to the growth of evolutionary-hereditarian thought in psychology, psychiatry and the social sciences. In the first decades of the 20th century, Wendy Kline has argued, feeblemindedness and mental delay became more sharply defined “as an outward sign of a fundamental genetic flaw rather than of a slight mental impairment.” By redefining feeblemindedness as moral deficiency, early 20th century eugenic theories defined this group as a “lost race” who had been denied the capacity to advance to civilization.

When it came to their students, educators for the deaf and the intellectually disabled thus employed eugenic thought in different manners. Both groups, however, took part in the larger process of the normalization and standardization of childhood and disability in early 20th century. Eugenics, education and psychology were sciences involved in the growing field of child studies. By the middle of the 19th century, psychologists and educators had begun to map children’s physical and intellectual development in relation to adults and the larger evolutionary scale, of nature and nurture. With its testing, experimentation and standardization, child studies promised the application of modern science at home and in school. In the early decades of the 20th century, schools became the testing grounds for a number of social and scientific

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98 Kline, Race, 25.
99 For an overview see e. g. Shuttleworth, Mind.
interventions that in the name of progressive reform aimed to improve individual, mankind and society. This was doubly true in special education. Here, the contemporary fascination with the otherness of the disabled met with the hopes put into the child, as both groups were placed in an evolutionary framework. The eugenic impulse to stratify society – and school children – by their mental and physical traits went hand in hand with the progressive goal of creating more efficient schools in order to address social, medical and moral issues.

Engaging with questions of heredity, health and prevention, and of standardizing and efficiency, schools for the deaf thus were part of a larger process of norming childhood and education that incorporated a host of sometimes competing, sometimes cooperating disciplines. Educators of the deaf shared the feelings of excitement and necessity that surrounded the multi-disciplinary field of child study. “The application of the results of child-study,” remarked the above-mentioned report on *Standardization, Efficiency, Heredity*, “is so new that it must be more-or-less of an experiment. But it is an experiment of much hope and promise.” The very title of the report – Standardization, Efficiency, Heredity – flashed the key words of a new scientific age in education, and more broadly of the allure of Taylorism that was to streamline industry and social organization. The report was to be the beginning of a new “epoch in the

100 For the influence of capitalism and evolutionary thought on perceptions of disability see e. g. Baynton, *Days*.

history of the education of the deaf;” the first attempt to measure “along scientific lines” the quality and efficiency of deaf schools and the “mental status” of their students. The goal of such modernization, guided only by “utilitarian facts,” was to discard “old theories, customs, and traditions” in favor of new, scientifically proven paradigms that would make schools for the deaf more efficient.102

In this enterprise, two entire chapters were devoted to questions of heredity, respectively dealing with “Mental Capacity and Heredity” and “Classification of Deafness and Heredity.” Eugenics and euthenics, the report commented, are the “[t]wo great subjects of scientific nature engrossing the attention of thinkers today.” Of this much-discussed pair of nature and nurture, the report clearly favored the latter. As “ancestors [...] bind in chains of relentless tyranny (heredity) many of their innocent descendants,” the educators believed, the influence of environment must necessarily be limited. In order to produce “wholesome, right-living offspring,” there was need, then, for the research of heredity in man and its considerate application – a premise that excluded “unwise legislation and harsh and barbarous measures”103

School hygiene was part of this mission for progress through scientific reform, and it meant many things in early 20th century America. It was part of larger public health campaigns to control infectious disease and to improve hygienic conditions. It also included concern over congenital and hereditary conditions. The lofty goal of making schools more efficient and the even loftier goal of eradicating disease and disability required inspecting and classifying

102 Johnson, Standardization, 19, 23, 26, 202.
school children, a measure that had been introduced in the US in the 1890s. Once stratified according to eugenic, medical and psychological criteria, students could be funneled into the appropriate institutions, given appropriate pedagogical and therapeutic intervention. As standardization thus improved efficiency, it was hoped, one could expect better individual outcomes and ease the teacher's workload.104

Educators' hopes to eradicate deafness were part of this larger debate over school hygiene and public health reform. In a 1907 article in the Volta Review for example, James Love Kerr, a widely respected English expert on deafness argued that detecting hearing loss early on would allow for medical treatment and correct educational placement. Establishing a system of “examination and supervision,” Love Kerr believed, would reduce the incidence of acquired hearing loss so drastically that in the future “hardly any but the congenitally deaf will ask admission to our institutions.”105

A general sense of scientific optimism, yet also of urgency characterized contemporary belief in medical supervision. In “recent years,” Harry Best pointed out, “medical science has won some great triumphs,” raising high expectations for the future prevention of deafness.106 Writing on “Heredity and intermarriage,” Linnaeus Roberts, an instructor at the Western Pennsylvania Institution, explained in 1912 that sometimes the “fatal tendency of deafness lurks in the family line” as a transmittable defect that “may produce deafness again.” Yet he too believed deafness to be decreasing. “With the 'spread of

106 Best, Deaf, 25.
intelligence and the progression of sanitary science," Roberts opined, "how could it be otherwise?" 107

Eugenics was as much part of this discourse as was the prevention of infectious disease. Discussing, in 1913, “The Causes of Deafness,” Frank Driggs, superintendent of the Utah School for the Deaf and Blind, similarly remarked on the “necessity of a more careful study of children.” In particular, he hoped for closer examinations of the “exceptional child.” Rather than psychological or pedagogical examinations, to Driggs this imperative meant a detailed study of the causes of deafness, both hereditary and environmental. He was hopeful that such endeavors marked the beginning of an era in which the “breeding of more perfect human beings” would be possible. For this cause, he campaigned for a “better cooperation between the doctor and the teacher in the study of children,” yet also for laws restricting marriage between families carrying the same “defective strain.” 108 Similarly, a 1924 Volta review article on the “Prevention of Deafness and the Teacher’s Responsibility Thereto,” pointed out “two sources of preventable deafness,” namely “the marriage of syphilitics and of those with congenital deafness.” 109

The Coolidge Fund for the Deaf – progressive science and promises of normalization

In its self-portrayal and mission, the Clarke School was very much part of these discourses on studying, preventing, and overcoming disability and defect

through the achievements of modern science. When, in the 1920s, the time came
to raise money for establishing a research department of their own, they could
draw from beliefs in scientific efficiency and progress, yet also from older
motives of charity for the worthy and deserving so that they might uplift
themselves.

It was Bell who pushed the school towards establishing a center of
applied research. In his role as president of the school board, he called attention
to Clarke’s financial situation in the 1921 annual report. In order “to maintain […]
its present efficiency,” the school was in need of an increased endowment.¹¹⁰ In
part, this situation was due to the growth of the student population since the
1870s, leading to an increasing need in buildings and staff. By the mid 1920s, the
school had on average 160 students between the ages of five and fifteen. The
great majority was from Massachusetts; the remaining students from other
states or – telling for the school’s national and international reputation – from
other nations, including Canada, Japan or India. For in-state students,
Massachusetts provided for board and tuition as according to state law; for out-
of-state and international students, board and tuition came to $800. Students
went through primary, intermediate and grammar schools, where, apart from
speech and lip-reading training and academic subjects, they were taught gender-
specific skills, such as “sewing, cooking and light housework” for the girls and
cabinet work or sometimes printing for the boys. Great emphasis was put on on
“develop[ing] the moral and social side of the child’s nature.”¹¹¹

¹¹¹ Clarke School Annual Report 1927, 12, 26-27. The annual report also regularly printed a copy
of the Massachusetts Law in Regard to the Education of the Deaf, see in this version page 40.
Yet Bell's plans for an increased endowment went beyond improving buildings and adding staff. He hoped to “broaden [the school's] scope” and envisioned a future research department that would – like his own work – integrate science and education to tackle the problem of deafness. Research was to include psychology, improving speech and residual hearing and “[i]nstruments for amplification of sound.”

Bell did not live to see his vision realized; he died in 1922. But the school was once more able to mobilize well-known figures to help them raise money for its ambitious plans. In particular, the President and First Lady, Calvin and Grace Goodhue Coolidge became involved with the fundraising. Before her marriage, Grace Goodhue had worked at the Clarke School. As a “young teacher endowed with rare gifts of tact, graciousness and sympathy,” she had given “herself wholly to the work of guiding little children across the narrow, perilous bridge which leads the deaf to the Promised Land of normal fellowship with their kind.” In 1903, she met her future husband, “a young lawyer of Northampton rooming at a house on the grounds of the School.” Both remained supporters of the school even as Coolidge moved away from Northampton and onward in his political career. In the late 1920s, the presidential name served to draw attention to the Clarke School and America’s deaf.

“Coolidge deaf fund launched,” a November 1927 article in the Pittsburgh Press announced and explained that at a luncheon “[p]lans for raising the endowment were outlined to many friends of the Coolidges and following the discussion the group went to the White House for tea.” Already more than half of

112 Bell 1921, Report, 7-10.
113 Coolidge, 9, 11.
the envisioned sum had been pledged, the article reported. Among the donors were mining engineer and financier William Boyce Thompson who gave $135,000, and with a donation of $100,000 each, businessman Henry L. Doherty, Andrew Mellon, and the founders of the Woolworth Company Fred M. Kirby and Earle P. Charlton.\(^\text{114}\) The eventual list of donors included 150 names, most of them contributing a sum between $500 and $5000. In a November 1928 letter to Charlton, Coolidge expressed his thanks and the hope that the fund “may also help to arouse a greater interest in the problems of the deaf and in this humanitarian work which has seemingly failed to keep pace with progress in other fields”\(^\text{115}\) Coolidge’s letter also included a note of thanks to influential financial journalist Clarence W. Barron, president of Dow Jones & Company, who had used his contacts and business skills to organize the fundraising.\(^\text{116}\) In honor of Barron’s dedication, the research department would later be named after him.

Coolidge’s rhetoric of progress and neglect resonated with other representations of the Clark School. “No special fund now being raised,” a November 1928 *New York Times* article asserted, “should have wider and more cordial response on the part of the people of the United States than the one which bears this name.” In supporting the fund, the article pointed out, donors joined Alexander Graham Bell and the First Lady in the honorable cause of educating the deaf and researching deafness. In a time in which popular opinion and scientific literature despaired over the threat of “defectives” as a group


beyond saving by bourgeois reform, deaf children were singled out as innocent beings worthy of charity. By employing science to uplift this population, the Clarke School engaged in what historian Theresa Richardson has called scientific charity. Educators, reformers and progressive era philanthropists were attracted to the mental hygiene and child saving movements and their visions of a scientifically ordered society. In preferring some causes to others, Richardson argues, philanthropists played an important role in legitimating and disseminating “a medical paradigm in the name of human progress.”

Oralism played a central role in presenting the deaf as a population able and willing to overcome adversity through hard work and the miracles of modern science. Clarke’s alumni, with their “creditable records,” the New York Times’ article continued, demonstrated that deaf children “may not be obliged to go through life dumb.” While deafness itself could not be cured, oralism did away with the outward sign of muteness. Oralism, with its promise of progress and normalization through the science of speech teaching, appealed to wealthy businessmen, from the founders of the Clarke School to the donors of the Coolidge Fund. As so often with charity, this appeal was based more on the idealized self-fashioning of its promoters than the realities of recipients’ lives.

The Coolidge Fund was accompanied by two publications that further appealed to the cause of transforming deaf lives via the educational-scientific miracle or oralism: *A Child at the Clarke School for the Deaf* (1927) and *The


118 Richardson, *Child*, 27.

Coolidge Fund for the Clarke School and the Deaf (1929). Garnering sympathy with its description of deaf children’s normalcy, *A child at the Clarke School for the Deaf* introduced its readers to a “group of little children, bright-eyed “and “expectant” of their lessons. Yet something lurked under this appearance of normalcy. “These healthy, normal looking children, who must put forth such effort to learn a simple name – to whom, slowly, one by one, the names of all familiar objects must be taught – are they under some malign spell?” Conjuring the fairy-tale image of a child beset by a bewildering otherness (a common theme in the portrayal of disability), deafness turned out to be nothing but a temporary setback. Just as a spell can be lifted, deaf children “can be best rescued from this complete isolation of mind by teachers of lip-reading and speech.” Throughout its 30 pages, the booklet contrasted the situation of the “lonely deaf child, frustrated, ‘walled in,’ emotionally at sea” with the humanizing and literally liberating impact of oralist education. Lifting the “[v]eil of silence,” oralism gave children “a power of which they had no knowledge,” thus bringing them “into warm and vital contact” with their environment. “Speech and lip-reading,” the booklet advertised, “are the way out into the sunlight where normal people talk and laugh and weep together.” The school left no doubt that the deaf child was indeed normal, merely an “exiled spirit” to whom oralism gave back its very “own birthright.”

Yet this language of liberation also set up a clear hierarchy of knowledge, competence and agency between helplessly suffering deaf people and the heroic oralist teachers who “liberated these prisoners of silence.” Unlike deaf teachers,

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who had often acted as role models by introducing their students to signing and the larger deaf community, the hearing teachers at the Clarke School stood firmly on the side of hearing normalcy. Likening teachers for the deaf with the “knights of old,” the booklet painted them as mythical figures who would “break through the barrier of deafness,” and in doing so “rescu[ing] these lonely, isolated little minds shut up in their prisons.” Oralist education was presented as an uplifting parable of virtues and rewards, a satisfying moral tale about overcoming disability by hard work. Giving the deaf child the “tools” for success, teachers demanded “[p]atience and eagerness and determination.” If “he works,” the booklet promised, “he will learn to be more like other children” – a logic that implicitly associated the non-oralist deaf with a lack of work ethics and determination.  

Unspoken, yet always present in this glorification of oralist success was its negative counterpart, the scenario to be avoided at all cost: The deaf child who would grow up to associate with the deaf community, who would segregate himself from hearing society, marry a deaf partner and thus perpetuate deaf difference linguistically, culturally and physically. As A. G. Bell had explained in his *Memoir*, “[s]egregation really lies at the root of the whole matter.” While the Clarke School could not (yet) fulfill A. G. Bell’s ideal of co-educating deaf and hearing children in day schools, it followed the principle of maintaining a “normal environment during the period of education” in every other way possible. Casting sign language as an “artificial barrier,” the school aimed to create an atmosphere in which oralism “penetrates behind the child’s mind.” Deaf children, the school insisted, “must not be institutionalized nor segregated.” In a

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121 Clarke School, Child, 18-19.
time when the segregation and institutionalization of disabled people seemed like the solution for a host of social problems, the Clarke School went to great pains to make clear that for the deaf, residential schooling was only a temporary means of normalization. Their adamant assertions of their students’ inherent normalcy were a defense from old prejudices and new eugenic stigma. Oralism, the booklet emphasized, made it possible for students to eventually return to their homes and hearing society at large, transformed and enabled to engage with their surroundings. By turning deaf children into “responsible citizens” who “in many case make contributions of great value to the sum total of human achievement,” the school believed to perform an important social service to the public. Preventing the “tragedy of waste,” the school “for sixty years has done its work of saving for usefulness and for individual development a whole group of handicapped persons who are not able to save themselves.” In keeping with the spirit of progressive American citizenship, individual redemption came through the realization of one’s capitalist productiveness.122

Whereas *A child at the Clarke School* focused predominantly on the school’s educational work, the 1929 *The Coolidge Fund for the Clarke School and the Deaf* turned deafness into a much wider humanitarian concern. The booklet painted a dire picture of the situation of America’s deaf. The problem of deafness in the United States, thus the claim, was severely underestimated. The 1920 US census had counted roughly 53,000 deaf people. By including the hard-of-hearing and those with moderate hearing loss, the *Coolidge Fund* turned deafness into a problem affecting an estimated ten million people. These numbers pointed to “vital need for an organization which will meet and grapple

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122Bell, *Memoir*, 45; Clarke School, *Child*, 10, 21, 27.
with the problem of the deaf in America on a national scale.”¹²³ Such lack of organizational backup, however, was true only from an oralist point of view—and even there only expressed the partial truth of fundraising rhetoric. By the early 20th century, a host of organizations addressed deaf people’s concerns, among them national organizations of educators, the highly active National Association of the Deaf or Bell’s Volta Bureau.¹²⁴

Yet there was no school-based research unit that approached deafness from a medical, scientific and pedagogical angle. As deafness had long been treated as “an incurable affliction,” the Coolidge Fund informed its readers, “we are today further behind in adequate practical dealing with the problem of deafness than with any other social problem.” Such wording rendered deafness as a social ill, a (potentially curable) disease at the scale of polio, tuberculosis and other afflictions deserving of large-scale public attention. And yet, the authors lamented, society still was ignorant about the fate of the deaf: “The plight of the deaf is not, like that of the blind or the crippled, obvious.” Because “they look like us, we suppose they must be like us,” the book described the harmfully naïve perception that left people unaware of the “depth of misery [...] hidden under their apparent normality.” Contrary to the attempts of the deaf community to assert their autonomy, the Clarke School stressed the pathological otherness of those who had not yet been reached by the normalizing effect of oralist education. It was then, to bring Coolidge Fund’s reasoning to a close, just


¹²⁴ For organizations of deaf people see Greenwald, Bell, 23, 66; Van Cleve; Crouch, Place, 93. While there was no other school-based research organization, in 1923 the Johns Hopkins University had started an Otological Research Laboratory under S. J. Crowe that mainly focused on environmental causes. See Crowe, S. J., and John W. Baylor. 1939. “The Prevention of Deafness.” Journal of the American Medical Association 112 (7): 585-590.
this hidden normalcy that allowed for the salvation of the deaf by the means of education, medicine and science. This, exactly, was to be the goal of the school's research division.\textsuperscript{125}

**The Clarence W. Barron Research Department: Patterns of collaboration and tension**

In 1929, Henry D. Wild, head of the school's corporation, could report that the fundraising for the Coolidge Fund was complete, thanks to the “the reputation of the School and the loyalty of its graduates.” The school, Wild assured, would continue to function “much as before,” yet “with even greater efficiency” now that “special attention” was given to research on deafness.\textsuperscript{126} Eventually, three divisions were established: Psychology, heredity research and experimental phonetics. The divisions gradually began working over the next few years, depending largely on the availability of suitable researchers.

In 1928 already, the school capitalized on its close connections to neighboring Smith College and its psychology department. German Gestalt psychologist Kurt Koffka, newly appointed William Allan Neilson Research Professor at Smith, agreed to direct research and began looking for coworkers and assistants.\textsuperscript{127} Research was to explore the emotional and intellectual differences between deaf and hearing children, with particular emphasis on their “conscious thinking.”\textsuperscript{128} In 1930, again through the connection with Smith

\textsuperscript{125}Clarke School, *Coolidge Fund*, 3, 18, 42, 47, 48.
College, the school had found a suitable candidate for doing heredity research: Anthropologist Morris Steggerda, who had already began investigating different patterns of inheritance. Finally, in the 1932-33 school year, the division for experimental phonetics began work under Clarence V. Hudgins. Studying the speech of deaf and hearing individuals, the division’s goal was to “eliminate some of the defects” in deaf people’s speech, and thus to improve oralist education. Later, the division also would explore the use of assistive devices, such as hearing aids.

The long-standing connection with Smith College allowed Clarke to maximize its resources. Both institutions had long worked together. Over the years, several Smith professors presided over Clarke’s board of trustees and by the late 1920s, the school closely cooperated with Smith’s departments for education, psychology and spoken English. Its “Normal Class for Teachers of the Deaf,” for example, profited from a lecture class on psychology given by various member of the college’s psychology department. Conversely, for Smith College faculty such as Steggerda and Koffka, the school provided access to an attractive research population, data and, equally important, access to staff to pursue the more menial daily tasks of research. School staff, mostly teachers with little background in research, were assigned to (or, presumably volunteered) to work in the phonetic, psychological and heredity research division. With the exception of phonetics research, (a profession not well established at Smith), a division of work developed between Smith College PhD

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131 Numbers, Word, 92.
132 “Normal Class for Teachers of the Deaf.” Clarke School Annual Report 1927, 29
level researchers, mainly responsible for devising research programs and analyzing data, and school staff, who along with their other tasks, observed and examined children, recorded and filed data. These encounters and collaborations between Clarke School staff, steeped in oralist beliefs about the nature of deafness and deaf people, and outside scientists who potentially had different perspectives and interests were not always without tensions and moments of disconnect. Below, I will explore in more detail what it meant when these two groups came together and negotiated the meaning of heredity, psychology, and applied science.

For the school, it was clear that the research division was another opportunity to maintain the school’s leadership in the field of oral education. Since its foundation, Wild wrote in 1930, Clarke had proudly “led in the building of new ways in the most difficult form of education known.” Conscious “of its new opportunity and of its increasing responsibility,” it now was pioneering again in the “unexplored field” of research that held much promise. All three fields of research were to contribute equally to the improvement of deaf education through science. The study of psychology, Wild noted, “may well lead to discoveries from which much practical pedagogical value may be gained.” Similarly, he believed, the time might be “ripe for addressing ourselves to the possible hygienic prevention of deafness through the study of hereditary processes.” In this field, the school “may again seize an unusual opportunity in sponsoring progress.” In this vision, heredity research became part of ensuring the school’s future success in achieving scientific progress and social amelioration. “For us,” Wild concluded, “the chief thing is that the psychological,
as well as the biological, study of deafness must inevitably lead to practical classroom benefits.”

The goals of Steggerda, Koffka and other outside scientists engaged in the Clarke School research were not necessarily so clearly centered on education. Whereas the school staff was invested in its holistic vision of science as a means for forming productive citizens and full human beings, they were at home in the world of academic science. The school’s exclusively oralist framework certainly influenced how they approached their research, especially since most of them had not worked on deafness or with deaf people before. Now, they began their work in an environment in which their encounters with deaf children were mediated and monitored by teachers and staff members. Unlike these teachers, however, outside scientists were not obligated to oralism; nor did they take the role of the oralist teacher as a paternalistic guiding figure. Instead, they approached deafness and deaf students with the distanced gaze of the scientist apprising an interesting population that could enlighten questions of inheritance, psychology or language.

Within the very set-up of the research department there was, then, a range of professional paradigms in regard to deafness. To be sure, with very few exceptions professionals in this period considered deafness a disease, pathology or disability to be fixed, ameliorated or prevented. Yet even in the 1930s, what was to be fixed and how depended on one’s professional outlook and personal beliefs. Thus, where historians of deafness have emphasized the unity and dominance of the oralist paradigm (usually with little distinction), I argue that these increasingly diverse professional paradigms are the germs for the

development of later receptiveness for more diverse (and, potentially, less pathological) perception of deaf people and deafness. In the remainder of this chapter, I will trace such tension and overlap by example of the psychology department.

**Gestalt psychology, child studies and oralism in Northampton: A confluence of influences**

The orientation and course of psychological research at the Clarke School was greatly influenced by its association with Smith College. In the late 1920s and early 1930s, the college was the American center of Gestalt psychology, an exclave of German-speaking emigrants who would soon become influential in US psychology. More worldview than a closed system, Gestalt psychology had begun its rise in Germany during the 1910s, building on the older traditions of experimental, physiological and phenomenological psychology. Experimental in methodology and philosophical in outlook, Gestalt psychologists searched for the organizational principles that steered human perception. These were so called Gestalten – structured wholes, configurations or units that were an expression of mind or brain structures, or even reality itself.¹³⁴

Gestalt psychology was exceptionally well suited for the kind of psychological studies that the Clarke School envisioned. Unlike the behavioral school that dominated most US psychology departments at the time, Gestaltists believed in gaining insight to one's perception, thought and mind, something oralist educators considered essential for work. Gestalt psychologists’ interest in

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the sensory dimension of perception – rhythm and sound, tone, color and shape – correlated with the desire of oralist educators to understand the mechanisms of speech and lip-reading. Finally, Gestalt psychologists were closely connected to the leaders of educational and developmental psychology, or were themselves active in these fields.\textsuperscript{135}

The school then shared with the Gestalt psychologists they hired a holistic understanding of the deaf child in its surroundings. Yet there were also significant differences in how the school and the psychologists thought about deafness and deaf people. As these psychologists engaged with what they considered a fascinating research population – namely deaf children – they came to conclusions that were at odds with the oralist paradigm (a pattern that would emerge, too, in the school’s heredity research). In particular, they began to relativize the practice of measuring deaf people by the standards of hearing society, and began to explore the social interaction between the deaf and hearing.

Relating psychological research at the Clarke School to different psychological schools adds nuance and subtlety to the history of how we perceive the normal or abnormal self, sensory differences and social relations. The Clarke School, I argue, offers an unexplored look at the early history of

\textsuperscript{135}If one takes into account the expansion of personality research and social psychology in this era (admittedly not well explored by historians), American psychology in the first third of the century is much less uniformly dominated by behaviorism than it is often portrayed. See e. g. Kruglanski, Arie W; Stroebe, Wolfgang. 2012. “The making of social psychology.” In Kruglanski, Arie W., and Wolfgang Stroebe (ed.). Handbook of the history of social psychology. New York: Psychology Press, 3-17. Farr, Robert M. 1996. The roots of modern social psychology 1872-1954. Oxford: Blackwell. For the connections between Gestalt psychology and developmental psychology see e. g. the works of William Stern or Koffka’s own work. Koffka, Kurt. 1921. Die Grundlagen der psychischen Entwicklung; eine Einführung in die Kinderpsychologie. Osterwieck am Harz: Zickfeldt; and the English translation: Koffka, Kurt, and Robert Morris Ogden. 1925. The growth of the mind; an introduction to child-psychology. New York: Harcourt, Brace.
Gestalt and social psychology in the US – a history in which the study of deafness played an important, yet so far overlooked role. It is here that we can see the germs of later socio-psychological definition of deafness, of deaf people as a minority group. This is contrary to predominant narratives that see the origins of such thought in the activism of the 1960s and 1970s.

The history of Gestalt psychology at Smith College (and the Clarke School) began with the hiring of psychologist Kurt Koffka at Smith College. His involvement, orientation and contacts would be crucial for the course of the psychology division over the next thirty years. Together with Wolfgang Köhler and Max Wertheimer, Koffka was one of the three founding figures of Gestalt psychology. Studying physiological psychology in Berlin, Koffka became interested in problems of audiological and visual perception, e.g. the brightness and contrast of colors, figure-ground perception, or – the topic of his 1908 dissertation – sound and rhythm. In Berlin, he also met Wertheimer and Köhler. Their school of thought soon was attracting a growing number of German and international students. In 1911, Koffka took a position at the University of Gießen where in the following twelve years, his lab became one of the centers of Gestalt psychology. His position in Gießen, however, was not secure; a situation that induced him to emigrate to the US in 1924. He spent several years as visiting professor at Cornell University and the University of Wisconsin and was influential in promoting Gestaltist thought and methodology in the US. With his prestige in the US growing, in 1927 he was offered the very well paid William Allan Neilson research professorship at Smith College. Here again, he attracted students and researchers, turning Northampton into a vibrant center of
psychology where European emigrants met and mingled with their American counterparts.\textsuperscript{136}

At Smith College, Koffka was soon pulled into the plans for the psychological research of deafness at the Clarke School. Busy with his own research, he had agreed to participate in this venture only if he was given both an assistant and experienced researcher. The assistantship was filled by Grace Moore, who was among Koffka’s first students at Smith. Deaf education was a professional and personal interest in the Moore family. Moore’s mother was a teacher at the Florida School for the Deaf; her sister was a student at the Clarke School. While earning her bachelor’s degree in psychology from Holyoke College, she often visited her sister at Clarke. In 1927, Moore became a student at Koffka’s psychological laboratory at Smith College and acted as liaison to the Clarke School. Her 1927 Master’s thesis, \textit{Thought and perception in the deaf child}, is one of the first applications of Gestalt psychology (or, as Moore translated it at this point, configuration psychology) to questions of child development and (special) education in the US. In this topic, she followed her mentor, who in the early and mid 1920s had made important contributions to the psychology of child development.\textsuperscript{137}


\textsuperscript{137}Heider, Grace M. 1927. \textit{Thought and perception in the deaf child}. M.A. Thesis. Smith College, Northampton, Mass. 1927, in particular the section on “Deafness from the Viewpoint of Configuration Psychology,” 25-31. Moore feeling to need to translate what later became an established term indicates the relative newness of the Gestalt school in the US. As Moore was Koffka’s student, we can assume that this translation found his blessing. For Moore’s and Eberhardt’s early work at the Clarke School see Heider, Grace M. 1961. “Erinnerungen an
Finding an experienced researcher for the Clarke School was more difficult. He or she had to possess teaching experience and a background in pedagogical and psychological theory. Here, Koffka finally thought of one of his and Köhler's students, Margarete Eberhardt, who “was the one person in the world, as far as he knew, who had all the qualifications for this many-sided position.”

Born in 1886, Eberhardt had indeed been broadly educated in pedagogy, psychology and music (a combination of interest she shared with more prominent Gestalt psychologists). She had attended the Leipzig Conservatory and Berlin Akademie für Tonkunst, taught languages and music in Germany and the UK, and studied psychology in the hope of pursuing a career in research. This was a difficult path for a woman in German academics in the 1920s. The philosopher and psychiatrists Karl Jaspers, for example, rejected her outright because she was a woman. Others, among them Köhler, Koffka, influential Hamburg psychologist William Stern and philosopher Ernst Cassirer were impressed with her experimental work on the perception of sound, tone and color. Given these difficulties in establishing herself in German academia, Eberhardt accepted Koffka's offer to join his team in Northampton.


Moore Heider, Erinnerungen, 76.

intelligible.” However, already in June 1929 Eberhardt was offered a position at the University of Hamburg, which she decided to take. Beyond her homesickness, she had not found much satisfaction in teaching undergraduate students at a women’s college such as Smith. Her work at the Clarke School, and her “boundless energy,” “quick perception,” and openness to sharing and learning knowledge were warmly remembered by Grace Moore with whom she remained connected in close friendship.\footnote{Eberhardt, Tagebuch, 65; Moore Heider, Erinnerungen, 77. Due to the 1933 Nazi seize of power, Eberhardt was only to remain in this position for a few years. In 1935, insisting on the freedom of speech, she was banned from teaching and research. She was only reinstated in 1948, when she became lecturer in psychology at the University of Hamburg. In the years before her death in 1958, she developed her psychological-philosophical work, Erkennen, Werten, Handeln. See Gedenkschrift, p. 90; Stadler, M. 1985. “Das Schicksal der nichtemigrierten Gestaltpsychologen im Nationalsozialismus.” In. Christoph F. Graumann, Graumann, Carl F. (ed.). Psychologie im Nationalsozialismus. Berlin: Springer-Verlag: 139-140.}

Koffka looked again to Germany for finding a replacement, and once more, Grace Moore, would bond with the newcomer – although in a manner that the school had neither expected nor approved of. For the 1930/31 school year, the Austrian psychologist Fritz Heider left his position in Hamburg to take a joint position at the Clarke School psychology division and Smith College psychology faculty. Born in Vienna in 1886, Heider had first studied architecture, then philosophy in Munich, Vienna and Graz. The Graz circle of Gestalt psychologist under philosopher and experimental psychologist Alexius Meinong influenced Heider’s later approach to social psychology. Unlike their Berlin counterparts, who placed the static psychological subject in a physically fixed field, the Graz school believed that the subject’s intentional acts shaped this field in first place, a
position that would influence Heider’s work on social psychology and the psychology of deaf people.\textsuperscript{141}

Heider did not enter academia immediately after graduating. Instead, he spent some years wandering around Europe working in diverse and eclectic jobs, including as an electrician, school counselor, gardener and teacher. Eventually, he went to Berlin, where attended the Gestalt group’s seminars and lectures and became part of their social circle. In 1927, he was offered a teaching position at the University of Hamburg Psychological Institute, led by William Stern, a leader in the young fields of childhood and individual psychology. It was Stern who, in 1930, recommended Heider for the position at the Clarke School and Smith College. Heider, whose family had contemplated emigrating to the US during his childhood, accepted, and in August 1930 arrived in Northampton. There he was welcomed by Grace Moore who showed him around the school and town. The two fell in love almost immediately and within a few months decided to marry; an affair that the Clarke School considered an outrageous scandal. School officials threatened Heider with dismissal; but he and Moore considered their love a private affair and married in December 1930.\textsuperscript{142}

In Northampton, the Heiders became part of a vibrant psychological circle that brought together emigrant psychologists – their number ever growing in the 1930s – and American psychologists. To the first group belonged Tamara Dembo


\textsuperscript{142} Laucken, Heider, 3-4; Heider, Leben, 87-97.
and Genia Haffmann, both emigrants from Russia who had studied in Germany with Kurt Lewin and developmental psychologists Wilhelm Peters. Among the latter group were psychologists Mary Henley, J. J. Gibson – later known for his work on visual perception at Cornell – and his future wife Eleanor Jack, a developmental psychologist concerned with perceptual learning.143 Many in this Northampton circle – Tamara Dembo and Fritz and Grace Moore Heider – would become influential in child, social and rehabilitation psychology. Their work prepared the ground for changing perceptions of deafness and disability in the 1950s and 1960s.

The mind of the (deaf) child – child psychology and the psychology of deafness

When Koffka, Eberhardt and the Heiders began working on deafness in the late 1920s and early 30s, they found a field that, at least on the surface, was occupied with pragmatic educational psychology. For progressive era educators, the young science of applied psychology promised to make teaching more scientific and efficient. Ahead of their colleagues in other fields, deaf educators, in fact, began already in the 1890s to apply standardized testing to schoolchildren, and hoping to establish objective standards. These standards, however, had been developed for hearing children, and it remained a matter of much debate whether they were suitable for deaf children. The first third of the

143 Ibid., 99-103. The encounter of American and German (-speaking) emigrant psychologist has usually been cast as one between two more or less monolithic blocks of Gestalt and behaviorism respectively. See e.g. Ash, Disziplinentwicklung. This perspective, however neglects other circles and psychological schools, e.g. child and developmental psychology or the Graz school of Gestaltism. As Sokal has pointed out for the US, psychology was a diverse and eclectic field, in which variations of behaviorism thought were a strong and sometimes dominant influence, but by no means the only available paradigm.
century saw a boom of psychometric studies of deafness concerned with questions of absolute and relative standards, often conducted by researchers who had little experience in working with deaf children. Their work seemed to show an apparently inevitable lag in deaf children’s emotional and educational development. Yet whether this was a matter of measurement, or of true and innate intellectual inferiority remained unresolved.\textsuperscript{144}

As elsewhere in the early 20\textsuperscript{th} century, then, the impulse to find norms for mental development reflected fears of the subnormal. Beneath the pragmatics of psychology lurked the troubling notion of deaf (ab)normality, of the deaf child stuck and halted in his predetermined trajectory. Such concerns were rooted in already in 19\textsuperscript{th} century child studies with its evolutionary framework. Here, the child was not only scrutinized as an interesting object in itself, but also as a token for the study of language, thought and consciousness, of what it meant to be human. It thus served, as historian of education Sally Shuttleworth has put it, “as an entry point for all the merging historical disciplines of evolutionary biology and psychology, anthropology, and historical philology.”\textsuperscript{145} If the path through childhood was a mirror for man’s evolutionary progress, the child necessarily was an animalistic creature to be civilized, much like the savage, yet more

\textsuperscript{144} In 1889 already, before Binet’s scale was widely introduced in the US, teachers at the New York School for the Deaf introduced standardized evaluation methods and promoted their use at other institutions. Binet’s scale was evaluated in comparison to hearing children by Rudolf Pintner, professor of educational psychology Columbia University and a pioneer in the psychology of deafness. He concluded that deaf children should not be assessed on a verbal scale. See e.g. Pintner, Rudolf, and Donald G. Paterson, 1915. “The Binet scale and the deaf child.” \textit{Journal of Educational Psychology} 6 (4): 201-210. There exist only short chronological accounts of the history of the psychology of deafness, written by practitioners in the field. See Pollard, R. Q. 1993. “100 years in psychology and deafness: A centennial retrospective.” \textit{Journal of the American Deafness and Rehabilitation Association} 26 (3): 32-46, in particular 33-36; Levine, Edna S. 1969. “Historical review of special education and mental health services.” In John D. Rainer, Kenneth Z. Altshuler, and Franz. J. Kallmann (ed.). \textit{Family and mental health problems in a deaf population}. Springfield, Ill: Thomas: xvii-xxvi.

\textsuperscript{145} Shuttleworth, \textit{Mind}, 284, 269, 4.
pliable. In this ontogenetic framework, the deaf child held a special fascination to educators and psychologists. Deaf people’s thought and language had long fascinated philosophers, linguists and, by the late 19th century, scientists concerned with evolution and psychology. As Christopher Krentz has pointed out, “[h]earing Americans often viewed deaf people as mysterious, captivating figures, wondering how they thought, what they experienced, and seeing them as a way to explore what it meant to be human.”

The Clarke School’s concerns about deaf children’s “lonely, isolated little minds shut up in their prisons” also expressed this fascination with the unknown and unexplored. The oralist paradigm equated lack of spoken language with the absence of conscious thought. “No one,” the school reported, “has yet discovered in what terms they think – since they know no word – unless it is in pictures.” Such half unsettled, half intrigued remarks cast deaf children as a strange other, an object of research whose mental life was so different as to be unimaginable. This state, however, was to be only a temporary one from which the child could be saved by the uplifting effects of education. Indeed, the school believed, “psychological research among the deaf [...] does not deal with the abnormal, but with the normal that for a time at least has been enclosed.” It thus could provide “first-hand material that can not be found anywhere else, because here alone it

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146 William James writing on thought and language reportedly was influenced by his personal correspondence with the deaf artist and photographer Theophilus d’Estrella. D’Estrella’s memoirs, in which he describes his childhood of being born deaf, living on the San Francisco streets and only learning sign language late influenced James’ conclusion that abstract thought was possible without language. See Pollard, *Psychology*, 33 and James, William. 1983. *Essays in psychology*. Cambridge, Mass: Harvard University Press, 278-291.


148 Clarke School, *Child*, 6, 18.
has been kept, up to a certain point, free from outside influences”\textsuperscript{149} In this framework, the deaf child embodied an intensification, rather than a deviation from the blank slate of childhood, displaying a naïve, ignorant innocence ready to be molded (after being thoroughly explored) into full humanity.

It was this transformation that the Clarke School hoped to achieve with their psychological research. As Henry D. Wild remarked in 1930, the “possibilities in this unexplored field” were most promising. Studying the “emotional development of the deaf child may well lead to discoveries from which much practical pedagogical value may be gained.”\textsuperscript{150} Educators were deeply invested in the very lives of their students, in turning them into responsible adults and full human beings. For many teachers, this ideal extended well beyond the students’ school years.

For the Gestalt psychologist coming to conduct research at the Clarke School, deaf children were a more abstract research group, and their goals for research thus differed from that of the school. Unlike teachers for the deaf, Koffka, Eberhardt and the Heiders were neither invested in the ideals of oralism nor in the mission to save and normalize deaf children. If anything they were influenced by German reform pedagogy that rejected strict discipline as practiced at the Clarke School as alien to and harmful for children.\textsuperscript{151} For the

\textsuperscript{149} \textit{Clarke School Annual Report} 1930, 13, 14.
\textsuperscript{151} An early anecdote was telling for the conceptual differences between Heider and the school. Heider had some experience working with children at residential schools, yet he was an outsider to the world of oralist education. His first and foremost impression of the Clarke School was that of the “very strict order” maintained, “although certainly by warm and friendly teachers.” There was “perfect order in everything they [the children] did.” This, Heider thought, “was too good to be true” and not a very natural state for children to be in. Curious what would happen if left to their own devices, he set up a classroom with a two-way mirror and asked the teacher to leave the class. Apparently, such lack of supervision was unheard of and puzzling to teachers and students alike. After some moments of confused
more academic psychologists interested in more general phenomenological and psychological questions, the deaf were a fascinating study population, a resource for gaining insight into the human psyche. Beyond this professional interest, however, deaf people remained an abstract group; described in the terminology of experimental science rather than the personal and often sentimental language employed by oralist educators.

Consequently, opinions on psychological research were to achieve and what research results meant differed between school staff and the psychologists, a fact that found its expression in different venues of publication. When Eberhardt and the Heiders wrote for the Clarke School (e. g. in the annual reports) or for oralist educators more generally (e. g. in the Volta Review), they focused on the potential or actual application of psychology for improving education. When they addressed a more general audience of academic psychologists and philosophers they focused on more generalizable, theoretical questions of perception, development, language and social environment. In the early 1940s the Heiders contributed a two-volume study to an American Psychological Association series of psychological monographs. These volumes were certainly meant as a contribution to the growing field of the psychology of deafness and served as a standard reference for many decades. Yet they were also studies of the nature of thought and language and of the makings of social silence, the children began to stir and wrecked havoc on the classroom. The teacher was “shocked at the scene of destruction,” and Heider did not repeat his experiment. What for the teacher was a threat to their carefully established order and the successful civilization of the deaf child, to Heider was an experiment in the (in)stability of social relations and the real (unruly, careless, playful) nature of children. See Heider 1983, Life, 128-129
relations. Their conclusions often relativized, and even undermined oralist beliefs in the primacy of speech or in the absolute norms of hearing society.¹⁵²

**Experimental Gestalt psychology at a school for the deaf: The theory and practice of sensory perception**

Psychology research at the Clarke School pursued two basic methodological approaches that roughly corresponded with these two monographs: The first volume reported on research in experimental psychology that took place in the late 1920s and first half of the 1930s and explored questions of perception, personality and learning. In the second half of the decade, the Heiders mainly focused on the social dynamics in the relationships between deaf and hearing people. Especially this second phase volume turned into an early sketch of Fritz Heider’s psychology of interpersonal relations and was in parts directly juxtaposed to the Clarke School ideology.

Experimental research began in 1928 under Margarete Eberhardt in her one year at the Clarke School. With various experiments and tests, she hoped to find “out what characteristic differences exist between deaf and hearing children as regards their intellectual and emotional make-up, in general, and their conscious thinking in particular.”¹⁵³ When the Heiders began their work in 1930,

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¹⁵³ Eberhardt 1929, *Report*, 25
they continued this line of research, yet expanded its scope. Bringing together Grace Moore Heider's experimental Gestalt psychology and Fritz Heider's phenomenological interest in perception, structures, and social environment, their study of deafness was the most extensive of its time and remained a standard into the second half of the century. At the same time, some of its more radical implications were ignored in deaf education and would only be picked up in the late 1950s professionals in sociology, rehabilitation and psychiatry. In particular, the notion that the deaf were a sociological minority living in a phenomenological different world, and thus could and should not be measured by the hearing majority's standards did not fit with the dominant oralist perspective.

Throughout the 1930s, the Heiders conducted a range of experiments with Clarke School students of various age groups. Students from nearby schools for hearing and deaf children served as comparisons. Children were asked to perform grouping experiments and to memorize words, to talk or write about their experiences, or were observed in free play. The Heiders also used the novel medium of film to observe children and meticulously transcribed their behavior and communication. These studies combined the school's interest in improving the teaching of speech and lip-reading and the psychologists' interest in perception.

These experiments provided useful insights for the school in regard to the psychological mechanisms of deaf children learning speech and lip-reading, and

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154 Apart from Gestalt psychology, these studies were firmly rooted in the booming field of (German) childhood psychology and child studies, referring frequently to the works of William Stern and his wife Clara, child psychologists Karl or Charlotte Bühler or education theorists like Piaget.

155 See Heider; Heider Moore, Studies I and II.
of how, in first place, they mastered learning and thought. Yet this very insight
also had the potential to undermine the oralist worldview. Oralist pedagogy
imagined pre-oral deaf children as a kind of tabula rasa, existing without
language, concepts or generalizations. It was speech that gave the child the tools
to acquire knowledge of the world, and, by providing thought and abstractions,
the self. Yet the conclusions of Heiders’ and Eberhardt’s studies of lip-reading,
personality, and perception contradicted this belief. Eberhardt’s 1928
investigation for example undermined the assumption that the deaf child came
to school without any preconceived concepts. Rather, her experiments had
shown, “the world of the young deaf child is already organized beyond the
perceptual level and that this organization closely follows that of speaking
people.” Thus, she concluded, “language is not essential for organized conceptual
thought, at least during its first stages.”

The Heiders’ research on communication among young deaf children
confirmed this impression. Deaf children, they wrote, lived in “a social
psychological environment.” They were capable of developing “tools of social
intercourse,” such as gestures and symbols, and were just as creative and
inventive in their play and interaction as hearing children. In their gestural
communication, “these young deaf children use combinations of gestures which
are equivalent to real phrases,” a conclusion that ran counter to oralist beliefs.
Yet the Heiders, too, considered gestural communication of limited use in
expressing tenses or abstract concepts.

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156 Eberhard, Margarete. 1940. “A Summary of some preliminary investigations of the deaf.” In.
Heider; Heider Moore, Studies I:1-5, here 5
157 Heider; Heider Moore, Studies II, 6, 14, 17.
Deaf children, the Heiders came to believe, lived in a different perceptual and social world – a thought that Grace Moore Heider had already formulated in her master thesis. Basic tenets of Gestalt psychology influenced this conclusion. Since sensory perception shaped experience, deaf people's speech and lip-reading must in consequence be based on particular “physiognomic characteristics of the words” that were different from that of the hearing. Consequently, differences in perception and pronunciation of words among deaf people could “be directly traced to the lack of the auditory factor in the sensory data of the deaf and to the greater significance of kinaesthetic factors.” Thus, “some of the persistent mispronunciations of the deaf may be individual deviations toward something that feels more suitable or more satisfying than the word as it is taught.”\textsuperscript{158} In other words, what seemed like a mispronunciation to the oralist teacher of the deaf, to the Gestalt psychologist emerged from a different plane of phenomenological experience, one that produced speech differences that were in fact natural in “their own aesthetic and expressive character.”\textsuperscript{159}

The deaf as a social minority: The relativizing effect of social psychology

The Heiders further pursued the notion of a phenomenologically and socially different deaf sphere in their late 1930s research on the social

\textsuperscript{158} Heider; Heider Moore, Studies I, 27, 41-42.

adjustment of deaf adults. Their quantitative survey of alumni from five schools, including Clarke, was the first extensive psychosocial study of deaf adults, surpassing Harry Best’s sociological-statistic research from the 1910s and 1920s. Via mailed questionnaire and personal interviews (for which the method of communication was not recorded) the psychologists questioned a socially and professionally diverse group of deaf adults about their life and experiences. Particular emphasis was put on the question of “what the deaf actually mind about being deaf and what means they use to bridge the gaps produced by deafness.” In presenting their results as a collection of long quotes and narratives intermittently interspersed with tentative summaries, the Heiders retained much of the participants’ subjective and personal insights. Such depictions of lived realities were rare in a period in which professional publications usually spoke about deaf people in a generalizing and often paternalistic clichés. The study’s conclusions, too, were unusual for its time, especially considering its origin in an oralist school: Deafness, the Heiders concluded, was a relational condition, the deaf a “social minority” whose problems were caused at least as much by “the attitudes of the hearing than on the sense defect itself.”

Unlike oralist educators, the Heiders were not committed to the ideal of deaf adults passing as hearing like they had been taught in school. Rather, they were an abstract population by which to study social adaption and interpersonal relations. To do so, one first had to assess and understand the characteristics of this study population. In order to study deaf people’s social adjustment and personality, the Heiders believed, one could not take the normalcy of the hearing

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161 Heider; Heider Moore, Studies II, 69, 130.
person as the unquestioned ideal. Just “as the doctor cannot say whether a given pulse rate is 'normal' until he know whether the patient has been sitting quietly or running to meet an appointment, so we cannot say what is normal for the deaf person until we know what tensions and problems his situation involves.” Rather, their survey set to define in first place “what the 'normal' and expedient ways of adjusting” to deafness were.162

Analyzing deafness from the angle of interpersonal and social relations, the Heiders concluded that much of its disabling effect was a matter of social bias rather than physiological defect, and thus required social change rather than medical solutions. Study participants complained about the “exclusiveness or inaccessibility of the hearing,” and found themselves the target of “active hostility, teasing, making fun of the deaf by the hearing.” Many participants reported that hearing people did not “consider the deaf full human beings.” Struck by the frequency and uniformity of such experiences, the Heiders concluded that the “deaf are probably justified, to a large extent, in this feeling,” leading them to form “a stereotype of the hearing” in turn.163

Given the omnipresence of social bias and exclusion, how did deaf people react – and were some reactions more psychologically healthy than others? For the Heiders, there were several equally valid possibilities that depended on individual circumstances, attitudes, and the “life tone of the individual.” Some deaf people chose to associate with the hearing “in order to be [...] as 'normal' as possible.” Others preferred distance, a reaction the psychologists found perfectly reasonable given that deaf people’s “difficulties arise not so much because the

162 Ibid., 55, 66.
163 Ibid., 85, 87, 95.
deaf are deaf as because other people hear.” There were, they observed, “localized groups of deaf for whom” the problems of dealing with hearing society “may have been reduced to a minimum by the fact that they live almost entirely among people of their own kind.” In these local communities, deaf people usually “communicated by some form of manual system, signs, finger spelling, or a combination of the two.” In the 1940s (and into the 1950s and ’60s) the very acknowledgment of signing adult communities was a rarity in professional literature. Indeed, the Heiders’ monograph was – to my knowledge – the first neutral assessment of the adult deaf community.164

Emerging from research at one of the country’s leading oralist institutions, then, was a definition of deafness as an interrelational social condition, and as a sensory condition that produced its own phenomenological reality.165 Predominantly, the Heiders concluded, deaf people lived “as members of a minority group within a social world in which the majority of people hear and the frustrations and difficulties involved in deafness are largely those created by the adjustment between the majority that has more and the minority which has less.”166 The study was not the first to acknowledge bias and misunderstandings between deaf and hearing persons, yet it was unusual in pointing to its social determinants. In an era in which cultural and physical difference was often conflated with deviance, educators (and often, deaf leaders, too), considered it a deaf person’s responsibility to adhere to linguistic, cultural and social norms. In this framework, failure to overcome one’s adversity was an

164 Ibid., 115, 120-121.
165 In many ways, this approach prepared Heider’s later, influential work on the psychology of interpersonal relations.
166 Heider; Heider Moore, Studies II, 120.
individual rather than a societal problem; indicative of the inability to apply oneself to the tenets of hard work, individual reform and educational uplift. The Heiders, on the other hand located the origin of bias in a dynamic social process in which both sides had formed more or less justified responses. Overcoming discrimination was not the responsibility of the individual victim, but rather was a socially interactive process, something that could only be achieved “when both the hearing and the deaf have a more rational insight into the situation.” Among the deaf, they acknowledged, many “recognize this fact.” 167

Conclusion

There are two important conclusions to be drawn from psychology research at the Clarke School. First, under the apparently unified surface of progressive research, there were clear differences in worldview and professional goals between outside scientists and school staff, and these differences led to divergences as the project went on. Genetic deafness research, I will show in the following chapter, followed a similar trajectory of overlapping and diverging paradigms. These nuances complicate narratives that take for granted that research of disability, deafness and childhood necessarily was a uniform process of medicalization and professionalization that marginalized or muted the perspectives of the objects of research. Clearly, for the Clarke School research results were a means toward their overall goal of transforming deaf children into successful citizens able to pass as “normal” in hearing society. Results that did not align with this worldview were ignored. To the Heiders, on the other hand,

167Ibid., 96. Results in Clarke School reports and Volta Review downplayed these results and emphasized individual responsibility for adaption and reform; a strategy that aligned with the school’s general educational philosophy. See e.g the Clarke School Annual Report 1943, 19-21
who were not obliged to these ideals, it was easy to imagine that deaf people could and should live in a different phenomenological and social sphere. This insight questioned whether an educational policy that aimed at apparent sameness indeed was best for engendering optimal development.

Second, on the level of interdisciplinary alliances it is important to note that the divisions of psychological and heredity research were separate, non-cooperating enterprises. Although it is hard to imagine that in a school and community as small as Northampton, there was not at least a fleeting acquaintance between those working in these two divisions, these potential professional or personal connections did not make its way into reports and publications. Unlike most other psychologists of their era, the Heiders showed little interest in questions of heredity and environment. Likewise, psychology was not among the interests of heredity researchers at the Clarke School. It is then a perhaps ironic twist of history that it was the Heiders research that was one of the foundations for more psychosocial definitions of deafness that would be picked up by psychologists and psychiatrists in the 1950s and '60s, and would go on to influence geneticists, too.

In many ways, the history of medical, social and scientific approaches to deafness is a story of progressive reform and those lost to and excluded from it. Tensions in the coding of disability during this period reveal optimistic and pessimistic prognoses about the abilities of the disabled and their social position. Physical and mental “abnormality” has long been associated with moral and social deviance. By the early decades of the 20th century, these older ideas were reinforced by eugenic ideas of innate hereditary defect and its association with moral, intellectual or social degeneracy. At the same time, disability was
perceived as something that could be overcome by personal effort, and, increasingly, under the guidance of science, education and paternalistic charity. Reversely, a person's failure to abide to this paradigm of overcoming and passing was considered his or her individual moral and innate incapability rather than the effect of bias or discrimination. Oral failures, educators charged, did not possess the willpower nor the intellectual capabilities to succeed. Similarly, feebleminded individuals were, supposedly, innately incapable of developing a sense of moral, personal or social responsibility.

These notions of worthiness and unworthiness, of the (in)visibility and potential normalcy of disabled people are crucial for understanding the varied uses of eugenic and educational paradigms and policies. Heredity research at the Clarke School was part of a less explored arena of eugenics that operated at the intersection of public health, education, child studies and medicine. In an atmosphere of scapegoating so-called defectives and degenerates for all social ills, educators of the deaf and deaf people fervently defended their moral and intellectual normalcy and social usefulness. At the same time, like most of their contemporaries they embraced eugenics as a new and fascinating instrument of social change that combined measures of public health and education and, as other branches of science, could contribute to the betterment of man and society. Such visions went to the expense and exclusions of those placed at the margins of respectability, ability and malleability, e.g. the multiply disabled, female or African American deaf.

The rise of evolutionary thought not only enabled the emergence of eugenics, it also profoundly influenced perceptions of deafness, deaf people, childhood and education. As oralists defined spoken language as the primary
signifier of humanness, they pathologized deafness as a potentially prehuman phase. Fears of the deaf child left behind, isolated in a mental state without real language and abstract thought, drove the urgency with which the Clarke School pushed for salvation through oralism. Deafness was less an innate difference – oralism promised normalcy and assimilation – than an (evolutionary) stage to be overcome. Emphasizing deaf people’s inherent normalcy turned deafness into something to be shed and left behind, either – in the current generation – by learning speech and inconspicuous behavior or – in the next – by breeding out the defective trait.

Schools in particular were locations of progressive reform, a place where healthier, better, more productive citizens were to be generated by applying the ideals of scientific progress. Special education, in particular, engaged with this vision. It took part in molding the careless child into a responsible adult and in transforming the “defective” or “subnormal” student into a productive citizen. Complementing their educational program with a multi-disciplinary research department, the Clarke School embodied these different strands of progressive educational ideals. Far more than just speech-training and education, the school provided, in the words of historian Stephen Petrina, an “educational hygiene” that was to become engrained in a student’s very being. By the early 20th century, Petrina writes, schools “had become an educational dispensary of ‘therapeutic milieu’,” that thought of students as patients.168 Certainly, oralism embodied such a therapeutic vision, yet it also aimed to transcend it. With the creation of the research department, students quite literally became patients and objects of research, subjected to audiological tests, health exams and

168 Petrina, Medicalization, 503, 508, 518, 527.
genealogical investigations. With these procedures, the school took part in the ongoing medicalization and standardization of childhood, education and disability. Yet, the school believed, hearing loss and its corollaries were only temporary. At the very least, they could be overcome to produce a state of almost-hearing normalcy. Providing students with ever-more detailed knowledge about their hearing loss, including its potentially hereditary nature thus had a prosthetic function. Based on this information, students and their parents were expected to make “good” decisions that conformed to the oralist worldview. This included opting for speech, the use of assistive devices, making “responsible” choices when it came to marriage and childbearing, and, overall, conducting oneself as a self-supporting, inconspicuously integrated and socially useful citizen.

Not everyone, however, was committed to, or familiar with this holistic vision of oralist education and its ideals of transformation and overcoming. The very set up of the research department brought to the school researchers who were interested in deafness for different reasons and had different venues of contact with deaf people. To these outside scientists, the deaf were, predominantly, an interesting research population among which certain hereditary traits or psychological patterns could be studied. Certainly, the school forged useful alliances with psychologists, anthropologists or geneticists that furthered its goals of making education more scientific and efficient. Yet behind this unified front, this chapter has shown, there emerged different professional paradigms that could form temporary alliances, yet could also reach quite divergent opinions on the nature of deafness and the deaf. Heredity research at the school similarly took place in such a complex and multi-disciplinary
framework. Following different phases of research and its application, the next chapter traces the pliability and limits of heredity research, eugenic ideals and oralist paradigms in the 1930s and ’40s.
III. **Educational perfection and hereditary prevention: research and counseling at the Clarke School in the 1930s and 40s**

**Introduction**

In 1929, the Clarke School's heredity research division working under the guidance of anthropologist Morris Steggerda. Already a leader in oral education, the school now hoped to establish itself as a center of heredity deafness research. This was not an easy task in a place where staff was knowledgeable about education and audiology, yet had no training in genetic research. Nevertheless, by employing respected scientists in the field, the school indeed became a respected institution. First, this was Steggerda in the 1930s, then, in the 1940s, pioneer of medical genetics Madge Macklin. Collecting data from current and former students, researchers assembled one of the most extensive longitudinal databases on the inheritance of deafness worldwide. Analysis, however, proved challenging. Strikingly, amassing an enormous set of pedigrees did not (yet) much advance the understanding of how, exactly, hearing loss was passed on. On the contrary, with more material and examples the picture only became more inconclusive and confusing. Yet rather than discouraging the school, the lack of clear results only reinforced their sense of urgency and belief in the necessity of hereditary research and counseling.

The school’s first two phases of heredity research occurred in a much-discussed period in the history of eugenics and genetics. It was an era that saw the demise of the Eugenic Record Office, the most prominent eugenic research institution in the early decades of the century, and the rise of medical genetics and heredity clinics in the 1940s. Applied heredity research, too, changed. In the 1920s and '30s the main eugenic concern had been with the dangerous masses of
the feebleminded and defective, whose irresponsible behavior authorities tried to contain through a wide variety of measures—including coercive sterilization legislation and immigration restriction. Although sterilization laws were applied into the 1970s, during the 1940s public and scientific attention shifted to the reproductive behavior of the normal middle-class family, for whom persuasion rather than coercion were considered appropriate. For them, genetic counseling, a term coined by geneticist Sheldon Reed in 1947, was to become the main instrument for achieving eugenic goals. Deaf people, the previous chapter has shown, insisted on belonging to this respectable group of eugenic targets, although they often were put in one category with the eugenic underclass.  

These developments have seen much attention from historians who have come to quite divergent judgments about the relationship between genetics and eugenics and the impact of medical and scientific progress. Particularly an older generation of historians saw a clear and growing separation between eugenics and genetics. Daniel Kevles’ influential *In the Name of Eugenics* identified a “coalition of critics” that voiced their concerns in the 1930s already. Social scientists, religious leaders, and some biologists and geneticists, he writes, rejected the biological determinism underlying the eugenic worldview. Coupled with the impact of the Holocaust, these influences were enough to cause the decline of the old, biased and unscientific “mainline eugenics” and the strengthening of “reform eugenics” that would become into the new field of human genetics. The latter was—supposedly—guided by medical, rather than

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political or goals. Based on a more sophisticated understanding of genetic processes, it could be turned into a tool for preventing future disease, defect and disability.\textsuperscript{170}

Kenneth Ludmerer similarly has set up a clear narrative of the rise and fall of the eugenic movement. Ludmerer, too, considers eugenicists pseudoscientists who rarely bothered to keep up with scientific progress and standards. By the early 1930s, he asserts, eugenicists' political abuse of genetics had become so blatant that geneticists publicly distanced themselves from their racist and socially biased colleagues. Realizing the difficulties of studying human inheritance, geneticists in the 1940s turned to studying lower animals and in doing so left human genetics to “amateur investigators of low critical standards.” Only with advances in statistics and experimental methods in the 1960s, when a new, critical generation of investigators entered the field, did human genetics gain any resemblance with the field we know today. At this point, old, eugenic institutions closed down and were replaced by “modern centers of teaching and research in human genetics.”\textsuperscript{171}

Genetic deafness research in general and at the Clarke School in particular does not follow these trajectories that distinguish between mainline and reform eugenics. Superficially, the Clarke School heredity division might well seem like a prime example for the naïvely misguided amateur science supposedly characteristic for eugenics. Its staff – teachers without any background in genetic research – could well be called “amateur[s] fresh with enthusiasm”


Research was a curious mixture of old-fashioned genealogy and cutting-edge science. On closer look, however, the school is ill fitted to make an example for a clear cut between pseudoscientific eugenics and medical genetics. It persistently pursued a goal that supposedly marked the distinction between politically motivated eugenics and the more noble pursuits of medical genetics: the prevention of suffering. Moreover, the school’s eugenic policies were distinctly unlike those associated with the persecution of the feeble-minded, defective and degenerate. In their belief in deaf people’s reason, social respectability and educability, the school pursued prevention not through coercion, sterilization and restriction, but through persuasion and education.

More recently, historians have been blurring the lines between eugenics and medical genetics. They have shown the persistence of eugenic motives in medical genetics, genetic counseling or public health; and vice versa, have traced interest in the medical applications of eugenics in what is considered the mainline strand. They have pointed to the application of sterilization legislation far into the 1960s and have located the rejection of eugenic ideals on family and gender not in the 1930s and 40s, but with the women’s movement assertions of reproductive rights during the 1960s.

Focusing on disability, disease and defect rather than race as did the

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172 Ludmerer, Genetics, 3, 19, 57.
earlier strand of eugenic literature is crucial for reframing the history of eugenics and genetic medicine. Disability studies has produced poignant critiques of the assumption that the mere absence of physical or mental “normalcy” automatically produces suffering. Instead, scholars have pointed to the sociocultural determinants of disability, e.g. in a medicalized culture intent on fixing the disabled person rather than disabling social biases and discrimination.\textsuperscript{175} Disability historians have also pointed to the connections between the sociocultural ideal of overcoming disability and the growth of professions asserting their ability to restore the disabled to sociability and economic productivity. The belief in the scientific manageability of disability turned it from a matter of charity to one of progress through science. The growth of professions addressing deafness is exemplary for this development.\textsuperscript{176}

Like other institutions at the time, the Clarke School was guided by the belief in the scientific manageability of deafness that would enable passing and overcoming. It was an unquestioned principle that it was deaf people who had to adapt to society – and not the other way around – and that the deaf were capable of doing so. This belief guided their educational as well as their eugenic policies.


The school's heredity research can only be understood if placed into a framework that takes into account the history of education and childhood studies, deafness and disability as sketched out in the previous chapter. It took place in an institutional context that shared some characteristics with other sites of genetic research such as the Eugenic Record Office, heredity clinics or fieldwork, yet as a school-based research unit also provided a distinct environment for pursuing the prevention of hereditary deafness.

Such locations of basic and applied eugenic research have seen little attention from historians. A notable exception is the New Jersey Vineland Training School where psychologist Henry Herbert Goddard pursued his studies of feeble-mindedness. Strongly influenced by eugenic principles, Goddard came to drastic conclusions about the educability of the feebleminded. By the 1920s, schools for the feeble-minded took on a gatekeeper function, warehousing students rather than educating them, and, supposedly retaining them from spreading their harmful genes.\footnote{Goddard, Henry Herbert. 1912. \textit{The Kallikak family: a study in the heredity of feeblemindedness}. New York: The Macmillan Company. Leila Zenderland biography of Goddard follows his work at the Vineland School and eugenic and psychological theories. See Zenderland, Leila 1998. \textit{Measuring Minds: Henry Herbert Goddard and the Origins of American Intelligence Testing}. Cambridge: Cambridge University Press. Alison Carey has shown how asylums were used as institutions for isolating the feebleminded. See Carey, Alison. 2009. \textit{On the margins of citizenship intellectual disability and civil rights in twentieth-century America}. Philadelphia: Temple University Press, 52-82. For the example of California see Stern, \textit{Eugenic nation}, 111-134.} This was not the case for schools for the deaf. Research at the Clarke School division was deeply embedded in the oralist mission to normalize students and assimilate them into hearing society. Long-standing beliefs about the nature of deafness (pathological) and of deaf people (potentially normal) shaped the dedication with which the school pursued the eradication of genetic deafness, yet shied away from coercive measures. Within
this framework, the school created their own, particular strand of heredity research. At times, how they imagined heredity to work may seem almost anachronistic, yet it was rooted in imagining students as idealized educational objects rather than abstract carriers of abstract traits.

As the previous chapter did for the psychology division, this chapter charts the overlap and tensions between school staff and outside researchers engaged in heredity research. The Gestalt psychologists whom the school had hired came to conclusions that challenged basic tenets of oralism. Oralist educators and heredity researchers, on the other hand, shared a basic consensus: It was crucial to identify individuals whose deafness was inherited and to discourage them from marrying another such person. This was the core of the alliance between the oralism and eugenics. This alliance went back to A. G. Bell who had defined deaf people’s reproductive behavior as problematic, and had enlisted eugenic thought and heredity research as a means of investigation and solution. Yet just as there had been tensions in relationship between Bell and other eugenicists, some 40 years later there were dissonances between Clarke School staff and outside geneticists. Although they had a shared goal – identifying and preventing hereditary deafness – they did not necessarily agree on how this was to be achieved. Different perceptions of disability, defect and disease, eugenics and heredity were at the root of these differences. I argue that the measures professionals recommended and the amount of agency they conceded to their subjects depended on disciplinary alliances, institutional context and encounters with deaf people as objects of research, educable students, future citizens or carriers of degeneration.
Heredity research in a school setting: teachers as researchers, counselors and health workers

In its methods, heredity research at the Clarke School was closely influenced by the short directorship of Morris Steggerda. Born in Michigan in 1900 to immigrants from the Netherlands, he had received an MA in 1923 and PhD in 1928 from the University of Illinois department of zoology. In the same year, he took a position as assistant professor of zoology at Smith College and began his association with the Clarke School. Although he ran the Clarke School’s research department for less than two years, he set its initial direction and shaped its trajectory for decades to come. Hardly ever mentioned in accounts of Steggerda’s life, his work at the school was an early manifestation of his meticulous anthropology.178

Steggerda was an anthropologist in the broadest sense. Up to his early death in 1950, he undertook hundreds of longitudinal studies, recording a vast array of ethnographic, religious, anthropometric, hereditary and psychological traits in populations as diverse as South American Natives, Smith College and Clarke School students, Jamaicans and his own extended family. He was noted for his extraordinarily meticulous, precise and extensive records. More interested in describing and measuring traits than in analyzing them, he left a vast archive that recently has drawn the attention of anthropologists, zoologists and ethnologists.179 Steggerda’s interest in the physical and mental variations

178 Unfortunately, Steggerda’s life and anthropological research has not been given much attention beyond his collaboration with Charles Davenport, and there is no biography of him. For the most comprehensive biographical sketch see Paul S. Sledzik. Sledzik, Paul S. The Morris Steggerda Human Biology Collection. National Museum of Health and Medicine Armed Forces Institute of Pathology Washington, DC, USA, Ethnographical Series, Volume 20: 281-286, here 281-282.
179 Sledzik, Steggerda, 281-283.
between individuals, among races and across populations brought him into contact with zoologist Charles Davenport, the director of the ERO. The two scientists met in 1926 and together undertook an extensive study of the native population of the West Indies. The result of this cooperation, *Race Crossing in Jamaica*, was published in 1928 and detailed a huge array of physiological, psychological and morphological traits in relation to the variability and abilities of racial hybrids.\(^\text{180}\)

Davenport and the ERO have become notorious as symbols of a racist, deterministic and coercive form of eugenics. Davenport's research, Kevles writes, tended to “incautious speculation,” if not oversimplification and was based on a science “that, even by standards of his own day, was usually dubious and often plain wrong.”\(^\text{181}\) Other historians, however, have emphasized that Davenport's genetics held and contributed to the standards of his time. He turned the ERO into the central institution of American eugenics, promoting its methods and goals and providing research opportunities for an entire generation of scientists and fieldworkers.\(^\text{182}\)

The ERO's success, Garland Allen writes, was closely connected to the rise of Mendelian thought as the guiding paradigm of heredity research. Mendelism gave scientists an explanatory model to study and predict a wide range of mental, physical and moral traits. An early supporter of Mendelism, Davenport

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\(^\text{181}\) Kevles, *Eugenics*, 48

established at the ERO an extensive indexing system of traits. Field workers, mostly college-educated young women, took family histories and catalogued them as detailed pedigrees. Analysis was based on the assumption that a myriad of mental, physical, moral or social traits followed a simple Mendelian pattern and were passed on as single recessive or dominant units. Although such a pattern was hard to prove in more complex traits, Mendelian genetics proved to be an appealing research paradigm because it supported the belief in man's ability to direct hereditary processes. Deafness, I will show below, was a good example of both this belief and of the difficulties of applying simple Mendelian patterns to a complex phenotypical and genotypical phenomenon.183

The Clarke School heredity division shared many characteristics with the ERO, from collecting information through fieldwork and interviews to its aggregation in pedigrees, and the hope to find simple patterns applicable to preventative methods. The division of work between female staff members and male scientists also resembled that of the ERO. There, between 1910 and 1924 250 young field workers –predominantly young, college-educated women – had been trained, traveling the country to collect traits of individuals and families in their homes, and in schools, hospitals, asylums and other institutions. Although their work has sometimes been dismissed as amateur science, historians more recently have pointed out that field workers did adhered to contemporary scientific principles, and did not necessarily follow Davenport’s beliefs. Female field workers, Amy Sue Bix and Diane Paul have convincingly argued, were more than merely cheap, unqualified labor. Like other middle-class women in the period, they were drawn to eugenic principles, and saw in the eugenic

183 Allen, ERO, 239-240.
movements a means for social reform through applied science. For some, the experience of working at the ERO served as a springboard for a career in science, education or social work.\footnote{Paul 1995, \textit{Heredity}, 51-57; Bix, Amy Sue. 1997. “Experiences and Voices of Eugenics Field-Workers: ‘Women’s Work’ in Biology.” \textit{Social Studies of Science} 27 (4): 625-68. Historians disagree about the quality of work, status and capabilities of these field workers. For Ludmerer, they were an example of uncritical amateur scientists whose work detracted from serious attempts at pursuing genetic science. See Ludmerer, \textit{Genetics}, 57.}

Although their training in the theory and methods of heredity research was less thorough than that of the ERO field workers, a similar argument can be made for the Clarke School staff who became involved in heredity research, Ruth Pierce Guilder (1888-1945) and her assistant, the teacher and audiologist Louise A. Hopkins. With a B.S. from Simmons College and an M.D. from the University of Illinois, Guilder had worked as an editor for the American Medical Association before she came to the Clarke School in 1930. When, in the same year, Steggerda gave up his positions at Smith College and the Clarke School to become a full-time researcher at the Eugenics Record Office, Guilder took his position as head of the heredity division.

Her position at the Clarke School thus was a step up from her editorial work, and her experiences at the school likely proved favorable for her later position as director of the Winthrop Foundation for the Study of Deafness at the Massachusetts Eye and Ear Infirmary.\footnote{Biographical sketch of Ruth Guilder, Clarke School Archive, Division Concerning Hereditary Deafness.}

Hopkins had graduated from Buffalo Seminary and taught high school math when she meet Guilder while working at Sleighton Farms, an institution for delinquent girls near Darlington, Pennsylvania. Why she decided to leave Sleighton Farms and come work at a school for the deaf, was not recorded, but
in 1929 she graduated from the Clarke School’s teacher-training program and became Guilder’s assistant in the heredity division. She worked there for the rest of her life, recording health and family data, and administering audiological tests to incoming as well as current students. In 1936, when Guilder left the school due to health problems, Hopkins replaced her as head of the heredity research division. Her work thus provided her with a clear upward trajectory, as she went from beginning teacher to director of an—albeit small—research division. As she interacted with other scientists and published her work, the division offered her professional opportunities in the still male-dominated sciences.¹⁸⁶

There was yet another striking similarity between the ERO field workers and the school’s teacher-researchers. Just as supposedly female qualities were sought out in teachers for the deaf, female field workers were considered to have qualities advantageous to interacting with and eliciting information from their clientele.¹⁸⁷ In deaf education, hearing, female instructors had seized new professional opportunities. In doing so, by the 1930s they had gradually replaced the older generation of male, deaf teachers who had been the role models of the manualist era.¹⁸⁸ Now, not only was the teacher required to have intact hearing, she was also to possess distinctly maternal characteristics. The teacher, explained a 1929 Clarke School publication, “must comprehend the mind of the bewildered, frustrated little child and by patience, sympathy, tenderness and

¹⁸⁶Biographical file, Hopkins, Louise Alice, Heredity Division, Clarke School Archives. The girls at Sleighton Farms were the objects of various reform and research projects, including visiting ERO field workers who studied their familial “abnormality.” See Hewes, Amy et al. 1925. “A Study of Delinquent Girls at Sleighton Farm.” Journal of the American Institute of Criminal Law and Criminology 15 (4): 598-619, in particular 608.
¹⁸⁷For a more thorough discussion on such gendered expectations see Bix, Field Workers, 632-637; Paul 1995, Heredity, 52-57.
love establish a foundation of confidence.\textsuperscript{189}

Guilder's and Hopkins' role as field researchers and the school's health workers thus offered them the rewards of scientific involvement and the altruistic-paternalistic gratifications of contemporary special education. More than the ERO field workers, and certainly more than Steggerda or other outside scientists, they were personally familiar with their research objects and part of an institutional culture deeply convinced of their educability and humanity. This pedagogical framework would closely shape counseling and the perception of genetic risks.

As we saw in the previous chapter, special education was a prime site of applied eugenics, providing locations where professionals could observe and control the reproductive and social life of their charges. How such eugenic policies played out, however, whether they acted against or became part of older educational paradigms could vary greatly. The school's heredity division thus was not simply a smaller version of the ERO. Whereas the ERO engaged in extensive campaigns for negative eugenics, the school maintained Bell's reserve towards all forms of coercion and his focus on encouraging positive eugenics. Venerating his achievements as a scientist and teacher, they pursued a politics in which positive eugenics – encouraging good marriages – was integrated into the larger framework of oralist schooling. Nor did Steggerda simply imitate Davenport in setting up the division. More interested in observing and recording anthropological traits than in applied eugenics, he instilled in his coworkers a distinctly reserved stance when it came to drawing conclusions about hereditary

\textsuperscript{189}Clarke School for the Deaf, Northampton, Mass. 1929. The Coolidge fund for the Clarke school and the deaf. New York, 91
patterns from their vast collection of data.

Tracing an elusive trait: Early 20th century hereditary deafness research

To educators of the deaf, the etiology of hearing loss in their students was an issue of concern. Here, matters of reproduction were closely tied to educational policies, administration, social and statistical categories. Yet for early 20th century researchers, the question of which forms of deafness should, in first place, be considered hereditary was vexing. They usually distinguished between acquired or adventitious and hereditary or congenital cases. It was, however, far from clear where to draw the line between these categories. Sometimes, the onset of deafness could be clearly associated with accidents or infectious diseases such as meningitis, scarlet fever or ear infections. In many cases, however, there was no such direct correlation. Congenital deafness served as a broad category that encompassed hereditary deafness and hearing loss acquired before or at birth. Cautious estimates concluded that between 20 to 30 percent of cases were hereditary or congenital. In his 1914 survey, sociologist Harry Best believed two thirds of cases to be adventitious, one third congenital. Best was aware that hereditary and congenital deafness “are not altogether one and the same thing,” yet cautioned that a more final distinction would have to wait until knowledge was more advanced. The 1920 report on Standardization, Efficiency, Heredity similarly placed 20 percent of cases in the congenital category, yet with the present knowledge considered it nearly impossible to give a clearer
There was, then, a general consensus that some types of deafness were inherited and, at least in theory, distinct from environmental forms. Yet how they were passed on remained unclear. In the wake of Bell’s 1883 *Memoir*, scientists, educators and deaf people themselves had been trying to pinpoint the exact modes of transmission of hearing loss. Probably the most exhaustive of these studies is Edward Allen Fay’s 1898 *Marriages of the Deaf in America*, which compiled several thousand questionnaires into a data set still used in modern genetics. Fay, who was supportive of sign language and deaf intermarriage, had undertaken his research to prove or disproof Bell’s theories. Unlike Bell, who had merely focused on the unions between two deaf people, Fay also included their families. He concluded that in regard to passing on deafness it was “exceedingly dangerous for a deaf person to marry a blood relative.” This seemed to be independent from the partner’s hearing status (hearing or deaf; acquired or congenital hearing loss), and the degree of interrelation. Yet why this was the case, and what conclusions to draw from his data remained puzzling.191

Bell, Fay and other early researchers had begun their research in the 1880s with a pre-Mendelian understanding of genetics. However, introducing the Mendelian principles of dominant and recessive traits after the turn of the century did not do much to clear the picture. Pedigree analysis seemed to

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191Fay, Edward Allen. 1898. *Marriages of the Deaf in America. An Inquiry Concerning the Results of Marriages of the Deaf in America*. Washington, D. C.: Gibson bros., printers and bookbinders, 131-133. For marital happiness in particular see 135. On current uses of Fay’s data, see e. g. the Alumni Project of Gallaudet’s Department of Biology and the Department of Human Genetics at the Medical College of Virginia http://www.gallaudet.edu/genetics/about_us_-_services_and_research/research_projects.html [01/15/2016]
suggest that a recessive pattern was the best approximation to describe the inheritance of deafness, yet often, even comparing two pedigrees seemed to contradict this conclusion. Much less was the analytic framework of recessive or dominant convincing on the level of analyzing larger population sets. In the light of such incongruity, it is not surprising that those writing about hereditary deafness resorted to older imagery to describe this phenomenon. A 1912 Volta Review article on *Heredity and Intermarriage* thus simply stated that the “fatal tendency of deafness lurks in the family line.”

