Constructing Parental Choice in Deaf Diagnostic and Intervention Practices in Ontario

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
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Abstract

The goal of Ontario’s Infant Hearing Program (IHP) is to screen all babies at birth, to identify the 3 or 4 out of 1000 babies expected to be deaf or hard of hearing from birth, and to provide supports and services to identified children under the age of six. Situating my research within disability studies to question normative assumptions about speech, language, and hearing, through interpretive analyses of IHP documents and parental interviews I examined how language and deafness are made meaningful through text and lived experience, and how parents come to make hearing technology and communication modality choices for their children amongst competing discourses of deafness and language. Although the identification of these few children is the IHP’s justification for screenings, I found the discourse of screening constitutes these children’s hearing levels as problematic and unwanted. Normative assumptions construct parental choice by presenting deafness as an unthinkable outcome of screening and spoken language services as the ‘right’ way to deal with this outcome.

I also found the services and hearing technologies offered, and when they were offered, differed depending on whether a child has additional diagnoses and are assumed able to learn spoken language, demonstrating a hierarchy of normalization. Furthermore, the IHP’s principle of fully informed choice and consent was found to narrowly reflect medical knowledges of deafness;
comprehensive information about sign language and Deaf culture was not included. My analysis also found parents may resist medical knowledges of deafness and request alternate services as they get to know their child beyond diagnostic assumptions. These findings indicate parents and their children may be better aided by services that promote a wider variety of communication options from infancy, regardless of expected outcomes. My dissertation concludes with an exploration of ways the IHP can imagine deafness as something other than a problem.
Acknowledgments

The research I have undertaken in this dissertation has been on my mind, in various forms, for many years. In those years, there have been many people who have provided me with support and influenced the trajectory of my research. This section serves to gratefully acknowledge everyone who has contributed in some way to my work on this dissertation, whether named or not.

First and foremost, I thank my esteemed supervisor, Tanya Titchkosky, who has taught me, from our very first telephone conversation when I was an applicant to the program, to think differently about disability. Her teachings assisted me in shifting from positivist theoretical perspectives rooted in science and medicine, to qualitative sociological perspectives that had me questioning the taken-for-granted “normal.” I thank Dr. Titchkosky for being a patient, caring, generous supervisor and mentor who always knew just the right thing to say, or just the right source to recommend; she provided insightful guidance to keep me moving forward and improve my work. I always left her office feeling more confident about my work, and about myself; it is a special skill to make people feel their work is valued and important, and she does that with ease. Thank you, Tanya, for all the ways you have contributed to my dissertation!

I am also thankful for the time my committee members, Barbara Gibson and Jeffrey Bale, committed to reading (and re-reading) my chapters, and their thoughtful comments and suggestions. Dr. Gibson’s knowledge and experience from rehabilitation sciences, particularly her knowledge with critical qualitative health research, was invaluable to me in considering how to bridge speech language pathology with disability studies research. I thank Barb for her close reading of my work; her insightful comments assisted me with clarifying my methods, thinking through theory, and supporting my claims. Dr. Bale’s experience in language planning and policy research and his interest in Deaf studies rounded out my committee. His suggestions for chapter organization and improved clarity and consistency in my writing, especially around controversial issues, were much appreciated. It was truly wonderful to have had such a collegial, inter-disciplinary collaboration between professors in rehabilitation sciences, language planning and policy, and disability studies, which translated into the inter-disciplinary nature of my dissertation. I am truly fortunate to have had such a wonderful team working with me; they made the process from start to finish an enjoyable, productive experience.
Thank you to Kari Dehli for taking time out of her retirement life to be my internal-external examiner. I fondly remember her brilliant teachings on Foucault, and am grateful for her encouragement to publish my first academic paper! Thank you to Susan Burch, for being my external examiner. Her co-edited book with Alison Kafer, Deaf and Disability Studies, was key for my thinking through the relationship between disability studies and Deaf studies. Finally, thank you to Megan Boler for volunteering her time as my alternate internal-external examiner. You all make up my dream team and I appreciate all you have done to help get me to this point!

I thank all those who generously shared their time with me to help me understand deaf education in Toronto: teachers of the deaf; education department heads; program leaders; speech language pathologists and audiologists; Deaf ASL teachers; parents; deaf friends and members of the Deaf community. I would not have even started down this path had it not been for the information I learned from their knowledge and experiences. I owe a special thanks to Sinéad Whelehan for introducing me to the struggles of both teachers and students in deaf education and for sparking my desire to examine the issues, and to Anita Small for broadening my knowledge of language injustices faced by the Deaf community and introducing me to Deaf community members and academics who have been instrumental in my thinking through the issues I address in this dissertation, for whom I am also very thankful. I am especially grateful to the parents who answered my call for participants and so openly shared their experiences with me. Without them, this dissertation would not have been complete. Thank you for sharing your stories with me.

Thank you to the OISE professors who have taught me so much, my fellow graduate students in disability studies, and students and professors who participated in our Disability Studies Reading Group; our theoretical musings provided fuel to keep me thinking about disability differently. Special thanks to Devon Healey and Leroy Baker who have been students with me for my entire PhD journey. I feel privileged to have studied with you, learned from you, laughed and cried with you, and hope that we continue to be there for each other as we move on to life after PhD completion. Thank you also to Rod Michalko for his creative and wise reflections; his work theorizing blindness resonated with me as I tried to make sense of society’s understanding of deafness.
Finally, thank you to all of my family and friends who have supported me, listened to my frustrations, celebrated my accomplishments, and encouraged me to keep going when I thought I may never finish this work! I especially thank Ian Edelist for being the most patient, loving partner, who kept me grounded and provided encouragement when I needed it most. I was not always easy to live with these last few years and I thank you for your unending support throughout the process. Thank you also for taking time to read and comment on drafts of my chapters when your own work keeps you busy enough! Thanks to Chaya Edelist and Keren Edelist for providing me with a constant source of amusement (and welcome distraction), giving me pep-talks, and engaging so willingly in our philosophical dinner conversations (what is normal?). Thanks also to Don and Gayle Monk and Lana and Jerry Edelist for supporting me and always showing interest in my work.

I would also like to acknowledge that segments of this dissertation have developed out of papers written for course work and articles that I have published elsewhere. Information about the SickKids CI Program and governmentality first appeared in “Listen and Speak: Power-Knowledge-Truth and Cochlear Implants in Toronto,” in Disability Studies Quarterly (35.1 [2015]). Theoretical considerations of cultural dichotomies were first explored in “Capitalising on Cultural Dichotomies: Making the ‘Right’ Choice Regarding Cochlear Implants,” in Social Theory and Health (14.3 [2016]:293-311).

Finally, thank you to U of T/OISE and the Ontario Graduate Scholarship for financial support during the writing of this dissertation.
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Chapter 1

1 Introduction

A chance meeting with a teacher of the deaf set me on an unexpected journey that has culminated in this dissertation. Although I attribute the start of my journey to this serendipitous meeting, this teacher reawakened long forgotten thoughts about the habilitation of deaf children that had troubled me during my graduate training in speech-language pathology, many years prior. To provide an understanding of my relationship with my dissertation research, I begin by sharing the history that led me away from research focused on the habilitation of deaf children, to research focused on how such habilitation produces meaning for those being habilitated. By doing so, I explain how I went from working in an allied health profession that makes a problem out of non-normative hearing, speech and language, to a disability studies scholar who questions the problem-making norms and assumptions inherent in speech-language pathology and audiology.

My personal history with speech-language pathology has lead me to question how parents of deaf infants in Ontario, Canada are brought into the knowledge of their child’s deafness, and how Ontario’s Infant Hearing Program constructs parental choice in a way that restricts sign language while supporting spoken language. Throughout this dissertation, I address this question through a genealogy of the Infant Hearing Program, as it is this program which acts as “an instrument and vector of power” over the materialization of childhood deafness and what parents should do about it (Foucault, 1977, p. 30). This opening chapter presents a genealogy, or “history of the present,” (Foucault, 1977, p. 31) of the medical language industry, a capitalist industry encompassed within the medical-industrial complex that includes cochlear implant manufacturers, otolaryngologists, audiologists, speech-language pathologists, auditory-verbal
therapists, teachers of the deaf, and researchers, all of whom contribute to the medicalization of both deafness and language. In this chapter, I explore how the history of the medical language industry informs the present-day conceptualization and habilitation of childhood deafness, beginning with my own historical experience with the industry.

1.1 Questioning speech-language pathology

I had decided in high school that I would pursue a post-secondary education that would lead me to a career in speech-language pathology (SLP). To obtain the necessary pre-requisites for a graduate degree in SLP, I majored in psychology and linguistics for my undergraduate degree, and developed an interest in the study of languages. This interest and the idea that perhaps I could work with deaf children as a SLP led me to take classes in American Sign Language (ASL), where I first learned about Deaf culture from signing Deaf people. Upper case “D” Deaf refers to a cultural epistemology of deafness in opposition to a biomedical epistemology. In the Western world, Deaf culture is celebrated as a vibrant, visual-based culture whose members communicate with sign language and share a Deaf worldview and Deaf values; a distinct socio-cultural-linguistic group.¹

When I began my graduate work in SLP, I was introduced to a very different way of thinking about deaf people and how they should communicate. Instead of a focus on ASL, my SLP training taught me about sound booths, audiological testing, hearing technologies, speech and hearing anatomy, spoken language development, speech training, and auditory-verbal therapy.