One of the most sophisticated analyses arguing for recessive inheritance was the 1932 PhD thesis *Deafness as a Eugenic Problem*, by a student of zoology at the University of Ohio, William J. Tinkle.  Deafness, Tinkle summarized for the *Journal of Heredity*, “runs in families just like traits known to be hereditary, causing children to resemble parents closely.” For his thesis, he had gone through the records of the Ohio State and Columbus Schools for the Deaf and had found 31 families in which two deaf parents had sent at least one of their children there. Additionally, he examined and interviewed former students. “A mastery of the rudiments of the sign language,” he noted, “aided in gaining the confidence of the people.” (One can speculate that Tinkle, a minister in the Church of the Brethren, had acquired these rudiments in order to preach to the deaf like numerous other clerical men) Previous research, Tinkle noted, had supposed that deafness was a recessive trait. Yet was there only one single gene that was responsible? If this was true, all children born to two deaf parents

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should be deaf, too. Since this was not the case – in Tinkle's Ohio population it was only 70 percent – there must be at least two recessive genes involved, one that “controls development of the cochlea, the other, the development of the eighth [cranial, vestibulocochlear] nerve.” Tinkle suggested that one form might cause hearing loss for high tones, the other for low ones.194

Audiograms, he thought, might help distinguish between the two types. This was a relatively new approach. Audiometers – devices that measure the range of hearing by generating the respective range of sound – had been developed soon after the invention of the telephone. Bell himself had constructed one of the first types. By the 1880s, commercial audiometers became available, and by the 1920s were replaced by more sophisticated electric models. By the 1930s, researchers such as Tinkle, and, as we shall see, Guilder and Hopkins at the Clarke School found uses beyond diagnostics or educational placement. Thus, to test his two-gene theory, Tinkle examined the hearing ranges of deaf parents of hearing children to see whether one parent was able to perceive high, the other low tones. This might have been an indication for whether they carried different recessive genes. The results, however, were negative. No such distinctions could be made and the theory of different recessive genes remained, for the time being, just that. Autopsies, Tinkle added, might be another venue for finding structural differences, yet, he regretted, there were “a number of practical difficulties in the way of a very extensive application of this branch of research in human genetics.”195

No matter the exact pattern of inheritance, Tinkle considered it necessary to “promote marriages between deaf and hearing persons, which are desirable if the deaf marry at all.” Here, he followed Bell’s paradigm, advising society to “stop segregating the deaf” and to “increase our day schools, teach lip reading and oral speech, and thus avoid taking deaf persons out of their normal environment.”

For Tinkle and other researchers, the inability to clearly define forms of hereditary deafness thus was closely connected to eugenic questions about marriage and reproduction. Deaf intermarriage was a question of educational as much as of public health policy, of changing a population's social environment as a means of changing their hereditary constitution.

A multidisciplinary long-term study: The Clarke School approach

The Clarke School, too, was faced with the incomprehensible nature of hereditary deafness that made it an even more threatening condition. They approached research with a combination of methods that mirrored the set-up of the research department and the staff’s professional background. Unlike other researchers who had used statistics or questionnaires to capture a momentary picture of a given research population, they surveyed multiple generations simultaneously over years and decades. In doing so, the school created a unique data set.

The “problem of inheritance of deafness,” Ruth Guilder explained their approach, “must be approached from three angles: the genetic, the otological and the general medical.” The school set out to gather such genetic, medical and

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196 Tinkle, Deafness, 18.
otological information from the students and their families. Interviews, questionnaires or family histories were used to create pedigrees which then could be analyzed for Mendelian patterns. Just as the ERO field workers did, Guilder and Hopkins visited students' families, inquiring about the incidence of deafness and other possibly connected traits. They also added to the pedigrees Bell had collected on Martha's Vineyard. Visiting the island, they were fortunate to meet some inhabitants in their 80s and 90s who told them “many interesting stories of the time when Dr. Bell visited this same community.”

To such anecdotal evidence they added data from the children's medical records, kept and updated by Guilder and Hopkins in their double role as researchers and school nurse. In some cases, children were admitted to the Evans Memorial Hospital in Boston “for an exhaustive diagnostic study.” For those studies, the school continued to engage outside experts whose collaboration made the program a multi-disciplinary and multi-institutional affair. Examinations were performed by Allen Winter Rowe (1879-1934), a specialist in endocrinology and the hospital’s director of research, and two zoologists from Smith College, Richard Post and Howard Parshley. Post “annually made anthropometric measurements of our pupils” to compare the growths of deaf and hearing children. Also involved were two Harvard scientists: Clyde E. Keeler, the university's first medical geneticist, who in 1921 was the first to link a nervous system defect to a single mutated gene, and Hallowell Davis, a leading authority on the ear and hearing, and a pioneering neurophysiologist – the first

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25-29, here 25.


American to have his brain waves recorded via EEG.200

Like Tinkle, the Clarke School researchers realized that audiological measurements were the most feasible way for distinguishing between different types of deafness. As an oralist school with ties to Bell Telephone Laboratories, an important manufacturer of audiometers, they were particularly well-equipped, and even received custom-made adaptions to commercial audiometers. By the mid 1920s, when the school purchased their first audiometer, they moved away from the older practice of a teacher subjectively evaluating a student’s degree of hearing loss. Now, audiometric testing was to provide objective and comparable assessments.201

As extensive hearing tests became the school’s standard, it was no longer enough just to know that a child was deaf. Now one needed to know the exact type and degree of their hearing loss. Their experience and growing collection of pedigrees helped Hopkins and Guilder develop four different categories of hearing loss that “served as a working bases for both scientific and educational purposes.” Heredity and audiological research thus combined to benefit the school in their quest to understand and ameliorate deafness. Just as an individual profile of hearing loss was the base for a successful oralist education, it was, “in many ways,” Guilder wrote, “the foundation for our research in the heredity of

deafness.” In 1931, Steggerda, Guilder and Hopkins presented their first Report of the Research Department concerning Heredity of Deafness. Mainly a collection of hand-drawn pedigrees, divided into hereditary, non-hereditary and mixed cases, it correlated deafness with data on birth date and place, death cause and general health, noting characteristics such as “Alcoholism,” “Tuberculosis” or “Feebleminded.” Rather cautiously, the report noted higher rates of hearing impairment in combination with tuberculosis, “circulatory diseases” and “suppurative ear condition.” Yet the researchers’ limited analytic means allowed no judgment about whether these were environmental or hereditary factors. Rather than defining clearly identifiable types, the study mainly confirmed the notion that some forms of deafness indeed were hereditary. This finding, in turn, was perceived with general eugenic and oralist presumptions. Thus Pedigree 4, an example of three generations of deafness “illustrates the idea of ’like marrying like.’” This, the authors warned, “is a dangerous practice when the heredity of an abnormality is involved.”

In the following years, research settled into a routine, as Guilder and Hopkins, collected pedigree and medical information of incoming and current students. Yet what this data might mean remained unclear, and results did little other than confirming the older concern about students passing on their condition. After Steggerda had left in 1930 (and apparently was not available for


consultation beyond the 1931 report), the school lacked a scientists trained for analyzing the accumulating material. “It is still too early,” Guilder summarized in the 1936-37 report, “to undertake a detailed analysis or to determine the final significance of this material.”

This gap between data collection and analysis, between the conviction that this kind research was important and the reluctance to specify its meaning would become typical for heredity research at the school.

Research in the 1940s: Of recessive genes and problematic pedigrees

After Guilder retired in 1936, Louise Hopkins continued to collect pedigree and health information from the incoming students, tested their hearing and filed the data. In the same year, she expanded her qualifications with an M.S. in audiology. By all accounts, Hopkins was dedicated to her research and convinced of its importance. Yet her additional degree is telling for the skills that appear to have mattered to herself, and to the school when they made her head of their heredity research division. Despite her position, Hopkins did not have the knowledge or experience to analyze the material accumulated since Steggerda’s time. For this task, the school invited in 1939 geneticist Madge T. Macklin from the University of Western Ontario’s medical faculty. Born in Philadelphia in 1893, Macklin had received her MD from Johns Hopkins in 1919 and moved to London, Ontario, where her husband had been pointed appointed professor of histology and embryology at Western Ontario University. Macklin herself received only received a number of consecutive short-term appointments

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there, and remained in this insecure position until 1945, when she became a
research associate at Ohio State University. She remained there until her death in
1962. In 1930, she was a cofounder of the Canadian Eugenics Society; from 1959
to 1960, she served as the first female president of the American Society for
Human Genetics.206

Mostly known for her contributions to the heredity of cancers, in
particularly breast cancer, and other, rare genetic conditions, Macklin’s career
bears the traditional periodization of eugenics with its transition from racist,
based mainstream eugenics to a medicalized form of human genetics in the
1940s and ’50s. For Macklin, eugenics was a form of preventive medicine; a
means to improve public and individual health. Genetic knowledge, she believed,
brought significant advantages to medical research and practice, improving
differential diagnosis and, eventually, therapy. Awareness of a condition’s
hereditary character warranted prevention, both for the sake of public health
and to prevent individual suffering. To make this point about disease eradication,
Macklin often used evocative, sometimes harsh eugenic language that subjugated
defective, suffering bodies to a heroic vision of efficient disease eradication.207

Deafness also made an excellent example for the need for genetic
knowledge in advancing prevention. The Clarke School, with its clear preventive
goal, educational ambition and ties to earlier eugenic research, offered an

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206 For a biographical sketch see “Madge Thurlow Macklin.” Notable Scientists from 1900 to the
207 Comfort, Nathaniel. 2006. “Polyhybrid Heterogeneous Bastards’: Promoting Medical Genetics
in America in the 1930s and 1940s.” Journal of the History of Medicine and Allied Sciences. 61:
415 - 455, here 415, 432-437. For Macklin’s advocacy for medical genetics see Macklin, Madge
Thurlow. 1932. “Should the Teaching of Genetics as Applied to Medicine Have a Place in the
Medical Curriculum?” Journal of the Association of American Medical Colleges 7: 368-73;
Macklin, Madge Thurlow. 1932. “Medical Genetics: A Necessity in the up-to-Date Medical
Inheritance of Disease to Medical Students: A Proposed Course in Medical Genetics.” Annals of
Internal Medicine 6: 1335-43.
intriguing opportunity to Macklin. The school gave her access to their vast collection of pedigrees and medical data, as well as the chance to educate an allegedly high-risk population group. Although her involvement was rather short – she spent several vacations at the school to work on the data collected by Hopkins – Macklin’s background in clinical and academic genetics shaped her analysis.208

In 1946, Hopkins and Guilder presented their results at the Annual Meeting of the American Otolaryngological Society in Chicago and published a summary in the Laryngoscope. The two-part piece reflected their respective work and expertise: Hopkins introduced the readers to the methods and material of the study; Macklin was responsible for genetic analysis. This division was telling about the way both sides conceptualized hereditary deafness. For Macklin, it was a clinical entity caused by specific, although as of yet unidentified genes (as were most genes at the time except for a few x-linked traits); for Hopkins a concerning characteristic that appeared unexplained and disturbingly in the student population. Where Macklin focused narrowly on deafness as a matter of medical genetics, Hopkins portrayed the school as an ideal, holistic institution combining education, care, and research.209

There was, Hopkins wrote, hardly any “richer field for research” for hereditary deafness than Clarke School for the Deaf. She noted the school’s long tradition in this field, going back to Alexander Graham Bell’ studies in the late

19th century. As the children entered the school at age 5 and lived there until they graduated at age 15, “we have the children themselves over a long period of years so that it is possible to study them from many angles, the genetic, the otological and the general medical.” In addition, the school’s “old and very loyal alumni group, a considerable number of whom, unfortunately, have had deaf children to send back to the Clarke School” made multi-generational family studies possible. The school also had the “absolute cooperation of the parents of our children, who are only too eager to do all in their power to help us in our efforts to learn more about the causes of deafness in childhood and the part played by inheritance in the production of deafness.”

Such an image portrayed the school as an ideal institution in which education and research had merged for the benefits of the research population and of science at large. The report’s pedigrees, too, conflated these dimensions. As in Steggerda's 1931 report, they provided an easily accessible visual presentation, compressing extensive research into symbols that indicated hearing status and age of onset, sex, consanguineous marriages or (former) Clarke School students. The list of causes for deafness painted a vivid picture of the many conditions and events that were thought to cause hearing loss in the 19th and early 20th century. Individuals were reported to be deaf from brain or scarlet fever, whooping cough, meningitis, abscessed ears, brain hemorrhage or measles. They had lost their hearing in the Civil War or had been in common or more unusual accidents, such as the unfortunate person who was “very hard of hearing since 15 when hit by hammer thrower at circus.” Presumptive hereditary deafness, on the other hand, was simply denoted as “born deaf.” Most

210 Hopkins 1946, Studies, 571-572.
pedigrees displayed both environmental and congenital cases.\textsuperscript{211}

Given this apparently impenetrable diversity of etiologies, Hopkins saw little actual progress toward prediction and prevention. Rather, she commented on "the devious ways in which deafness, even the so-called congenital deafness, appears and disappears in the family tree." Such language was reminiscent of older, folk understandings of heredity. Blurring the lines between congenital and environmental causes, to Hopkins familial deafness was a matter of fate and misfortune, as of yet beyond the reach of scientific explanation. Rather than shedding light on the mechanics of hereditary deafness, research had only shown how complex and widespread a phenomenon it was. Hopkins thus concluded: "recent advances in the science of genetics make us realize that the problem is much more complicated than it may at one time have thought to be."\textsuperscript{212}

Macklin, for her part, teased out patterns of inheritance from data she acknowledged to be messy. Like others in the field, she assumed hereditary deafness to be a recessive condition. The Clarke data seemed to rule out the simplest hypothesis of a single gene since marriages between deaf people produced both deaf and hearing children. So far, forty such matings between alumni had been found at the school. Fifteen had only deaf, eleven only hearing, and eight both hearing and deaf children. Six couples had no children at the time of the study. Perhaps, Macklin speculated, there might be "more than one type of congenital nerve deafness," with "each dependent upon its specific gene, and each gene being a recessive one." Yet what these types—and their respective

\textsuperscript{211}Ibid., 571. For the pedigrees in particular see 577-582.

\textsuperscript{212}Hopkins 1946, Studies, 571.
Sometimes a deaf child was born to a family with no history of hearing loss. Recessive inheritance could explain such sporadic cases. For Macklin this puzzling and concerning phenomenon was an example for the benefits provided by genetic knowledge – and the dangers of remaining ignorant. A closer look at the sporadic cases at the Clarke School revealed a concerning trend. Up to 66 percent “may actually be examples of isolated instances of hereditary deafness.” Yet often, parents or their physicians denied the hereditary dimension of their children's condition. Mistakenly, many attributed deafness to infectious diseases, even if a family had several deaf children. In other cases, two individuals with supposed environmental deafness had married and had “all deaf offspring, indicating the hereditary nature of their deafness.” Yet even in those cases, many did not acknowledge genetic factors. Favoring genetic over environmental factors, Macklin further cautioned that even if an instance of infectious disease had been recorded in childhood, one could not be sure whether it had really caused the hearing loss.214

Whether it was deafness among Clarke School students, or other conditions Macklin encountered throughout her career, heredity was an invisible risk, looming even over individuals previously considered safe. As long as it remained unrecognized, it could not be predicted or controlled. Such an alarming – and alarmist – realization had significant implications for heredity counseling. Awareness of genetics should, Macklin advised, “make us cautious in assuring deaf persons whose deafness is presumably caused by infection that their

213 Macklin, Clarke School, 584, 594. For Macklin's theories of complex inheritance see Comfort, Bastards, 438.
214 Ibid., 586-587.
children will not be deaf.” Deafness thus compellingly demonstrated the
importance of genetic knowledge for diagnosis and prevention. 215

Keeping with the theme of an invisible genetic state, Macklin suggested
“that a child may be genotypically deaf, but phenotypically hearing.” To make her
point, she drew from her medical background and belief in the underlying
genetic causes of disease. In diabetes, she explained, the affected individual did
not exhibit signs of the disease until enough of the pancreatic islet tissue had
been destroyed. Up until this point, the individual was “a potential diabetic.”
Similarly, a “deaf person might be genetically deaf but still have enough hearing
to pass for a hearing person.” This was consistent with finding some level of
hearing loss in hearing family members of deaf students. Only knowledge of
genetics allowed one to look beyond a temporary phenotypical state and
recognize an individual’s true, genetic nature, his medical fate. 216

The notion of passing, of course, was an important theme for the school
and its teachers whose job it was to make their students appear hearing.
Macklin’s usage, however, points to the tensions the Clarke School faced in
incorporating genetic knowledge into scientific oralism. On the one hand, the
school insisted that their students had the potential to achieve an all-around
normal life. Yet by engaging in heredity research, they anxiously attempted to
reveal what had made (some of) their students different in first place, revealing a
trait that would limit their normalcy in marriage and reproduction. That heredity
also might affect other family members or the “phenotypically” hearing, did not
ease this anxiety. Rather, it prodded the school to expand its sense of

215 Ibid., 596.
216 Ibid.
responsibility toward an even larger group.  

The need for prevention and the urgency to promote awareness about heredity was a common denominator between Hopkins and Macklin, or more widely, between the world of medical genetics and scientific oralism. Yet where Macklin was rooted in the world of academic science, of proving or disproving certain theories, Hopkins thought about families, students and their potential offspring. And where Macklin sought for genes and disease patterns, for Hopkins, the pedigrees, with their multiple cases of congenital deafness, confirmed older fears about the dangers of deaf intermarriage.

These differences also were apparent in the most extensive summary of the school’s findings so far, the 1949 Clarke School Studies Concerning the Heredity of Deafness. Hopkins was the study’s primary author, with Guilder, who had died in 1945, listed second. Macklin’s research was only briefly mentioned. Hopkins wrote confidently and authoritatively about the otological aspects of deafness, yet her tone became tentative and vague when it came to heredity. She avoided any analysis or conclusive statements. Thus, most of the 162-page volume was dedicated to presenting all pedigrees collected between 1930 and 1940. Some of these pedigrees reached as far back as six generations. In others, the staff had been able to link one family to another, seemingly unrelated one, tracing them both to a common ancestor.

Once more, pedigrees were divided into three groups: extrinsic,

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219 Ibid., iii, 1, 8, 10
congenital and cause unknown. Yet where exactly to draw the line was as perplexing as ever. “We must not confuse congenital deafness with hereditary deafness,” Hopkins cautioned and added that the “whole problem of the cause of deafness is at the moment in a state of flux.” Recent research had shown that German measles (rubella) in pregnant mothers caused deafness in the fetus. Mothers who had taken quinine during pregnancy also were reported to have deaf babies. Because of these new insights some of the school’s cases had to be reclassified.²²⁰

For the remaining cases, Hopkins concluded that “the basis for the appearance of deafness in these congenitally deaf children is a factor for deafness which they inherit from their parents.” How this factor operated, and how they mapped onto an otological typology of deafness remained completely unclear. Once more, Hopkins pointed to audiology as a means for finding comparable patterns. It was a methodology suited to her expertise and the school’s technological capacities. In 1935, their audiometer had been modified, expanding its intensity range to 25 decibels at each octave. This upgrade made possible a much more detailed appraisal of the frequency and degree of hearing loss.²²¹ Moreover, it made visible a “striking similarity” in the audiograms of family members. These findings, Hopkins concluded “is what we might expect on the basis of heredity.” This line of research also corroborated Macklin’s speculations about genotypical abnormality underlying apparent phenotypical normality (although this was not the language in which Hopkins expressed

²²¹Hopkins 1949, Studies, 5-6.
herself). Thus, sometimes the audiograms of hearing family members revealed hearing loss even before the test objects noticed it themselves.\footnote{Ibid., 9.}

Such detailed description of audiological methods and results stood in strong contrast to the treatment other traits received. “When the study was commenced,” Hopkins commented, “we were unaware of the part that other defects and diseases play in contributing to deafness.” Thus, they cautiously collected a vast range of minor to major conditions, reminiscent of Steggerda’s list of anthropological traits. It ranged from stammering and varicose veins to appendicitis, cataracts and goiter to cancer, cardiovascular and renal disease, mongolism, hydrocephalus or mental illness. Twinning was also noted. Yet how and whether these traits were connected was not something Guilder, Hopkins, or, indeed, Macklin had pursued.

Nevertheless, Hopkins’ descriptions are telling for her understanding of hereditary traits as vague entities that “appeared in in the families.” Stammering, she commented for example, “has been suggested as due to some hereditary factors inasmuch as there are more stammerers in the family of one who stammers than there are in the general general population.” The school’s pedigrees seemed to confirm this assumption. Pedigree 123-A showed “six males through three generations who stammered.” She noted that the “line of descent was direct in this family, and the fathers transmitted directly to sons.”\footnote{Ibid., 1, 155-157.}

This was the language of someone (yet) unfamiliar with common genetic concepts – gene, recessive, dominant – yet deeply concerned about the phenomenon of hereditary deafness; a combination that resulted in a tone of
cautious vagueness about results and urgency pressing for more research. Consequently, the monograph refrained from offering any analytic model. It merely stated that heredity clearly was responsible for deafness in a significant number of pedigrees, and that shared ancestry seemed to play a role. Hopkins referred readers to Macklin's 1946 analysis that had shown “two independent genetic factors” to be involved in producing hearing loss. Macklin's analysis, she continued, “may be taken as a point of departure for a review by other investigators, who, in this monograph, have available the basic data on which her conclusions are based.” Given the many unknown factors, however, the school believed that providing “these data in full, without an analysis or commentary, will be more useful in the long run than committing ourselves at this time to the support of any particular hypothesis.” For this purpose, the “full records are available at the Clarke School and may be examined by serious students of the problem of deafness”224

The monograph concluded with a call for cooperation between “geneticist, otologists, auditory physicists and physicians” as the way to “the final solution of the problem of heredity and its relation to deafness.” The latter was a pressing issue as teachers for the deaf were often “called upon to advise the pupils and their hearing brothers and sisters as to the likelihood of deafness” in their own offspring. At “the present time,” Hopkins admitted with regret, “we do not have enough knowledge to make accurate predictions possible.”225 Research in the 1940s allowed no certain individual diagnosis or prognosis for supposedly hereditary cases. Deafness simply appeared and disappeared “deviously” in

224Ibid., iii, 154.
225Ibid., iv.
many family trees, casting an ominous shadow on the otherwise explicitly promising future of the school's students. It was exactly this gap between definite knowledge and the wish to realize this future that drove heredity counseling at the school.

**Counseling, education and prevention: applied heredity research at an oralist school**

Heredity deafness research at the Clarke School was always meant to be applied research. It had never been an abstract trait tracked for academic pursuit, but something that staff and teachers observed in their daily work, when multiple children from one family visited the school, when a deaf student was the only one in his family or when the cause of deafness was marked as unknown. “No one,” Hopkins wrote in 1946, “who is coming in daily contact with deaf children and their parents or deafened young people can fail to be extremely concerned and puzzled by the problem of inheritance of deafness.” Physicians were “often at a loss to explain the single occurrence of deafness in a family in which there has been no known history of deafness.” Teachers, too, were faced with difficult questions: “What advice shall be given a former pupil who is contemplating marriage with a former deaf classmate? What can we say to the hearing brothers and sisters when they ask whether they may have deaf children if they marry?” Parents similarly bore the unpleasant responsibility to acquaint their child with the extent of its condition once “complete realization of his deafness first comes upon him.”

Despite, or perhaps because the vague nature of hereditary deafness, the

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school felt responsible for providing students and their families with an awareness of their (assumed) genetic status. Other deafness professional also were to be educated. Talks to future teachers from Smith College targeted professionals potentially in contact with deaf persons. This also included “a group of social workers and public health nurses” from a Hampshire County Social Welfare Workers’ Club. Macklin, too, contributed. In 1940, she gave “a most interesting talk” on the modes of inheritance and pedigree analysis to the school’s Teacher Education Department. Individual counseling sessions were also available to the graduating class. At least as important were the “demonstration and interpretation of family charts... given to the members of our own graduating class.” This group, prepared for further education, marriage or professional life by years of rigorous oral education, now received additional, hereditary advice concerning their potential spouses. “Upon request,” Guilder reported, “those who wished it were given an opportunity for individual conferences.” Whether these were mandatory was not noted in the report, though presumably participation was at least recommended, if not expected. Through such activities, heredity research, education, and – it was hoped – practical eugenics merged. The Clarke School was one among a growing number of institutions dispersing heredity counseling in the 1940s. Combining genetic advice, education and research, the school shared some important qualities with the heredity clinics that emerged in this period. They were founded by some of the leading geneticists of their generation: Lee Dice established the Michigan...
Heredity Clinic at the University of Michigan, William Allan the Department for Medical Genetics at the Wake Forest University Medical School, and Clarence Oliver the Dight Institute for Human Genetics at the University of Minnesota. These clinics constitute an important link between the more public health, state-guided eugenic approaches of the 1920s and 30s and the medicalization and professionalization of genetics from the 1940s on. By attaching them to medical schools, their founders hoped to integrate genetics more closely with medical practice and education, and to further eugenic behavior on a more individual level. With their work, the clinics pursued the medical-eugenic goal of preventing disease, defect and suffering at the individual and the population level. For the most part, the leaders of the heredity clinics distanced themselves from coercive eugenic measures such as sterilization or marriage restrictions and pursued a politics of persuasive education and counseling – at least for the part of the population they considered capable of making such reasonable decisions. In this, they shared with the Clarke School the belief that once adequately educated on genetic risk, the desire for a ‘normal’ family would guide reproductive decisions.

Unlike educators for the feebleminded, the school never propagated an image of the deaf as unsuited for marriage or incapable of raising children. Rather, married family life was an attribute of normal citizenship. In this sense, the school’s reproductive policy resembled the pronatalist strand of eugenics.

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that encouraged good marriages. What were considered favorable qualities varied even from a eugenic standpoint, although “good” traits were generally closely tied to values of middle-class respectability. From the standpoint of an oralist school, too, moral and eugenic ideals mingled: a good marriage was that of a deaf to a hearing person, signaling successful integration into society.  

As much as the school had in common with heredity clinics, as much separated them. Heredity clinics operated in a context of academic science, clinical medicine and outpatient counseling. Their educational mission was limited to spreading awareness of genetic condition and imprinting a sense of genetic responsibility in clients seen a few times at best, or who were part of a research population with whom geneticists had no enduring personal contact. The Clarke School, on the other hand, pursued a much wider, more holistic approach that aimed at the formation of a well-rounded deaf citizen who succeeded socially and professionally in hearing society.

Applied heredity research at Clarke took place at a residential school where staff observed students over many years, got to know their families and followed their post-graduation careers. Such familiarity enabled the school to pursue a particularly close tracking of their research population. They could, as Hopkins had pointed out, built a rich collection of material as they followed students throughout their entire educational career and beyond. For each student, the division kept a comprehensive folder tracing his longitudinal development. It consisted of a family pedigree, consecutive otological and audiometric reports and more generally the student medical history, ideally

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230 Wendy Kline has shown the eugenic influence on the postwar pronatalist focus on the family. See Kline, *Race*, 124-156.
from birth, but certainly since his or her entry at the school.”

This material was used in a multitude of ways that combined research, counseling and oralist education. By compiling a student’s file, Guilder hoped that eventually “we may be of greater assistance to the teachers through our studies of the individual child.” In particular the school’s use of audiological profiles demonstrates how closely intertwined were the short-term goals of special education and the long-term goals of heredity research. An audiogram was not only indicative of a student’s educational needs and potential. Together with his medical file and pedigree, it also placed him into an intergenerational network, and provided him and the staff with information for reducing the impact of deafness on the educational, medical and hereditary level.

Although they conducted heredity research, Guilder and Hopkins were primarily the school’s audiologists and health care workers, dedicated as much to oralist education as to the more abstract eugenic effects of their research. Heredity research and counseling was firmly embedded in an oralist framework, with staff believing as firmly in their students’ ability to overcome deafness as in their own responsibility to minimize deafness by all means possible. Just as psychological research would provide insights to improve educational theory and practice, and just as audiology would improve the efficiency of oralist schooling, so would heredity research enable normal family life for future generations. That in regard to genetics this remained more vision than reality, did not diminish the staff’s sense of pursuing an urgent mission.

Eugenicists’ focus on biological limits and educators’ emphasis of human

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231 Hopkins 1946, Studies, 575.
malleability have often been considered incompatible. Historian Diane Paul concluded that hereditary determinism contradicted the American belief in education and experience: “Eugenicists,” she wrote, “had to counter the powerful American faith in education and in the efficacy of moral effort.”

The Clarke School, however, reconciled both strands. Unlike with the feebleminded, it was not (hereditary) hearing status that implied a person’s worth, but his or her ability to overcome his handicap through the laborious effort of learning oral communication and thus to pass as ’normal’. Hard work, the school never tired of repeating, was rewarded with acceptance by and success in hearing society. Assessing a child – and by extension his family – for hereditary deafness did not necessarily change this set of values. Within the larger scheme of eliminating the plight of the deaf, it was yet another new and promising tool to prevent or even eliminate deafness in future generations.

At the same time, however, residential schools for the deaf established an all-encompassing environment that patrolled social, moral, linguistic and reproductive behavior. The school’s ideal of the oralized deaf citizen severely restricted the meaning of “good” behavior, defining as deviant or defective the deaf person who did not learn to speak and lipread sufficiently, who did not (or did not want to) pass as hearing and joined Deaf clubs and associations. When it came to founding a family, this was more than a matter of individual failure. Marrying another deaf person had taken on strong undertones of eugenic irresponsibility, of not only bringing harm to oneself, but to one’s children and to society at large. Heredity research thus had an immediate impact on the student who was subjected to such examination. In the eyes of the Clarke School, it

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provided him with the knowledge to make good, rational decisions in yet another realm, enabled him to continue his trajectory as a successfully integrated person. In this manner, the medicalization and technologization of deafness went hand in hand with redefining who a deaf person could become. As oralism promised normalization – increasingly aided by improved diagnostics and assistive technology – it left little room for identities beyond this strongly medicalized and pathologizing frame.

**Conclusion**

Throughout its first two decades, the Clarke School heredity division operated under a consistent paradigm. The school had been founded to prove the inherent normalcy of deaf people and had profited from the rise of oralism that dismissed sign language as socially isolating, evolutionarily backward and educationally outdated. It promised the inspirational success of overcoming disability and isolation in order to realize one's full human potential. This was not only an educational achievement, but also increasingly also one of science and medicine. In this endeavor, the school considered itself a pioneer. Their overarching goal was a form of applied research that would help the school in its mission of integration, assimilation and normalization.

Yet when it came to understanding the mechanism of inherited deafness, progress was painstakingly slow. Research, however, was driven by the belief in the usefulness of genetic knowledge and the urgency of its application. Results confirmed the concerning tendency for intermarriage and revealed ever new ways in which hereditary deafness manifested. Although it ran in many families, pedigrees rarely yielded generalizable rules that would have allowed reliable
predictions for an individual couple. Thus, physicians, educators, eugenecists and sometimes even parts of the deaf community agreed, it was best if deaf individuals with a family history of hearing loss refrained from intermarriage. Yet underneath this consensus different disciplines had quite different perception of the meaning and nature of genetic deafness. At the Clarke School, we saw such differences emerge between outside experts such as Steggerda and Macklin, at home in the world of academic science, and the school staff. These were teachers turned researchers, yet still considered themselves part of a proud school tradition of oralist practice based on science. Often, these school staff and outside geneticists were out of sync even as they worked together, the one side thinking of genetic deafness as a matter of pedigrees and familial networks of students with whom staff were personally acquainted; the other as a matter of anthropological traits, genes, carriers and public health. Certainly, Hopkins’ understanding of genetics was far less refined than that of Macklin, yet it was also rooted in older notions of heredity, and in the school’s holistic approach that enabled less abstract, and less harshly eugenic considerations.

Counseling and education brought together the levels of individual assessment, clinical entity and population. Here, the abstracted knowledge was taught and applied to those from whom it had originally been gained. This interaction between diagnostics, research and counseling had characterized the Clarke School research from the beginning. Hereditary research operated within this alliance of medicalization and normalization, of defect and correction. Yet unlike many other institutions pursuing heredity research in the 1930s and 40s, the school avoided a simplistic biological determinism that denied the potential of human development to those labeled as defective. It was not (hereditary)
deafness but rather the ability to learn speech and lip-reading that revealed (and determined) a child’s abilities and educational career.

The school thus operated with a persuasive paternalism that assumed medical and cultural agency over students. In this hierarchy of knowledge, agency was transferred from the students and families from whom it was extracted to teachers, scientists and physicians. Researchers claimed interpretative authority over family history, pedigrees and future reproductive choices. Education, research and counseling intertwined, demonstrating the comprehensive character of oralist schooling. The school’s oralist paradigm portrayed citizenship and participation in hearing society as its ultimate goal. Yet maintaining these elusive ideals came with the price of forfeiting deviant linguistic and reproductive choices to cultural norms. Whether or not Clarke’s alumni eventually followed the school’s advice, research and counseling marked their encounters with the medical world during their school years and beyond.

It was essential for students, the school maintained, to learn about their condition’s character and implications. Only with this information could they navigate doctor visits, effectively use adaptive technology, and make the ‘right’ reproductive decisions. Just as teachers steered their charges away from the conspicuous use of sign language and other expressions of deaf culture, the school aimed to instill in them a sense of responsibility for preventing deafness in future generations. Teachers assumed a position as paternalist counselor for a group portrayed as unaware of the mechanism and dangers of inherited deafness. If only educated on these dangers, the school believed, those affected by genetic deafness would opt for a ‘normal’ family. They thus attempted to evoke in their students a normative ethics of “moral reproduction” that would
take into account the societal impact of passing on one's hereditary traits. The school's heredity counseling thus created an atmosphere in which deaf intermarriage was staunchly disapproved of. Yet it remains unclear what effect counseling had on individual decisions in regard to marriage or reproduction. Unfortunately, sources do not report on the actual counseling process or students' reaction; a situation that reflected the school's assumption that students would be grateful and appreciative. Yet if anything, the rate of intermarriage between Clarke School alumni seemed to remain constant.

In the eyes of the school, access to citizenship relied on normalcy, and to some extent, this normalcy relied on medicalization. In order to restore deaf students to hearing standards, it was necessary to first determine how they differed on the psychological, audiological and hereditary-medical level. Medicalization thus was a double-sided enterprise. While the oralist paradigm praised the inherent normalcy of the deaf—they could, after all, overcome their difference—science and medicine searched for their underlying difference. Both approaches shared the belief in overcoming disability through this very understanding of difference, through ever-earlier interventions to correct—or even prevent—deviance from the norm.

Certainly, there was a gap between the school's vision as a center of applied research and reality, in which heredity research as of yet provided little useful information. The next chapter will explore this gap, and the growing tensions between outside and inside research in the 1950s and 1960s.
IV. Big Science; a small school: the expansion and diversification of genetic deafness research in the 1950s and 1960s

Introduction

The 1950s and '60s were a critical moment in the understanding of genetic deafness – and in destabilizing the coalition between genetics and oralist education. At least since A. G. Bell’s 1883 memoir, scientists and teachers had tried to understand the mechanism underlying the inheritance for deafness – for the most part in vain, as the previous chapter demonstrated. This changed in the 1950s, when advances in genetics and biomedicine made possible to distinguish different subforms and hereditary patterns. Although individual diagnosis remained difficult, geneticists for the first time had available more precise models for predicting reproductive outcomes – and thus often felt confident to encourage marriages between two deaf people. For teachers of the deaf, on the other hand, deaf intermarriage remained a taboo.

Research at the Clarke School illustrated these developments. In the 1930s and '40s, the school had established itself as a leading center of genetic deafness research. In the following two decades, it tried to maintain this status, and, indeed, in the 1960s once more managed to draw in a prestigious institution – this time in form of the NIH – for another research project. It was an encounter between two unequal partners: on the one hand the oralist school that specialized in speech and hearing, and maintained a holistic vision of education and science; on the other specialized NIH scientists, interested more in biomedical traits than educational outcomes. Moreover, where the Clarke School had financed previous research, research in the 1960s was federally funded and used NIH scientists, support staff, lab resources and computers. As a
consequence, the school was much less able to determine the course of research. Rather, they mainly contributed an interesting data set and research population. Thus, by the end of the 1960s, the school had been pushed to the periphery of genetic research. It was no longer a center, but merely a site of fieldwork, albeit one that contributed to significant advances in understanding genetic deafness during this period.

Historians have pointed to the immense changes taking place in biomedicine and genetics during the 1950s and '60s. This period saw the establishment of federally funded bioscience and the professionalization of medical genetics, now diversifying in subfields such as cytogenetics, population, or biochemical genetics. These developments also affected deafness research. After over half a century of diligently amassing pedigrees and medical data, advances in cytogenetics, biomedicine and biomedical computing finally made possible more sophisticated analyses that revealed underlying patterns and thus researchers allowed to define and distinguish an ever-growing number of subforms of deafness. More nuanced knowledge also changed approaches to heredity counseling – at least among geneticists. If it could be determined that deaf people would not pass on this trait, then, from a geneticist’s perspective, there was nothing to discourage them from marrying. For oralist educators, on the other hand, it still was a truism that deaf intermarriage signified failure to

achieve the ideal of integration into hearing society. Thus, advancing knowledge weakened the alliance between geneticists and oralist educators. While previous chapters have followed the emergence and development of this alliance between eugenics and oralism, this chapter will trace how heredity research and oralist education grew apart again.

Historians of eugenics and genetics have pointed to the tentative and conflicted emergence of non-directive, patient-centered counseling in this period. This occurred alongside to geneticists shifting their attention from to the “normal” middle-class family. Genetic deafness research adds several twists to these narratives of continuity and change of eugenic thought. For the most part, historians have focused on the fraught, ritualized and incomplete process by which geneticists, physicians, biologists or anthropologists revoked their eugenic past. Yet other professions concerned with genetic deafness – educators, audiologists, speech therapists – were not involved or invested in this enterprise of (superficial) sanitation. Unlike the young discipline of institutionalized genetics, which wished to recreate their public image, the oralist educators at the Clarke School quite unabashedly referred to the eugenic past in their visions of a better eugenic future. Eugenics as part of progressive reform of medicine and education seemed to merge seamlessly into genetics as part of biomedical solutions to disease and disability.

To explain these different beliefs and approaches, it is necessary to look more closely at the fields, professions and institutions in which deafness and heredity were discussed. The dominant strands concerned with deafness – psychology, education and audiology and other disciplines described in chapter II – were primarily concerned with childhood deafness. This had not changed
much in mid-century America, when childhood disability captured public attention. The polio epidemics of the 1940s and '50s were emblematic for this fascination. Polio stood for fears of waste and neglect in children, the nation's future and most vulnerable population, yet also evoked an unbroken in the powers of science and medicine. Fundraising campaigns such as those held by the March of Dimes introduced televised charity events – the telethon – and created the polio poster child to portray children as particularly worth of investments in science, public health or education. This framework, historians of disability have pointed out, shaped encounters between professionals and patients, reinforced paternalistic patterns, and, at worst infantilized individuals with disabilities as eternal children. Setting up a clear trajectory of cure and overcoming, it left little room for more deviating views of disability.235

Yet medical hegemony does not equal medical uniformity. Like the previous chapters did for psychology and heredity research in the 1930s and 1940s, this chapter will look beneath the surface created by the common goal of

curing and preventing, and ask what was to be prevented and how so. Placing the Clarke School in a network of interdisciplinary and international research, I will follow its changing status alongside three different axes: Advances in understanding genetic deafness; the professions and disciplinary alliances that drove these advances; and continuity and change in the beliefs of how to best address genetic conditions and counsel those affected.

**Genetic deafness research in the 1950s: Case studies, syndromes and reproductive counseling**

The 1950s were a decade of quiet routine for the Clarke School's heredity division. Louise Hopkins continued to collect pedigrees and audiograms, yet no outside scientists were invited to investigate the accumulating material. Nevertheless, with the 1949 publication of the *Clarke School Studies on the Heredity of Deafness*, the school had become part of an international network of researchers who corresponded with each other and cited a shared corpus of work. Comparing more closely a number of US and foreign approaches, I will show the different meaning new knowledge about genetic deafness within specific frameworks of goals and beliefs.

The Clarke School research was met with great interest among laypeople and scientists. Scientists requested copies of the monograph for their own research – e.g. Japanese geneticist Toshiyuki Mori, the Egyptian Hearing Center or Dutch physician and audiologist L. S. Wildervanck from the Koninklijk Instituut voor Doofstommen in Groningen. For some of these researchers, the school data was a means to theorize about different hereditary types of hearing loss. Others hoped that the Clarke data might be useful for analyzing other
(supposedly) hereditary disorders. The National Veterans Epilepsy Center, for example, asked about the incidence of epilepsy in deaf persons.\(^{236}\) From the late 1940s on, references to the Clarke School research became standard in the field.

Midcentury researchers of genetic shared an interest in delineating more closely different subforms of deafness, and thus to improve diagnosis, prognosis and counseling. In this endeavor, they relied on the well-established methodology of following phenotypical traits in pedigrees in the hope of finding distinct patterns of inheritance. The potential and limits of this method dictated the lines of research. Nonsyndromic forms, in which deafness was not inherited with another trait, were difficult, if not impossible to identify in this manner and their research made little progress in this period.

Research of syndromic deafness, on the other hand, profited from decades of amassing pedigrees and databases. Cranio-facial, skeletal or pigmentary traits linked to deafness could be followed with relative ease within and across families, even without understanding the underlying hereditary, biochemical or chromosomal mechanism. Differentiating syndromic forms was not a merely theoretical enterprise, but also impacted reproductive counseling. In a time before genetic testing, syndromic traits offered a means to diagnose specific subforms in individuals and thus to predict the reproductive outcome between two deaf persons.

Much, then, united researchers across national and professional borders. There were, however, also significant – and growing – differences in the meaning

and application of research. In the early decades of the 20th century, the two
previous chapters demonstrated, professionals could agree on one thing when it
came to deaf people's reproduction: Given the apparent ubiquity and obscurity
of hereditary deafness, it was best if deaf people did not intermarry, or, at the
very least, did not have children. This simple truth had been at the base of the
alliance between educators and heredity researchers. By the 1950s, however,
this consensus was beginning to dissolve. This development was due as much to
more sophisticated understanding of hereditary mechanisms as to changing – or
unchanging – professional paradigms. How geneticists, educators, audiologists
or physicians approached prevention and treatment differed as much as did
their assumptions about deaf people's abilities and (reproductive) agency. Points
of contact with deaf people (or lack thereof) were particularly important, and
varied from the close, personal and daily interaction at schools for the deaf to the
more sporadic encounters in medical practice or genetic counseling to merely
dealing with anonymous, decontextualized medical-statistic data.

Waardenburg Syndrome was a case in point, demonstrating the close
connection between research, medical practice, and counseling. A combination of
inherited hearing loss with pigmentary and facial traits – differently colored eyes
and a white forelock – it could be diagnosed without any complicated tests. The
first to give extended attention to these traits was Petrus Johannes Waardenburg
(1886-1979), a Dutch ophthalmologist and internationally respected expert for
the genetics of eye conditions. A founding member of the Netherlands
Anthropogenetic Society, he served as its president from 1949 to 1963 and
belonged to genetic societies in Denmark, Italy and Germany. His work was
typical for the close ties between medical practice, heredity research and applied
Waardenburg practiced ophthalmology in Arnhem, but also held a position as external lecturer in medical genetics at the Rijksuniversiteit in Utrecht until, in 1952, he was appointed professor of genetics at the Institute of Preventive Medicine in Leyden. Throughout his career, he provided genetic counseling and served as an expert in paternity cases in Dutch courts.\(^{237}\)

Observing and collecting hereditary traits in his ophthalmologic practice, Waardenburg had encountered a patient with hearing loss and dystopia canthory, a lateral displacement of the inner corner of the eye. He found that other researchers had observed similar cases in which this trait was combined with a striking white forelock and heterochromous eyes. Intrigued, he began an extensive study at five Dutch institutions for the deaf, accumulating a research population of 1050 individuals and their families. In this population, he reported in 1951, he had found twelve cases of his new syndrome; a number that correlated with 1.43 percent of the institutionalized deaf. In the general population the syndrome occurred only at a rate of 0.0042 percent.\(^{238}\)

Waardenburg Syndrome introduced an important concept to hereditary deafness research: the variety of expression in dominant genes. The pedigrees Waardenburg had collected showed a pattern of inheritance that had often puzzled researchers. Even if both parents were deaf, they sometimes had


hearing, sometimes deaf children. Such an occurrence had been explained in three ways: The parents had different forms of recessive deafness; one or both were environmentally deaf, or the father was not actually the biological father. There was, however, a different scenario: a rare dominant form with a low penetrance and varying expression. Not everyone who had inherited the gene for Waardenburg’s new syndrome was equally affected on the phenotypical level. Moreover, Waardenburg reported, different traits had a different level of penetrance. Only 17 percent of affected probands showed the characteristic white forelock, twenty percent had hearing loss, and 25 percent heterochromous eyes.239

Research on syndromic forms such as Waardenburg Syndrome brought another realization: Different types of genetic deafness were as numerous as they were rare. Into the 1940s, researchers had hoped to tie down the heredity of hearing loss to one, maybe a few recessive types. Sometimes they speculated about a rare dominant form. Yet by the 1950s, it was becoming increasingly clear that it was caused by a multitude of recessive, dominant or sex-linked, syndromic and nonsyndromic forms, each often quite rare. Two genetically deaf parents, researchers thus realized, were likely have two different types of deafness, and thus to have hearing children. This insight would have important consequences for counseling. The old eugenic – and, indeed, folklore – truism about the perpetuating effects of “like marrying like” no longer held true.

Thus, a more sophisticated understanding of the mechanism of genetic deafness enabled geneticists to pursue prevention via a more individualized form of reproductive counseling. Waardenburg, now at the Leyden

239 Waardenburg, Syndrome, 201, 231-234.
Anthropogenetical Department, presented genetics as a profession that could dispel concerns over family traits and provide patients with important information. In a 1956 article dedicated to the Danish geneticist Tage Kemp, he laid out his position on intermarriage, counseling and sterilization. Rather than generalized restrictions, he argued for a sophisticated medical-genetic analysis of each individual couple. “Last year,” he wrote, recounting a case, “I was consulted by the parents of a congenitally deafmute 27-year-old woman, who had met a young man at their club and wanted to marry him.” (Whether the couple shared their parents medico-genetic concerns was not recorded)

Waardenburg gave his blessings for the union. After taking a detailed family history, he concluded that both families “possessed the gene for deaf-muteness in a heterozygotic form.” The young woman had been diagnosed with Usher Syndrome (hereditary deaf-blindness), her fiancé with “sporadic deaf mutism.” Both conditions were inherited in an autosomal recessive manner, yet were different genetic entities. Consequently, despite “this hereditary tendency for deaf-mutism on both sides,” Waardenburg, “had no objections to marriage.” The children of this union, he assured the family, would be “phenotypically normal.” They would be, however, carriers for both deafness and Usher Syndrome and needed “to be strongly advised not to marry in future any blood relatives.”

Thus, Waardenburg sanctioned marriages between deaf people, as long as they did not perpetuate the trait. His narrow focus on reproductive outcomes and his interaction with deaf people in a reproductive counseling situation marked the differences between Waardenburg’s position and that of oralist

educators. If the main goal was to prevent deafness, the marriage of two deaf persons per se no longer had the negative associations it had long held for both oralist educators and geneticists. On the contrary, the genetic expert could hope to find a precise diagnosis and assuage the fears and hopes of the individual, couple or family. Nevertheless, like generations of professionals before him, Waardenburg, too, was concerned with reproductive patterns at schools for the deaf. School officials, he advised, should be careful to “minimize the possibility of persons of the same hereditary type becoming too closely acquainted on account of the biological consequences.”

This development marked a growing tension and estrangement in the alliance that geneticists and educators had formed over A. G. Bell’s *Memoir upon the foundation of a deaf variety of the human race*. For educators, with their holistic interest in preparing deaf children for complete assimilation into the hearing world, deaf intermarriage meant potential failure. For a long time, eugenicists and geneticists had shared disdain over deaf intermarriage, respectively associating it with the sociocultural and biological perpetuation of deafness (or both). In the 1950s, however, specialized disciplinary knowledge resulted in divergent conclusions about what constituted risk, pathology or failure, about what should be prevented and on which level to intervene.

National traditions of eugenic thought, deeply embedded in the politics and practice of health care and public health, shaped definitions of risk and pathology. Next to the Netherlands, Scandinavian researchers contributed strongly to 1950s genetic deafness research. The development of deaf education

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241 Waardenburg, *Intermarriages*, 115. Waardenburg believed that there were several recessive and dominant forms and based this conclusion on his own work and that of German, Dutch and British researchers, including the Clarke School.
and communities in Denmark, for example, followed a pattern similar to that of other countries, including the US. A phase of establishing deaf schools, deaf communities and sign languages in the mid 19th century was followed by the implementation of oralism by its end, leading to an “isolation phase” in which there was little real exchange between hearing professionals and the deaf community. Denmark had also developed its own model of eugenics, rooted in a welfare state-approach to public health. Here, Tage Kemp, to whom Waardenburg had dedicated his article above, had established himself as a leading figure in the 1930s. He was the first director of the Copenhagen Institute of Human Genetics, founded in 1938 with the Rockefeller Foundation’s support. The institute became the center of a countrywide system of registration that was considered exemplary by geneticists worldwide. It drew from nearly complete Danish civil records and reports from institutions for the mentally ill or disabled. Eugenics also profited from the expanding Danish welfare state, which brought individuals within the reach of public health measures.²⁴²

This database and research provided the basis for genetic, family and marriage counseling. In his function as a leading geneticist and the institute’s director, Kemp frequently received requests for advice from physicians inquiring whether a couple might pass on “some hereditary taint or other.” Deafness was among these “taints.” From the close to 8000 requests the institute had received by 1953, 69 concerned deafness, Kemp reported in a 1953 article on “Deaf-

mutism and genetic counseling.” In such cases, he and his staff turned to the institute’s card index, which “may furnish information about the persons in question and their families.” In 24 instances, no eugenic indication could be found. The “patients and their families,” he stated, “could be comforted.” For the remaining cases, he recommended abortion, sterilization or a combination of both. For 22, these measures were completely, in seven partially justified on eugenic grounds.243

Kemp’s definition of a partially eugenic indication for abortion or sterilization was typical for the Scandinavian brand of eugenics as a measure of public health and social welfare. A mixed indication was given “when the same patient presents a medical or a psychiatric indication as well as an eugenic, perhaps also social or humane indications.” This social or humane indication was an ambivalent category that might denote a women’s desire for not having any more children or the geneticist’s belief that she should not. “In such cases,” Kemp continued, “it is conceivable that even a rather slight probability of hereditary encumbrance will be included in the deliberations concerning the sterilization or the interruption of the pregnancy.”244

Kemp supported negative eugenic measures like abortion and sterilization, yet thought that such measures should not be coercive. Rather, he believed that a patient or family educated on their genetic make-up would come to a reproductive decision that furthered general eugenic welfare. This stance was typical for Denmark’s eugenic policies and mirrored in its sterilization law,

244 Kemp, *Deaf-mutism*, 77.
passed in 1929 as the first in Europe. Unlike in the US and later in Germany, sterilization in Denmark was to be voluntary. In practice, such a distinction often hardly mattered for the targeted populations in asylums and institutions. Nevertheless, Kemp’s advice in cases of hereditary conditions such as deafness was to recommend eugenic measures rather than to enforce them.245

In the international genetic community, Kemp was a well-respected figure, and the Scandinavian take on eugenics an attractive model for a field eager distance themselves from the atrocities of Third Reich Germany. With his belief in voluntary eugenics, based on genetic education and responsibility, Kemp stood for a form of eugenics that his American colleagues, too, came to embrace in the 1940s and '50s. Eager to portray genetics as a democratic science important to Cold War efforts, leading US geneticists such as James Neel or Lee Dice of the Michigan Heredity Clinic in Ann Arbor emphasized their dedication to countering degeneration without reverting to totalitarian coercion. Neel or Dice imagined a situation in which the counselor presented the couple or family with genetic information and relied on their desire for a “normal” child in making the eugenically right decision.246

Such a voluntary model relied on a patient’s capability and willingness to be educated and to adopt the professionals’ white, middle-class values on

gender, family, defect and normalcy. This idealized middle-class family became the focus of geneticists in baby boom America. Yet there was also a persistent, if muted concern with the reproductive behavior of other groups, who were supposedly unable to follow rational advice. A lingering phantom rather than a clearly defined entity, they remained a troubling portent of degeneration. For those who, for sociological or eugenic reasons, were unsuited for reproduction and child rearing, (voluntary) sterilization remained the recommended procedure. In 1952, for example, Lee Dice, founder of the Michigan heredity clinic, recommended voluntary sterilization “of those persons who carry obvious hereditary defects.” He added that “[c]ompulsion should play no part in such a program, except only in the most extreme cases of irresponsibility.” Yet his skepticism about the responsible behavior of the “hereditarily defective” — disabled people — became clear in his description of this group. Their sterilization, he perpetuated deeply rooted social prejudice, was “especially desirable from sociological considerations, because those persons who are defective mentally or who suffer from other serious handicaps often are not qualified to rear a family.”

Where deaf people were placed in this framework of reproductive educability, depended much on disciplinary paradigms, and on how personal or professional contact with deaf people attenuated preconceptions. Oralist educators insisted on their students’ capability for making responsible reproductive decisions, yet expected assimilation to hearing norms in professional, private, marital and reproductive life. Geneticists usually were not

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committed to these oralist norms, but focused much more narrowly on reproductive outcomes. By the 1950s, Kemp and Waardenburg could cast themselves as experts assuaging irrational fears about heredity by encouraging “good” reproductive behaviors beneficial to individual and population. They did not note how they communicated with their deaf clients and we can assume that there was very little actual exchange over lived experience or potentially “deviant” perspectives. Nevertheless, there is also no indication that they considered the deaf any less capable of coming to “good” and reasonable reproductive decisions than other counseled individuals.

American perspectives: Curtailing the reproduction of the “institutionalized deaf”

Not everyone, however, considered deaf people part of such reasonable, educable middle-class respectability, as the 1955 dissertation of zoologist-geneticist Perry Close demonstrates. Close had studied zoology at the University of Texas, Austin under Clarence P. Oliver (1898-1993). Oliver was a student of eminent geneticist Herman J. Muller, and had worked on drosophila and radiation genetics before moving on to the study of human genetics in the late 1930s. He was an important figure in establishing this field, connecting it more closely with medicine. In 1941, he founded the Dight Institute of Human Genetics at the University of Minnesota, one of the first heredity clinics in the US. When Oliver left the Dight Institute for the University of Texas in 1946, the directorship was taken over by geneticist Sheldon Reed who would coin the term genetic counseling in 1947. Oliver also was a charter member of the American Society of Human Genetics and served as its president in 1953; five years later, he was
president of the Genetics Society of America. It was Oliver who suggested a study of genetic deafness to Close. Close did not record why his mentor was interested in this topic, although it is likely that he had encountered genetic deafness in his own work. Oliver’s ideal of applying the study of genetics to public health shone through in Close’s study of deafness. His was the approach of a scientist studying a population from afar and on paper, of applying large-scale public health solutions to a deviant group. The deaf, for him, were mainly a disembodied research population about whose life, social position or education he knew very little.248

Tellingly titled *Heredity and Productivity in Families of Institutionalized Deaf*, Close's thesis reverberated with lingering fears of deaf reproduction and intellectual incapability. In fact, Close made exactly those associations with feeblemindedness and defectiveness that educators and organizations of the deaf had fought so adamantly earlier in the century.249 He based his longitudinal study on statistical records from the Texas School for the Deaf. Founded in 1856 as a residential school for white deaf children, its entrance records offered rich material for genetic analysis. The Clarke School data also featured in his study. In the preface, Close thanked Louise Hopkins for making available some of the data she had collected.250 While they shared methodology and data, Close’s eugenic-
statistic perspective lacked Hopkins commitment to education and their personal acquaintance with deaf people. His objects of research were the “institutionalized deaf” – a noteworthy term for students at a residential school. Even though students' “institutionalized” state ended with graduation, such terminology perpetuated old fears about the impact of deaf people's reproduction on society at large. Institutionalization conjured images of stagnancy and incapability, and of dependency on taxpayer money – connotation that educators and deaf people alike had been trying to escape.”

Close’s contact with deaf students apparently was minimal, and his assumptions about deaf education and the lives of deaf people based on outdated texts. For the most part, he relied on school records already compiled by a teacher, a convenient solution that minimized the time he himself had to spend at the Texas School. His general perception of deaf people seems to have come from the negative portrayal of residential schools in A. G. Bell’s Memoir. Unlike Bell, however, Close’s viewpoint was not tempered by personal relationships with deaf people. Reiterating Bell’s oralist warnings about the dangers of residential schools, he noted that schools for the deaf had meant to “alleviate the handicap of deafness,” yet actually were responsible for producing deaf matings and thus for perpetuating the trait. Primarily responsible for this reproductive pattern was the “universal manual language” that was taught at schools for the deaf, and that in turn produced “deaf communities which often center around deaf clubs.” Such remarks show Close's general ignorance of and disinterest in the social and educational aspects of deafness. He had missed the oralist turn that A. G. Bell and his followers had brought about already in the late 19th century and had remained the prevalent ideology since. In the 1950s, schools for
the deaf still promoted speech and lip-reading; they certainly did not encourage sign language. Close’s reading of Bell excluded the oralist potential for transformation and thus meant talking about “deaf-mutes” when, for almost a century, oralists had been adamant that deaf people were in fact not mute.251

Close’s reliance on a 70-year old study is telling of Bell’s lasting influence as a leading expert of genetic deafness, yet also for the multiple ways in which his work could be read. Specifically, folded into the Bell’s 1883 Memoir was a pedagogic manifesto for oralism, a thought experiment in evolution and a eugenic treatise. Some institutions, such as the Clarke School, incorporated both the educational and eugenic dimensions in their teaching, research and counseling. Bell’s Memoir, however, could also be stripped of its original educational paradigm and explicit belief in deaf people’s abilities and be read solely as a eugenic-medical text. To Close, student of one of the leading human geneticists of the time, deafness was simply a “disease;” “spread” of which should be limited by the “development of genetic-hygienic measures.” The deaf, in turn, were a pathological population whose reproductive and genetic qualities he studied with mathematical-statistic precision, and described from a scientific distance rather than with the sentimental closeness that characterized the Clarke School publications.252

Nevertheless, with this focus on eugenic threats, Close’s study of reproduction shared one of Bell’s main concerns: Was hereditary deafness increasing, either in number or proportion? While he could not find any clear indications, he still noted several disconcerting trends. As had researchers in the

251 Ibid., 72-73.
252 Ibid., iv, 72-73.
early decades of the 20th century, Close pointed to recent medical progress – now this meant “chemotherapeutic and antibiotic drugs” – in preventing environmental hearing loss. And like earlier researchers, he feared that with environmental deafness thus contained, hereditary cases would rise proportionally. For this prognosis, Close referred to Kemp, who in 1953 had predicted a decrease of “deaf-mutism caused by exogenous factors.” Without “prophylactic measures,” Kemp believed, this development would result in a proportional increase of genetic cases, which already made up 50 percent.253 This trend was worrying enough on its own. It was even more so, Close believed, given deaf people’s tendency for intermarriage. With more genetically deaf people, the likelihood that two of them married and passed on their defect rose, thus perpetuating the proportional rise of genetic deafness. A seemingly harmless preference thus could lead to an actual increase.254

Identification was key to averting this concerning possibility. Here, Close recommended pedigree analysis, in particular to find recessive carriers. Audiological testing, too, held some promise for detecting invisible genotypes. A family’s first-born child could be used as an instrument of risk assessment. Testing the first-born’s hearing before a second pregnancy, Close suggested, could provide useful information about the risk in future pregnancies. Audiological tests now also took on a predictive function in monitoring the inside of the womb. “The ability of premature infants to hear and the response of the fetus to sound,” Close speculated, “suggests the possibility of prenatal hearing tests” as early as the sixteenth week of pregnancy. The undesirability of a deaf

253 Kemp, Deaf-mutism, 4.
254 Close, Heredity, 71.
fetus and the option of a “therapeutic” abortion was implied in this rather crude form of potential prenatal testing. Schools, including the Clarke School, had made audiological tests a crucial piece of assessing an individual’s educational placement, family history and medical diagnosis. Close now expanded the use and usefulness of audiology and turned it into a eugenic-predictive instrument evaluating the unborn.255

Diagnosis was one important step toward preventing deafness, yet it remained without effect unless those affected were appropriately educated. Generally, Close, too, took an approach of directive persuasion over direct coercion. He conceded that “few in this country would subscribe to such drastic measures as sterilization or complete isolation of hereditary deaf persons.” Rather, he supported “[e]ducational genetic-hygienic measures” as the “most practical and immediately useful controls.”256 Most hereditarily deaf persons, Close believed, were unaware of the “true nature of their condition.” In this belief, he mirrored Hopkins, Macklin and other researchers. Instructions in “elementary biology or hygiene” would spread awareness of the “risk inherent in marriage involving hereditary deaf persons.” Combined with genetic counseling, such education might decrease the number of deaf children born to such couples. Yet Close’s tone also mirrored geneticists’ unease with leaving reproductive autonomy to those considered not quite capable of such far-reaching decisions. Deaf people, he voiced his concerns, might not be intellectually suited for eugenic education. “Educational measures among affected hereditary deaf,” he cautioned, “present special problems.” The trait of deafness, he believed, “seems uniquely

255 Ibid., 73.
256 Ibid.
resistant to educational measures since it confers a drastic reduction in learning ability."\(^{257}\)

Close's fears about deaf people's reproduction were based more on moral judgment than empiric facts. Twice he warned that "for recessive deafmutes to marry recessive deafmutes is a near certain disaster – all of their progeny will almost certainly be deaf." Contemporary knowledge of hereditary deafness, however, did not support such a prediction. Nor did Close's own analysis, according to which recessive deafness was caused by several different genes. Consequently, whether or not the children of two recessively deaf individuals would be deaf was an unpredictable possibility rather than an unavoidable certainty.\(^{258}\)

Close, then, shared with oralist educators a concern over deaf intermarriage and its reproductive outcomes. Yet when it came to beliefs about deaf people, they were on opposite ends of the spectrum. Teachers carefully maintained the image of the responsible deaf citizen, rejecting any association with intellectual and moral subnormality. For teachers, the educability and inherent normalcy of their (successfully oralised) charges was a central dogma. Where Close operated with a generalized assumption of deaf ineducability, educators believed that by the end of their school career, students had been 'restored' and fully socialized into the hearing world. In order not to incriminate their own worldview, they had to balance concerns over defective heredity with affirming the image of the able and capable future deaf citizen. The geneticist Close on the other hand had no such commitments to restoring deaf normalcy.

\(^{257}\) Ibid., 74-75.

\(^{258}\) Ibid., 1, 133-134, 8, 49.
Only superficially aware of educational theory and social reality, he could freely communicate his fears of deaf degeneration. Evoking such deeply ingrained concerns, he positioned himself as an expert uniquely capably of addressing these questions. “For the layman to take it upon himself to decide such matters,” he warned, “may be as risky as self medication. The wisest course for interested parties to follow is to seek the advise of a specialist in such matters.”259 With such an association of autonomous decision-making with the dangers of ignorant self-mutilation, Close’s nominal commitment to non-directive counseling turned out to be little more than rhetorical veneer.

Recessive genes, invisible carriers: Reassessing pathological populations

Concern over unidentified and asymptomatic recessive carriers had long occupied geneticists. Madge Macklin, for example, had in the 1930s evoked the widely known tale of Typhoid Mary by likening carriers of defective genes to those of disease germs. With such evocative language, she argued for restrictive eugenic measures. Yet unlike with carriers of many infectious diseases, there were no easy tests to identify genetic carriers. During the 1940s, geneticists had advanced statistical methods for computing the percentage of recessive carriers in a population sample, yet these advances were of little help in determining an individual’s genetic status. The main instrument for individual appraisal remained extensive pedigree data by which a geneticist might ascertain whether a certain condition followed a recessive pattern. Such an appraisal, however, was only possible with clearly monogenic traits that followed a Mendelian pattern.

259 Ibid., 134.
By the 1950s, it had become clear that there were dozens of non-syndromic recessive forms; a realization that greatly complicated the diagnostic process. Even if one had found a seemingly clear pattern of inheritance in one pedigree, this might not apply to another family. Conversely, even if the hearing loss in one pedigree seemed to follow a recessive pattern, it was not clear, whether all family members really had the same form of deafness. Thus, if deafness was not inherited with another, easily followed trait, distinguishing subforms often was impossible. Nevertheless, as researchers began to realize how widespread a trait genetic deafness was, they, too, worried about identifying not only families where deafness was clearly recurring, but also those who did not know they were carrying this trait.\textsuperscript{260}

In the absence of any established test for identifying carriers, researchers grasped for tentative methods, but reached no consensus. Some hoped to find more subtle forms of hearing loss in hearing parents with a deaf – something William Tinkle had already attempted in the 1930s. Erik Wedenberg from the Stockholm Karolinska Hospital Department for Otolaryngology and Audiology explained in a 1958 article that in many genetic conditions, the homozygous individual “may be symptom free, but, if he is subjected to sufficiently delicate physical or chemical tests, it can be demonstrated through deviations from the normal that he is a bearer of a disease factor.” In a “number of blood diseases and metabolic disorders,” he continued, carriers had been discovered in this manner. For deafness, where the underlying biochemical mechanisms were still completely unknown, chemical testing remained a vision for the future. Instead,\textsuperscript{260}

Wedenberg used the well-established methods of audiology and reported that “the parents’ audiogram revealed considerably more frequent and more extensive auditory impairment than are normal in the population as a whole.”

Others disagreed. In a 1957 study on consanguineous marriages among parents of students at the Dutch Royal Institute for Deaf Mutes, L. S. Wildervanck could detect no audiological difference in the hearing parents of recessively deaf children. He concluded that it was “impossible to solve this problem [the detection of heterozygous carriers] audiometrically.” Carrier detection had to await a more refined understanding of the biochemical and genetic base of hearing loss. Nevertheless, an important insight emerged from this research: The line between unaffected, recessive carriers and affected individuals was not always clear. Rather, there seemed to be a spectrum of hearing loss among family members. This realization softened the harsh division of us vs. them that had marked genetic deafness research (and eugenics more in general) during the first third of the century. It turned genetic hearing loss into a condition that potentially could affect anyone.

“*The self-direction of human evolution.*” 1950s eugenics at the Clarke School

Concern over carrier testing and identification also occupied Louise Hopkins at the Clarke School during the 1950s. Two things become apparent

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when comparing her writing in the mid 1950s with her 1940s reports. First, as indicated by her correspondence, she had since clearly familiarized herself with the goals and methodologies of genetics as a field. Second, in doing so, she had been much influenced by Macklin and her take on the goals of applied eugenics. (School records indicate a tentative friendship between both women) Yet this influence only went so far. Where Macklin’s language and proposed methods tended to be quite crass, Hopkins maintained her special brand of Clarke School eugenics. Reaching back to A. G. Bell, it was informed by a general scientific optimism, oralist beliefs about the place of deaf people in the world, and a strong sense of the school’s mission in helping them achieve assimilated citizenship.

Once again eugenic interpretations of risk and pathology were influenced by the school’s larger pedagogic mission and the paternalistic portrayal of deaf people as needing and accepting of scientific guidance. In a 1954 article on “Heredity and Deafness” in *Eugenics Quarterly*, Hopkins evoked Mendel, Bell and Faye as well as the school’s own research to confidently state that “[e]ugenics, ’the self-direction of human evolution,’” – the much repeated slogan of the 1921 International Eugenics Congress – “is coming to mean something very real not only to scientists but to every intelligent man and woman.” In this process, she saw herself and the school in the authoritarian position of a knowledge-broker. Even though research still had not yielded “sufficient knowledge to speak dogmatically about deafness,” the Clarke School staff considered it their “duty... to give young deaf people and their families the benefit of the knowledge which we have and to help them realize the true situation.” Both the school’s oralist
education and heredity advice were to lead the deaf child from ignorance to enlightenment.263

The Clarke School, Macklin, Close, Waardenburg and other researchers thus imagined applied genetics within a dynamic of ignorance, enlightenment and eugenic duty. One's true genetic self was hidden until brought to light by scientific prodding. Being told of one’s genetic make-up constituted a point of no return from where on responsible behavior was expected. Where before an unsuitable mating might have been excused by ignorance, now it was irresponsible deviance. These assumptions rested firmly on a paternalistic model of medical authority in which pathology was unilaterally defined by the expert and was to be internalized by the patient.

Nevertheless, beliefs on the best type of genetic guidance varied. Whereas for Waardenburg, knowledge of different recessive forms meant relaxing restraints on deaf intermarriage, for the Clarke School the threat of recessive carriers meant expanding the borders of pathology. Here, one can clearly see Macklin's belated influence on Hopkins's conception of heredity. She now had incorporated Macklin's fear of the phenotypically normal, yet genotypically diseased person. This concern was only strengthened by the school's close connection between audiological and heredity research. The audiological data collected in the last decades had made possible a more differentiated, yet also more inclusive definition of hearing loss. Rather than as a dichotomy of hearing

or deaf, Hopkins now defined hearing loss as a gradual and more far-reaching phenomenon. In particular in families with one or several deaf members, she explained, “there are not only deaf individuals and hearing individuals but also individuals with all gradations of hearing defects.” Thus, it was no longer only the individual student who was afflicted, but the entire family.264

Hereditary disposition could play an important role in such families. Macklin, in 1946, had used the example of diabetes for explaining gradual, invisible degeneration leading to disease. Some apparently normal individuals, Hopkins now wrote about deafness, were “born with an auditory apparatus which functions normally for a time but is inadequate to withstand disease and other effects of poor environment.” The realization that genetic deafness was “by no means always present at birth,” but could develop gradually, meant assuming a genetic etiology where before one had assumed hearing loss caused by environmental or unknown causes. Operating with the concepts of recessive carriers and genetic dispositions turned genetic deafness into an all-encompassing, invisible threat. It might affect everybody yet could be actually confirmed only in some cases, thus leaving a lingering insecurity about a person's normal or pathological status.265

In this mindset, the scenarios of passing on deafness included not only the deaf, but also hearing family members, in particular hearing children of deaf parents. Even people deafened by accident or infectious disease, Hopkins explained, echoing Macklin’s belief, had to realize that “they may be a carrier of deafness which may be handed down to their children in the future. To many

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264 Hopkins 1954, Heredity, 193, 196, 199.
265 Ibid.
deaf people,” she continued ominously, “this is an entirely new idea.” The ambiguity of an unknown genetic status and the paternalistic instinct to guide a student through “some of the most important problems which he must face in adult life” further pathologized deafness and the reproduction of those – directly or indirectly – affected.266

Historians have written much about the continuity of eugenic thought and practices in the period from the 1940s to the 1960s. They have pointed to the tenuous introduction of non-directive and non-coercive forms of hereditary counseling, the pro-natalist policies of baby boom America with its focus on “normal” middle-class suburban family, and the early years of advocacy by parents of children with disabilities.267 Yet these histories predominantly focus on genetic professionals, and have not given much attention to other professions dealing with those affected by genetic conditions. As far as deafness professionals are concerned, the new paradigms in genetics and genetic counseling were taken up in very different ways – or not at all. Whether one felt the need to distance oneself from the “old,” bad and coercive eugenics much depended on what eugenics had meant in first place.

To Louise Hopkins the term still carried the same strong note of scientific optimism that it had in the 1930s. For the Clarke school, it had always been clear that their students did not belong to the same class of defectives targeted by sterilization legislation or other coercive forms of eugenic. Hopkins and her institution seemed to have been unaware of the mid-century rebranding of

266 Ibid.
genetics as a democratic, non-totalitarian science. In a way, the school had always relied on non-coercive, persuasive forms of hereditary advice. Like the genetic counseling of the 1950s, it was based on the assumption that the informed individual would come to the “right” decision. For the school there was thus no need to change the course of their heredity research and counseling.

Yet this longer tradition of non-coercive counseling also reveals the underlying biases, assumptions and power structures between counselor and counseled individual or couple. Like other medical professionals at the time, midcentury geneticists operated with a paternalistic authority that depended on the uni-directional transmission of expertise from professional to patient. Yet there was also a tentative opening towards considering patient perspectives in medical or reproductive decision-making, leading to an exchange and engagement with diverse and occasionally deviant patient perspectives. At the Clarke School, on the other hand, the idealization of oralised deaf life prevented this softening of medical authority, which was reinforced by the paternalistic long-term relationship between teacher and (former) student.268

The 1950s thus saw the slow unraveling of he coalition between geneticists and oralist educators that had been forged in the aftermath of A. G. Bell’s Memoir, and had been strengthened at the Clarke School in the 1930s and ’40s. During this earlier period, both groups had agreed that if deafness “ran in the family,” it was better for deaf people not to marry or to have children. Now, educators, medical professionals and geneticist still agreed that deafness was a grave pathology. Yet it was no longer clear how and by which means it was to be

268 For the tentative changes in genetics and geneticists' exchanges with parents of disabled children that would lead to subtle reconceptualizations of disability and genetic responsibility see Stern, Telling Genes, 75-100.
best addressed. Geneticists’ ability to diagnose an individual with a (syndromic) subform (at least sometimes), meant that they could predict (with more or less accuracy) whether a certain marriage would result in deaf children. If not, from the geneticist’s perspective there was no reason for them not to have children. Geneticists thus reduced their treatment of deafness to genetic traits, something that was unimaginable to oralist educators. To the latter, the reproduction of normalcy and the normal family encompassed something much bigger, a holistic ideal of training deaf children to pass as hearing in every aspect of their lives. Deaf intermarriage (and thus family life) remained a deviation from this ideal and should not be encouraged, even if it did not produce deaf offspring. In the 1960s, this estrangement between geneticists and oralist educators would continue to grow, although once more both groups encountered at the Clarke School for another research project.

**Big Science, small school research: Deafness research in the 1960s**

The developments that had marked the 1950s – the growth and institutionalization of large-scale biomedicine with its ever bigger projects and funding schemes, new methods and rapid successes – accelerated in the 1960s. These transformations in the infrastructure and funding of science would push the Clarke School from being at the center of hereditary deafness research to its sidelines, a place merely for field work.

Looking back, the founding and funding of the school’s research department had been a prime example of progressive reform financed by private philanthropic charity. More or less wealthy private donors had given their money in exchange for taking part in a secularized version of saving the
deserving disabled through science. The Coolidge Fund had provided a very respectable sum for setting up a research division that in organization, staffing and location was inseparable from other aspects of school life. For the first three decades of its existence, this generalizing and holistic set-up had worked reasonably well. Research in the 1960s, however, took on distinctly different characteristics and dimensions. The “big science” that had emerged in the aftermath of World War II was supported by an expanding structure of federal funding, and institutionalized with the foundation of the NIH. Biomedical science now required expansive laboratory space and expensive equipment, highly specialized scientists and a supporting network of laboratory staff and administrators.269

Maybe more than any other field, the expansion of human genetics exemplifies these changes. Into the 1940s, it had possessed barely any academic foothold. During the 1950s and 60s, it rapidly acquired a professional society, journal and public standing as a science crucial to advancing medical and scientific progress. The establishment of graduate programs in genetics tied it to universities and their hospitals, and the opening of heredity clinics secured an ever-closer association with the medicine. Ties to the basic sciences furthered for an increasing specialization into subfields such as cytogenetics, biochemical, population or immunogenetics. Developments in cytogenetics in particular provided the field with a new paradigm for defining genetic conditions and for speculations about the correlations between geno- and phenotypes, inheritance

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and environment. For the most part, however, these discoveries had little impact on changing or improving therapeutic options. Treatment for Phenylketonuria (PKU) was a notable and much cited example, as I will show below. Genetic deafness research shared with the field the advances in identification, diagnosis, and the elated hopes they elicited – yet also, and maybe more pronounced than elsewhere, the almost complete lack of therapeutic benefits.270

The general trend toward disciplinary specialization also reached the Clarke School. In the late 1950s and early 1960s, the school reorganized their research priorities. When the research department had been founded in 1928, all three divisions had been given equal weigh and resources. And indeed, throughout the first two decades, each division contributed quite equally to the optimistic oralist endeavor of eradicating (the effects of) deafness by understanding its medical-genetic, psychological or phonetic-audiological dimensions. As the school entered its tenth decade, it gradually moved away from basic research towards providing services in their longstanding area of expertise: audiology and speech pathology. These became the core sciences into which the school invested and by which it affirmed its “role as a leader among oral schools.”271

In 1967, on occasion of its 100th anniversary272, the school opened a new diagnostic and research center. It was dedicated to and named after C. V.  

270 Comfort, Perfection,132, 165, 191, 198; Lindee, Genetic Disease.
271 Clarke School Annual Report 1967, 9
272 The event that was proudly celebrated with an international conference on One Century of Oral Education in the United States, held at the Clarke School and the Lexington School for the Deaf in New York. The international audience of teachers, administrators and scientists had ample opportunity to observe the success of oral education as Clarke School teachers demonstrated the achievements of students from all age groups. See the Clarke School Annual Report for 1967, 55-61 and the conference report, International Conference on Oral
Hudgins, who had led the phonetics division from the early 1930s until his death in 1962. The center provided in-school services, yet also served the wider community with a weekly outpatient clinic and offered audiology classes to graduate students at the University of Massachusetts. Graduate students also had the opportunity to take part in the center’s clinical and research activities. Cooperation with the Bell Telephone Laboratories and hearing aid companies made the school a center of applied research. The division also cooperated with the Northampton public schools and the Smith Vocational Trade School, secured grants from the Vocational Rehabilitation Administration and regularly published in audiological journals.\footnote{273}

Psychological research also continued in these years, yet with Fritz and Grace Moore Heider leaving in 1947, it lost its connection to larger centers and themes of research. Unlike the Heiders, who had been interested in deafness as part of larger psychological and phenomenological questions, their successors mainly pursued a pragmatic educational psychology. Whereas the Heiders’ work had become a classic in the field, their successors did not publish any major contributions.\footnote{274}

Finally, the role and goals of the heredity division had become somewhat obscure. Next to collecting students’ pedigree and etiological information, staff also served as a part time health worker who chronicled the students’ health, administered vaccinations and vision tests and distributed fluoride tablets “for


\footnote{274} See the reports of the psychological division in the Clarke School annual reports from this period, written by psychologist Miriam Fiedler who followed the Heiders in the post of division head, and, for a research program in particular her report in the 1952/53 report, 55.
the reduction of dental decay." To some extent, such nursing tasks had always been part of the staff's work, yet it was a far cry from 1960s medical genetics with its reliance on extensive laboratory equipment, access to clinical resources and ever more specialized scientists.

For its research department, the school had long pursued a policy that demanded relatively few resources and relied much on outside experts. While this had been a viable approach in the past, in an ever more specialized world of biomedical research, special education and audiology, this model began lack cohesion in mutual goals and knowledge. When Steggerda trained Hopkins and Guilder to perform basic tasks such as administering tests or collecting and sorting data, this had been close enough to the research standards of the time, and indeed resembled the work of the eugenic field workers. With her MD, Guilder, had proven to be a good fit, and Hopkins had grown into her role, connecting her audiological expertise with heredity research.

In 1960s, after thirty years of administering hearing tests and collecting pedigrees, Hopkins retired. To fill her position, the school once more turned to the old solution of putting school staff in a research position; they promoted the teacher Ruth B. Hudgins (1907-2009) to head of the heredity division. Hudgins' background suggested little to recommend her for conducting heredity research. She had initially trained as a classical pianist, but had given up this career path after graduating from Oberlin College. Instead, she went on to receive an M. Ed. from Smith College and taught at its Nursery School before she

joined the Clarke School staff. The school did not record why Hudgins was chosen for the position, although one might speculate that the head of the research department, her husband Clarence W. Hudgins might have had some say in the matter.

By the early 1960s, then, the Clarke School was still dedicated to providing their students with the necessary information to prevent deafness in the next generation, yet it had lost touch with the scientific and ideological developments in medical genetics. Still, Hopkins urged in her last report, the school should investigate and publish the data she had continued to accumulate year for year. Displaying the sense of pioneering so typical for the school, she pointed to the material's potential: “No other school for the deaf or research center has as much material on heredity of deafness. It should not remain locked away in our files.” Hopkins successors agreed with this assessment. Once more, they managed to attract a major research institution, yet with this new arrangement the differences in understanding genetics, deafness and applied research between the school and outside researchers were becoming ever more pronounced.

Big science at a small school: The NIH collaboration with the Clarke School

That there was a significant gap between the world of the Clarke School and that of biomedical research became apparent in their search for suitable

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collaborators. An accomplished audiologist and speech pathologist, C. W. Hudgins realized that this was outside his realm and asked for the advice of Amelia Polnik, a zoologist at Smith College. Polnik provided the school with a list of potentially interested researchers. It including distinguished scientists, including geneticist Newton E. Morton from the University of Wisconsin Department of Medical Genetics and geneticist James V. Neel from the University of Michigan Department of Medical Genetics.279

Polnik also recommended biochemical geneticist Kenneth Brown, with whom she had studied at the University of Michigan. Born in Chicago in 1929, Brown had received a BA from the University of Michigan department of zoology in 1949 and an MD in 1960 from its medical school. In the years between his BA and MD, he had worked as a graduate assistant at the department of zoology, a position that allowed him to pursue a variety of interests: He had taken part in field studies of blood groups among native Americans in Arizona, had compared amino acid levels in wild and laboratory rodents, and had worked with geneticist Kurt Stern in an analysis of antibody titers in inbred strains of mice. For his MD thesis, he had gone back to a field study of Native Americans, this time in California. Apart from a brief clinical internship, then, Brown was primarily a biochemical and population rather than a clinical geneticist, and never, really, a practicing physician. His professional associations reflected this orientation: His CV listed him as member of the American Society of Human

279 Clarenve V. Hudgins to Clarke School principle Dr. George T. Pratt, March 10th, 1961, Studies concerning Hereditary Deafness (Correspondence), File 3, Drawer 1, Clarke School Archives, Division for Hereditary Deafness.
In 1961, Brown had just finished an internship at Blodgett Hospital, Grand Rapids and was about to take a position as clinical associate at the Human Genetics Section of the NIH Institute of Dental Research (NIDR). Established in 1949, the NIDR’s primary focus was on improving dental health, e.g. by conducting community studies on the effect of fluoridation. A biochemical laboratory, added in 1958, provided the resources for more detailed analysis. Genetic research had been on the NIDR’s agenda since the 1950 when the institute had hired oral pathologist Carl Witkop (1920-1993). Interested in the genetics of defective enamel, Witkop initiated a field study at the Maryland Brandywine jail. He later extended his research to an isolated Southern Maryland community, interesting from a genetic angle because of its multiracial background and long history of intermarriage. The study not only shed light on the genetics of enamel defects, but also found other hereditary conditions such as albinism and sickle cell anemia. In the aftermath of the study, the NIDR established a Human Genetics Section, headed by Witkop; an important step for the young field of dental genetics. In 1963 this section was expanded into a

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branch of its own and in 1964, Brown was promoted from clinical associate to investigator at this new branch.\(^{281}\)

Deafness had not initially been among Brown's interests. He was, he wrote in reply to Hudgins inquiry, “far from being an otolaryngologist.” Recently, however, had had encountered a “family with conductive adult onset deafness” while consulting for the Grand Rapids Hearing and Speech Center. This encounter had left him “intrigued by some of the problems in diagnosis and possible etiology of hearing defects.” A potential involvement with the Clarke School, Brown pondered, “might be a natural step in the further study of this type of problem.” The data, he commented after reading the 1949 monograph, “cry out for analysis, and I can imagine what treasures your associates have collected in the last 20 years.” A potential project, he continued, would “seem worthwhile both in its intrinsic nature and in its practical hopes of obtaining valid answers based on a reasonable bulk of data.”\(^{282}\)

As with Steggerda, the Clarke School offered Brown a research population with an array of interesting traits. Yet since Steggerda’s time, human population sciences had changed quite a bit. Steggerda, the broadly educated anthropologist had collected an almost infinite range of physical, social and cultural characteristics, more enamored with documentation than with analysis. Brown,

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\(^{281}\) Despite these early successes, the history of genetic research at the NIDR was rather short. By the late 1960s, the branch suffered from Witkop leaving for a professorship in human genetics at the University of Minnesota; in 1967 it lost its Cytogenetics Section to the NIDR laboratory of biochemistry. In 1974, finally, the Human Genetics Branch was closed down. See Harris, Ruth Roy. 1989. Dental Science in a New Age: a History of the National Institute of Dental Research. Rockville, Md: Montrose Press, 273-275. For the history of the NIDR also see the NIH Almanac at http://www.nih.gov/about/almanac/archive/1999/organization/nidcr/history.html [07/04/2015]. For Witkop’s work see e. g. Shapiro, Burton; Cervenka, Jada. 1993. "Carl J. Witkop, Jr. (1920-93): In memoriam." American Journal of Human Genetics 53: 528-529.

\(^{282}\) Kenneth S. Brown to Clarence V. Hudgins, March 6, 1961. Studies concerning Hereditary Deafness (Correspondence), File 3, Drawer 1, Clarke School Archives, Division for Hereditary Deafness.
on the other hand, was a biomedical scientist who collected pedigrees, blood and tissue samples in order to find underlying biochemical mechanisms with the aid of laboratory techniques and computerized statistics. His approach was characteristic for large-scale population studies geneticists pursued in the 1950s and 1960s. A wide range of professionals used population genetics to assess public health, study the effect of nuclear radiation or to explore evolutionary history. They deposited this material in large databases and conducted increasingly sophisticated statistical analyses with ever more powerful computers. Often, these studies were conducted on “isolated” or “primitive” populations abroad, and were inextricably tied up in Cold War politics and in the work of international organizations such as the World Health Organization. Yet the US, too, still offered interesting opportunities for population research – including the Clarke School, with its enormous database and sizable study population.283

Hudgins and Brown's respective visions for their collaboration are telling for the status and role they assigned to the Clarke School. Although Brown and the school shared an interest in defining and preventing genetic deafness, their correspondence reveals few points of contact between the biochemist unfamiliar with the inner workings of an oralist school for the deaf and the audiologist ignorant about the details of genetic science. Hudgins had planned to assemble the accumulated material into a publication like the 1949 monograph. Such a publication would have been descriptive rather than analytical, presenting a

number of pedigrees with markers for traits such as sex, hearing status and other noteworthy features. In this manner, Hudgins hoped, the data would be useful “to students working in the fields of genetics.” Brown on the other hand, whose “interests tend more to the genetics of biochemical defects,” immediately imagined a more extensive study. Instead of only analyzing the existing material, he suggested additional, biochemical studies that would yield more extensive and significant data.

For all his interest, Brown was not sure whether he would be able to work with the school. In particular, he was unsure whether the NIH would allow him to work in a consulting position. By July 1961, however, he was excited to announce to C. V. Hudgins that, upon arriving at NIH, he found that “there is a going project which will be of interest to you in that it does involve young people with hearing deficits.” This study of genetic deafness and renal dysfunction (Alport Syndrome) had been initiated by George Cassady, a senior resident in pediatrics at Harvard Medical School, and geneticist Maimon Cohen, a junior assistant health service officer at NIH.

Biochemical laboratory and clinical studies such as Cassady’s and Cohen’s increasingly became the norm in genetic deafness research. They changed how researchers understood and interacted with their objects of research. In the

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284 C. V. Hudgins to Kenneth Brown, February 24. 196. Studies concerning Hereditary Deafness (Correspondence), File 3, Drawer 1, Clarke School Archives, Division for Hereditary Deafness.
285 Kenneth S. Brown to Clarence V. Hudgins, March 6, 1961. Studies concerning Hereditary Deafness (Correspondence), File 3, Drawer 1, Clarke School Archives, Division for Hereditary Deafness.
286 Kenneth S. Brown to Clarence V. Hudgins, March 6, 1961. Studies concerning Hereditary Deafness (Correspondence), File 3, Drawer 1, Clarke School Archives, Division for Hereditary Deafness.
287 Kenneth S. Brown to Clarence D. Hudgins, July 28th, 1961. Studies concerning Hereditary Deafness (Correspondence), File 3, Drawer 1, Clarke School Archives, Division for Hereditary Deafness.
1950s still, researchers had often relied heavily on statistic material that could be accessed with little or no contact to the patient population. Other researchers, such as Waardenburg, had combined their private practice with observing hereditary traits. In the 1960s, research increasingly moved to the laboratory and the clinic. Often, tests and examinations were repeated several times, requiring probands to return or stay at the hospital. Cassady’s and Cohen’s study of Alport Syndrome was a case in point. The syndrome manifested intermittently and its severity ranged from asymptomatic individuals to those who died early in life. A “single examination and urinalysis,” Cohen and his coauthors cautioned, “is insufficient to classify individuals who are not obviously affected.”

The need to see the study population repeatedly for tests reinforced the condition’s clinical character and the reliance on specialized researchers and laboratory resources beyond those available in private practice. At the same time, potentially lethal conditions such as Alport Syndrome reinforced an understanding of the objects of research as patients rather than statistical entities. The authors’ conclusion about the pattern of inheritance, too, was illustrative for the increasingly sophisticated manner in which genetic syndromes were conceptualized in the 1960s. The syndrome, the authors concluded, was not inherited in a simple dominant or sex-linked manner, as had been suggested because more females were affected. Rather, it was likely to

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depend on a more complex mechanism of chromosomal crossing in which the
defective gene tended to associate with the X-chromosome.289

The biochemical angle of Cassady’s research held great appeal to Brown.
He joined their project, and by October could report that they had taken a field
trip to Indiana to study a large kindred with genetic kidney disease and had
initiated a project at Gallaudet College in Washington, D.C. The population there
was “a particularly rewarding one from a point of view of the particular entity of
hereditary renal disease and deafness.” Even though Gallaudet students were
selected “for their general good health by the very nature of the requirements of
educational background,” preliminary examinations found that as much as ten
percent seemed to be affected.290

Brown suggested that combining the NHI study of deafness and renal
disease with the Clarke School project would allow him to work with the school.
Moreover, it would make available the NIH’s “great fund of analytic technique
and equipment” that would “of course increase the range and value of such a
study.” For Brown, he commented to Clarence Hudgins, “the occurrence of other
diseases among the children with hearing loss would greatly increase their
genetic interest for me.” By expanding their research focus, he speculated, “we
would detect other entities in the course of these studies which might lead to a
more rewarding genetic analysis than was possible” previously.291 Even though

289 Cohen et al, Renal dysfunction, 389.
290 Brown to Hudgins, October 18th, 1961. Studies concerning Hereditary Deafness
(Correspondence), File 3, Drawer 1, Clarke School Archives, Division for Hereditary Deafness.
For the result of Brown's cooperation with the renal disease group see Cassady George,
Deafness (Correspondence), File 3, Drawer 1, Clarke School Archives, Division for Hereditary
Deafness.
deafness might seem unrelated to the NIDR’s work, he assured Hudgins in October 1961, the association with dental research “does not limit us in the slightest in regard to our particular research interests.”

With his own and the NIH’s involvement cleared up, Brown devised an extensive plan for data collection and analysis. This initiative and planning, too, redefined the roles of the Clarke School and outside scientists such as Brown. Although Steggerda and Macklin had devised the analytic framework for their studies, they had more or less accepted the parameters and conditions set by the school. Brown, on the other hand, had the institutional backing and resources to redefine these parameters – and the drive of a young scientist to prove himself as the leading investigator in a major project of his own.

Yet another detail made clear these shifting roles and responsibilities. Hudgins had wanted the study to be published as the second volume to their Clarke School Studies Concerning the Heredity of Deafness, with the school’s name prominently displayed before that of any of the involved scientists. Brown, however, successfully claimed the rights and responsibilities of analysis and publication for himself and the NIDR, with “appropriate acknowledgments to the School and to Dr. Hudgins and Miss Hopkins and others who have participated in the project.”

In an April 1962 letter to Clarke School principal George T. Pratt, he laid out the respective tasks and responsibilities: The Clarke School was to review the existing pedigrees and follow up on any missing entries, for example when

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292 Letter Brown to Hudgins, October 18th, 1961. Studies concerning Hereditary Deafness (Correspondence), File 3, Drawer 1, Clarke School Archives, Division for Hereditary Deafness.
293 Brown to Pratt, April 23rd 1962, Folder Kenneth Brown Correspondence, C.V. Clarke School Archives, Division for Hereditary Deafness.
alumni had married and founded families. The NIDR in exchange would provide
guidance to the Clarke staff and convert the information to data cards suitable
for computerized analysis. As for clinical investigations, the Clarke School was to
provide examinations rooms and a clerk, nurse and field worker to communicate
with parents, and to prepare home visits and examinations. The NIDR team,
consisting of a physician, a dentist and a laboratory technician, would
accompany the Clarke staff on their fieldwork to collect clinical samples.
Furthermore, they would examine the entire student body and all available
parents. The new data thus collected would be encoded, too, and incorporated
into the existing material.²⁹⁴

Although Brown’s suggested course of action significantly differed from
the original plans, Clarence Hudgins, principal Pratt and the school board agreed,
and in 1962, the cooperation between the Clarke School, the NIDR and the
National Institute of Neurological Diseases and Blindness was formalized. With a
budget of $ 54,440 over the course of four and a half years, the project’s goal was
to differentiate subtypes of hearing loss and to establish correlations with other
conditions.²⁹⁵ The Clarke School, then, had once more succeeded in finding
outside collaborators for their research goals. Yet, the circumstances of
collaboration, the division of labor and resources were markedly different from
earlier phases of genetic research at the school. Although Steggerda and Macklin
Clarke had institutional roots, they had not brought with them much more than
their own expertise. Now the school dealt with one of the country’s largest

²⁹⁴ Brown to Pratt, April 23rd 1962, Folder Kenneth Brown Correspondence, C.V. Clarke School
Archives, Division for Hereditary Deafness.
biomedical research institutions. This distribution of tasks and expertise marked the end of an era at the school: From being a leading center of genetic research, it had become a location for fieldwork.

Field work, blood samples and computers: Doing biomedical research at the Clarke School

With responsibilities laid out and the collaboration formalized, research began in late 1962 and lasted into 1966. The research team saw one unexpected addition: Louise Hopkins returned from retirement to make available her intimate knowledge of the material. Research began with assessing existing pedigrees, sending out 3500 questionnaires to former students, visiting families and conducting interviews and examinations. In late 1962, Brown and population geneticist Chin S. Chung visited the Clarke School alumni reunion in Chicopee, Massachusetts together with Carl Witkop and oral surgeon Edward Graykowski, both from NIDR. To find conditions occurring together with deafness, the scientists also conducted a range of examinations. William Hart, director of the Bethesda, Maryland Eye Research Foundation examined 61 children. 990 persons visited the school for physical and audiological examinations, and additionally, Brown and Chung paid visits to some of the students' families. In 1964, Brown began examining students for thyroid disease as associated with hearing loss, and in October 1966, he conducted eye examinations and ECGs on all students.296

New and existing material together amounted to an ever-growing bulk of data that was beyond the analytic capacities of any scientist alone. In the early

1960s, however, there was a new and promising approach: Computerized statistics. The NIH was one of the forerunners of computerizing biomedical research. By the end of the 1950s, the NIH’s administration had been computerized, providing the infrastructure and motivation for expanding this technology to actual research tasks. In 1960, under the impact of the Sputnik Shock, NIH established the Advisory Committee on Computers in Research (ACCR) to facilitate the use of computers in biomedicine and to fund such projects within different NIH institutes. The NIH thus assembled under its roof the few experts familiar both with computer technology and biomedical research. As Joseph November has pointed out, researchers in the 1960s mostly considered computers a kind of super-fast calculators, capable of performing arithmetic operations at a new speed and scale. This approach, he argues, limited their application to a narrow field, yet in genetics, it allowed significant advantages when it came to following the segregation and linkage of traits in large populations. In deafness research in particular, advanced computing would make a real impact, enabling scientists to tackle large sets of population data such as that at the Clarke School.297

Working in the middle of these developments at NIH, Brown had planned from the beginning to code the Clarke School data onto punch sheets for electronic data processing. For the computing, he brought in his colleague Chin Sik Chung as an expert in the computerized analysis of genetic data, “ideally suited to participate in this project.”298 Born in Korea in 1924, Chung had

298 Brown to Pratt, January 20th 1962, folder Kenneth Brown correspondence, Clarke School Archives, Division for Hereditary Deafness.
received a PhD in genetics from the University of Wisconsin, Madison in 1957. He worked as a visiting scientist at the NIH from 1961 until 1964, when he took a position as professor of public health and genetics at the University of Hawaii. As "an experienced population geneticist," Brown wrote to Pratt, Chung had “done modern genetic analyses on population material using high-speed computation technique.”

In a time in which many biomedical researchers remained skeptical about the usefulness of computers, Chung advocated for them being a huge asset to population genetics. With the “use of digital computers in genetic analysis,” he explained in a 1963 article, it was “now possible to approach problems which would have proved too tedious to be feasible in the past.” He saw two main applications for the new technology: information storage and, more importantly, “computation for the solution of complex mathematical and statistical problems.” In particular, “some mathematical and statistical treatises of genetics which are attractive only in theory can be tested with relative ease with the aid of computers.” Aware that this was new territory to most of his readers, Chung assured “that we let computers work for us, but let us not become enslaved by the intricacies of computers.”

One of the tasks for which computers became an invaluable asset was segregation analysis. Understanding which traits behaved like Mendelian traits and were inherited together was crucial for mapping genes onto chromosome

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300 Brown to Pratt, January 20th 1962, folder Kenneth Brown correspondence, Clarke School Archives, Division for Hereditary Deafness.

regions and for distinguishing different subtypes. In large data sets, such calculations were beyond the scope of a single researcher. By the late 1950s, geneticist had available a set of programs, known as SEGRAN (short for segregation analysis), that did exactly this. Fed with a variety of genetic parameters, SEGRAN made possible the calculation of a variety of parameters including the probability that an affected couple would have affected children or that a trait occurred sporadically.302

At the University of Wisconsin, Chung had belonged to the team that had first applied SEGRAN to genetic deafness.303 In 1959, he, O. W. Robinson, and Newton E. Morton, all at the University of Wisconsin’s Department of Human Genetics, had published “A Note on Deaf Mutism” in the Annals of Human Genetics. By example of Ireland – a country small enough that the entire deaf population had been ascertained – the three authors demonstrated the use of “more precise genetic methods” than applied previously. Their sophisticated statistical analysis concluded that autosomal recessive inheritance was responsible for about 68 percent of cases. Up to 36 genes might be involved in producing recessive types. Autosomal dominant inheritance, with a gene defect at at least two locations, made up 22 percent. Seven percent were inherited from the affected parents, the other fifteen new mutations passed on by hearing parents. The remaining nine percent, the authors ascribed to “sporadic cases, due to unrecognized infection or more complex genetic mechanisms.” Finally, they concluded that there was no evidence for sex-linked inheritance.304 With

302 Ibid., 69, 72.
303 Ibid.
these results, the North Ireland study was trend-setting for the direction population research would take in the 1960s and '70s. Biomedical computing made possible to examine older sets of population data and offer new, more refined interpretations of the hereditary patterns at play. The very possibility of analyzing the deaf population of an entire – albeit small – nation was an exciting new venue.

Thus, with Chung joining Brown, Clarke's NIH study had available a unique team of geneticists who combined their expertise in biomedical computing, biochemical genetics and deafness research. The two scientists now used SEGRAN for the Clarke School material. As Brown explained in 1967, applying “modern computer techniques” to large bodies of data would enable scientist to address several questions that had long vexed researchers. Most generally, this approach could help determining the frequency of different types of deafness and their patterns of inheritance. Understanding of syndromic deafness, too, could be refined in this manner. At the Clarke School, as much as two third of the genetic cases seemed to be syndromic. Most of these, however, could not be associated with one of the fifty syndromes known at this point. Here, Brown hoped, computerized segregation analysis would allow “a meaningful genetic and physiological study of these individual groups.” Finally, analysis might make “possible to identify the normal parents who run special risk of having such children prior to their conception and through therapy prevent the defective development.”

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Brown's statement evoked – and conflated – different expectations about the role and abilities of genetics: risk prognosis, diagnosis, and therapy. Advances in statistical analysis contributed to refining knowledge of different types of deafness and their frequency. With this knowledge, it was possible to generate general risk patterns and apply them to individual patients or families. Pedigree data and medical history helped to refine these appraisals. Risk prognosis, however, was exactly that. It gave the likelihood of a specific outcome and was not identical with actually diagnosing an individual with a certain type of deafness. The latter remained difficult, if not impossible. Thus, in some ways generalized risk prognosis was a substitute for individual diagnosis. This certainly was characteristic of the field of genetics in general, although it was more pronounced and long lasting in deafness where genotypes were particularly diverse and complex. Nevertheless, prognosis and diagnosis were often conflated; and often were brought up together with the last dimension Brown evoked: the (prenatal) therapy of hearing loss. Here, however, hopes remained purely speculative and mainly served to stoke a premature optimism.

Further results confirmed this trend. By 1970, Brown and Chung could offer more definite results on the question of the number and frequency of recessive genes. Here, research was closely tied to reproductive outcomes. Id-century researchers had tried to find a number of genes large enough to account for the diversity apparently present in genetic deafness, yet small enough to account for reproductive outcomes. Chung's North Ireland study, for example, had assumed 36 recessive genes that occurred with about equal frequency. This

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306 Here, it is important to note, that Brown, Chung and other researchers in the field of genetic deafness used the term "gene" in the sense of a causative factor behaving in a certain (more or less) predictably way (e.g. recessive, dominant) rather than as an entity mapped onto a specific region of a chromosome.
assumption, however, proved problematic. If these genes were indeed equally frequent, it was highly unlikely that two deaf parents had the same gene. Thus, the number of deaf children resulting from such marriages should be very low.307

The Clarke School data, however, showed a different picture. In this population where many alumni got married to other deaf people, if not other alumni, the rate was significantly higher. The study had revealed 87 sibships resulting from marriages in which at least one parent was a former student. To produce such a relatively high rate, Brown and Chung concluded, the number of recessive genes must be much smaller and unevenly distributed. In other words, only if there were few types and/or one of them was frequent, a deaf person was likely to marry another deaf person with the same type of recessive deafness and have deaf children. They gave an estimate of five common genes and “many more rarer genes causing deafness.” This, however, was a speculative compromise rather than a definite conclusion. Lacking the ability to distinguish more clearly these “presumed entities,” Brown and Chung believed that further distinction must rely on “clinical delineation.”308 Large-scale population genetics could not do with observing phenotypical traits in the individual.

When the Clarke School and NIDR concluded their contribution in 1966, both partners could point to some significant successes. The involvement of Brown and Chung, and more generally the resources of the NIH had made possible a study that was up to the standards of contemporary biomedical research. Rather than mapping and comparing single pedigrees, Brown and Chung

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307 Interestingly, the possibility of different populations having a different distribution and frequency of genes was not addressed much in this period.

Chung for the first time computed and correlated all the data collected among Clarke School students, alumni and their families in the last thirty years. Their results had contributed to advancing knowledge on the frequency and number of genes causing deafness and associated conditions.

Yet while research had once more made the Clarke School population an important model of reference, the school’s status had changed irrevocably. Although it remained a leader in oralist education and adjunct disciplines such as audiology or speech pathology, it no longer could claim the same for heredity research. In this realm, it had been marginalized by the move towards large-scale, specialized and laboratory biomedical research. Although it had never had a geneticist on its permanent staff, it had been able to provide resources for research, train school staff, and control the manner of publication of the resulting material. Now it was Brown and the NIH who brought in resources, staff and money and determined the course of research and its publication. Nevertheless, for the school, this collaboration seemed to offer a payoff for decades of collecting pedigree data, medical information and audiograms. As Brown explained in a letter to principal Pratt in 1962, the clinical data his team would gather on students and their families would “remain at the Clarke School for the use of school physicians and future workers.”

It remains unclear, however, whether this ideal connection between research and application ever was realized for the cases identified by Brown, much less beyond.

The collaboration between the NIH and the Clarke School, then, was one example for the increasing specialization of professions concerned with

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309 Brown to Pratt, April 23rd 1962, Folder Kenneth Brown Correspondence, C.V. Clarke School Archives, Division for Hereditary Deafness, 3
deafness; a development that often ran counter to the school’s holistic quest of integrating different sciences under the umbrella of oralism. To explore these specializing fields, I will now turn to the discussions of childhood deafness, birth defects, early detection and (biomedical) prevention in the 1960s.

**Deafness and Cold War science: Curing childhood disability**

With their work on genetic deafness, Brown and Chung entered a professional cluster that shaped its members perceptions of deafness and determined how they encountered deaf people. Although deafness occurs in all age groups, professionals mostly viewed it as condition to be detected, approached and fixed in childhood, when the individual was still malleable, and lasting damage could be prevented. Placing deafness in the larger field of childhood disability, teachers, administrators, geneticists, audiologists and physicians had established their expertise during the first half of the century. They had formed a closed professional culture, united in its goals, though not always in its methods.

Conference proceedings provide insight to the professional environment for debating childhood disability and genetic deafness in mid-century America. Participants were united by their shared optimism in the power of science, medicine and education.\(^3\) The rapid expansion of the biomedical sciences in the postwar decades reinforced the belief in the scientific manageability of deafness.

New institutional opportunities and expanding federal funding provided...
opportunities for resource-intensive research projects, mass population screening or new disciplinary collaborations. Advances in basic research made scientists hopeful for improving prevention and therapy. Often, this belief in progress through science was infused with the language of Cold War science, reasserting American superiority. For example at a 1967 Nashville *Symposium on Deafness in Childhood* teacher and administrator Leo E. Connor commented that under the “impact of 'sputnik', the education of the deaf in particular seem to be entering a scientific phase that stresses the evaluative and technological aspects of the teaching-learning process.”⁳¹¹ The perspectives of deaf children and their parents remained conspicuously absent in this technologized vision of education. Much less was there any mention of the deaf adult, apart from idealized evocations of their successes. This was telling for approaches to deafness in mid-century America.

Conferences made visible this almost complete separation of spheres between hearing educators and researchers on the one hand, and their deaf subjects on the other. In the 1950s, deaf people rarely had the opportunity to attain the professional qualifications to enter science, higher education or administration, although this was rapidly changing. Even if they succeeded in doing so, they were often excluded from entering professions or professional associations on ground of their deafness.⁳¹² If conferences and professional meetings included any deaf participants at all, it was as lay people who were not

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³¹² For the period between 1869-1960, Gannon list ten deaf people known to have earned a doctoral degree, although this number was rapidly growing. See Gannon; Gilbert 1981, *Deaf Heritage*, 338, 439.
granted participation in scientific or professional discourse. Rather, they were to showcase the achievements of oral education, such as at the Clarke School’s centennial anniversary that featured a panel of oral deaf adults and a demonstration of the oral skills of current students. Beyond these displays of oralist success, conferences and meetings spoke about, not with their intended targets. In their scientific-administrative language, conference reports presented an image of deafness in which solutions came from the professionals providing and administrating them rather than from the group to which they were applied.

Taking part in these gatherings, one could remain completely unaware of the gradual changes taking place in perceiving deafness, deaf people, and disability more in general.\textsuperscript{313} The 1960s, in fact, saw a trickle of projects that blurred the absolute line between hearing professionals and deaf objects of research. Significantly, this development first emerged not in the field of childhood deafness, but in the work with deaf adults, who in this period began to assert their identity, culture and social position with renewed confidences and prepared for the more pronounced and visible activism of the 1970s and 1980s. Oralism, too, would soon be challenged. The 1960s saw groundbreaking work on the linguistics of sign language, and the development of communication systems that at least included manual elements. Yet for the moment, these approaches remained outsider positions. If the teachers and audiologists, physicians and scientists described in this chapter were aware of these challenges to their

authority, paradigms and worldview, as of yet, they had no reason to acknowledge them.314

In mid-century America, then, oralism remained the dominating ideology, at least in the sphere of childhood deafness. Established opinion upheld the ideal of the successfully oralized child who would grow into a successful, integrated citizen, abiding to a form of social conformity that hid disability to the point of being invisible. The “finished product” of oralist education, Leo Connor described the goal in 1967, “is an independent, mature deaf young man or woman able to accept and be accepted in the world of the nonhandicapped. Any less ideal,” he summarized, “is failure.”315 In a culture which perpetuated narratives of overcoming disability through scientific and educational progress, such failure almost always was the failure of the individual rather than that of society in accommodating difference.

Oral failure, defined as the reliance on (or preference of) sign language, remained conflated with mental deficiency: “The bright deaf child will take to lip reading like a duck to water;” renowned Scottish otolaryngologist Terence Cawthorne claimed at the Nashville conference: “A bright deaf child will triumph over his disability in an amazing way, while another child equally deaf will, because of lower intelligence, be unable even with expert help to make much progress in overcoming his defect.” Only for the latter, Cawthorne repeated the predominant mindset, should one allow manual communication. Placing language and gesture on their respective evolutionary position, he believed that it was the “ability to speak and the precious gift of language” that distinguished
man from beast and enabled him to think. Sign language, on the other hand, remained a curiosity, reminiscent of the London Zoo’s “chimpanzees’ tea party” (when the chimpanzees were dressed as humans and served afternoon tea) or “certain primitive groups who use gesture instead of speech.”\textsuperscript{316} Whether for the individual or the population at large, deafness was something to be overcome by the normalizing effect of oralist education and the progress of medicine and technology.

Belief in the ability of science and education to overcome deafness could go so far as to negate its existence altogether. At a 1964 Toronto conference on the \textit{Identification and Management of the Young Deaf Child} consensus was to avoid the word “deaf” as much as possible. “I myself,” declared the Danish otologist and audiologist Christian Rojskjaer, “am allergic to the word ‘deaf.’” The term was “a relic of the past, a relic of the time before the audiological era,” denoting “something negative” and “hopeless.” It evoked a tragic image of the deaf person as a cripple of prescientific times and carried a stigma of backwardness that no longer should remain unfixed.\textsuperscript{317} Richard Brill, superintendent at the California School for the Deaf, thought it necessary to temper such an “operational definition,” that “jumps a step.” The term deafness, he believed, still had its place to “describe the individual who cannot hear and understand connected speech” with his eyes closed. Nevertheless, when asked whether he considered it “possible to educate a person out of his deafness,” he, too, agreed, stating that education “might move the child across the borderline.”


For Brill then, there was a clear, yet somewhat flexible dividing line between the pathological state of deafness, and the “fixed” state of the oralized child. Whether one had crossed this line and had moved forward was measured by the ability to speak and understand spoken language.318

On a more technical level, such debates about terminology pointed to the ongoing difficulty in defining deafness in first place. This was one of the goals of a 1964 NIH conference on the Incidence, Prevalence, and Causes of Severe Hearing Impairments and Deafness held in Washington, DC in 1964.319 Initiated by the National Institute of Neurological Diseases and Blindness, it was “the first of its kind to be held in this country.” The NIH, the conference report noted, was “anxious to move ahead with an extended research program in deafness” yet found itself bogged down by incongruent definitions and statistic material. Thus, Powrie Vaux Doctor, Chairman of the Gallaudet Department of History and Political Science, pointed to the existence of at least six different definitions of deafness from “as many different professional areas, such as the definition of the audiologist, the rehabilitation worker, the social worker, the psychologist, the otologist, and the educator of the deaf.” The resulting cacophony of records, Doctor lamented, made it impossible to tell whether the incidence of deafness was actually decreasing, increasing or remaining stable.320

Kenneth Brown, too, was “appalled” by what he described as “the lack of information on the numbers and characteristics of the deaf.” Compared to other conditions on which he had worked, he wrote in 1964, it was “a complete void.”

318 Ibid. Italics in original.
320 Ibid., 2.
In part, this was the exaggeration of a newcomer to a field that had, in fact, invested quite a lot of resources into etiological research. At the same time, Brown’s dismissive judgment spoke of the gap in methodologies between the biochemical geneticist of the 1960s, and the more old-fashioned world of collecting pedigrees and medical histories as pursued at schools for the deaf. There was, he pointed out, no “exactly defined base population” against which samples could be read. Without this base information, any study, such as the one at the Clarke School, “is very limited” and was only valid for the original research population. It was, he concluded, “a very distressing situation that so little is known about the epidemiology of deafness in this country as a whole.”

Thus, even though researchers in the field of childhood deafness shared a sense of urgency in addressing basic and applied research, there was less uniformity and unanimity than a superficial look suggests. While professionals shared the conviction that deafness was a grave disability, they increasingly operated with different assumption about what, exactly, caused pathological effects and how they were to be prevented. Was deafness a biochemical deficiency to be reversed, an audiological defect amenable to technological intervention, a speech pathology to be educated away, a statistical trait to be followed in a population, or an issue for genetic counseling? Population research and medical genetics offered only one of several approaches.

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321 Ibid., 8.
Diagnosis, detection and the prevention of harm: Medical genetics

and the push for early identification

During the 1960s, developments in genetics enabled an optimistic vision of identifying, and perhaps even curing genetic conditions. Advances in cytogenetics, in particular, raised hopes. It enabled scientists to observe, identify and diagnose chromosomal abnormalities, and thus to link phenotypical traits to an actual genetic location (although not yet for deafness). Researchers now could tie long-known entities such as Down Syndrome or some forms of cancer to chromosomal abnormalities, and in doing so changed the very definition of these conditions.³²²

Phenylketonuria (PKU) offered another, more biochemically oriented model of genetic disease – and, significantly, the hope for a cure. In the 1930s already, the Danish physician Asbjørn Følling had found an unusual substance in the urine of developmentally delayed children. His investigations demonstrated that it was caused by their inability to metabolize the amino acid phenylalanine, and that this inability was inherited in a recessive manner. A diet low in phenylalanine, it was found, could significantly improve the children’s state and even revert damage. Although a rare condition, PKU offered a new paradigm for the treatment of hereditary conditions. That in PKU this condition was mental retardation – a common condition long considered hopeless and incurable – made this discovery even more important. In 1960, US bacteriologist Robert Guthrie developed a simple blood test to detect PKU in infants, thus making possible large-scale population screening. By the end of the 1960s, most states had implemented mandatory infant screening, making PKU the first condition

³²²Comfort, Perfection, 165, 192-198; Lindee, Truth, 75-79.
with almost universal screening. In doing so, PKU screening set a precedent for a public health programs that relied on the mass-scale sampling of an entire population.\textsuperscript{323}

Chromosomal abnormalities such as Down Syndrome or biochemical conditions such as PKU offered a model of genetic disease with practical benefits to medicine. During the first half of the century, physicians had tended to think of genetic diseases as rare conditions that were insignificant to medical practice and usually incurable. By midcentury, the ability to locate and visualize genetic conditions eased the transition of genetic thought into medicine, raised hopes for refining diagnosis, and finding cures. Medical genetics portrayed itself as a discipline capable of preventing suffering in the (yet unborn) individual and, simultaneously, to improve public health. Yet although cytogenetic and biochemical technologies indeed offered diagnostic advances, treatment for the most part remained limited to prevention in the form of genetic counseling and “therapeutic” abortion.\textsuperscript{324}

The field of deafness shared many of these general developments. When it came to deafness, physicians, teachers, and other professionals did not need convincing that genetic knowledge was crucial in dealing with deafness. Unlike with other, more rare or more recently defined genetic conditions, it was a long-standing truism in the field that a significant, yet undefined proportion of hearing loss was genetic. Yet as much as professionals worried about the passing on of deafness, their means for prognosis, counseling and prevention had been

\textsuperscript{323} Diane Paul and Jeffrey Brosco have analyzed the transformations of PKU from a rare condition to a model for newborn screening. See Paul, Diane B., and Jeffrey P. Brosco. 2014. \textit{The PKU paradox: a short history of a genetic disease}. Baltimore: Johns Hopkins University Press.

\textsuperscript{324} For these developments see Lindee, \textit{Truth}, 10-12, 20, 75; Comfort, \textit{Perfection}, 198.
severely limited. In the 1960s, finally, advances in differentiating and diagnosing subforms brought together more closely diagnosis, prevention and hope for therapy.\footnote{For discussion of another condition long considered hereditary, yet with which debate was invigorated by mid-century developments see Stephen Pemberton’s discussion of hemophilia. Pemberton, Stephen Gregory. 2011. The bleeding disease: hemophilia and the unintended consequences of medical progress. Baltimore: Johns Hopkins University Press.}

The old vision of the potential usefulness of genetic deafness research for medicine now became a (partial) reality. The rapidly expanding number of forms of syndromic deafness reinforced this notion of deafness as a genetic condition that called for medical care. In previous decades, diagnosing hereditary deafness had been predominantly a matter of eugenic prevention of a trait in the coming generation. In the 1960s, it became a medical concern in the current generation. The realization that a significant numbers of genetically deaf individuals might be affected by undiagnosed kidney, heart or thyroid conditions brought a new kind of urgency to debates about detection and prevention. Alport Syndrome, for example, demonstrated the urgency for early diagnosis and intensified research efforts. Although it “might represent a significant disease among the deaf,” Brown explained in 1964, it had been neglected. Contrasting present neglect with the possibilities of biomedical research, Brown and others created a sense of urgency that made applied genetics a matter of scientists social, ethical and medical responsibility to reach a group threatened by genetic disease.\footnote{NIH 1964, Proceedings, 8.}

examinations could, potentially, refine this approach: It may, he hoped, “lead to practical tests which may serve as markers of the genetic condition and may also help in early detection.” With these new possibilities, he urged, the laconic assessment of “cause of deafness unknown” was no longer acceptable. He elaborated: “careful clinical examination will often discover minimal expression of a genetic condition and so identify the true nature of the hearing loss.”

Geneticists’ call for early diagnosis joined a general drive for ever earlier identification and diagnosis of hearing loss – in the toddler, the infant, and perhaps even the fetus. Employing a rhetoric of saving or inhibiting human potential, professionals pushed for the use of tests and assistive technology and portrayed early diagnosis as a matter of public health and individual well-being. Early diagnosis and intervention, professionals argued, would improve medical and educational outcomes and was prerequisite for preventing serious damage. Depending on professional orientation this damage was educational (the much-dreaded “oral failures” who had not been reached early enough by oral education), medical (failure to diagnose and treat associated conditions), or genetic (the failure to provide hereditary information necessary for reproductive decisions).

Audiologists in the 1960s experimented with different technological advances in testing the hearing of ever-younger children. There was the classic

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328 Ibid., 628, 630, emphasis in original.
peep-show test, in which the child was to react to sounds of different frequency; or tests that measured a child’s reaction time to auditory responses. Especially promising were methods did not rely on the infant or toddler’s subjective response, or their ability of motivation to partake in testing.  

Once applied to the fetus, such technologies fueled eugenic hopes for prevention. After listening to a presentation on hereditary deafness at the 1964 conference on the *Identification and management of the young deaf child*, the conference’s president Hallowell Davis regretted that there was not “very much that can be done about this type of hereditary defect except perhaps through the approach of eugenics.” However, he pointed to Erik Wedenberg’s research on testing fetal hearing as an indication “whether a therapeutic abortion might be justified or not.” Currently, fetal responses to sound could be detected only after the 26th week of pregnancy. “Even in Sweden,” Davis commented, “where the laws concerning therapeutic abortion are relatively liberal, this is too late for a legal abortion; but the method and observations are of interest nevertheless.”

Although audiological tests for hearing loss had little in common with the blood test for PKU, PKU screening helped argue for the urgency of early screening. At the 1964 Toronto conference, Marion Downs, director of clinical audiology at the Colorado School of Medicine presented the results of their newborn screening program, one of the first in the country. Inexpensive and simple, Downs argued, it did not “interrupt the nursery routine,” and was “more

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330 For infants and toddlers, researchers devised tests that gauged different types of electrical responses to sounds. Electrodermic audiometry for example measured galvanic skin response as an expression of changes in the autonomic nervous system, while electroencephalography measured different brain function in reaction to sound. For a discussion see *Young Deaf Child*, in particular 80-162.

331 *Young Deaf Child*, 26-28. Davis had been one of the outside scientists assisting with the Clarke School heredity research in the 1930s. See chapter 3.
productive of results than tests for PKU.” She rejected objections from Davis and other conference participants who pointed out that the detection of hearing loss was not as immediately pressing as that of PKU. Downs insisted on her point, arguing that the first six months after birth was “the only time the entire population is available to us.” Missing this opportunity, thus the implied assertion, was alike to leaving the child to a life of defect that could have been prevented.

As a hereditary, metabolic and treatable condition, PKU was a much-cited paradigm for biochemical research applicable to medicine. Unlike with PKU, there were no curative therapies for deafness, yet it nevertheless inspired new lines of research. At the Toronto conference for example, otologist Robert A. Bertrand from the Montreal Notre Dame Hospital Hearing and Speech Center reported on their new interest in biochemical investigations. His team had noted “that a certain pattern of deafness seemed to appear frequently in three particular families.” Children in these families were born with normal hearing that deteriorated by their 18th month. They had, he believed, “a type of congenital deafness that apparently depends on an inborn error of metabolism.” Here, Bertrand pointed to PKU as “an example of a specific inborn error of metabolism which is proven, accepted, and curable.”

A literature search did not provide any clues about the nature of the phenomenon Bertrand’s team had discovered. Deafness “apparently had not been reported in relation to errors in metabolism.” Bertrand and his colleagues

332 Young Deaf Child, 39-43. For Downs’ career and influential work in pediatric audiology see her bio at the Denver Marion Downs’ Clinic. https://mariondowns.com/about/about-marion-downs [01/06/2015]
nevertheless “undertook a series of biochemical examinations,” measuring “amino acids and certain enzymes.” They had not yet been able to define the exact relationship between hearing loss and those biochemical abnormalities, but were “now doing routine tests on blood samples and urine samples” for all incoming children. Blood and urine tests thus joined the battery of standard tests a deaf child was subjected to in order to determine its audiological, educational, physical and genetic status. Conversely, routine testing could contribute to refining definitions of subforms and syndromes, thus strengthening the connection between clinic and research.334

Screening a child for hearing loss was one thing; diagnosing the cause of deafness another, far more complicated, and often fruitless endeavor. Yet here, too, awareness of underlying genetic conditions could offer valuable clinical information. As Brown and Chung explained at the 1963 Convention of American Instructors of the Deaf at Gallaudet: “genetic information is a perfectly good type of clinical information to use in the discrimination of the different causes of congenital deafness; and, conversely, clinical information can provide better criteria on which to base genetic hypotheses.”335 One year later, Brown similarly pointed out that this diagnosis also had a prognostic value, and could help to predict whether a couple’s children would be deaf or hearing. Clinical value for the current, and prognostic value for the next generation were closely intertwined.336

334 Ibid.
336 NIH 1964, 9.
The increasingly close connection between diagnosis, (potential) therapy and prevention reinforced the urgency for establishing genetic registration, education and counseling. The Clarke School, Brown explained to the audience at the NIH conference, “illustrates the advantage of a register system with a well-documented population.” He “encouraged conference participants to start to collect pedigrees,” ensuring them that “it does not require a high degree of sophistication.” Their analysis of the Clarke School data, Brown proudly exaggerated, “presented the first opportunity to give soundly based scientific information to deaf people who are contemplating marriage with other deaf people.” This, the conference report added, “of course, is a common situation.”

What professionals did not agree on anymore was what to do with this common situation. The likelihood that a deaf couple carried the same type of gene for hearing loss was scarce, L. S. Wildervanck clarified at the 1963 Gallaudet convention. “There is no reason,” he commented, “to discourage a marriage between individuals respectively suffering from the common recessively inherited deafness and deafness belonging to a hereditary syndrome.”

New diagnostic tools thus could differentiate the generalizing – and confining – label of 'hereditary deaf'. At the same time, new knowledge shifted the diagnostic gaze to the population at large. Brown confirmed that the single different genes causing hearing loss were rare. By his “rough estimate” they nevertheless totaled to a significant number: “about one fourth of the normal population carries at least one of the recessive genes causing deafness.”

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337 Ibid. 13-14.
339 Brown, Childhood, 196.
1950s had expanded her attention from the deaf individual to the carrier family, scientists now encompassed the entire population.

Screening programs contributed to this development. Referring to “outstanding examples of success” in mass screening for conditions such as thalassemia (recessive autosomal Mediterranean anemia), Ladislav Fisch consequently suggested that one should screen for heterozygote, unaffected carriers for deafness, too. As “[c]arriers of the same gene may be warned in time of the danger of marrying each other,” such an approach could “be of prime importance in prevention.” In the future, he speculated, it might be possible to identify carriers by their pharmacogenetic reaction to certain drugs. By the end of the 1960s, more than ever before, prevention had become a flexible term that could, at least in theory, include medical treatment of deaf children after birth as well as preventing their creation altogether. If it were “possible to identify the normal parents who run special risk of having such children prior to their conception,” Brown explained at the 1967 Vanderbilt conference, it might be possible “through therapy to prevent the defective development.”

Not everybody, however, was ready to give up the old cautionary stance: Summarizing the contributions to the 1967 conference on Deafness in Childhood, George E. Shambaugh Jr. noted that “Dr. Brown’s chapter is most interesting.” Shambaugh, a well-respected otolaryngologist at Northwestern University, felt “encouraged by the fact that two deaf parents could expect to have 60 percent normal hearing children.” Yet, he maintained, “I still would not encourage two

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341 Brown, Childhood, 199.
deaf people to marry if they are congenitally deaf.” The old oralist suspicion of deaf intermarriage, tangled with social belief and moral judgment, was hard to dismiss. Yet increasingly, the next chapter will show, scientists began to operate in settings that challenged older oralist assumptions.

The end of heredity research at the Clarke School

The collaboration with Brown and the NIDR was the last time the heredity division engaged in a research project. There had always been differences in background and knowledge between division staff and outside scientists; over the decades this gap became more and more pronounced. After Hudgins retired as head of the division in 1974, her position was filled by audiologist Peter Jones. Like Hudgins and Louise Hopkins, Jones was concerned about hereditary deafness, yet had no qualifications in genetics. And while Hopkins’ work had provided her with some level of contact with the larger world of genetic deafness research, this does not seem to have been the case for Jones. At the Clarke School, however, was engaged in heredity counseling, and devised educational material on heredity.

When the division celebrated its fiftieth anniversary in 1980, Jones could proudly point out that it had “been the only permanent unit studying causes of deafness at a school for the deaf in the United States.” Over half a century, more than 1000 pedigrees had been collected, sometimes leading up to eight

generations back. In this manner, “the course of any gene for deafness” – gene stood in here for a phenotypical trait – “may be traced from one generation to the next.” Yet Jones was unsure whether their work really had realized its goals. When Morris Steggerda had begun his work in 1930, Jones recalled, he had hoped that “scientific conclusions might be drawn about deafness and its inheritance.” Fifty years later, Jones had to concede that although research had yielded some results, “the 'scientific conclusions' anticipated by Dr. Steggerda have proved elusive.” This statement was telling more for the status of heredity research the school than that of genetic deafness research in the 1980s. The field, the following chapters will show, in fact had seen enormous progress in the understanding of genetic deafness. Yet the Clarke School no longer was part of driving these advances.344

When it came to applied research – counseling and education – the results were ambivalent, too. Despite fifty years of counseling, deaf intermarriages “appear to be the rule.” The educational persuasion that Bell had imagined seemed to have failed. So, apparently, had his vision of oralist education as a eugenic instrument. Bell, Jones remarked, had “proposed to counteract [deaf intermarriage] by having the deaf educated with their hearing peers – 'mainstreaming', in the present sense.” By the 1980s, with the advancement of hearing aids and more inclusive special education legislation, mainstreaming had become much more prevalent than in Bell’s time. Yet Jones was not convinced that mainstreaming indeed changed deaf people's marital preferences. Nevertheless, he felt assured that “Bell’s fear that genetic factors alone would

produce a deaf variety of the human race now seems inappropriate.” Instead Jones believed that “[a]ny deaf culture which might arise, would probably result from social, rather than genetic forces.” In the 1980s, when Deaf community and culture were becoming a visible reality in American society, talking about it as future potential was quaintly out of touch – and telling for the oralist vision the school still tried to project.345

The 1980 anniversary report thus already spelled out the division’s eventual demise. Pride in its achievements was mired with the slow realization that the school had lost touch with scientific developments, perhaps had even failed to reach its goals. In 1983, Jones confessed that “it might seem that our little division has been left behind. That is not true, “ he assured. But he conceded that in recent years genetic research had moved from “from pedigree studies to biochemical and tissue analysis,” and thus beyond what the school could accomplish. Given these developments heredity research “no longer merits a high priority for the school’s limited resources.” By the end of the 1982-1983 school year, the division was closed down. As a final act, Jones prepared their material "so future researches will be able to find what they need.” Wistfully, he concluded, “I have been doing heredity research for the past nine years and hope to have made some contribution to society.”346 This statement summed up not only Jones’ work, but more generally that of the school. For the Clarke School, education was more than just conferring facts. Whether it was forming the deaf child into a full citizen or researching the scientific underpinnings for this endeavor, they framed their work as a contribution to the larger, individual and

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345 Ibid., 6.
social good. Yet the projected unity between educational and scientific practice, individual and social goals had always been frail, and the objects of research and education less pliable than assumed.

**Conclusion**

The 1950s and 60s were a critical period in advancing the understanding of genetic deafness. They were also the era in which the alliance between geneticists and oralist educators began to weaken. Compared to the 1930s and '40s, researchers had made definite progress in defining subforms of deafness, in particular those of syndromes tied to discernible phenotypic traits. By the 1960s, with the help of biochemical analysis and computerized statistics, research on nonsyndromic forms, too, made progress. Calculating the distribution of potential genes and examining their biochemical determinants, scientists came to realize how complex and diverse a phenomenon genetic hearing loss was, and how widespread the underlying genes. Where researchers early in the century had speculated about some vague hereditary matter, and by the 1930s and '40s had assumed a few recessive and dominant forms, the number of known forms grew constantly in the 1950s and '60s. By the late 1960s, practitioners could consult the first comprehensive textbooks that listed the steadily growing number of subtypes and syndromes, patterns of heredity, frequencies and generalized prediction of risk.\(^{347}\) Although definite diagnoses in individual cases often remained elusive, and therapies even more so, scientists were hopeful that

advances in medical technology – prenatal ultrasound or biochemical tests – would soon close this gap.

Historians have argued about the impact of advancing knowledge on eugenic practice. Sometimes, in particular when geneticist rewrote their profession’s past, this has been cast as a matter of real, factual science surpassing the biased pseudoscience of eugenics. Historians have come to more nuanced conclusions. Nils Roll-Hansen, for example, has argued that it was not so much ideological changes but a better understanding of hereditary mechanisms that made postwar eugenics / genetics more moderate and considerate of individual rights. Borrowing from Daniel Kevles’ his analysis rests on the succession from mainstream eugenics – “founded without a clear genetic theory” and tied to questionable sciences such as physical anthropology – to reform eugenics which was “based on a well developed genetic theory.” Thus, in Roll-Hansen’s model, bias and coercion is tied to lack of knowledge; acquiring knowledge, in turn, has a moderating and democratizing effect.348

Yet such a simple progression and opposition of ideology is too narrow. What meaning new insights into genetic deafness took depended much on professional and institutional background. The changing meaning of deaf intermarriage provides a good example. If there had ever been any doubt that Clarke School alumni married each other or found deaf spouses elsewhere, research under Steggerda, Macklin and Brown had made clear that this was a common occurrence. Yet what it meant and what should be done about it varied between professions concerned with deafness, and indeed, even within genetics.

For the population geneticist, deaf intermarriage was an interesting segregating behavior that provided statistic material useful for teasing out hereditary patterns and underlying genetic defects. In a way, this approach was reminiscent of Bell who had asked whether assortative mating among deaf people would lead to changes in racial make-up. For Bell, closely acquainted with deaf people (including those married to each other), this question had personal dimensions and was closely tied to his oralist beliefs. For the population geneticists of the 1950s and 60s, operating with decontextualized collections of statistical data, deaf intermarriages usually were little more than impersonal data points.

For the more clinically-minded geneticist, the issue of two deaf people wanting to marry was a matter of prevention via differential diagnosis. If the two individuals were not both genetically deaf, or apparently carried different genes, they would not perpetuate their biological defect. Consequently, from a medical-eugenic standpoint there was little reason to discourage their union. On the contrary, in the pronatalist atmosphere of Cold War America, enabling rather than restricting marriage and “normal” family life demonstrated the capabilities and accomplishments of applied genetics. In this sense, encouraging or discouraging deaf people’s unions could be positive as much as negative eugenics.

In this manner, geneticists’ less restrictive stance certainly was tied to ideological changes. Although the goal of prevention remained unchanged, they considered the ability to identify, and, potentially, control certain traits scientific progress. Not committed to the more holistic ideals of oralism, geneticists now tried to control traits in order to accommodate the individual in which they resided. In the setting of an oralist school, on the other hand, deaf intermarriage
was an educational and social, if not a moral problem, a matter of noncompliance. The Clarke School thought of genetic deafness as a matter of pedigrees, of familial networks between students with whom staff had spent years and whom they hoped to shape into successfully integrated citizens. Deafness was something students were to leave behind, not to recreate in their children. In this context, audiological findings of subclinical hearing loss in many family members aggravated fears over recessive carriers. The pathology that previously had only resided in deaf students, now extended to a much larger, and much less easily controlled group.

As these examples make clear there was no monolithic progression of knowledge about deafness and applied science. Rather, it is crucial to look at a wider array of disciplines and institutions to understand the relationship between professional paradigms, sociopolitical determinants and scientific advances. The history of genetics and even more so genetic counseling has been written with an almost exclusive focus on heredity clinics, genetics departments and genetic counseling programs. Although historians disagree about the finer lines of periodization, they commonly point to some level of distancing from earlier eugenic thought and practices. Often, the establishment and professionalization of medical genetics as a field served as the vehicle by which to achieve this distance. Geneticists in the 1950s and 60s portrayed their science as one aiming to relieve and prevent individual suffering, rather than engineer races and populations.

Yet, as I have shown in this chapter, heredity research and counseling were also practiced in other institutions in which the values and goals of heredity research followed a different trajectory. Clarke school staff, even those
employed within the heredity division, did not primarily identify as eugenicists or geneticists, but as teachers or audiologists using heredity research as a tool in their oralist endeavor. Even Louise Hopkins, who most engaged with the larger field of genetic deafness research, appears to have been unaware of the ideological changes occurring in genetics. For school staff, the matter of immediate importance was securing the success of their students and, in turn, maintaining the school’s leadership position. In this, they were reasonably successful, and had not (yet) to defend their oralist beliefs. Unlike postwar geneticists, they were under no pressure to justify the worth and value of their research. Standing outside the reframing of genetics, they operated within a holistic framework of pedagogical guidance. When geneticists by the 1950s advocated for applied heredity research to be non-coercive, this was what the Clarke School had propagated all along. Yet what exactly persuasive counseling meant, what level of agency the counseled was to possess, and what its outcome was to be, did not necessarily mean the same to oralist educators and geneticists.

Both oralist educators and the midcentury geneticists appearing in this chapter operated within a framework that mainly understood deafness as a form of childhood disability. This was a preconception formed by the dominant approach to deafness since the late 19th century and enhanced by the mid-century polio and rubella epidemics. Childhood disability was an area of intense public concern, yet also of enthusiastic scientific optimism. A narrative of urgency tied together these two poles. If only medical and educational interventions were applied early enough, and parents attentive enough to any signs of abnormal developments, children could be saved from permanent
damage. Conversely, however, the child not reached early enough was almost a lost cause.

Like audiology or deaf education, genetic deafness research, too, pushed for ever earlier, even prenatal identification by various (and not always reliable) means. This vision of the fetus and infant supervised by and equipped with medical or audiological technology seemed strikingly modern. Yet it was also reminiscent of much older oralist thought about giving the deaf child the humanizing effect of spoken language as early as possible. In this preventive framework, genetics could offer important clues for diagnosis and, at least potentially, treatment. The realization that a great number of conditions – some grave, some non-pathological – were inherited along with hearing loss added to this push for early diagnosis. This knowledge also added a new dimension to the medicalization of deafness. No longer was the deaf person only to be treated for hearing loss, now he or she also needed to be monitored for renal or cardiac disease, vision loss or metabolic conditions.

The focus on childhood deafness not only determined lines of research and its application, but also how researchers envisioned and encountered their research population. Children were seen as a particularly vulnerable and valued population, yet also one envisioned in infantilized and idealized terms. Mainstream deafness research remained a field in which hearing professionals defined problems and applied scientific solutions to a (supposedly) passive and often abstract population. This unilateral approach, however, no longer was the only conceivable model anymore. By the late 1950s, some researchers in the fields of rehabilitation, psychology or psychiatry began working with deaf adults and engaging with the deaf community. These encounters, the remaining
chapters will show, unsettled long-held beliefs about the nature and meaning of deafness.
V. Between pathology and particularity: Genetics and deafness at the New York State Psychiatric Institute, 1955 to 1969

What is the emotional makeup of the average deaf person? Is he or she more likely to be maladjusted or emotionally disturbed than a hearing counterpart? Do depression, schizophrenia or manic behavior manifest themselves differently in deaf patients? If so, how should mental health professionals handle their “unique needs” and “unusual problems”?349

From 1955 to 1969, the Department of Medical Genetics at the New York State Psychiatric Institute (NYSPI) aimed to resolve these questions. Surveying the entire New York State deaf population, staff researched social position, educational and professional achievements, criminal tendencies, reproductive behavior, family life, marriage patterns and susceptibility to mental illness. Applying sociological concepts such as stigmatization and minority group dynamics to their work, researchers discovered the deaf as a “neglected population.” To remedy this neglect, the NYSPI established the first specialized mental health services for deaf people in the US that were conducted in sign language. This, certainly, was an unusual position in a time when oralism still dominated approaches to deafness. Even more unusual, perhaps, was the fact that this position developed in psychiatric genetics, a profession not usually known for sensitivity for cultural influences or minority needs. Yet under genetic psychiatrist Franz Kallmann – generally considered a staunch genetic determinist – the NYSPI developed a model influenced by contemporary

349 Draft Proposal, undated [ca. 1953], MSS 166, Levine, Edna Simon, Box 15, Folder 22, Mental Health project for the deaf, objectives and progress reports, Gallaudet University Archives. Washington, DC., 1
sociological, psychosocial and psychotherapeutic thought. Relativizing the pathological nature of deafness and and acknowledging the sociocultural differences of deaf people, the project differed significantly from research portrayed in previous chapters and developed a highly influential model for professional approaches to deafness in the 1960s and 70’s.

The NYSPI project was launched during a time of far-reaching changes in psychiatry. Concern with the mental health of returning veterans and the population at large led to an unprecedented rise of federal funding for mental health projects and institutions, and, not the least, to the foundation of the National Institute of Mental Health in 1949. Buoyed by this attention, psychiatrists, psychologists, sociologist and social workers engaged in a wide range of experimental projects that were characterized by their interdisciplinary approach and hopes for larger social reform. The deaf, too, came to be included in this postwar vision of psychiatric services as an instrument of individual and social reform.\

Community psychiatry combined concern with the mental health of the population at large with finding more efficient, humane and affordable forms of care for asylum patients. It required that psychiatrists engage and collaborate

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with the communities to which they released their patients, and understood their social dynamics and peculiarities. In the case of the NYSPI, this meant getting to know the New York state deaf population in a collaboration that had unexpected consequences. In the beginning, NYSPI psychiatrists saw in the deaf mainly a neglected target group to be brought within the reach of psychiatric services. Yet psychiatrists’ engagement with the New York State deaf community – self-confident and well-organized – was no one-way street. As they came to know their previously unknown subculture, and as they engaged with well-respected community members and deaf patients, their regard for deaf people grew and their assumptions about deafness were shaken. Deaf normalcy came to mean something different to the NYSPI researchers than it had to previous scientists working on genetic deafness. Collaboration engendered a sense of identification with deaf people, and blurred the line between professionals and study population.

The project’s origins point to the confluence of different professions and schools of thought in an era of social change and activism. Initiated by Edna Levine, a well-known psychologist of deafness, whose work oscillated between clinical descriptions of deaf difference and advocacy for the Deaf community, the project was adopted and supervised by Franz J. Kallmann (1897-1965), head of the NYSPI Department of Medical Genetics. A broadly educated German émigré, Kallmann’s career spanned 40 years of professional work in two countries during an era of profound changes in genetics, psychiatry and society. Historians have mainly focused on his research on schizophrenia, judging him by his early German work. His time in the US (spanning two thirds of his career) has been treated like more of an afterthought. His ten years of work with the deaf has seen
hardly any attention. I argue, however, that only by considering Kallmann’s entire career alongside developments in in psychiatry, eugenics and genetics is it possible to understand how (psychiatric) genetics could align with both totalitarian and democratic political systems, and how individuals or groups came to be defined as deviant, worthy or defective.

The NYSPI project influenced perceptions of deaf people, and of reproductive and genetic counseling in three ways: First, by establishing a range of specialized services for deaf people, provided by staff trained in sign language, the project introduced the logic and rhetoric of minority-specific counseling to genetic deafness research. When the language of rights began to permeate genetics and psychiatry in the 1960s, both psychiatrists and geneticists could portray themselves as experts furthering democratic ideals by offering services to “neglected” minorities. Traditional medical paternalism remained, yet the ideal of collaboration with patient and patient communities, as opposed to coercion or legislation, left room for more diverse and less pathological perspectives of deafness and deaf people. This collaboration and ensuing depathologization, however, was based on a narrow definition of community and minority, based on the dominant American ideology of white middle-class

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respectability, which was espoused both by NYSPI researchers and deaf community leaders.

Second, these developments were crucial for shifting perceptions of deafness, and of the deaf as a research population, service recipients or partners in research. From its beginnings in the 19th century, most research on genetic deafness had relied on school, marriage or medical records as convenient clusters of data. Although there were a few school-based projects like that at the Clarke School, most research required little to no interaction with deaf people. New York State provided the conditions for a much more thorough, long-term involvement. It had mental health care professionals and a mental health care administration interested in applying the tenets of community psychiatry. The state was home to a large, diverse and well-organized deaf community to serve as a study population. At the same time, with the nation's largest asylum population, New York State's mental hospital hosted enough deaf patients to make a specialized program feasible and attractive. Collaborating with deaf individuals, professionals and organizations in mental health care and prevention, NYSPI psychiatrists came to question previous research. Tracing their often ambiguous and multilayered definitions of deaf normalcy and pathology, I will show how the language of minority rights and discrimination became entwined with professional self-portrayals that pushed the notion of psychogenetic selfhood.

Third, the project established an important cross-disciplinary cluster of psychiatrists, psychologists, and geneticists who acknowledged, accepted or even embraced deaf culture and community. Previous chapters have focused mainly on professions that worked with deaf children, and / or considered
deafness part of the larger problem of childhood disability. Yet by the 1950s, the adult deaf came into the focus of professionals in rehabilitation, social work, sociology, psychology and psychiatry. These professions saw an unprecedented rise of influence in mid-century American science and society, including genetics. Psychological theories about selfhood, and psychotherapeutic approaches to counseling were crucial in forming genetic counseling as form of advice giving. Here, historians have pointed out, psychology usually served to underpin conservative gender and family norms, for example in marital counseling. The NYSPI project fits these interpretations, yet it also shows that psychology could be a transformative as much as a conservative influence. In counseling the deaf, NYSPI researchers picked up research on deafness, social dynamics and minority formulated by the Fritz and Grace Moore Heider in the 1940s already.

Defining deafness as a psychosocial category, and working with deaf adults had a profound impact on reproductive counseling. The issue at hand here was not to save and prevent damage in a vulnerable and innocent population, but to reach an underserved group of more or less normal, capable adults, to educate, and to provide services. Aiming primarily at the prevention of mental illness rather than at deafness itself, the NYSPI thus foreshadowed later projects that considered hearing loss the unifying factor of their target population, yet not necessarily a pathological condition in itself. Thus, the NYSPI project introduced

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yet another model to these diversifying opinions on deaf marriage and reproductive outcomes.

**Franz Kallmann: From sterilizing the feebleminded to counseling the deaf**

Franz Kallmann, who led America’s first sign language-based psychiatric services, remains one of the most controversial figures in the history of genetics and psychiatry. A life-long supporter of eugenically motivated psychiatry, he is often dubbed the founding father of US psychiatric genetics. He was a Jewish-born supporter of totalitarian eugenics who had been forced into emigration by national socialist racial policies. Depending on national contexts and professional traditions, portrayals of Kallmann range from those of a highly esteemed founding father to a hardcore genetic determinist, and almost a Nazi himself – a peculiar characterization for a Jewish-born scientist.353

Born in 1897 to a Jewish family in Neumarkt, Silesia, Kallmann graduated with a medical degree from the University of Breslau in 1922, and for the next three years worked as a neurologist and surgeon in the Breslau Hospital der Grauen Schwestern zu Neumarkt. During this time, he converted to Protestantism, like many German Jew of his generation.354 Interested in neurology, psychiatry, but also criminology and forensics – his doctoral thesis

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354 Mildenberger, *Pursuit*, 185-186. There is conflicting information on the confessional background of Kallmann’s family. Diane Paul for example calls him a “half-Jew” without specifying further whether this “half” corresponds to the categorization of the Nuremberg laws (in which case Kallmann could have had two Jewish grandparents) or the more colloquial use of having one Jewish parent. See Paul 1998, *Heredity*, 66. I follow Mildenberger who had access to Kallmann’s personal papers and correspondence.
was titled “Accidental Stab Wounds as a Cause of Death” – he continued his studies under psychiatrist Karl Bonhoeffer and neuropathologist Hans-Gerhard Creutzfeldt at the Charité in Berlin. There, Kallmann also began pursuing his lifelong interest in psychotherapy that would inform his later counseling work. He studied under the leading heads of the Berlin Psychoanalytic Institute: Franz Alexander, Otto Fenichel and Sàndor Radò.\textsuperscript{355} Radò, too, would later emigrate to the US and act as director of the Columbia Psychoanalytic Clinic for Training and Research where Kallmann taught.\textsuperscript{356}

With these additional qualifications, Kallmann became head of the neuropathological laboratory in the Berlin Herzberge Heil- und Pflegeanstalt in 1928. Here, he began to study the inheritance of schizophrenia. He systematically combed through hundreds of patients files, some of which dated back to the late 19th century, tabulating reproductive and hereditary patterns. His goal was to predict, and thus to prevent the condition.\textsuperscript{357} In 1931, a research visit at the Deutsche Forschungsanstalt für Psychiatrie (DFA) in Munich provided him with an opportunity to connect to the leading figures in German biological psychiatry. Founded in 1917 under the patronage of psychiatrist Ernst Kraepelin, and aided by Rockefeller Foundation and German-American financier James Loeb, the DFA was one of the world’s first institutions solely dedicated to psychiatric research.\textsuperscript{358}


\textsuperscript{357} Roelcke, \textit{Genetik}, 184.

\textsuperscript{358} Roelcke, \textit{Genetik}, 173.
At the DFA, Kallmann worked with psychiatrist Ernst Rüdin, head of the influential Genealogisch-Demographische Abteilung (GDA), the first institution worldwide dedicated to the study of psychiatric genetics. Rüdin was among the most influential figures in German psychiatry and eugenics. He developed a statistical, demographic approach to psychiatry that used tabulated population data to determine individual risk for mental disorders. Between 1917 and 1945, the GDA sent questionnaires to hospitals, asylums, prisons and courts, collecting 30,000 family files for about 200,000 mentally ill individuals.\(^{359}\) Rüdin’s work and reputation attracted young scientists from Germany and abroad, many of them supported by Rockefeller Foundation fellowships. For this generation of upcoming psychiatrists—Kallmann among them—his statistical prognosis linked psychiatric genetics to individual diagnosis, public health, and fears about degeneration. Rüdin’s students dominated German psychiatry in the Weimar Republic, under the National Socialist regime and beyond. Far from being tainted by their association with National Socialism, theirs and Rüdin’s work remained standard well into the 1950 and 60s. His students Franz Kallmann and Elliot Slater went on to found the first institutes of psychiatric genetics in the US and the UK.\(^{360}\)

Like many of his contemporaries, Rüdin was driven by the widespread fear of hereditary degeneration. In 1905, he had been a cofounder of Germany’s first eugenic society, the Gesellschaft für Rassenhygiene and belonged to its conservative right wing. During the Weimar Republic, the GDA was among the


most vocal supporters of a sterilization law. For Rüdin, sterilization was the logical consequence of a predicted empirical risk for mental illness. Like many contemporaries across the political spectrum, he also considered sterilization legislation necessary to curtain public health cost in the increasingly dire economic situation of the late Weimar Republic. Unsurprisingly then, Rüdin welcomed the 1933 Law for the Prevention of Genetically Diseased Offspring, which was based on Weimar plans, but executed in the totalitarian spirit of the new regime.361

Kallmann, too, supported sterilizing the hereditarily tainted, and continued to do so after 1933, although, now marked as Jewish, he himself faced persecution. His research on schizophrenia as a recessive trait, Kallmann thought, would provide crucial evidence for sterilization legislation. With Rüdin’s support, he was able to present the results of his schizophrenia research at the 1935 International Congress for Population Sciences in Berlin. In front of an audience of international eugenicists and population scientists, he proposed to sterilize not only schizophrenic patients, but also asymptomatic heterozygote carriers. The latter, his analysis of patient files and pedigrees supposedly demonstrated, carried a significantly increased risk for schizophrenia. Moreover, pointing to frequent occurrence of feeblemindedness in patient families, he believed that, in any case, their offspring were “eugenically unwanted.”362


Given his Jewish roots and the persecution he faced, Kallmann’s support for a National Socialist law may seem surprising. Yet, as Mildenberger has pointed out, even individuals marked as racially other by the NS regime often shared some of its ideological goals. Many eugenicists opportunistically hoped that the new regime would enable them to realize an authoritarian biopolitical utopia, with them in leading roles. Kallmann was no exception, yet in his case this hope proved to be a delusion. For a while, he was able to maintain his position at the Herzberge hospital because of the so-called Frontkämpferklausel that protected Jewish World War I veterans from being expelled. Yet despite the continued support of Ernst Rüdin, his situation became increasingly precarious. In late 1935, he was suspended from his position without pay. Unable to find a position in Europe due to general anti-Semitic sentiment, Kallmann reached out to US colleagues. He was supported by Rüdin, and his DFA colleagues Theobald Lang and Hans Luxenburger, the former known for his research on the genetics of homosexuality, the latter a well-known criminologist and twin researcher. In 1936, Kallmann emigrated to New York. There, the anthropologist Franz Boas recommended him to Nolan D. C. Lewis, head of the New York State Psychiatric Institute, who agreed to establish a small division for genetics lead by Kallmann.