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¹ Lower case “d” (deaf) is used to refer to deafness as an audiological diagnosis, whereas upper case “D” (Deaf) is used to refer to the cultural concept of deafness. Throughout this dissertation, I use lower case “d” except when referring explicitly to members of the Deaf community. In Chapter 3, I further explain my use of terminology and how the practice of using a simple binary notion of “deaf” and “Deaf” has been recently questioned in the field of Deaf Studies.
(i.e., a biomedical epistemology of deafness). Although I took the elective course, “Psycholinguistics of Gesture and Sign,” and there was a Visual Language Lab in the department which promoted an awareness of visual communication methods, the SLP’s role in facilitating the use of sign language in practice was not clear, especially considering the department’s strong auditory-verbal history and the mandatory courses in audiology, aural habilitation and speech training. As I had an interest in working with deaf children, and I knew very limited ASL, I chose to work at the Montreal Oral School for the Deaf for one of my practicum placements. This school focused on teaching deaf children to learn to listen and speak. In addition, as a cash-strapped graduate student, I applied for and received the IODE’s “Silence to Sound” award. In retrospect, it was easy to gain experience and monetary support in teaching deaf children to speak, but not so easy to access the same in teaching deaf children to sign.

I felt a nagging discrepancy between what I knew about Deaf culture and sign language, and how hearing, speech, and language were presented to me while training for a career in speech-language pathology. The way I managed the discrepancy between Deaf culture/sign language and audiology/spoken language was to compartmentalize them: some deaf people used sign language, others used spoken language. I assumed it was only those who were learning spoken language that needed SLP therapy and that was why our studies focused on aural habilitation and speech training. I was not completely cognizant of the role SLPs played in demoting sign language through the profession’s focus on auditory-verbal therapy, until later learning more about the history of deaf education and the language struggles currently faced by many deaf and hard of hearing teenagers, which will be reviewed below.

After obtaining my graduate degree and professional designation, I worked with disabled children and youth, some of whom were hard of hearing, and later, people who had experienced
traumatic brain injury. It was many years after graduating that I once again took ASL classes, to better communicate with a deaf friend. During this time, I met a teacher of the deaf who initiated my realization that speech-language pathologists and audiologists have a role in perpetuating the discrepancy between sign and speech, and in shaping the ways in which we think (and don’t think) about deafness and language. What I learned from this teacher was that there are deaf teenagers not fluent in any spoken or signed language graduating from Ontario high schools. She expressed her struggles trying to teach the curriculum to students who did not share a common language with each other or the teacher, not because they all used a different first language, but because they had not become fluent in any first language or communication system. The struggles of these students stunned me: with all I had learned about language development, bilingualism, and Deaf culture, it was inconceivable to me that the education system of a metropolitan city could still be failing some deaf children in this way.

I met with educators and speech-language pathologists to gain a better understanding of the issues and to learn how deaf and hard of hearing children are educated in Ontario, and discovered that most deaf children are taught in mainstream classrooms using spoken language, with little opportunity to learn sign language. The problem with an exclusive focus on spoken language is that spoken language is not always accessible to deaf children, even with hearing technologies such as hearing aids and cochlear implants (Humphries et al., 2012). Those children who have difficulty accessing and learning spoken language but who are educated with an exclusive auditory-verbal approach may therefore not become fluent in spoken language, and would have limited opportunity to learn sign language. I wondered if SLPs had any place in deaf education; surely speech-language pathologists would advocate on behalf of deaf children for communication development more generally, not just spoken language? Considering my experience in graduate school, I should not have been surprised to learn that SLPs have a role in
teaching listening skills, speech skills, and spoken language skills, but not sign language.

Although individual SLPs and educators may perceive merits in teaching deaf children ASL as well as spoken language, the current milieu is one of inclusive mainstream education, which supports a spoken-language-only approach to education as the ideal.

After learning about the education system and the supports available to deaf and hard of hearing children, I concluded that the issue begins before children enter school. This led me to turn my attention to the government programs that support new parents in making decisions about hearing technologies and communication modalities during the time after audiological diagnosis. This brings me to my dissertation research which focuses on the Ontario Infant Hearing Program (IHP). The IHP provides hearing screenings to all babies in Ontario to identify the few babies that will be deaf in early childhood and provides supports and services for hearing and language development for deaf and hard of hearing children under six years of age and their families. More information about newborn hearing screening and the IHP is provided in the following section.

I considered pursuing my research through the University of Toronto’s Speech-Language Pathology Department, as it is affiliated with The Hospital for Sick Children and their Cochlear Implant Program, and has ties with the IHP. However, I decided that the biomedical perspective of the department (and the profession more widely) was not suited to the kind of critical research I thought was needed to question the assumptions of hearing and language inherent to the program. One person I met while trying to understand the situation was a Deaf man who was just finishing his graduate degree, and he suggested the field of disability studies may be a good fit for my research. This is how I came to seek out disability studies research and qualitative sociological methodologies, rather than positivist research that would have me instead
examining the outcomes of screening, or searching for specific ‘objective’ factors that lead to parental decision making.

Disability studies is an interdisciplinary and theoretically diverse field which considers disability as being socially and politically constructed and which questions dominant, normative conceptions of what it means to be disabled and what it means to be human (Davis 2013; Titchkosky and Michalko 2009). My research easily joined in disability studies’ commitment to question dominant conceptions of disability and normality, as it stems from a place of critical reflection and a desire to understand how the ways we think of language and hearing can shape the way communication options are presented to and understood by parents, and ultimately, how deaf children are educated and how deaf subjectivities are developed. In Chapter 3, I more fully discuss my theoretical and methodological grounding in disability studies.

It is important to understand how the policies and practices of the IHP and current deaf educational practices are situated within the historical context of deaf education and the methodological debates that continue to this day. For the remainder of this introductory chapter, I provide background information on universal newborn hearing screening, the Ontario Infant Hearing Program, and auditory-verbal therapy as the dominant method of treatment, which all lead the way to a spoken language approach to deaf education and imagines sign language as unimportant and even harmful for spoken language development. I consider the issue as a form of language governmentality that situates spoken language as the highest aspiration for deaf children while concomitantly devaluing sign language (and those who use it), thereby conducting parents into an exclusive spoken language approach for their deaf children. This “history of the present” leads to a discussion of how the IHP’s current language policy and practices have emerged from the longstanding debate between “oral” and “manual” methods of deaf education and the place that hearing technologies hold in this debate, while examining the
different conceptions of deafness inherent to each. The chapter concludes with an outline of the remaining chapters of my dissertation.

1.2 Universal newborn hearing screening

Prior to the introduction of universal newborn hearing screening (UNHS), a program which involves screening all newborn infants for hearing loss, infants were assumed to hear the sounds around them unless and until someone, typically a parent, noticed something awry. This assumption of hearing may have come into question for individual children when they did not develop speech and language according to the expected developmental milestones. As a result, prior to UNHS, most deaf children were not identified as such until about two and a half years of age (Ontario Ministry of Health and Long Term Care, 2002). There has been much biomedically informed psycho-social-linguistic research demonstrating that a stimulating and language rich environment during infancy and early childhood supports later cognitive and language development. This research led the Ontario government to implement various child development services for families with young children, beginning with the Preschool Speech and Language Initiative, and Healthy Babies/Healthy Children, followed by the Infant Hearing Program (IHP) in 2002 (Ontario Ministry of Health and Long Term Care, 2002).

The IHP’s stated purpose is to identify deaf children in infancy and provide hearing and language supports and services to prevent language delay in deaf and hard of hearing children. With early identification and support for language development in early childhood provided by the IHP, it is expected that deaf and hard of hearing children “will be assisted in the acquisition of the communication skills needed for performance of daily activities and for personal and social sufficiency at home and at school” (Ontario Ministry of Health and Long Term Care, 2002, p. 1). The IHP is closely tied to the province’s three hospital-based Cochlear Implant (CI)
Programs, as profoundly deaf infants are often referred to a CI Program to determine their candidacy for unilateral or bilateral cochlear implants. Cochlear implants are expected to provide profoundly deaf children, who previously had no access to sound, the opportunity to “develop normal speech and language, go to college and do regular stuff” (Frketich, 2007). How cochlear implants are presented as a ‘miracle cure’ for deafness is discussed in section 1.6 below.

The intention of UNHS to level the communication development playing field between deaf and hearing children is however not always realized. My discussions with parents who were receiving, or had recently received services from the IHP, revealed that some children are not identified during infancy despite the IHP’s procedures, and not all deaf and hard of hearing children, including those with cochlear implants, enter school with the language skills needed to cope with the demands of school, or continue to learn language on par with their hearing peers as suggested.² To understand how some children are still falling behind in language despite the IHP’s intent to prevent language delay, it is important to consider the assumptions being made about language (and ‘delayed language’) and what it means to be deaf. This questioning of assumptions and examining the meanings of deafness and language form the foundation of my dissertation. To understand the assumptions being made, more information about the IHP is first necessary.