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364 Mildenberger, Pursuit, 184-188; Roelcke, Genetik, 185. In the long term, Rüdin’s support for Kallmann was mutually beneficent. When Rüdin, who was involved in conducting research on euthanasia victims, needed a denazification certificate after the war, Kallmann provided this so-called Persilschein (named after a popular German laundry detergent) to his former mentor and supporter. See Mildenberger, Pursuit, 195-6; Roelcke, Genetik, 181.
The NYSPI was exceptionally well-suited for integrating a German emigrant who combined biogenetic psychiatry with psychoanalytic thought. Founded in 1895, and from 1929 located at the Washington Heights Columbia-Presbyterian Medical Center, the NYSPI emphasized biomedical research as a means to understand and cure mental illness. Its research departments over time came to include bacteriology, neuropathology, chemistry, biochemistry, neurochemistry, internal medicine, medical genetics, biological psychiatry and behavioral physiology. Associated with Columbia University, it served as a research facility and training grounds for residents at the Columbia School of Medicine.365

A line of influential figures in US psychiatry headed the institute, many of them with roots or education in Germany and Switzerland: Swiss-American psychiatrist Adolf Meyer – usually considered the founding father of American scientific psychiatry – led the Institute from 1902 to 1904 before he left for Cornell and later for the Johns Hopkins Phipps Clinic. Swiss-born and educated August Hoch, a student of William Osler, directed the NYSPI from 1910 to 1917 and introduced Freudian psychotherapy to the Institute. Other directors included Dr. George Kirby, president of the New York neurological society, and Dr. Clarence Cheney, former president of the American Psychological Association. From 1936 to 1953, the NYSPI was led by Nolan D.C. Lewis, a neurologist, psychoanalyst, and former student of Meyer. Open to both psychoanalytic and biochemical models, Lewis created a psychoanalytic clinic as well as departments for neurochemistry and genetics. Under his directorship,

365 Kolb; Roizin, Institute, 99, 129.
numerous researchers who had fled from Europe found a new institutional home at the NYSPI.366

At first, Kallmann's division of genetics was a one-man endeavor. After surviving some financial insecurities, however, it soon became a regular department. It was associated with Columbia University, where, from the mid-forties to his death in 1965, Kallmann served as professor of psychiatry. Modeled after Rüdin's Munich GDA, Kallmann's department was the first institute for psychiatric genetics and the second institute for human genetics in US.367

Methodologically, he continued to pursue the empirical-statistical research paradigm he had learned under Rüdin, although he quickly adapted the principles of applied eugenics to his new surroundings. In 1938, he was able to publish the results of his German schizophrenia research in the US, which political repressions had prevented in Germany. After several more publications on the genetics of schizophrenia, he published in 1953 a monograph on *Hereditas in health and mental disorder; Principles of Psychiatric Genetics in the Light of Comparative Twin Studies.*368 Quick to embrace new developments in biochemical

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genetics and chromosome research, Kallmann opened, in 1960, one of the first cytogenetic laboratories dedicated to psychogenetic research.  

These works secured Kallmann’s reputation in US genetics and psychiatry. He was a member of the American Eugenics Society; in 1948 he became a co-founder of the American Society of Human Genetics and acted as its president in 1952. In psychiatry, Kallmann had the support of influential figures who combined psychoanalytic and biological models of mental illness. NYSP director Nolan D. C. Lewis praised Heredity in Health and Mental Disorder for offering “a progressive, constructive attitude towards all phases of the problem.” Among Kallmann’s supporters was another émigré who had received his education in Germany and Switzerland and had worked at the NYSP: Paul Hoch, the president of the Society of Biological Psychiatry, who shared with Kallmann an intense interest in schizophrenia. In 1955, Hoch became the New York State Commissioner of Mental Health and in this role supported Kallmann’s work, including his projects with the deaf.

Kallmann was remembered as an esteemed colleague and scientist. John D. Rainer, Kallmann’s successor as the head of the NYSP Department of Medical Genetics, described him as “a scientist in the broadest sense with a fertile imagination [...] always a good physician, a knower of man, a student of human fortitudes and weakness, a family counselor and a clinical psychiatrist in the

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369 Kolb; Roizin, Institute, 178l
370 Roelcke, Genetik, 185-186.
noblest tradition." Notably, these reflections ignore Kallmann’s German work, a strategy he had pursued himself. Into the 1990s, colleagues and coworkers followed his self-portrayal as a morally upright scientist who had left Germany disgusted with “the political abuse of genetics for racial purposes.” Historians of science have since deconstructed this tale of noble exile and resistance for the sake of an ethically pure genetics. Florian Mildenberger, Anne Cottebrune, and Volcker Roelcke see in Kallmann a typical representative of a deterministic, population-oriented eugenics that promised to cure society of hereditary taints at the cost of individual rights. This form of social engineering became attractive in the 1920s and 30s, flourished under the National Socialist regime and influenced international psychiatric genetics well into 1960s.

While giving a more nuanced image of Kallmann, these studies tend to take the first, German third of his career as the standard by which to measure him. It is not surprising then, that his work with deaf people has only been mentioned in passing, if at all, in the historiography of eugenics, genetics and psychiatry. Yet his last project, encompassing ten years of active research, was the culmination of a lifetime’s work in psychogenetics, eugenics and preventive mental health. To understand the transitions in Kallmann’s life and science, we need to move beyond viewing him solely as a eugenicist or genetic psychiatrist and see his work in the context of interconnected 20th century reform movements that shaped psychiatry.

375 See Mildenberger, Pursuit; Cottebrune, Kallmann; Roelcke, Genetik.
Kallmann’s career fell into a time of major transitions within psychiatry, when numerous schools of thoughts, professions and reform movements competed and collaborated in order to change mental health care and to understand the nature of mental illness. The mental hygiene movement, strong in the first half of the century, urged for greater general awareness for mental health as a means to reform society; eugenicists captured larger social concerns about the mentally defective threatening society and abusing tax payer money; and asylum reformers looked for new forms of therapy beyond the walls of the institutions and for ways in which to make their profession more scientific and efficient.376

As much as these were distinct disciplines and movements, there was also considerable ideological, institutional, and personal overlap. What united eugenicists, mental health care professionals and reformers was the belief in scientific solutions for mental disease, whether they took the form of social engineering or individual therapy. Etiological models also showed considerable overlap. While contemporary psychiatry professionals argued about the respective influence of heredity and environment, the late 20th century

distinction between bioneurological and psychosocial etiologies was not part of their thinking. Freud, after all, had been a neurologist first, and Adolph Meyer, the most influential American psychiatrist during the first half of the century, developed a complex system biosocial system of mental balance.377

Although national mental health policies could differ greatly, German and American reformers followed each other’s work closely. For a German emigrant such as Kallmann, the shared concern with mental health, heredity and prevention on both sides of the Atlantic eased the transition from one sociopolitical framework to another. Anne Cottebrune has argued that Kallmann was fighting “an uphill battle” against psychiatric establishment in mid-century America which was dominated by psychodynamic schools. Yet this clear opposition between psychodynamic and biological models is a retrospective construction that overlooks the eclectic diversity of methods and models among professions concerned with mental health.378 Mental hospitals, responsible for the large majority of psychiatric patients, continued to rely heavily on the somatic therapies. Here, the novel therapeutic interventions introduced between


Here, it is also necessary to reevaluate Cottebrune’s argument about Kallmann’s transfer of psychiatric-eugenic knowledge from Germany to the US since this argument in fact reproduces his own mythified self-portrayal as the founding father of psychiatric genetics. See Cottebrune, *Kallmann*, 297, 301.
the 1920s and the 1960s added too a general sense of change and progress. These therapeutics ranged from the so-called heroic treatments of the 1930s, 40s and 50s – insulin treatment, electroshock and lobotomy – to eugenic measures such as sterilization (applied disproportionally to asylum inmates), to the availability of the first psychotropic drugs in the 1960s.379

Kallmann’s ambiguous legacy spans these transitions, reaching from totalitarian eugenics to minority-specific psychiatric counseling. He was a well-integrated member of mainstream American science and psychiatry, skilled at utilizing the immense funding opportunities opening up in postwar psychiatry, biomedicine and rehabilitation. The NYSPI mental health project for the deaf was at the nexus of these transformations from eugenics population studies to psychiatric genetics, from the mental hygiene movement to community psychiatry, and from propagating population improvement to social justice and minority rights. I will now turn to the larger landscape of American mental health policies in the 1950s and ‘60s, taking New York State as an example for the unfolding of mental health reform and community psychiatry, and that of the alliance of psychiatric genetics and minority psychiatry.

379 Historians have explored the shared traditions that determined the appeal of heroic therapies in the interwar period and during WWII. See e.g. Hans-Walter Schmuhl, and Volker Roelcke. 2013. “Heroische Therapien”: die deutsche Psychiatrie im internationalen Vergleich, 1918-1945. Göttingen: Wallstein Verlag. Eugenics, historian Ian Dowbiggin has pointed out, had enabled early 20th century psychiatrists to expand their expertise from the asylum to the general population. Asylum directors in particular were among the supporters of legislation to restrict the marriage, reproduction and immigration of the mentally ill. See Dowbiggin, Ian Robert. 1997. Keeping America sane: psychiatry and eugenics in the United States and Canada, 1880-1940. Ithaca, N.Y.: Cornell University Press, 121, 233.
Mental health reform, community psychiatry and psychiatric genetics: The case of New York State

Like other fields in biomedicine and public health, American psychiatry profited immensely from the steady expansion of federal funding that marked the two decades after World War II. Cold War fears and politics fueled much of this growth. Science and medicine, according the general belief, had been crucial to winning the war and would remain crucial as America fought to maintain its leading role in the global theatre. The National Mental Health Act of 1946, and the foundation of the National Institute of Mental Health in 1949 were the result of this growing federal involvement in and funding of health care research and services. They provided the legal framework, and financial, institutional and professional resources to improve and expand research, training and care, and to invest in the prevention of mental illness. 380

A general, broad occupation with mental health also drove the expansion of mental health services, research and funding. This concerned, first, the traditional clientele of psychiatry: asylum patients. Their situation in severely overcrowded and understaffed state hospitals became a matter of public debate after a series of books and newspaper articles by journalists and former patients had indicted inhumane conditions. 381 Beyond the asylum, researchers found that

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380 For this development see Grob 1991, Asylum, 5-7, 45-65 and the essays in Pickren; Schneider, Psychology, in particular Pickren, Wade E. “Science, Practice, and policy: an introduction to the history of psychology and the national institute of mental health”: 3-15 and Rice, Charles E. “The research grants program of the national institute of mental health and the golden age of American academic psychology”: 61-111.

enlisted men were affected by psychiatric conditions at an alarming rate. This appeared to be a threat to the nation’s ability to defend itself. Numerous projects monitored facilitated their reintegration to civil society, and thus shifted psychiatrists’ attention to the average citizen with his average neurotic behaviors and mental health problems. These also seemed to be alarmingly widespread.\(^{382}\)

By the 1950s, the incidence, etiology and prevention of mental disorders in the general population had become a growing concern. Psychiatrists anxiously observed civilians for signs of mental health disturbances caused by the stress of modern life and Cold War threats. Consumerism contributed to this general interest in mental health. In an era of general prosperity and suburban growth, mental health services became a consumer good, and psychotherapy a popular tool for analyzing sated, frustrated and superficial middle class life. Although it took (white) middle-class life as its norm, this expansion turned psychiatric services into a public good that was to be made available to the entire population. Psychiatric services for the deaf, I will show below, relied on this rhetoric of the right to psychiatry, of mental health as part of the “good life.” In histories of minority services, this ideological shift has been given little attention.

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although it is crucial for the development of psychiatric, health and professional activism of the late 1960s and early 1970s.\textsuperscript{383}

Community psychiatry emerged in the 1950s at this intersection of expanding research and funding, concern over issues of mental health, a general willingness to reform psychiatric care, and to find more economically viable ways for doing so. The first generation of psychotropic drugs added to this development. More than any other form of treatment before, they made possible to release institutionalized patients into more open settings; or to prevent their institutionalization in first place. Community psychiatry also fit the development of postwar psychiatry into a multi-disciplinary enterprise. Psychologists, rehabilitation specialist, psychiatric nurses and other associated professions found their niche in a growing field, and brought in a range of psychosocial approaches. Federal legislation soon enforced and encouraged the move toward community based mental health care. The 1954 Community Mental Health Services Act, for example, aimed to prevent mental illness by investing in the improvement and availability of mental health services.\textsuperscript{384}

With its enormous in-patient population – by 1945, the New York State mental hospitals were overcrowded with 75,000 residents – and well-developed mental health administration, New York State was a spearhead in establishing

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community psychiatry and tying it to rehabilitation services. Paul Hoch, commissioner of the Department of Mental Health, had taken an early interest in the open hospital movement of the 1920s and 30s, and in the extension of mental health care beyond the asylum. By 1940, the NYS department of Mental Hygiene had established four aftercare clinics; by 1954, New York City operated several halfway houses that offered support for patients transitioning from the hospital to the community.385

It was in this constellation of psychiatric reform and interdisciplinary approaches, of Cold War fears and optimism that Franz Kallmann’s second career unfolded and the NYSPI projects for the deaf emerged. Broadly educated in various psychiatric schools, and experienced in epidemiological research and practical hospital work, Kallmann possessed the qualities to succeed in 1950s US psychiatrics. His belief in genetics as a widely applicable science enabled him to develop a system of care that combined family and genetic counseling, treatment and prevention, all working toward the lofty goal of freeing society from mental illness. In his publications on schizophrenia, twin research, mental illness and the role of heredity, Kallmann developed a vision of genetics as a guiding science in “a world of emotional unrest and rapid economic change,”386 an “antidote to rebellious anguish, revolutionary destructiveness, or supernatural symbolism in frustrated people.”387 Genetics, he believed, encouraged responsibility for

386 Kallmann, Twin studies.
oneself and society and established the family as an “indispensable biological, social, and educational unit.”

Kallmann’s psychogenetics of careful self-monitoring and social responsibility, of detection and prevention proved attractive to American psychiatrists. Once psychiatry moved to the community, it became responsibly for not only the institutionalized, but also for the potential patient beyond the walls of the asylum. For this population of average people, prevention came to be of prime importance. Claiming the ability to predict the occurrence of mental illness, genetic psychiatry asserted its usefulness in preventive mental health. Buoyed by post war scientific optimism, psychiatrists such as Kallmann could cast themselves as the guardians of society’s (mental) well being. The geneticist, Kallmann wrote in 1962, acted as a “guiding man” in a “trembling world seeking peaceful solutions to such threats as grossly disproportionate population growth, creeping social unrest and haphazard transmutation of cultural values.”

Like other leading US geneticists, Kallmann, successfully translated older eugenic fears into positive assertions of democracy, truth and freedom compelling to Cold War America. Where before it had been the feeble-minded and defective that threatened America, now it was a more generalized, uncontrolled population growth that threatened a democratic world order. A “truly democratic society,” asserted Kallmann in 1962, “owes it to its citizens that anyone who is beset by doubts, whether well funded or not, should have

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388 Kallmann, Twin studies, 276.
389 Kallmann, Future, 251.
access to competent guidance.”

Appealing to American values, he declared a person’s “inalienable right to know what their prospects are of achieving a contented and productive marital life, including a number of healthy children.”

The New York State deaf were to be the first population to which Kallmann hoped to apply such an all-encompassing system of mental health care.

To help “deaf people get more out of life, too.” The origins of the NYSPI Mental Health Project for the Deaf.

The 1950s and ’60s thus witnessed an expansion of psychiatric services, alongside an explicit belief in psychiatry as a science for individual and social reform. The deaf, however, seemed to be excluded from this development.

Attending a psychology conference in the early 1950s, Edna Levine, clinical psychologist and former teacher at the Lexington School for the Deaf, observed that attention was on “ways of helping people live fuller, happier lives.” Yet not “one word,” she noted with concern, “was said about the deaf.”

Levine considered this untenable. She and co-attendant Boyce Williams, an influential deaf consultant to the Rehabilitation Services Administration, began lobbying for a mental health center in order to help “deaf people get more out of life too.”

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390 Kallmann, Future, 253.
391 Kallmann, Twin studies, 246.
392 Levine papers, April 58, Box 21, Folder 31, Speeches, Mental Health Center for the Deaf, Gallaudet University Archives, 1
393 In his 38 years as a consultant to the Rehabilitation Services Administration Programs for the deaf, hard of hearing, and speech impaired, Boyce Williams was highly influential in improving services for deaf people. For his achievements, Williams received a National Association of the Deaf Distinguished Service Award and a honorary doctor of law degree from Gallaudet College. See biographical sketch, Gallaudet University Archives at https://www.gallaudet.edu/library-deaf-collections-and-archives/collections/manuscript-collection/mss-072.html [01/25/2016] and “Boyce Williams. Visionary leader November 2014.” Gallaudet University sesquicentennial celebration. http://www.gallaudet.edu/150/celebrate/visionary-leaders/boyce-williams.html [01/25/2016]
Psychiatric services, then, for Levine were more than just medical intervention. They were a means to achieve the ‘good life’ of postwar, consumerist, suburban America, something to which the deaf, like other minorities, still did not have full access, yet to which they were, in Levine’s opinion, entitled.394

Williams, too, had been concerned about the lack of mental health care facilities for deaf people. He had conducted “an intensive nine year search throughout the whole of the United States for adequate mental health facilities for the deaf” without success. Now, he “pledged his wholehearted support to this present pioneer endeavor”395 Levine and Williams were able enlist the support of “all the important organizations working with and for the deaf.”396 A draft proposal, for example, noted that attendees at the American Instructors of the Deaf meeting in Vancouver in 1953 pledged “to earnestly solicit the active assistance and encouragement of all interested organizations and individuals to the end that a Mental Hygiene clinic for the Deaf shall become a reality.”397

Searching for an institution to realize such a mental health care center, Levine contacted Kallmann, “who was also interested in the same goal.”398 Whether this was the first time Kallmann thought about working on deafness, or, as Levine’s wording suggests, he had come across deaf patients in his extensive research in the New State mental hospital before, is unclear. Something about

394 Levine papers, April 58, Box 21, Folder 31, Speeches, Mental Health Center for the Deaf, Gallaudet University Archives. Washington, D.C., 1.
396 Levine papers, April 58, Box 21, Folder 31, Speeches, Mental Health Center for the Deaf, Gallaudet University Archives. Washington, D.C., 2.
397 Levine, Draft proposal, 2.
398 Levine papers, April 58, Box 21, Folder 31, Speeches, Mental Health Center for the Deaf, Gallaudet University Archives. Washington., 2.
Levine's proposal, however, must have struck a chord with him and engendered a mutual excitement for the project.\textsuperscript{399}

In many ways, the mental health project for the deaf was the realization of Kallmann's eugenic psycho-genetics. As he explained in 1962, their “recently completed pilot study of family and mental health problems in a deaf community such as that of New York” served to “illustrate the range and complexity of legitimate research and guidance functions which falls into the province of psychiatric genetics.”\textsuperscript{400} Similarly, Kallmann’s colleague John D. Rainer described it as “a psychiatric genetic department in action.”\textsuperscript{401} It was, however, also a product of its time, in which the (mentally ill) deaf had come to the attention of researchers like Kallmann as a minority group in need of services. The project was a micro-laboratory mirroring changes in theory, treatment and policies. It combined biological and hereditary models with pharmaceutical and psychodynamic treatment in a multi-disciplinary approach to mental disease. As a form of community psychiatry, it aimed to reintegrate the mentally ill into society. Designed as an outreach program to the deaf community, it was to provide psychiatric services to a group of people formerly underserved and misunderstood by psychiatric institutions. The project, Kallmann wrote, laid out “a minimum action program for an aggregate of clearly frustrated but nonvociferous people who in an enlightened society would seem to need family

\textsuperscript{399} Levine papers, Box 5, Folder 49, correspondence Kallmann Franz J., Gallaudet University Archives. Washington,

\textsuperscript{400} Kallmann, \textit{Future}, 253. Emphasis in original.

\textsuperscript{401} Here, Rainer quoted Kallmann himself. See Rainer, \textit{Schizophrenia}, 428.
guidance services with as much justification as any of their hearing counterparts.”

Kallmann’s justification of psychogenetics as a matter of rights and services points to an important shift in portraying the targets of eugenic improvement, from the irresponsible feeble-minded to the more or less average citizen and family. Like many other eugenicists, Kallmann had been an ardent proponent of coercive sterilization in the early decades of the 20th century. By the 1950s, such coercive measures had fallen out of favor. Instead, the reasoned expert upheld the ideal of eugenic responsibility toward oneself and society. “In a democratic society, which rejects compulsory methods of public health planning,” he wrote in 1953, “it would seem a mandatory obligation for public health authorities to make adequate provision for expert guidance on problems of marriage, parenthood, and inheritance where it is needed and sought voluntarily by morally responsible people.” Genetics, he claimed, was a crucial instrument for “democratic population policies” that aimed to “maintain a biologically self-sustaining form of societal structure.”

For Kallmann, this self-sustaining unit, foremost, was the family.

Thus, where the defective and feeble-minded had been treated as quasi-offenders persecuted for endangering public health, Kallmann’s new objects of research, the deaf, were defined as an oppressed minority group who had been denied access to their basic right to psychogenetic services. In this scenario, it was up to the psychiatric experts to give back to this “nonvociferous” population their voice. This paternalizing position would weaken over the course of the

402 Kallmann, Future, 253.
403 Kallmann, Twin studies, 2, 248
project, not the least as the project staff discovered deaf people’s metaphorical voice in a non-voiced language.

Enlisting Kallmann and the NYSPI ensured access to funding, staff, and resources. With his connections throughout the state’s mental health care system, Kallmann in 1955 secured a $27,800 Research and Demonstration Grant from the Office of Vocational Rehabilitation (OVR) for “establishing a mental hygiene clinic for deaf adolescents and adults.” The ORV, a 1955 press release explained, had taken an interest in improving mental health services after finding it “exceedingly difficult in the past to work and plan effectively for job adjustment with emotionally disturbed deaf people.” This difficulty stemmed from the “inability of trained mental health workers to penetrate substantially the communication barrier of profound deafness.” Support was renewed in 1963 for a three-year project that established an inpatient unit for deaf patients and in 1966 for another three-year project that initiated a range of preventive and rehabilitative services in various settings such as schools and support groups.

In 1955 the project staff consisted of Kallmann and two young collaborators, Columbia residents Kenneth Z. Altshuler and John D. Rainer. Like Kallmann, they had neither experience in working with deaf people nor previous knowledge of the vast body of literature on the psychiatric, psychological or educational aspects of deafness. Give the hardened ideological positions on the

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nature of deafness, as detailed in previous chapters, this ignorance proved more benefit than hindrance.

Altshuler had come to the project by coincidence. After receiving a BA from Cornell in 1948 and an MD from the University of Buffalo in 1952, he was attracted to psychiatry because of the field’s breadth, encompassing medicine as well as “the study of the person.” In 1955, after serving in the Navy for three years, he continued his psychiatric residency program at Columbia University. Originally assigned to the Bronx VA hospital, he was looking for a residency at Columbia in order to avoid the commute to the Bronx “and then find a place to park, which was impossible.” He was told to contact “a man downstairs, named Franz Kallmann,” who was “starting a new project on working with the deaf.” Kallmann accepted Altshuler as a full-time researcher and resident while the latter completed his training in psychoanalysis. Psychoanalytic training, Altshuler commented, was something “you had to do at that time if you were going to be considered a good psychiatrist.” After some initial hesitation, Altshuler began to appreciate and embrace Kallmann’s emphasis on the role of biogenetic factors in mental health, and in particular copied his mentor’s statistical methodology. As Altshuler described their roles, Kallmann “was the chief and there was another young doctor like me [Rainer], and we were his two Indians, and we became the world’s experts by default.”

In an era interested in the psychological aspects of disability and the sociological aspects of rehabilitation, the NYSPI project was able to attract

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406 Interview with Kenneth Z. Altshuler, Dallas / Baltimore, February 6th 2014, Interviewer: Marion Schmidt, 1; Faculty Profile, Altshuler, Kenneth Z. University of Texas Medical Center: http://profiles.utsouthwestern.edu/profile/10141/kenneth-altshuler.html

407 Altshuler, Interview 2014, 2.
collaborators from a wide range of disciplines.Over the coming years, project staff grew to include more psychiatrists and psychologists, as well as educators, rehabilitation specialists, social workers and other professionals working with deaf people in various functions. Statistician W. Edwards Deming, widely known for popularizing the use of sampling techniques, helped with study design and data analysis; biological anthropologist Diane Sank, who would later work on the heredity of mental disorders, contributed to the analysis of the family studies and genetic deafness. Some of the era’s leading figures in the psychology of deafness also contributed. Although Edna Levine left the NYSPI in 1959 due to other obligations, she later called herself the “god-mother of the project.” Austrian-born child psychiatrist Hilde Schlesinger, too, contributed her expertise. Following the NSYPI model, Schlesinger founded the Mental Health Services for the Deaf at the University of San Francisco in 1968 (now the their Center on Deafness).

Levine and Schlesinger stood for a new direction in the psychology of deafness. Like earlier generations of psychologists they explored the psychological and psychiatric effects of deafness. Yet they also acknowledged, if not embraced deaf culture and community. Moreover, this new generation of psychologists influentially advocated the use of sign language in deaf education, rehabilitation and, more generally, family and daily life. Levine for example was

408 These approaches have not yet been explored in disability studies. For a contemporary example of such a sociological and psychodynamical approach see e.g. the contributions in Garrett, James F (ed). 1952. Psychological aspects of physical disability. Washington: Federal Security Agency, Office of Vocational Rehabilitation, and for the the deaf, Edna Levine’s contribution, 125-146.


410 Levine papers, Box 5, Folder 49, correspondence Kallmann Franz J. GUA
involved in compiling the first comprehensive ASL dictionary and served as president of the Psychology Commission of the World Federation of the Deaf.

Schlesinger co-authored the influential 1972 *Sound and Sign: Childhood Deafness and Mental Health*, and the 1978 *Sign language of the deaf: psychological, linguistic, and sociological perspectives.*

Beyond portrayals of 19th century educators, the work of professionals supportive of sign language has not seen much attention in Deaf history. Yet looking at how and where such allies and supporters emerged is crucial for understanding the circumstances under which sociocultural definitions of deafness gained social and professional valence. The NYSPI was an important institution in which these changes unfolded. Significantly, it operated outside the oralist establishment. It brought together a wide range of professionals who considered the deaf one of the groups in postwar America in need of medical and rehabilitation services, yet now well-reached by them. This general goal united professionals with different backgrounds and approaches, from Levine's

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rehabilitation psychology to Kallmann’s psychogenetics. Although these circumstances encouraged a definition of deaf people as a social minority, this was not necessarily equivalent with a less pathological definition of deafness. Yet, as I will show below, it engendered a different form of identification with one’s target population, and thus, a different kind of justification of professional authority.

Psychopathology and the “normal adult” deaf: Ambivalent results from an “unknown” population

A sense of pioneering in an under-researched field permeated the NYSPI research. As Kallmann recalled in 1962: “the project began in something of a clinical and statistical vacuum.” 413 This was a telling statement. It ignored about half a century of psychological and psychiatric research on deafness. Yet it expressed a partial truth. Previous work had mainly focused on the social, emotional and intellectual development of deaf students in comparison to their hearing counterparts. The authors of these studies often were teachers who also served as school psychologists. Kallmann and his colleagues, on the other hand, worked primarily with psychiatric adult patients and the adult deaf person became the focus of their research. This group indeed had been neglected in psychological and sociological research. Only a few studies, including the Heiders’ 1940s Clarke School survey mentioned in chapter 2 had been concerned with the lives, attitudes and achievements of deaf adults. 414

413 Kallmann Future, 253.
414 Clarke School for the Deaf, Northampton, Mass, Grace M. Heider, and Fritz Heider. 1941. Studies in the psychology of the deaf, No. 2. Evanston, Ill: American Psychological Association. section II, “The adjustment of the adult deaf.” Sociologist Harry Best’s work is another rare example of research dedicated mainly to the adult deaf population See Best, Harry. 1914. The
As Levine remarked in 1963, the deaf adult had remained “a relatively unknown quantity in educational thinking.” Yet he “most likely holds the key to many of the unsolved problems in the education of the deaf.”\textsuperscript{415} The NYSPI researchers understood their study of the normal deaf adult as a means to better understand its pathological counterpart. “Unless one knows how the best adjusted members of a deaf group deal with such important personal matters as mate selection, marriage and parenthood,” Rainer wrote in 1963, “one cannot be constructive in attempting to help those who appear poorly adjusted.”\textsuperscript{416} In other words, the first project from 1955 to 1963 delineated “what it was like to be a normal deaf person.”\textsuperscript{417} In this, and in their final results, they resembled the work of the Heiders in the 1940s, yet with a more pragmatic outlook. The Heiders’ survey of deaf adults had operated on a rather theoretical level, taking the deaf as an example to study social relations and personal adaption. The NYSPI project, on the other hand, had clear diagnostic and therapeutic goals.

Applying Kallmann’s empirical-statistical research, staff members surveyed the New York State deaf population for their sociological, medical, genealogical and psychological characteristics. They sent out 8200 questionnaires to all deaf residents over the age of 12. Addresses had been ascertained in cooperation with federal and state agencies, schools for the deaf and New York State’s numerous deaf clubs and organizations. 1700 individuals...
replied; in 1958 they received a second questionnaire asking more specifically about family structures, reproductive patterns and behavior, age of onset of deafness, hearing status of parents, siblings and spouses, number of children and age at marriage. Follow-up interviews with deaf people and their families, “performed by psychologically trained research workers skilled in manual communication,” further investigated education, vocation and patterns of social interaction.

Twin studies provided a second set of data. Initially, the questionnaires had searched for New York State pairs of twins of whom at least one was deaf. Since this only resulted in nine pairs of twins and one triplet, the study extended to include New Jersey, Philadelphia and Washington D.C., raising the total to 110 pairs of twins and two set of triplets. As Rainer explained in 1963, twin studies offered “a rather unique human laboratory experiment for comparative investigations into the interactions of genetic and environmental factors in personality development.” Rainer clearly referred to Kallmann, who after coming to the US, had taken up twin studies as one of his main research methodologies. His 1953, Principles of Psychiatric Genetics in the Light of Comparative Twin Studies, developed empiric twin studies as a sophisticated instrument of modern genetic research. In contrast to Kallmann’s earlier twin studies, however, their use in the work on deafness went beyond questions of genetics and environment, biomedicine and psychiatry. They adopted a broader

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419 Altshuler, Kenneth Z. “Sexual Patterns and Relationships.” In Rainer; Altshuler; Kallmann 1963 Family and mental health: 92-112, here 92.
420 Sank, Deafness, 46.
perspective of deafness and deaf people from a variety of professional and – an
important departure from Kallmann's earlier work – patient perspectives.422

Among the most significant departures from previous studies of the deaf
was the NYSPI's effort to delineate a normalcy specific to their subpopulation
rather than comparing them to the hearing majority. Only with such a baseline
established, Rainer commented, was it “possible for the deaf to benefit from all
the effective methods of diagnosis, therapy and prevention afforded by modern
psychiatry and related disciplines to the same extent as do hearing persons in
distress.” Staff members’ self-portrayal as pioneers – or conversely their lack of
grounding in previous research – signaled a willingness to start anew and
discard old biases in favor of what was considered a more scientific and
objective approach. Instead of relying on assumptions and prejudices, Rainer
emphasized in 1963, the project was to “render intuitive attitudes articulate by
securing statistically verified data through research.”423

In some instances, findings indeed seemed to confirm previous biases. In
other areas, however, this inquisitive openness led the way to a more nuanced
and less pathological understanding of deafness. Previous neglect was to be
compensated for by attention and cooperation. For staff members, the
excitement over mining “an area so rich in theoretical and practical problems”
merged with the ideal of helping “a group so deserving and needy of psychiatric

422 Searching the New York State Mental hospitals for schizophrenic patients and their families,
in particular twins, Kallmann had collected 794 twin index cases with schizophrenia and a
total of 2000 index cases of pairs of twins with other mental conditions. See Kallmann 1953,
_Heredity; Kolb, Institute, _74, 177. For Kallmann’s disregard of individual perspectives and
Kallmann contact with Hans Luxenburger’s empiric twin studies at the Munich GDA see
Roelcke, _Genetik_, 178, 188.
423 Rainer 1963, _Introduction_, xii, xv.
help [...] so grossly neglected by our profession.”

As previous chapters demonstrated, the motives of benevolence and help have been a constant in professional approaches to deafness and the deaf, often tinged with the expert’s paternalism. Yet unlike previous projects, the NYSPI not only sought to reach professionals in psychiatry, education or rehabilitation, but also to address members of the New York State Deaf community directly as valued collaborators in maintaining community mental health.

Interested in the social and emotional effects of hearing loss, the NYSPI project described deafness in psychiatric rather than audiological terms. The 1963 project report defined it as “stress-producing hearing loss, from birth or early childhood, rendering a person incapable of effecting meaningful and substantial auditory contact with the environment.”

Influenced by battlefield experiences, stress had become a leading explanatory category in psychiatry during and after World War II. Influenced by battlefield experiences, psychiatrists emphasized environmental or social factors as the causes for mental illness and breakdown; and subscribed to the optimistic belief that removal of stress was equivalent to regain mental balance. In deafness research, the emphasis on stress meant a shifting understanding of its effects from innate to social or interpersonal.

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The project’s definition of deafness also relied heavily on sensory deprivation research. Historian of science Mical Raz has traced the popularity of deprivation research from experimental studies in the 1940s to an explanatory model for numerous phenomena in a wide range of disciplines in the 1950s. Experiments that temporarily disabled one or more senses, or isolated objects in dark, silent rooms produced a variety of psychiatric disturbances and, conversely, explained their development. Soon theories of deprivation included models of cultural and social deprivation, e.g. in the study of mental retardation, yet also in connecting low socio-economic status and educational achievement. Impoverished environments, poor housing, lack of social or intellectual stimulation in low-income and single-mother households were thought to deprive children of essential sociocultural stimuli, with devastating results for their development. Usually, these studies took the white middle-class family as an unquestioned norm, and had a strongly judgmental character. Yet in the politically charged atmosphere of the late 1960s and 1970s, cultural deprivation also could be used to point to social injustice and the disadvantaged situation of minorities. Here, deprivation became a staple theme in Civil Rights rhetoric.427

Deafness seemed to lend itself particularly well to the study of deprivation, and vice versa. Professionals studying deafness had long been intrigued by the effects of hearing loss on intellectual and personality development, yet only in the 1960s did psychiatrists and psychologists begin to

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explicitly these explicitly under the paradigm of deprivation. Several NYSPI collaborators evaluated the effects of sensoneural and psychosocial deprivation caused by hearing loss. George S. Baroff, a senior research psychologist at the NSYPI department of medical genetics, noted that deaf people “are not lacking in socialization.” Despite their “developmental lacks and the omnipresent communication barrier,” he reported, deaf adults did not turn into “withdrawn, isolated personalities” but were able to “establish adequate socialization patterns” and to “participate in and utilize general community services.”

Delinquency and outstanding achievements among deaf people formed two ends of the spectrum that the project aimed to illuminate. For the latter, staff members had identified deaf inhabitants of New York State of significant “status, prestige or recognition” with the goal of identifying “pertinent variables” for successful adaption. While clearly admiring their study objects, the authors considered it necessary to point out that “[t]hese accomplishments in no way minimize the stultifying effects of deafness.” These extraordinary overachievers' success, they cautioned, should not be taken as the standard for the average deaf person. In particular, the authors warned that “[a]spirations toward occupations contingent upon verbal facility are likely to remain unfulfilled and would merely lead to frustrations and feelings of inadequacy.”

These studies relied on preconceptions of deaf people as established by psychological research earlier in the century. Namely, psychological studies

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428 Apart from the examples in this chapter see e. g. Myklebust, Helmer R. 1964. The psychology of deafness: sensory deprivation, learning, and adjustment. New York: Grune & Stratton.
431 Feingold et al., Achievement, 134, 136.
claimed that deaf people lagged in their emotional and intellectual development, and were limited in their abilities for verbal expression and abstract thought. While these studies were never unanimous – most believed that deaf people possessed normal intelligence, but had failed to develop – they had perpetuated presumptions about the traits they were exploring. Thus, while conferring unusual adaptive skills to some deaf individuals, the NYSPI researchers found the majority lacking in some ways – at least initially. Like other midcentury attempts at social betterment via social science, these studies understood deficits as a failure to develop due to social, cultural, familial or, in the case of disability, physical factors. Consequently, thus the hope, if these factors were removed, these deficits could be overcome. Whether it was the disabled or disadvantaged youth, prisoners or juvenile delinquents, scientific intervention and social reform offered a hopeful narrative of personal reform and social change.

At the other end of the social spectrum the project found a disturbing apparent overlap in the personality structure of deaf people and criminal delinquents. Both groups seemed to lack in maturity. This supposed lack of maturity among deaf people again was a long-standing bias, as previous chapters have show. Deprived of sound and speech, the authors theorized, the deaf suffered from a lack of “ability to conceptualize and synthesize ideas.” “With

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For developments in the history of psychology see chapter II. In the 1960s, the psychology of deafness established itself as an authority in special education and rehabilitation, that drew its justification from identifying and potentially preventing deficits. With her 1960 *Psychology of Deafness* Edna Levine contributed one of the first and major textbooks, combining evolutionary with Freudian thought. Helmer Myklebust, another pioneer in the field, combined evolutionary thought with sensory deprivation theories. See Myklebust, Helmer R. 1964. *The psychology of deafness: sensory deprivation, learning, and adjustment*. New York: Grune & Stratton. Both argue for the evolutionary, social and intellectual primacy of spoken language – a position somewhat at odds with Levine’s lobbyism and later work. Hans Furth, on the other hand, was one of the first to approach the psychology of deafness as a possibility of “thought without language.” See Furth, Hans G. 1966. *Thinking without language; psychological implications of deafness*. New York: Free Press.
their capacity for abstract reasoning so limited,” they summarized, “it is no wonder the deaf have difficulty adjusting to the complexities of modern society.”

These personality traits of impulsiveness, immaturity, irresponsibility and low verbal intelligence were also found in “individuals who are always getting into trouble with the law.” In this comparison, the deaf population became a testing ground for the hypothesis that “criminal activities can be viewed as manifestations of varying degrees of immaturity, defined according to a scale of personality integrations.”

Deaf people, however, did not turn out to be a useful model population. Their differences posed a perplexing dilemma to the observing psychiatrists. If the deaf as a group were immature, why were they not a group of delinquents, but, overall, rather well-adjusted, even happy and successful? Deaf people’s differences, it turned out, were not always pathological. Nevertheless, the nature of these differences fascinated researchers, as they grappled with the line(s) between hearing and deaf normalcy or pathology. “[Q]ualitative and quantitative differences between the deaf and the hearing in the nature of their social and community integration exist,” summarized George S. Baroff in 1963.

Yet what was the consequence of these differences? Delineating the normal range of behavior among deaf people, staff members were faced with finding standards of judgment. Could something that was considered

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434 Baroff, George S. “Patterns of socialization and community integration.” In Rainer; Altschuler; Kallmann 1963 Family and mental health: 113-115, here 115.
pathological in a hearing person be normal in a deaf individual? Should one stress pathological elements or emphasize adaptive abilities and achievements? Unlike previous researchers, NYSPI researchers were willing to acknowledge deaf difference in linguistic preference, behavior and reproductive patterns as non-pathological, yet struggled to define the attributes of a normal – socially integrated and mentally healthy – deaf person. Some of the resulting ambivalence and contradiction is captured in the project’s definition of deafness as a “stress-producing” condition on the one hand and the deaf as a social minority with a “unique subculture” on the other. These two definitions were not necessarily incompatible – the absence of hearing could contribute to the formation of a subculture – yet the values attached to each term differed. A stress-producing condition is something to be avoided or reversed; a subculture has an intrinsic value. Over the years emphasis moved from the pathological to the socio-linguistic end of the spectrum.

**Minority cultures and politics: Midcentury exploration of disability and difference**

The insights gained in the project set in motion a slow evolution in the perception of deafness and deaf people. Moving from innate, biological to sociocultural explanations engendered a more relativist perception of ability and difference. In the beginning, NYSPI researchers had defined deafness as an innate disability that caused deficits and deprivations to which different people adapted with various degrees of success. Commenting on the attitudes toward deafness, Altshuler and Baroff noted that 62 percent of the study population took their

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435 Klaber; Falek, *Delinquency*, 143.
deafness with “stoical acceptance,” yet pointed out that “[s]ignificantly, almost 10 per cent denied that deafness was any handicap.” Bewildered by this statement, the authors eventually judged that “the emphatic denial of handicap probably signified as deep a satisfaction as an admission of disturbance.” This ambivalent statement struggled with the respective value of inside and outside perspectives. Altshuler and Baroff recognized that for these ten percent not considering deafness a disability had a positive effect, yet for the psychiatrist, such a position was disturbing, possibly even a pathological denial of reality.

These tensions continued to characterize the project, yet significantly, research on and exchange with the deaf population changed the outside perspective of researchers. Increasingly, project contributors portrayed deaf people as a stigmatized minority group whose deficits were caused as much by maladjustment to and discrimination by majority society as by hearing loss per se. Over the course of the 1960s, the sociological minority model became increasingly prevalent, inspired and influenced by larger trends in American science and society.

In mid-century America, the social sciences gained an unprecedented public influence in explaining to a general audience social and political developments; the dynamics of family, gender, and parenting; racial relations and social unrest. Anthropologists tried to find universal human traits and gave greater attention to cross-cultural comparison. Sociologists and psychologist focused on group dynamics to better understand bias, discrimination and political orientation in the aftermath of Hitler Germany and fears of Communist

436 Altshuler, Kennetz Z.; Baroff, George S. “Educational background and vocational adjustment.” In. Rainer; Altshuler; Kallmann, Family and mental health, 116-130, here 126.
Sociologists such as Erving Goffman also studied the situation of asylum patient and explored stigma and “spoiled” identity. A number of psychiatrists and psychologists became influential public figures, offering moral and social guidance in a society concerned over mental disturbances, identity and social roles. Thus, Abraham Maslow explained human needs, and Carl Rogers proposed a more humanistic approach to psychology. Others, such as Erich Fromm more generally criticized the apparent superficiality of consumerist postwar America. 438

Psychology and the social sciences also gained unprecedented influence over defining disability, illness and health – an indispensable development for professionals coming to understand deaf people as a social group with specific, yet not necessarily pathological qualities. “Sociologically,” Arthur Falek and Michael Klaber explained in 1963, “the deaf form a unique subculture, membership in which is determined solely by their physical disability.” 439


Similarly, Altshuler and Baroff theorized that deaf people experienced and internalized “minority group stereotypes” and feelings of inferiority.440

In taking a psychosocial approach, this perspective shifted blame and responsibility. Whereas before inferiority had been an innate fact of disability, now it was caused by inequality and bias. As Edna Levine specified: “Having to grow up in a world of public ignorance and indifference, confused professional thinking, and untested professional hypotheses is the major handicap of early severe deafness.” Such a “condition of psycho-educational malnutrition,” she alleged, stemmed from the unfortunate, yet long standard “proposition that the deaf child could be molded into a hearing one,” if only he was treated as such. Here, deprivation was used to criticize the current and past state of deaf education as an injustice committed against deaf people and their natural rights and needs. Rather than the rigid, forced adherence to hearing normalcy that had dominated deaf education for so long, Levine advocated for exploring, accepting and working with deaf children’s difference.441

Leaving behind the dogma of normalization, the new paradigm legitimized minority difference within larger society. This move at once normalized and politicized deafness. Likening the deaf to other disadvantaged minorities turned their situation into an issue of social justice, denied rights and missed chances. In the 1968 workshop on Psychiatry and the Deaf this view was brought forth forcefully by psychologist Hilde Schlesinger. Deaf people’s difficulties in education and social adjustment, she suggested, “may be due not to deafness but to environmentally produced deprivation of those cultural factors

440 Altshuler; Baroff 1963, Background, 127.
441 Levine, Edna S. “Historical review of special education and mental health services.” In. Rainer; Altshuler; Kallmann 1963, Family and mental health, xvii-xxvi, xxvi.
shared by the middle-class American culture.” Like immigrant children, Schlesinger argued, deaf children lived “within two cultures – the larger hearing America and the smaller deaf culture.” Immigrant children who grew up bilingual, unashamed of their roots, she believed, were able to adapt most easily to US culture. They developed a self-confident trust in their own cultural standards, a “healthy ethnocentrism,” that was a prerequisite for normal intellectual and emotional growth. Deaf children were not so fortunate. Majority culture and misguided educational policies prevented them from developing that healthy ethnocentrism. They experienced “that one of their native tongues” – sign language – “is not quite so good, not quite as acceptable, as the spoken language,” even “forbidden.” Social disapproval then created negative attitudes that hindered the development of spoken language, too.442 No longer a sign of backward pathology, sign language had become, to the contrary, a symbol of healthy childhood development, of comfort with one’s physical and sociocultural self.

Attitudes toward sign language can serve as a historical gauge for attitudes toward deafness. Sign language is a marker of difference; oralism signifies the attempt to integrate into hearing society. Oralism still dominated deaf education and educational theory in the 1950s and 1960s, as demonstrated in the last chapter. Yet the NYSPI research occurred in a time when the deaf community’s specific characteristics came into the focus of sociologist, psychologists and linguists as having a value of its own. Benjamin M. Schowe Jr., a teacher and librarian at the Ohio School for the deaf, remarked in 1958 that

442 Schlesinger, Hilde. “Cultural and environmental influences in the emotional development of the deaf.” In. Rainer; Altshuler, Psychiatry and the deaf, 128-131.
people often reacted with surprise “when they hear that sign language exists in all schools for deaf children.” Yet, he continued, despite “the fact that sign language is suppressed in many schools because it is believed to prevent a deaf child from learning to speak and from becoming a good lip-reader, it still exists in every one of them.” Recently, he noted, “we have begun to hear of increasingly more people who are studying the unsuppressible phenomenon of sign language.” Schowe referred to work of British linguist Sir Richard Paget, who had developed a system of manually coded English and to Dutch linguist Bernard T. Tervoort, who studied the syntax of sign language among deaf children.443

In the US, too, sign languages became the object of linguistic research. By far the most influential was that of linguist William Stokoe, widely credited with the “discovery of American Sign Language as a true language.”444 The theme of discovering an unknown language carried the excitement of linguistic fieldwork in exotic locations, of bringing, as Stokoe put it in 1960, “within the purview of linguistics a virtually unknown language.” Not only did he seek to prove that American Sign Language was indeed a language, but with his studies, Stokoe also hoped to “add to the sum of linguistic knowledge,” even to change the very definition of language itself. Believing that symbols – whether spoken or signed – were only carriers of meaning, Stokoe suggested that a “language is a system of 


arbitrary symbols by means of which persons in a culture carry on the total activity of that culture.”

More positive perceptions of sign language have often been portrayed as a revolutionary victory of reason and educational efficiency over ideology. However, as Douglas Baynton has pointed out, such a black and white portrayal neglects larger shifts in the perception of language, emotion and difference. The reevaluation of sign language, he argues, occurred at a time of greater openness toward expressions of sexuality, emotion and body language in the 1960s and ‘70s. In 1960, suspicion toward overtly physical forms of expression was still a serious concern for Stokoe. Aware “that the deaf are sometimes popularly supposed or even seriously said to exaggerate facial expressions,” he felt compelled to defend sign language users from this damaging assumption. His “filmed data as well as all the communication behavior observed at Gallaudet College confirms the conclusion that the kinesic behavior of the educated deaf in American culture” – note the class qualifier – “is nowhere sharply separated from the cultural norms.”

The enhanced status of sign languages coincided, as Baynton put it, with the “reemergence of a romantic ‘noble savage’ image,” that idealized gestural


languages as a natural, if not innate form of expression. In this spirit, linguist Richard Paget suggested that "words are originally and essentially pantomimic gestures of our jaws, lips, tongue etc., and that spoken words are therefore closely related to the pantomimic hand-gestures by which early Man a million years ago and the uneducated born-deaf of today naturally express their ideas." He lamented that by rejecting signed languages, "the leading advocates of pure oralism" failed "to recognize the natural instincts of the deaf." Claiming that "the un-educated born-deaf do not, by nature, think in the same way as hearing people," Paget called for reconsidering the goals of deaf education. Should one really educate "the deaf so that they shall appear to be normal under all usual conditions?" He considered this "almost impossible." Wasn’t the goal rather “to educate their minds so that they may, as soon as possible, come out into the hearing world as its intellectual equal, although deprived of hearing and poor in speech?" 

The old opposition between sign language and oralism thus could be cast once more as a question of nature, instinct and innateness vs. the (appearance) of normalcy. Yet now, values were reversed. During the first half of the century, sign languages had been associated with primitivity. Just because they were to some extent natural and innate, they had to be overcome in a uniform process of evolution toward European civilization. By the 1950s however, with a lessening of ethnocentrism and changing standards of physical expressivity, public and professional sympathies increasingly accumulated on the side of signing communities.

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449 Baynton 1996, Signs, 156.
450 Paget, Preface, xi, xii, xv.
In an era of decolonization conflict and racial tension, interest in the sociology and psychology of minority groups opened new perspectives in perceiving the deaf as such a group, too. In the 1954 *The Deaf and Their Problems* British teacher for the deaf Kenneth W. Hodgson commented: “For the deaf themselves the real problem, of course, is not deafness but the fact of living in a hearing world,” a conclusion to which the Heiders had already come in the 1940s. “Theirs,” Hodgson continued, “is a minority problem.” Such a portrayal turned deafness into a matter relative to one’s social position rather than an innate disability. “The deaf who lack natural speech are like foreigners in their own country,” Hodgson wrote. For him, this similarity invited comparison with other minorities and even colonial power structures. “In this country,” he remarked for Great Britain, “we have still a tendency to regard deafness as part of the White Man’s Burden.” Instead of paternalistically doing “things for the deaf because we are reluctant to realize how much they can do for themselves,” he called upon their “social self-reliance” as the only way to “full citizenship.”

Hodgson’s framework clearly was the struggle for decolonization in the British Empire, a process that engendered psychosocial research on political unrest. Particularly influential was the work of Mauritian-born and Algeria-based psychiatrist Frantz Fanon. Active in the Algerian liberation movement, he observed and described the psychopathological effects of colonial oppression, e.g. in his 1952 *Black Skin, White Mask*, 1959 *A Dying Colonialism*, and 1961 *The Wretched of the Earth*. To activists in decolonializing countries, but also to social movements in Western countries Fanon’s work provided a powerful model for

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understanding the situation of minorities in terms of oppressed identity and infantilized disfranchisement.\textsuperscript{452}

Fanon’s work also inspired disability activists. In 1969, the disability scholar and activist Leonard Kriegel used Fanon’s work to frame his experiences of visiting polio rehabilitation facilities in Harlem as a white teenager in the 1950s. Kriegel provocatively titled his reflections \textit{Uncle Tom and Tiny Tim: Some Reflections on the Cripple as Negro}, drawing from Fanon’s work to theorize the alienation and denial of humanity both African American and disabled people experienced in American society.\textsuperscript{453}

Although not explicitly part of these more radically political strands, linguists like Stokoe, educators like Schowe and Hodgson, psychologists like Levine and Schlesinger, and NYSPI psychiatrists nevertheless operated within this psychopolitical framework and borrowed its rhetoric and terminology. This sociopolitical perspective turned deafness into an extrinsic at least as much as an intrinsic disability: It was discrimination, prejudice and ignorance from society that ostracized, excluded and disadvantaged the deaf individual. Deaf difference was no longer inherently pathological. Rather, it could be legitimized by referring to other sociocultural minorities such as African Americans or Hispanics whose culture or language was oppressed by majority culture.

\textsuperscript{452} The biography of Alice Cherki, a psychiatrist and former colleague of Fanon, provides a personal insight to his background and work. See Cherki, Alice. 2000. \textit{Frantz Fanon: portrait}. Paris: Seuil.

A “world you will no doubt find strange”: Engaging with deaf patients and the deaf community

By the 1950s, a century of research projects had spoken about, but rarely with deaf people. The NYSPI staff, on the other hand, from the very beginning signaled their willingness to engage with the deaf in a more egalitarian manner. Their increasing involvement with the New York deaf community was a decisive factor in changing portrayals of deafness and deaf people in project publications. From the initially sporadic contact with isolated deaf patients in mental hospitals, the project developed a model of active collaboration with their target population that mirrored other emerging networks of patients and health care providers. As Nancy Tomes has shown, the concept of community psychiatry required some involvement if not of former patients then at least of community members. In the 1960s, however, mental health care reform remained the initiative of experts, leaving patients “primarily as objects rather than agents of policy making.”

In a way, the NSYPI project then was typical in its character as an “expert-driven” initiative that approached the target community from the outside. The project’s language was not free of contemporary professional paternalism that distinguished between expert knowledge and lay contributions. Cooperation, Rainer and Altshuler reflected in 1971, required that the deaf first overcome the stigma of mental illness and develop an “ever growing, gratifying awareness that mental health and its maintenance are valuable commodities,” an “increasingly proud and active interest in our work” in order to make “increasing and

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appropriate use of the services.” Yet in this very emphasis on cooperation, interaction and mutual learning, the project deviates from Tome’s periodization, and indeed was unusual for its time.455

The collaboration between the NYSPI and the New York State deaf developed slowly. When the project first started, Altshuler recalled, “the deaf got the impression that we were going to be treating them as as special and imperfect.” However, “once we explained that what we were trying to do was develop for them a parity of service, so that they had equal services with the rest of the state, they became very good friends of ours, and cooperated very well.”456

In gaining the trust of clients and community, the project had a significant advantage: From the very beginning, it had the express support of various deaf organizations and leaders who were represented on the supervising board. Important middlemen served as intermediaries between psychiatrists and the deaf community. Edna Levine, for example, provided connections to the deaf community; deaf rehabilitation consultant Boyce Williams straddled the line between expert and community member.

The very attempt to to provide some kind of accountability to and representation of the deaf community was highly unusual in mid-century America. It must have seemed like a welcome change to the deaf people engaged in the project. Boyce Williams for example lauded the project in 1958 as an example of progressive “social action” and contrasted it with the “many places where nothing is done for the deaf.” He also conveyed a sense of ownership and

455 Rainer; Altshuler, Expanded care, v.
456 Altshuler Interview, p. 3. Also see Rainer, Altshuler, Services, 96.
influence when he remarked that “to have the same services as the hearing would be one of our finest achievements.”

Project publications (all prepared by hearing NYSPI scientists) emphasized partnership, cooperation, and mutual learning, and cited the staff’s “debt to the deaf community of the State of New York.” “It should be clear,” Altshuler wrote in 1967, that “just as psychiatry has much to offer the deaf, so too, the deaf have very, very much to offer us as psychiatrists.” This is an ambivalent statement. Clearly, the deaf were an interesting research population with unusual etiologies, yet also one with whom a close and rewarding relationship had developed, as Altshuler emphasized. All staff members, he reported, had developed a strong “dedication and a loyalty,” and found “some special emotional satisfaction [...] in reaching the deaf.”

Altshuler’s remarks, and the project at large, point to two interrelated developments in portraying professional authority and professional relations to patients and / or objects of research. Historians have portrayed midcentury medicine as paternalistic, sometimes authoritarian, and have attributed change to the patient, anti-psychiatry or disability movements, reform and protest movements of the 1960s and ’70s. Yet the NYSPI project challenges this narrative. Certainly, there remained paternalistic undertones in their language

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459 Rainer; Altshuler, Background, 2.
and expectations that the deaf needed to develop a distinct form of psychiatric and genetic self-awareness. Yet aligning itself with a community of deaf adults, imagined by and large as a functioning social group or minority, NYSPI staff drew justification for their work from acceptance by and knowledge of this community. Emphasizing the ideal of reciprocal partnership, they framed their professional roles not so much as one of fixing disabilities, but as service-providers. While not unproblematic, this consumerist framework apparently resonated with deaf community leaders and individuals, and offered venues for contact and exchange.\footnote{Certainly, this paternalistic stance was a reality in many realms of 1950s medicine; and a the role expected from physicians. By example of breast cancer, Baron Lerner, for example, has traced these attitudes and patients' reactions. See Lerner, Barron H. 2001. The breast cancer wars: hope, fear, and the pursuit of a cure in twentieth-century America. New York: Oxford University Press, ch. 4.}

Conferences and workshops strengthened the ties and interaction between psychiatrists and community and helped define services. The first and largest of those bipartisan meetings was organized and hosted by the NYSPI in June 1958, and included delegates from nearly 40 deaf organizations.\footnote{New York State Psychiatric Institute, and John D. Rainer. 1958. Mental health planning for the deaf, report of a conference of New York State organizations for the deaf, held at the New York State Psychiatric Institute on June 14, 1958.} They represented national, state and regional organizations, including the National Fraternity Organization for the Deaf, the Empire State Association for the Deaf, the Bronx Silent Club, the local chapter of Gallaudet alumni as well as religious organizations, e. g. the Hebrew Association for the Deaf. Unusual for the time, but in keeping with the NYSPI desire to engender communication, the meeting was held in spoken English and sign language. Conference photos show for example Boyce Williams and Mr. Culver, President of the Empire State Association for the Deaf signing to the audience. For the latter, a Reverend Simon is interpreting to
spoken English. Conversely, in another photo, Kallmann is giving the banquet address, with another interpreter next to him.462

Max Friedman, “specialist in vocational problems of the deaf” and a deaf member of the project’s advisory council gave the introductory speech. Addressing the deaf audience as much as the hearing professionals, he did not shy away from criticizing the latter for being “reticent in reporting its work to the deaf.” The staff, Friedman felt, “leads too cloistered a life.” The conference thus was designed to inform the community about the project’s work and to encourage collaboration on both sides. This included a heightened awareness of mental health issues. “It is no disgrace,” Friedman admonished his audience “to need the assistance of a mental health clinic, but it would be an everlasting disgrace if we deaf people, through false pride, should fail to support this most worthy project.” Although the history of mentally ill deaf patients is still unwritten, such remarks evokes the shame and stigma associated with mental illness generally associated with mental illness – yet also of at a willingness to address these issues.463

In mid-1950s New York, then, deaf individuals and organizations had entered a dialogue with psychiatrists and mental health professionals. They added their voice and insight, at once object of research, potential recipient of care and advocates for their community. At the 1968 Psychiatry and the Deaf conference, a panel of three deaf people presented their perspectives on “Adjustment Problems of the Deaf” to the assembly of psychiatrists and

462 Ibid., photo insert, unnumbered.
463 Ibid., 11-12.
rehabilitation workers. The three speakers presented a well-organized, capable and vocal group whose achievement and deficits were presented as a matter of social disadvantage rather than inherent inability.

Max Friedman, introduced as “one of our outstanding leaders on a national scale,” self-confidently welcomed his audience “to a world you will no doubt find strange and to a people who badly need your services.” Psychiatrists, he pointed out, had been trained in the ways of the hearing rather than the deaf whose “actions, thinking, and responses are apt to be unlike those of any other group.” Friedman saw little wrong with these differences: “the communication problem is, to many of you, an insurmountable problem,” he put the blame on the hearing, rather than the deaf. He welcomed the mental health project as a means to overcome a “great shortage of psychiatrists who can work with the deaf” and offered the help of the plethora of organizations for the deaf in New York State. They all, he assured, stood “ready to be useful should you call on them for help or guidance.” Offering insights to deaf community, Friedman thus portrayed himself as a self-confident partner for improving community services.

Friedman was followed by Naomi Leeds, president of the Mental Health Association of the Deaf, Inc. The Association had been founded in 1963 with the goal to raise awareness of mental illness in the deaf community and to support the mentally ill in the transition from clinic to community. It was not a patient organization; rather, it had been established by Leeds and four other women after they learned about the “blight” of deaf patients in mental institutions.

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465 Friedman, Panel, 29.
466 Leeds, Panel, 31.
Moved by their experience, Leeds and her collaborators garnered the “generous contributions” of New York City deaf clubs and organized a membership who paid “their dues not only with money but with their hearts, hands and time.” In the 1960s, the association organized meetings, fundraisers, and lobbied for the integration of mentally ill people in the community. Association members also volunteered in the hospitals in which the NYSPI had organized services for deaf people. Drawing from a long tradition of deaf community theater, in 1966 they staged a play, *Return to Thine Own House*, portraying the fate of a mentally ill patient returning home. The play, adapted to sign language, was characteristic of the general fascination with the mental health issues of the average person in midcentury America.467

As the emergence of organizations like the Mental Health Association make clear, mental health care in the 1950s and 60s was no longer solely dominated by psychiatrists, administrators, and politicians. Increasingly, it was also influenced by diverse patient, minority and community groups. This was particularly true for New York, with its highly complex mental health care system and diversity of social, political and ethnic organization. Some of these groups were part of a larger movement that challenged medical authority and began to to severely indict the mental health care system as oppressive and belittling. Others, like the deaf organizations in this chapter, took a more

467 While the association does not seem to exist anymore, it was active into the 1980s. For ist activities the Mental Health Association of the Deaf files at the Empire State Association for the Deaf Collection, Rochester Institute of Technology Archives. The files also contain programs for other plays, and photographs of performances. For the tradition of community theater see Padden, Carol, and Tom Humphries. 2005. *Inside deaf culture*. Cambridge, Mass: Harvard University Press, 102-105. Halliwell has analyzed in detail midcentury portrayals of mental illness in film and theater. See Halliwell, Revolutions, 44-155.
cooperative stance. They complemented professional services with self-help, and, apparently, did not question conventional models of mental health.\textsuperscript{468}

This collaborative spirit certainly was rooted in a sense of having, very recently, achieved real progress in participation and recognition. For a long time, deaf professionals had been very nearly absent in the very professions that served them. By the 1950s, a few individuals – among them Boyce Williams or Max Friedman – had achieved influential positions in public administration. The last of the three panel speakers, Alan Sussman was another example of these new professional opportunities opportunities, yet also of the restrictions deaf people still faced. A Brooklyn native born to deaf parents and a Gallaudet graduate, Sussman had received a master’s degree from New York University, and while working on his doctorate served as the “only deaf counselor in the Division of Vocational Rehabilitation in the State of New York.” At the 1968 meeting, he lamented the lack of professional opportunities and lingering discrimination that forced most deaf people to accept work below their education level and abilities.\textsuperscript{469}

\textsuperscript{468} For the history of patient involvement in US psychiatry see Tomes, \textit{Outsiders}, 115. The NYSPI was not exempt from more confrontational encounters with patients or community members. In 1957, they proposed a mental health center at Washington Heights (where NYSPI was located) a neighborhood that lately had been seeing population change as the established white population moving out; African Americans and Puerto Ricans moving in. This, NYSPI researchers believed, necessitated a study of the “plight of the mentally ill in major metropolitan areas” Yet a community meeting set up to discuss needs and plans were interrupted by student protestors who established a local black man as head of the advisory committee. Thus derailed, the project did not take off. See Kolb, \textit{Institute}, 86-90

\textsuperscript{469} Sussmann 1968, Panel, p. 33. From this springboard position at the NYSPI project, Sussman made an impressive career: He served as assistant professor of psychology at NYU, directed a Brooklyn community mental health care center for the Deaf, and became professor of counseling at Gallaudet where he influenced a younger generation of deaf professionals. For Sussmann’s work and career in counseling see e. g. Sussman, Allen E., and Larry G. Stewart. 1971. \textit{Counseling with deaf people}. [New York]: Deafness Research and Training Center, New York. University School of Education.
Sussman’s report highlights the unusual degree of deaf involvement in the NYSPI project. It actively promoted the employment of deaf staff members as a valuable asset who “should be recruited or trained whenever possible.” Moreover, it encouraged the involvement of “educational and volunteer programs” such as the Mental Health Association as a supplemental support system. Where previous research had painstakingly and paternalistically maintained the line between hearing expert and deaf object, the NYSPI staff signaled its willingness for cooperation and encouraged deaf people to enter a career in psychiatry.

When it comes to explaining why some form of exchange and collaboration developed between the New York State deaf community and psychiatrists, a closer look at shared goals and assumptions is helpful. Although the project came to define the deaf as a sociocultural minority, this was a rather static and uniform definition of minority. Certainly, deaf culture and sign language must have been foreign phenomena to the NYSPI researcher, although maybe less so in New York than in more ethnically uniform locations. At the same time, they also must have felt a sense of communality with the leaders of deaf organizations who, like them, were from a white middle-class background and embraced civic respectability. Historians have pointed out that deaf individuals and organization employed a rather conservative strategy in their lobbying and portrayed their group as moral, productive and socially useful citizens. Their emphasis on responsibility and self-management reverberated

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470 Rainer; Altshuler, Expanded care, iii-iv.
471 It is safe to assume that the deaf population of New York State displayed a similar level of racial and ethnic diversity as the state’s total population, yet race was not discussed nor recorded as an analytic category. And while publications, conference reports and photographs show a good number of women (including project initiator Edna Levine), people of color apparently were not includ.
with the ideals of Kallmann and other professionals of citizens aware of their
civic duties to individual and public health. In this manner, deaf organizations
and NYSPI researchers were collaborators in the vision of the deaf not as a
deviant, but as a valuable, under-appreciated group who through the help and
support of the NYSPI would achieve their rightful place in society and mental
health care. Certainly, the project vastly improved mental health care services for
the deaf. Yet this communality of goals also meant incorporating and
internalizing norms of mental and physical health.

Thus, looking at different forms of health and community activism, it is
important to note that rather than patient activism per se, the project presented
more a form of community involvement. Despite the apparent diversity of deaf
organizations involved, none explicitly was organized or lead by deaf psychiatric
patients. Nor were there any non-white leaders involved. It is safe to assume that
the deaf population of New York State displayed a level of racial and ethnic
diversity similar to the state’s total population, yet race was not discussed nor
recorded as an analytic category. And while conference photographs show a
good number of women (including project initiator Edna Levine), people of color
were not displayed. Underneath the ideals of community psychiatry, then,
uniform community leadership points to the tensions of representation and
representability inherent in professional, minority, disability or patient activism.

Not “being closed out of communication”: Psychiatric services in sign
language

Working with deaf patients, psychiatrists soon were confronted with the
question whether research, counseling and therapy should be conducted only in
spoken English or also in Sign language. At first, Altshuler recalled, they tried to remain neutral in “this running battle.” That alone was a strong statement in the still predominantly oralist late 1950s. Yet practical considerations soon forced the psychiatric staff to learn sign language. Working with psychiatric patients, most of whom communicated manually, made relying on lipreading and speech seem impractical, if not impossible. “If you wanted to communicate with these folks,” Altshuler elaborated, “you had to know the language, and not knowing the language meant you were closed out of communication.”

Significantly, in this rendering of communication issues, it was psychiatrists who were closed out here, not deaf people. Relying on interpreters was no solution. Professional interpreting did not become available until the establishment of the National Registry of Interpreters for the Deaf in 1964; relying on friends and family members difficult in hospital settings. Moreover, interpretation introduced a potential source of miscommunication that might prove catastrophic in the assessment of a psychiatric patient. Thus, learning sign language became a requirement for NYSPI staff working with deaf patients. Staff members took part in weekly lessons before they were assigned to deaf patients and had “to learn on the job.”

Some of these classes were given by Reverend Donald Simon, who also served as interpreter – a common situation in a time before schools and colleges offered sign language classes. Members of the local deaf community also gave classes. A photograph from a series in the 1958 conference report shows Max

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472 Altshuler, Interview 2014, 3
Friedman teaching sign language to staff members, a class of young men and women in white coats. The very composition of the photo reversed the established rhetoric of power and learning between deaf and hearing people. Demonstrating a sign, Friedman is standing at a lectern at the front of the room, towering over the sitting staff. They look up to him, smiling and observant. Kallmann’s face is only visible at second glance at the very back of the room, maybe observing, maybe learning himself. Even if we take into account that this picture was at least partially staged, and that images conceal as much as they reveal, this was radically new imagery.474

Learning and employing sign language soon proved to be rewarding. When the project first looked for deaf patients in state hospitals, Rainer recalled in 1968, “it was inspiring to us as well as to the patients, that, with our newly-acquired skills of manual communication, elementary as they were at the time, we were able to see the awakened contact, the chance to talk and listen, of persons who had not communicated with anyone in years.”475 This “anyone” can be taken quite literally, given the general social isolation of mental health patients and the fact that state hospitals often did not have enough staff to take care of even basic needs.

New venues of communication allowed for new insight into the behavior of deaf patients. Once psychiatrists began engaging with patients in their own language, the label of “impulsive aggressive bizarre behavior” – a standard diagnosis attached to deaf patients in New York State’s mental hospital system – turned out to be a chimera. As Altshuler explained: “we found, once we learned

474 Rainer 1955, Planning, page
475 Rainer, Background, 2.
the sign language, that it wasn't always bizarre, it was based on some rationale, even if the rationale was a little whacko.” Establishing communication thus normalized the formerly incomprehensible behavior of deaf patients and brought them within the reach of psychiatric therapeutics such as medication, vocational rehabilitation or psychotherapy. Sign language also was crucial for establishing a working relationship with the New York State deaf community. Even making a “little talk in stumbling sign language,” Altshuler recalled, was rare in a time when most professionals working with deaf people had never learned it.

Examples such as the multidisciplinary work at the NYSPI make clear that the acceptance of ASL in hearing society and among hearing professionals was more evolution than a scientific and social revolution caused by Stokoe’s “discovery” of ASL. It was rooted in a contemporary understanding of language that, certainly, was in change, but also retained older elements. In particular, more theoretical reflections on the nature of spoken versus signed languages remained ambivalent. Thus, in 1963, George Baroff brought forward the commonplace assumption that as a “pictorial representation of symbols” sign language was well-suited for “communicating the tangible or concrete,” but could not represent abstract thought or ideas. Consequently, to be able to reason abstractly, a deaf person had to move beyond signing.

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476 Altshuler, Interview, 5.
477 Altshuler, Interview, 2.
478 For such a portrayal see e.g. Maher, Stokoe, who writes on p. 3 that “[e]xperts in deaf education have compared what Stokoe did for American Sing Language to the pioneering work of geniuses such as Galileo, Copernicus, and Einstein.”
479 Baroff, Socialization, 159.
These assumptions about the nature of thought in language were in transition. Thus University of Chicago neuropsychiatrist Roy Grinker commented in 1968 that since “logical structures of the mind are innate” (a reference to Noam Chomsky's linguistic theories which had also influenced Stokoe), they could be expressed and reinforced in many languages. This multi-leveled ambivalence continued to characterize the project: Openness towards exploring sign languages and their educational potential coexisted with lingering belief in their inferiority; and fascination with the difference of gestural communication was, once more, compared to the “speechless” and intellectually inferior communication patterns in animals. Nevertheless, at the NYSPI the basic assumption of deaf difference as a valid social category would guide research on individuals within their family and social environment and would influence psychiatric and genetic counseling.

Family and mental health problems: Researching genetic patterns and awareness among the New York State deaf

Gathering data about family life, marriage and reproductive patterns was an integral part of the project's twin and population studies. Over the years, staff used this data for different purposes, including basic research on genetic deafness and family and mental health counseling. In the first years of the project, the NYSPI researchers also joined the larger enterprise of identifying different forms of genetic deafness, which, as detailed in the previous chapter, saw significant progress in the 1950s and 60s.

Focusing on a subgroup of the deaf, those who had become prelingually deaf, anthropologist Diane Sank identified five forms: autosomal recessive (about 25 percent), autosomal dominant (about eight percent), and sporadic (about fifty percent). The last was caused either by a “newly arisen mutant gene” or environmental factors. Sex-linked or multifactorial patterns of heredity accounted for the remaining cases. Statistical and sociological analysis, Sank reported, allowed a more detailed description of subforms. “The practice of assortative mating, i.e. the tendency of the deaf to marry the deaf,” she explained, “is a striking feature of the social habits of deaf persons.” Sank noted that in marriages between two deaf people, not all children were deaf. Thus she concluded that either dominant genes for early total deafness were not always expressed, or that a large number of recessive genes must cause hearing loss, making it “rare indeed for two deaf individuals, each homozygous for the same set of recessive genes, to marry and all have deaf children.” As previous chapters have shown, these were common conclusions among geneticists in this period.

Yet, how many genes were underlying these phenotypical patterns was still very much a matter of debate. In their models, geneticist had to assume a large enough number of genes to account for the great phenotypical diversity; yet a number small enough to account for common reproductive outcomes. For Sank, the relatively low number of deaf children resulting from deaf intermarriage pointed to a high number of genes. She estimated that at least 45 different genes caused autosomal recessive deafness. This number was higher than previous estimates – Sank referred to the 36 genes suggested by Chung et

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482 Ibid., 40, 43.
al. in their Northern Ireland study presented in the previous chapter. Pointing to the project’s twin studies, Sank also speculated about the interaction between environmental and genetic influences in producing hearing loss, an approach and conclusion clearly influenced by Kallmann’s.\footnote{Ibid., 64, 65. Also see Sank, Diane. 1963. “The role of heredity in early total Deafness.” In. Volta Review 1693 (65):461-470. For Chung see Chung, Chin Sik, O. W. Robison, and Newton E. Morton. 1959. \textit{A note on deaf mutism}. London; New York: Cambri and the discussion of their work in chapter 4.}

Like other geneticists in the 1960s, the researchers put hopes in biochemical identification and intervention. Once again, the example of phenylketonuria (PKU) offered a hopeful paradigm for finding and fixing biochemical conditions. By the 1960s, PKU had become a paradigmatic condition that demonstrated the successful application of medical genetics to disease prevention. Scientists believed PKU to be just the first of many biochemical disorders that could be treated once the underlying mechanism was recognized, and believed deafness to be among these disorders, as the previous chapter demonstrated.\footnote{See Paul, Diane B., and Jeffrey P. Brosco. 2014. \textit{The PKU paradox: a short history of a genetic disease}. Baltimore: Johns Hopkins University Press, 22, 96. For a closer review of the literature on PKU see the discussion in chapter 4.} Research, Rainer commented in 1963, should “be pursued diligently so that the chromosome-determined biochemical (enzyme) deficiency can finally be detected.” One could then develop “proper replacement or protective therapy” to counteract the biochemical mechanisms that caused hearing loss. Yet this all lay in the future. “Meanwhile,” he contended, “there are other measures on the preventive level for lessening the burden of potential unhappiness and social and personal deprivation due to deafness.”\footnote{Rainer, John D. 1963. “Recommendations for future research.” In. Rainer; Altshuler; Kallmann, 1963. \textit{Family}: 232-233.}
Rainer’s statement summarized the project’s program in regard to genetic deafness for the following years. After Kallmann’s death in 1965, pursuing basic research in the ever more complex field of genetic deafness was beyond the staff’s capacities. Instead, Rainer – who succeeded Kallmann as project director and head of the NYSPI medical genetics department – Altshuler, and their collaborators focused on providing improved and specialized services in family, psychiatric and genetic counseling. For this purpose, Rainer and Deming wrote in 1963, empirical data, could be “useful both in helping to understand the family patterns and behavior of this group for counseling purposes, and as an aid to further investigation of the genetic and selective patterns of mating of the deaf.”

Deaf people’s tendency for intermarriage had been an area of much concern at least since the 1880s, when Alexander Graham Bell had written on the potential creation of a deaf race. The NYSPI researchers, too, commented on this tendency, yet for them, it was more of a fascinating phenomenon than a harmful development. “The assortative mating patterns found among the deaf,” Rainer and Deming remarked, “are of considerable interest both from a psychiatric and genetic standpoint.” Deaf people’s preferences regarding the hearing status of their spouses and children, Altshuler explained, could illuminate several psychosocial issues, including the “amount of concern harbored by the deaf about genetic consequences.” Intermarriage rates also provided insight to the sociological factor of “caste status [...] associated with the various types of deafness.” Such anthropological terminology was not unusual in genetics – after

487 Ibid., 17.
all, the two disciplines had long been closely connected – yet Altshuler’s use of “caste” nevertheless is illustrative. Primarily a psychiatrist, he was more interested in the social behaviors and psychological factors underlying genetic variety than genetics itself, and chose a term evocative of sociocultural restrictions. In doing so, he tapped into contemporary fascination with the sociology and ethnopsychiatry of oppressed people at home and abroad. Rather than a genetic concern, then, assortative mating was an interesting behavior that served as a proxy for exploring sociological and psychological phenomena. Choosing a hearing wife thus was found to be an “asset to individual achievement,” a meant to foster one’s “identity and relationship with the hearing world,” and an attempt to overcome the “caste-status” of the deaf. 488

When it came to the hearing status of their children, Altshuler noted, “only 6.5 per cent of people who wish to marry prefer to have deaf children” while “most persons from deaf families do not care one way or the other about the hearing status of their children.” Tellingly, it was not the indifference or preference for deaf over hearing children that perplexed the researchers, but ignorance of how to achieve this end. “Even among persons who prefer their children to be deaf,” Altshuler exclaimed, “there is no attempt to select the type of mate most likely to produce the desired result!”489 Such an attitude appeared to Altshuler like lethargic ignorance toward realizing one’s wishes (or at least learn about the likelihood of them coming true) when science and medicine were actually able to provide insights toward their realization.

489 Ibid., 99, 107, 108.
For the NYSPI staff, the “pronounced lack of knowledge among the deaf about the workings of heredity” pointed to the dire need of making available “specialized counseling services.”\textsuperscript{490} At conferences and in publications, Kallmann, Altshuler, Diane Sank and others promoted the need for professionals to work with deaf people. Foremost, teachers, rehabilitation specialist and social workers themselves must catch up on genetic knowledge. Currently, Rainer lamented in 1963, “marriage and parenthood counseling facilities” for deaf people often did more harm than good. “Even the most intelligent people in this area,” he criticized, “have a tendency to exaggerate anxieties over things they do not understand.” Only a “genetically trained counselor” he asserted his expertise, could efficiently encounter “superstition and misinformation” and thus prevent “tragic situations.”\textsuperscript{491} Psychiatric genetics, in other words, was the only field truly qualified for counseling the deaf in matters of family, marriage and reproduction. When working with the deaf, Diane Sank specified, this meant not only being “familiar with the life, language and particular adjustive norms of the deaf, but also” knowledgeable on the “\textit{genetic} aspects of deafness.”\textsuperscript{492}

At the 1963 International Congress of the Deaf and the Forty-First Meeting of the Convention of American Instructors of the Deaf in Washington, D.C. Kallmann also pointed to the “remarkable dearth of information about \textit{genetically rooted family problems}” offered at schools for the deaf.\textsuperscript{493} Students’ secluded upbringing in residential schools, he believed, contributed to their

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\textsuperscript{490} Ibid., 107. \\
\textsuperscript{491} Rainer 1963, \textit{Introduction}, pp. xiv. \\
\textsuperscript{492} Sank, Diane. 1962 “The genetic and adjustive aspects of early total deafness.” In. Kallmann et al., \textit{Genetics psychiatry}: 149-166, here 151. \\
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immaturity in regard to marriage and family planning. “Cut off from the specialized services proffered by genetic counseling centers, these highly sheltered students cannot possibly know that general guidance counselors and family doctors, commonly consulted in such family matters, are themselves likely to lack adequate genetic training.” To remedy this problem, Kallmann offered the expertise of his own field. He recommended that “guidance counselors in schools for the deaf have to understand the working of heredity, since they are looked upon as authorities on human genetics.” At the very least, they should refer students to the nearest heredity clinic. Ideally, “to be adequately prepared for family living in the fullest sense,” students needed “access at the proper time to special counseling programs designed to acquaint them with the biological facts of life, including some fundamental principles of human heredity.” From the perspective of Kallmann’s psycho-genetics, sex education and marriage preparation were instruments of a mental hygiene rooted as much in biology as in society.494

Diagnosing the deaf with a harmful ignorance in matters of heredity and mental health, he prescribed a program in which psychiatric genetics would lead the way to a more aware and responsible approach to genetic and psychiatric matters, a happier family life, and thus, in the logic of pronatalist Cold War America, a better, more resilient and democratic nation. Moving between Cold War and Civil Rights rhetoric, this highly appealing vision at once reaffirmed social and gender norms while at the same time conceding to deaf people their own variety of such norms.

494 Ibid., 639, 642.
“Prepared for family living in the fullest sense”: Eugenic goals, individual happiness and deafness in society

Whereas the last chapter traced the effect of more sophisticated knowledge of genetic deafness (a biogenetic category) on genetic counseling, the section below follows the impact of perceiving deafness and deaf people as a sociological and psychosocial category. The development of minority-specific norms, community cooperation and specialized services had significant implications for research on and counseling for genetic deafness.

Adherence to social norms remained an important value for NYSPI psychiatrists, yet the norms to be achieved changed. As long as deaf clients moved within the norms of middle-class respectability and sexuality, the question was not primarily how to eradicate or prevent deafness, but how to adapt psychiatric services, so the deaf, too, could be reached by the benefits of psychogenetic hygiene. As genetic counseling moved toward less directive forms of advice giving, the definitions of pathological conditions became more relative, dependent on client believes and expectation. Shifting the emphasis from the physical state of hearing loss to the stress, maladjustment and emotional disturbance it (potentially) caused, changed the goals of family and genetic counseling: Rather than (only) physical normalcy, the end goal was the emotional well-being and social adjustment of the individual in family and society. “The most fruitful approach to prevention of maladjustment,” explained

Kallmann and Rainer in 1963, “is to center attention on preparation for family living, since it is in this context that most unhappiness and behavior disorder manifest themselves.”

In the postwar decades, Diane Paul has pointed out, genetic counseling increasingly incorporated social factors, taking into account not only a couple's genetic make-up, but also their socioeconomic background. This change mirrors a larger shift in the self-portrayal of genetics. In Cold War America, eugenics as a profession of large-scale social engineering was replaced by a paradigm of individual genetic responsibility as an instrument to achieve individual fulfillment and social harmony. Careful to distance themselves from coercive eugenics, NYSPI researchers portrayed genetics as a rational science that, by countering misconceptions about heredity, enabled rather than restricted (normal) family life.

Adopting psychosocial definitions of defect and disability was part of these changes that depended as much on Cold War rhetoric as on the language of health, civil rights and minority activism. Historians have explored how geneticists’ concern shifted from the domestic feebleminded and defectives to overpopulation and reproductive health abroad. Against a backdrop of concern over America’s role in the world, they could present their science as one capable of upholding American values of freedom and democracy. NYSPI project staff, too, portrayed genetics as a democratic, benevolent and enabling science. The availability of genetic services, Diane Sank wrote in 1961, was the hallmark of a democratic society where social services benefited the individual. “The

availability of adequate” genetic services, she believed, “represent a definitive yardstick of a sound and benevolent system of general population policies, deserving this name in an enlightened twentieth-century society.” That geneticists also borrowed language from larger discussions about health care access, and from the social movements fighting for better health care access has received less attention. Yet it was exactly this combination of Cold War evocations of democracy and the ideals of minority health rights that gave the NYSPI project a flexible enough framework to be attractive to conservative Cold Warriors like Kallmann and to more left-leaning staff members.

As Beatrix Hoffman has shown, World War II significantly changed American perceptions of entitlement to health care. Although wartime health services reached only part of the population, they raised expectations for such federal and state programs to continue after the war. When, in 1944, President Roosevelt spoke on the right to universal access to health care, and when President Truman reaffirmed this vision in the second half of the 1940s, they picked up on this shift in public opinion. Truman’s proposal for universal health coverage was defeated in 1950, yet the postwar era nevertheless had seen an expansion of federal services in maternal and childcare and in rehabilitation. The growth of general hospitals and expansion of mental health services, too, was part of this process.499

The various social movements forming in the 1950s and 60s also made concerns over public and minority health part of their agenda, and demanded equal access to healthcare. Thus, the peace movement worried about nuclear

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498 Sank 1961, Total deafness, 165.
fallout and nuclear warfare, the women’s movement linked political with reproductive rights, and Black activism targeted segregation and discrimination, lack of resources and the consequences of housing policies on community health. Often, these movements developed in opposition to institutionalized medicine, producing poignant criticism of health inequalities.  

Merely focusing on this opposition, however, neglects how professionals also tapped into the ideals of postwar reformers and social activists. It was exactly the heightened attention to health care justice and disadvantaged groups that allowed Kallmann and his colleagues to put forward a vision of genetics as an integral part of a set of services for individuals and groups to solve their familial, health or social problems. Claiming responsibility for the deaf as one such group who had been denied access to basic services lent legitimacy to the project. Thus, in 1963, Rainer and Kallmann declared that no “group is more entitled to counseling for marriage, parenthood and genetics than the deaf.” Such language resonated with a larger vision to equalize access to health care and include groups formerly neglected.

Vague as it was, this statement nevertheless recalled the ideals of a socially engaged psychiatry that spoke out against the discrimination of the disadvantaged. If one argued for the general benevolence of genetics for individual and families, expanding its reach to “underserved” minorities must appear logical and inevitable. To question this expansion was to support discrimination against deaf people and was therefore implicitly undemocratic.

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501 Rainer; Kallmann, Preventative planning, 217.
This line of thought turned genetic knowledge into a crucial form of self-knowledge, a prerequisite for a fulfilled life as an equal in a still unequal society. To be an enlightened, rational citizen meant acting according to the principles of modern science.

With their focus on the mental health of deaf people, the project engaged with contemporary discourse on minority, democracy and health in a manner that subtly changed social roles and expectations. This becomes clear when looking at the types of counseling and advice provided. Between 1955 and 1963, the pilot clinic provided 200 deaf individuals with diagnosis and treatment. Among the services available was genetic, family and marriage counseling, “sorely needed by the deaf.”

Diane Sank described some of the scenarios the psychiatrists encountered as well as their principles of counseling: “[G]uidance” for example, was “sought by hearing men who want to know whether it would be advisable to marry a hearing women with deaf parents, or vice versa.” Beyond the genetic risk, Sank explained, it was crucial to consider the “emotional stability of the two persons involved, their attitude toward acquiring deaf relatives with the attendant possibility of social stigma, and other genetic health risks for the children of the given mating.” Similar considerations should inform the advice to hearing-deaf couples wishing to marry. Successful marriages were possible, Sank thought, yet she warned of the “potential pitfalls in marital adjustment that eventually result in broken homes.” An “extremely stressful disability,” often “associated with a

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502 Rainer; Altshuler, Comprehensive services, 4.
severe degree of maladjustment,” deafness not only affected the individual, but the entire family.503

Whether it was a hearing man who wanted to marry a hearing girl with deaf parents or a deaf person wishing to marry a hearing person, counseling was a complex enterprise. “Counseling in such instances,” Altshuler, Baroff and Rainer advised, “cannot be limited to estimates of the statistical risk of deafness in the couple’s future children.” Rather, the counselor had to “take into account the emotional stability of the two persons involved and their attitude toward acquiring deaf relatives with the attendant possibility of social stigma.” The client’s family and living situation also needed to be considered, for example whether a hearing family was capable of raising a deaf child or vice versa.504 Such a multitude of hereditary, sociological and psychological factors required an individualized approach. When it came to family planning, Rainer believed, “the importance of considering each family on its own merits cannot be overemphasized.”505

From the perspective of preventive mental health, the consequences of acquiring a deaf child, spouse or relative were relational and relativistic: It was as much a social issue, determined by attitudes, biases and preferences, as a biological problem. Moreover, the definitions of healthy and normal depended on one’s professional perspective. To Kallmann, the psychiatric geneticist, the grave effect of mental disease on individual, family and society, outweighed the disadvantages of physical disability. “It is tragic indeed,” Kallmann remarked in

503 Sank 1961, Total deafness, 151.
1953, “to be married to a psychotic wife, or to have to send a schizophrenic son to a mental institution.”

In some cases, he believed, an individual’s desire for family life needed to circumvent natural procreation: The “decision to marry and the decision to have children,” he wrote in 1962, “will have to be dealt with as two separate problems.” Adoption was the alternative when genetic conditions made procreation unwise. Yet, he warned, geneticists should be familiar “with current adoption procedures.” As a psychiatrist, Kallmann thought mental illness caused more suffering and damage than physical disability – a position that clearly influenced his research on deafness and psychiatry. The “hazards of unwittingly adopting the natural child of two schizophrenics,” he believed, “overshadows the risk of harelip or diabetes in a child of one’s own.”

Beyond Kallmann’s professional values, this hierarchy of disability and worth also mirrored general social stigma in a society that considered physical disability a tragic fate to overcome, yet mental illness a frightening loss of selfhood.

With this constellation of multiple risks, psychosocial factors and varied client backgrounds, the counselor’s role went beyond merely eliciting and evaluating facts. He moved between soothing individual fears and furthering the eugenic goal of bettering society and mankind. The “qualified counselor,” Kallmann explained at the 1963 International Congress of the Deaf, needed to “understand the given person’s fears and hopes, defenses and rationalizations.”

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506 Kallman, Heredity, 246, 263.
507 Kallman, Genetic research, 254. For the role of geneticists in adoption and eugenic considerations see Stern, Telling genes, 53-74.
Ideally, "sessions of this kind amount to explanatory or manipulative forms of short-term psychotherapy aimed at reducing anxiety and tension."

Yet the cooperation between the German emigrant, born in the 1890s, and his American collaborators, whose careers started in the 1950s, also reveals important shifts in beliefs about professional authority and client autonomy. Through the contact with Kallmann, Altshuler and Rainer had come to embrace psychogenetics as a crucial element of modern psychiatry. Like their mentor, they believed that raising genetic awareness among deaf people was one of the foundations of preventive mental health. Their opinions differed from his, however, regarding the goals to be achieved, and the level of influence the counselor should exert on his clients. Kallmann had always had a clear vision of how psychogenetics would eventually lead to a society free of mental illness – a goal that required individual sacrifices. For Altshuler and Rainer, on the other hand, psychological and emotional consolation on the individual level took precedence over eugenic population improvement. “While it is unlikely that deafness or mental illness will disappear through such eugenic measures,” Rainer and Altshuler wrote in 1966 in reference to their genetic services, “the relief of anxiety or avoidance of certain tragedy of even a single person cannot be overvalued.”

Although by the 1960s Kallmann no longer supported coercive sterilization, he continued to advise that in some instances couples should refrain from having children of their own. Altshuler and Rainer, on the other hand, believed this to be the decision of the informed patient. In the 1968

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508 Kallmann, Counseling, 641.
509 Rainer; Altshuler, Comprehensive services, 96.
workshop on *Psychiatry and the Deaf* Altshuler reported on the project’s psychiatric preventive program for deaf students. In cooperation with local schools, the NYSPI operated a pilot program that explored group and family dynamics and offered support in the form of student and parent groups. In the discussion following Altshuler’s presentation, one of the attendees asked: “Do you give some genetic counseling in regard to future babies, and the possibility of more hearing deficit?” Pointing to earlier project findings on the lack of genetic knowledge among deaf people, Altshuler explained that genetic education had been one of the goals of the group meetings. Here, there was progress, he noted approvingly and pointed to an “attitude of healthy questioning” that was developing among deaf people and their families. More of the clients, who came for advice to the outpatient clinic, asked “whether they should marry someone who is deaf, and what about the likelihood of deaf children.” Yet with the present knowledge, Rainer added, “it isn’t too easy to give definitive advice except that hereditarily deaf persons should not marry cousins.” Nevertheless, he believed that “at this stage of our scientific knowledge, probably one should be advised to try to avoid marriage between two persons with recessive hereditary form of deafness.” When another audience member asked whether they aimed “to control deafness as a genetic factor,” the answer remained ambivalent. In the spirit of non-directive counseling, Altshuler emphasized that couples were given results and counseling, yet that they did “not attempt to influence their choice of marriage partners. We believe that they are entitled to make their choice on the basis of as much information as possible and full awareness of what is likely to ensue.”

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By the early 1970s, then, the project’s goals in regard to genetic deafness had become ambiguous. With the growth and specialization of psychiatric care for the deaf, the project had also moved away from basic genetic research in favor of providing a range of specialized psychiatric and counseling services. Here, hereditary counseling was only one aspect of family and marriage counseling in a larger program of preventive mental health. In this, the NYSPI resembled the Clarke School, where it was embedded in their educational mission. Unlike the Clarke School, however, what was to be prevented was not primarily the physiological state of hearing loss, but potential adjustment problems in intellectual and emotional development. Here, social biases and familial dynamics were at least as important as individual behavior.

Conclusion

At first glance, Franz Kallmann and his NYSPI department of human genetics may seem like an unexpected location for a paradigmatic shift from a medical-pathological to a more sociocultural model of deafness. Other scholars have described him as an example of the long-lasting influence of deterministic, anti-individualistic eugenics beyond World War II. Some continue to indict his hereditary determinism and stigmatizing view of minorities. Sociologist Graham Kinloch, for example, referred to his schizophrenia research as an example of “extremely negative” majority attitudes toward deviants “defined as

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Rainer; Altshuler, Psychiatry.11-23, here 16, 20, 21.
psychologically and genetically defective.”512 Yet at the same time, although in other circles, his project with the deaf has been lauded as an example for minority-specific genetic and psychiatric services.513

My analysis does not necessarily contradict these findings. Rather, it shows how in postwar America, biological categories of normalcy or pathology were imbued with psychosocial definitions; a development that allowed a mutually fruitful collaboration with some groups – yet not with others. Whereas Kallmann’s condemnation of homosexuality appears to have been a life-long constant, he believed in the agency for insight, participation and responsibility of (heterosexual) deaf people.514

To understand these developments, it is necessary to look at the variety of reform projects in postwar psychiatry and rehabilitation. Here, genetic, biochemical, psychodynamic and psychosocial models of mental illness overlapped, providing older visions of social engineering with a new sociopolitical framing. The rise of community and open psychiatry, so crucial for the NYSPI mental health project for the deaf, is a prime example. It resonated with administrators trying to cut cost by downsizing patient populations, with proponents of new forms of social and work therapy, and with the goals of the mental hygiene movement to prevent mental illness in the population at large.

This development cannot be understood without taking into account the growing influence and lobbying power of non-professional mental health reformers, patients and their family members, who aptly employed the rhetoric of minority needs and discrimination.

By the early 1950s, deaf people, too, had become part of this network of expanding psychiatric services, multi-disciplinary approaches, and civil rights rhetoric. The NYSPI project was based on a consensus between professionals and deaf community members: Both sides believed that the deaf had been neglected in psychiatric care, and it was time for professionals and lay people to make up for this neglect. Operating under the tenets of community psychiatry required that psychiatrists engaged with and got to know their target population, in this case the New York State deaf, and even turned them into mental health care professionals themselves. In deafness research, such a more collaborative engagement with deaf adults set the NYSPI apart from other institution that dealt with either depersonalized statistical data or populations of children and their families. Disregarding previous research as biased or irrelevant, the project set out to characterize the New York State deaf population as a placeholder for the “normal” deaf person. Grappling with the meaning and nature of deaf difference, staff members oscillated between defining the same phenomena as pathology or specific normalcy. While some of their studies pointed to the deficiencies caused by sensory deprivation, others acknowledged deaf people’s adaptability and accomplishments.

Thus, the the deaf came to be defined as a subpopulation at particular risk for emotional maladjustment and mental illnesses caused by the effects of hearing loss itself, yet also by discrimination, bias and lack of educational or
professional opportunities. Whether this potential for mental maladjustment and emotional unhappiness became reality depended on the individual's situation in social context. Counseling thus required a comprehensive appraisal of an individual's, couple's or family's situation as well as an awareness of the specific socio-psychological issues faced by the deaf.

If deaf people were different from the hearing, they required a system of specialized services that took into account their specific needs. Requiring that staff would learn their clients' language and offering services and therapy in sign language was the most visible sign of this minority-specific approach. It made the NYSPI a forerunner and example for psychiatric and genetic services that justified specialized services by referring to the rights of a “neglected” minority. Countering supposed neglect with tailor-made services foreshadowed later projects that considered hearing loss the uniting factor of their target population rather than their most important pathological trait.

Historians have pointed out that despite more individualistic approaches in postwar (genetic) counseling, the field continued to perpetuate contemporary norms of family, gender and ability. The NYSPI project, too, was rooted in the standards of its time. The project however, shows how such norms could morph and evolve due to extended contact with the client population. In a more relational and relativistic framework, a hearing child born to a deaf family could be as much of a challenge as a deaf child born to a hearing family. Here, a form of genetic counseling that fashioned itself as offering emotional support and even “short-term” therapy incorporated new sociological insights into the social dynamics of illness, health and difference. More sociocultural understandings of disability and identity did not replace genetic thought, but imbued it with a
psychosocial dimension. It turned genetics into an essential form of self-knowledge, important not only for reproductive questions, but for achieving a happy, fulfilled life more generally. These hybrid bio-cultural identities would come to play an important role in the push for genetic awareness and genetic services for deaf people in the following decades.515

The NYSPI thus established a professional cluster of psychiatrists, psychologists, rehabilitation workers and geneticists whose approach differed significantly from the oralist-medical model explored in previous chapters. Exploring the growing gap in professional paradigms defining deafness, I have suggested why some professional groups came to identify more with a medical; others more with a sociocultural model of deafness. In the 1950s and 60s, professionals in psychiatry, rehabilitation and genetics found a new paradigm in social reform and social involvement, in serving underserved minorities and paying attention to the social impact of science. Here, we can see how ideologically-loaded terms like democracy and discrimination, minority and culture are used to justify medical or scientific intervention, and to establish forms of identity based on the confluence of scientific and social activism. This commitment to social dynamics and cultural factors sensitized the field for the demands of the disability and Deaf movement that by the 1970s publicly challenged the medical-pathological model of disability and deafness.

515 Historians have usually tied the developments of such biomedical regimes as a development of more recent neoliberal politics and developments in genetic technology. See e.g Thomas Lemke, for example, who has written about the individualization of (genetic) risk as a result of these developments. Lemke, however, focuses predominantly on expert discourse in the biosciences and big politics, and in doing so, gives hardly any attention to the interaction between researchers and the objects of applied genetic research. See e.g. Lemke, Thomas. 2007. *Gouvernementalität und Biopolitik*. Wiesbaden: VS Verlag für Sozialwissenschaften: 129-48.
VI. Genetic and emotional risk, self-finding and self-surveillance: The case of Usher Syndrome

Introduction

In 1965, a group of psychiatrists and psychologists from Chicago visited the “world’s first and only state mental hospital program for deaf mentally ill patients” at the Rockland Mental Hospital, NY, one of the the state hospitals where the NYSPI pursued their work with the deaf. There, they met with Kenneth Altshuler and John D. Rainer who introduced the group to their work with deaf psychiatric patients. The program, the visitors noted, provided deaf patients with a “therapeutic setting” rather than the “custodial isolation” still customary for mental health patients. Observing the groundbreaking work at the Rockland hospital, the Chicago delegation became “‘infected' by the enthusiasm of those concerned with deafness” and decided to establish specialized psychiatric services for deaf people in Chicago, too.516

Among the Chicago delegation was McCay Vernon, a young psychologist with a background in deaf education and a strong interest in psychiatric and neurological disorders. In the 1970s and 80s, Vernon would become one of the most influential and prolific figures in the psychology of deafness. Early in his career, he encountered deaf psychiatric patients with vision loss, and became intensely interested in their fate. He diagnosed them with Usher Syndrome, a recessive genetic condition characterized by congenital hearing loss and progressive vision loss caused by a form of retina degeneration, retinitis.

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pigmentosa. Vernon was appalled by the living conditions of deaf-blind people who were often institutionalized with little regard to their needs and abilities. To counter the general ignorance of Usher Syndrome among physicians and deaf education, Vernon launched an awareness campaign. Initially, this was very much a one-man endeavor, yet with his excellent connections to deaf and professional communities, he soon found support for his demands to educate professionals and lay people, and to establish screening and prevention programs.

Usher Syndrome, Vernon repeated time and again, had been known for a hundred years, yet it had been grossly and irresponsibly neglected by professionals. This certainly was an effective rhetorical tool for raising awareness and pushing people into action, yet it conflated the Usher Syndrome of 1900 with that of 1960 or 1980. Ophthalmologists had indeed first described the inheritance of hearing loss and retinitis pigmentosa in the 1850s, and in 1914, the Scottish physician Charles Usher had described diverse forms of congenital deaf-blindness, yet throughout the first half of the century, this combination of symptoms garnered little attention. It was only in the 1950s and 60s that researchers began to differentiate an ever-growing number of syndromic forms of deafness. Vernon's research and lobbying would not have been possible without this watershed moment in the history of knowledge about genetic deafness that has been described in detail in previous chapters. The realization that a significant part of the deaf population might be affected by renal, cardiac disease or vision loss led to calls for early identification and

diagnosis. Vernon employed these concerns skillfully, tapping into a general sense of urgency, missed chances and neglect.

By the late 1970s, not the least because of Vernon, Usher Syndrome was no longer an obscure phenomenon, but had become a condition familiar to deaf people and deafness professionals. In some sense, Vernon had reached his goal. Yet Usher Syndrome did not mean quite the same thing anymore. What had in the 1960s been portrayed as a grave congenital disability threatening the future of the unborn and burdening public health, by the early 1980s had become a primarily psychosocial condition endangering the emotional equilibrium of individuals and families. This chapter will follow this transformation. Unlike previous chapters, it will focus on a single form of genetic deafness as paradigmatic for the changes in approaching deafness, disability and genetic conditions from the late 1960s to the 1980s. At stake in discussions about Usher Syndrome and those living with it were notions of genetic risk, prevention and awareness, disease and disability identities, professional authority and patient autonomy. The increasing focus on the social and psycho-emotional dimension of disability that I already traced in previous chapters also significantly influenced perceptions of Usher Syndrome.

Diabetes, Christopher Feudtner has argued, has become a transmuted disease. After the introduction of insulin therapy in the 1920s, he writes, type I diabetes turned from a usually fatal disease of childhood to a chronic condition that allowed patients a somewhat normal life, yet brought with it a whole new range of unexpected long-term sequelae. In the course of this transformation, regimes of treatment, management of long-term outcomes, and the public perception and identities of diabetes and diabetes patients changed significantly.
As the world of marriage and childbearing, higher education and professional careers opened up for diabetic people, so did the questions of reconciling their life plans with the self-discipline required by insulin treatment. Risk of long-term effects had to be weighed against present plans and wishes. Phenylketonuria (PKU) has seen a similar transformation. As one of the first treatable intellectual disabilities, it offered a hopeful model for other supposedly biochemical conditions. Yet maintaining a life-long diet low in phenylalanine was not a simple cure, but required constant self-surveillance. It meant an awareness of being different and dealing with insecurities about long-term effects.\footnote{Feudtner, Christopher. 2003. \textit{Bittersweet: diabetes, insulin, and the transformation of illness}. Chapel Hill [etc.]: The Univ. of North Carolina Press; Paul, Diane B., and Jeffrey P. Brosco. 2014. \textit{The PUK paradox: a short history of a genetic disease}. Baltimore: Johns Hopkins University Press.}

There was no such breakthrough therapeutic success for Usher Syndrome. Treatment options, in fact, have not changed much since the 1960s, despite early hopes for biochemical cures. Nevertheless, I argue, Usher Syndrome, too, was a transmuted condition, and it was in part just the lack of biomedical therapeutic success that accounted for its transmutation. As different professional groups, and increasingly, deaf and deaf-blind people themselves, rallied around issues of prevention, rehabilitation and research, the meaning, boundaries and supposed effects of Usher Syndrome changed, as did the prospects of those living with it. We can thus understand changing approaches to Usher Syndrome as a sequence of different disease regimes, a concept Maren Klawiter has employed in her study of breast cancer to analyze the relationship
between social movements and professionals as they create different roles for “diseased,” “risky” or “disabled” subjects.\textsuperscript{519}

The social role and status of people with Usher Syndrome and those at risk for it meandered between these categories of diseased and disabled, and was much in flux during the 1960s, 70s and 80s. Usher Syndrome is rare in the general population, but occurs with a frequency of 3-6 percent among American deaf people. Screening programs singled them out as a neglected risk group. Usher Syndrome thus joined a group of conditions in which mass screening did not truly screen the entire population (as in PKU), but focused on a specific group with a particularly high prevalence. Historians have written about such screening programs for Tay-Sachs disease among Ashkenazi Jewish populations, sickle cell disease among African Americans, and thalassemia in Mediterranean peoples. Wailoo and Paul in particular have described how the definitions and perceptions of sickle cell disease or PKU changed over time alongside with the social position and perception of the group with which they were associated, namely African Americans and people with (intellectual) disabilities.\textsuperscript{520}

For a long time, previous chapters made clear, experts had talked about, but not with deaf people. This was even more true for the deaf-blind. Yet by the mid 1970s, deaf-blind people themselves began to influence discourse of Usher Syndrome in multiple ways. This development was reflective of the overall growth of patient and disability activist networks in the last third of the century.


More specifically, it was the result of community and identity building among deaf-blind people since mid-century. In this period, and specifically in the aftermath of the 1964-65 rubella epidemic, educational and rehabilitation services for deaf-blind people expanded greatly and for the first time reached a comprehensive level. In part, this was due to the continued attention to rehabilitation and disability that the previous two chapters have traced. Schooling and rehabilitation programs brought together deaf-blind children, adolescents and adults who had often led very isolated lives, but now began to feel as part of a larger community. Inspired by the social movements of their time, they demanded a more self-determined life.

A detailed history of deaf-blindness and deaf-blind people is beyond the scope of this dissertation, although there is much need for one. There is, unfortunately, little literature on this subject. Even biographies of famous deaf-blind people such as Helen Keller or Laura Bridgeman have until very recently been mostly edifying (and cloyingly saintly) narratives of the endurance of the human spirit.\footnote{For a portrayal of Keller that addresses both the common narrative of her as a dramatized and tragic heroine and gives an account of Keller as person, socialist, and activist see Nielsen, Kim E. 2009.The radical lives of Helen Keller. New York: New York University Press. Elisabeth Gitter's biography of deaf-blind Laura Bridgeman and her teacher Samuel Howe addressed contemporary notions of disability and charity, but does not dissect the meanings of deafness and blindness. See Gitter, Elisabeth. 2001. The imprisoned guest: Samuel Howe and Laura Bridgman, the original deaf-blind girl. New York: Farrar, Straus and Giroux. The history of blindness is in itself still an underdeveloped field with mostly chronological accounts that focus on organizations or single individuals without providing much analytical insight. See e. g. Matson, Floyd W. 1990. Walking alone and marching together: a history of the organized blind movement in the United States, 1940-1990. Baltimore, Md: National Federation of the Blind; National Federation of the Blind. 1970. The first thirty years: a history of the National Federation of the Blind (1940-1970). Des Moines, Iowa: National Federation of the Blind; Koeptler, F. A. 1976. The unseen minority: A social history of blindness in America. New York: D. McKay Co; Lowenfeld, Berthold. 1975. The changing status of the blind: from separation to integration. Springfield, Ill: Thomas. Fergusson provides a rather one-sided critique of professional policies, see Fergusson, Ronald J. 2001. We know who we are: a history of the blind in challenging educational and socially constructed policies : a study in policy archeology. San Francisco, Calif: Caddo Gap Press. Kornbluh offers a nuanced analysis of}
education specialists, usually treats deaf-blindness as the combined effect of two constituent deficiencies, and thus as a doubly tragic condition. A 1930 survey, one of the first, of deaf-blind people's living situation portrayed them as *Those in Dark Silence*, drawing from popular stereotypes that are more telling about sociocultural ascriptions than lived realities. In their compound effect – deaf-blindness equals the stereotypes of deafness and blindness together – such portrayals portray deaf-blind individuals as passive, isolated and helpless and negate their human potential and autonomy.\(^{522}\)

Contrary to such conflations, deaf-blind people have often found themselves between communities, identities and movements. While scholars and activists of disability and deafness have respectively criticized stereotypes about deafness and blindness, they, too, tend to maintain clear dividing lines between the two groups and identities. Thus, they define the blind as identifying with the label of disability (however defined and valued), while the deaf consider themselves part of a sociocultural, non-disabled minority.\(^{523}\) This often left deaf-blind people struggling for a sense of belonging in either community. Their sense of exclusion and not-quite-belonging figures prominently in both professional and personal portrayals of Usher Syndrome. I can sketch these developments

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only roughly, and will address them in the moments of exchange between hearing-sighted, deaf and deaf-blind individuals and professionals. Individuals with Usher Syndrome, I will show, influenced perceptions of and approaches to deaf-blindness with their demands for self-determination and independence, and their emphasis on ability instead of defect.

Questions of diagnosis, screening and identification in particular brought to the foreground complex issues of science and disease management, and of belonging and selfhood in the face of physical changes. Calls for screening assigned a risk role to the genetically deaf population, and to those affected or their family members. Yet what and who, exactly, was at risk was an ambiguous matter that changed over time. Was it the unimpaired future of the unborn child, the family who was affected by the birth of a disabled child, the individual whose life and outlook would change dramatically, public health and the public budget, which were impacted by the cost of care for a handicapped population? And who, in the first place, was disabled?

These questions will feature prominently throughout this chapter. Interacting with an increasingly political, unapologetic and visible Deaf community, professionals such as Vernon vigorously and fervently embraced a vision of the Deaf as a sociocultural minority, yet at the same time defined deaf-blindness as a most dreadful disability. Simultaneously, Deaf, disability and health activism provided deaf-blind people with the tools and rhetoric to reject such one-sidedly negative portrayals. As individuals with Usher Syndrome came together and spoke at conferences and other venues, they in turn influenced professional. This chapter will follow these confluences and tensions between biomedicine and multiple forms of activism, support and pathologization,
genetics, psychology and culture. Tracing negotiations over what it meant to be deaf, blind or deaf-blind, to have a chronic and heritable condition, I suggest a history of Usher Syndrome at the intersection of patient, disability and Deaf history, and the history of genetics and biomedicine. Focusing on the alignment of professionals with patient or minority groups allows me to point to little-explored tensions: While these alliances had the potential for equalizing the power relationship between scientists and their target population, it also provided new venues for asserting professional authorities rooted in activism.

**Deafness and psychosis at the Chicago Michael Reese Hospital:**

**Pathology and advocacy**

Their impressions of the NYSPI facilities for deaf patients inspired the Chicago group to establish a similar pilot program at the Chicago Michael Reese Hospital. In 1965, they received a planning grant from the Vocational Rehabilitation Agency (VRA) “for the purpose of establishing a coordinated training program for professionals to help them work with persons handicapped by defects in speech and hearing.” From 1966 to 1969, a second VRA grant allowed them to pursue research on deafness and psychosis and to offer specialized services.524

The project was supervised by eminent psychiatrist Roy Grinker, director of the University of Illinois Psychosomatic and Psychiatric Institute. Mostly known for his work on war neuroses and role in veteran rehabilitation, Grinker's work integrated psychosomatic and neurological thought – an important angle in the Chicago project, and, eventually, also in perceptions of Usher Syndrome.

524 Grinker, *Foreword*, 8-11.
McCay Vernon became project director. With Vernon's "vast knowledge of problems of the deaf and his wide acquaintance with professionals working in the field," Grinker commented, the project was "able to recruit good people and proceed quickly to begin with our studies."\textsuperscript{525}

Unlike Grinker, Vernon had worked with deaf people before – it might well have been him who "infected" his colleagues with an interest in deafness. Like Schlesinger and Levine, Vernon had entered psychology via deaf education. Born in 1923, he began his career as a teacher, coach, and residence hall counselor at the Florida, Texas and Colorado Schools for the Deaf. Simultaneously, he earned an MS in Education of the Deaf at Gallaudet University in 1954, and an MA in psychology from Florida State University in 1957. With his background in special education and psychology, he worked as research associate at the University of Illinois Institute for Research on Exceptional Children while he pursued his PhD research at Claremont Graduate School. His PhD thesis analyzed the connection between etiology and intelligence in multiply handicapped deaf children. Exploring the intellectual and emotional development of deaf children remained one of the dominant themes in his career.\textsuperscript{526} Vernon also had private ties to the Deaf community to which his first wife, Edith Goldston Vernon, deaf herself, introduced him. Her influence and his experiences in deaf education turned him into a lifelong, outspoken and often uncompromising advocate for the legal and civil rights of deaf people.\textsuperscript{527}

\textsuperscript{525} Ibid.


\textsuperscript{527} For this advocacy, Vernon would receive numerous honors and awards, including the Alice Cogswell Award and a Honorary Doctor of Letter from Gallaudet University in 1973 and 1975 respectively, a declaration of merit from the World Federation of the Deaf in 1975 and the Powrie V. Doctor Chair of Deaf Studies Award from Gallaudet in 1979 and 1980. For
Like their colleagues in New York, the Chicago team, too, was concerned with bringing psychiatric services to a neglected minority with still undefined needs. There was, Vernon commented in 1971, still a “basic lack of understanding of the effect of deafness on human behavior which results in severe psychological and educational damage to deaf persons.” To remedy this situation, the project offered out- and inpatient mental health services, a preschool program for deaf children, and guidance and communication classes for families with deaf children. For rehabilitation and job placements they cooperated with local vocational services. In the spirit of community psychiatry, the project also aimed to “get the well-functioning members of the deaf community involved in our work at Michael Reese, at least peripherally.” Clients, among them also a few deaf-blind individuals, came from all over Illinois.

The NYSPI had gradually come to define the deaf as a sociocultural minority with its own language and organizations. Established ten years later, the Chicago project began with this definition, yet moved further into an explicitly politicized direction. Borrowing from the radicalized, politicized language of Civil Rights and minority movements, the Michael Reese researchers – and Vernon in particular – indicted majority society for oppressing the

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529 Grinker, Foreword, 10.
language and culture of deaf people. At the same time – and often counteracting definitions of the deaf as a sociocultural group like any other – the Michael Reese group delineated the psychopathological effects of deafness. Where the NYSPI research defined deafness psychosocially as a potentially “stress-producing” condition, the Michael Reese researchers took a neurological approach. To them, psychiatric disturbances occurring with hearing loss were an expression of neurological damage. This ambivalent, sometimes almost irreconcilable combination of advocacy for Deaf culture and researching deaf pathology strongly influenced Vernon’s early research of Usher Syndrome as a neuro-psychiatric phenomenon, and of people with Usher Syndrome as a neglected group.

**Brain lesions and minority politics: deafness as psychosocial discrimination and psycho-neurological deprivation**

In hindsight, Vernon’s positions on deafness during the 1960s and 70s seem peculiarly bifurcated. In essence, he and other contemporaries moved (or, often, meandered) between describing disability as an innate pathology that caused defect and thus was a matter of positivist science and medicine; and as sociocultural condition determined by social bias and discrimination, and thus was a matter of social justice and civil rights. These perceptions of disability, defect, social belonging, and identity are telling for the theoretic and political frameworks available to professionals at the time. From which framework they drew, Vernon’s example demonstrates, depended on the valence it held within a particular context or with a particular audience. Significantly, by the 1960s deaf people had become one of these audiences to at least to some professionals; a
community one spoke to, not (only) about. Below, I will explore these positions in detail to help explain the transformation of Usher Syndrome from a psychiatric condition and a matter of innate suffering and eugenic prevention to a psycho-emotional issue negotiated with patient, deaf and disability communities.

“Brain damage,” Vernon wrote in 1971, “plays a major role in a significant number of the behavior disorders in deaf persons.” There was, he claimed, a critical overlap between the most common causes of deafness and of brain damage: maternal rubella, meningitis, prematurity, heredity, and serological complications. Consequently the “behavior noted as characteristic for deaf persons may not be caused by deafness at all” but rather caused by an “interaction between central nervous system damage and deafness.” To Vernon’s contemporaries, such allusions to behavior disorders and particular characteristics would have translated to the traits established by psychological research as typical for deaf people. As previous chapters have shown, professionals believed deaf people to display delayed and lower maturity and lower abilities in verbal skills and abstract thought.

Vernon’s attempt to diagnose the majority of deaf people with some undefined brain damage has often been considered offensive. Yet his attempt to identify neurological damage as the real cause for deaf difference is part of a long-standing trend in the history of deafness and disability. Susan Burch and Octavian Robinson have pointed to the exclusive strategy employed both by professionals and the deaf community. Ostracizing multiply disabled deaf people served to portray the “normal” deaf individual as an able citizen. The increasing

532 Vernon, Final Report, 15-16.
attention to multiply disabled deaf children and adults from mid-century on, too, was mired in such attempts to define normal and abnormal lives and behaviors. Vernon similarly attempted to normalize the “healthy,” non-brain-damaged deaf at the expense of pathologizing the majority of supposedly “brain-damaged” deaf.533

Not only was there a supposed link between deafness and brain damage, deafness itself must cause neurological pathologies, the Michael Reese group speculated. The “sensory deprivation of deafness,” wrote Vernon and his Michael Reese colleague psychiatrist David Rothstein in 1968, might lead to a “total reorganization of the central cognitive processes, or a retrograde neurological impairment which generalizes to speech and language associational areas.”534

The impact of deafness, they concluded, depended on the “degree to which the underlying neurological substrate is involved.” Where these neurological lesions supposedly occurred, and how they would affect neurological function, remained purely speculative. Yet neurology offered an attractive model for locating – in the supposed concreteness of brain matter – difference in deaf people’s educational achievements and social adaptation. Usher Syndrome was to become one such example of a neurological lesion that caused sensory impairment and psychiatric disturbances.


534 Vernon; Rothstein, Prelingual Deafness, 365-366.
This, however, was only one side of Vernon's approach to deafness, employed predominantly when he addressed other psychiatrists or psychologists. At the same time as he and other Michael Reese staff located pathology in the brains of deaf people, they also addressed larger sociocultural factors affecting deaf people, and in doing so criticized pathological attitudes toward the deaf in hearing society and family. Here, Vernon and his colleagues exchanged the psychologist's clinical, detached and distanced perspective for the voice of the social activist, indicting discrimination against the deaf as part of larger social injustices toward minority groups. These publications on the social situation of deaf people often lacked any references to the pathological effects of deafness their other work tried to establish. Instead, it was society that was pathological.

“The average deaf youth,” Grinker wrote in 1969, was part of “a minority group that is more often the butt of crude humor than of understanding. He is generally forced to communicate through a 'foreign' language and modality, his natural language (the language of signs) being forbidden.” Although he did not cite her directly, Grinker's condemnation echoed the analysis which psychologist Hilde Schlesinger had formulated at the NYSPI meeting Grinker had attended in 1968. There she had spoken about the estrangement deaf children experienced when “one of their native tongues” — sign language — “is not quite so good, not quite as acceptable, as the spoken language.” Combining ethno-psychiatry, psychodynamic and cultural deprivation theory, Schlesinger had argued that
deaf children lacked the “healthy ethnocentrism” necessary for healthy emotional and social development.535

Vernon, too, built on Schlesinger's work on deaf children and family dynamics, although with a more strident and politicized tone. Even in the deaf child’s family, he wrote in 1971, “deafness was denied, as were the family's feelings of sorrow, grief and anger about it. Growing out of this denial,” he continued, “were unrealistic, incongruous, and unattainable goals.” This was a not too subtle criticism of oralist education with its ideals of complete assimilation. In particular, this “pathological family denial of deafness” manifested itself in the lack of communication between hearing and deaf family members. Most hearing families knew no sign language. This ignorance isolated the deaf person in their own families. The “stress and deprivation,” this caused, Vernon concluded, “was a leading pathogenic factor in the etiology of the mental disabilities noted in the patient population.”536 Strikingly, neuropathological explanations, a major paradigm in Vernon's writings above, were never mentioned.

If the current situation of the deaf was an expression of social and familial pathologies, then improvements required not as much a change in treating their neuropathologies, but in the family, if not society at large. Like at the NYSPI, staff members learned basic sign language and general communication skills as one important step toward this goal. To overcome the isolation of the deaf child, the project established a nursery program for deaf children, as well as

communication and language classes. The nursery school employed manual and oral communication, an approach often called “combined method” or “total communication.” Although teaching any sign language still remained highly controversial, this approach rose quickly in popularity in the 1970s.

For supporters of sign language such as Vernon and his Chicago colleagues, sociological and psychological theory became a weapon yielded against oralists. Eugene Mindel, child psychiatrist and head of the nursery program, resorted to Freudian thought to explain the rejection of sign language as unconscious and irrational indicators of individual psychological insecurities. The “unconscious association between the use of a gestural language and one’s primitive impulses,” he believed, created irrational “repressive pressure” toward sign language. Rejecting sign language thus became a sign of unresolved psychodynamic conflicts rather than a rational position. Likewise, Mindel diagnosed supporters of oralism with the very pathological traits singled out in Theodor Adorno’s famous study of the authoritarian personality, originally devised in the wake of WWII and fascism. In this reading, the incapability to accept change in deaf education was caused by an unhealthy, rigid adherence to established authority structures and thus a sign of pathological egocentrism. Petty as these accusations might seem, they reveal a shift in the stance of professional supporters of sign language. Long accused of being backward and ignorant, this growing group now moved from defense to offense. Now it was supporters of sign language that charged oralists with being behind the times for nothing but selfish, irrational even undemocratic reasons.

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537 Gannon, Deaf Heritage, 368-369.
If framed with political theory, the rejection of sign language thus could be cast as a sign of pathological ethnocentrism, of harmful majority discrimination against the deaf minority. In a 1969 article on the “Sociological and Psychological Factors Associated with Hearing Loss,” Vernon bemoaned that, despite a normal distribution of intelligence among the deaf, their educational achievement was “grossly below national averages.” The reason for this failure, he believed, clearly was due to “education’s rigid adherence” to oralist programs. This policy of “educational deprivation,” he complained, left the “the average deaf adult [...] grossly undereducated” with “crippling psychological and sociological implications” for his professional and social life.539

Like Mindel, Vernon provocatively charged professionals working with the deaf with an emotional and psychological inability to incorporate new approaches. Attacking his very readership in the *Journal of Speech and Hearing Research*, Vernon complained that only “few members of the professional specialties represented in ASHA,” – the American Speech Hearing Association –, “had more than superficial contact with adult deaf persons.” Ironically, the very persons who held “primary control over the eventual sociological and psychological fate of adult deaf people” lacked personal knowledge of and experience with their clientele.540

The psychology and sociology of minority group dynamics offered a compelling model for explaining deaf people’s deficits in educational and professional achievement as a matter of willful ignorance and neglect on side of the hearing, and of internalizing majority values on side of the deaf. Together


540 Ibid., 541, 547, 549.
with social worker Bernard Makowsky, Vernon offered the readers of the *Deaf American*, the official publication of the National Association of the Deaf (NAD), an analysis of their “second class citizenship.” “Intelligent, informed and concerned deaf citizens,” Vernon and Makowsky wrote, “must look at many aspects of their own sometimes limited life situation and that of fellow deaf people and ponder the question – Why?” Why did some minority groups – Jews, Mormons, and “Orientals” – succeed in American society while others – “Puerto Ricans, Negroes and American Indians” remained disadvantaged? 

Successful minority groups, Vernon and Makowsky believed, had developed successful strategies for maintaining their identities in the public and political sphere. Social and political participation was as a crucial determinant in “characterizing progress of a minority.” In this regard, Jews, Catholics, Mormons and Orientals had reached a high degree of independence and autonomy, not the least in the realms of political representation and education. Confessional schools or programs provided their children and teenagers with “opportunities to learn necessary aspects of both the minority and majority values,” and thus to cherish their own culture. Disadvantaged minority groups such as “Puerto Ricans, Indians, Negroes and deaf people” on the other hand “tend to be forced into segregated schools over which they have little control” and in which they were “told that their languages and customs [...] are undesirable.”

The situation of Native Americans made for a particularly compelling – and emotionally charged – comparison. Just as Native Americans had been

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542 Ibid.
disenfranchised and were “virtually controlled by a non-Indian bureaucracy,” Vernon and Makowsky believed that deaf people, too, had been profoundly estranged and disempowered in their own country. The field of education, for example, lacked deaf professionals in leading administrative position. Deaf teachers were still being discriminated and excluded from professional organizations and educational programs. Many schools would not hire them. “As with the Indians,” the authors concluded, “this must result in a feeling of helplessness among these minorities that stems from the fact that there is no control of their own destiny.” Such oppression, they wrote with reference to Schlesinger, led to an “unhealthy denial of self,” a lack of “healthy "ethnocentrism'.”

In the politically charged atmosphere of the late 1960s, evoking the struggles of racial and ethnic minorities served to devalue oralist positions as undemocratic aberrations. Drawing from psychological and sociological studies of minorities in American society, and from a growing literature on the psychosocial effects of deafness, Vernon and Makowsky declared that it was “undemocratic” to impose the values of hearing society on deaf people. The “effort to deprive and make deaf persons ashamed of manual communication and other aspects of themselves as deaf people have analogs in the hair straightening, skin bleaching and other examples of minority group attempts to deny their identities and become something they are not.”

There was potential for change, however. Recently, African Americans had realized that rather than internalizing majority values, they needed to reach

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543 Ibid., 3; Schlesinger, Cultural influences.
544 Vernon; Makowsky, Minority, 6.
“acceptance and pride in being what one is and a full realization of the potentialities this offers.” Just like them, Vernon and Makowsky called upon deaf people to take their fate in their own hands, too. “If progress is to come about,” they believed, “it will probably result from aggressive deaf leadership, new knowledge gained from psychology and sociology and from new professionals entering the field of deafness.” Clearly, Vernon and Makowsky included themselves in this group, thus portraying their work as contributing to a revolutionary retribution of power. Inciting anti-professional sentiment, they excluded themselves from this sentiment by casting themselves as much-needed allies in the struggle against a hostile establishment of old-fashioned professionals.545

By the late 1960s, Vernon and his colleagues at Michael Reese, Edna Levine, Hilde Schlesinger, and, to a lesser extent, the NYSPI psychiatrists, contributed to two somewhat overlapping, yet increasingly conflicting paradigms in talking about deafness and deaf people, about disability and defect. Since at least the mid 19th century, a variety of professions had been describing the pathological effects of hearing loss in ever-greater detail. Locating these pathologies in (yet to be found) brain lesions, the neuropsychiatry of Vernon and his Michael Reese colleagues was only the latest addition to this tradition. At the same time – and often within the same publication and project – psychosocial definitions of disability combined with social activism, severely indicting the prejudice and discrimination against deaf people. Deafness, in this view was something cultural and natural, as innate and unchangeable as skin color, a trait that was disadvantageous only because of hearing society. Oppressing one’s deaf

545 Vernon; Makowsky, Minority, 3-6.
self was as harmful and unhealthy as denying one's ethnic belonging. Each paradigm – the classic oralist-medical and the newer, ethnosocial – offered different models for asserting professional expertise and authority, from saving disabled children to aligning with the struggle of oppressed minorities. In discussions about Usher Syndrome the tensions but also the connections between these two models become particularly apparent. Usher Syndrome, I will show below, came to be understood as a problem of public health and discrimination; as a grave disability, yet also as an essential and acceptable part of one's identity.

**Finding patients, (re-)defining a syndrome: Vernon's early work on Usher Syndrome**

Usher Syndrome, Vernon, and other writers following him kept repeating, had been known for over a century. This, however, was more a dramatic hyperbole to indict public “inertia” than a realistic appraisal. The association of hearing loss and retinitis pigmentosa indeed had been first described by German ophthalmologists Richard Liebreich and Albrecht von Graefe in the 1850s. In the wake of their publications, the various forms and causes of retinitis pigmentosa became a popular topic of research among ophthalmologists and researchers of heredity for whom it became a model disease of genetics. In 1914, the Scottish ophthalmologist Charles Usher presented a comprehensive study of 69 cases of retinitis pigmentosa, among them eleven “deaf-mutes” and 19 cases of hearing loss. For his study, he collected pedigrees of families affected with retinitis pigmentosa, described their ocular symptoms in great detail, and sorted them by potential cause, such as syphilis, tuberculosis, or heredity, maternal fright or
shock. Usher also listed associated conditions, including hearing loss, mental
deficiency, deformities or epilepsy, but did not define any specific syndromes or
their patterns of inheritance.546

Into the 1970s, the eponym “Usher Syndrome” for the combination of
retinitis pigmentosa and hearing loss was used only inconsistently. More often,
authors simply referred to the combined inheritance of deafness and retinitis
pigmentosa. In 1966 still, geneticist H. Warner Kloepfer commented on the
“confusion and often contradictory information” in the literature on Usher
Syndrome. Earlier researchers had not conducted ophthalmological and
audiological examinations but relied only on questionnaires, which made a
precise (retrospective) diagnosis impossible. Moreover, cases that had once been
considered Usher Syndrome later were often reassigned to other syndromes. For
example, before Waardenburg Syndrome (deafness with cranial and pigmentary
anomalies) was defined in the early 1950s, its traits were often considered a
variation of Usher Syndrome.547

Thus, it was only the increased focus on syndromic forms of deafness in the
1950s and 60s that made Usher Syndrome visible as a form of hereditary deaf-
blindness, distinct from other forms of environmental and inherited deaf-
blindness. What, on the biochemical level, caused this specific hearing and vision
loss, however, remained unclear. Similarly, it was not clear whether these were
the only symptoms associated with this conditions. Researchers had noted that

546 Liebreich, Abkunft; Usher, Inheritance, 122-236.
syndrome of congenital deafness and retinitis pigmentosa: (Usher’s syndrome.).” The
Waardenburg’s work see chapter 4.

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mental deficiency or psychiatric disturbances seemed to regularly occur in individuals with the syndrome, yet were unsure whether this was part of their condition or caused by it. Some authors speculated that the psychiatric changes observed in patients with retinitis pigmentosa where caused by underlying metabolic changes or could be traced to a single, recessively-inherited gene mutation.\footnote{For an overview of 27 major and other minor forms of syndromic deafness known by the mid 1960s, see Arthur LJ. 1965. “Some hereditary syndromes that include deafness.” Developmental Medicine and Child Neurology. 7 (4): 395-409. For a discussion of e.g. psychopathology see Wortis, S. Bernard, and Donald Shaskan. 1940. “Retinitis Pigmentosa and associated neuropsychiatric changes.” The Journal of Nervous and Mental Disease. 92 (4): 534; Hallgren B. 1958. “Retinitis pigmentosa in combination with congenital deafness and vestibulocerebellar ataxia; with psychiatric abnormality in some cases; a clinical and genetic study”. Acta Genetica Et Statistica Medica. 8 (2): 97-104; Small JG, and GM Desmarais. 1966. "The familial occurrence of retinitis pigmentosa, mental disorders and EEG abnormalities". The American Journal of Psychiatry. 122 (11): 1286-9.}

In this situation of relative obscurity of hereditary deaf-blindness, yet interest in hereditary syndromes, Vernon established himself as a leading expert on Usher Syndrome. His definitions and opinions would dominate the field for decades. He had first encountered deaf people with Usher Syndrome during his PhD research on the etiology of deafness at the California School for the Deaf. By 1969, he had identified six more deaf-blind students.Measured against the hundreds, perhaps thousands of deaf students and patients he had seen in his ten years as a teacher, coach and psychologist, these eight deaf-blind individuals could have easily been forgotten. For Vernon, however, with his interest in etiology, in multiple disabilities and their influence on intellectual and emotional development, these encounters triggered an interest in a more systematic study of this rare condition.\footnote{Vernon, McCay. 1969. "Usher’s syndrome—deafness and progressive blindness: Clinical cases, prevention, theory and literature survey.” Journal of Chronic Diseases. 22 (3): 133-151. Also see Vemon, McCay. 1976. “Usher’s Syndrome: Problems and Some Solutions.” Hearing and Speech Action. 44 (4): 6-7, 9-13.}
Alongside his PhD research and work at Michael Reese, Vernon began an extensive study of Usher Syndrome. The Michael Reese project on deafness and psychosis offered him the opportunity to assess a large number of deaf patients for visual impairments in a hospital setting with a multi-disciplinary staff. Given the speculation about psychiatric disturbances in deaf-blind people, the mentally ill deaf seemed particularly suited for finding individuals with Usher Syndrome. Here, Vernon pointed to Rainer's and Altshuler's New York study according to which five percent of deaf patients in the New York State mental hospitals had retinitis pigmentosa. The NYSPI researchers had seen no causative relation between these conditions. Vernon, however, framed these findings with his search for neurological lesions as the cause for behavioral differences and mental illness in deaf people. Deaf-blindness, he believed, caused mental disturbances: “approximately five per cent of psychoses in the deaf population are due to Usher's Syndrome,” he speculated.\(^{550}\)

In 1967, Vernon reached out to geneticists, ophthalmologist and other professionals working with deaf people, asking them to share “findings on your research on retinitis pigmentosa.” His correspondents included Kenneth Brown, whom Vernon asked for a reprint of his 1966 Clarke School study on genetic deafness. Another was Bruce Konigsmark, founder of the Johns Hopkins Otoneuropathology Laboratory and author of the seminal *Hereditary Deafness in Man.* To Ian Shine from the Genetics Department of the University of Hawaii Vernon explained his motivation: “Unfortunately, my lack of competence in factors of heredity do not permit me to understand or study the processes of genetic transmission as much as I would like. Instead I have tried to study

behavioral and other neuropsychological manifestations of those genetically deafened.”

In a 1969 article, he summarized the results of this survey and defined Usher Syndrome as an incurable, hereditary, neurological “chronic incapacitating disease.” Based on case studies of eight patients, he reviewed early childhood development, intellectual abilities, emotional adjustment and associated conditions, and classified them as abnormal. It was difficult, he conceded, to judge “what normal behavior would be for persons in this traumatic life situation.” Yet one could observe in the deaf-blind population an array of psychopathological conditions including psychosis, mental retardation, schizophrenia, depression, auditory hallucination or vestibular involvement. This combination of traits, he believed, pointed to the possibility “that Usher’s syndrome involves central nervous system damage with behavioral manifestations.” The nature of these traits strongly suggested a common single central brain lesion – yet to be discovered – as the causative factor in Usher Syndrome.

Based on his findings, Vernon proposed a five point plan for prevention. He would maintain its basic outline for the rest of his career, although priorities would shift. The plan aimed, first, to educate medical and educational professionals. Currently, Vernon lamented, they had at best partial knowledge of the syndrome and its manifestations. Greater awareness among medical professionals would make possible steps 2 and 3: screening of all congenitally

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deaf children, the high risk group for Usher Syndrome, with a battery of ophthalmological and audiological tests, and providing them with counseling. Among this group, Vernon claimed, the syndrome was the leading cause of deaf-blindness. Conveniently, this risk population was “small, identified, centralized and available” in schools for the deaf. Setting up a program of detection and genetic counseling “to avert further spread of the disease” thus was both “feasible and potentially effective.” His fourth and fifth points concerned the screening and counseling of family members as potential recessive carriers. Improving education and rehabilitation figured only as an afterthought. “An adjunctive benefit” of early diagnosis, he remarked off-handedly, “would be better educational planning for the detected cases.”

A more extensive, unpublished version of this prevention plan and consequent publications on Usher Syndrome illuminated Vernon’s belief in the primacy of prevention vs. investment in education or rehabilitation. These writings employed the language of economic and human cost, suffering and misery that had long dominated public and scientific discourse of disability. The cost for prevention, Vernon argued, “would be infinitesimal compared to the cost of educating, training, or even merely providing custodial care for a deaf-blind person.” The money spent on educating one deaf-blind child – $182,000 in 1976 – would be “enough to pay for several years of nation-wide screening.” Genetic screening and counseling, he acknowledged, may “pose many ethical and philosophical problems,” yet the nature of Usher Syndrome tilted the calculation

553 Vernon, Usher Syndrome, 140.
554 Ibid.
of ethical cost and benefit. “[W]hen the drawbacks of counseling are weighted against the awesome nature of deaf-blindness, it is apparent that they are the lesser evil.”

Vernon correspondence with organizations and federal agencies was characterized by employed the same depersonalized language of economic waste and failed investment in the nation’s health and future. With typical, uncompromising fervor, he criticized the very institutions from which he hoped to garner support. In a blistering 1969 letter to Robert Finch, Secretary of Health, Education, and Welfare (HEW), he accused HEW for setting up the expensive Helen Keller National and Regional rehabilitation Centers in the aftermath of the 1964-65 rubella epidemic while ignoring the problem of Usher Syndrome. Appealing to economic savings, Vernon criticized channeling resources into “custodial care” – a noteworthy choice of words from a former teacher for the deaf – when an “an inexpensive prevention program” for Usher Syndrome had the potential for a much bigger impact.

Research, too, could be cast in the language of economic savings vs. current misspending. Finding a cure or in utero test, Vernon argued, would be “cost-effective in that the expenditures would not approach the cost of maintaining even minimal services for deaf-blind people.” In the future, he hoped,

556 Vernon 1976, Usher’s Syndrome, 9.
557 This fervor and quick judgment did not always endear Vernon to others working in the field. In a 1974 letter, Louis J. Bettica, assistant director of the Helen Keller Center, acknowledged Vernon’s work in bringing Usher Syndrome to the “attention of a group of people who had little awareness of this combination.” However, he admonished, “[i]t seems to me Mac, that you like some other workers for the deaf simply will not believe that anyone else can do a competent job with this group.” Apparently, Bettica was not the only one with this impression of Vernon, as he added that “if I were to listen to what people say about you, I would have to believe that writing this letter is the height of futility.” Louis J. Bettica, ACSW Assistant Director to Vernon, Nov. 25, 1974, McCay Vernon Correspondence - Usher’s Syndrome, Box 5, Folder 24 1966-1974, GUA.
558 Letter Vernon to Robert Finch, Secretary of HEW to Vernon, June 3, 69, McCay Vernon Correspondence - Usher’s Syndrome, Box 5, Folder 22, 1966-1974, GUA.
biochemical research would be able to “cure and arrest” what was “believed to be caused by an inborn error of metabolism” (an established term for a genetic enzyme defect). Screening and dietary treatment for PKU offered a hopeful example, as did the recent discovery of the biochemical cause of Refsum disease – another hereditary syndrome that included retinitis pigmentosa, hearing loss and neurological symptoms. It was caused by an enzymatic defect in metabolizing phytanic acid, found in beef, dairy products and some kinds of fish. Similar to the course of treatment in PKU, symptoms can be prevented with a diet low in phytanic acid. Such hopes remained ambivalent. Detecting the biochemical mechanisms underlying Usher Syndrome, Vernon wrote, might help to develop “a dietary supplement [to] arrest, prevent, or at least reduce the effects of the disease.” Yet as with most other genetic conditions, prenatal prevention remained the most likely and effective option. “Options such as therapeutic abortion,” Vernon speculated, “would become a reality if Usher’s [...] could be diagnosed in the fetus or the carrier.”

Vernon’s campaign thus aptly and successfully tapped into contemporary notions of disability and disease prevention. Yet when it came to public and professional attention to deaf-blindness, he lamented, Usher Syndrome was overshadowed by the rubella epidemic of 1964-65.

559 Vernon 1976, Usher Syndrome, 9, 11.
Deaf-blindness in the 1960s and '70s: Rubella, damaged children and vulnerable families.

In 1964-65, the US experienced a massive epidemic of rubella (German measles) with 12.5 million registered cases. Among them were tens of thousands of pregnant women. Usually mild in children and adults, rubella, a viral infection, poses a serious threat to the unborn. It can cause a condition that became known as Congenital Rubella Syndrome (CRS) and most commonly includes a distinctive combination of cataracts, hearing loss and congenital heart disease. Subsequent studies would later show that CRS affected not only the eyes, cochlea and the heart, but most other organ systems as well, causing intellectual disabilities, autoimmune disease and inflammatory conditions.\(^{561}\)

During the epidemic, 11,000 pregnant women who had contracted rubella either miscarried or aborted once they learned of the damaging effects. Between 20,000 and 30,000 babies were born with CRS. 2,100 of them died shortly after birth; between 2,000 and 8,000 children were born deaf, and of these 38 percent had another significant handicap. For 2,500 to 4,400 of them, (one of) the additional handicaps was deaf-blindness. In part, these widely varying estimations were due to shifting definitions about what degree of visual and auditory impairment constituted deaf-blindness.\(^{562}\)

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The dilemma of pregnant women who had contracted rubella and the fate of the children born with CRS grabbed public attention. Leslie Reagan has argued that the rubella epidemic acted as a catalyst for debates over abortion, public health and disability in the 1960s and 70s. Access to abortion for pregnant women diagnosed with rubella varied widely, depending on location, race and social position. Often, women were denied abortion, or had to fight for access until very late in their pregnancy; an experience that galvanized many of them into lobbying for legalizing access. At the same time, parents of children with CRS played an important role in advocating for better services, educational opportunities and social acceptance for their children.\textsuperscript{563}

Educators for the deaf tried to anticipate the needs of the rubella cohort. With an expected number of deaf-blind children about the three to five times the number of the entire deaf-blind school population – 576 at the time of the epidemic, only 177 of them enrolled in schools – the need for expanding and improving education and rehabilitation was obvious. The rubella epidemic accelerated public investment in these services for deaf-blind people. In 1967, the Vocational Rehabilitation Act Amendment for the first time acknowledged deaf-blind people' suitability for vocational rehabilitation. In 1976, the Helen Keller National Center (HKC) for Deaf-Blind Youths and Adults opened its doors in Sands Points, NY. It offered rehabilitation and training services and facilities. Ten regional Centers for Deaf-Blind Children followed and supported the work of the HKC.\textsuperscript{564}


\textsuperscript{564} Schein, Jerome D. “A brief history of services for deafblind people in the US.” In In. Graham, C. L. (Ed.) (2007). \textit{Transition Planning for Students who are DeafBlind}. Knoxville, TN: PEPNet-South: 7-19;
The history of Usher syndrome shares some of the themes prevalent in the history of CRS: Both conditions were portrayed as a “human burden,”\textsuperscript{565} or an “unnecessary tragedy;”\textsuperscript{566} the one to be prevented through vaccination, the other amenable to genetic awareness and counseling. Professionals emphasized the low cost of prevention versus the familial, financial and social resources necessary for the education and rehabilitation of the “damaged” child. “The urgency” of prevention, a 1974 report on \textit{Serving the Deaf-Blind Population} stated, “is manifest if we look only at the high annual cost associated with the special education for deaf-blind children: from12,000 to 14,000 per child.”\textsuperscript{567}

Yet there were also important differences in the way these conditions were conceptualized. “The new ‘handicapped’ child born of German measles,” Reagan writes, “were pitied not only because they had disabilities but also because their expected prosperous future had been interrupted.”\textsuperscript{568} Children with Usher Syndrome, on the other hand, had been disabled from inception, although vision loss only manifested itself later in life. The meaning of prevention also differed. With the discovery of the rubella virus in 1962 and consequent development of a vaccine, maternal rubella became a preventable condition. Following large-scale vaccination campaigns, almost all states in the US had made rubella vaccination a school entry requirement by 1978. By 1984

\textsuperscript{565} See e. g. Stuckless, \textit{Burden}, 70-79.
\textsuperscript{567} Brewer, \textit{Deafblind population}, 10.
\textsuperscript{568} Reagan, \textit{Pregnancies}, 8.
rubella was considered contained.\textsuperscript{569} Usher Syndrome, on the other hand, remained an incurable condition. While scientists put hopes into a finding the underlying biochemical defect, prevention meant finding affected and non-affected carriers, genetic counseling, and, potentially, abortion.

Perhaps most important for public perception of Usher Syndrome and CRS was the difference in occurrence. Before widespread vaccination, and especially during and after the 1964-65 epidemic, maternal rubella and CRS was a common condition that affected ten thousands of women and children in the US alone. Usher Syndrome on the other hand, is a rare condition with a prevalence of four in 100,000 births in the general population.\textsuperscript{570} It is considerably more common among deaf people – estimates range from 1 to 6 percent – yet, as with many other rare genetic syndromes, educators and physicians were largely unaware of its existence. To Vernon, this was a scandalous neglect. “It is almost unbelievable,” he lamented in 1974, “that a condition which causes 3\% to 6\% of deaf children to become blind is still relatively ignored by professionals working with deaf adults and children.”\textsuperscript{571} This statement he would repeat incessantly in the following decade.

**Popularizing Usher Syndrome: between patient voices and eugenic prevention**

Convinced that Usher Syndrome was a great, yet neglected threat to the deaf, Vernon dedicated considerable time and work to campaigning for his

\textsuperscript{569} Gruenberg, Ernest M. “Introduction.” In. Gruenberg, \textit{Brain syndromes: ix-xiv, here xii, xiii; Plotkin, History, 165-166.}

\textsuperscript{570} For current estimates see the Usher information page of the National Institute of Deafness and other communication disorders, \url{http://www.nidcd.nih.gov/health/hearing/pages/usher.aspx#b}

\textsuperscript{571} Vernon 1974, \textit{Usher Syndrome}, 100.
prevention plan. It was never fully implemented. Yet as he corresponded with patients and professionals, his one-man endeavor grew into a network of people interested in raising awareness for Usher Syndrome, researching its causes and in improving living conditions. With patients and experts alike, he discussed genetic, audiological, psychological and ophthalmological implications. Among the corresponding professionals were psychiatrists John D. Rainer and Kenneth Altshuler from the NYSPI, ophthalmologist Donald R. Bergsma, neuropathologist Bruce Konigsmark and geneticists Kenneth Brown and Walter Nance. Traces of these conversations with professionals, and, in particular with patients, found their way into Vernon’s writing. These encounters did not lessen his belief in the primacy of prevention. Yet contact with patients provoked a shift from the abstract and politically expedient language of economic savings and disease prevention to the more personal tone of the caring psychologist soothing individual concerns.

Vernon’s first 1969 article on Usher Syndrome was soon followed by other publications in various venues, including those aimed at deaf people. Soon, he began receiving letters from persons who, after reading one of these pieces, realized that they or a family member had Usher Syndrome. For these individuals and their families, Vernon acted as a confidant who provided comfort, information and referrals to experts and services. Reading Vernon’s 1969 article prompted a man already diagnosed with retinitis pigmentosa to write to Vernon “to ask you if you would permit me to come and see you to

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discuss Usher's Syndrome.” For some correspondents, it was only after reading one of Vernon's articles that they learned the name or full extent of their condition. In 1974, a mother from Florida complained that even though her son had been diagnosed with Usher Syndrome, the diagnosing physicians “did not give us any information on this disease.” Vernon replied empathetically. “You face some difficult times in helping your son get the most he can from life.” He continued to offer the mother “any help I can.”

Realizing the hereditary nature of their condition raised concerns about marriage and childbearing. A concerned mother wrote to Vernon in 1974 after having read his article in the *Volta Review*. Her son, the woman reported, “is deaf and his wife is deaf and also has retinitis pigmentosa. We would appreciate getting more information on Usher’s syndrome.” In his reply, Vernon directed her to John D. Rainer who now headed the NYSPI Department of Medical Genetics. In scope and content, these letters resembled those that the directors of heredity clinics (and, indeed, the Clarke School) had been receiving since the 1940s. Yet Vernon was no geneticist, and despite his zeal for genetic awareness and prevention, his replies did not provide diagnosis or genetic counseling. Rather, these instances foregrounded Vernon's capacity as a therapist, who offered guidance in emotionally-challenging situations.

Extended contact with patients and their families, with their hopes, feelings and expectation changed the way Vernon wrote about Usher Syndrome. Many of the patients writing him, he commented in 1974, “were bright,

573 McCay Vernon Correspondence - Usher's Syndrome, Box 5, Folder 22 1966-1974, Gallaudet University Archives.
574 Ibid.
575 Stern, for example, gives examples of the avenues of contact and interaction between clients and counselors, including learning about heredity clinics through media reports. See Stern, *Telling genes*, in particular, 32-52.
successful individuals, who, in some cases, were hard of hearing and partially sighted rather than severely deaf-blind.” Their existence, he now concluded, pointed to a bias in research. Earlier studies, including his own, had predominantly focused on institutionalized populations. Now it became apparent that there was a group of patients in which symptoms were not (yet) severe; who were not institutionalized and dependent, but lead successful, independent lives.576

Communication with these patients also altered Vernon’s definition of Usher syndrome as a neuropsychiatric disorder. In the 1960s, he had published abstract case and population studies that reconstructed pedigrees, medical histories, and institutional careers. By the mid 1970s, he had quietly dropped the notion of an underlying neurological lesion for psychiatric disturbances and replaced it with a different kind of psychological focus: The psycho-emotional effects of living with Usher Syndrome. He asked in 1976, “What happens to persons with Usher’s syndrome and why?”577

Deaf individuals with Usher Syndrome provided Vernon with valuable contacts with the Deaf community. Some had leading positions in organizations of the deaf. One of them was Joseph Wiedenmayer, who had spent the first twenty years of his career as a diplomat in foreign service (hiding his hearing loss and increasing vision loss), then worked for the A. G. Bell Association and the Council of Organizations Serving the Deaf (COSD). An umbrella organization of 28 national organizations for the deaf, the COSD had been established in 1967 with federal support. Until its disbandment ten years later, it held annual forums

577 Vernon 1976, Usher's Syndrome, 7, 9-10
on topics such as legal rights, medicine, family or education, and served as a contact point and mediator between its member organizations. In October 1969, Wiedenmayer wrote to Vernon after having read one of his articles. “I am very interested in the subject,” Wiedenmayer explained. “This is because this is my own physical handicap.” However, he, continued, “I did not know [...] that this condition was called Usher’s Syndrome.” He closed his letter with “[o]ne question: Is it likely that one or more of my descendants will contract retinitis pigmentosa and how can the disease be prevented?”

Wiedenmayer became an important contact for Vernon as he tried to engage the COSD in his prevention and awareness campaign. The organization was responsive to his plea for support, yet their financial means were limited and dependent on grants and donations. After the COSD declined taking part in Vernon’s plan to mail information material to all American medical, rehabilitation and education professionals working with the deaf, Vernon again appealed for Wiedenmayer “to get the A. G. Bell Association or C.O.S.D. to underwrite a mail-out.” As a “man who has had a personal experience, at least with the threat of Usher’s Syndrome,” he wrote, Wiedenmayer was “better able to understand the need for prevention than, for example, the people in the Bureau of Education of Handicapped Children who are building ten regional

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578 Wiedenmayer himself became active in advocating for the needs of the deaf-blind, e.g. through publishing an educational booklet. See Wiedenmayer, Joseph. 1971. Look or listen: specific suggestions to improve understanding between visually impaired persons who are hard of hearing, and their friends or specific suggestions to improve understanding between the blind who can’t hear well and their friends. Washington. For the history of the COSD see Gannon, Deaf Heritage, 336-337.

579 Letter J. Wiedenmayer to Vernon, Oct 17, 69, McCay Vernon Correspondence - Usher’s Syndrome, Box 5, Folder 22 1966-1974, Gallaudet University Archives.
centers for the diagnosis and care of the deaf blind persons but who expressed no concrete interest in prevention.”

Film was another medium for reaching a large audience, and one in which Vernon became interested in the 1970s. Together with Gallaudet College and his colleagues at Western Maryland College, where he had became professor of psychology in 1969, he began producing documentaries that introduced a general audience to deafness and the lives of deaf people. In the early 1970s, Vernon and Eugene Mindel – Vernon’s former colleague at the Michael Rese project – turned their book about childhood deafness *They grow in silence* into an award-winning documentary. Also involved was L. Earl Griswold, professor of sociology at Western Maryland College who shared Vernon’s interest in deafness and in film as a medium for public education. Although sympathetic to sociocultural minority perspective, they produced films about rather than by deaf people, addressing the general public or professionals.

A 1978 educational film about Usher Syndrome followed this pattern. Written, scripted and narrated by Vernon, it was produced by Griswold and prepared together with Gallaudet College. Supported by a cast of experts, Vernon offers a 20-minute overview of the syndrome’s medical and genetic

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characteristics and pointed to the urgent need for awareness and prevention. Although the film was subtitled, it gave a mixed message about the intended audience and the role of deaf-blind people.

One of the most active members of the emerging Usher Syndrome community starred prominently – at least in a way: Gallaudet student Arthur Roehrig. Soon after his diagnosis in 1972, Roehrig began acting as a source of advice and reference for other people facing Usher Syndrome. His personality, activism and engagement, however, were muted in the film. While we see him signing to other deaf and deaf-blind people, his and their thoughts, emotions and opinions are assumed, yet never solicited. To the hearing-sighted audience, he was made to stand for the isolation of the deaf-blind. Serving as a poster boy for Usher Syndrome, Roehrig was to demonstrate its effects and implications, without ever himself facing or addressing the audience. Other individuals with Usher Syndrome only occur as anonymous examples.