² As part of this doctoral research, I conducted semi-structured interviews with 12 Ontario based parents of deaf and hard of hearing children, aged one to ten years, who use or had recently used IHP services. Interviews were done to gain an understanding of parents’ experiences in navigating the expectations and normative assumptions inherent in the IHP, parents’ understandings of what it means to be deaf and what it means to have language, and how parents came to make language and hearing technology decisions for their children. University of Toronto Research Ethics Board approval was obtained for these interviews in December 2015. Details about the participants and interview procedures are discussed in Chapter 2.
1.3 The Infant Hearing Program

Ontario announced the province’s goal of screening all newborns for impaired hearing within a month of birth with the introduction of a Universal Newborn Hearing Screening program (UNHS) in 2000. UNHS came into effect in 2002 under the umbrella of Ontario’s Infant Hearing Program (the official abbreviated title for The Infant Hearing Screening and Communication Development Program). The three major components of the program are: 1. Universal newborn hearing screening (hospital pre-discharge well-baby screening; hospital pre-discharge high risk baby (NICU) screening; well-baby screening in midwifery care; and community screening and high risk monitoring); 2. Assessment (hearing loss confirmation and audiological assessment; and medical referral and management); and 3. Follow up support and services (family support and access to information; hearing technology; and communication development) (Ontario Ministry of Health and Long Term Care, 2002). The principles of the IHP are listed in Table 1 below. Although many of the principles may not always be met, my interest is focused on how parents experience the second principle regarding “fully informed parent/guardian choice and consent,” which will be examined in Chapter 5.

Table 1. Principles of Ontario’s Infant Hearing Program

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<th>Principles of Ontario’s Infant Hearing Program</th>
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<tr>
<td>1. There will be access to the services of this program across Ontario.</td>
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<tr>
<td>2. Every aspect of this program will be provided based on fully informed parent/guardian choice and consent, and will comply with confidentiality requirements.</td>
</tr>
<tr>
<td>3. All services will be child and family centered taking into consideration the cultural and ethnic diversity of the people of Ontario.</td>
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<tr>
<td>4. A seamless system of services will be developed that integrates this program with other existing children’s programs and services.</td>
</tr>
<tr>
<td>5. The components of this program will be developed using the principles of evidence based practice.</td>
</tr>
<tr>
<td>6. The program will be monitored and evaluated on an ongoing basis.</td>
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<tr>
<td>7. The quality of the program will be continuously improved based on the evaluations.</td>
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Source: Ontario Ministry of Health and Long Term Care, 2002, p. 2
The IHP aims to complete two-stage screening of all infants born in Ontario within two months of age. Most infants born in hospital are expected to receive their first screen within the first 24 hours after birth (Ontario Ministry of Health and Long Term Care, 2002). Infants who get a refer result after the initial screening are referred for further screening and/or audiological assessment. The IHP notes that “‘fail’ is never used in conjunction with a screening result because it alarms parents unnecessarily and because it does not capture the true significance of not recording an OAE [oto- acoustic emission]” (Ontario Ministry of Health and Long Term Care, 2002, p. 9). Audiological assessment is expected to be completed by three months of age, and intervention begun by six months of age (Ontario Ministry of Children and Youth Services, 2014a). If the audiology assessment confirms the infant is deaf or hard of hearing, the audiologist begins discussion of the need for hearing technologies (hearing aids or cochlear implants), the infant is referred to an otolaryngologist for medical assessment, and the family is scheduled to meet with an IHP family support worker to learn about the services that may be available to them, and to review their options for hearing technologies and communication modality.

The IHP is divided into 12 regional centres that service different geographical regions of Ontario. Although all regions must follow IHP policies and procedures, each region may implement the program differently, depending on what services are available in that region: “The development and implementation of EHCD [early hearing and communication development] programs will vary provincially and regionally, depending on the human, financial and material resources, and on the policies and priorities of those provinces and regions” (Canadian Working Group of Childhood Hearing, 2005, p. v). Although it is out of the scope of this dissertation to examine the differences between regional centres, the availability of certain services and the philosophy of service providers in different regions of Ontario were
discussed by many of the parents I interviewed. How the available services were presented to parents, and which services were available, were factors influencing parental decision making which will be discussed in Chapter 5.

The regional centres are funded by the Ontario Ministry of Children and Youth Services and are responsible for: implementing newborn hearing screening; monitoring high risk infants; providing audiology assessment for infants with a refer result; providing amplification specifications when needed; providing language development services; and providing a family support worker to offer information and support to parents (Southwest Region Infant Hearing Program, 2010a; Ontario Ministry of Children and Youth Services, 2010). The IHP also provides referrals to related services, such as the preschool Home Visiting Program (HVP) provided by the Ontario Ministry of Education, and one of the three provincial Cochlear Implant Programs (Ontario Ministry of Education, 2017b). If a child receives a cochlear implant, most of their services move from the IHP to the hospital’s CI Program (Ontario Ministry of Children and Youth Services, 2010).

The IHP offers parents three main communication development options: an oral approach (spoken language), a visual approach (sign language), or a dual approach (a combination of oral and visual) (Mount Sinai Hospital, 2016). In Ontario between November 2001 and March 2009, 8% of parents chose the visual approach, 3% chose the dual approach, and the remaining 89% chose the spoken language approach (with 73% of those choosing auditory-verbal therapy) (Small & Cripps, 2012). My email enquiries to the IHP about more current statistics yielded inconclusive information. It was clear, however, that despite the IHP offering simultaneous or sequential spoken language and sign language services (i.e., the dual approach), the majority of parents chose a spoken language only approach and the remaining few chose sign language (MCYS Program Consultant, personal communication).
These statistics tell only one story about parental ‘choice.’ Many parents I interviewed indicated they understood their options as being one or the other, sign or speech; they were not aware there was an option to receive services for both sign and speech. There seems to be a discrepancy between the IHP’s principles and messaging about both the importance of parental choice and consent, and about how much support and service is provided for each communication option, and what is being relayed to and/or interpreted by parents. There is therefore a need to critically examine how meanings of deafness and language are represented by the IHP and comprehended by parents to understand how parents make sense of the communication options and come to understand what “deaf” means for their children. The IHP’s reliance on normative biomedical assumptions about language and deafness eradicates cultural conceptions of deafness, hereby presenting a social issue as if it were an individual issue. Chapters 4 through 6 examine how these assumptions are manifest.

Although IHP documents state that parents have the option of both spoken language and sign language, only a few regional websites even mention that sign language is a communication option provided, and most regional centres provide information about spoken language while excluding information about sign language on their websites. For example, the Southwest Region’s Infant Hearing Program’s website provides a list of strategies to promote language development, yet all the strategies are specific to spoken language (Southwest Region Infant Hearing Program, 2010b). This website also provides much information about audiology and hearing technologies, but no information about sign language. Many of the regional centres’ websites also provide information about developmental language milestones and “tips on how you can help your child develop speech and language skills,” with no mention that language could also include sign language; communication and language are assumed to refer to spoken language (Markham Stouffville Hospital, n.d.). An exception to this is the provision of
“Developmental milestones in American Sign Language (ASL)” on the Ontario government’s webpage, “Services for children who are Deaf or hard of hearing” (Ontario Ministry of Children, Community and Social Services, 2016).

The predominance of auditory-verbal therapy as a treatment approach also explains the limited mention of sign language as an option. Auditory-verbal therapy (AVT) is a treatment approach to teach deaf children to learn spoken language through listening, with the assistance of hearing technologies such as hearing aids and cochlear implants and without the use of any visual cues (e.g., lip reading, gestures, signs). In effect, the use of AVT as the dominant option for learning spoken language makes the dual approach a moot option, as sign language is incongruent with the principles of auditory-verbal therapy.

1.3.1 Auditory-Verbal Therapy

The end goal of AVT is placement in mainstream education and integration into hearing society using spoken language (Goldberg, 1993). The principles that must be followed in an auditory-verbal therapy program, as stipulated by the AG Bell Academy for Listening and Spoken Language, are listed in Table 2 below (AG Bell Academy for Listening and Spoken Language, 2017). The AVT approach relies heavily on parent participation in the development of their children’s listening and speaking skills: therapists provide assessment and treatment plans and then “guide and coach” parents to implement the treatment plan in daily life. Parents are expected to regulate their children’s auditory and linguistic environment at all times in an effort to maximize the potential for spoken language development. To rightfully use the AVT approach in Canada, professionals such as teachers of the deaf, audiologists and speech-language pathologists must be certified by the AG Bell Academy to ensure knowledge of and compliance with the AVT principles.
Table 2. Principles of Auditory-Verbal Therapy

<table>
<thead>
<tr>
<th>Principles of Auditory-Verbal Therapy</th>
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<tbody>
<tr>
<td>1. Promote early diagnosis of hearing loss in newborns, infants, toddlers, and young children, followed by immediate audiologic management and auditory-verbal therapy.</td>
</tr>
<tr>
<td>2. Recommend immediate assessment and use of appropriate, state-of-the-art hearing technology to obtain maximum benefits of auditory stimulation.</td>
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<tr>
<td>3. Guide and coach parents to help their child use hearing as the primary sensory modality in developing listening and spoken language.</td>
</tr>
<tr>
<td>4. Guide and coach parents to become the primary facilitators of their child's listening and spoken language development through active consistent participation in individualized auditory-verbal therapy.</td>
</tr>
<tr>
<td>5. Guide and coach parents to create environments that support listening for the acquisition of spoken language throughout the child's daily activities.</td>
</tr>
<tr>
<td>6. Guide and coach parents to help their child integrate listening and spoken language into all aspects of the child's life.</td>
</tr>
<tr>
<td>7. Guide and coach parents to use natural developmental patterns of audition, speech, language, cognition, and communication.</td>
</tr>
<tr>
<td>8. Guide and coach parents to help their child self-monitor spoken language through listening.</td>
</tr>
<tr>
<td>9. Administer ongoing formal and informal diagnostic assessments to develop individualized auditory-verbal treatment plans, to monitor progress and to evaluate the effectiveness of the plans for the child and family.</td>
</tr>
<tr>
<td>10. Promote education in regular schools with peers who have typical hearing and with appropriate services from early childhood onwards.</td>
</tr>
</tbody>
</table>

Adapted from the Principles originally developed by Doreen Pollack in 1970. Adopted by the AG Bell Academy for Listening and Spoken Language on Nov. 6, 2009.

Source: AG Bell Academy for Listening and Spoken Language, 2017, p.3

In reviews of the available research on speech and language outcomes following AVT, Eriks-Brophy (2004), Dornan et al. (2009), and Eriks-Brophy, Ganek, & Dubois (2016) report that AVT is associated with significantly improved oral communication and literacy, but due to the paucity of empirically based research, conclusions regarding a causative link between AVT and
such improvements cannot be made. There have not been any conclusive studies demonstrating
the efficacy of AVT, nor studies that demonstrate that sign language and visual cues are
detrimental to learning spoken language, yet AVT is a widely-used technique throughout North
America, Australia, the United Kingdom, and other international locations (Brennan-Jones,

As AVT is the dominant treatment technique in Ontario for children whose parents decide on
the spoken language option, many parents of deaf children who would like their child to learn
spoken language with the aid of hearing technologies are highly discouraged and often
prohibited from also teaching their deaf child ASL (Canadian Hearing Society, 2005; Snoddon,
2009). This prohibition of sign language is implied by the bureaucratic professionalization and
regulation of parents and their deaf infants to exclusively focus on listening and spoken
language within an AVT treatment approach, and is also manifest in how services are funded, or
not funded, within the IHP. For example, past research indicates that Ontario’s IHP did not
provide funding for ASL if a child received a cochlear implant (CI), and parents had to commit
to an AVT approach for the child to even be considered a candidate for a CI (Cripps & Small,

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3 Eriks-Brophy et al. (2016) outline problems with the requirement for strict scientific research (e.g., random
control trials) and suggest an updated evaluative framework that considers the quality of the research methodology
rather than just the level of evidence. I suggest the points made in the following footnote also be considered.

4 Geers et al., 2017 is a recent study claiming that sign language hinders spoken language and reading development
for children with CI. However, the authors’ classification of “sign language exposure” is too broadly defined to
make any conclusions about the effects of sign language. The authors make no differentiation between sign
language and all other uses of sign (e.g., Total Communication, Signing Exact English), and parents were not asked
why they use signs with their children. Hearing parents often introduce signs to their deaf children to address
difficulties in spoken language communication. Therefore, the authors make unsupported conclusions presented as
scientific truth that visual communication hinders spoken communication, when the children may have been having
difficulty with spoken language before the introduction of signs. These value-based assumptions about causation,
the conflation of sign language with signs used to support speech, and a lack of consideration of all relevant factors
(e.g., educational approaches and intervention methods used), are common to studies that purport to support the
harms of sign language for learning spoken language. (See also Geers et al., 2011 and Moog & Geers, 2003.)
More recently, according to some parents I interviewed, although CI Programs continue to discourage sign language, the IHP will fund sign language support if initiated by and insisted upon by the parents. Snoddon’s interviews with hearing parents of deaf infants revealed that parents who requested the dual approach faced resistance from the IHP in accessing ASL for their children, while being offered easy access to auditory-verbal therapy and encouraged to consider cochlear implants (2009, p. 111). Auditory-verbal therapists and CI Programs have acted as gatekeepers of language, advising parents not to teach their children ASL, which in their opinion (based on problematic quantitative research that conflates sign language with total communication approaches and makes unfounded assumptions of causation) would interfere with spoken language development (Snoddon, 2009).

As over 90% of deaf infants have hearing parents who are unlikely to be fluent in sign language (Mitchell and Karchmer, 2005), there is a significant number of deaf children in Ontario who are potentially without access to a visual language. In addition, AVT is for the most part, used to teach deaf children spoken English; auditory-verbal therapists conduct sessions in English and parents have traditionally been told to only speak English with their deaf children, regardless of the parents’ first language (Rhoades, 2005). Although there have been efforts in more recent years to educate therapists about the importance of encouraging parents to speak in the language used in the home and there have been some protocols developed for bilingual support, English remains the dominant language of AVT (Douglas, 2012; Rhoades, 2005).

One factor in the dominance of the auditory-verbal therapy option in Ontario is the increasing rate of cochlear implantation of deaf children, as all children who receive a cochlear implant (CI) in Ontario are expected (or in Toronto, required) to undergo auditory-verbal therapy (AVT). This requirement relies on the problematic assumption that learning sign language will hinder the development of audition and spoken language. If parents do not agree with and
commit to the AVT treatment approach, then their child will not be considered a CI candidate (Snoddon, 2009; Cripps & Small, 2004). This AVT requirement exists despite research showing deaf children who learn ASL as a first language early in life develop better spoken and written English language proficiency than deaf children who do not learn ASL (Freel et al., 2011; Goldin-Meadow & Mayberry, 2001; Strong & Prinz, 1997). Additionally, withholding access to a visual language creates undue risk of language deprivation, as spoken language is not always accessible to deaf children, even with the use of hearing aids and cochlear implants (Humphries et al., 2012). Advanced hearing technologies do not guarantee that a deaf child will learn to listen and speak, even with AVT, and on the SickKids CI Program website it is acknowledged that cochlear implantation does not guarantee that a child will learn spoken language (SickKids, n.d.a). This prohibition of sign language also effectively eliminates the deaf child’s (and their parents’) opportunity to learn about and become part of Deaf culture. The increasing rate of cochlear implantation and auditory-verbal therapy in Ontario and the resultant decrease in ASL (Small & Cripps, 2012) is therefore both perplexing and disconcerting. This control over the language(s) that parents use with their deaf children reveals much about how the Infant Hearing Program governs parent-child interactions and deaf subjectivities.

1.4 Governing through (and into), language

The IHP’s policies and practices have significant meaning and real-life effects for the families and deaf children serviced by the program, which I explore in chapters 4, 5 and 6. Humphries et al. (2012) address the numerous ‘harm’s of cochlear implants (CI), including both physical harms from CI surgery, as well as harm that may occur from the provision of misinformation regarding overall health. Overall health harms may include linguistic deprivation resulting from a speech only approach, and linguistic deprivation resulting from medical acts that fail to
inform, provide misinformation, or abnegates trust (Humphries et al., 2012). The possibility of such risks of CI due to the withholding of visual language and information about visual language, supports the need for research that questions this practice. In a reflection of second language policies in Canadian educational contexts, Cummins (2014) notes the lack of evidence supporting the denial of ASL for children undergoing AVT, while citing evidence of the importance of bilingualism for children with CI. Cummins concludes, “Not only are children who receive cochlear implants denied the opportunity to develop bilingualism, crucial time during their early years is spent learning how to decode speech instead of engaging in genuine communication that develops concepts and expands their minds” (2014, p. 7). My research seeks to reduce these potential harms resulting from the IHP’s and Cochlear Implant Programs’ policies by drawing attention to how they relate to meanings of deafness and language that circulate within the program to construct only one reasonable choice (spoken language).

The geographical focus of my research is Ontario, Canada; however, the deaf language issues that led to my research are not exclusive to this area. For example, Berg, Ip, Hurst and Herb (2007) found that less than half of the United States’ CI centres in their study provided information regarding Deaf culture and identity to parents, and when they did provide such information, it was provided by audiologists rather than Deaf adults. This is problematic because audiologists are trained in assessing and treating ‘hearing disorders’ and as such, their understanding of and approach to Deaf culture would take a different perspective than Deaf people themselves. Mauldin’s (2012a) ethnographic study of the lived experiences of professionals and families at a CI centre in the United States also found that CI professionals were not literate in Deaf culture. Like the CI centres in Ontario, the centre that Mauldin studied (like many CI centres in the U.S.) also prohibited the use of sign language. This governing of language is steeped in a medical view of deafness and is couched in terms of the needs of the
auditory system to develop to its full potential to maximize speech and language abilities, creating an acultural, medicalized version of deafness while repressing sign language. As sign language is similarly governed throughout North America, my research could have implications beyond Ontario. An analysis of how deafness and language are represented in different texts by various agents involved in the IHP provides insight into what allows for the devaluing of sign language and the normalizing discourses that both shape and perpetuate the policies and practices of the IHP and other institutions that exclusively promote spoken language for deaf children.