The film opens with a scene of Roehrig on the Gallaudet campus, showing a bearded, dark-haired man in his late 20s who navigated his surroundings with a cane. "Always an active boy," Vernon narrates, "Art enjoyed a variety of sports in high school and in college, but he found himself increasingly bumping into things, even during the day." This, he explained, was due to Usher Syndrome, which had left Roehrig with a tunnel vision of only 5-10 degrees. Although legally blind, the remaining central vision allowed him to move around independently in daylight. "As he gets older and the disease progresses," Vernon foreshadowed, "most of the residual vision will be gradually lost."583

583 Ibid.
With Vernon providing the overarching narrative, expert interview partners explained medical details and in doing so, supported the central motives of Vernon’s prevention campaign: Late diagnosis was common, Dr. Eliot Birdsen of Harvard Medical School confirmed. Because “everybody is focused on the problem of deafness,” he explained, the syndrome usually was only diagnosed in the patient’s adult years. Here, Vernon’s voice-over picked up the narrative again, and over an idyllic image of a mother and her (presumably healthy) toddler, warned about the adverse outcomes of such a delay. It “often produces tragic results such as numerous families on record into which several children have been born, all of whom will grow up to be deaf-blind, because the diagnosis of the oldest child was not made early enough to provide a basis for genetic counseling and family planning.” Yet early diagnosis was possible through electroretinography which measured retinal response to light stimuli. As Birdsen explained, electroretinography was “a pathway not only in determining abnormalities, but also in ensuring families of normality.” For individuals at risk for Usher syndrome he recommended that the procedure be done between the ages of 6 and 15. Testing was possible earlier, even at birth, although it was less reliable and required sedation. Birdsen added that his department conducted such early testing “if it will influence family planning.”

As was typical in medical genetics, family planning was presented as a prime reason for early diagnosis. Vernon’s narration gave several scenarios that might occur in genetic counseling: For the hearing, sighted family with a first affected child, it was of “great practical importance [...] to get early diagnosis” because the likelihood of having another child with Usher Syndrome was 25

584 Ibid.
percent – the expected proportion for a single-gene recessive condition. Early diagnosis was even more urgent when individuals with Usher Syndromes planned a family themselves. If they wished to marry another deaf person, the partner should be tested for Usher Syndrome, too. Here, the scene switched back to showing Roehrig sitting on a campus bench, engaged in conversation with a young woman. The couple used tactile sign language, or touch-signing in which the hands of the signers are in contact, the most facile form of communication among deaf-blind individuals fluent in sign language. On this scene of seemingly carefree young love Vernon commented that “Mr. Roehrig dates a young woman who also has Usher’s Syndrome. It is of crucial importance that they realize that should they marry and have children, all of their children would be expected to be affected with Usher’s Syndrome.” What Roehrig and the young woman themselves thought of this matter was not recorded. What they ought to think, however, was clear: Children were not an option in the union between two individuals with Usher Syndrome.585

Early diagnosis, Vernon continued, also was crucial for career and educational planning. Here, too, Roehrig served as a warning example. Because Roehrig was not diagnosed until age 27, Vernon commented, “he spent wasted years of extended professional preparation for a career as a teacher of deaf children, which was inappropriate for a deaf person with a progressive loss of vision.” Presumably, Vernon considered a vision-impaired teacher incapable of interacting with deaf children; an assumption that mirrored contemporary standards of physical fitness expected of deaf as much of hearing teachers. Once again, such a statement failed to solicit for Roehrig’s perspective. Nor did

585 Ibid.
Vernon’s categorical statement consider possible adaptations that would allow a vision-impaired teacher to continue working.

What was to be done for these people? In the future, research might discover the underlying genetic and biochemical mechanisms of Usher Syndrome. Currently, however, there was no cure or treatment. “Until research wipes out Usher’s Syndrome,” Vernon commented, “the key question is, what can be done to help those who have the disease.” He pointed to rehabilitation and education services, for example the Helen Keller National Center for Deafblind Youths and Adults, “an outstanding rehabilitation facility” and added that anyone “knowing of a deaf-blind person sixteen years or older should contact the center immediately.” Here again, the film clearly addressed professionals working with deaf-blind people, perhaps family members or acquaintances, yet not deaf-blind people themselves.

The movie concludes with Vernon at his desk, commenting on “one of the greatest tragedies of Usher’s Syndrome and other forms of deafblindess.” Of the estimated 20 to 50,000 deaf-blind people in the US, only 2000 were known to the responsible agencies. Even those who now went through rehabilitation programs at the Helen Keller center, had “spent years of their lives in hospitals for the mentally ill where they were shut away in attics, or in homes where nobody knew how to serve them or to communicate with them.” The final shots were devoted to series of scenes showing deaf-blind people interacting. “Given a chance,” Vernon narrated over a scene of Roehrig with a young woman, “those with Usher’s Syndrome and other deaf-blind can have rich, fulfilling lives, despite having one of the severest handicaps known to man. Independent living is a
reality for some; self-respect, companionship and communication with other human being."

This empathetic, hopeful conclusion partially counterbalanced the strong eugenic message of early detection, counseling and prevention that prevailed throughout most of the film. Nevertheless, it was still the expert who spoke and brought about change, not deaf-blind or deaf people themselves. Their thoughts and opinions remained absent, almost irrelevant. Observing deaf-blind persons with the distant gaze of the clinician or rehabilitation specialist, the film maintained a strict separation between the spheres of the professional and the patient. This separation, however, was dissolving. In the very community that Vernon had helped to create with these prevention efforts, different interpretations and perspectives emerged. Professionals and patients such as Roehrig or Wiedenmayer emphasized services over prevention, and the social over the physical.

Usher Syndrome as form of community genetics: cooperation and contact between patients and professionals

Throughout the 1970s and early 1980s, a number of conferences brought together geneticists, ophthalmologists, teachers and rehabilitation workers, deaf-blind people and their families to exchange experiences and discuss new developments. The first of these was a 1973 Symposium on Usher’s Syndrome at Gallaudet College. The foreword framed Usher Syndrome as one many forms of genetic deafness expected to rise proportionally with the improved prevention of environmental hearing loss. As pointed out in previous chapters, this was a common theme in research of genetic deafness and genetics in general since the
1930s, first motivated by improving hygienic measures, then, from mid-century on, by mass vaccination and the widespread availability of antibiotics. There was, then, a “growing number of bewildered young adults and families with Usher’s syndrome victims” who had “no understanding of the problems and little recourse to agencies able to provide guidance or appropriate services.” Bringing together experts and patients, the symposium was to assess their situation and offer suggestions for improvement.586

Three years later, in 1976, the Helen Keller National Center convened a workshop on Usher Syndrome bringing together diverse professionals, deaf, and deaf-blind individuals. Their contributions, Harry J. Spar from the center commented, showed that “while there is a strong thread of deep interest in and basic knowledge of Usher’s Syndrome that binds them together, there is a fairly wide divergence in the understanding the implications that this syndrome hold for rehabilitation and employment.”587 Also in 1976, the Rochester School for the Deaf organized a Seminar on Usher’s Syndrome; in 1977, a Dallas, Texas conference pondered its Personal, Social, and Emotional Implications and in New York in 1980 the second Annual Workshop on Usher Syndrome took place.588

The overarching themes of these meetings were screening, diagnosis and genetic counseling; how to improve services, education, and rehabilitation; and the personal, social and emotional implications of coping with the diagnosis and

living with deaf-blindness. Developments in basic research were discussed, yet
the main emphasis was on practical implications. Doin E. Hicks, dean of
Gallaudet’s pre-college program, observed at the 1977 Texas conference that
there were fewer than twenty publications on Usher Syndrome with “practical
value to the educator/rehabilitation worker.” Most of these, he remarked, had
been authored by Vernon or relied heavily on him.589

Participants – often the same speakers attended several conferences –
engaged in an ongoing conversation on the meaning and implications of Usher
Syndrome and deaf-blindness. Overall, the room given to preventive measures
decreased, not least because no test existed to detect the syndrome in the
unborn or unaffected carrier. Instead, with the growing input of deaf-blind
people themselves, conference participants explored the socio-emotional
process of coping, overcoming, and adaption among patients and family
members. This shift from the genetic to the psychosocial emphasized the familial,
interconnected character of Usher Syndrome. It was a condition with which the
whole family had to come to terms.

These conferences brought together the psychologist Vernon with some
of the leading figures in genetic deafness research. Comparing their opinions on
genetic counseling for Usher Syndrome reveals a somewhat ironic moment in the
reception of eugenic motives in psychology, and of psychological motives in
genetics. From the moment he had put Usher Syndrome on his agenda, Vernon
had pinned his hopes on genetic research and counseling. Whether at the
individual or the population level, genetics was the means to eradicate Usher

589 Hicks, Doin, E. 1977. Usher’s Syndrome: Programmatic considerations. Training conference
Usher’s Syndrome. Personal, Social, and Emotional Implications. September 28-30, 1977, Dallas,
Texas, 2.
Syndrome and thus to prevent future suffering. For Vernon, counseling was a form of directive information-giving with clearly defined expectations: Prevention was more important than individual hopes for children or marriage. Geneticists, on the other hand, had been moving away from this absolute stance.

In the late 1940s, Sheldon Reed, one of the founders of genetic counseling, had developed a model of non-directive, client-centered counseling influenced by Rogerian psychotherapy. His approach certainly did not obviate older eugenic motives or restrictive definitions of the “normal family,” yet it introduced into genetics the notion of client autonomy in steering individual outcomes. The previous chapter has shown the growing emphasis on the psychotherapeutic and emotional benefits of counseling and the psycho-emotional dimensions of coping with (potential) disease and disability in the individual and his family. Disease prevention and public health remained important motives, yet geneticists and genetic counselors had lowered their expectations of how much preventing a given trait or gene in an individual really would affect its prevalence in the total population.590

This trend toward emphasizing the psychosocial dimensions of genetic conditions extended to Usher Syndrome. At the 1973 Gallaudet Symposium, geneticist Walter Nance rated the psychotherapeutic benefits of counseling as superior to medical or eugenic effects. Usher syndrome remained incurable, and plans for population improvement and prevention such as those put forward by

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Vernon were unrealistic. Unlike Vernon, who considered marriages of individuals with Usher Syndrome inappropriate, Nance encouraged them to be “optimistic,” as their chances for unaffected children were much better than usually assumed. Genetics, he wrote, echoing a common theme among geneticist, could dispel fears created by misinformation, social bias and ignorance. Nance assured patients and their families that “the load of abnormal recessive genes is a burden that all society bears.” Given this ubiquity, “the social stigma that was formerly attached to genetic diseases of all types can be seen to be a reflection of ignorance.” Thus, the “real value of counseling lies in the psychological benefits that the family can derive from a clear understanding of the cause and of the prognosis of the disease and educational benefits the patient may obtain because of early diagnosis.” Much more than merely a science of prevention, genetics was to be a gateway science, opening a path for a more aware – and thus more self-determined – life.

Other professionals, too, picked up the paradigm of psychotherapeutic benefits and informed decision-making, although definitions of these concepts were far from uniform. Prevention, explained University of Texas obstetrician-gynecologist M. J. E. Harrod at the 1977 Dallas conference, “is one important goal of counseling, but more important by far are the goals of understanding and responsible decision making that counseling can promote.” Harrod, too, emphasized the psychological elements of genetic counseling and awareness. “The realization that their consanguinity is responsible for the genetic disorder,”
he elaborated, “can have a serious psychological impact on some couples, particularly if there was familial disapproval of their marriage.” In any case, the “medical and personal implications of the diagnosis are so overwhelming that the family cannot be expected to fully comprehend even the clinical information they receive at this point.” Consequently, it was necessary to give the family a “period of acceptance and adjustment to the situation before they will be ready to deal with the genetic aspects of the condition.” Giving too much information too soon, on the other hand, would likely result in “a counseling failure” – an uninformed reproductive decision.593

Harrod’s summary highlighted one of the dilemmas of non-directive counseling: it required the counselor to give up his own position and goals. Although he believed that there were “no 'wrong' decisions in this view of genetic counseling as long as they are truly informed decisions,” he maintained that given a person's eventual blindness usually “parenthood is out of the question for that individual, regardless of his or her own feelings about the issue.” Deaf-blind people, in other words, did not make for good, responsible parents. Their autonomy was only granted within the limits of coming to the appropriate reproductive decision. Among carrier couples, too, Harrod continued, “many parents will choose to limit their families” or choose “pregnancy through donor insemination.”594

Clearly, genetic awareness, counseling, and decision-making could be envisioned in different ways. Ironically, it was a geneticist – Nance – who tempered Vernon’s vision of all-encompassing prevention and instead

594 Ibid.
emphasized the emotional and personal benefits of genetic knowledge. Others, such as Harold were caught between the desire to acknowledge the principles of non-directiveness and patient autonomy on the one hand, and their own conceptions about the “right outcome” on the other. These examples point to gaps in our understanding of how different profession took up new paradigms in family and genetic counseling. Historians have mainly focused on geneticists and genetic counselors themselves and have given adjacent professions such as obstetricians-gynecologists or, indeed, psychologists relatively little attention. Yet as the example in this and the previous chapter have shown, psychologists and psychological thought had a profound impact in redefining genetic conditions. This tendency toward emphasizing the emotional-psychosocial dimension of genetics provided both opportunities for more patient-centered narratives, and for assertions of scientific authority from disciplines formerly only marginally involved in genetic discourse.

**Expert discourse: The psychosocial dimensions of Usher Syndrome**

Because deaf-blindness is relatively rare, its effects on psyche, education, social life or work had seen relatively little attention until the middle of the century. By the 1970s, with the aftermath of the rubella epidemic and increasing awareness of Usher Syndrome, psychologists, educators and rehabilitation workers – mostly hearing-sighted, sometimes deaf – tried to apply theories of normal and abnormal development to deaf-blindness. This discourse was determined less by the actual lived experiences of deaf-blind people than by common stereotypes and narratives that structured perceptions of deafness and blindness. The common assumption from a hearing-sighted perspective was that
a condition so unimaginable and incomprehensible as deaf-blindness must entail grave psychopathological defects. Thus, when Vernon presented an overview of Usher Syndrome at the 1976 Rochester seminar, one of the panelists, the child psychologist Dr. Kily asked him to address the “anxiety that this syndromes produces in all of us.” Kily's “all of us” is telling here. The “we” referred to a panel of professionals – audiologists, psychologists, educators – and one deaf parent, theorizing about the effects of deaf-blindness in order to categorize and tame it, rather than affected individuals providing an inside perspective.595

Sensory deprivation research provided a framework for understanding the effects of combined vision and hearing loss. Such experiments deprived individuals from sensory input for a certain period of time, yet it remained unclear whether abrupt and temporary deprivation in sighted, hearing persons under laboratory conditions really was comparable to congenital hearing loss and progressive vision loss in everyday life. These experiments, Kily pointed out, were known to cause psychiatric disturbance – should one expect that those with Usher Syndrome would experience them, too? Vernon replied by pointing to the early studies of Usher Syndrome – among them his own – in which a significant number of patients had been diagnosed as “psychotic and retarded.” Yet he was no longer certain what these results meant. “Were these cases of misdiagnosis? Were these reaction to the trauma of being deaf-blind?” Or, his brain syndrome hypothesis reappeared, were “they part of the same neuro-physiological lesion or problem that caused the deafness or blindness”?596

In the young field of the psychology and psychiatry of deaf-blindness, the NYSPI could claim a relatively long history. Working with deaf psychiatric patients, staff had encountered several individuals with Usher Syndrome. Kenneth Altshuler, in particular, had focused on deafness and psychopathology and continued to do so after he left the NYSPI in 1977 to become chairman of the Department of Psychiatry at the University of Texas Southwestern Medical Center at Dallas.\(^{597}\)

At the Dallas meeting, Altshuler deployed this experience to delineate the psychology of deaf-blindness. Although he understood it as a cumulative condition, deafness clearly provided the framework for understanding the behavior of deaf-blind people. Altshuler approached deaf-blindness as a deviation from the norm with grave consequences for normal development, especially in the “undeveloped, immature organism.” If both deafness and blindness were “present from early on, an enormous range of general experience is excluded, experience on which is based the development of mature relationships, a full sense of self in regard to the world, and experience which are the nutrient for the structure of logic thinking and knowledge to grow.” Consequently, even in the best case, deaf-blind people tended to be “generally naïve, somewhat immature [...] not depressed, and seem reasonably comfortable in sheltered environments doing limited, but productive tasks.”

people thus displayed a more extreme form of the characteristics that Altshuler and others considered typical in deaf people. Immaturity, naiveté, and impulsivity in particular were among the traits that educators and psychologists had identified as being caused by the deprivation of deafness.598

The deaf-blind were thus cast as a population with only limited potential, a judgment certainly based on Altshuler’s experience with mostly psychiatric patients – or at least with deaf-blind individuals institutionalized at mental hospitals because educational or rehabilitative facilities were unavailable. Unlike the deaf, to whom he conceded considerable adaptive abilities for living a life of relative normalcy, based on his experiences with the New York State deaf community, his encounters with deaf-blind people produced much lower expectations. That they were capable of having an independent, self-determined life clearly was difficult for him to imagine. He believed them to have the potential for “some modicum of those features which make up our uniquely human kind of adaption.” In this endeavor, the deaf-blind person depended on professional psychological support.599

An important mechanism for achieving these goals was professional support, not only for the deaf-blind individual, but also for the entire family. His profession, Altshuler asserted, could “help deaf-blind people to have pleasurable human relationships, a sense of relative independence, and realistic economic productivity.” Parents, too, Altshuler cautioned, must realize that the “deaf and blind child is not the same as the normal child.” Without professional help, this


599Altshuler, Deaf-blindness, 375-376.
frustrating and anxiety-inducing realization might cause lasting damage in the parent-child relationship. Other professionals, too, focused their attention upon the emotional coping process of the entire family. For example Carolyn Torrie, a consultant in social services and planning, at the South Central Regional Center for Services to Deaf-Blind Children at the University of Texas Callier Center for Communication Disorders reported on a case study of ten families with children who had Usher Syndrome. They had been invited by the South Central Regional Center for a day-long workshop to help identify their needs.\(^{600}\)

These parents' input pointed to the need for specific services to help address their “pain and confusion.” For Torrie, too, professional literature on deafness offered a framework for understanding the situations of families with Usher Syndrome. Initially, when these parents had learned that their child was deaf, they had been devastated and confused, but eventually found some kind of equilibrium. Now, the knowledge that their son or daughter would also lose their vision rekindled these “old feelings of grief, pain and anger.” This situation added “a new dimension of crisis proportions,” in which “usual coping methods may not suffice and new ways of adjusting may be needed.” Here, counselors trained in social work and family dynamics could help “enable them to learn that all is not hopeless for their children, that their lives do not have to develop into emptiness.”\(^{601}\) For deaf-blind children and adolescents themselves, Torrie recommended group counseling programs where students could “share their anxieties, despair, anger and concerns” and “learn to take strength from the mutuality of their concerns for each other.” The ability to cope with the emotions


\(^{601}\) Ibid., 382.
triggered by the diagnosis, she emphasized, had implications on family planning as well. Unless the affected teenager and his parents “can handle these stages of adjustment, they will not take on the burden of accepting Usher’s Syndrome as an inherited disorder, with the implication of this in questions such as producing more victims.”

Such language portrayed the syndrome as unrelenting aggressor, yet also suggested that one could and should prepare against it – given the lack of treatment foremost on the level of awareness. From such a psychosocial angle, Usher Syndrome posed a range of emotional challenges for the affected person and his family. It was framed as a familial, interconnected and intergenerational condition that required the acceptance of loss and limitations from the entire family. If the affected person and their family failed at this task, they not only endangered their own future, but also that of the unborn. The inability to cope swiftly enough to be receptive to genetic counseling when it mattered, Torrie and Harold warned, might result in more “victims,” harmed not only on the sensory, but also on the psycho-emotional level.

By the mid 1970s then, Usher Syndrome was still a matter or risk. Yet the conceptualization of this risk had moved from the body to the psyche, and from the single, isolated or institutionalized person to the family unit. Its physical determinants had been staked out; it had also become clear that not much could be done to change their course. What was primarily at risk now was the psychological integrity of the affected individual, and, by extension, his or her family. This shared at-risk status was founded as much on the emotional impact of having a family member who would become deaf-blind as on the actual

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602 Ibid., 385, 387-388.
genetic connection between family members – or a lack thereof in some family constellations. What before the diagnosis had been a normal family unit, now was one that needed constant professional and self-surveillance for signs of emotional disturbance, deviance and mal-development.

In her analysis of breast cancer activism, Maren Klawiter has used the notion of disease regimes to understand such shifts in the conceptualization of a condition between professionals and “risky subjects.” For breast cancer, this relationship depended on a shift in perceiving (potential) patients. What in the first half of the century had been a temporary (and ideally invisible) sick role for women who actually had breast cancer and, ideally, recovered, by the 1970s became a condition that potentially affected all women. Urging healthy and asymptomatic women to be constantly aware of the risk to develop breast cancer, and thus to assume a permanent risk role, Klawiter writes, “transformed the disease from an either-or condition to a breast cancer continuum.”

Usher Syndrome was limited to a much smaller at-risk group within the genetically deaf population. Yet once diagnosed, patients and their families now, too, had moved onto a continuum of psychological risk that required permanent action and surveillance and ordered life in a pattern of adaption and coping that could, but did not necessarily, map upon the progress of vision loss, or, indeed, of genetic risk. This psychologized mode of thinking about risk and Usher Syndrome would shape discourse in the 1980s. Before showing how this shift to the psychosocial affected debates about screening and diagnosis, services and coping, I will trace the emerging identities and narratives of people with Usher

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603 Klawiter, Breast cancer, 38, 290.
Syndrome and show how they shared, influenced and diverged from established ways of talking about their condition.

**Negotiating (dis)ability: Deaf-blind people between professional and activist cultures**

Historians and activists have claimed that for the most part the disability and Deaf movements have gone separate ways. Katherine Jankowski, for example, argues that since the deaf have a language and culture binding them together they are more oppressed socio-linguistic community than part of the disabled community. The latter, she writes, consists of “hearing people who have more in common with the general populace than they do with Deaf people.”

Such a depiction addresses important points in the self-perception and portrayal of each group. Yet relying on singular and exclusive identities obstructs the reality of life situations in which different claims and spheres overlap or conflict, e.g., in the lives of African American or multiply disabled deaf people.

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Syndrome is a case in point. Here, disability, patient and deaf identities interacted on multiple levels as people with Usher syndrome negotiated their sense of belonging, difference and (dis)ability.

In their rejection of stifling definitions of defect, patient and disability movements have often been cast as inherently anti-medical and anti-professional, and thus, as propelled solely from within. Some movements indeed took such a radical turn, e.g. some militant branches of the anti-psychiatric survivor movement that also formed during the 1970s. However, as Klawiter has pointed out, social movements need not necessarily be contentious. Nor do they necessarily stand apart from or in opposition to professional spheres. Instead, she argues, social movements can be conceptualized as cultures of action that employ different social resources and cultural motives, and are not mutually exclusive in their membership and identities. When, for example, activists and professionals pushed for expanding breast cancer screening, they engaged in a “consensus” culture of action that put its hopes on the progress of science and medicine. Activists did not see themselves as fighting against professionals, but as allies who together fought sociocultural and financial barriers to screening.

Going beyond a simple dichotomy of oppressive science and liberating activism, cultures of action offer a useful model for understanding Usher

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Syndrome activism. By the mid 1970s, increasingly self-confident patient-activists began inserting their perspectives into what before had been mostly an abstract conversation among hearing-sighted and sometimes deaf professionals. These activists drew from different sources of inspiration and identification, in particular Deaf, disability and patient activism, but also the growing literature on Usher Syndrome and deaf-blindness that they in turn influenced. Patient-activists called upon classical elements of disability and Deaf activism – assertion of autonomy, calls for better services and equal opportunity, battling discrimination and bias. Their assertions of self-worth and ability often stood in stark contrast with the perspectives of non-affected professionals who tended to focus on the restricting and disabling effects of deaf-blindness. All in all, however, activists saw in professionals their allies for improving their social, professional and medical situation.

Many people with Usher Syndrome had grown up in the Deaf community. They had visited schools for the deaf and after graduation continued to socialize in Deaf clubs, associations or churches. As they were diagnosed with Usher Syndrome, they feared potential exclusion from a highly visual culture and a community that considered blindness one of the worst disabilities. Changing these preconceptions became an important point in their agenda. At the same time, their experience of community enabled them to develop a deaf-blind identity and community that sought the connection to Deaf culture. Visual signing, for example, could be adapted to tactile signing, allowing continued communication with deaf friends, family and coworkers.

Although the deaf-blind certainly faced discrimination within the deaf community, deaf professionals also were sensitized by their own experiences to
the social biases and paternalism both the deaf and the deaf-blind still faced. For example Albert Pimentel, director of Gallaudet's public service programs commented at the Helen Keller Center in 1976 that being deaf himself he was aware of the limits society put upon deaf-blind people. Pimentel's insight was fed not only by his personal experiences, but also by his activism. He had long lobbied for the rights of deaf people, for example in the NAD and as the first executive director of the National Registry of Interpreters for the Deaf, founded in 1964. For too long, he commented, education and rehabilitation had been dominated by hearing professionals. Only “as some of our well-meaning friends retired or finally developed more awareness of currents trends,” had deaf people themselves found the chance to influence education and rehabilitation services. In this situation, they had found inspiration and orientation in the activism of other underrepresented and discriminated minorities. As “the Civil Rights Movement for other minorities emboldened some of us to explore the 'can't do' areas,” he continued, “the disability of deafness suddenly became a more manageable handicap for many deaf people.” 609

Deaf-blind people now were in a similar position of lingering paternalism, he believed, adding that he “would like to see people with Usher's Syndrome spared this frustrating process.” Unlike hearing-sighted professionals who usually focused on the as-of-yet unknown deficits caused by deaf-blindness, Pimentel instead emphasized ability and self-determination. It was wrong to exclude deaf-blind people from any educational or professional opportunity.

“With our limited knowledge,” he observed, “it's better at this point to let those with ambition who live with Usher's Syndrome point the way.”

The accounts of deaf-blind people in this period also engaged in deeply rooted cultural narratives about disability and disease, selfhood and identity that offered sense and consolation in a personally overwhelming and socially estranging situation. Simultaneously, these narratives made their situation comprehensible to the non-affected. This discourse drew from a growing literature on the psychosocial effects on disability which in itself recycled cultural ideals of resistance and triumph over adversity, of disease and disability as as part of a larger, more general turn to self-help, self-finding and self-acceptance. This narrative provided an important area of overlap between patients and professionals who increasingly focused on the psychosocial dimensions of Usher Syndrome. Although activists and professionals did not necessarily utilize these motives in the same manner, they offered a common ground for defining Usher Syndrome as a matter of emotions and of psychosocial adaptation. This psychologization of Usher Syndrome in turn created new opportunities for professional assertions of expertise – but also for more positive depictions of autonomy and fulfillment.

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610 Ibid., 51-52.
Living with Usher Syndrome: stories of self-discovery and self-realization

To trace these developments, I focus on Arthur Roehrig, the main protagonist of Vernon's documentary, and Linda Annala (1948-2007), a teacher who like Roehrig belonged to the first generation of Usher Syndrome patient-activists. Both frequently spoke at conferences and later became leaders in diverse deaf-blind organizations. Roehrig, in particular, has become a public spokesperson for deaf-blind people, traveling across the country for presentations, workshops and interviews. He worked as a counselor and coordinator for the deaf-blind at the Gallaudet Public Service Program and later served as the long-term president of the American Association of the Deaf-Blind (AADB), an organization that had been founded in 1937 as a correspondence club. In 1975, a first in-person meeting in Cleveland, OH brought together 25 deaf-blind individuals and established a tradition of annual or bi-annual meetings. Annala was active in the Louisiana deaf-blind community. Their narratives share a pattern of disturbance and confusion caused by deteriorating vision, followed by discovery and diagnosis which then initiated the long process of coping, overcoming and finding one's true self as well as a new group identity.612

612 For newspaper coverage about Roehrig's activities see e.g. Crowley, Carolyn. Giving Eyes and Ears to Those in Need; Deaf-Blind. Worker At Gallaudet Plans For Data Network. The Washington Post, January 22 1982; Getto, Dennis R. Doubly disabled, he speaks out for others. The Milwaukee Journal, Thursday August 2 1984:8. For Annala see e.g. Vernon, McCay. “Tribute to Linda Annala.” The Deaf bayou e-news. http://www.deafbayou.com/content/view/917/70/ For the history of the AADB see the scant information on their website and annual reports at http://www.aadb.org/. For the memoirs of people deafblind from other causes see e.g. the life writings of Robert Smithdas, the first deaf-blind person in the US who received a Master’s degree: Smithdas, Robert J. 1980. “Reflections of a Deaf-Blind Adult.” American Annals of the Deaf, 125 (8): 1015-1017; Smithdas, Robert J. 1958. Life at my fingertips. Garden City, N.Y.: Doubleday. For a
At the 1976 HKC workshop, for example, Annala gave an account of how she “came to grips with having Usher’s.” She could not remember specifically when her vision began deteriorating. As a teenager she noted that she was the only one among her friends who could not follow signed conversations in dark places such as cars or movies. She found such situations “frustrating and difficult” and “would either look away or concentrate on the movie.” Some years later, her friends picked up on her vision problems before Annala herself did. They suspected that she had tunnel vision, a suspicion she “promptly denied […] because I could see sideways.” In hindsight, she identified several other such missed moments. Here, her own desire to ignore her vision problems and professional ignorance played together. For example, when she began having vision disturbances in her senior year of high school, an ophthalmologist dismissed her as having “nerves.” It “was nerves, all right,” she commented drily, “but not the kind the doctor meant.”

Annala graduated from Gallaudet with a BA, received a Master in Deaf Education from Western Maryland College, and began working as a teacher at the Illinois School for the Deaf in Jacksonville. Although she dealt with her vision problems, her friends remained concerned. In 1973, two of them, a couple, read an article on Usher Syndrome in Gallaudet Today, the school’s alumni newsletter – probably by Vernon. Recognizing the symptoms in Annala, they addressed the topic and asked her to see an eye specialist. Acceding to their concerns, she “tried a simple experiment. I wiggled my middle finger on each hand from the side of my head to the front of my face.” She was surprised to find she could not see her

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hands from some angles. In this moment of self-diagnosis, she “realized that this was the 'tunnel vision' my friends were trying to tell me about.”

Her self-diagnosis, however, was not confirmed by the ophthalmologist she saw soon after this incident. He checked her distance vision, yet did not conduct a vision field test. He thus missed her impaired side vision and concluded that Annala's eyes were fine. This verdict was a temporary reprieve. While her friends were “visibly upset,” she continued her work and life as usual, until, one month later, she had a car accident caused by her narrowed visual field. This event “caused general concern on the part of my friends and colleagues.” She dismissed these concerns, yet doubts about her vision remained. Then, in early 1974, Annala went through a spiritual conversion during which she “asked the Lord to either heal my vision or give me the name of the abnormality and to guide me.” She received an answer that was as clear as it was unwanted: another car accident.

Shortly after, Annala herself came across an article on Usher Syndrome – again probably by Vernon – in the Deaf American, the official NAD publication. Facing a written description of her symptoms finally provided enough points of identification. After a conversation with her friends, “the concerned couple,” she decided to give up driving and “to face the future with this eye condition known as 'Usher's Syndrome'.” Self-diagnosis and acceptance thus preceded the official, medical diagnosis, which she received a bit later from a Jacksonville eye specialist “who was kind enough to break it to me gently.” It is noteworthy here that the process of naming her condition came from reading publications that

614 Ibid., 19-20.
615 Ibid., 20.
had large deaf readerships. Vernon's campaign apparently had the some of effect he had aimed for. The final confirmation and additional information came from a New York expert on retinitis pigmentosa, who believed that Annala's vision loss would progress slowly. She “rejoiced in this news since it gave me hope for many more years to learn about this disease and how to live with it; also, to champion the cause for others, making the future bright for those who suffer from Usher's Syndrome.”616

Roehrig’s path to diagnosis was very similar, although his narrative referred more explicitly to the language of psychology and counseling. At the 1973 Gallaudet Symposium, he described what he called the “three levels of awareness of deteriorating vision in the victim of Usher's syndrome,” from the unconscious to the semi-conscious and finally to diagnosis. Like Annala, he had noticed early that his night vision was worse than that of the other students at the St. John’s School for the Deaf in Milwaukee. This occasionally proved to be cumbersome, yet it caused him no real difficulty. (With some amusement, he recalled an incident when, on a gloomy winter afternoon, he accidentally drove his sled into his teacher – a nun – because he had not seen her dark clothes in the twilight.) Roehrig accepted this difference “easily” since he “had been allowed to continue to do many things that normally sighted people do.”617 He graduated and became a teacher at the Maryland School for the Deaf where in 1971, during his second year of teaching, he noticed that his vision had deteriorated to the point where he had trouble understanding his students. He had entered, in his own words, a state of being “semi-consciously aware of my visual impairment.”

616 Ibid.
He became “depressed and worried” and stopped teaching to see several ophthalmologists.618

In 1972, Roehrig became an in-patient at the NIH for more thorough examinations and counseling. Talking to a social worker about necessary adjustments to his vision loss (e. g. learning Braille), he “became consciously and hopelessly aware of what would happen to my eyes in the next few years – I mean blindness.” He was “naturally depressed and cried all night because I knew I would be blind some day.” In hindsight, however, he could state that this realization was “not as traumatic as some people might think.” Here, his perspective countered the conventional narrative that saw diagnosis as a tragic and hopeless endpoint. Instead, Roehrig considered it a stage that could be overcome with human resilience.619

In doing so, he couched his experiences in explicitly psychological language. This certainly was informed by his professional background as a teacher and counselor. Both as a patient and a professional, Roehrig had clearly familiarized himself with the fields of rehabilitation counseling and the psychology of disability. When he gave an account of his own process of coping with Usher Syndrome, he drew from this literature that in itself was based on larger cultural motives of overcoming obstacles through self-realization of the capable, self-directed individual. On the psychological level, Roehrig commented, being “honest with myself and totally aware of who I am and what I have has helped me develop my self concept.” Having Usher Syndrome, he came to realize “was neither my fault nor my parents’.” It was something he was born with, and

618 Ibid., 34-35.
619 Ibid., 32, 36.
eventually nothing more or less than the “individual differences among all people.”

Casting deaf-blindness as an individual variation depathologized it and turned desperation from the most defining effect of Usher Syndrome into a stage toward development and growth not all that different from challenges through which other people lived. This was the topic of Roehrig’s presentation at the 1976 HKC workshop. Couching his experiences in the psychological language of self-acceptance and self-help, he emphasized that a “person needs to understand him/herself and Usher’s Syndrome both intellectually and emotionally” before he or she could come to terms with the situation. Appealing to self-realization and fulfillment, he skillfully employed universal motives that were not limited to deaf-blindness, but with which his audience, no matter their sensory status, could identify. In turn, this allowed him to reclaim the autonomy for a more positive portrayal of life with Usher Syndrome.

Margaret Lock and Vinh-Kim Nguyen have characterized such a discourse about self and selfhood as an essential part of biomedicine and bio-citizenship. Patient movements, they write, embraced techniques of public and private self-examination and presentation as a form of self-help and empowerment. In doing so, they enabled new forms of identity and sociality around a shared condition. Resting on the assumption that the reflection about and the sharing of one’s inner reality is cathartic, such practices form a specific form of disease management. When they are formalized in support groups, such “confessional technologies” link “the clinic to many sites where the self is elicited through talk

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620 Ibid., 36-37.
and can indeed produce biological transformation – blurring the boundaries between the psychological and the biological self in practice.”

In Usher Syndrome, such techniques of self-inspection would come to play an ever-greater role, providing common ground for professionals, patients and their families. Yet how one envisioned the physiological, psychosocial and emotional dimensions of deaf-blindness varied greatly. Genetics, for example, was not only pathologizing, but also deployed to offer a more humanizing and normalized vision of Usher syndrome, one that emphasized alikeness rather than difference. “Every human being,” Roehrig pointed out at the Helen Keller Center in 1976 “has 2 to 7 defective genes.”

Here Roehrig picked up on geneticist Hermann J. Muller’s “load of mutations,” first described in his 1949 Presidential Lecture before the American Society of Human Genetics. At this time, Muller tapped into concerns over unaffected carriers of recessive traits and over nuclear fallout, providing a distinctly alarmist and negative perspective. He had estimated that the average person had eight mutated genes, yet feared that with nuclear fallout from atomic bomb testing and civilian use this rate might rise to yet-unknown rates. This point made genetics a pressing concern of public health that affected everyone and was everyone’s responsibility. Yet there was also a normalizing and destigmatizing element in this narrative. In genetic counseling, reference to the ubiquity of defective genes often served as a soothing message, reassuring parents that their own or their child’s condition was not their fault. It was part of

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623 Roehrig, Living, 25.
the repertoire of genetics as affirmative psychotherapy that Kallmann or Walter Nance had pushed.624

When Roehrig talked about fear, blame and responsibility, he drew from this tradition, yet used it in his own way to redefine defect and disability. He did not note where he had come across the concept and somewhat arbitrary number of 2 to 7 defective genes. It may have been in conversation with various professionals. He also clearly had read up on his condition and – as a counselor at Gallaudet – likely had come across a 1975 publication on heredity and deafness that explicitly addressed a deaf audience. This short booklet, prepared by Walter Nance for the Gallaudet Public Service division, was “written to help you understand your heredity.” It presented basic information about genetic concepts such as traits and gene, patterns of inheritance and questions specific to deafness. Most importantly, the booklet presented heredity as the source of human uniqueness and singularity, a theme that Roehrig picked up in his depiction of Usher Syndrome as human variance. Nance also promoted genetic knowledge as an important means of self-knowledge, of gaining “a deeper understanding of ourselves.” “Knowing how traits – any traits – are inherited,” he believed, “is a step forward in understanding ourselves.”625


Sometimes, however, genetic conditions “involve traits that may complicate a person's life or endanger his health.” The booklet noted that “each of us carries between four to ten genes that could cause genetic problems.” Thus, “each of us shares the burden for potential genetic illnesses in the world.” Such genes could cause medical or financial complications. Moreover, Nance noted that “[e]motional adjustments to the condition must be made by the individual and his family if he is to live an independent life.” Yet, he emphasized, there was “nothing wrong with inheriting a genetic condition,” no need to “feel ashamed.” Rather than stumbling unprepared into such a situation, it was useful to acquire a general awareness of the workings of heredity. The important thing here was to “be honest and realistic in coping with the problems a genetic condition may cause.”

By the mid-1970s, then, geneticists had begun to communicate with their audiences in a manner that made genetics seem as much a matter of emotional adaptation than of medical intervention, of finding one's place on a spectrum of human variation rather than of restricting this variation. Yet genetic education turned out to be a two-sided sword once genetic “objects” entered their own perspectives. Such appropriations were not necessarily what geneticists had imagined. What it meant to be honest or realistic in the face of a genetic condition could mean very different things. Instead of Vernon’s urgent language of preventing wasted existences, Roehrig seized genetic awareness as a means of normalizing and humanizing his condition. Defective genes were a communality shared with all of mankind, their expression merely a matter of chance and not a devaluation of the affected person.

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626 Nance, Heredity, 26.
Reasserting independence: discrimination, activism and identity

For both Annala and Roehrig, diagnosis brought with it the realization of being part of a larger group of similarly affected people. What before had been dismissed as personal oddities, inattention or clumsiness, not only was “not their fault,” it was something they shared with others: an imagined, and, increasingly, face-to-face community. Sensitized by their own path to diagnosis, Annala and Roehrig sought out and identified others who showed the same traits. At Gallaudet, Vernon commented in 1974, “it is not the medical, audiological, or other professional staff who have diagnosed the most cases. It is a student, Mr. Art Roehrig.” Roehrig, he explained, had no medical equipment, “yet as a person who has the disease, he cares” and knew how to recognize the signs of diminishing vision in the people around him. For Vernon, this was yet another sign of professional neglect and lack of resources, an example that was to spur into action physicians and teachers. For Roehrig, however, these became moments of recognition, identity and community. 627

The realization of communality extended into the past. Roehrig for example recalled his mixed feelings of discomfort and sympathy when, as a thirteen year-old, he had first met a deaf-blind person. Unable to care for herself, this elderly woman received nothing but basic care from her family and struck Roehrig’s younger self as being “very lonely and isolated.” Now, as he was becoming deaf-blind himself, he remembered this encounter and went through the estranging experience of finding himself in the position of the other who had previously upset him. He “thought back to that old lady and decided that I would never let myself get into the same situation.” Similarity ended with Roehrig’s

declaration of independence as an act of distancing himself from a frightening past and future.⁶²⁸

Advocating and being able to offer advice and support to others with Usher Syndrome gave Roehrig and Annala a sense of purpose. Right after diagnosis, Annala recounted, her future had “looked dark and dismal.” She decided that “my future would be brighter, if I would champion the cause and improve conditions of people like myself who were deaf and gradually losing their sight.” In offering her support, she hoped to spare others her own, isolated experience of despair. Her experiences of exchanging her feelings and experiences encouraged her to “help make the future more promising for the young people who are now in high school, vocational training programs or in colleges.”⁶²⁹

Annala and Roehrig emerged as spokespersons for those living with Usher Syndrome. At meetings and conferences, they reported on their own situation and that of others, pointing to private difficulties and professional restrictions. Where professionals portrayed low achievement, isolation and restrictions as the natural corollaries of deaf-blindness, they pointed to social determinants, such as the “lack of interest and awareness on the needs of deaf-blind people by the general population.” This disinterest, Roehrig pointed our, “exacerbates the problem of social and personal interaction.” Attitudes toward deaf-blindness, he stated in 1976 with some resignation, were “generally very negative and difficult to change.”⁶³⁰

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⁶²⁸ Roehrig, Living, 23.
⁶²⁹ Annala, Usher Syndrome, 19, 20, 22.
⁶³⁰ Roehrig, Living, 23, 25.
Similarly, Annala felt restricted by negative attitudes. In particular, she felt the bias of her immediate daily surroundings: other deaf people. Among the biggest obstacles she hoped to overcome was the “the aversion on the part of others, particularly deaf people who use sign language, to communicate with the deaf-blind person.” Here, too, she clearly saw herself as a mediator between the larger deaf community, to which she had belonged for all her life, and the newer, smaller, as yet undefined community of the deaf-blind. “As a person who has this disease and as a teacher for the deaf,” she explained to the audience at the Helen Keller Center, “I want to continue to champion the cause, breaking down the barriers of ignorance and fear on the part of the deaf population.” In this narrative, social bias and discrimination rather than sensory restrictions were the most feared and disabling aspects of Usher Syndrome.

Advocacy meant overcoming personal fears and admitting weaknesses for the sake of oneself and others – once more, general goals of self-realization rather than themes specific to patient or disability activism. In 1976, Annala reported that only recently had she been “able to open up and share with my friends in Jacksonville what it really is like to have Usher’s and my number one fear of being left in isolation when I am no longer able to see as well as I can now.” Her personal commitment was rewarded with a strengthened sense of achievement and community. “I was pleased,” she concluded, “to have achieved an awareness of Usher’s Syndrome, on a small scale” on this occasion. And she continued: “I would like to see this done on a larger scale by educating the

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631 Annala, Usher Syndrome, 21, 22.
majority of the deaf population about the needs of people with Usher's Syndrome.” 632

Life with Usher Syndrome, so the message went, was manageable and worthwhile if one was willing to adapt and had good support systems. Self-determination was a key concept for Roehrig. Here, he clearly borrowed from the independent living movement that was one of the driving forces of disability activism in this period. Disability activists rejected being judged by rehabilitation specialists’ ideas of normed functionality, the notion that a person with impairment X should, or should not to be able to do Y in a certain manner, e.g. walk with crutches rather than use a wheelchair. Rather, they called for a definition of independence that was of their own design and reflective of their specific preferences and circumstances. An important part of this endeavor was to form a positive self-image in the face of deviating from social norms of independence and capability. 633

Roehrig’s advocacy was a variation of this program. His list of steps toward more self-determination serves as a poignant reminder of the very limited autonomy deaf-blind people had over the very basic circumstances of their lives. They were, he admonished, to be included in planning services, and should be allowed “to live where they want to live.” The ability to be assertive of one’s needs was inextricably tied to the personal goal of self-acceptance and 632 Annala, Usher Syndrome, 22.

personal growth. “I would like you to remember,” he addressed his audience “that I am not responsible for having Usher's Syndrome, but I am responsible for learning to live with the condition. Therefore, it is important for me, like all other human beings, to continue learning through life.”

His words are as much as assertion of self-worth as they are a reminder of deaf-blind people's basic human rights. "I really feel that every victim of Usher's syndrome is an important person, and special plans must be made for him," he appealed to his audience at the 1973 Gallaudet meeting. Similarly, he urged at the 1976 Helen Keller Center meeting: “every person with Usher's Syndrome wants to be respected primarily as a human being and to be treated like others.”

Although he cast the needs of deaf-blind people in the language of rights, Roehrig advanced a framework that was much more about interpersonal relationships and personal fulfillment than about abstract legislation. “As long as a person is alive,” he wrote, “he has a right to be known, understood and loved.” He or she must receive “every opportunity to experience and understand everything he is able to see, hear, touch, smell, and taste” as long as possible. Although with a wistful undertone, this read very much like an affirmation of life, and of the right to participate in it like any other person.

Negotiating their place in society and in the Deaf community meant reframing the meaning of defect and disability, normalcy and variation. Having grown up deaf, Roehrig did not consider deafness a disability. “Congenital deafness,” he generalized about those with Usher Syndrome, “is accepted easily because the sense of hearing is never experienced.” The prospect of blindness

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634 Roehrig, Living, 24, 27.  
635 Roehrig, Discovery, 39; Roehrig, Living, 26.  
636 Roehrig, Discovery, 37.
could be “traumatic” at first, yet it, too, was “usually accepted, although more slowly.”

Here, he believed, it helped to recall that deaf-blindness was not unique. “[E]very human being can, at any time, become doubly or multiply handicapped.” From this perspective, full hearing and sight was only a temporary state; its disruption a challenge that could be overcome like other life occurrences. Emphasizing the essential humanity of deaf-blind people, Roehrig advised others that they could “function as a normal person in most ways despite his double handicap,” and had “every right to live as much of a normal life as possible.”

Significantly, normal here denoted not as much an aspiration to or affirmation of senso-physical normalcy as the right to participate in the normal life of the average American, of having a job, family, a house.

Beyond the interpersonal level, employment was the second important area of bias and prejudice. It was not a lack of capability that made it difficult for deaf-blind people to find employment, Roehrig emphasized, but discrimination and inflexibility on the side of employers. Here, he drew from the broader demands of the disability movement for accommodation and equal access. “The basic problems with respect to employment,” he pointed out, “is that jobs and buildings have been purposefully or inadvertently planned for people who can see, hear, and are highly mobile.” With 36 million people with disabilities in the US, however, such conditions were not acceptable. Identifying with “people who cannot see, hear, and / or walk,” Roehrig turned the situation of people with Usher Syndrome into a more broadly appealing matter of disability rights.

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637 Ibid., 32.
638 Roehrig, Living, 24-25.
639 Ibid., 25
Roehrig was in college at just the moment when student protests invigorated numerous social movements, including disability rights. In the late 1960s, Lindsay Patterson writes, a number of physically disabled students – many affected by polio – entered college campuses against considerable pushback from educators and administrators. Forming their own sports teams and advocacy organizations, these activists turned their college years into the formative period of a growing network that they sustained and expanded after moving into professional life. Once out of college, young disabled professionals again encountered discrimination. They took their experiences in battling college administrators to the larger political scene and staged well-publicized protests.\footnote{Patterson, Lindsey. 2012. “Points of Access: Rehabilitation Centers, Summer Camps, and Student Life in the Making of Disability Activism, 1960–1973.” \textit{Journal of Social History} 46 (2): 473-499, here 472-3.}

The years 1972 to 1973 saw one of the biggest successes of the early disability movement. For almost a year, members of the group Disabled in Action protested against president Nixon who had vetoed against the inclusion of disabled people in the new Rehabilitation Act. With their wheelchairs, Disabled in Action members blocked traffic on Madison Avenue in New York; an action that proved highly effective because police cars were not equipped to handle wheelchairs. The group staged similar actions in Washington, DC, Berkeley, and Boston. In 1973, President Nixon finally signed the Rehabilitation Act including a new Section 504 that, for the first time, prohibited discrimination on the basis of disability in federally funded programs. The sense of victory was short-lived.
Enforcement of Section 504 was so weak that in 1977 disability activists once more engaged in protests.\footnote{Ibid., 472-3, 487.}

In the 1970s, then, individuals with Usher Syndrome came to find a common identity and a sense of belonging. Their coming together was the consequence of expanding screening and diagnosis, and of improved access to rehabilitation and education. They found themselves with a diagnosis that offered an explanation for their difficulties, yet also strongly pathologized their condition as lives that had better not happened. Against this, they put forward a portrayal of Usher Syndrome that emphasized ability and human variation instead of defect and dependency. Certainly, such a depiction of the life with Usher Syndrome as worth living did not impress or convert all professionals they encountered. Nevertheless, their self-assertions fell into a time in which disability and patient activism had shaped among professionals an awareness of the importance of including patient perspectives.

Professionals and deaf-blind people found a common language in portraying Usher Syndrome as a psycho-emotional condition. Here both sides pointed to the harmful effects of social bias, exclusion and discrimination, and to the need to improve the deaf-blinds' social, educational and professional situation. The framework of self-help and self-realization conceded agency to the object, yet also expertise to the professional, and thus was well-suited for a consensus culture of action. Yet patients and professionals did not necessarily use these concepts in the same manner. Whereas Roehrig and Annala described their lives with Usher Syndrome as a path to self-finding and self-acceptance, in a manner that emphasized both their inner strength and ordinary humanness,
professionals emphasized the risk of emotional damage that came with the process of diagnosis and coping. In the 1980s, focus on Usher Syndrome in childhood would again subtly shift the relationship between professionals and patients, as it introduced a particularly vulnerable population.

**Usher Syndrome in childhood and youth: Narratives of screening success and emotional vulnerability**

Awareness of Usher's increased significantly by the early 1980s, thanks to a variety of forces, including Vernon's campaign, the growing awareness of the needs of multiply handicapped deaf children, and the large numbers of students with Congenital Rubella Syndrome. Two developments marked approaches in this decade. With greater awareness of Usher Syndrome and of the situation of those affected, professional focus moved from preventing the passing on of a genetic trait to preventing the potential emotional damage of becoming deaf-blind – a move similar to the NYSPI's focus on the potential psychopathology caused by deafness rather than deafness itself. Second, with the success of screening programs, Usher Syndrome was increasingly diagnosed in children and teenagers, a population supposedly particularly vulnerable to emotional damages.

In order to identify individuals particularly at risk for such emotional or developmental damage, professionals tried to identify good, normal and healthy ways of coping. They operated in a framework in which deviation from physical and norm almost necessarily caused emotional distress, yet in which balance that could be regained over time and with professional support. Ed Hammer, project director of South Central Regional Center for Services to Deaf-Blind
children for example emphasized that emotional distress was not only normal, it was a necessary stage in the process of coping. He remarked in 1977 that to “act normal in an abnormal situation is to deny the impact of the situation. Greater concern needs to be given to the person who does not experience 'mini-psychosis' when discovery is made of the impending loss of vision.” This,” he cautioned, “may be the person who is out of touch with reality.”

Even normal behavior thus, was suspicious of emotional deviance.\footnote{Hammer, Ed. 1977. “Needs of adolescents who have Usher's Syndrome.” In. Dallas conference 1977: 389-394, here 389.}

The moment of diagnosis was given particular attention as a potentially damaging moment of transformation from healthy to diseased. Vernon published extensively on this matter, and in 1976 described diagnosis as “a profound psychomedical issue.”\footnote{Vernon 1976, Usher Syndrome, 10.} He believed that no matter how compassionately a professional explained the course of Usher Syndrome to a patient, it still was a devastating experience to the patient. As Vernon stated in a 1982 article co-written with Linda Annala and geneticist Joan Boughman: “The entire psychodynamic process of coping with the diagnosis is life-long, extremely difficult, and changes as the persons grows older and the visual loss progresses.” Usher Syndrome thus had become a condition that required continuous psychological support and supervision to keep the patients and their families from sustaining lasting emotional damage.\footnote{Vernon, McCay, Joann A. Boughman, and Linda Annala. 1982. “Considerations in Diagnosing Usher’s Syndrome: RP and Hearing Loss.” Journal of Visual Impairment and Blindness 76 (7): 258-261, here 259, 260.}

This was a challenging enough a task in adults. Yet in the 1980s, the very success of vision screening in childhood brought up new problems and ethical ambiguities. In particular, the question of when to tell the affected that he or she...
would progressively lose their vision raised complex ethical and psychological issues of autonomy, patients' rights, and self-awareness. And since doctor visits and medical procedures in children usually involve their parents, Usher Syndrome in underage individuals brought in a third group to discussing its nature and negotiating responsibility and agency.

From the mid-1970s on, schools for the deaf began to implement vision screening programs. By the early 1980s, early diagnosis in childhood or adolescence had become a reality. Larger schools and colleges took a leading role in this development. The National Technical Institute for the Deaf at the College of Rochester Institute for Technology, for example, had established a Visual Problems Task Force in 1976. Its goal was to screen all current and future students in order to determine special needs.\textsuperscript{645} Similarly, in 1977 the South Central Regional Center for Services to Deaf-Blind Children was founded with support from the Bureau of Education for the Handicapped, DHEW. For these services they cooperated with the Johns Hopkins School of Medicine, by then a global center for medical genetics; Vernon's group at Western Maryland University; and the Department of Human Genetics at the Medical College of Virginia, headed by Walter Nance. Serving state schools for the deaf in Oklahoma, Louisiana, Iowa, Missouri and Arkansas, the center designed and conducted vision screening tests for a number of conditions, including retinitis pigmentosa, glaucoma, macular degeneration, cataracts and optic atrophy. If a student was

identified with one of these conditions, the center provided educational, rehabilitation and counseling services.646

Gallaudet, too, contributed to this enterprise. In 1978, their Public Service Programs published a manual to help teachers and other non-medical staff at schools for the deaf screen students for Usher Syndrome. The manual had been developed with the help of Vernon, Roehrig – now “Special Assistant for Deaf-blindness at Gallaudet College” – and NIH ophthalmologist Donald Bergsma, who had worked with geneticist Kenneth Brown at the National Institute of Dental Research.647

In simple language, the manual explained the nature of Usher Syndrome and illustrated normal and impaired visual fields. Early diagnosis was the stated goal in order to prevent the “educational, social, and emotional development problems” that came with living with unidentified vision problems. The authors outlined common behavioral signs found in people with Usher Syndrome, such as “turning the head while reading a book,” bumping into people, tripping over objects on the floor, or “failing to glance at another person’s hand waving from the side.” Preliminary screening for such peripheral vision loss could be performed with simple equipment – tape, a pen and a chair. With these materials, available in every classroom, a teacher could test whether the student, sitting and looking at a fixed spot, registered an object entering his peripheral field from the side or the front. Results were noted on a recording sheet. If


abnormalities were present, the student was referred to an ophthalmologist for in-depth examination. 648

By 1981, when Arizona State School for Deaf and Blind teacher Creagh Walker Day surveyed 59 residential schools for the deaf for such screening programs, 21 schools answered affirmatively. Half of those also offered support services in the form of personal, vocational and genetic counseling or curricular modifications. This was an encouraging sign, Walker thought. Students, however, were still diagnosed too late. 84 percent were older than twelve when they received their diagnosis. “Early identification,” he believed, “is crucial to provide the maximum support services to children and their families” 649

Earlier identification, however, brought with it new problems and ethical questions. Whereas before Usher Syndrome had been diagnosed in people in their 30s, 40s or 50s, in the middle of their professional and family life, now it was found in children and teenagers. When should they be told, and how? Nobody, reasoned Vernon and Wanda Hicks in 1983, “would advocate telling a 3 or 4-year-old that he or she will grow up to be deaf and legally blind.” Yet what was the right age to tell a deaf person that he or she would lose most, if not all of their vision, and what did an ever earlier diagnosis mean for prevention, counseling and rehabilitation? 650

648 Gallaudet, Screening, 3, 9, 14-25.
As Usher Syndrome became more widely known among educators and rehabilitation workers, the matter of how and when to communicate the diagnosis to students and their families became a much discussed topic on conferences, in guidebooks and articles. Vernon's work on the socio-emotional impact of Usher Syndrome was widely cited, although professionals did not necessarily agree on the impact of knowledge vs. the benefits of temporary ignorance. In this debate, prevention was weighed against emotional stability; timely adaptation against the impact of learning about vision loss; plans and hopes in the present against future impairment. Communicating the diagnosis to parents rather than the under-age patient also reinforced the character of Usher Syndrome as an intergenerational condition in which the entire family would experience the emotional impact of diagnosis and coping.

Despite the potentially devastating emotional impact, Vernon, Boughman and Annala favored an early diagnosis. “Some of the psychological trauma associated with the diagnosis of Usher's Syndrome,” they wrote in 1982, “can be avoided by early, even presymptomatic, diagnosis of the disease.” Knowing early on would allow parents, teachers and physicians to gradually inform the child about his vision loss, and would allow the parents to consider their genetic make-up in their family planning. Conversely, “diagnostic delay and inaccuracy deprives the patient of the help available from genetic counseling, counseling on psychological coping techniques, educational guidance, and career counseling.” Professional delay and failure, in other words, cost patients time much needed in their adjustment process.⁶⁵¹

⁶⁵¹ Vernon; Boughman; Annala 1982, Diagnosis, 259, 260.
Many professionals followed Vernon's arguments about the benefits and necessity of early diagnosis. "It is hard to imagine a condition more tragic than Usher's Syndrome," University of Houston professor of Optometry James W. Walters commented in Dallas in 1977. The tragedy, he continued, "is only compounded by a failure to render an early diagnosis." Unknowingly, families might conceive another child with Usher Syndrome652 Prevention thus remained an important theme. At least as important, however, were the psychological, educational and rehabilitation benefits of early diagnosis. In his 1981 survey, Day emphasized that students “with the Usher Syndrome have the right to be informed and involved in decisions regarding their handicap.” Only once they were aware of their condition could students and their families profit from vocational, genetic and personal counseling, rehabilitation and special education. Such support services, Day wrote, “will enhance students’ chances of accepting and adjusting to their handicap.”653

Others were more skeptical about the ability of children and teenagers to deal with the knowledge of impending vision loss. The more mature adult personality, professionals believed, was better equipped to deal with the blow of diagnosis, while children and adolescents, still developing, were more prone to emotional damage. Roehrig for example favored a soft approach. Children, he believed, “should be informed what will happen to their vision only when they are psychologically ready.” When this was the case, he left undefined. Before this point was reached, parents should encourage in the child just enough awareness

653 Day, Screening, 45.
of their vision impairment to allow safe navigation of everyday life. Ed Hammer, project director at the South Central Regional Center, similarly framed the process of learning about deaf-blindness within the larger challenges of teenage-life: “Not only is the adolescent becoming adjusted to having a new body,” once diagnosed with Usher Syndrome he was also “challenged to adjust to the body not being trustable because it is flawed.” The double challenge of growing up and adjusting to visual impairment, Hammer observed, led “to questioning of the person, physically and emotionally.”

Communicating the diagnosis, the 1978 Gallaudet screening manual cautioned, was an “emotion-charged issue. Those who relay the information must exercise judgment to deal both honestly and sensitively with the student.” How much a student was to be told at a given point depended on his or her individual maturity, emotional stability and intellectual capacity. Awareness should not interfere with the emotional readiness to continue with one’s normal life. “It is inadvisable,” the manual cautioned, “to tell a student that he will become totally blind, for that eventuality is remote and uncertain. Students can and should continue to participate in all normal activities, including sports.”

Safety in daily living was one argument for early awareness. Children with Usher Syndrome, Doin E. Hicks explained in 1977, should be aware of their impending vision loss to prevent injuries. He agreed that “the capacity for psychological damage may be as great as for physical damage,” and conceded that affected individuals” should be permitted to ’live for the present’ so long as” they planned appropriately for the future. Yet it was “as foolish to shield the

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654 Roehrig, Living, 26.
655 Hammer, Needs, 393.
656 Gallaudet, Screening, 11.
individual from information about the progressive phases of the disease as to shield the nonhandicapped child from information about the reality of eventual death.” As so often, this ambivalent statement likened disability to death, yet by doing so also turned it into a basic and inevitable fact of life.657

With younger children, professionals agreed, it was the parents who should initially receive the diagnosis. With the support of psychologists, counselors or social workers they could then proceed to explain the condition to their child when and as they saw fit. In this manner, Vernon, Boughman and Annala wrote in 1982, “much of the anguish associated with diagnosis can be transferred to parents who can sublimate their grief by providing a supportive environment.” Parents thus joined the diagnosing physician in his position of knowledge and responsibility. They were to monitor their child for signs of visions loss, readiness to learn about the future, and signs of emotional distress.658

Unlike physicians or other professionals, however, parents were not neutral third parties. Their own feelings toward their child’s condition and future affected how they now approached him or her. In their discussions on the family dynamics of diagnosis and coping, professionals acknowledge parents’ difficult emotional situation, while simultaneously identifying them as yet another problem factor in their children’s adjustment. Some parents, Harry Anderson, counselor at the Florida School for the Deaf-Blind, reported, refused to tell their children about the diagnosis “to spare them the hurt.” This reaction was

only too understandable given the overwhelming situation. Yet, he believed, it was “a tragic mistake on the part of the parents.” Professional support could solve this dilemma and ease familial strain. Whereas the parents were mired in subconscious emotional conflict, professionals could recognize these processes and offer rational solutions for accepting their children.659

By the 1980s, then, deaf-blind children, teenagers and their families found a much-improved (though by no means perfect) support-structure of rehabilitation and education services. In 1983, for example, Gallaudet operated a pilot program at their Model Middle School for the Deaf (MSSD) that was to a model supportive service for students diagnosed with Usher Syndrome. Lead by Vernon and Wanda Hicks, the program offered group therapy and self-help sessions, talks from experts and practical adjustment in classrooms or dormitories.660 Rehabilitation and education were to prepare the students for an independent life while guarding their emotional balance, and were the most important aspects of the project. Genetic counseling and prevention played hardly any role, certainly in part because these were not yet pressing issues to teenagers. This was almost a complete reversal of Vernon’s earlier emphasis of genetic prevention over education and rehabilitation services, and makes visible the reconceptualization of Usher Syndrome as a psycho-emotional condition. As such, it fell as much into the realm of the psychologist as of the geneticist. It was

659 Anderson, Experience, 6.
660 Vernon; Hicks, Group counseling. MSSD had been founded in 1969 in the aftermath of the 1965 Babbidge Report. Named after Homer Babbidge, chairman of the HEW Advisory Committee on the Education of the Deaf, the report severely indicted the state of deaf education. As a result, demonstration middle and elementary (Kendall Demonstration Elementary School) schools were established at Gallaudet to improve the education of future teachers of the deaf. See Armstrong, Gallaudet, 82-84. For other services see e.g. Pimentel HKC Workshop 1976, 54.; Hicks, Wanda. 1977 “Continuing Education for Deaf-Blind Youth & Adults.” In. Usher Syndrome conference 1977 Dallas: 395-399, here 396.
the psychologist who could ensure emotional stability and growth by fostering a “correct” and “healthy” form of dealing with their situation, and who could offer support and insight to other professionals working with deaf-blind people.

Improved services were also due to the lobbying of parents themselves. At MMSD, Vernon and Wanda Hicks had reacted to concerns from the students’ parents who felt “that their own feelings about the children’s future were such that someone less intimately involved should discuss these issues.”661 Like other parents of children with disabilities in the second half of the century, these parents were crucial in pushing for integrating their children into family and society, and for accepting and working with their differences, impairments and contributions.

Yet parents’ involvement also changed the power dynamic between professionals and individuals with Usher Syndrome. Whereas the individuals diagnosed in the 1960s and ‘70s had been adults who had soon began adding their own perspectives to professional narratives, by the 1980s the typical Usher Syndrome patient was a child or teenager. This, again, was a population about which professionals, and now parents spoke, yet who were not yet granted much insight into their own behavior and psyche, and who required guidance and surveillance.

**Conclusion**

In the period from the 1960s to the 1980s, Usher Syndrome underwent several significant transformations: from an obscure, hardly known variety of deaf-blindness to a severely limiting, hereditary, neuro-psychiatric condition,

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661 Vernon; Hicks, *Group counseling*, 65.
and finally to a progressive sensory disability that carried the risk for severe psycho-emotional disturbance, yet also the potential for as much of a fulfilled life. This development moved along two narrative axes that reflected diversifying professional paradigms, changing perceptions of deaf and deaf-blind people, and, not least, larger changes in framing genetic conditions.

One strand was a story driven by the need for prevention in which Usher Syndrome was a pressing issue of public health, cast in the language of economic savings. Prevention was not so much a matter affecting the person now living with Usher Syndrome, but of future misery and suffering. This narrative arose in the late 1960s from the confluence of older eugenic-genetic-medical motives with psychiatric reform and new neurological paradigms. Expanding psychiatric and rehabilitation services for minorities brought attention to deaf-blind patients institutionalized in asylums and mental hospitals. Their state raised questions about the underlying etiology and about the psychosocial effects of such severe sensory deprivation. Researchers at the NYSPI had noted its hereditary component and had speculated about its relationship to mental health. But it was Vernon who turned Usher Syndrome into a hereditary psycho-neurological condition, tying it to a supposed brain lesion that caused not only hearing and vision loss, but also severe psychiatric disturbances.

This model rested on a number of connected assumptions and definitions: of disability as individual suffering and as an economic loss for society, of the patient as institutionalized and mentally disturbed, and of the professional as the ultimate authority. Vernon’s early definition of Usher Syndrome mirrored the circumstances in which he encountered patients and professionals. His awareness campaign of the late 1960s and early 1970s considered the
improvement of services and living situations as being only secondary to eugenic prevention, even as a waste of resources. For Vernon, it had always been clear that two individuals with Usher Syndrome should not marry, both for the sake of their future family and the greater good. The individual was given little choice in this matter; and was considered ignorant or irresponsible if he or she acted against these recommendations. Ironically, I have shown, it was geneticists who tempered his overly ambitious hopes for eugenic prevention. Among geneticists, such an authoritative stance was no longer en vogue. Geneticists in the 1970s and '80s, relativized the effects of large-scale screening and prevention on public health, and instead pointed to the emotional benefits of genetic self-awareness. Genetic counseling, in this scheme, could mean preparing to live with a condition as much as preventing it.

This psychologized version of genetics and disability proved to be highly appealing. Growing awareness of Usher Syndrome in the 1970s and '80s occurred within a framework of increasingly visible and assertive patients, disability and Deaf movements, social and professional activism and redefinitions of professional authority. As as patients and physician, advocates and professionals interacted, they negotiated notions of sickness and health, defect, disability and normalcy. Here, a new image of the individual with Usher Syndrome crystalized. Rather than helpless and hopeless, isolated or institutionalized patients, they were ordinary people with families and careers.

Driven by these forces and actors, a second, more recent narrative thus cast Usher Syndrome – and in turn genetics – as a journey to self-awareness and self-acceptance. Depending on context, this narrative could take different turns. Physicians, psychologists, teachers and rehabilitation emphasized the emotional
risk individuals with Usher Syndrome and their families faced – and their need for professional support. Prevention, here, primarily came to mean preventing emotional damage to the individual and family through constant professional guidance and surveillance. With this turn, by the 1980s, Usher Syndrome had become a psychological as much as a genetic condition. It was a condition that created stress and emotional upheaval for everyone involved: the patient who had to come to terms with a different future than imagined; the family, who was dealing with feelings of guilt; professionals who had unconscious biases and underlying fears about dealing with deaf-blind individuals. These complicated emotions needed to be brought out in the open and acknowledged in order to develop appropriate coping mechanisms and to provide appropriate services and support.

Patient activists such as Roehrig and Annala, on the other hand, tended to emphasize the capability and tenacity of affected individuals rather than their deficiencies. They usually supported the drive for prevention, yet clearly gave primacy to improving their living situation and social position. Drawing from the tenets of Deaf and disability activism, and in particular the independent living movement, they emphasized their basic humanity and rights to a self-determined life. Early activists like Roehrig and Annala also emphasized the emotional impact of coping with losing one’s vision, yet portrayed it as a change to adapt to rather than as an end point. Here, patient activists tapped into larger themes of realizing selfhood by overcoming or adapting to life’s obstacles, a move that relativized and normalized Usher Syndrome as one challenge among others. Emphasizing their capability to master difficulties out their own volition
and on their own terms, this narrative had a strongly empowering motive that was further strengthened by pointing to social bias and discrimination.

Genetics, too, could be deployed in this manner. To activists, the notion of genetics as form of self-knowledge granting access to a deeper understanding of the self resonated with a vision of Usher Syndrome as a journey to more profound self-knowledge and self-acceptance. This was not necessarily genetic awareness as most genetic professionals envisioned it, yet it was emblematic of the manner in which genetic discourse was not merely an expert conversation reinforcing the ideal normal body. Rather, it could be mobilized for making the case for human diversity. Activists took from genetic discourse the often-repeated mantra that one was not at fault for having faulty genes, and that disability was something that could affect anyone. It was, activists argued, part of human variation and difference.

With its overlapping discourses of disease and disability, physical and emotional risks, professional authority and patient autonomy, the history of Usher Syndrome thus contributes to the still unexplored zone between the histories of science and medicine, deafness and disability. Attitudes toward deaf-blindness mirrored not only assertions of professional, medical, and scientific authority, but also the effects of professional activism and identification with the values of the target community. Vernon belonged to a generation of hearing professionals who fervently advocated for Deaf Culture, portraying himself as a worthy ally to Deaf activists. His goal was not the eradication of the Deaf community, but of a trait that was usually considered a grave and tragic disability within this community: blindness. However, this consensus became fragmented as individuals with Usher Syndrome pointed to the discrimination
and exclusion they experienced within the Deaf community and in hearing society.

As in the NYSPI project, then, deafness was a more a shared risk factor than the targeted trait, although in syndromic forms such as Usher these dimensions could hardly be separated. Where in the beginning this was mainly a genetic risk for disease and disability, it had become a question of identity and emotions. In the history of Usher Syndrome we can see how older motives of eugenic prevention as a public health measure were transformed in the encounter with an increasingly active and self-confident disability and Deaf movement, producing a notion of genetic awareness that was at once relativized and essentialist. This emphasis on the medical, emotional and even political benefits of genetic awareness drove the establishment of culturally-sensitive genetic services for deaf people that I will explore in the last chapter.
Chapter VII. Genetic awareness, neutrality and empowerment: The rise of culturally sensitive counseling 1960-1990

In the early 1970s, geneticist Walter Nance counseled a deaf couple on their risk of having a deaf child. This was a standard procedure for Nance who had worked in the field for over ten years. Yet the couple's reaction was not so standard, and, indeed, questioned his approach and beliefs. What, the young woman asked, was wrong with being deaf? For Nance, who believed in the tenets of non-directive counseling, there was no clear answer to this question.662

That geneticists took into account the perspectives of their deaf clients was not self-evident, as previous chapters have shown. During the first half of the century, heredity counseling assumed rather than inquired about counselees' motives, concerns, and beliefs. This changed in the 1950s and 60s with the rise of non-directive, client-centered counseling and with the introduction of psychosocial motives. Nance taking an interest in client perspectives thus had much to do with the time in which he established his career. As has become clear over the course of the previous chapters, the period from the mid 1950s to the late 1970s was pivotal in diversifying perceptions of deafness and disability, establishing new forms of Deaf and disability activism, in advancing in knowledge about genetic deafness and in changing paradigms in genetic counseling. These changes were crucial for the development of culturally-sensitive counseling for deaf people which I will follow in the work of three geneticists: Walter Nance, Joann Boughman, and Kathleen Shaver Arnos.

If geneticists were to reach deaf people, Nance decided, they had to adapt their language and practice to Deaf values and culture. Boughman, one of Nance’s PhD students and later colleague, took this notion a step further. Becoming fluent in sign language, she performed genetic counseling in a language that was not her own. This experience heightened her sensibility to the bias inherent in genetic terminology such as “risk,” “defect,” or “normal.” By the late 1970s, Nance and Boughman were joined by another PhD student and soon-to-be coworker, Kathleen Shaver Arnos. Arnos had studied psychology under McCay Vernon. He sensitized her to the sociocultural model of deafness and encouraged her to study its genetic aspects. Like Boughman, Arnos became fluent in sign language and advocated for Deaf culture among geneticists and, conversely, for genetics among the Deaf community.

The three geneticists realized a series of projects. In cooperation with Vernon, they researched and provided counseling for Usher Syndrome. As the previous chapter has shown, this was a field that simultaneously had strong eugenic-preventative motives and was affirmative of Deaf culture and community. In close collaboration with the Washington, DC, area Deaf community and Gallaudet linguists, Boughman and Arnos developed a set of ASL signs for genetic terminology. Finally, in the early 1980s, an NIH-funded project on the link between Congenital Rubella Syndrome (CRS) and diabetes took them to fieldwork at Maryland and Virginia schools for the deaf, providing yet another opportunity for cultural immersion. As the children with CRS entered college, Nance’s team followed them to Gallaudet.

These projects paved the way for establishing, in 1984, a Genetic Service Center (GSC) at Gallaudet that promised “an innovative approach to genetic
counseling services for the deaf.” Simultaneously drawing from decades of genetic deafness research, and an ever-growing literature on Deaf culture and community, under Arnos leadership the GSC explicitly defined deaf people as a sociocultural minority whose access to genetic services were hindered by “cultural and language barriers.” Successful counseling, Arnos believed, required awareness of Deaf culture, of reproductive choices and values among deaf people and a working knowledge of ASL.663

A form of genetics that portrays itself as a matter of minority rights, as part of preserving Deaf culture and community does not fit within the usual parameters of Deaf and disability history. The history of Deaf activism is usually portrayed as a rejection of the medical model and the professionals associated with it. It is a story of conflict, liberation and the eventual – yet fragile – success of sign language and Deaf culture over medicalized oralism.664 This one-sided focus, however, takes science and medicine as one monolithic entity rather than as a mosaic of ever-changing professional paradigms and identities. Certainly, throughout much of the 19th and 20th century, the history of deafness was marked by the often dogmatic antagonism between manualists and oralists, and by a medicalized perspective that considered expressions of Deaf culture and community as deviant.


Yet the previous chapters have shown how professional perceptions of deafness and deaf people became ever more splintered. By the 1960s, professionals could take a medical definition, side with the cultural minority model or settle for any gradation between these two positions. Rather than juxtaposing science and Deaf culture, then, this chapter again looks at the cooperation, exchange and alliances between different professional groups and deaf communities. Shifting perceptions of pathology went hand in hand with changing professional identities, definitions of expertise and new justifications for professional intervention. Thus, by the 1960s deafness professionals no longer gained authority only by claims to curing or preventing, but also from siding with deaf people or other disadvantaged minorities. They presented genetics, psychology or sociology as a means to support and empower these minorities and identities. Following Nance, Boughman and Arnos as they moved between these models, I demonstrate what scientists gain from siding with one or the other, and point to the permeability between medical and sociocultural definitions of deafness, disease and disability.