The IHP and related Cochlear Implant Programs do not consider sign language a worthwhile resource of benefit to deaf children with CI, but rather a detriment: sign language is presented as a danger to learning to listen and speak, a visual language competing with spoken language for the same brain resources (Mauldin, 2014; Sharma & Campbell, 2011). The ideologies of language and deafness are completely intertwined: sign language-as-problem coincides with deafness-as-problem. This neurological argument supporting sign language-as-problem is another example of the productive power of the IHP’s approach to childhood deafness to disseminate biomedical meanings of deafness while disregarding alternate meanings. In this sense, the IHP’s language policy has consequences not only for how we think of language and the opportunity for deaf children to learn spoken versus sign language, but also for how we think about what it means to be deaf. In chapters 4 through 6, through a critical discourse analysis of texts produced by the IHP and parents’ experiences with those texts, I examine how meanings of deafness and language govern parental action through the construction of parental choice, and the subsequent consequences it has for families with deaf children and the creation of deaf subjectivities. In the following section, I situate the IHP’s policies and practices within the broader debate of deaf education, focusing on the historical and current situation in Ontario.
1.5 The deaf education debate

The way the IHP favours spoken language over sign language can be situated within the broader history and debate around deaf education. The education of deaf children has been fraught with methodological debates since residential schools for the deaf were established in Europe and the United States in the 18th and 19th centuries, and the debate continues to this day. The debate has been focused on two opposing methodologies: oralism, which promoted lipreading and speech training without the use of any signs, and manualism, which advocated for the use of manual signs in education. These methodologies and the way they have been put into practice have changed with advancements in hearing technologies and the development of Deaf culture, and are now referred to in more neurological terms reflective of the modality of communication: auditory-oral/auditory-verbal approach (spoken language) or a visual approach (sign language). The changing terminology reflects how the auditory-verbal approach is influenced and supported by the medicalization of deafness and has taken a biotechnical turn with the increasing use of cochlear implants. The way deaf students have been educated has oscillated between favouring one side or the other, as well as combined methods that make use of both modalities (e.g., Total Communication). I refer to the debate between sign language and spoken language as the Deaf/Hearing debate in chapter 2.

In Toronto and throughout Ontario, the mainstream public school system (where most deaf and hard of hearing students are educated) predominantly uses an auditory-oral approach in the instruction of deaf students, where students are taught in regular classrooms along with hearing students. When deemed necessary, itinerant hearing resource teachers provide consultations to classroom teachers to support students by ensuring necessary accommodations are made and audition is maximized (Ontario Ministry of Education, 2016). The Toronto District School
Board has a Deaf and Hard of Hearing Program to support students, and there are segregated classrooms in a few schools that offer varying levels of support for students who are not considered ready for an exclusive auditory-verbal approach and/or integration (Toronto District School Board, n.d). Other public school boards in Ontario include deaf and hard of hearing students under the umbrella of special education – deaf students may join segregated special education classrooms, and/or receive services from Regional Hearing Resource Teachers, but there are no specific classrooms for deaf and hard of hearing students (York Region District School Board principal, personal communication; York Region Special Education Plan, 2016).

A small number of deaf students attend Ontario’s four Provincial Schools for the Deaf, including Centre Jules-Léger which serves the Francophone community. These Provincial Schools offer a bilingual-bicultural approach to education, where both ASL (or Langue des signes du Quebec (LSQ)) and English (or French) are taught. In the three Anglophone schools, “This approach promotes American Sign Language (ASL) as the first language and English as the second language” (Ontario Ministry of Education, 2017a). Both ASL and English are languages of instruction and study, and ASL is used as the language of dialogue. Students are taught to read and write (and speak, if desired) in English, and they learn about both ASL and English linguistic structures, and both Deaf and Hearing cultures with a consideration of multiculturalism (Ontario Ministry of Education, 2017a). Although education is not within the

5 In 2014, there were approximately 425 students registered at the five provincial schools (including the W. Ross Macdonald School for the Blind). Enrollment at these Provincial Schools has been decreasing. For example, “From 2004 to 2014 enrolment in schools for the Deaf has decreased 34 per cent. Specifically, there was a decrease of 47 per cent for Robarts School for the Deaf” (Ontario Ministry of Education, 2016).

6 At the time of submission of this dissertation in September 2018, the Provincial Schools had updated the name of their education approach to a “bilingual-biliteracy-bicultural approach,” although the approach itself is consistent to what I have described above, with special emphasis on students learning “how the functions and contents of ASL
mandate of the IHP, it was evident from my parental interviews that when parents choose the IHP’s oral approach, it is assumed their children will be mainstreamed into a regular school with spoken language as the only language of instruction.

Historically, hearing people have defined and controlled the educational practices of deaf children, and educators who are Deaf have held a precarious place within deaf education. The involvement of hearing people within positions of power in deaf education continues to this day, and with declining enrollment, the Provincial Schools have had to fight for their continued existence, and Deaf high school students have protested the lack of appropriate university-stream courses available in sign language (Rushowy, 2014). Wrigley suggests the oral-manual debate was and continues to be “an argument primarily between two camps of the Hearing that seek the same goal: the creation of a Deaf identity acceptable and convenient to Hearing social and administrative concerns” (1997, p. 51). To provide some background about the debate and insights into how deaf people have been historically conceptualized in Ontario, I will briefly outline the history of deaf education in the U.S. and Ontario.

1.5.1 Oralism

The oralist movement began in the mid to late 19th century with most schools for the deaf worldwide introducing a purely oral method by the end of the 19th century (Carbin, 1996). Up until that time, deaf schools in the U.S. used a combined method of both oral and manual methods of communication for instruction. Proponents of the combined or manual approach thought that signs and the manual alphabet would help teach the students written (and transform into English equivalents (and vice versa)” (Ontario Ministry of Education Provincial and Demonstration Schools Branch, 2018).
sometimes spoken) English, and that the students would no longer need the signs once English was mastered (Peet, 1884). This exemplifies Wrigley’s argument that the goal was to shape a deaf identity to fit the standards of the majority hearing culture, regardless of which side of the debate one supported.

The oralist stance, as revealed by Samuel Gridley Howe, the founding director of the Perkins Institution for the Blind in Massachusetts in 1832 and a key figure in oralism, was that to become human, deaf people must learn speech; he “equated humanity, normality, and hearing” (Perkins School for the Blind, n.d.; Edwards, 2012, p. 186). Howe viewed deaf people from a hearing perspective and considered them isolated from society, and that residential schools for the deaf perpetuated this isolation. This contrasted with the perspectives of deaf people at that time who attended residential schools, who indicated the schools brought deaf people together as a community and out of isolation (Edwards, 2012). Nationalist rhetoric is apparent in Howe’s arguments that “by teaching a mute to articulate, we bring him to closer association with us by using our vernacular in our way” (as cited in Edwards, 2012, p. 14, italics added). Teaching through sign language and even methodical signs⁷ was thought to create an us/them paradigm; the only way to become true members of a nationalist society was to speak the vernacular of the nation. Manualists considered deafness a problem in terms of communication development, whereas oralists viewed the beginnings of Deaf culture with its own sign language as a problem (Edwards, 2012, p. 190). With oralism, there was a shift in thinking about educating deaf

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⁷ Methodical signs refer to various sign systems invented by hearing people to teach deaf people the syntax and morphology of spoken languages. Methodical signs are not considered a language but rather a system of manual signs used to represent the word order of spoken languages (“using the sign language in a hearing way”) (Edwards, 2012, p. 174).
children to impart knowledge (whether it be academic, moral or religious) through whatever means possible, to ensuring integration with the majority hearing society (Edwards, p. 193).

Oralists also raised class issues as ammunition against the manual schools, as they considered deaf people to be of a lower class by virtue of their deafness and their use of sign language rather than spoken language. The oralists pointed out that the manualists were teaching deaf children above their class since they focused on academics instead of manual labour. Howe therefore reported he would teach trades appropriate for the student’s ‘class’ in his proposed oral school (Edwards, p. 197). Edwards (2012) notes that this resulted in a system where those who learned spoken language successfully had better access to higher education and were better accepted into the middle class than those that did not, thereby ensuring those without spoken language would remain uneducated and of lower class. Parallels are apparent with the treatment of members of other marginal ethno-linguistic groups within a nation-state; the history of French Canadians as lower class labourers is one such example within Canada (Heller, 2011). The oralists created a divide that continues to this day between deaf people who speak and those who sign, with signers often being devalued and considered lower class labourers.

The arguments of the most well-known oralist, Alexander Graham Bell, provide an epitome of linguistic oppression and a certain definition of ‘human’ that is characteristic of nationalism. Bell manipulated incomplete statistics from the deaf schools and government censuses to present a case that the deaf population was rising due to intermarriage, and proposed residential deaf schools be disbanded and deaf children not be allowed to spend time together, but rather become integrated with hearing children as much as possible. He also promoted eugenics by advocating for legislation to prohibit “congenital deaf mutes” from marrying other deaf people or even hearing people with congenital deafness in the family (Bell, 1883). Unlike most teachers of the deaf, Bell considered sign language a language in its own right: “the sequence of the sign-
words has to a certain extent become obligatory, thus forming a sort of gesture syntax or grammar” and advocated for the study of its linguistic properties (Bell, 1884, p. 52). He also conceded that deaf children learned the language with ease and it was the perfect mode in which to develop the deaf child’s mind. Despite this, Bell strongly encouraged abolishing sign language from educational institutions as it was “not the language of the millions of people among whom his lot in life is cast. It is to them a foreign tongue, and the more he becomes habituated to its use the more he becomes a stranger to his own country” (Bell, 1884, p. 52).

Bell laid out a dangerously well-constructed and comprehensive argument about the harms of sign language and the need to abolish it to prevent “deaf persons who form a sort of deaf community or society having very little intercourse with the outside world” (Bell, 1884, p. 56). Bell claimed that “the constant selection of the deaf by the deaf in marriage is fraught with danger to the community” (Bell, 1884, p. 57); the numbers of deaf people could increase and threaten the homogeneity of a normalized, English-speaking nation. It seems as if Bell considered non-speaking deaf people as not-quite-human Others: “A deaf person who speaks, however imperfectly, is regarded by the public more as a foreigner than as a deaf-mute…he is recognized as one of ourselves” (Bell, 1884, p. 69, italics in original). Bell’s discourse goes beyond nationalist discourse as he insinuates that learning spoken language is not just necessary for acceptance as a member of the nation, but for acceptance of deaf people as human. Although a deaf person’s speech may not sound ‘normal,’ Bell suggested to sound like a foreigner speaking the language of the nation is more acceptable than a citizen to not speak the language, demonstrating how language is tied up with nationalism, and how disability (“deaf-mute”) renders someone as not “one of ourselves.” Discourse such as this continues today and is discussed briefly in section 1.6 below. This continuing representation that any way of being deaf aside from learning to listen and speak as being unworthy of citizenship or even humanity,
makes it necessary to evaluate how the meaning of ‘being human’ is produced by programs that purport to make deaf people ‘better’ humans and citizens.

1.5.1.1 Oralism in Ontario

Ontario’s first school for the deaf opened in 1858, just as the oralist movement was beginning in the U.S. The school’s founder, J.B. McGann, fashioned his teaching methods after those proposed by Samuel Gridley Howe. Like Howe, McGann’s goal was to “train my pupils to think in the English language” (McGann & Terrill, 1888, p. 85). Unlike the first American schools for the deaf which used the combined method, Ontario’s first school for the deaf was based on an oralist ideology and approach from the beginning.

The combined method was introduced with the first government-run public deaf school, the Ontario Institution for the Deaf and Dumb, opened in Belleville in 1870. An experienced American teacher of the Deaf, Jones Palmer, was recruited as the principal, bringing sign language and manual education with him, as was still practiced in most American schools at that time (Carbin, 1996). In 1879, Robert Mathison took charge of the school and defended the combined method of instruction at a time when oralism was being promoted across North America (Carbin, 1996). Mathison advocated for a transfer of the school from the Department of Prisons, Asylums, and Public Charities (indicating the education of deaf children fell under a charity model) to the Department of Education in 1904. After the transfer, the Department of Education determined oral methods should be introduced to the school, which led to Mathison’s resignation, as he was in opposition to this decision. His successor was a hearing doctor with no experience in teaching deaf children. Dr. Charles Bernard introduced oral methods and in 1912 the oral method was taught school-wide. Oralism gained momentum, supported by parents who wanted the use of signs eliminated in the oral classes, and by 1930 the Department of Education
prohibited sign language in the classrooms, hallways and dining hall, and deaf teachers were no
longer sanctioned to teach (Carbin, 1996). Unbeknownst to Mathison, the move from the
Department of Prison, Asylums and Public Charities to the Department of Education created an
environment suitable for oralism: the education of deaf children became medicalized with the
appointment of a doctor as headmaster; the curriculum became more aligned with the regular
curriculum of public schools; and there were higher expectations for the school to shape deaf
children into citizens who could contribute to the growth of Canada’s economy, and the
knowledge of English, not sign language was considered the appropriate vehicle to do so.

1.5.1.2 The rise of oralism in North America

From the beginnings of deaf education, hearing people taught deaf students the written language
of the state; spoken language gained importance once it became clear deaf people were viewing
themselves as a group with their own sign language and culture with written English as a second
language. Deaf people had been previously othered as an unfortunate class of people in need of
assistance, yet as more and more deaf people congregated at deaf schools and developed their
own deaf culture, their Otherness began to signify a group of people with a different culture and
language from the hearing norm. Sign language was considered a threat to the homogeneity of
the nation, attested by Bell’s eugenic manifesto against a deaf variety of the human race (Bell,
1883). This ideology in America, supported by the international shift to oral education as a
result of a resolution banning sign language in deaf education passed by the International
Convention of Educators of the Deaf in Milan in 1880 (attended by an overwhelming majority
of oralists), became dominant for the next century worldwide (Wrigley, 1996).

Another likely factor contributing to the acceptance of the oralist ideology was the lack of
appreciation of sign language as a language that could allow for reasoning and thinking
commensurate with spoken language. Even in schools that used sign language as a method of instruction, it was considered a means to an end; a way to teach the written vernacular as well as to cultivate intelligence and morality, but not as a language in and of itself. Most teachers who advocated for sign language in deaf education did not consider it a language on par with spoken language. Mr. McIntire, an opponent of articulation (oralism) stated in institutional reports,

> Signs are used, not as an end, but as a means to an end. The great end proposed is the cultivation of the intellectual and moral powers of the individual in such a manner as shall render him a useful member of society, and lead him, by the faithful discharge of all his duties, to prepare for, and to aspire to the happiness which awaits the good in a future world. (Pratt, 1869, p. 226)

Schuyler Long, a Head teacher of the Iowa School for the Deaf, wrote a book to preserve the sign language and encourage its use at a time when oral language had all but taken over the schools. Despite his strong belief in the importance of sign language, he too considered spoken language as the higher language to which sign language could not compare:

> In using signs to express thought an idea is presented in word pictures rather than in an orderly arrangement of single signs that correspond to single words in grammatical order. Hence there is not always an exact interpretation of the thought in words, but in pictures only. For this reason the language is manifestly imperfect when compared with written or spoken language. (Schuyler Long, 1910, p. 9-10)

Although calling it ‘the sign language,’ Schuyler Long promoted methodical signs in English word order rather than sign language: “the haphazard, slipshod manner of using signs is to be strongly condemned and the English order should be followed as nearly as possible” (1910, p. 11). While trying to keep the language alive, he was at the same time making it clear hearing teachers knew how best to use sign language; the language used by the students was not really a language at all as their signs did not conform to English word order. Branson and Miller (1998, p. 13) contend the manipulation of sign language to conform to the grammar and syntax of
spoken language is a form of intense linguistic imperialism. It is unclear how many manualists thought this same way and to what extent methodical signs versus sign language was used for education, but it would be many decades before sign language came to be recognized as a language with its own grammar and syntax distinct from spoken language. The oralist philosophy was supported by an apparent consensus amongst (hearing) teachers of the deaf regardless of their teaching methodologies: hearing loss was a defect that required special intervention; it was important to learn spoken language if considered capable to do so; sign language was inferior to spoken language; and deaf children were an inferior and unfortunate class.

1.5.2 Sign Language and Deaf culture

American educational materials, journal articles, and books about deaf education in the 19th and early to mid 20th centuries refer to the signs used by deaf people and in deaf education as “the sign language.” This was before American Sign Language was named as such, and likely referred to the various dialects of sign language in use at the time, as well as the methodical signs used for education, and reflected the idea that all sign languages were based on pantomime and hence mutually understandable. Before attending school, most deaf children used their own “home sign” to communicate with their friends and family. In Martha’s Vineyard, where there was a high proportion of deaf residents, a village sign language had developed and was used by both deaf and hearing villagers. Many of the deaf children from Martha’s Vineyard attended the first deaf school in Hartford (Padden, 2010). Sign language developed over many years across the U.S. as various home signs and village signs intermingled with French Sign Language, as introduced by Laurent Clerc, a teacher of the deaf from Paris who became the first deaf teacher in America. These separate sign systems eventually creolized to become what is now known as American Sign Language (ASL) (Carbin, 1996; Padden, 2010; Woodward, 1978). Various
dialects of ASL are now used throughout North America, except in the French speaking areas of Quebec, where Langue des signes Québécoise (LSQ) is the sign language used.

The opening of residential schools for the deaf gathered large groups of deaf people together, which fostered both the development of ASL and the creation of a deaf community (Carbin, 1996). In the 1970’s, academics and the deaf community began to use upper case “D” Deaf to refer to the distinct culture of signing Deaf people8 (Ladd, 2003; Wrigley, 1996). Deaf culture is considered by advocates to be the heritage of deaf children and sign language their birthright (Lane, 1992). Deaf culture empowers Deaf people; it is a celebration of human diversity and the overcoming of oppression and adversity. Deaf history, the Deaf way of life, and sign language serve as sources of pride and belonging for Deaf people.