These newer models of professional authority, activism, disability and deafness rested on larger social changes in US society. Minority and social activism – ranging from African Americans and Latinos to gay and lesbian, women, deaf and disabled people – radicalized and diversified. Health and access to health care were important themes within these movements, for example in the Women's movement challenge to medical paternalism, or in the Black Panther's community health care services. The disability and Deaf movements, too, participated in these debates, as they challenged older traditions of
portraying disability in terms of pity, misery and charity with assertions of independence, pride and equality.665

Women demanding professional opportunities in the medical field also had an impact on genetic counseling. The emergence of dominantly female, MA-level counselors in the 1970s challenged the authority of the predominantly male MDs or PhD scientists who dominated the field. Inspired by second-wave feminism, these newcomers emphasized reproductive autonomy and portrayed genetic counseling as an assistive and supportive profession. Client autonomy and non-directive counseling became the much-discussed slogans of genetic services in the 1970s, fueling the new field of bioethics. Disease prevention (and its economic benefits) remained an important motive, yet the shift toward non-directive, client-centered counseling opened up venues for less absolute definitions of disability and defect. It required from the counselor awareness of his own biases and preconception, and applying this awareness in a (psycho)therapeutic exchange that was to result in genetic awareness and, consequently, in greater emotional peace and well-being for the client.666


Historians of medicine have also pointed to the role of patient-expert networks in changing the social roles of patients and disabled people. This was true for genetics, too, where from the 1960s on geneticists began engaging in an exchange of opinions, beliefs and goals with their target populations. Parents of children with disabilities, Alexandra Stern has shown, challenged geneticists’ beliefs in the disabled child as a tragedy, yet also relied on geneticists as mediators providing access to other professional services. Similarly, Huntington’s Disease patients and their families explicitly sought to elicit scientists’ interest in research for a genetic test and perhaps a cure, and contributed their skills and time in raising funds and awareness to this endeavor. As Keith Wailoo’s history of sickle cell anemia demonstrate, the perception of individuals with genetic conditions was also deeply entangled in racial bias that determined and limited access to research resources and medical services. Challenging medical and social discrimination, sickle cell disease came to be seen as a sign of oppression or as a symbol of Black suffering in American society to Civil Rights and Black Power activists.667

Sociologists and historians of genetics have analyzed a number of other such genetic communities – an entity that sociologist Aviad Raz has defined as resulting from the “interplay of community genetics (the medical organisation of carrier testing and screening within community settings) and genetic alliances

(the emerging social networks of individuals genetically at risk.” What is perceived as genetic risk and what as its appropriate solution, Raz argues in his comparison of Israeli and US approaches, depends strongly on cultural frameworks of health and disease in the individual, family and the nation. The example of deaf-blindness in the last chapter has shown how professionals and community members could agree on the positive nature of deafness and pathology of blindness, yet also how notions of risk were transformed from a statistic entity into a psychosocial category. This chapter will further probe how patient and client perspectives challenged professional perspectives, and how counseling in sign language contributed to these changes.

With its attention to the needs and genetic make-up of a specific target population, the GSC thus was part of broader trends in the history of genetic research and services. Yet even within the framework of a multitude of genetic communities, the extent of exchange between Nance, Boughman and Arnos and their target community was unusual. Susan Lindee, for example, has described geneticist Victor McKusick’s research of hereditary diseases in Amish communities as a form of fieldwork that extracted different kinds of information, and was to provide the Amish with better access to genetic diagnosis and services. McKusick, however, remained as much an outsider to the world and values of the Amish, as the Amish did to the world and values of medical genetics.

Boughman and Arnos (and, to a lesser extent Nance) on the other hand made their assimilation to Deaf culture and community a condition of client-

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669 Lindee, Truth, 62, 77.
centered research and services. In doing so, they became cultural ambassadors negotiating the disconnect between a medical-genetic community that considered deafness a pathology to be cured and prevented, and the Deaf community which considered it the distinguishing trait of their sociocultural minority. They thus came to form a professional cluster that simultaneously advocated the need for genetic knowledge among the deaf population, and promoted awareness of deaf culture and values to the genetics community. Moreover, unlike most other genetic communities, GSC researchers were not predominantly driven by the search for a cure or other biomedical solutions. Rather, in their questioning of traditional definitions of pathology and genetic risk, and their self-understanding as client rather than society-centered the GSC aligned itself with some demands of Deaf activism.

Nevertheless, in its promotion of genetic self-awareness, the GSC remained firmly rooted in a form of biological essentialism that considered awareness of one's genetic make-up an indispensable part of navigating life. In the politicized atmosphere of the 1970s and 80s, when Deaf activism entered the political arena, they portrayed genetic awareness as a form of political empowerment, of taking charge of one's body and life. This apparent tension between cultural and biological definitions of selfhood – unacknowledged by the geneticists in question – will appear repeatedly in this chapter as I analyze shifting borders of disability, pathology, belonging and activism. What, this chapter asks, did geneticists gain from aligning themselves with Deaf culture rather than with the older paradigm of curing and overcoming deafness? How did they turn the language of minority rights and cultural difference into one of
genetic empowerment, and how did this confluence of science and social activism change the nature of genetic deafness research?

**Walter Nance – Cure, culture and counseling.**

“It is a sobering experience,” Walter Nance recalled in 1977, “to spend an hour communicating the facts of genetics to a deaf couple through an interpreter, only to be confronted by the question from the shy young bride, 'What is wrong with being deaf?’”670 This anecdote vividly described the mismatch in values and expectations between himself and the deaf clients he had encountered in his work as a geneticist in various settings. A young physician more interested in exploring family and population traits than in curative medicine, he had entered genetic deafness research in the 1960s, moving into a field in which deafness was a pathological entity. By the late 1970s, however, he had developed a more relative definition, no longer automatically assuming it was something to be cured or prevented. In contrary, he believed that if a deaf couple wished to have a deaf child, the geneticist might well be able and willing to assist them in realizing this wish. Changes in genetics, counseling, and in perceiving deaf people and deaf culture greatly facilitated and accelerated Nance’s reorientation. In the following, I explore his path from medicine to genetic deafness research, his early career at Vanderbilt University, his time at Indiana University and early work at Gallaudet University, which brought him into closer contact with deaf people; and finally his move, in 1975, to the Medical College of Virginia, where he and his students began developing culturally-sensitive genetic services for deaf people.

670 Nance, Unmet need, 212.
Born in 1933 in Manila to the family of an American surgeon in the Philippine Public Health Service, Nance was exposed to different cultures and languages throughout his childhood. The family soon moved to Shanghai – he grew up speaking English and Chinese – and lived there until 1941 when the US State Department ordered the evacuation of all civilians from China. Nance, his two siblings and his mother moved to New Orleans while his father returned to the Philippines where he was captured and spent the war in an internment camp. In New Orleans, at the age of 12 or 13, Nance contracted polio after swimming in the Mississippi. The disease left his left arm paralyzed, although with physical therapy and surgeries he regained some mobility. Reunited with Nance’s father after the war, Nance’s father settled down as a physician in Oak Ridge, Tennessee, which had only been established in 1942 as a production site for the Manhattan nuclear bomb Project. After finishing high school at Phillips Exeter Academy, a distinguished private preparatory school in New Hampshire, he returned to Tennessee to attend the University of the South in Sewanee in 1950. In Sewanee, he majored in mathematics, graduated with a BA, and in 1954 was accepted to Harvard Medical School.671

While Nance was in college, his parents had another child, his brother Benji, “the sibling,” he believes, “that arguably has had the most influence on my life.” At birth, the obstetrician, a close family friend, diagnosed Benji with Down syndrome. Benji, Nance recalled, “was one of the most severely affected infants with Down syndrome I’ve ever seen,” never learning to sit or walk. He “had a profound effect on all of our lives.” Unwilling to accept the diagnosis, his parents

took Benji “to [Johns] Hopkins, they took him here, there, everywhere to try and find somebody who would diagnose a treatable disease.”

The Nances’ experience was quite typical for parents of intellectually disabled children in the 1950s. Parents were told that there was nothing to be done for their children and that it was best – for the child and for the family’s ability to return to a “normal” life – to send the child to live in an institution. Benji would spend most of his life in a private nursing home. Like other parents at the time, Nance’s mother, feeling unable to help her own son, “sublimated [her personal situation] by getting interested in mental health work.” She was involved in founding the first mental health clinic in Oak Ridge, Tennessee, and other locations. Through his family’s experiences and work Nance thus came into contact with the budding networks of parent and mental health activism that were crucial for changing perceptions of intellectual disability and improving the situation of the mentally ill and intellectually disabled. His own family’s experiences vividly illustrated the emotional challenges of living with a severely disabled child, the lack of institutional support and the disconnect between the physician’s judgment and the parents’ hopes.

At age ten, Benji had grown too old for the private nursing home and was moved to a public facility in Tennessee. He died two months later of a respiratory infection. At this point, Nance had been accepted to Harvard Medical School. Benji’s life and early death, and the experience of a genetic disorder in his own

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672 Ibid., 28-29.
674 Interview Nance 2006, 1-3, 9.
family had triggered his interest in medicine and fascination with genetics. Patients with a family history of certain conditions reinforced this fascination. Twin studies, in particular, caught his interest and became a lifelong research focus. After graduating from Harvard in 1958, Nance entered his residency in internal medicine at Vanderbilt University with an intense interest in the genetic bases of the conditions he encountered. Among his Vanderbilt colleagues, he soon “got a reputation [...] of being more interested in the family history than the present illness.”

Nance entered human genetics at a time when the field was rapidly professionalizing and asserting itself as a separate medical specialty that connected medicine with the biosciences. He later reflected that it had been “tremendously exciting” to see genetics “unfold and be a part of this creating and witnessing a birth of a new specialty in medicine.” Some of these developments were outlined in previous chapters, such as advances in methods and knowledge that drove the growth of specialized subfields, e.g. cytogenetics, biochemical or population genetics. The establishment of genetics as a medical specialty was driven in particular by Johns Hopkins geneticist Victor McKusick. Intent to familiarize scientists and physicians with this new field, McKusick established, in 1960, an annual summer course in Bar Harbor, Maine, at the Jackson Laboratory. The Bar Harbor Course became an annual event with a growing number of attendees who came to form a tightly-knit community. Nance attended the first course in 1960s; it became his introduction to the world of research genetics and

\[675\] Ibid., 3, 29, 30, 32.
to a network of like-minded scientists that encouraged his decision to pursue a
career in genetics.676

Nance's colleagues at Vanderbilt were supportive of his interest in
genetics. His chairman, the physician, medical educator, and scientist David
Rogers, jokingly suggested one day, "Walter, maybe you better go study genetics
before you hurt somebody." Rogers' father was the eminent psychoanalyst Carl
Rogers who developed and popularized the person-centered, non-directive
counseling that also influenced genetic counseling. At the time, Carl Rogers
taught psychology at the University of Madison. When David Rogers visited
Madison one year, he encountered geneticist James F. Crow, the chair of the
Department of Medical Genetics. The encounter with Crow, who strongly
advocated for the growth of human genetics, left a lasting impression: Rogers
decided that Madison was the place for Nance to receive his training in genetics.
It was this coincidence that took Nance to one of the most distinguished and
diverse genetics departments in the 1960s.677

From 1961 to 1963, Nance received an NIH Postdoctoral Fellowship in
Human Genetics that allowed him to spend three years at the Department of
Medical Genetics at the University of Wisconsin, Madison. His time in Madison
coincided with the department’s establishment as a leading institution in
biomedical genetics. Nance called his time in Wisconsin the “halcyon days of my

676 Ibid., 3-5, 58. For the growth of genetics in medicine and the history of Victor McKusick's Bar
Harbor course see See Comfort, Nathaniel C. 2012. The science of human perfection: how genes
became the heart of American medicine. New Haven: Yale University Press, 165-192. Also see
Journal of Medical Genetics 115 (2): 75-82.

677 Interview Nance 2006, 3-4, 58. For Carl Rogers see e.g. "Carl Ransom Rogers." Encyclopedia of
describes how Sheldon Reed's notion of genetic counseling was influenced by Rogers. See
Stern, Telling genes, 125-131.
education.” He decided to pursue a Ph.D. in genetics and became a student of biochemical geneticist Oliver Smithies who he “admire[d] exorbitantly.” Smithies is most known for his introduction of starch as a medium for electrophoresis – a method for analyzing macromolecules – and for developing a technique for replacing transgenic with genomic DNA by homologous recombination. For this technique, highly useful for altering animal genomes in research, he eventually received the 2007 Nobel Prize in Physiology or Medicine. With this mentor and environment, Nance emerged himself in learning as much as he possible could. Never having “had any formal courses in genetics,” he “just started from scratch and took everything that was available.” His MD gave him unusual independence and authority for a postdoc researcher pursuing another degree, and enabled him to work with various faculty members on a wide range of topics in biochemical and medical genetics. Even though he would later focus on genetic deafness and twin studies, he continued to pursue a wide range of interests, including cancer, diabetes and other endocrinological and metabolical disorders, cardiovascular disease and retinitis pigmentosa.678

Nance’s openness toward new fields and methodologies also contributed to the relative ease with which he adopted new approaches in counseling and new perspectives of deafness. His institutional placement, too, reflected this interdisciplinary approach. After finishing his residency in 1963, he became assistant professor of medicine and head of the division of medical genetics at the Vanderbilt University School of Medicine. At the same time, he continued to pursue his graduate research and received his PhD in genetics from the

678 Interview Nance 2006, 3-5. For the history of the University of Madison department of genetics see Comfort, Perfection, 188.
University of Madison, Wisconsin in 1968. Simultaneously working at the Vanderbilt School of Medicine, where he saw patients with genetic conditions, and working with the biochemically oriented geneticists in Madison intensified Nance’s interest in “trying to characterize new genetic disorders, basically at the clinical level, with the ultimate hope of learning more about them at the genetic and molecular level.”⁶⁷⁹

One of these disorders was deafness. Nance first encountered a deaf patient with a family history of hearing loss in the late 1960s. Intrigued, he paid a visit to the patient’s family in a very rural part of southwestern Tennessee. The patient, he learned there, “was a product of a first-cousin marriage.” This familial connection confirmed Nance’s suspicion that the hearing loss in this case was hereditary. The encounter also alerted him to the advantages of using pedigree data in genetic deafness research. In the early 1960s, comparing patterns in and across pedigrees remained an important technique. Combining family and population studies allowed the identification of similar phenotypes, and, potentially, of subforms of hearing loss. Ideally, one could then speculate about underlying genes.⁶⁸⁰

In deafness research, schools had long been a favorite location for finding long-term and large-scale data for genetic analysis. Medical records and family histories, often collected over generations, provided ample material for pedigree and population studies. Nance, too, soon realized this potential. Following his initial patient’s history into a family network of more affected individuals, Nance became intrigued with the possibility of identifying deaf individuals with the

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⁶⁷⁹ Interview Nance 2006, 3-5, 66-68.
⁶⁸⁰ Ibid., 37-38.
same surname as “a way of grouping individuals who had the same type of genetic deafness.” This realization led him to the Tennessee School for the Deaf in Knoxville where generations of deaf students had generated rich records.\footnote{Ibid., 1.} Compared to the path professionals took into deafness research, Nance’s interest in populations and traits most closely resembled the work of Kenneth Brown work at the Clarke School. This manner of entry to the field would strongly influence Nance’s approach to deafness as a preventable, biochemical genetic condition.

**The primacy of audiology: Genetic research in the Wilkerson Hearing and Speech Clinic**

Nances first forays into genetic deafness research soon found an institutional context in the Bill Wilkerson Hearing and Speech Center in Nashville. The Wilkerson Center had been established in 1951 by otolaryngologist Dr. Wesley Wilkerson to provide speech training and medical services to deaf children, and to research hearing loss. In particular, the center offered services to toddlers and preschool children, a group few schools targeted. Wilkerson’s model had been the California John Tracy Clinic, which offered in-house and mail courses for parents of young deaf children. Like the John Tracy Clinic, the Wilkerson Center was strictly oralist in orientation, providing parents with the tools to help their deaf toddlers acquire speech and language as early as possible. For this purpose, the center also established a preschool education program for deaf children at local schools. The program was
administered by Martha Buchman, a teacher trained at the Clarke School. Nance’s first decade of research thus took place in a setting that perceived deafness strictly as pathology to be cured, reversed or prevented. In many ways, the Wilkerson Center was built on the longer tradition of scientific oralism as explored in previous chapters. Yet where the Clarke School had always put speech therapy first, the Wilkerson Center’s approach was built around the use of latest hearing aid-technology.

Instead of the traditional “speech and hearing,” explained the first director, audiologist Freeman McConnell, hearing explicitly had been put first in the center’s name, claiming primacy over the older field of speech pathology. Their “auditory method” promoted fitting deaf toddlers – or even infants – with hearing aids as early as possible as the first step in rehabilitation. The rise of rehabilitative audiology occurred in the wake of treating hearing loss caused on the battlefields of World War II. The availability of individual portable hearing aids from the 1940s on furthered this development and made rehabilitative audiology attractive to deaf education. Hearing aids, Cleveland Hearing Clinic supervisor Ruth Bender wrote in her 1970 *The Conquest of Deafness*, had promised to become the “most revolutionary change” in adaptive technology. They would break the “barrier of silence” and finally make possible the “use of more normal techniques and materials in teaching deaf children.” Advances in

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683 McConnell, Wilkerson Center, 32, 86.
hearing aid technology appeared to finally fulfill the very ideal of oralist education: deaf children’s “assimilation in the education of normally-hearing.”

As other representatives of scientific oralism, McConnell believed that with the advance of modern technology, deaf children could be turned into (almost) hearing ones. “[A]ll deaf infants,” McConnell asserted, “should be given the opportunity to hear through use of wearable hearing aids providing consistent and continuous acoustic input.” Ever-earlier intervention transferred responsibility from schools and teachers to parents. Parents, McConnell believed, “assume the major responsibility for the child’s developing use of hearing and language.” For the Wilkerson Center, deafness was a fixable disability, if only professionals, parents and the child tried hard enough.

As at the Clarke School, the work of the Wilkerson Center was complemented by research and professional training. Together with Vanderbilt University, the center offered a research and training program in audiology and otolaryngology. Numerous research projects, many supported by external grants, explored language acquisition in children with hearing loss, diagnostic audiology or hearing aid technology. Although most research was concerned with audiological questions, genetic deafness research, too, was an important area of collaboration between Vanderbilt and the Wilkerson Center. From 1966 to 1974, both partners received a grant of almost $4.2 million from the National Institutes of Neurological Diseases and Blindness for their Experimental Studies in Hereditary Deafness. Project members formed the multidisciplinary Vanderbilt

684 Bender, Ruth E. 1970. The conquest of deafness; a history of the long struggle to make possible normal living to those handicapped by lack of normal hearing. Cleveland: Press of Case Western Reserve University, 169, 178.

685 Ibid., 87.
University Hereditary Deafness Study Group. Freeman McConnell served as project director, Walter Nance and Vanderbilt otolaryngologists and audiologists as principal investigators. Medical social worker Anne Sweeney became assistant director of the Wilkerson Center Heredity Deafness Unit.686

Adding this unit to their services, the Wilkerson Center complemented its profile as a comprehensive provider of services addressing deafness. Historians have given little attention to genetic research and counseling conducted at such hybrid institutions that education, research and rehabilitation like the Wilkerson Center or the Clarke School. Certainly, the center shared certain traits, including its clinical routine and research methods, with early centers of medical genetics, such as the Department of Medical Genetics at Wake Forest University under C. Nash Herndon. Its weekly clinic, operating from 1966 to 1974, when funding was discontinued, brought together physicians with a “special interest in genetics, internal medicine, neurology, cardiology, otolaryngology and radiology, audiologists” as well as a psychologist and a social worker (Anne Sweeney). In this context, genetic counseling “was given to relevant family members as they were encountered in the clinic and appropriate medical referrals were made for other medical problems.” Counseling informed patients on “the risk of having a hearing impaired child.” With the patient’s consent, researchers also forwarded the genetic results to their family physician.687

686 Ibid., 69, 115-118. For Sweeney, see the Anne J. Sweeney Papers. Eskind Biomedical Library Special Collections, Vanderbilt University Medical Center, Nashville, TN.

Another important feature the Wilkerson unit shared with heredity clinics was its location in rural surroundings considered ideal for population studies because of high rates of intermarriage and low geographic mobility. Thus Nance commented in 1975 that central Tennessee “offered unusually rich resources” for research due to a “high degree of geographic stability and consanguinity.” Over the six years of its operation, the clinic “provided an abundance of family material, far exceeding the capacity of the project staff to complete.”

Yet in other regards, the center operated in a framework that resembled more that of the Clarke School than that of heredity clinics and genetic departments. Both institutions were guided by the tenets of scientific oralism, utilizing science and medicine to improve rehabilitation and education, identification and prevention. At the Wilkerson, too, heredity research was embedded in a larger educational paradigm that envisioned and regulated the life of the deaf child and his family far beyond reproductive matters. Clients came to the Wilkerson Center for rehabilitation, or for audiological or preschool services, and only then were recruited for genetic research. Their long-relationship with the center was build around questions of education and rehabilitation, and hereditary advice was embedded in this framework.

This commitment had practical consequences for counseling. Similar to the Clarke School, Wilkinson Center staff perceived genetic deafness as embedded in matters of family networks and education. The final report for example reported on a family with an x-linked form of deafness with “nine deaf males in three generations, all manual language users.” There was, however, also

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a “three-year-old affected child who may become an oral communicator because of early discovery and therapy.” Respectively associating oral and manual communication with success and neglect (or failure), the report promoted a philosophy of salvation through early discovery. Like at the Clarke School then, education and rehabilitation for the current generation was complemented with hereditary counseling to prevent deafness in future generations. Patient perspectives did not enter writing and research. Whether the manual language users in this and other families indeed considered sign language a deficit (and not rather an efficient tool of communication in multi-generational deaf families) or wished their children to receive audiological rehabilitation was not unquestioned.

Like other researchers in the 1960s and 70s, the Tennessee group believed that with the causes for environmental hearing loss identified or controlled, genetic etiologies deserved special attention. Here, they contributed to exploring an ever-increasing number of known forms of genetics hearing loss. All in all, the group identified nine new forms of deafness, including several dominant and one x-linked form and a potential subform of Usher Syndrome. This was a major achievement for a rather small project, and telling for the rapid progress research saw in this period. Non-syndromic deafness was of particular interest to the Nashville group, presenting, as Nance and his coauthors wrote in a

689 Ibid., 4.
690 McConnell et al, Final report, 1, 3-4. Also see e.g. Nance Walter E., and Anne Sweeney. 1971. “Evidence for autosomal recessive inheritance of the syndrome of renal tubular acidosis with deafness.” Birth Defects Original Article Series 7 (4): 70-2. Nance and Sweeney speculated that the frequent occurrence of cochlear lesions and renal disease was due to a metabolic error in electrolyte transport.
For an overview of known forms and syndromes see Fraser, George Robert. 1976. The causes of profound deafness in childhood: a study of 3,535 individuals with severe hearing loss present at birth or of childhood onset. Baltimore: Johns Hopkins University Press.
1973 article, “a large group of genetically heterogeneous and challenging diseases for the clinical geneticists.” As an example, they presented two unrelated, large Tennessee kindreds with numerous deaf members who at first glance showed no other noteworthy traits other than hearing loss. Meticulous and multidisciplinary research, however, the authors argued, had made visible subtle, but telling features. “[C]loser scrutiny,” they wrote, “has revealed significant psychosociologic and audiolologic differences between 2 kindreds.” In kindred A the authors had noted a certain “lethargy” as well as a “native common sense and a strength of countenance as is often seen in the faces of the mountain people of Kentucky and Tennessee.” This problematic assertion of group character, strongly reminiscent of earlier eugenic studies, remained an anomaly in Nance’s work. Pointing to the usefulness of audiological tests, on the other hand, built on a much longer tradition in genetic deafness research. “[D]etailed audiolologic studies, “Nance and his coauthors believed, “may assist in locating possible carriers relative to genetic counseling in kindreds with known hereditary hearing loss.”

With the Vanderbilt Hereditary Deafness Group, Nance began his research in a setting that championed an oralist, medical and curative approach. Similar to the Clarke School, genetic research, counseling and education were closely connected. In this institutional setting, Nance’s early research remained distant, abstract explorations that connected his interest in family history with the identification of traits and biochemical phenomena. The focus was on the population rather than the individual who featured mainly as an interesting

specimen and as part of a kindred. Deaf patients and their family members appear as passive objects of research, as recipients of services that would assess and restore them. Soon, however, in very different institutional settings, Nance would encounter different, probing and more active deaf perspectives.

**Venturing into Deaf culture: A geneticist at Gallaudet**

By the late 1960s, two different models of deafness had become available to professionals willing to cross disciplinary borders, one defining it as a debilitating, yet remediable disability, the other as the uniting trait of a disadvantaged social group. As they vied for the support of professionals, parents and deaf people themselves, these models offered different ways of justifying social, political or scientific authority to different audiences. Oralist institutions like the Clarke School, the Tracy Clinic or the Wilkerson Center, with their associated professions of teachers, audiologists and speech therapists, delivered a powerful message to hearing parents of deaf children. In a “moving and poignant” parable of human perseverance against adversity, the deaf child was to overcome his difference to become like his hearing peers and family.692 Psychologists such as McCay Vernon or Edna Levine, on the other hand, criticized treating the deaf child as if he or she was hearing, merely with piece of assistive technology attached. To them, this represented a very denial of deafness that was detrimental to developing a healthy self-esteem and personality. Aligning themselves with larger causes of social and health justice allowed them to justify their research with the politically-charged language of minority rights, oppression and diversity and to portray themselves as advocates

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692 McConnell, Wilkerson Center, 3.
of Deaf culture, community and sign language. Disability, in their perspective was as much external, caused by discrimination and prejudice, as it was a physical fact.

Vernon, Levine, and to a lesser extent the NYSPI aligned themselves with communities of deaf adults. The 1970s were a transitional period for the American Deaf community. The 1970s, historian Jack Gannon remarked, "was the decade of more awareness of deaf people, better understanding, and increased involvement." Not the least, the social and professional positions of deaf people were changing along with American society at large. Since the late 19th century it had been a community whose members primarily worked in blue-collar professions, espoused working class culture, and read, as their national newspaper the *The Silent Worker*. Schools for the deaf mainly educated their male students for skilled work such as printing or woodworking. By the 1960s, improving educational and professional opportunities provided deaf people with upward social mobility to the college-educated middle class. The number of deaf people in administrative positions and higher education, already on the rise in the 1960s, grew at an impressive rate. Higher education also opened up for deaf people. 1974, 23 deaf Americans had been awarded a PhD; many more would follow in the next decades.

As Deaf studies scholars Tom Humphries and Carol Padden have pointed out, these changes in professional make-up had a profound influence on long-established institutions of Deaf cultures, such as the clubs, sport teams and associations. Deaf clubs, with their working-class pastimes of bars, card-games

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and community theater began losing their allure to a more educated and more mobile middle-class. Professional agencies took over their functions as centers of information, and new forms of political activism replaced them as locations for community-formation and lobbying. Activists engaged in awareness-raising, protests and anti-discrimination lawsuits. During the 1970s, the Deaf community entered public awareness as one of America’s minorities striving for equality and justice alongside other Civil Rights movements. Awareness programs – the first Deaf Awareness Week was launched in Colorado in 1972 – and conferences – for example the 7th World Congress World Federation of the Deaf at Gallaudet in 1975 – drew public attention to the Deaf community as a self-confident sociocultural minority.695

The growing visibility and acceptance of this activist and sociocultural minority approach was essential to Nance’s reorientation toward a more egalitarian, two-sided relationship with his objects of research in the early 1970s. He and his contemporaries did not necessarily consider this model as an irreconcilable opposite to a more medical-pathological approach. As with the protagonists described in previous chapters, contact with deaf people in different social and institutional situations shaped and changed his attitudes toward deafness and deaf people.

Although he began working on deafness in a strictly oralist environment, Nance soon encountered a different understanding of deafness. He was

introduced to Gallaudet College, the most important center of Deaf culture in the US, through his research of genetic deafness at the Wilkerson Center. When he heard about the Nashville project, George Fellendorf, executive director of the A. G. Bell Association, contacted Nance to tell him about Edgar Allen Fay’s 1898 *Marriages of the Deaf in America*. Looking at Fay’s 500-page volume with the tabulated pedigree information of 10,000 marriages, Nance realized its value for current genetic research. Some of Fay’s material was housed at the Volta Bureau, the A. G. Bell Association’s headquarter in Washington, D. C. The main part, however, were located at Gallaudet. As had his visits to the Tennessee School for the Deaf, visiting Gallaudet and Fay’s materials stoked Nance’s interest in studying the marriages of deaf people as a way to chart different forms of hereditary deafness, in particular syndromic forms.\(^{696}\)

As with his earlier visits to the Tennessee School for the Deaf, Nance initially considered Gallaudet merely “a tremendous resource” for pedigree data. Yet his visits to the campus brought him into contact with a self-confident community of signing deaf adults. As the only liberal arts college for Deaf people in the US (and the only college for the deaf until the establishment of the Rochester Institute of Technology National Technical Institute for the Deaf in 1965), Gallaudet had been the center of deaf social life since the late 19th century. For the college-educated deaf elite, it was a place where Deaf culture and community was lived and passed on. Many deaf students found their partners

\(^{696}\) Nance Interview 2006, 36-37; Vanderbilt Final Report, 8; Fay, Edward Allen. 1898. *Marriages of the Deaf in America. An Inquiry Concerning the Results of Marriages of the Deaf in America.* Washington, D. C.: Gibson bros., printers and bookbinders. Fay’s data remains an important research resource in genetic deafness research. An ongoing project of the Gallaudet Genetic Service Center, in cooperation with the Department of Human Genetics at the Medical College of Virginia tries to connect current pedigree data with Fay’s pedigrees. See https://www.gallaudet.edu/genetics/about_us_-_services_and_research/research_projects.html
there and later settled in the DC area. With a network of well-educated students and alumni, Gallaudet and the DC area also became the most visible center of Deaf activism in the 1970s and 80s.\(^697\)

Gallaudet presented Nance with a very different image of deafness and deaf people than had his experiences at Vanderbilt and the Wilkerson Center. Being “thoroughly exposed to a large number of individuals who were communicating in sign language,” he recalled, left “a strong impression.” He commented: “I realized that if this was going to be a major interest of mine that I needed to know about and hopefully embrace the attitudes of the deaf towards their hearing loss.”\(^698\) In order to reach to this group as a geneticist, one had to understand their particular needs and preferences.

Nance began to collaborate with Gallaudet on several research projects at a time when it was transformed from a small, isolated liberal arts college into a modern research university and center of academic research on Deaf culture and sign language. Until the mid 1950s, Gallaudet had served the dual – and strictly separate – purposes of providing deaf students with some degree of higher education and offering a master’s degree to future teachers of the deaf. The latter received their degree from the Department of Education (called the Normal Department), which, into the 1970s, barred deaf students from admission. For the deaf students who received a college education, expectations were low. Many did not graduate. Insufficient facilities, equipment and inadequate quality of teaching did little to inspire academic rigor. Professors often taught multiple


\(^698\) Interview Nance 2013, 2, 3.
objects, yet had little expertise in any of them. Among the 58 faculty members of the 1955-56 academic year, only nine held a doctoral degree, 33 a Master’s and 18 had no advanced degree at all. At this time, the college had begun to address these issues and in 1955 achieved accreditation from the Middle States Association. Greatly expanding the number of programs and services, and improving their quality significantly increased Gallaudet’s attraction in regard to research and education in the 1960s and 1970s. Enrollment numbers rose from 294 undergraduates in 1955 to more than a 1000 in 1970. The growing faculty, counting 200 by 1970, now included an increasing number of deaf and hearing PhDs. Research, which before had been sporadic, erratic, and of low priority in a faculty hardly qualified for any research activity, now became integral to Gallaudet’s mission. By 1964, the college had established five research units: a Hearing and Speech Center, the Offices of Institutional Research and Psychological Research, a Sensory Communications Research Laboratory, and the Linguistic Research Laboratory under William Stokoe. The establishment of the Powrie V. Doctor Chair of Deaf Studies in 1972 marked the beginning of the formalized academic study of Deaf culture, language and community.699

Beginning his work at Gallaudet just at the moment of this transformation, Nance helped expand research activity there. In the early 1970s, he began cooperating with the Gallaudet Offices of Institutional Research and Psychological Research. Renamed Office of Demographic Studies in 1966, it helped establish sociological research of Deaf culture and community at Gallaudet. From 1966 to 1968, the office was led by Jerome D. Schein, a clinical

psychologist who had become Professor of psychology at Gallaudet in 1960. As a new faculty member, Schein was required to acquire some proficiency in sign language, which he learned enthusiastically in informal sessions with deaf staff members. His experiences at Gallaudet turned Schein into a lifelong advocate for the Deaf community and sign languages. Surveying the DC metropolitan area deaf population, his 1968 *The deaf community: studies in the social psychology of deafness*, in some ways replicated the NYSPI study of the New York State deaf population to which he referred frequently. Schein, however, went further in asserting deaf people’s normalcy and particularity. His study described the DC area deaf as an average subpopulation that had successfully adapted to majority society while also maintaining their own subculture. Deafness, Schein wrote, “is not a disease, it is a functional disorder.” At the same time, however, it could also be a social category that marked the belonging to a community.

With his definition of deafness as a functional disorder and a sociocultural marker, Schein’s work mirrored some of the ambivalence and admiration that had already characterized the NYSPI research. Yet in the more politicized and polarized 1970s, he, like McCay Vernon, addressed more vehemently the causes and consequences of bias and discrimination – the external functions that turned deafness into a disorder in the first place. These were social as much as they were scientific. In a 1968 talk on the “The psychology of Deafness” for example, Schein indicted the methodological errors upon which the field rested. In “the

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land of Psychometrics,” he admonished, “the danger is in the conceptual error which stems from confusing the existence of a condition with its logical necessity.” The low educational achievements of deaf children, he believed, were not caused by the deaf child's inability to learn as well as its hearing counterpart, but was by educators’ belief that this was the case: “the disadvantaged child, on first entering school, already has learned not to attend, not to try, as well as having learned active ways of misbehaving.” Thus, the “comparative language deficits found in deaf children, like those in mentally retarded or Negro or Sephardic children, must first be attributed to failure to teach.” Retardation, Schein believed, was not a primarily matter of innate deficiency, but of “environmental factors associated with low economic status – sensory, linguistic, and experiential deprivations.” Once more, deprivation and minority research could be utilized to argue for socioeconomic over innate factors. “To expect the average deaf child to achieve as much as the average hearing child,” Schein ended provocatively, “is as fantastic as to expect a man to walk on the moon” – a feat that would be realized the very next year.702

With Schein, the Office of Demographic Studies thus had a director well-suited for turning current political thought and social activism into academic research. Much of the Office's research, however, was much more mundane, owing to Gallaudet's position as an administrative center of deaf education. Among the Office's most important tasks was the Annual Survey of Deaf and Hard of Hearing Children and Youths, established in 1968. Every year, the Office of Demographic Studies sends out one confidential form per student to all

702 Ibid. 91, 93-95, 97. For deprivation theory in deafness research see chapter V, for its use in sociolinguistics and in educational programs see Raz, Mical. 2013. What's wrong with the poor? psychiatry, race, and the war on poverty. Chapel Hill: University of North Carolina Press, 52-58.
schools serving deaf and hard and hearing children from preschool age through 12th grade. The form collects demographic, audiological and educational information. While participation is voluntary, to this day it is considered the most extensive database of childhood deafness in the US. Survey data has been used to plan the educational needs of deaf children, to measure their achievements, or to devise specialized versions of standardized tests.\textsuperscript{703}

Collecting data on family background, etiology and onset of deafness, the annual survey also provided valuable information for genetic research. From 1969 on, Nance and his research team, first at Indiana University and later at the Medical College of Virginia, utilized this data in various NHI-funded projects to identify genes for hearing loss. In the mid 1970s Nance also served as a member of the Annual Survey’s National Advisory Committee. Further collaborations included a pedigree linkage study of the 1973-74 Gallaudet student body, a 1975 booklet (featured in the last chapter) called \textit{What Every Person Should Know about Heredity and Deafness}, and Nance’s involvement in Usher Syndrome community around McCay Vernon.\textsuperscript{704} These venues provided Nance with an opportunity to develop a definition of deafness as a heritable, yet not necessarily pathological trait. Genetic counseling and awareness, he believed, would provide deaf people with medical-genetic uses, yet at least as much with psycho-emotional benefits.


Counseling the deaf – or being counseled by the deaf?

Communicating an “unmet need.”

“No single group,” Nance claimed in 1971, “can profit more from [genetic] counseling than the hearing impaired.”705 In the history of genetics, the profits gained from genetic information have been defined in a multitude of ways: Genetic counseling can inform the individual, couple or family about their risk for a certain hereditary trait, and thus act as a form of disease prevention. From mid-century on, geneticists also increasingly emphasized the emotional and psychological benefits of being aware of one’s genetic make-up, and thus, implicitly, of knowing one’s future. In this scenario, the geneticist became, to use Kallmann’s phrase, a short-time therapist dispelling fears or aiding clients to come to terms with a difficult situation.

As a physician, Nance had experience with both the element of disease prevention and of providing advice and emotional support. Over the course of the 1970s, however, his emphasis in counseling deaf people shifted from generalized disease prevention to individual psychosocial benefits. In a way then, Nance’s development mirrored that of Vernon, yet where Vernon wrote for an audience of educators, psychologists and rehabilitation workers, Nance was a physician and bioscientist engaged in debates about applied genetics. Moreover, where Vernon continued to pursue a clear preventive and eugenic goal, Nance dismissed Vernon’s overly optimistic hopes of changing the total gene pool through screening programs or individual counseling.

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For Nance, this transition in approaches was embedded in larger debate over non-directiveness and patient autonomy in genetic counseling. A notoriously vague term, non-directiveness has an ambivalent history. Keeping with Cold War rhetoric, postwar geneticists had adopted this term alongside the ideal of client autonomy. They considered it a more democratic way of pursuing eugenic goals, not based on coercion, but on establishing an equalized relationship with a rational client. Nance embraced non-directive approach because it catered to individual needs rather than social goals. Non-directive, client-centered counseling, he and others believed, was safely removed from earlier misuses of genetics in the name of eugenics. This was, no doubt, a powerful and invigorating paradigm, yet misleading in its claim to be free of sociocultural influences and economic pressures. As the history of genetic counseling for deafness has demonstrated, the assumption that counselor and client shared the same definitions of good and rational reproductive behavior was tenuous at best. 706

Non-directiveness also became the professional paradigm of genetic counselors who were neither geneticists nor physicians, but graduates from new, MA-level programs. The first of these programs had been established in 1969 at Sarah Lawrence College in Bronxville, New York. Similar programs followed at the Universities of Pittsburgh and Denver in 1971, Rutgers University in 1972, and the University of California at Berkeley and Irvine in 1973. The vast majority of graduates from these programs were (and remain to this day) women. A degree in genetic counseling, Stern has pointed out, provided much-demanded

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professional opportunities for women in health care. This new group presented a
challenge to the predominantly male MDs and PhDs who, up to this point, had
exclusively provided genetic counseling in heredity clinics and medical genetics
departments. In the early 1970s, some leading members of the American Society
for Human Genetics (ASHG), the leading organization of the field, voiced their
alarm about the rise of MA-level counselors. In their opinion, this new group
lacked the education and expertise to provide genetic guidance. Despite the
animosity of those early years, however, by the end of the 1970s, MA-level
counselors had successfully carved out their niche in the expanding genetic
healthcare scenery.\textsuperscript{707}

Sympathetic to the second wave Women’s Movement, this group of
predominantly white middle-class counselors tied non-directiveness to feminist
ideals of female reproductive autonomy. Like with their male counterparts, this
did not mean giving up preventive goals; merely that these goals were negotiated
or assumed to be shared between client and counselor. Non-directive counseling
thus was not without ethical conflict, yet it nevertheless made possible
definitions of health or disability that were relative to a group or individual. At
the NYSPI, for example, the emphasis on the psycho-emotional benefits of
counseling in particular allowed for a more relative assessment of the impact of
hearing loss on an individual, couple or family.\textsuperscript{708}

For Nance, this shift toward non-directive counseling occurred alongside
a changing audience. In his publications with the Gallaudet Office of
Demographics, for example, he now addressed deaf people themselves.

\textsuperscript{707} Stern, Revolution; Stern, Telling genes, 15, 24, 102-122.
\textsuperscript{708} Alexandra Stern has shown a similar impact in the exchange between counselors and parents
of children with disabilities, in particular those with Down Syndrome Stern, Telling Genes,
102-145.
Promoting genetic knowledge to physicians and professionals required pointing to its benefits in diagnosis, treatment and patient management. Addressing and interacting with deaf people, on the other hand, meant portraying deafness not as a disease to be cured but as an acceptable genetic variation. With professional and lay audiences alike, Nance advocated genetic awareness as a benevolent and useful form of self-knowledge, necessary for navigating life, health and reproduction. Below, I will trace the transformation in his thinking about deafness and the benefits of counseling for different audiences.

Addressing physicians and deafness specialists, Nance emphasized the usefulness of genetics for diagnosis, prognosis and potential therapy – a theme that would certainly resonate with this audience who had long been acutely aware of the hereditary dimensions of hearing loss. Genetics, he assured the readers of the *The Annals of Otology, Rhinology, and Laryngology* in 1971, had much to offer to physicians. “Genetic counseling,” he explained, “is one universally applicable forms of therapy for hereditary deafness.” In the past, he conceded, “the information provided by the genetic counselor was mostly pessimistic in nature.” Yet “the advent of prenatal diagnostic techniques has added a whole new dimension to genetic counseling.” Genetic deafness was to join the growing number of conditions that could be prenatally diagnosed by amniocentesis or ultrasound. Genetic information was crucial to medical practice, offering diagnostic clues. Like other geneticists in the 1960s and 1970s, Nance hoped to tie together biochemical defects with their underlying genetic patterns. In the future, he speculated, different forms of deafness could be treated, if not cured on this biochemical level. “Here, truly,” he praised
euphemistically, “we have a cure looking for a disease.” This statement was entirely speculative – the disease of deafness was well-defined; biochemical cures remained elusive – but nevertheless evoked a powerful image of the superior capabilities of genetics vs. other sciences concerned with deafness.

Jervell-Lange-Nielsen Syndrome offered a dramatic example for the usefulness of early diagnosis. In this autosomal-recessive condition, sensoneural deafness occurs together with often fatal heart arrhythmias. Undiagnosed, individuals with the syndrome often died young and suddenly after fainting attacks caused by physical exertion or excitement. In the future, Nance speculated, these arrhythmias might be detected by fetal ECG. He left open whether a positive fetal electrocardiogram should be an indication for abortion, or merely an opportunity for close monitoring of the child. Syndromic deafness thus showed the benefits of genetic knowledge for treatment – if not of deafness, then for the graver accompanying conditions – and pointed to possibilities for prenatal diagnosis.

At the same time as he advocated biomedical solutions, Nance also pointed to the psychotherapeutic usefulness of genetic counseling. In this realm, he considered genetics superior to medicine or audiology, which at the time could do little “to improve the hearing of the majority of children with hereditary deafness.” Promising clear diagnosis and predictive benefits, and thus, Nance believed, reassuring knowledge, genetics was the exception. The “service that can be performed to make a specific genetic diagnosis and providing accurate

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and compassionate counseling,” he argued, “is indeed impressive.” This mechanism depended on the – supposed – psycho-emotional benefits gained in moving from ignorance to awareness of one’s condition, a process which the geneticist facilitated with their counseling. “Perhaps the most significant effects of genetic counseling,” Nance commented, “are psychological in nature.” This assertion of superiority of and independence from medicine presented genetics as a gateway or master science, serving both emotional and medical needs.711

Psychological reasoning and considerations, the last two chapters have shown, grew in importance in genetic deafness research and counseling from mid-century on. This was true more generally for professional approaches to disability. Rehabilitation specialists, educators and psychologists shifted their attention from the functionalist appraisals of defects to the psychosocial effects of chronic conditions and disabilities. Understanding disability as a process of adaptation, negotiated between the individual and his surroundings, relativized definitions of innate defect.712 This shift occurred alongside a more general psychologization of society. After World War II in particular, historian of psychology Roger Smith has pointed out, “people internalized the belief that each person has the right and duty to make choices, founded on individual differences of inward feeling and outward capacity.” In doing so, they “looked to psychology to describe identity, to explain choice and to help to act with more freedom.”

711 Nance, Hearing impaired, 222.
712 This shift in professional paradigms has seen hardly any attention from disability scholars or historians of medicine and genetics. For some contemporary examples see e.g. Barker, Roger G. 1953. Adjustment to physical handicap and illness; a survey of the social psychology of physique and disability. New York: Social Science Research Council; Garrett, James F. (ed.). 1952. Psychological aspects of physical disability. Washington: Federal Security Agency, Office of Vocational Rehabilitation, in particular Edna Levine’s contribution on deafness, 125–146. For the influence of these psychological models on genetics see e.g. Shore, Miles F. 1975. “Psychological issues in counseling the genetically handicapped.” In Birch, Charles, and Paul Abrecht. 1975. Genetics and the quality of life: [papers of a symposium]. Sydney: Pergamon Press: 160-172.
Psychology, Smith continues, “flourished – and flourishes – because it was the means to square a circle at the heart of modernity: it appeared to meld, humanely and democratically, individuality, the values of liberal politics and effective social management, reconciling the interests of the individual and of society.”

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The rise of psychotherapeutically-oriented genetic counseling followed these same motives of individual and group identity, combining liberal beliefs in freedom with hopes for social management. Sheldon Reed, the “founding father” of genetic counseling, looked to Rogerian principles and strongly believed in the psychotherapeutic qualities of genetic counseling. Thus, establishing the likelihood of passing on certain conditions, the geneticist could encourage parents to complete their family with a “normal” child, plan for life with a disabled child and, like a true therapist, help them overcome feelings of guilt or shame about their genetic make-up.

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Nance echoed this professional paradigm when he explained in 1971 that “[a]ll normal individuals carry abnormal genes, and knowledge of their ubiquity can dispel unfounded feelings of confusion, shame, and guilt and help parents to face their child’s handicap in a rational manner.” Following Reed, he aimed to dispel the perception, still prevalent “[e]ven among physicians,” that “families with hereditary diseases are 'somehow' tainted.”

715 Like the psychiatrist at the

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715 Nance, Hearing impaired, 223.
NSYPI, he presented genetics as an enabling and reassuring profession, offering psychosocial therapy alongside genetic information.

While parents were not to blame for their genetic makeup, deafness remained coded in the language of disease and disability whereas the hearing child was associated with a happy, normal family. Counseling, Nance wrote, “can prevent the tragedy of a second affected child.” As a form of “remediation,” it might “allow the parents of an affected child to complete their family with normal children.” Such use of ‘normal’ and ‘disabled’ in genetic counseling, Ladd-Taylor has pointed out, contributed to the exclusion of disabled children from the idealized “normal” family. It portrayed the disabled child as a failed attempt, to be placed in an institution, and to be replaced as parents tried again to conceive (or adopt) a ‘normal’ child.

Genetic knowledge, Nance believed, was indispensable for deaf people and their families. Yet it was unattainable for most. “[G]enetic counseling of the deaf and for the parents of the deaf,” he explained to various audiences in the mid and late 1970s, was a “major unmet need.” Several examples from his experience underscored the gap between counseling needs and adequate facilities. Thus, in a survey of the 1973-74 Gallaudet student body, he had had inquired about other cases of deafness among the student’s families. The replies, he concluded, showed that families vastly underestimated the occurrence of genetic deafness. “These data,” Nance concluded, “dramatically illustrate the need for genetic counseling of the deaf.” By the 1970s, declaring genetic services

716 Ibid., 222, 231.
717 Parent organizations increasingly challenged these narratives of disability and suffering. See Ladd-Taylor, Reed, 78-80; Stern, Telling genes, 77-97.
an unfulfilled need was an established theme in genetic deafness research, merging the language of minority rights and democracy with that of consumerism and serving clients. Kallmann and the NYSPI in particular had contributed to this persuasive rhetoric of rights to services.  

Yet, “few schools for the deaf have organized genetic counseling programs,” Nance continued. A Gallaudet Office of Demographics survey, asking for the existence of genetic counseling at the 1,020 programs for deaf or hearing-impaired children in the US, had yielded only 49 positive answers. The Clarke School for the Deaf, he added, was “a conspicuous exception to this generalization.” This neglect, Nance believed, was not due to a general hostility or rejection of genetic principles on the part of educators. “As a group,” he thought, “superintendents of schools for the deaf are acutely aware of the value of and need for genetic counseling in their institutions.” Rather, it was human geneticists who were at fault. “[P]reoccupied with problems in which genetic counseling is often almost irrelevant,” they “neglected several potential markets in which their services are badly needed.” It was, thus, not deaf people’s fault for being genetically uninformed. Rather, Nance locating fault with geneticists and deafness professionals, echoing the criticism of the NYSPA or of McCay Vernon, who had similarly pointed to the lack of counseling services at schools for the deaf, and to the lack of geneticists serving the deaf.

With his comments about potential markets, Nance also furthered a consumerist-capitalist notion of genetic medicine, in which geneticists surveyed

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719 Nance, Hearing Impaired, 213-214.
720 Nance, Studies, 9.
different genetic conditions for their medical and professional profitability. This problematic definition turned patients into paying clients without ever addressing socioeconomic inequalities, and assumed that once services were fitted to the target population, they would be used appropriately. In identifying these markets, he once more pointed to schools for the deaf as the ideal location for establishing genetic counseling centers with “large numbers of patients with genetic diseases.” Unlike a clinic, “where only a minority of patients seen actually have a genetic disease,” schools for the deaf, but also for the blind or other institutionalized populations were locations where “the unique abilities of the geneticists” could be “fully used.” This vision of a school-based genetic counseling program with specialized counselors would later be realized in the Gallaudet Genetic Service Center.

Like the NYSPH mental health program for the deaf, Nance portrayed the deaf as a specific subpopulation with specific needs. What these needs were, however, remained unclear. “The process of genetic counseling,” he admonished in 1975, “has been extensively studied in hearing patients, but little is known about the factors which contribute to successful genetic counseling among the deaf.” Operating under the ideal of non-directiveness and influenced by his experiences at Gallaudet, Nance’s work in the 1970s staked out the determinants of a form of genetic counseling desirable to deaf people.

Non-directiveness, Nance recognized, depended on successfully establishing good rapport and communication with one’s clients. Communication obstacles were an obvious problem in genetic counseling for deaf people. If the

722 Ibid.
723 Nance, Studies, 10
counselor could not communicate in sign language, Nance and his student Susan Rose Pilant advised in 1977, he or she should use an interpreter. The availability of professional interpreters was in itself a new development. The National Registry of Interpreters for the Deaf had been established only in 1964. In turn, paid and certified professional interpreters gradually replaced the long-standing (yet often ethically challenging) tradition of voluntary, unpaid interpreting by friends or family members. Ideally however, the genetic counselors signed fluently enough to communicate directly. Their own counseling, Nance and Rose Pilant commented, had become more successful “since we have hired a genetics assistant who speaks manual language.” The latter probably referred to Joann Boughman.\(^{724}\)

Once communication was established, encounters with deaf clients revealed startling differences between the counselor’s values and that of the client. What, asked some clients such as the young bride quoted above, was wrong with being deaf? What, indeed, was wrong with it? If one believed in genetics as a science serving the individual rather than society, in client autonomy and non-directiveness, there was no longer a normative answer to this question. Yet the reliance on client autonomy and rationality also offered a solution that largely excluded sociocultural influences that would have complicated the client-counselor relationship, as the following example shows.

Nance was not the only one to ponder divergent values between deaf people and genetic professionals. In 1977, Nance presented his work at a conference on genetic counseling, organized by the National Institute for Child

\(^{724}\) Nance et al., *Opportunities*, 323, 330. For the history of the National Registry of Interpreters for the Deaf see Gannon, *Deaf heritage*, 327-328.
Health and Development. Following their presentation, he engaged in a discussion on the potential stigma implied in seeking genetic counseling. Deaf people, a Dr. Miller (whose first name and background remained undefined), pointed out, were “reluctant to accept counseling” because they found it stigmatizing. In Miller’s experience, deaf people thought that they “could survive and function normally.” Why then, Miller asked, should the deaf “point the finger” at themselves by attracting the attention of genetic professionals, why “should they limit [their] families, why even consider genetic counseling?” Given the stigma involved, he asked, did geneticists have “any right to counsel these people?” For Miller, the question of counseling deaf people was not primarily a medical or scientific one, but an issue of deaf people’s social position in a society where scientific scrutiny might bring more disadvantages than benefits. His reference to stigma evokes sociologist’s Erving Goffman’s influential studies of the social dynamics of exclusion and difference by example of disability.725

Nance’s reply operated on a different level. Where Miller thought in terms of sociocultural relations, Nance’s model of genetic counseling focused more exclusively on the relationship between counselor and clients. It rested on the belief for the autonomous rational individual searched for information to lead the best life possible. Genetics was part of this set of knowledge, as long as the counselor remained neutral and did not impose his values. Thus, Nance replied to Miller’s concerns, from his “point of view, you have a right to counsel them. In general, people like to be informed about the future; what they do with that information is another question.” “Some deaf individuals,” he continued, “do not feel that deafness is a handicap.” This group, he conceded, appeared to be a

725 Nance et al., Opportunities, 330-331.
minority. Nevertheless, their opinion should be accepted: “I would certainly respect the right of a deaf couple to want a deaf child.” To achieve this end, he continued, the geneticist could even “help them select a partner.” For Nance, genetics was to be an enabling profession, willing to assist clients with their reproductive preferences, no matter whether they were considered “normal” or “deviant.”

Sociocultural influences were largely excluded from these considerations, or were assumed to be resolved in the counseling session as it led to a more informed, rational and autonomous state.

By the late 1970s, then, Nance had discarded his earlier universal definition of deafness as a disease to be cured. His self-understanding as a scientist interested in variation, rather than a physician aiming to cure disease helped facilitate this shift. To him, encountering deaf clients with diverging values and expectations pointed to geneticists’ failure in providing meaningful, non-offensive information. Nance’s focus on the counselor-client relationship, rather than larger sociocultural conflicts also eased this transition. In order for genetic counseling to be “therapeutic,” it had to explore and acknowledge the target population’s beliefs, and had to adapt counseling practice accordingly. Only in this manner, the deaf, too, would become genetically informed. By acknowledging divergent values among his deaf clients and communicating them to his colleagues, Nance became a mediator between these two communities. He remained, however, an outside observer of the Deaf community and never learnt sign language himself. Two of Nance’s students, Joann Boughman and Kathleen Shaver Arnos, took this mediator role farther as they became fluent signers and assimilated participants in the Deaf community. More than Nance, these

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726 Ibid., 330-331.
experiences would sensitize them for the sociocultural determinants underlying the relationship between counselor and counselee.

**Joann Boughman – from risk to chance**

Like Nance, Boughman had not known deaf people before entering genetics, and like Nance, encounters with deaf clients changed her perspectives on deafness and counseling. Unlike Nance, however, her professional identity formed in a decade of social activism, and changing professional values, many of which have already been outlined above. The 1970s were a decade of unprecedented visibility of Deaf culture and the rise of modern Deaf activism, of student movements staging antiwar protests and establishing counter cultures, of the women's movement demanding reproductive autonomy and professional opportunities, and of patient and disability activists unsettled traditional notions of scientific authority.

In this invigorating social climate, Boughman went further than Nance in her identification with the Deaf community. Her encounters with deaf people turned theoretical reflections on client autonomy and non-directive counseling into a practical issue and challenged preconceptions about genetic risk, disability and the modes of counseling. Research on and counseling for genetic deafness, Boughman became convinced, should be a cooperative enterprise with input from geneticists and the deaf community. This required the geneticists not only to learn about Deaf culture (as Nance had done), but also to become an accepted part of it. Sign language for Boughman was the vehicle to achieve assimilation and to turn genetics into a profession serving the community – a common ideal among health professionals in the 1970s. Only by eliminating the intermediary
position of the interpreter, was the counselor able to react immediately and without distortion to clients’ emotions, questions and fears.

Born in 1949 in Indiana, Boughman had entered Indiana University as an education major, but after working in a hospital laboratory during summers, changed her major to medical technology (clinical laboratory science) in her junior year. She graduated with a BS in 1972. Genetics had not been among her interests, until a friend suggested the field to her and “literally took me by the hand and took me over to the [Indiana University] genetics department.” She applied and was accepted to the PhD program in medical genetics where Walter Nance became her advisor. Indiana University had a distinguished history in genetic research. Herman J. Muller had been professor of zoology here when he received the Nobel Prize in 1946, and during the 1940s James Watson had studied at IU under phage geneticist Salvador Luria. By the early 1970s, the department of medical genetics attracted students from all over the US. They were trained in basic genetic research and its clinical applications, including courses in probability and statistics, biochemistry, biochemical and population genetics. The last was a field to which Boughman was particularly drawn and remained involved with for the rest of her career. For those entering human or medical genetics, education also included training in genetic counseling.

Boughman chose a traditional path for pursuing her interest in genetics and genetic counseling, yet she entered the field at a time when alternate career paths opened up with the emergence of MA-level genetic counseling programs in

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728 Interview Boughman 2013, 1-2, 4, 6.
the 1970s. Their predominantly female graduates have been credited with changing and diversifying the field, associating it with reproductive rights and assistive services. Unlike PhD geneticists whose focus was on research, and MDs whose goal was to prevent genetic conditions, MA-level counselors entered the field to assist clients in making genetically informed decisions in emotionally challenging situations. In doing so, they tapped into an older tradition of portraying female healthcare professional in caring, assistant and helping roles. Genetic counseling thus became a field associated with female qualities – with the usual implications for pay and status.729

While the history of MA counseling programs has been explored rather thoroughly, it has been treated as a development separate from that of the education of PhD geneticists, which, so the assumption, were predominantly male and received a traditional education. Yet, as Boughman’s example demonstrates, women were still entering PhD programs in genetics, and, like their MA-level counterparts, were inspired by the ideal of counseling as a caregiving profession. Boughman’s counseling training at the Indiana University Department of Genetics indicates that the development of a more individualized, psychologized genetic counseling was a more general trend and not limited to MA-level counseling programs. At IU, training included theoretical lessons as well as case studies, role-playing and supervised counseling. Students would first observe sessions in the genetics clinic, then would begin doing counseling on their own as a faculty member observed them through a two-way mirror. Students, Boughman felt, profited from faculty experience: “[W]atching numerous people do these things you would get a feel for where your comfort

zone was and how you would deal with the couple themselves.” Understanding and reacting to clients’ emotions and expectations in relation to their sociocultural and educational background was an important part of training; the application of non-directive counseling a much discussed topic.\textsuperscript{730}

This psychosocial, and indeed, psychodynamic approach was a far cry from the authoritative information giving practiced in the heredity clinics of the 1940s and ’50s. While Sheldon Reed’s iconic 1947 definition had imagined genetic counseling as a “kind of social work,” he nevertheless clearly considered the counselor as the one who worked on the counseled. Certainly, Reed’s notion of genetic social work influenced the IU program, yet more so, their approach drew from definition of genetic counseling a form of psychotherapy, as influenced Kallmann and Rogerian approaches. Understanding the counseling situation as socially dynamic process necessitated the counselor reflect on his or her emotions as they influenced the relationship between counselor and client. This reflective position potentially destabilized professional authority. This socially dynamic approach would be highly influential in Boughman’s counseling of deaf people, as was her conviction that it was emotional work, a helping and caring profession.

Her choice of subject for her PhD research, a \textit{Population Genetic Studies of Retinitis Pigmentosa}, was driven by her interest in population studies and wish to develop information meaningful to the target population.\textsuperscript{731} As the last chapter has shown, Retinitis pigmentosa – the cause for blindness in Usher Syndrome – began receiving considerable attention in the 1970s. This was due,

\textsuperscript{730} Interview Boughman 2013, 1-2, 4, 6.
in part, to advances in genetics, in part to McCay Vernon’s Usher Syndrome awareness campaign. Eventually, and almost inevitably, her work would bring Boughman in contact with Vernon. As detailed in the previous chapter, they collaborated in the 1980s.

Her first interest in retinitis pigmentosa had been raised by a talk at a department seminar. Soon after, Nance’s work provided her with a chance to apply this interest to counseling. Surveying the students at the Indiana School for the Deaf, Nance had encountered a young deaf man who seemed to have retinitis pigmentosa. At this point, Boughman had started assisting Nance as a medical technologist in his genetics clinic, drawing blood or providing medical tests. He asked Boughman for a second opinion, and, after she confirmed his diagnosis, she accompanied him for the counseling session that would become a turning point in her professional life. It took place on the day of the student’s high school graduation. He was the salutatorian of his class and his parents had come from out of town for the celebration. Facing the young man “in his cap and the gown,” Nance and Boughman had to explain to him and his family that he would lose his vision. At this point neither of them knew sign language. Relying on an interpreter to convey the diagnosis added communication insecurity to an already emotionally charged situation. To Boughman, this “was an absolutely devastating experience.” After discussing the event with Nance, she decided to learn sign language herself: “it was devastating to have to try to give this information to somebody. But to have to depend on a third party and not know
exactly what they were interpreting, exactly the words they were using, I can’t ever do that again.”  

By the 1970s, it was no longer unusual for hearing people to learn sign language. In fact, by this time, more hearing than deaf people took ASL classes for a variety of reasons, including a growing curiosity in Deaf culture and community. Sometimes, it was even (erroneously) considered the third most common language in the US. This interest certainly was stoked by the signing deaf artists, actors and activists who had entered mainstream media. Most prominently, the National Theatre of the Deaf, founded in 1967 by deaf actors with the support of Edna Levine and Boyce Williams, brought ASL as a language of the fine arts to stages and TV screens all over the US. As Douglas Baynton has pointed out, this growing appreciation of sign language was tied to larger changes in American society. 1970 pop and counter cultures considered physical expressivity authentic and natural, and celebrated foreign cultures – including those found within the US. In the 1950s and 60s psychological and sociological explorations of deaf communities had been mainly a professional enterprise limited to a few disciplines. In the 1970s, this interest generalized and was stoked by Deaf activists’ awareness raising and calls for equality. In this politicized atmosphere, learning sign language meant coming into contact with a group that was asserting their role in a more diverse American society.  

Boughman, then, was one of many professionals and lay people learning sign language in the 1970s. For her, taking classes and becoming “relatively

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732 Interview Boughman 2013, 2-3.
733 For the growing popularity of ASL among hearing people and visibility of Deaf culture see Gannon, Deaf Heritage, 372-376, Baynton, Signs, 154-157; Padden; Humphries, Deaf culture, 157-163. For the National Theatre of the Deaf see Gannon, Deaf Heritage, 346-356; Padden; Humphries Deaf culture, 109-116, 123-124.
fluent in sign” proved to be a transformative experience. It triggered an interest in learning more about Deaf culture, initiated her to the Deaf community and opened new venues for counseling deaf clients. “It was kind of like the ocean,” she described her experience, “first it’s small waves and then it just kind of consumes you.” Even though she “used an interpreter whenever appropriate,” she now was able to communicate and interact more directly with deaf clients.734

A shared language, new insights: counseling in sign language

Learning and operating in a different language brings with it the realization that words and concepts do not match perfectly. Rather, they mirror larger social or cultural differences, making translating as much cultural as linguistic work. This basic realization was at the core of a key experience brought about by Boughman’s counseling in sign language: Risk, she realized, was a relative concept, depending on client experience and background.

As a population geneticist, she had come to know risk as an abstract, statistic entity to be calculated from pedigrees and population data. Risk studies, Stern has shown, expanded in genetics after World War II. This growth was particularly strong from the 1960s on, when advances in cytogenetics, biochemical genetics and computational biology allowed for more precise, individualized predictions. Geneticists use three different forms of risk assessment: Most simply, they can look at Mendelian patterns of inheritance, assigning for example a 50 percent chance to passing on a dominant or a 25 percent chance of passing on a recessive trait. With many conditions, however, simple Mendelian inheritance was not applicable. This was particularly true for

734 Interview Boughman 2013, 2.
deafness, where many forms still could not be diagnosed, much less be tied to a clear Mendelian pattern. For such cases, empirical risk calculation, based on epidemiological patterns in specific populations, became popular from the 1950s on. Bayesian probability statistics, finally, allows operating with unknown quantities and provides a dynamic instrument for adjusting risk estimates as data input changes. These two methodologies proved particularly applicable for genetic deafness, where decades of research provided significant amounts of pedigree or medical information.\footnote{Stern, \textit{Telling Genes}, 31, 37, 41-42.}

Empirical risk tables provided a dynamic approach to individualized risk assessment, even if the form of deafness could not be identified or its pattern of inheritance was unclear. Nance and his students Susan Pilant Rose and Frederick R. Bieber had produced such tables for deafness, using genetic, statistic and medical data. These tables, Nance and Bieber explained in the 1979 \textit{Clinical genetics: a Source Book for Physicians} covered the “commonest counseling problems arising in normal by normal, deaf by normal and deaf by deaf matings.” If, for example, a deaf child was born to hearing parents, deafness could have genetic or environmental causes. Based on a large body of statistic data – more than 49,000 children born to more than 12,000 families – Nance and Bieber gave the initial recurrence risk of having another deaf child as 25 percent. If more deaf or hearing children were born to the family, the risk increased or lowered accordingly.\footnote{See Bieber, Frederick R; Nance, Walter E. 1979. “Hereditary Hearing Loss.” In. Jackson, Laird G., and R. Neil Schimke. \textit{Clinical genetics: a source book for physicians}. New York: Wiley: 443-461, here 456-458. Also see the theses of Rose and Bieber: Rose, Susan Pilant. 1975. \textit{Genetic studies of profound prelingual deafness}. PhD Thesis, Indiana University; Bieber, Frederick Robert. 1981. \textit{Genetic studies of questionnaire data from a residential school for the deaf}. PhD thesis, Virginia Commonwealth University, Dept. of Human Genetics. For risk evaluation in}
Employing these diverse risk technologies in her counseling, Boughman observed that her clients often understood risk in a manner quite different from her own statistician’s perspective. She was not alone in this observation. As genetics professionals communicated risk assessments to their clients, they observed how people tended to perceive the same numerical risk in very different ways. Thus, for some a risk of 10 or 25 percent was significant, for others acceptable or negligible. From the 1970s on, these observations fostered research on the social dimension of risk perception.737

Boughman’s clients, however, not only diverged in their perception of risk quantity, but also questioned what counted as risk or defect in first place. One counseling session in the late 1970s, in particular, made this clear. As she explained to a deaf couple their “risk” for having a deaf child, the husband, Boughman recounted, “said [signed] stop.” Referring the difficulties of raising a hearing child, the prospective father explained, “we don’t want to know the risk of a deaf child, we want to know the risk of a hearing child.” At “that moment,” she recalled, “my entire perspective was reversed.”738

With her categories of risk thus destabilized, the counseling session then turned into a “two-way learning experience.” Boughman apologized to the clients for her bias and shared her emotions about this “defining moment.” The couple, she recalled, appreciated her honesty and willingness to share her thoughts. Counseling became an intercultural exchange in which the counselor explored and revised her emotions together with the clients. In doing so, Boughman,

cases where the cause of deafness could not be identified also see Fraser, Profound deafness, 336-342.
738 Interview Boughman 2013, 4.
became both dependent on and indebted to her clients’ willingness to share their values and beliefs. She explained: “I will be forever grateful to that couple in that moment, because it really did change me.” Her “genetic counseling experiences,” she explained, “helped formulate and define my understanding and feelings about that, deaf culture and appreciate their position.” In this constellation, counseling practice informed research on developing forms of genetic knowledge that mattered to the target population.\footnote{Ibid.}

Historians of genetic counseling have assessed its practitioners by the goals and ideals they pursued, by their assertions of professional expertise and authority, and by autonomy they granted to clients. In counseling deaf people, professionals had pursued different strategies, from the holistic approach of oralist educators to the more narrowly defined reproductive counseling provided by geneticists. Even among those who favored a minority model of deafness, believes and approaches differed significantly. At the NYSPI, Kallmann had maintained a directive stance when it came to preventing mental illness, while his younger collaborators believed in providing neutral information for autonomous decision-making. McCay Vernon combined directive reproductive advice for individuals with Usher Syndrome with advocacy for Deaf culture, and Walter Nance downplayed eugenic or medical effects in favor of emotional benefits. Although some took into consideration client perspectives, all these approaches maintained the line between layperson and professional.

Equalizing the power differential between counselor and clients, Boughman introduced a new language of negotiation. Retold as a conversation between equals, this counseling session clearly put the authority to define the
value of deafness in the hands of those who had lived experience rather than with the professional exploring its biogenetic determinants. Boughman's reconceptualization of genetic risk occurred alongside a redefinition of deafness as being on the normal end of the hearing-not-hearing dichotomy. Sign language, rather than English served as the vehicle for this conceptual change, signaling the expert's willingness to assimilate to client culture.

Conducted counseling not in her native language, but in that of her clients, heightened Boughman's sensibility for conceptual differences tied to language and culture. Counseling in English, she had often used “risk” and “chance” interchangeably. Confronted with the corresponding signs, the visual impression of the “the closed fist [risk] and the open hand [chance]” drastically visualized “the difference in the concepts.” This experience changed her counseling practice and terminology not only in regard to deafness, but “in all other counseling situations as well:” From “that time on, I didn't use the word risk, I used chance.” Inherent in this shift from “risk” to “chance” was a redefinition of disability and defect in relation to normalcy, a less restrictive, more relative approach contrasting with earlier definitions of a normal child or family.\(^740\)

Eager to share her experiences, Boughman relayed her experience to her colleagues at the Indiana University Department of Genetics, a group that was frequently engaged in discussions about counseling terminology. With herself in the role of intercultural mediator, the session became an example she used “a thousand times [...] in teaching in all kinds of situations because it was just one of those defining moments in one's life.” Her colleagues, Boughman recalled, were “interested in watching a counseling session done in sign language.”

\(^740\) Ibid., 4, 7.
Observing such sessions was a particularly powerful way to convey the
difference between sessions with and without an interpreter, of direct or
mediated communication. In this manner, she commented, fellow professionals
“could see changes” that were attributable to the use of sign language itself.
Because of its visual qualities, she considered ASL better suited than English to
explain the difference between the abstract concepts of “risk” and chance” – a
belief that contrasted sharply with the long-held conviction that sign languages
could not convey theoretical thought and abstractions. Sign language, Boughman
believed “is so beautiful and so expressive that they [....] could appreciate it even
if they didn't know how to sign.” Her admiration for ASL as an effective and
beautiful language signified closeness and identification, if not assimilation,
rather than scientific distance or assumptions of superiority on part of the
hearing scientists.\footnote{Ibid.}

In the following years, Boughman continued to put herself in the role of a
cultural ambassador between the deaf and the genetics community. Using ASL as
her medium of choice, she could rely on a growing interest among hearing
people in sign languages and Deaf culture. Her experiences encouraged her to
envision a model of applied genetic research that was community based. Such
models had been appealing at least since the establishment of community
psychiatry in the 1950s. In the 1970s, however, community-based healthcare
models became more politically radical; more people's health projects rather
than the professional-led reform projects of the 1950s and 60s. Most famous,
probably, were the clinics and medical services offered by the Black Panther
movement. The women's movement similarly operated clinics for women,
advocated medicine for women by women, and published self-help manuals, such as the Boston Women's Health Book Collective's 1969 Our bodies, Ourselves which remains in print until today.\(^\text{742}\)

These clinics and services often were marked by a distinctly anti-professionalism and tended to reject established medicine as suspicious of institutionalized racism or misogyny. Yet the patient communities that emerged at the same time in medicine and genetics make clear that this period also furthered collaborative models between professionals and affected populations. Moreover, these different approaches to community health shared certain motives, such as equal access to health care, an approach sensitive to community needs and values, and the need for professionals from within the community.\(^\text{743}\)

The movements and their values influenced Boughman's conception of genetic services to deaf people. After finishing her PhD in 1978, she followed Nance to the Department of Medical Genetics at the Medical College of Virginia where she first worked as an instructor before becoming assistant professor in 1978. For a while, she was the only signing geneticist on Nance's team. In 1979, however, she and Nance began supervising a PhD student, Kathleen Shaver Arnos, who, like Boughman, was intensely interested in using sign language to provide culturally sensitive genetic counseling to the deaf population.


\(^{743}\)Ibid.
Kathleen Shaver Arnos: Psychology, genetics and underserved minorities

Unlike Nance and Boughman, who had come to deafness via genetics, Arnos came to genetic deafness research via psychology. Yet she, too, had always been interested in basic science, enough to begin her undergraduate career at Western Maryland College (now McDaniel College) majoring in biology and chemistry. The college would prove to be an influential institution for Arnos’ developing interest in deafness and deaf people. In the 1970s, Western Maryland developed into a center of deaf graduate education, in particular for those pursuing a career in teaching. Its masters program in deaf education, established, in 1967, from the beginning accepted deaf students, and operated under a total communication approach that gave ASL and English equal valence. Both were groundbreaking moves at the time, and attracted a cadre of motivated young deaf professionals who brought with them their beliefs about Deaf culture and community. Western Maryland College, then, provided, Arnos with a first point of contact with deaf people, their language and culture. After she changed her major to psychology, she became a student of Vernon McCay, who had been professor of psychology at Western Maryland since 1969. His classes, where he simultaneously used English and ASL piqued her interest, and soon she began taking sign language classes. Taught by native signers, these classes offered another opportunity for encounters and exchange.


Vernon and Arnos, it turned out, shared an interest in genetics, psychology and deafness. After she had written a paper for one of Vernon's classes on the “genetic link to hearing loss,” Vernon introduced her to Walter Nance whom he knew through their collaboration on Usher syndrome. Nance encouraged her to pursue a PhD in human genetics with him at the Medical College of Virginia (MCV) in Richmond. She was accepted and in 1979 joined Nance's program after graduating from Western Maryland College with a BA in psychology. Influenced by Vernon's work, Arnos entered her PhD studies with a specific goal in mind: To become a genetic counselor for the deaf. Vernon had sensitized her to the “great need [...] for someone who is fluent” in ASL and encouraged her to become “the first genetic counselor who works in the deaf community.” In a manner, this recommendation was one of Vernon's typical hyperboles that disregarded other professionals' work as irrelevant. After all, he had worked for several years with Nance and Boughman, who had pushed been advocating for genetic counseling for deaf people. Nevertheless, there was also some truth in Vernon's statement. Arnos probably was the first professional to enter her career with the specific goal of working in the deaf community.

At MCV, Arnos found advisors strongly supportive of this goal. Nance and Boughman had themselves adapted their research and counseling according to the feedback they received from deaf clients. Boughman and Arnos in particular bonded over their shared love for sign language and Deaf culture. Boughman welcomed the arrival of a person with whom she could practice sign language. “Kathy and I,” she recalled, “would sign to each other and drive everyone around us crazy.” Working with her, Boughman explained, “we stimulated each other

746 Ibid., 1-2.
interest in absorbing the culture and jumping in.” Nance, she recalled remained “a little more removed, nonetheless clearly caring of the community, but [he] never kind of dived in the same way we did.” He was, however, “always very supportive” and “learned to appreciate the fact that the skills that we brought to the situation enhanced his abilities.”

Arnos’s arrival thus spurred both her and Boughman to immerse themselves in Deaf culture. This immersion, Boughman believed, was instrumental in gaining deaf people’s trust in a science that in the past had often disapproved of their reproductive choices, or had even tried to restrict them. Overcoming any potential bias, she explained, was “one of the reasons, especially, that Kathy Arnos and I opened ourselves up to the Deaf community.” They had to become “part of the Deaf community” first, Boughman thought, before they “became geneticists to them.” For Boughman, this demonstrative humbleness and respect was not particular to working with deaf people, but rather a characteristic of “human nature,” a basic principle of cooperating with client communities: “every time you demonstrate not only lack of bias, but acceptance and then move to clearly a respect, I think all of that ends up [...] bringing you in.” It was important for her to signal that “I’m not coming in from a different level and looking down at you, I’m actually looking up at you, I need you to pull me up to your level.” Assimilating to Deaf culture meant offering an analysis of the biochemical and genetic mechanism of hearing loss and associated conditions, yet leaving the bioethical meaning and practical application to deaf people themselves.

747 Interview Boughman 2013, 8, 11-12, 19.
748 Ibid., 8, 11-12, 19.
By the late 1970s then, Arnos, Boughman, and Nance had come to form “small supportive culture for each other,” nourished and strengthened by the awareness of trying to accomplish something new that “took some energy, took some effort.” In the early 1980s, they realized several projects that aimed to further the goal of culturally-sensitive genetic deafness research and counseling: Together with McCay Vernon, they contributed to research on Usher Syndrome and worked on improving services and awareness. Nance’s team also worked on Congenital Rubella Syndrome (CRS), a project that brought them into close contact with several schools for the deaf and Gallaudet University. Together with linguists from Gallaudet, Boughman and Arnos developed a set of ASL signs for genetic counseling that was to improve availability and accessibility. Their work culminated in 1984 with the creation of a genetic service center at Gallaudet.

**Rubella research: Field trips to the deaf community**

During the 1970s and 80s, children and teenagers with Congenital Rubella Syndrome (CRS) formed a large and distinct group at schools for the deaf. 85 percent of students born in 1964/65 and enrolled in schools for the deaf were estimated to have CRS. Their specific health and education needs were still being explored. By the late 1970s, it had become clear that many of them experienced medical complications beyond the classical Congenital Rubella Syndrome (CRS) triad of visual, auditory and cardiac impairment. Individuals with CRS showed an unusually high rate of late-onset metabolic and endocrinological conditions, including diabetes mellitus, thyroid dysfunction or

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749 Ibid., 18-19.
growth hormone deficiency. From 1979 to 1988 Nance received an NIH grant for exploring the link between CRS and diabetes. Arnos' PhD work was part of this project; Boughman served as an additional investigator. Their research, the three scientists hoped, would help illuminate the role of viral infections in autoimmune disease and determine whether there was a genetic susceptibility to the initial rubella infection.

For this purpose, they conducted a longitudinal epidemiological study of students with CRS enrolled at the Maryland School for the Deaf, the Virginia School for the Deaf and Blind and the Gallaudet Model Middle School for the Deaf (MMSD). Following the rubella cohort for four years, from 1979 to 1984, brought the researchers into contact with the deaf communities surrounding these schools and with Gallaudet, a contact they appreciated and explicitly sought. For Boughman and Arnos, in particular, with their ability to communicate in ASL, this was yet another opportunity to immerse themselves in the culture of their study population. In talking to study participants, they emphasized the need for community cooperation, the voluntariness of participation, and the benefits of research for involved students. For Arnos, her work with the rubella cohort reinforced her fascination with the cultural and the biological aspects of deafness, and strengthened her conviction that only knowledge of both realms would lead to better services. Similarly, for Boughman the experience of

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engaging with students at schools for the deaf, of getting to know them as individuals, pointed to the necessity of direct communication and cultural sensitivity.\textsuperscript{752}

Field trips in particular provided the opportunity for immersion into deaf culture and community, to interact with patients directly – for both Arnos and Boughman an indispensable characteristic of a good geneticist. In dealing with students and their families, in entering the closed-off world of a residential school with its own language and rules, their knowledge of ASL and ability to move between cultures was an indispensable tool. Their ability to communicate in the students’ language proved to be an icebreaker, turning the outside scientists into more familiar figures. Students, Boughman emphasized, “got to know us as people then, not just [as] the folks in the white coats and drew their blood.”\textsuperscript{753} The common denominator of “just people” removed the distance between scientist and object of research, the hierarchy between adult and teenager and, not least, the difference between a hearing and a deaf person. It emphasized a cooperative model in which both parties were needed to make for a successful study, and, eventually, improved health care.

Being able to communicate directly allowed her and Arnos to explain the purpose of the study to the teenage participants, to assuage fears about the testing process, to make make sure that students really wanted to participate – and to offer them a way out if the prospect of needles and tests proved too frightening. This was an important step beyond acquiring informed consent from parents. Often, when students had to stay overnight at the school’s health center

\textsuperscript{752} Interview Arnos 2012, 5; Interview Boughman 2013, 12-14.  
\textsuperscript{753} Interview Boughman 2013, 12.
to ensure they were fasting for the glucose test, Boughman and Arnos would spend the night at the school, too, to help students cope with any fears or insecurities. The “fact that we could talk them through” the testing process, Boughman recalled, “made a huge difference.”

This cooperative model, she believed, was not only ethically superior to a more paternalistic model of medical authority, but also yielded more data. Engaging in longer conversations with students and their families yielded a level of detail and textured information unattainable when relying on interpreters and questionnaires.

To Arnos, these field trips were among the project’s most interesting and enjoyable features, to the point that she later remarked: “I earned my Ph. D. with field work!” The term 'field work' evokes images of ethnographers, anthropologists and sociologists collecting folk tales and studying popular culture. In these disciplines, fieldwork oscillates between immersion and identification with the study population on the one hand, and assuming a position of analytical distance on the other. In genetics, too, there has been a long history of surveying rural, isolated areas, if not exotic populations abroad for inbreeding qualities and interesting family traits. Describing structural changes in genetics in the 1960s, Susan Lindee has described how different types of data – family tales and family bibles, religious and family records, tissue or blood samples – became incorporated in genetic research through field work. Alice Wexler has similarly described the emergence of a research community around Huntington’s Disease, initiated by patients and patient relatives hoping to engage scientists in the search for a cure. Such close cooperation and patient activism

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754 Ibid., 13. Also see Interview Arnos 2013, 4.
755 Interview Boughman 2013, 13.
756 Interview Arnos 2012, 3.
tied scientists to the goals and values of a community, which could reach from searching a cure to acknowledging that a trait might not require a cure after all.\textsuperscript{757}

The MCV rubella fieldwork combined the ethnographic tradition of living amongst one's study population with the biomedical study of their traits. It resulted in a level of identification and assimilation with the study population that remained rare in biomedicine. Arnos' and Boughman's position as intercultural ambassadors engendered a feeling of responsibility toward their client communities that reached beyond medical or genetic needs. During their field trips to local schools for the deaf, Boughman and Arnos would spend time not only with children in the rubella cohort, but with students of all ages. For “some of these [younger] kids,” Boughman commented, “we were the first hearing adults from the real world that knew sign language.” The two scientists “were more than willing” to satisfy the children's curiosity about the strange phenomena of hearing adults who signed fluently, taking “every [...] chance to bridge the gap.”\textsuperscript{758}

On the scientific level, the study remained inconclusive. It confirmed that metabolic diseases considerably more frequent in CRS cohort, yet did not find a potential inherited susceptibility to rubella and diabetes.\textsuperscript{759} The study did, however, emphasize the need for specialized health services for this group – including screening for metabolic conditions, but also for genetic causes. During the study, the researchers had found that a number of children and teenagers


\textsuperscript{758} Interview Boughman 2013, 14.

\textsuperscript{759} Shaver; Boughman; Nance, CRS diabetes, 531.
diagnosed with CRS had actually been misdiagnosed. To the eyes of a trained geneticist they obviously had a genetic syndrome. This brought up difficult ethical considerations. What to tell them and their parents? How to provide them with a correct diagnosis and counsel them without shaking their beliefs and identities, without raising guilt in the parents for missing the real cause of their children’s condition? The experience of coming across a subpopulation of deaf teenagers who “had not been identified, not been counseled,” reinforced Arnos’ belief in “the need for setting up services within the deaf community,” in providing “sensitive information-giving and sensitive counseling.”

She, Nance and Boughman had steadily pursued this goal in the previous years. There were, however, still obstacles to making available such services to deaf individuals. The lack of genetic terminology in ASL was one of them.

“Acceptable manual signs” for genetics – Incorporating genetic terminology into American Sign Language

In American Sign Language, fingerspelling – spelling each letter in the manual alphabet rather than using a single or compound sign – is used for proper names, places or titles and more generally for rarely used terms. Many of these terms acquire specific signs as needed. Many science-specific concepts fall into this category, and did even more so in a period before a sizable number of deaf people had entered medicine and biomedical research. Genetics, too, lacked specific signs into the 1980s. Particularly for non-native signers like Boughman and Arnos constantly having to recur to fingerspelling in their

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760 Interview Arnos 2012, 4-5.
761 For an explanation of the uses of fingerspelling, sign formation and a chart of the manual alphabet see e.g. http://www.lifeprint.com/asl101/fingerspelling/fingerspelling.htm
counseling and lectures was a hindrance. They lamented in 1983 that “communicating in a language, in which all specialized terms must be spelled out because specific signs for these terms do not exist can be unproductive and frustrating.”

To ease the communication of genetic concepts in ASL, Boughman and Arnos set out to develop “acceptable manual signs for genetic terminology” in the early 1980s. Incorporating genetic concepts into the native language of the target community signaled a new dimension of bringing genetic knowledge to deaf people. It mirrored Boughman’s and Arnos’ belief – born out of years of experience – in the equality of ASL as a linguistic system not only capable of expressing abstract concepts, but suited best to do so in this situation. This was to be a cooperative enterprise. As they were fluent yet nonnative signers, developing acceptable signs meant relying on the D. C. area Deaf community and collaborating with a team of Gallaudet linguists. By deferring to deaf people’s expertise, the project equalized, or even reversed the relationship between geneticists and their target population.

To develop useful and acceptable signs, the team first gave talks on genetics and genetic counseling to seven different groups, including native deaf signers, registered interpreters, and hearing people with diverse levels of signing ability. After the lectures, several of which had been given at local Deaf Clubs, they surveyed the audience for different existing or necessary genetic terms, “many of which had to be fingerspelled during the lecture since no sign was available.” For some concepts, they discovered pre-existing terms, including a

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763 Ibid.
sign for Usher Syndrome. Other signs for genetic syndromes were then based on the same concept, i.e. e. where Usher Syndrome was signed with the right hand in U shape at the level of the forehead then forming an S shape at the chin level, Down Syndrome repeated this pattern with a D and an S shape.\textsuperscript{764}

From these suggestions, the project team assembled a preliminary set of 23 signs. A group of Gallaudet linguists and students from science and linguistic classes then evaluated a videotape of each sign for its “conceptualization, ease of formation, clarity, and necessity.” In the end, twelve signs remained as the “most acceptable and essential in the counseling situation.”\textsuperscript{765} They were consequently published in the 1983 \textit{Signs For Genetic Counseling}, which introduced the signs to \textit{Genetic Counselors, Clients, and Sign Language Interpreters}.\textsuperscript{766} Each of the twelve terms was accompanied by a photo of the sign, signing instructions and a definition. The booklet thus not only was a dictionary, but also offered an introduction to the most important concepts of genetics. Signs included different syndromes – Usher, Waardenburg, and Down syndrome as “the most common chromosomal problem seen in newborns” –, genetic terminology such as chromosome, dominant or recessive inheritance, and the increasingly common diagnostic technology of amniocentesis. The booklet also introduced the sign for genetics, defining it as “the scientific study of heredity; the study of traits in the family.”\textsuperscript{767}

Notably, the booklet thus presented a neutral definition of genetics, one that aimed at the \textit{study} of genetic traits rather than the \textit{prevention} of a single

\textsuperscript{764} Ibid.
\textsuperscript{765} Ibid. 1317.
\textsuperscript{767} Ibid., 4.
trait, such as deafness. This was in keeping with Nance's earlier work, notably with his 1975 booklet on genetic deafness, yet a significant deviation from an older research tradition aiming specifically at reducing the incidence of deafness. The booklet further defined genetic counseling “for deaf clients and their families” as “different from any other counseling situation” because it affected all family members. Consequently, the common practice of relying on a friend of family member for interpreting was inappropriate. A professional interpreter was better equipped to handle these situations. Although this definition distanced genetic from other forms of counseling by emphasizing its familial character, it nevertheless foregrounded its advice-giving aspect and distanced it from scientific or medical procedures.

Boughman believed that signaling their reliance on Deaf native speakers helped the project gain respect from the Deaf community: “it was part of being accepted, the fact that here were these scientists that understood that there was more to it than just their science content, that we wanted to move forward, we wanted to do it right, we wanted to do it their way.” Describing the project as a mutual learning process, she later called it as “[o]ne of the best things that I ever did in my career.” The cooperation with linguists gave her new insight into the structure and adaptiveness of ASL, and in turn stoked her admiration. Participating in the creation of new terms created a sense of accomplishment, an emotional process of identification with, and participation in Deaf culture and community. When Boughman gave a talk a few years later, she noted with pride
that the interpreter used “her” signs. She commented: “I did something useful, because spelling the word “chromosome” each time is a real drag.”

Developing ASL signs for genetic concepts meant adapting genetics to Deaf culture; conversely it also meant bringing the deaf community closer the culture of genetic research. Translating genetic terminology meant popularizing the underlying concepts to deaf people. In this spirit, the booklet noted the “growing awareness of the importance of genetic factors in deafness increases the need by deaf clients and their relatives for genetic counseling services.” Determining one’s specific type of deafness, the booklet explained would enable deaf people to be counseled on “the chances” – note the neutralized terminology – of having deaf or hearing children.

By the early 1980s, then, Nance, Boughman and Arnos had had worked together for several years to make their science acceptable and accessible to deaf people. Arnos and Boughman in particular had acted as ambassadors between two cultures. Despite these efforts, however, they still found the relationship between the deaf and the genetic community unsatisfactory. “Nobody knew sign language,” Boughman said of her hearing colleagues. “Nobody crossed into Deaf culture. The deaf didn’t come into our clinics,” just as geneticists were not “going into the Deaf community and offering their services.” Other geneticists “just weren’t in there.” She ascribed this mutual distance to the “language” and “cultural barrier” that allowed “assumptions” to be “made on both sides.” On the side of geneticists, she felt, these were “paternalistic assumptions” that deaf people “don’t want to know” about genetics. On “the inside,” from deaf people,

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768 Interview Boughman 2013, 13.
769 Gallaudet College 1983, Signs, 1.
she detected “the fear” that “they’re going to tell us we’re bad people.” The Gallaudet Genetic Service Center, established in 1984 hoped to close this gap.

**Taking genetics to the heart of American Deaf culture: The Gallaudet Genetic Service Center**

By the early 1980s, the rubella cohort of 1964/65 had reached college age. Many of them attended Gallaudet. For 1984, Gallaudet expected a peak enrollment of 2000 undergraduates, up from an average of 1200. For Arnos, who had received her PhD in human genetics from Virginia Commonwealth University in 1983, this meant following the “rubella kids from high school into college,” as she continued for Nance’s CRS project. She became the project’s research coordinator at Gallaudet, serving as liaison between MCV and the Gallaudet Research Institute.

Aynos soon took part in other campus activities that gave her an opportunity to teach and counsel. She took over the Summer Institute in Biology for Teachers of the Deaf and Hard of Hearing. This summer course was to improve teachers’ science education, which was usually very rudimentary. Among the topics covered were physiology, anatomy, environmental science and genetics. Genetics, Arnos recalled, was “very relevant” to these teachers’ who “knew the families with dominant inheritance and recessive inheritance and [...] the syndromes.” She and Boughman also worked together as genetic consultants in the Gallaudet Summer Learning Vacations, a program for deaf children and their families. Both also counseled families with Usher Syndrome. These venues

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770 Interview Boughman 2013, 18.
771 Interview Arnos 2012, 3, 7-8.
were opportunities both to educate teachers, students and their families on genetics and for the geneticists to assimilate to campus culture.\footnote{Ibid., 3, 7-8. For the accommodation for the rubella cohort on campus see Armstrong, \textit{Gallaudet}, 93-94.}

Working in the DC area, Arnos came into contact with the DC Genetic Services Program, a regional consortium of four genetic centers. Supported by the Department of Human Services (DHS), the consortium aimed to bring genetic services – testing, counseling and education – to disadvantaged population groups. To facilitate this development, the DHS solicited proposals addressing “linguistic and cultural barriers to genetic counseling” through its program for Special Projects of Regional and National Significance (SPRANS) program. Deaf people, Arnos believed, clearly fell into this category. The program, she conceded, may have been written with “Hispanic people, language barriers, spoken language barriers” in mind, yet it was “easy to find justification for cultural and linguistic barriers” with deaf people, too.\footnote{Interview Arnos 2012, 9.}

In May 1984, under the institutional auspices of the Gallaudet Division of Research, she submitted a proposal for SPRANS funding for “an Innovative Approach to Genetic Counseling Services for the Deaf.”\footnote{Proposal: Demonstration of an Innovative Approach to Genetic Counseling Services for the Deaf.}

The proposal portrayed deaf people as a group in need of specialized genetic services. It showed the rising appeal of the sociocultural minority model, yet also its limitations when it came to legitimizing genetic services. The proposal defined deafness “a debilitating disorder that poses cultural and language barriers that severely limit access to genetics services.” The limiting – indeed the disabling – effects of deafness thus were both physical and
Physically, deafness was a “debilitating disorder,” the “most common physical impairment in the Unites States today,” with 2000-4000 deaf infants born per year and an estimated total of 1.6 million “affected individuals.” Sociologically, deaf people were an “articulate minority in our society.” Yet this status too, was tied to physical characteristics. Unlike “other U. S. minorities whose linguistic isolation is based solely on the use of a foreign language,” deaf people’s status as a minority depended on a physical, and potentially genetic trait.\footnote{Ibid., 2-3.}

Thus, while this genetic trait in itself was not considered pathological (at least not by the target population), it often was associated with other conditions clearly pathological to both geneticists and deaf people. Once more, syndromic deafness served as a condition over which to negotiate the medical and genetic services acceptable in a sociocultural minority-approach. As Arnos pointed out, “the [a]ccurate diagnosis of genetic syndromes in deaf individuals [...] has tremendous implication for the treatment of associated disorders.” Again, timely diagnosis of Jervell-Lange-Nielsen syndrome was brought up as a matter of life and death. Usher syndrome served as an example for the need to prepare for potential personal, professional or educational accommodations. The proposal also drew on the MCV study of rubella and diabetes, remarking that “many CRS individuals may marry other persons with genetic deafness and have the right to information about the possibility of having deaf children.”\footnote{Ibid., 2, 6-7.}

Bringing together these sociological and medical dimensions, Arnos argued for the need for genetic services. It was their genetic make-up that made
“individuals with prelingual deafness” a “genetic high-risk group” in which “heritary factors are known to account for no fewer than 50% of the cases.” Yet it was society that had created “cultural and language barriers.” Genetics professional in particular had failed to learn about Deaf culture. “Only three geneticists in the United States,” she pointed out, “are fluent in American Sign language” (two of them being Arnos and Boughman themselves). And she continued: “The failure to provide needed diagnostic and counseling services at a time when millions are spent to screen for genetic diseases that have an incidence of less than 1 in 10,000 in the population [...] is a national shame that bears mute testimony to the political impotence of the deaf.”

This was familiar rhetoric in the history of disease awareness campaigns in general, and the push for genetic deafness research and services in particular. Vernon had felt that rubella received an inappropriate share of public attention compared to Usher Syndrome. Nance had pointed to geneticists being distracted by rare diseases. With its themes of neglect and misguided effort, this competition for compassion created a sense of urgency, singling out deafness and deaf people as particularly worthy of attention. This, too, was a common theme in deafness research, as previous chapters have shown.

In making these claims, the GSC proposal mobilized three different, yet increasingly overlapping sets of expertise and advocacy: For about a century, eugenicists, geneticists and educators had bemoaned the lack of genetic knowledge among deaf people, and had tried to bring them genetic awareness. At the same time, Arnos could draw from about thirty years of research of that portrayed deaf people as a disadvantaged sociocultural minority, produced

777 Ibid., 3, 7.
mainly by sociologists, psychologists and psychiatrists. Increasingly, this literature drew legitimization from the authorship, activism and academic involvement of Deaf people themselves. From the 1950s on, some geneticists had utilized both genetic and sociological reasoning in portraying the deaf as a neglected population deprived of their democratic right to genetic services. Placing themselves in this tradition – the proposal referred to Sank and Kallmann's work – the GSC justified genetic services by shifting notions of responsibility and blame. Where previous generations of geneticists had anxiously watched deaf people's reproductive patterns, chastising them for their irresponsible marriages, Nance and his coworkers blamed genetic ignorance on geneticists and their failure to provide adequate services. Conveying a sense of atonement for past mistakes and misconceptions, this portrayal turned geneticists into a vanguard of social progress, ahead of other professionals still entangled in bias and discrimination. Whereas the eugenicists of the first part of the century drew legitimization from improving race and mankind, geneticists now had portrayed their work as a matter of empowering the individual and ending minority discrimination.

**Counseling at the GSC: The empowering dimension of genetic awareness**

The proposal was successful. In 1984, the Gallaudet Genetic Service Center began operating as part of the college's student health services. Cooperation with the DC Genetic Services Program helped maximize resources.

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and extended the center's reach beyond the immediate campus community. Education, screening, counseling and research circumscribed the GSC's scope. Screening served the double purpose of providing genetic counseling and of collecting data to add to Nance's genetic deafness database at MCV. These new pedigrees, the team hoped, could be traced back to Fay's family and marriage data from the turn of the century, thus making it "possible to establish genealogical linages in a substantial portion of such cases." Counseling and education, too, served overlapping goals. "[G]reater access to helpful information," was the prerequisite "for informed decisions about family planning" and "preventive medicine."779

Initially, the center's staff consisted of Arnos as its director, a secretary and a part-time clinical nurse fluent in sign language. Over the years, and with extended funding, staff grew to include more genetic counselors. Beyond this core staff, the center drew from external partners and advisors. These included Boughman (now at the University of Maryland), Nance with the MCV's genetics department, and pediatric geneticist Kathleen Toomey at Children's Hospital National Medical Center. These partners brought a unique set of skills and experiences to the project: Individually or as a team, Nance, Boughman and Arnos had done research at schools for the deaf and at Gallaudet for over a decade, had counseled numerous deaf clients, and had already developed a distinctive approach to counseling.780


Establishing culturally-sensitive, non-directive counseling genetic services, Nance, Arnos and Boughman had learned, began with making sure that counselor and client understood each other. Consequently, inquiring about communication preferences was a crucial first step when an individual or couple came to the GSC. The vast majority of clients preferred ASL, yet the center also provided “a signed English interpreter, an oral interpreter” and the option “to communicate directly with the physician through speech and speechreading.” Their experience had also shown that adapting to the client population not only meant switching languages, but replacing potentially offensive terminology such as describing deafness as a risk or pathological state. The GSC staff thus developed and used “written and visual materials that contained culturally neutral terminology.”

An equally important first step was to inquire why a client was seeking genetic evaluation. Motivations, Arnos reported, ranged from medical or reproductive concerns to plain curiosity. Some clients wanted to learn their chances for hearing or deaf children, some explicitly wished for deaf children, some simply wanted to know why they were deaf. The latter motive, she noted in 1992, was quite common. The majority of GSC clients – both from Gallaudet and the D.C. area – “had sought counseling because of curiosity and stated that “their reproductive decisions would not be altered by knowledge obtained in genetic counseling.” Medical concerns were more pronounced in clients with syndromic deafness who “did express concern about transmitting medical

782 Interview Arnos 2012, 10.
conditions other than deafness to their children." Clients also sought genetic counseling for conditions unrelated to deafness. The GSC saw Jewish couples interested in Tay-Sachs testing, clients who inquired about cancer risks in their family, or families with rare genetic disorders.

Compared to more traditional locations for hereditary advice, where most clients inquired about the risk of having or passing on a pathological condition, this was an unusually wide range of motivations. This probably was a result of the GSC’s specific set-up and location. As I will show below, staff actively elicited inquiries more exploratory about identity than pathology. And unlike most genetic counseling centers, the GSC was not attached to a medical school or clinic, but embedded in a humanities campus and center of Deaf culture. Thus, while the GSC was like the Clarke School heredity division part of a larger educational and cultural institution, it operated under almost opposite goals and assumptions.

After establishing client expectations and communication preferences, the GSC followed a standard course of action. The staff collected a range of potentially useful information, including standardized family histories and audiograms. These were routinely done at Gallaudet’s Hearing and Speech Center. During the monthly clinic day a visiting physician performed a physical examination, looking for signs of environmental causes or syndromic deafness. On average, this monthly genetics clinic saw 6 and 12 clients. Once all information was collected, the clinic team—a clinical geneticist, physician and

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783 Arnos et al., Innovative Approach, 349.
audiologist – reviewed the data. Finally, counselor and clients met for one or more genetic counseling sessions.785

Ideally, by this time the counselor was able to provide a definite diagnosis. Yet in about one in four cases, the type of deafness could not be identified. By the mid 1980s, more than 100 forms of genetic deafness had been identified; by the early 1990s, the number had grown to about 200. At the same time, however, many other forms remained un- or under-defined. Diagnosis was particularly difficult if the client was the only deaf person in the family. Families with many deaf individuals, on the other hand, also provided a challenge. Having a pedigree with several cases might provide a hereditary pattern, yet often the types of deafness did not match and seemed to stem from different causes. The center, Arnos recalled, would see “a lot of big deaf families [...] where everyone was deaf and initially, it could have been dominant, it could have been recessive – we couldn’t figure it out.” There was “just such a variety of conditions that we saw, that we were working with.” In cases where the type of deafness could not be identified, generalized empirical risk tables – developed by Nance and his students Frederick Bieber and Rose Pilant – provided the best tool available.786

Thus, although knowledge of different forms and syndromes kept increasing, the medical benefits of diagnosis remained limited. The inability to provide a definite diagnosis might well have been seen as a failure, both by the counselor and the client. After all, the majority of clients came to the GSC to learn about the cause of their deafness. Yet it also reinforced the nature of counseling

785 Arnos Interview 2012, 10; Arnos et al., Innovative approach, 347.
as an interdisciplinary enterprise, and as an intense encounter between the
counselor and client (and their family) that resolved psychosocial tensions.
Counseling, Arnos believed, was as much psychotherapy as fact-giving. To
establish the emotional benefits of being genetically informed, she evoked
themes well-established in the field. “Many benefits of genetic counseling,” she
and her staff echoed Nance, Reed, or Kallmann, “are unrelated to reproductive
decisions.” For hearing parents, they wrote, counseling could “help to relieve the
guilt that some hearing parents may have carried around with them for many
years.” It could also “help the family to accept and adjust to the birth of a deaf
child.” Conversely, in deaf parents, it could “help them to deal with any fears they
may have about raising a hearing child.” 787

For both groups, the counselor offered emotional support and acted as a
mediator in referring parents to educational and psychological resources. Like
other genetic counselors in this period, then, Arnos was carving out a niche for
her brand of culturally sensitive genetic services. Retreating from decisive,
directive or definite positions, genetic counseling instead gained authority as a
discipline at the center of professions dealing with deafness. It was to be a
helping, supportive profession, offering all-encompassing services, emotional
support and contact to other professions and resources.

In a decade of politicizing deaf and health care activism, the GSC also could
claim that knowledge of one’s genetic self was empowering. This dimension
became apparent in the 1980s brochures that advertised its services mainly to
deaf people and their families, and drew a direct line from individual genetic
knowledge to self-determination and empowerment. “Do you wonder about... the

cause of your hearing loss? The chance that you might have a hearing impaired child?” one of the brochures asked. “The Genetic Service Center can help,” the text continued and listed the services available: A comprehensive evaluation, genetic counseling, and “support services to provide continued help.” If “you’re interested,” the brochure encouraged, “fill out the form below and return it to the address below, and the Genetic Service Center will contact you.” With its purposefully neutral terminology – chance instead of risk, wonder instead of worry, the absence of any reference to prevention – this brochure cast acquiring genetic information as a positive step, something one might do out of curiosity rather than medical necessity. While genetic evaluation might provide a definite diagnosis, its implications – “the impact if may have on you and your family in the future” – were left open, conditional upon individual beliefs and circumstances.788

Yet genetic information also acquired an explicitly political dimension: To “become informed” was to “become empowered” another brochure asserted, and explained that “this is your opportunity to learn more about emerging issues in genetics and learn more about yourself.” And it continued ominously that “advances in genetics will no doubt impact Deaf culture.” Implied in such description was a call for action. If genetics would impact Deaf culture, it was imperative for deaf individuals to become informed, so they could assert their genetic and cultural self in the sociopolitical arena.789

788 Genetic Services Center, Brochures, n. d., Departmental Files, Box 28, Folder 99.1, Gallaudet University Archives While the brochure was undated, it was printed before the change of name and status from Gallaudet college to Gallaudet university in 1986.
789 Ibid. This brochure was printed in almost identical style, although after 1986.
Education and outreach: Advocating for the GSC model on and beyond campus

Education and outreach were among the stated goals of the GSC. Two audiences, in particular, were to be familiarized with the model of non-directive, culturally sensitive counseling: The deaf population, supposedly under-informed about genetics, and the medical-genetics community, supposedly misinformed about Deaf culture and identity. In targeting these two groups, the GSC institutionalized the mediator position that Nance, Boughman and Arnos had adopted individually in their previous work with diverse professional groups and deaf communities. Advocating for their model, they portrayed the GSC as the vanguard of appropriate and successful genetic services.

As previous chapters have made clear, it was an established belief in genetic deafness research that deaf people lacked genetic awareness, maybe more so even than the general population. Throughout the 20th century, professionals involved in heredity research had routinely pointed to this troubling ignorance and had advocated for integrating genetics into general education. For much of the century, however, the aim of education had been the prevention of deafness, a goal that was reflected in the language and terminology of counseling and in educational material.

This was not a matter of the past. In the late 1970s for example, the Clarke School developed material on deafness education for high school students, including units on heredity. The project was born out of the belief that deaf people lacked “consumer awareness” – the ability to understand the complex and often deceptive world of mass and health care consumerism. Deaf people, believed Peter Jones, the school’s “genetic audiologist” and last head of the
hereditary deafness division, “are particularly vulnerable to fraud, misrepresentation, and misinformation, not only because of their limited ability to understand consumer information on everyday topics, but also because of the absence of useful information about deafness itself.” The material Jones developed to counteract this misinformation was consequently included in the curriculum for “students in our Middle and Upper Schools.”

In the school’s tradition of combining research, counseling and education, Jones continued visiting “each senior health education class to review with them the causes of deafness, and illustrate genetic deafness with their own pedigrees.”

Arnos, Boughman and Nance shared with the Clarke School the belief that genetics should be an integral part of the curriculum, part of the corpus of knowledge every person should acquire to be fit for life, work or higher education. The GSC, too, rested on a consumerist model of health care, yet unlike the Clarke School, they assumed their clients to be savvy and capable consumers from the beginning. Genetic awareness, they believed, was a means to become an even more empowered consumer – a message that on the surface was not all that different from that of the Clarke School. Yet unlike the Clarke School and similar programs, the GSC no longer aimed at a specific outcome – the prevention of deafness – but rather identified it as a one of many possible cultural and genetic states. It was genetic informedness and self-awareness that mattered – no longer (necessarily) what one did with it. Nevertheless, underlying both approaches – yet rarely addressed within a framework of explicit non-directiveness – was the

791 Teaching Deaf Teenagers about Deafness, Hereditary Deafness Division, Clarke School Archive
assumption that acquiring genetic self-awareness would alter one's behavior, if only to turn an unaware individual into an informed consumer of genetic services.

The GSC promoted their message to high school, college and graduate students, their families, teachers and faculty, and to other professionals working with deaf people. From 1984 to 1990, staff members gave more than ninety educational presentations throughout the country, attended by 1,600 individuals. In the same six-year period, 126 lectures and workshops in 23 states familiarized an audience of 4,600 professionals and consumers with the GSC's work. The venues and audiences ranged from other geneticists and counselors to otolaryngologists, parent support groups, schools for the deaf and Deaf advocacy groups.792

Beyond workshops, brochures and lectures, academic publications helped to popularize the GSC model. Two articles from the early 1990s in particular mobilized established themes in genetics and genetic counseling to advocate for culturally-sensitive counseling for the deaf and the advantages of genetic awareness. Arnos and her coauthors (co-workers at the GSC) could draw from established tropes in the development of genetic counseling and genetic deafness research, a quickly expanding corpus of work on Deaf community, culture and language, and growing public awareness of Deaf culture and community.

By 1992, Arnos could confidently state that “[s]ociologists, linguists, and anthropologists now recognize deaf people as a cultural and linguistic variation in society.” Deaf people, she argued, were yet another of the ethnic, linguistic or

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792 Ibid.
religious minorities to whom geneticists had begun to pay more attention.\textsuperscript{793} In particular, she pointed to the 1989 \textit{National Symposium on Genetic Services for Underserved Population} in Arlington, Virginia.\textsuperscript{794} Co-sponsored by the the Mid-Atlantic Regional Human Genetics Network (of which the GSC was part), the March of Dimes Birth Defects Foundation, and the Genetics Services Branch of the Bureau of Maternal and Child Health and Resources Development, the Symposium brought together 200 professionals, consumers and delegates from diverse organizations to discuss “barriers to care.” These included “ethnocultural distinctiveness, geographic isolation, language barriers, religious beliefs, personnel shortages, racial differences, and economic disadvantages.”\textsuperscript{795} In front of an audience committed to health care equality and justice, Arnos talked on in a workshop on “Overcoming Language Barriers” on “Special Considerations in Genetic Counseling with the Deaf Population.”\textsuperscript{796}

The interest of geneticists and genetic counselors in sociocultural minorities has received little attention among historians. Stern has pointed to the lack of diversity among genetic counselors who, to this day, are overwhelmingly white, middle-class women.\textsuperscript{797} This assessment is certainly true, too, for the protagonists in this thesis, from the Clarke School researcher over Kallmann and his team, to Vernon, Nance, Boughman and Arnos. Yet these same white, middle-class geneticists were able to cast themselves as activists for a

\textsuperscript{793} Ibid.,345.
\textsuperscript{796} Arnos, Kathleen. 1990. “Special Considerations in Genetic Counseling with the Deaf Population.” In. Paul; Kavanagh (eds.), \textit{Underserved populations: 199-208.}
\textsuperscript{797} Stern, \textit{Telling genes}, 25.
more just, accessible healthcare for so-called neglected, underserved populations. Increasing diversity – within clients and professionals – became a valued goal that required getting to know one’s objects of research. A genuine interest in the lives of these groups often led researchers to realize the relativity of their own values and norms.

This tradition of combining health activism with cultural relativism was mirrored in the contributions at the National Symposium on Underserved Minorities. Against this backdrop, deafness could be cast as something socially negotiated as much as physically innate. It enabled Arnos and her coworkers to present the GSC as part of a larger movement that assessed the effects of “ethnic, cultural, linguistic, economic, and religious differences” on genetic counseling in order “to propose workable solutions to eliminating barriers.” Applying this sociocultural minority model, they acknowledged, might seem foreign, even difficult for “medical professionals” who had been “taught using a pathological model of human disease, including deafness.” They cautioned counseling “deaf individual or couple, who may prefer to have deaf children may challenge the genetic counselor to examine their own approach to nondirective counseling.” In this sequence of events, it was the counselor who had to rethink his professional position and values, not the client. ⁷⁹⁸

Deaf clients’ preferences thus were no longer an expression of deviant, pathological desires, but rather had become a testing case for the much discussed dogma of late 20th century genetic counseling: non-directiveness. Genetic counseling, the authors reminded their audience, “emphasizes informed decision making and provision of medical, psychological, and social support;
genetic counseling is not advice giving.” Successful counseling, Arnos and her coworkers wrote, required the counselor “to be aware of the context in which counseling is given and respect cultural and linguistic differences of the patient.” Just as in psychotherapy, successful counseling required that the professional engaged in a critical self-reflection on his values and emotions during the counseling process.799

As Arnos and her colleagues criticized the “pathological model” of deafness prevalent among medical professionals, they also offered advice for how to overcome it. A “nondirective approach to genetic counseling,” they explained, “can be enhanced by the use of culturally sensitive terminology.” This required an awareness on the side of the counselor that the “medical terms that we use can reflect cultural bias, although it may be unintentional.” Drawing from Boughman’s and Arnos’ experiences, they explained that deaf “couples may consider it a ‘risk’ to have a hearing child rather than a deaf child.” Similarly, they emphasized, Deaf people “do not consider themselves to be handicapped” and “reject the emphasis of the medical community on prevention of deafness.” As “with any other cultural group, deaf people have no desire to be ‘cured’ of their native language and culture.” Such wishes and beliefs might be jarring for the counselor – as they had been, initially for Nance and Boughman –, but overcoming them was simple: “It is very easy for a genetic counselor to make changes in the choice of terms to account for cultural differences.” He or she could, “for example, use the word ‘chance’ or ‘possibility’ instead of ‘risk’ and ‘deaf and hearing’ instead of ‘normal and affected’ or ‘normal and abnormal.’”800

799 Ibid.; Arnos et al., Innovative approach, 345.
Cultural sensitivity, Arnos and her coworkers argued, was the road to successful counseling, to raising genetic awareness among deaf people. If “genetic information is presented in a manner that is sensitive to their cultural and linguistic differences,” their experience had shown, “deaf people are very enthusiastic about participation in the genetic counseling process.” Reversing responsibilities – it was not deaf people, but geneticists who had to change – they presented the deaf as an untapped market of willing consumers of genetic services. Deaf “individuals,” they wrote, “have a deep curiosity about the cause of their own deafness and the implications for future generations.” Confirming that deaf people indeed were interested in genetics, not only justified Arnos’ own position as a geneticist of this community, but made a much more general claim. Curiosity about one’s genetics was an essential, natural characteristic, found universally among hearing and deaf people – and geneticists thus were just satisfying this curiosity rather than creating it.

“They let us in”: The GSC as part of campus culture

Nevertheless, Arnos and Boughman had been apprehensive of the reactions from the Gallaudet community to the establishment of a genetic service center on campus. Given the history of genetic deafness research, Boughman realized, such an institution might raise suspicions. Yet – at least within the range of Boughman’s and Arnos’s experience – reactions were predominantly positive. There was, Boughman recalled, “a hunger for knowledge of why and how” a person was deaf. Interest was so great, that “we learned very quickly that [...] we weren’t going to have to sell this to anybody [...] they were lining up to

801 Ibid., 212.
come see us.” Many of the first clients were not students, but faculty members curious about this new addition to campus services. Once the first clients had been seen and left with a good impression, “word travel[ed] fast.” Visiting the GSC, Boughman observed, became an “acceptable activity to do,” something people would do to satisfy their curiosity about this new institution and its services without having “to be at all surreptitious.” Indeed, of the 659 clients who sought genetic evaluation and counseling from October 1984 to December 1990, most were self-referred. The majority of them were students and young couples, with a mean age of 23 years.

Eventually, Boughman believed, the GSC “became part of the [campus] culture,” a development she attributed to their approach, inside connections and their decade-long history of working with Gallaudet and different schools for the deaf. Conversely, the GSC’s success extended the acceptance of genetic services beyond campus. Working and being accepted at Gallaudet, the heart of American Deaf culture signaled acceptance to the larger Deaf community. “[O]nce you get the stamp of approval at Gallaudet,” Boughman commented, “you’re okay.”

How much the GSC and the hearing (but signing) staff members had become a part of the campus community became visible in the late 1980s. In March 1988, Gallaudet University made national headlines in what became known as the Deaf President Now (DPN) protests. In the months leading up to the announcement of the next president of Gallaudet – all of whom so far had been hearing – students, alumni and members of the NAD had advocated for a deaf president. They built considerable support and organizational cohesion, yet

802 Interview Boughman 2013, 17-18.
803 Arnos et al., Innovative approach, 347-349.
804 Interview Boughman 2013, 17-19.
their expectations were disappointed. Although there were two deaf candidates, the board – whose members were predominantly hearing – announced on March 6th that they had decided for Elizabeth A. Zinser, a hearing administrator with no background in deaf education. The announcement was met with disbelief and anger. In the following week, students, faculty and the DC area Deaf community engaged in a highly publicized protest.805

The announcement of Zinser’s presidency galvanized an already existing network into concerted action. Students boycotted classes and shut down campus and, together with other protesters, marched to the Capitol where rallying speeches were held. In part due to Gallaudet’s prominent location in the nation’s capital, in part because of the media skills of the protesters, DPN quickly attracted considerable media attention. National and local newspapers, radio and TV stations reported on the protest as an issue of minority rights, democracy and rightful presentation. Protesters, who portrayed their demands as a matter of civil rather than disability rights, received letters of support from prominent figures, including senators, Vice-President George H. W. Bush and Reverend Jesse Jackson. After a week of protests and campus boycotts, Zinser stepped down. I. King Jordan, one of two deaf candidates and previously dean of the Gallaudet College of Arts and Sciences, became the first deaf president of Gallaudet.806

806 Armstrong, Gallaudet, 114, Jankow, Rhetoric, p. 121. For the alignment with Civil Right movements rather than disability movements see Christiansen and Barnartt 1997, DPN, 172-174; for media interaction see Van Cleve; Crouch 1989, Place, 172. For letters of support from prominent public figures see http://www.gallaudet.edu/dpn_home/issues/letters_of_support.html
DPN raised questions of belonging, identity and ownership. Occupying campus, students decided who was part of their community – and who was not. During the week of boycott, they blocked campus entrances, “not interested in keeping that many people out; instead, they were screening out mostly hearing administrators and especially Elisabeth Zinser.” This screening process, however, did not affect the GSC’s operation and its staff was allowed to pass. “We came and went,” Arnos remembered, “through the front gate. They let us in.” She was “absolutely sympathetic” with the demands for self-governance. It was “about time that a deaf person became president.” Boughman, by then at University of Maryland, also strongly identified with the protesters and observed the activities “with a great deal of interest.” For Boughman, the protests were an outstanding example of student self-advocacy, of expressing a belief in a better future. Protesters, she believed, were motivated by “a deep-seated, pure feeling, not an anti-feeling as much” as a feeling of being right. “I thought it was great,” she concluded, “I was kind of turning cartwheels myself.”

DPN has become one of most powerful symbols of Deaf activism. The protest, Gallaudet historians Barry Crouch and John Vickrey Van Cleve wrote only a year later, in 1989, “announced to the world that deaf Americans were now a mature minority.” Similarly, Gallaudet sociologists John B. Christiansen and Sharon N. Barnartt described DPN, “an explosive culmination to years of relatively quiet struggle by an oppressed minority.” A Deaf president, Jankowski argues in her 1997 analysis of Deaf rhetoric, “came to symbolize the rejection of the predominant pathological and paternalistic status of Deaf people.” As an

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808 *Interview Arnos* 2012, 16-17.
809 *Interview Boughman* 2013, 21.
“example of an ideological conflict,” it posed a “threat to the dominant group” – hearing society – and “illuminates the surfacing of Deaf ideology in a rhetorical process of empowerment.”

This portrayal, however, rests on a clear bifurcation between the hearing society and deaf minority, activists and professionals. It ignores changing social climates, and the fact that the Deaf community had always had a fringe of hearing family members, friends, and indeed increasingly, professional allies.

Very little has been written about the role or opinions of hearing staff and faculty members, about the opportunities and challenges DPN provided for their professional roles and authorities, and how they interacted with the motive of Deaf empowerment. Hearing staff members, Christiansen and Barnartt comment, were among the most important supporters of the protesters. Some “actively and enthusiastically participated in DPN activities;” others sympathized because of long-standing disagreements between administration and faculty.

The GSC suggests a surprising, maybe ironic twist to this story of identification and politicization. A relative newcomer on campus, it belonged to a science that the Deaf community had traditionally associated with oppressive eugenics beliefs, most vividly with Alexander Graham Bell call for marriage restriction. Yet by the late 1980s, genetics had established itself on a campus now ruled by the spirit of Deaf self-government. While the GSC likely was not universally accepted – neither with diverse d/Deaf communities nor all genetic professionals – it had successfully taken on a mediator role between those two groups.

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Conclusion

In many ways, genetics counselor for deafness at the GSC looked very different from what Walter has practiced at the Wilkerson Center in the late 1960s. At the Wilkerson Center, deafness, unquestionably, was a pathological condition to be reversed or prevented through professional intervention. At the GSC, on the other hand, the birth of a deaf child could be a joyful event, facilitated by genetic professionals willing to serve client wishes, and assimilated to Deaf culture.

At the same time, the work of Nance, Arnos and Boughman built upon long-standing themes and developments in the history of genetic deafness research. Schools for the Deaf had long been centers of genetic deafness research and counseling. Decades of record-keeping provided ideal conditions for mapping out ever more intricate and diverse patterns of inheritance. Nance, too, had early on recognized the potential of these records at the Tennessee School for the Deaf. Alone or with Boughman, Arnos and other students he conducted research there and at other schools. Schools also provided avenues for counseling and genetics education, with the target population concentrated in one institution.

Extending this approach to Gallaudet University was only logical. Yet the location of research and the nature of the research population, this and previous chapters have shown, strongly influenced geneticists’ perception of deafness and deaf people. Deaf people, Nance, Boughman, and Arnos learned, did not necessarily consider their condition pathological, but rather as something that tied them to a valued community. As a visibly different signing enclave and the increasingly politicized center of Deaf activism, visits to the Gallaudet campus
left a strong impression. To provide this group with genetic services, Nance and his collaborators believed, geneticists would have to reframe their science as one that posed no threat to Deaf culture and community. This included learning sign language, changes in terminology and portraying genetics as a science answering basic questions, yet also capable of aiding individual reproductive preferences.

A confluence of developments in the history of deafness and genetics favored these conclusions. Spanning the roughly 30 years from the mid 1960s to the early 1990s, this chapter captured a period in which the relationship between physicians and patients, geneticists and their study population changed significantly. Most aptly, perhaps, this change is captured in replacing the patient with the client or consumer of health care or genetic services. In genetics in particular, client-centered, non-directive was considered a means to promote reproductive autonomy rather than collective genetic responsibility. It was the client or the consumer who was to decide which services to use, which decisions to make – and what was a pathological condition in first place.

Focusing on the individual, emotional benefits of counseling blurred the lines between hearing normalcy and pathological deafness. Alexandra Stern has traced the rise of psychogenic and psychoanalytic motives in genetic counseling to geneticist Paul Popenoe’s brand of postwar marital and heredity counseling during the 1950s and 60s. In his American Institute of Family Relations, Popenoe reified contemporary gender norms as a means to preserve conservative family values and to encourage the reproduction of the eugenically fit.812 Sheldon Reed’s influential approach to genetic counseling similarly defined the emotional benefits of counseling in terms of restoring the balance of the normal family that

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812 Stern, *Eugenic nation*, 152, 180
had been disturbed by the birth of a disabled child. Early in his career, Nance had picked up on this psycho-emotional approach to genetics as a matter of blame or stigma associated with disability. His deaf clients, however, questioned what a having a “normal” family or child meant in first place. Committed to the ideal of non-directiveness, confrontation with divergent client values lead to a reorientation, if not a reversal, of his perceptions of deafness. For Boughman and Arnos, too, genetic counseling was an interactive, psychotherapeutic process between client and professional. This required from the counselor self-awareness and self-reflection.

Thus, while emphasis on the psychological benefits of counseling could reinforce physical or gender norms, it could also contribute to more individualistic and relative definitions of genetic defect. This development was also aided by a more sociologically-minded strand of psychology that had influenced genetics from the 1950s on. For their mental reorientation, Nance and his coworkers could draw from a growing popular and academic literature that promoted a sociolinguistic minority model of deafness, disability and defect. At outlined in previous chapters, this literature emerged during Nance’s early career in the 1960s. By the mid 1970s, when Boughman entered the field, an alternate, cultural model of deafness had become available and increasingly acceptable in some professional circles and – due to increased activism – in society more in general.

As professional definitions of deafness diverged, so did justifications for professional intervention. Rather than eradicating deafness – a goal that remained prevalent among physicians, audiologists, educators, and and certainly, too, geneticists – the social sciences, psychology, genetics was
envisioned as a means to eradicate inequality and discrimination. This model resonated with Nance's self-perception as an exploring geneticist rather than physician with a therapeutic mission, and with Boughman's and Arnos' ideal of genetic counseling as a helping and caring, rather than a directive profession.

In Deaf studies and Deaf history, science and medicine tend to be portrayed as forces that oppress the expression of Deaf culture and community. Historically, this portrayal certainly has often been accurate, although frequently at the price of sketching a black-and-white image of oppressors and the oppressed.\footnote{For this position see e.g. Branson; Miller, \textit{Difference}; Jankowski, \textit{Rhetoric}; Lane, Harlan L., Robert Hoffmeister, and Benjamin J. Bahan. 1996. A journey into the deaf-world. San Diego, Calif: DawnSignPress.} The GSC's story, however, shows a more complicated picture. Turning patients into clients and consumers, it portrayed genetics as a service customized to the beliefs of a minority, yet (often still) at odds with majority perceptions of deafness.

Moreover, Nance, Arnos and Boughman explicitly turned around established notions of fault and resistance. Deaf people, they believed, were not disinterested in or resistant to genetics education. Rather, it was genetics professionals who had failed to provide the deaf with meaningful services and applicable information. With their ignorance of Deaf culture, language and community, they had turned the deaf into a neglected population in first place. This professional self-portrayal put Nance, Arnos and Boughman in a strategic mediator position. To the deaf community it signaled remorseful willingness to overcome past biases. To genetic professionals it offered a way of overcoming deficits in a manner that resonated with contemporary ideals of more democratic health care, patient autonomy and informed decision-making.
Obscuring the line between experts and objects of research, Arnos and Boughman sought to assimilate themselves and their science to the values of their target population. Identifying with the demands of Deaf activism allowed them to argue for an overlap between the ideologies of genetics and Deaf activism. Rather than a threat, they claimed, genetics was to be a science of empowerment for the deaf individual and community. Such a portrayal conflated different dimensions and traditions within genetics and Deaf activism. Being informed about one’s biological self was not only a form of controlling individual fate, of attaining personal fulfillment and emotional equilibrium, but became part of political empowerment, too. Conversely, the informed consumer of health services became a social activist expressing the values of a sociocultural minority. Finally, casting geneticists in the ambivalent role of scientists-activists, this portrayal gave a new spin to the notion of genetic counseling as a helping science. Supporting the selves of their clients even if they diverged from majority culture, genetics services at the GSC became a supportive science of late 20th century identity politics.  

VIII. Conclusion

In the early 2000s, Walter Nance speculated about the future of the American Deaf community, which he had come to know well over the course of his career. Reflecting on the “social and ethical aspects of genetic deafness,” he speculated that with recent advances in biomedicine “Deaf culture may well disappear in our country by the end of this century.” Yet, he argued, it was not genetics that Deaf people had to fear most. Rather, he believed, it was cochlear implant technology that “almost certainly represents a much greater threat to deaf culture than genetic testing.”

Cochlear implants are devices that circumvent defective hair cells in the inner ear (chochlea), relaying sound messages to the brain. Developed in the 1970s, and approved by the FDA in 1985, they were initially intended for and tested on adults with profound sensoneural deafness who did not profit from conventional hearing aids. The fastest-growing market for cochlear implants, however, has been children and toddlers. Here, implants are often touted as cures for neurosensoral deafness, although such claims obscure the need for continuing intensive therapy. Operating at the intersection of neurology and audiology, cochlear implants also have given a new boost to oralism. Tapping into the language of neuroscience, proponents of oralism now point to a critical period in learning language and the irreversible neurological “rewiring” that occurs if the child is not reached by spoken language early enough. Given that most deaf children are born to hearing parents, the familiarity of spoken

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816 As of 2012, 58,000 adults and 38,000 children have received implants in the US, of an estimated total of 324,000 implants worldwide. See https://www.nidcd.nih.gov/health/hearing/pages/coch.aspx
language remains highly attractive, despite the growing popularity of ASL as a second language in the US.\textsuperscript{817} In the Deaf community, on the other hand, cochlear implants have been controversial. Especially since the 1990s, when implants were approved for toddlers, Deaf activists have charged parents of exposing their child to a risky surgery, of taking the deaf child away from the community to which it belongs, and of rejecting Deaf culture. Once more, deaf children are in the middle of a highly emotional debate about their identity, belonging, and future.\textsuperscript{818}

Yet when geneticists such as Nance make claims about the relative danger of cochlear implants vs. genetics, they create a simplified scenario of competing technological threats that is more telling about how they would like to see their profession than analytical about the social impact of technological progress. Such a scenario assumes that geneticists are able to control the application of genetic technology and to steer public opinion on genetics and pathological traits. Despite Nance’s claim about genetics being a lesser threat, deaf people’s


As with all cranial surgery in small children, CI’s are associated with certain risk of injury during surgery, and with a somewhat elevated long-term risk of meningitis. For a current appraisal see the FDA’s info page at http://www.fda.gov/MedicalDevices/ProductsandMedicalProcedures/ImplantsandProsthetics/CochlearImplants/ucm062843.htm
reproductive habits are still viewed with suspicion in the 21st century. The availability of individualized genetic services has only added to this suspicion.819

Thus, the year 2002 saw what must be one of the most publicized and controversial instances of two deaf people founding a family. When the couple Sharon Duchesneau and Candy McCullough looked for a sperm donor for their second child, a sibling for their deaf daughter, they hoped that he or she would be deaf, too. To Duchesneau and McCullough, who identify as Deaf, this outcome would have been a special joy, although they would have welcomed a child of any hearing status. To improve their odds, they first contacted a sperm bank for the possibility of a deaf donor, yet were told that deaf men were excluded from the pool of eligible donors. They then approached a male friend from a multi-generational deaf family who had a form of dominant genetic deafness. This combination provided good chances for the desired outcome. When their son was born, he indeed turned out to be deaf, a cause of joy for the Duchesneau-McCullough family – and of public debate over the meaning of disability, reproductive rights, and parents’ rights and responsibilities. The highly emotional reactions ranged from accusations of creating designer babies to selfish child abuse. While the public attention on the Duchesneau-McCullough family has by now faded, their decision has become a popular teaching case in bioethics and medical ethics, disability and Deaf studies.820

819 Gallaudet philosopher Theresa Blankmeyer-Burke writes on the contrary that the “ethical issues of cochlear implant surgery seem almost quaint and outmoded” compared to genetic technology as the “newest potential threat to the continued existence of the Deaf community.” See Blankmeyer-Burke, Theresa. 2011. Quest for a deaf child. Ethics and genetics. PhD thesis, University of New Mexico, B.

820 Blankmeyer-Burke has covered this case most extensively, and in her thesis provides a detailed analysis of bioethical issues at stake in the use of genetic technology from a Deaf studies perspective. See Blankmeyer-Burke, Quest.
Debates over the nature of deafness and the responsibilities of deaf people in reproduction thus are far from being resolved, despite the significant advances advocates of Deaf culture have made. These debates revolve around questions of the meaning of disability, disease and suffering, citizenship and identity, scientific authority and intervention. However, unlike in the beginning of the century, sympathies and alliance no longer are clearly drawn between deaf individuals on the one side, and hearing professionals and society on the other. In the last decades, Deaf culture and community has found a place in a more multi-cultural, diverse America – certainly controversial or offensive to some, but not necessarily more or less so than other minority cultures and identities. For scientists and professionals interested in a sociocultural model, the academic fields of Deaf studies and Deaf history now provide an easily available set of theories and beliefs.

This situation is the result of the developments I traced in this thesis, moving in an apparent paradox: As knowledge about (hereditary) deafness expanded, so did opinions on what to do about it. Over the course of the century, deaf people came under the scrutiny of an ever more varied set of professionals, including eugenicists and geneticists, otologists and audiologists, teachers, sociologists, linguists, philosophers, psychologists and psychiatrists, rehabilitation workers and counselors. Beliefs about deafness and heredity, however, did not evolve uniformly or progress evenly. Rather, as knowledge expanded and diversified, they formed overlapping and co-existing sets of paradigms. How beliefs about genetics aligned with those about deafness and deaf people profoundly affected how genetic and scientific knowledge was applied.
There were several factors at play in the development of such professional clusters, alliances and paradigms: Institutional context was crucial, as I have shown by example of oralist schools, psychiatric institutions, hearing-and-speech centers, and of Gallaudet College as a center of Deaf culture, activism and research. The very meaning ascribed to deafness and deaf people in these contexts varied immensely, from the paternalistic, yet also caring, long-term relationship between teacher and students, to considering the deaf an interesting but mostly anonymous research population, to partners in providing health care services for a minority culture with which professionals identified. More so than with other research populations, communication – or lack thereof – was a key issue, enmeshed in strong ideologies about the nature of thought, language and being human.

The Clarke School research is a prime example for the different beliefs existing even within a medical-pathological model of deafness. Here, we can follow the development and dissolving of professional alliances throughout the century. From its foundation in 1867 to the present, the school has been a leading oralist institution, and was crucial in developing a specific form of scientific oralism that incorporated the newest technology to assimilate the deaf as quasi-hearing into hearing society. With the establishment of the research department in 1928, the school began collaborating with outside scientists with their own goals and assumptions about the meaning and goals of deafness research. Interested in social dynamics and interpersonal relationships, Fritz and Grace Moore Heider, the psychologists working at the school in the 1930s and '40s defined the deaf as sociological and phenomenological minority that should not be measured by hearing standards. Their results thus undermined basic
oralist beliefs. While ignored by the school, the Heiders’ work provided an important impetus for the changing perceptions of deafness and disability in the 1950s and ’60s. Future research on the early roots of the social minority model of disability and deafness will have to take into account this little explored cross-pollination between the psychology of deafness, disability and social dynamics.

The eugenicists and geneticists working at the Clarke School in the same period shared teachers’ concerns about hereditary deafness – yet did not agree necessarily what to do about it. Madge Macklin’s public-health approach of eradicating pathological traits – if necessary by restricting the rights of its carriers – was worlds removed from the school’s holistic vision of heredity advice as yet another means of integrating deaf students into hearing society by eradicating, as much as possible, their difference. Nevertheless, oralist educators could form an alliance with eugenics and early medical eugenics over the truisms that it was best if deaf people did not marry each other.

By the 1960s, however, as geneticists began making more precise prediction about reproductive outcomes, this alliance weakened. If a deaf couple was unlikely to pass on their condition, there was no reason for a medical geneticist to advice them against having children (much less against marriage). For the oralist educator, on the other hand, deaf intermarriage still spelled a failure of oralist assimilation. The great advances in mid-century knowledge of genetic deafness thus meant very different things to different people.

I have located pivotal changes in the perception of deafness and disability, heredity and prevention, individual rights and social needs in the 1950s and 60s. These changes have often been overlooked because they were more subtle than the social or professional activism of the 1970s and ’80s, or because they
occurred in fields or institutions not usually on the radar of historian of genetics, deafness or disability. For example, the history of psychiatric genetics at the NYSPI has been given some attention, yet their groundbreaking projects with the deaf have not.

Like other mid-century reform projects driven by an optimistic belief in the malleability of individual and society – quite different from the more pessimistic eugenic rhetoric of even a decade or two earlier – the NYSPI researchers relied on some kind of exchange (however nominal or idealized) with their target population. Within this explorative framework, the NYSPI engaged in a multidisciplinary project that mapped out the needs, pathologies and relative normalcy of the New York State deaf – a well-organized community on the cusp of gaining more influence, and embracing opportunities to do so. Thus, under the paradigms of community psychiatry, we saw the reemergence of deaf perspectives in professional narratives – and indeed a blurring of the line between hearing professionals and deaf patients.

The NYSPI project was also crucial in transforming perceptions of the deaf as a target population of genetics and adjacent professions. No longer were they solely, or even predominately targeted for (the prevention of) their deafness, but rather as a group with a uniting characteristic that might put them at risk for certain conditions. Here, moving from asylum inmates to providing services to the community at large facilitated a shift in terminology from the medicalized patient to the autonomous client of consumerist postwar America.

All this did not mean that older eugenic rhetoric, goals and beliefs had disappeared. Yet eugenic thought was transformed by the encounter with new psychological and sociological approaches that put emphasis on sociocultural
determinants, and in doing so relativized absolute definitions of normalcy and pathology. These explorations were tied to an acute interest in and concern over the position of minorities in US society, not the least because they might potentially become susceptible to subversive thought. It was in this general climate of Cold War fears and liberal social reform that geneticists found new justifications for scientific intervention and social engineering. By defining the deaf a minority underserved by essential services, geneticists included genetics in a set of knowledge and services to which everyone was entitled. This approach granted them the ability and authority to level such social inequalities, and to produce informed and rational democratic citizens and families.

These were the motives from which genetic deafness researchers drew in the 1970s and 80s, albeit in a more pronounced and often explicitly political form. Debates over the prevention of Usher Syndrome make visible how campaigning for eugenic public health measures could coexist with radicalized professional advocacy for Deaf culture and community. Combining social activism with the delineation of pathology, McCay Vernon, for example, likened deaf people to America’s oppressed minorities, and called for their liberation from biased hearing society. Yet he did not expand this model to the (deaf)blind, who for him clearly led a life of deprivation and suffering.

In the last third of the century, however, interpretation was no longer solely in the hands of hearing professionals such as Vernon. Emphasizing ability and autonomy, deaf-blind individuals challenged established narratives of suffering and defect. The motive of endangered selfhood dominated 1980s discourse of Usher syndromes, yet could be cast as a clinical description of loss, or as a universal human search for belonging and fulfillment. Here, deaf-blind
people's position between the deaf and the blind community, as patients, health or disability activists alerts us to the highly fractured nature of identity politics, and the variety of ways in which genetic motives were appropriated.

The Gallaudet Genetic Service Center similarly struggled with portraying the deaf as sociolinguistic minority while justifying the need for genetic services to funding agencies who operated under the paradigms of scientific progress and cost-saving public health measures. The fact that Arnos and her colleagues were successfully in securing federal funding is a testament to how well-known the sociocultural minority model of deafness had become in the US by the early 1980s. Yet, I would argue, what was at least as appealing, and indeed a rallying point both in dominant discourse and within the Deaf community, was the notion of the deaf as a population at risk, if not for deafness, then for conditions considered pathological in both communities.

The work of the NYSPI, Vernon, Nance, Arnos and Boughman has contributed greatly to popularizing ASL, Deaf culture and community within a science long concerned with eradicating deafness. Within the relatively small field of genetic deafness research and counseling, their model of culturally sensitive counseling has been influential. Most counseling literature today at least acknowledges the existence of Deaf values. For example the 2014 National Center of Biotechnology Information (NCBI) Gene Review on Deafness and Hereditary Hearing loss lists not only the hundreds of different forms of genetic deafness now known, but also points to the existence of the American Deaf community as a community with “unique social and societal attributes.” Deaf people, the authors explain, “may view deafness as a distinguishing characteristic and not as a handicap, impairment, or medical condition requiring
a ‘treatment’ or ‘cure,’ or to be ‘prevented.’” Citing Arnos, they note that the “use of certain terms is preferred,” e.g. “probability or chance versus risk” and that terms “such as ‘affected,’ ‘abnormal,’ and ‘disease-causing’ should be avoided.”821

Gallaudet and the Medical College of Virginia (MCV) genetics department – headed by Nance – have served as institutional centers where scientists become acquainted with this worldview and later disseminate it in different contexts.822 For example Arti Pandya, chief of genetics and metabolism at University of Chapel Hill, originally “viewed hearing loss with a medical lens, considering it a disorder.” Yet as she joined Nance’s department at MCV, and began working with Arnos at Gallaudet, she became aware of Deaf culture and “realize[d] that ours was an extremely narrow view.” This discovery motivated her to “delv[e] deeper to understand their attitudes and the impact that discoveries in the genetics of hearing loss has on the Deaf community at large.” Pandya has since worked with Arnos on studies that explore the attitudes of deaf people toward genetic counseling.823

For others, the influence of the Gallaudet / MCV group was more indirect. When UCLA genetic counselor Christina Palmer began providing genetic testing and counseling for deafness in the early 2000s, she came into contact with

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822 Although the GSC stopped providing genetic counseling in 2009 due to lack of funding, Gallaudet’s genetics and biology research and education has expanded.

California Deaf communities. Wanting to learn more about her clients, she contacted the Deaf Studies department at California State University, Northridge and was referred to ASL scholar Patrick Boudreault. They decided to collaborate to provide culturally sensitive counseling for deaf people at UCLA, and to explore the attitudes of deaf people toward genetic testing. Boudreault’s insight and insider knowledge, Palmer commented, was invaluable for her as a hearing person, the “reason, really, why we were so successful with that project.” When they began their project, they contacted Arnos for advice and training and profited from the GSC's experience. In an ongoing project, Palmer and Boudreault, the latter now at Gallaudet, collaborate to provide bilingual cancer genetics education in ASL and English to the Deaf community.824

Without a question, these projects have been invaluable in equalizing and expanding access to health care services and information for deaf people, and in acknowledging patient and client perspectives rather than taking for granted the definitions of professionals. Yet underneath the progressive, liberal beliefs that drive these projects and secure their success in current US society, there is an


often problematic definition of minority and identity, tangled with the ideals of mid and late 20th century genetic counseling. The very attempt to define the specific normalcy of a certain minority rests upon the tendency to perceive this minority as a uniform other. Moreover, in this process, professionals tend to interact and identify most with those community members that bear the greatest likeness to professionals’ own white middle-class values.

This was certainly the case when NYSPI researchers interacted with the leaders of the state’s deaf community, who were, like them, predominantly male and white. Similarly, although Nance, Boughman and Arnos certainly interacted with a wide range of deaf and deaf-blind individuals, they were shaped by the identity politics pursued by an elite of Deaf activists in the 1970s and 80s. Thus, questions of race, class and disability are strangely absent from discussions about genetic services for deaf people, a fact that mirrors bias among hearing professionals and within the Deaf community. Ironically, then, the very attempt to diversify genetics by adopting the values of the target community also perpetuates the patterns of bias and exclusion within these communities. Attempts to create ever-smaller subcategories of minorities only reinforce this pattern. To avoid this trap, geneticists and historians of genetics, disability and deafness need to pay greater attention to the intersection of identity politics and professional activism.

Non-directive counseling has often been cast as neutral and apolitical, and thus as safely removed from eugenic abuses of genetics. Yet the very attempt to distance oneself from political abuse has always been deeply political. Where the eugenicists of the first part of the century had drawn legitimization from improving race and mankind, by its end geneticists found justification in a
different political ideology.Aligning themselves with the struggle for equality and diversity, white middle-class geneticists portrayed themselves as activists for a more just healthcare system accessible to a so-called neglected, underserved populations. This narrative turned geneticists into the vanguard of social progress, ahead of other professionals who were still tangled in bias and discrimination. If a deaf client expressed a wish for a deaf child, this was no longer to be seen as deviant and pathological. Rather, it had become a test case for the much discussed dogma of late 20th century genetic counseling: non-directiveness.

This move, however, turns non-directiveness into an absolute value that cannot not be criticized without simultaneously criticizing the ideal of a diverse and tolerant society. Since the 1970s, counselors have reflected much on the value and practicality of non-directiveness, and in recent years have been critical of the ideal of the counselor as an impartial figure. However, this has been mostly an internal discussion concerned with professional paradigms rather than with the expectations raised in exchange with clients, or with the conflation of professional activism and neutral counseling.

When, in the 1980s, GSC scientist, claimed genetic knowledge to have an empowering quality, this reads very differently from early 20th century discourse on the eugenic prevention of a pathological trait. Yet there are important continuities in the changing perceptions of genetic deafness and of the deaf as a target population. Debates over the meaning of genetics are often reduced to questions of nature or nurture, genetic determinism or sociocultural influences. It is a striking feature of genetic deafness research that for most of the protagonists in this thesis, this was not true in such absoluteness. For most
professionals, genetic knowledge was just one aspect of a larger project of managing deafness. It was essential for navigating life, yet not necessarily deterministic. This belief in the essentiality of genetic knowledge is something that educators, eugenicists, psychologists and psychiatrists, and geneticist, and indeed, some deaf or deaf-blind people shared.

There are several problematic assumptions in this genetic essentialism. Attempts to bring genetic knowledge to deaf people rested on a liberal model of rational citizenship. By and large professionals operated under the assumption that once the deaf were properly educated on genetics, it would become an important and meaningful category of knowledge to them. Thus, teachers at the Clarke School believed that deaf student would make the decision expected of them in an oralist framework. Nance, Arnos and Boughman believed that if genetics professionals practiced culturally sensitive counseling, deaf people would naturally recognize genetics as a crucial form of self-awareness, even of personal and political empowerment.

This espousal of genetic awareness as indispensable might seem self-evident to us now, steeped as we are in the rhetoric of genetic disease and genetic testing, of the Human Genome Project and its successors. Yet we should not take this perspective for granted, given that genetic selfhood is a recent construction tied to modern and postmodern ideas about identity and society. Historians and sociologists of psychology have pointed to the impact of Western liberal citizenship and capitalist consumerism in forming our private and social identities, and in creating a culture of self-achievement and self-improvement. Nicolas Rose in particular has pointed to the importance of psychology and psychiatry as disciplines promoting the notion of a hidden true self that requires
constant management under professional surveillance. These themes of self-awareness, self-realization and improvement have been central in creating the appeal of late 20th century individualized genetics. Without them, vice versa, many of the claims about genetic citizenship would have been impossible.825

This form of genetic essentialism rests on a compelling narrative in which geneticists are the arbiters of an apparently natural progression from ignorance to enlightenment. Knowledge, here, always trumps ignorance. Debates over the benefits of testing individuals at risk for Chorea Huntington’s disease or breast cancer have challenged these assumptions somewhat. Some individuals with a family history of Chorea Huntington – a dominant condition – decide not to get tested, believing that the certain knowledge of having a debilitating and eventually fatal condition would be more emotionally and socially damaging than not knowing. A positive test for a mutation of the “breast cancer genes” BRCA 1 and 2, on the other hand, does not denote the certainty of developing breast cancer, but just enhances the individual’s constant at-risk status. Nevertheless, in an age of information-technology and supposed self-determination, not knowing is considered at best quaint, if not a sign of


Surveying 20\textsuperscript{th} century genetic deafness research may seem to present a clear progression toward understanding pathology, difference and disability as culturally and socially constructed; whether it be by majority or minority cultures. Yet this cultural relativism seems to dissolve in the 21\textsuperscript{st} century. Recently, some scholars believe to have observed a reversion to more biologistic beliefs about identity and ethnicity, a supposed geneticization of self and society. Scholarship on the American Deaf community serves as an example. Within the last decade, Deaf scholars and activists have supported the definition of Deaf people as an ethnic minority with explicitly genetic claims.

For example a 2000 article by Deaf historian Ulf Hedberg, and hearing psychologist Harlan Lane and psychiatrist Richard Pillard (both long-time advocates for Deaf culture) uses genealogical and evolutionary thought to theorize about Deaf identity. The authors trace the genealogies of several multiple-generation deaf families during the 18\textsuperscript{th} and 19\textsuperscript{th} century, and tie them to the creation of Deaf communities. The authors conclude that "a difference in the genetic basis" of the communities researched "is responsible for the difference in emergence of class consciousness." Thus, a dominant pattern of inheritance produces families with deaf members in each generation who pass on their language and values. With recessive pattern, on the other hand, deafness might skip a generation, and the family has fewer deaf members overall. This
isolates deaf people and has produced an assimilationist climate that hindered the creation of a Deaf class consciousness. Lane and Pillard’s 2011 *The People of the Eye: Deaf Ethnicity and Ancestry* reaffirms these theories within a more explicitly ethnographic framework.827

Others have grounded culture in biology to appeal to the preservation of a vaguely defined, yet politically appealing biocultural diversity. In the introduction to the 2014 essay collection *Deaf gain: raising the stakes for human diversity* Gallaudet Deaf historian Joseph Murray and Deaf studies scholar H-Dirksen Bauman write that “the gene for deafness has stubbornly persisted over thousands of generations;” proof that “deafness is not an evolutionary error but a natural human variation that continues to thrive.” In the same volume, historian David Armstrong argues for Deaf gain – the notion that Deafness and Deaf people contribute positively to the variety of human experience – from an “evolutionary perspective,” pointing to the specific evolutionary value of sign languages.828 Such an anchoring of identities and political claims in biology and genetics – in the supposedly hard sciences – is not limited to the Deaf.


community, as witnessed by the enormous rise in popularity of neurological selfhood and neurodiversity recently. Debates over the nature of gender, too, have long revolved around notions of innateness. Here, too, some scholars have suggested a return to biological determinism e.g. in debates over “gay genes.”

Scholars have suggested two interpretations of this tendency to locate selfhood and belonging in innate, embodied and unchangeable dimensions – be it brain or genes – one more critical, the other more affirmative or celebratory. Historians and sociologists of science have tied the strengthening of biological selfhood to a more general model of biomedical citizenship emerging around the turn from the 20th to the 21st century. In the age of individualized genetics, they argue, dominant values and norms have become internalized as biomedical discourse has dissolved firm categories of sickness and health in favor of a constant at-risk status of the potential patient. Thus, rather than a diminishing of professional influence, it is simply the methods of enforcing biomedical ideals that have changed. Disability and Deaf scholars and activists, on the other hand, tend to celebrate some forms of genetic or neurological selfhood as a successful assertion of autonomy and agency, as a re-appropriation of knowledge from the scientific regime of normalcy, and, as a celebration of human diversity. Thus, we

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have one narrative that reaffirms the absolutizing power of science and medicine, while another celebrates the re-appropriation of knowledge by disabled actors.\footnote{830}

Both interpretations, however, rest on the belief that these identities and ideologies are recent developments. They suggest a tripartite periodization: a medical-eugenic era with professional definitions of bio-pathology, a period of cultural relativism and social activism during the 1960s, 70s and 80s; and of actor-driven bio-identities of (bio)diversity in the present. This, I believe, obscures important continuities that become apparent when moving away from a strict separation between the spheres of activism on the one hand, and science and medicine on the other. Scientists and physicians, of course, have always been involved in politics and social movements, and eugenic thought had engendered a particular zeal for social reform. Yet from midcentury on, I have traced a different form of social activism that rested on a merger of claims to biological essentialism and cultural relativism. NYSPI scientists, Vernon and his colleagues in Chicago, and, later Nance, Boughman and Arnos aligned with adult communities that asserted their sociocultural difference with increasing confidence and success. Occurring in a time in which the authority of science and

medicine became increasingly challenged, such alliances and alignments provided new forms of professional identity that portrayed the scientific expert as an ally in the struggle of minorities. Kallmann merged psychotherapy, genetic essentialism and American ideals of democracy; Vernon combined advocacy for Deaf culture with restrictive delineations of neuro-pathology in a manner reminiscent of current debates over autism and neurodiversity. During the 1970s, Walter Nance began portraying deafness as human diversity – both in the genetic and cultural sense; a notion echoed in Arthur Roehrig’s 1976 assertion that Usher Syndrome, too, was part of human diversity.

Throughout the 20th century and into the 21st, genetic counseling has been an endeavor of education and persuasion, of trying to convince deaf people to make genetics part of the knowledge guiding their lives. Especially in the first part of the century, this was mostly an authoritarian enterprise that left little room for alternate identities. Non-directive counseling – the dominant paradigm from the 1960s – claimed to have disposed of such subtly coercive approaches. Culturally-sensitive counseling for deaf people in particular was intended to relativize definitions of pathology and disability as something entirely dependent on patient perspective. Nevertheless, or, just because it employed themes of Deaf autonomy, it has contributed to making genetics an essential part of self-knowledge. This was not a simple process of imposing values and norms, but an exchange in which deaf or deaf-blind people formed their own ideas about the meaning of genes and heredity. Sometimes, they rejected these categories as irrelevant or restricting. At other times, they accepted or embraced genetics as an important part of their identity, or as a useful rhetorical tool. Certainly, recent claims to Deaf genetic identity is a re-appropriation of genetic knowledge by
Deaf people themselves. Yet when some Deaf activists now consider the Deaf to be an ethnogenetic group of shared ancestry, we may well trace some of this ethnobiological identity politics to geneticists' attempt to fulfill an unmet need for genetic services among the deaf, and to encourage genetics awareness as a form of political empowerment.
IX. Bibliography

Archival material

Clarke School Heredity Research Division files, Clarke School Archive, Northampton. In 2013, the Clarke School Archives were relocated to the Special Collections & University Archives, University of Massachusetts Amherst Libraries.

Edna Levine Collection, Gallaudet University Archives, MSS 166

Boyce Williams Collection Gallaudet University Archives, MSS 072

McCay Vernon collection, Gallaudet University Archives, MSS 048

Fritz Heider collection, and Grace Moore Heider collection, Kenneth Spencer Research Library, University of Kansas Libraries.

Anne J. Sweeney Papers. Eskind Biomedical Library Special Collections, Vanderbilt University Medical Center, Nashville, TN.

Mental Health Association for the Deaf, Empire State Association for the Deaf Collection, Rochester Institute of Technology Archives.

Interviews


Joann Boughman, Adelphi, MD, Tuesday, August 27th 2013. Interviewer: Marion Schmidt.


Christina Palmer, Los Angeles, California, August 13th 2013. Interviewer: Marion Schmidt.
Published material


Barker, Roger G. 1953. *Adjustment to physical handicap and illness; a survey of the social psychology of physique and disability*. New York: Social Science Research Council.


Bender, Ruth E. 1970. *The conquest of deafness; a history of the long struggle to make possible normal living to those handicapped by lack of normal hearing*. Cleveland: Press of Case Western Reserve University.


Callahan, Raymond E. 1962. *Education and the cult of efficiency: a study of the social forces that have shaped the administration of the public schools*. Chicago: University of Chicago Press.


Macklin, Madge Thurlow. 1932. “Should the Teaching of Genetics as Applied to Medicine Have a Place in the Medical Curriculum?” *Journal of the Association of American Medical Colleges* 7 : 368-73.


“Meet Dr. Arti Pandya, UNC Children's chief of genetics and metabolism.” UNC's Children News, Care 2015 (2).


Wildervanck, L. S. 1957. “Consanguinity and congenital deaf mutism in the Netherlands; are the parents of deaf children detectable as heterozygotes.” Acta Genetica Et Statistica Medica. 7 (1): 244-8.


Wolfe, Audra J. 2013. Competing with the Soviets: science, technology, and the state in Cold War America.


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