Today, the majority hearing culture recognizes and seemingly legitimates Deaf culture through the academic field of Deaf Studies, the introduction and popularity of American Sign Language (ASL) as a foreign language course in Ontario high schools, the use of bilingual-bicultural education in schools for the Deaf, and through media awareness. One such example is a popular teen television show, “Switched at Birth,” which has numerous d/Deaf and hard of hearing characters and d/Deaf experiences are central themes of the show. Baby sign language has also gained popularity amongst hearing parents and their hearing infants, to encourage communication prior to the development of speech. In Toronto, the Deaf Culture Centre serves as a hub for hearing and deaf people to learn about Deaf Culture. The Deaf Culture Centre celebrates current and historical achievements of the Deaf community with a museum, art gallery, historical archives, ASL literature, poetry and performance art (Canadian Cultural

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8 Ladd (2003) provides a thorough examination of the history of Deaf culture and the various problematic issues that arise in defining Deaf culture and identifying those who may or may not be considered a member.
Society of the Deaf, 2017). Residential schools for the Deaf are the traditional places of acculturation into Deaf culture, as most deaf children’s parents are not Deaf and do not use sign language. However, as most deaf children are now educated in mainstream schools with the auditory-verbal approach, acculturation into Deaf culture may happen in their later years, outside of the school setting (Small & Cripps, 2012). Although the number of students is small, the Provincial Schools for the Deaf currently teach sign language and promote the development of Deaf culture, using a bilingual-bicultural educational approach.

After nearly a century of deaf children being educated with an oralist approach, the efficacy of oralism came under question in the 1970’s and manual signs were introduced back into deaf education. This teaching methodology, termed Total Communication (TC), encompasses a variety of methods that combine spoken language and manual signs, including fingerspelling. Total Communication was introduced to the Provincial Schools for the Deaf in the 1970’s (Small & Mason, 2008). The idea behind TC was that manual signs could assist deaf students in learning the spoken and written majority language; sign/gesture systems were developed and used to support the learning of the majority spoken language (e.g., Signing Exact English). A decade later, with no improvement in reading and speaking outcomes for deaf students, the efficacy of TC was questioned and in the 1980’s, sign language (ASL in most of North America) began to be promoted as the language of instruction and bilingual-bicultural education was introduced into schools for the Deaf (Cummins, 2014). Bilingual-bicultural education was mandated by the Ontario Ministry of Education in 1993, after a pilot project at one of the Provincial Schools in 1991-1992 (McGuire, 2005). Although the Ontario Provincial Schools for the Deaf follow this educational model, few students attend the Provincial Schools. Most deaf students in Ontario are mainstreamed in regular classrooms in their local school, a realization of the oralist goal of integration of deaf students with hearing students, using the majority spoken
language. There are also a few segregated classrooms for deaf students in the TDSB that continue to use TC (Toronto District School Board, n.d).

Although Deaf culture and the importance of sign language in education has been recognized by the government and is mandated at Ontario’s Provincial Schools for the Deaf, the advancement of hearing technologies and auditory-verbal therapy that occurred around the same time as the development and acceptance of bilingual-bicultural education likely dampened the uptake of ASL among hearing parents of deaf children. The increased use of cochlear implants in young deaf children has transformed oralism into an auditory-oral or auditory-verbal approach to signify the learning of spoken language via audition (as opposed to relying on only visual and tactile cues such as lip-reading, tongue placement and vibrations of the vocal tract). Cochlear implants have altered and strengthened the oralist agenda, supported by the dominance of a biomedical conception of deafness. Technology, science, and biomedicine, enacted through the process of cochlear implantation and the use of other advanced hearing technologies, support how language and deafness are represented by the Infant Hearing Program. How cochlear implants sustain and strengthen a conception of deafness as a condition that can and should be ‘fixed’ is discussed briefly in the next section.

1.6 Cochlear implants as miracle cure

There is a long history of hearing people developing techniques and technologies to try to normalize deaf people by making them learn to hear and speak. The latest of these is auditory-verbal therapy (AVT) and cochlear implants. Unlike hearing aids which are devices worn in the ear to intensify sounds, cochlear implants require surgery and provide a different way of hearing suitable for some people who cannot hear with the amplification of hearing aids. The cochlear implant (CI) is a device that converts acoustic sound from the environment to electrical signals
that get interpreted as sound by the brain’s auditory cortex. Cochlear implants are implanted in
the skull with an electrode array inserted into the cochlea to convert different wavelengths of
sound to electrical signals that stimulate the auditory nerve and signal the brain to hear sound.
Before CIs, profoundly deaf people did not have a way to access sound, as hearing aids did not
provide enough amplification. Cochlear implants were first developed for use with deaf adults,
but with little uptake from this population, CI manufacturers turned their attention to deaf
children (Blume, 2010). In 1990, cochlear implants were first approved for use in the United
States and Canada for children over two years of age. Since that time, they have been implanted
in children with increasing frequency and at younger ages; infants are implanted as young as
eight months in Toronto (Blume, 2010; Papsin, 2011).

Many newspaper articles reference the CI as a medical miracle, (e.g., “modern-day miracle”;
“It’s like a scene from the Miracle Worker” (Murray, 1989); “From deaf to hearing is really
miraculous” (Socha, 1992)). Such rhetoric represents audism, “the hearing way of dominating,
restructuring, and exercising authority over the deaf community” (Lane, 1992, p. 43) and
propagates the medicalization of deafness while establishing doctors as performers of miracles.
Deafness and by extension deaf people are viewed as hopelessly marginalized before the CI: the
miraculous CI can make the impossible possible by allowing deaf people to hear. Local media
coverage of Toronto’s Hospital for Sick Children’s (SickKids) CI Program circulates this audist
and ableist rhetoric. For example, in a 2011 Canadian Broadcasting Company (CBC) News
series focused on the celebration of the 1,000th cochlear implant procedure performed at
SickKids, two young adults who had received implants as children were interviewed about how
much they have been able to accomplish in life because their implants allowed them to hear and
speak, the insinuation being they would not be so successful and happy without the implants and
spoken language (Sheppard, 2011). In the same CBC news segment, the SickKids CI Program
director attributes the CI to children’s ability to communicate and be productive citizens of society stating, “These children are phenomenal, phenomenal communicators, phenomenal contributors to society” (Sheppard, 2011).

In local newspaper articles, the SickKids CI Program director has also made the following statements: “We improve the sociability, education and employability of Ontarians” (Brown, 2011); “This is a technology that dramatically increases the ability of its recipients to become educated and employed” (Ferguson, 2011); “[The] Director of SickKids Cochlear Implant Program, said the program allows Ontarians with hearing loss to remain or become contributing members of society. ‘And that, frankly, is miraculous’” (Artuso, 2011). These statements are troubling in numerous ways. From an evidence-based perspective, these statements lack supporting evidence and actual outcomes are misrepresented and incongruent with the more cautiously modest information provided on the SickKids CI Program website. Information on the website for parents about expectations following CI includes the following statements: “The cochlear implant will NOT provide normal hearing; will NOT guarantee intelligible speech or age appropriate language skills; will NOT guarantee educational success” (SickKids, n.d.a, original capitalization). In addition, in the director’s attempts to publicize the program to ensure continued public support and government funding, the director has perhaps unintentionally circulated representations of deaf people without CI and/or who speak sign language, as incompetent, uneducated, unemployable, and devalued members of society. The director’s statements exemplify how technologies are valued by contemporary society as a solution to the ‘problem of inability,’ a solution that ensures participation in and contribution to society, while judging only those deaf people who can listen and speak as worthy citizens.

In her doctoral thesis, Beitiks (2012) explores how technological solutions to disability are represented within popular culture reality television shows as “techno-makeovers.” She posits
that “these cases suggest that U.S. popular culture has played a key role in promoting technology as a moral solution to disability, also strengthening the cultural perception of technology and capitalism through the image of ‘doing good’” (Beitiks, 2012, p. 25). The CI as an unquestioned moral solution to deafness is supported by the supposed morally neutral stance of the doctors that promote such technologies, aided by media ‘success stories’ that further serve to neutralize morally questionable social practices. However, the examples in the above paragraph demonstrate how doctors, like everyone else, hold certain viewpoints that are not morally neutral, resulting in a biased presentation of information and the circulation of negative representations of deafness as a disability that requires biotechnological solutions to ensure communication development and acceptance into society. Further problematization of the role of ‘bias’ and ‘objectivity’ within the IHP’s policies and procedures is discussed in chapters 5 and 7.

1.7 Summary

Despite the outward appearance of the acceptance of the use of sign language by deaf infants, the Infant Hearing Program and related programs such as the SickKids Cochlear Implant Program, perpetuate long-held notions of the inferiority of sign language, resulting in a language policy that presents sign language and deafness as problems. This inferiority is also evident in the dwindling number of deaf students enrolled in bilingual-bicultural education at the Provincial Schools for the Deaf, and mainstream educational settings where manual signs may be used in segregated classrooms as a means to an end, with spoken language as the ultimate goal. With the IHP offering parents communication options for their deaf children, including a combined auditory-oral and visual approach, it may appear as if the longstanding debate that began between oralism and manualism is waning. However, with cochlear implants presented as
a miracle cure for profound deafness, and sign language considered detrimental to learning spoken language based on unreliable research and despite other research to the contrary, few Ontario parents choose a visual or combined approach for their deaf infants. The current cultural milieu continues to be heavily influenced by those old normalizing oralist ideologies.

Hearing technologies and educational methodologies have changed over time, leading to increased expectations for hearing and spoken language outcomes. What has not changed is the goal to integrate deaf people into an acceptable way of being according to the majority hearing society’s standards. Another change is the debate now begins in infancy rather than at school age, as there are multiple medical and allied health professionals involved in providing information and services to parents of deaf infants. The three communication development options provided by the IHP make service providers appear as if they are impartial actors offering parents unbiased, or fully informed choices, rather than taking one side or the other of the debate. In this dissertation, I demonstrate that although “fully informed parent/guardian choice and consent” may be the intention of the IHP, deeply rooted audist ideologies influence how the policy is enacted through the ways in which choice is presented to parents, and how parents react to those choices.

To determine how parental choice is constructed, and by extension, life chances and self-understanding among deaf children and their families, I turn my examination to how deafness and language are made meaningful by health service providers in Ontario. I follow an interdisciplinary critical approach informed by disability studies research by questioning the societal norms and assumptions about speech, language, and hearing, to examine how various meanings about deafness, disability, culture, and language are circulated, and how such meanings and the ideologies to which they correspond are represented in enacted language policies. These policies in turn have significant real-life consequences for those who are
governed by them. Examining how deafness and language are represented in different texts by various agents involved in the IHP provides insight into what allows for the devaluing of sign language and the normalizing discourses that both shape and perpetuate the IHP’s policies and practices.

The “history of the present” outlined in this chapter, provides a backdrop for how the meanings of deafness and language in IHP-related texts can support a language policy that results in the dominance of spoken language and AVT despite the different communication options that are stated to be available to parents. In the following chapters, I analyze the relations between the professionally-produced texts and the recalled lived experiences of families in navigating the IHP process, to provide an account of how the texts produce only one ‘reasonable’ choice for communication, therefore limiting the ways deaf experiences can be imagined. I use the term “deaf subjectivities” to refer to how experiences of deafness are imagined (or conceptualized), which then influence how deaf children understand themselves in relation to others, and how others understand them.

In Chapter 2, I discuss the key theoretical concepts that frame my research, outline the research questions that guide my analysis, and describe my research methods. Chapter 2 ends with a discussion of past research taking a critical perspective on Ontario’s IHP and other infant hearing and CI programs. In Chapter 3, I explore the different ways that deafness and disability have been theorized in the past, and discuss how my research makes sense of d/Deaf and disability and my decision to take a disability studies rather than Deaf studies perspective. Chapters 4, 5, and 6 present an analysis of IHP texts and parental interviews, while Chapter 7 summarizes key points and provides suggestions for alternate IHP practices and future research.
Chapter 2

2  Researching between text and lived experience

In Chapter 1, I presented a genealogy of the medical language industry as it relates to the habilitation of deaf children, to provide a history of present-day deaf diagnostic and intervention practices in Ontario. This “history of the present” has led me to conceptualize the Infant Hearing Program’s (IHP) policies and procedures through language governmentality: how the IHP governs parents toward spoken language over sign language, despite the IHP’s stated intention to fully inform parents of different options for communication development in an unbiased manner (Ontario Ministry of Health and Long-Term Care, 2001, p. 6). To determine how language and deafness are made meaningful by the IHP, I take an interdisciplinary critical, postmodern approach in my research by using a disability studies perspective to examine how parents of deaf children (and the children themselves) are governed through and in language. In other words, I examine how the language of the IHP texts demonstrate the power relations that govern the choices parents make in communicating with their deaf children. In this chapter, I pursue these interests by first discussing the main theoretical perspectives and research questions that guide my analysis, outlining the research methods used, and providing an overview of past research examining related issues.

There has been a longstanding debate and a wealth of quantitative and qualitative research that continues to be conducted by supporters of both the auditory-oral (including auditory-verbal) and sign language approaches to the education of d/Deaf children (Marschark & Spencer, 2009). There is also a history of conflict between cochlear implant (CI) stakeholders and the Deaf community (Blume, 2010; SickKids, 2010), which is manifest in the way Hearing culture and
Deaf culture are juxtaposed. For example, in previous research, I demonstrated how cochlear implant service providers present a strict dichotomy between sign language/Deaf culture and spoken language/Hearing culture to support parents in making the “right” choice of spoken language and cochlear implants (Edelist, 2016). Those on the sign language side of the debate continue to advocate for access to sign language and bilingual-bicultural education amidst a cultural milieu that currently favours auditory-oral language and mainstream education.

My position as a researcher resides outside of a Deaf/Hearing dichotomy. I am in full support of deaf children learning sign language and having experience with Deaf culture; indeed, the lack of access to sign language support for deaf children and their families was the impetus for my research. However, it is important to acknowledge that as a hearing person, my research is positioned outside of a Deaf culture perspective. While I described it in terms of an educational debate between manual versus oral methods in Chapter 1, I have chosen not to directly engage in this Deaf/Hearing debate; like Titchkosky (2003a), I conduct my research from the margins to understand how deafness is interpreted and experienced.

This quest requires us to treat the on-going objectification of disability [deafness], as it interacts with the lived experience of disabled people, as being no-thing at all, but rather a gap or space within which the social significance of disability can be examined and explored. (Titchkosky, 2003a, pp. 235-236)

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9 The Deaf/Hearing dichotomy juxtaposes Deaf culture with Hearing culture, where Hearing culture uses audition and spoken language and Deaf culture uses sign language. Deaf culture opposes the oppressive audist practices of Hearing culture, which attempts to control the educational practices and language used by deaf children. I am hearing, but am not situating my research within the hegemonic Hearing point of view. Likewise, my research does not take a Deaf perspective as I am not Deaf. I reflect on Bhabha’s (1994) conception of the Third Space to consider the margins between deaf, Deaf, hearing and Hearing. Bhabha contends cultural meanings are created by the goings-on between cultures, in this hybridity of the Third Space. The Third Space of Deafness is explored further in section 2.4 below.
Rather than adding to the arguments for one side or the other of this contentious Deaf/Hearing debate, and while recognizing that the dichotomy is not as discrete as it is made out to be, my research examines how conceptions of deafness and language construct parental choice and create various deaf subjectivities through enacted language policies. In other words, how is what it means to be deaf and what it means to have language being constructed through text and the lived experience with those policies? The meanings attributed to ‘having language’ and ‘being deaf’ have material consequences not only for how deaf children are educated and develop language and cognition, but also how they come to know who they are, how they understand themselves in relation to others, and how others come to understand them.

Through an interpretive discourse analysis of texts produced by the IHP, I examine how meanings of deafness and language represented in these documents support a spoken-language only approach while making deafness and sign language a problem, and how the IHP texts are then taken up by parents. Specifically, I examine how an exclusive spoken language approach is enforced through the construction of parental choice, and the subsequent consequences it has on the establishment of deaf subjectivities. An interpretive analysis informed by disability studies of parental experiences with the IHP texts, provides insight into how parents perceive the service delivery options that are available for their children. In moving between text and the lived experiences recalled by parents, I make use of what I consider to be the complementary theoretical perspectives of Michel Foucault’s governmentality and bio-power, and post-modern feminist theories, most notably those of Dorothy Smith and Judith Butler, especially as they have been interpreted by Tanya Titchkosky within disability studies. Applying an interpretive analysis within these perspectives allows a thorough examination of how the IHP texts reflect and shape social relations and parental choice.
2.1 Genealogy and the social: the materialization of governmentality

Foucault’s concepts of governmentality and bio-power as revealed through genealogical analysis provide a starting point to consider the inter-relationship between multiple discourses and how power, knowledge, and truth combine to influence the policies and practices of the IHP within a certain socio-historical-political structure. Foucault’s genealogy is a critical history that looks beyond origins to discontinuities of interpretation:

A genealogy of values, morality, asceticism, and knowledge…will cultivate the details and accidents that accompany every beginning…The genealogist needs history to dispel the chimeras of origin…He must be able to recognize the events of history, its jolts, surprises, its unsteady victories and unpalatable defeats…History is the concrete body of becoming. (Foucault, 2003a, p. 354)

Scott describes genealogical analysis as,

When any taken-for-granted idea or established fact is understood to be an interpretation of reality rather than reality itself, its history can be written by specifying its operations and resurrecting its forgotten alternatives. It is not, then, an inevitable consequence of the march of time, but a set of options that prevailed by ruling out others. The result of this kind of enquiry is an opening to reinterpretation. (Scott, 2007, p. 28)

Genealogy therefore allows me to determine what is taken for granted in the history of the IHP, how such history leads to the becoming of deaf subjectivities, with the possibility for deaf becomings being reinterpreted as something other than ‘deaf as problem.’ I use the term deaf
becomings to acknowledge the evolving experience and understanding of deaf subjectivities within changing historical socio-political contexts.10

Foucault proposes that the importance of government became a central issue of the population in the sixteenth century: “How to govern oneself, how to be governed, how to govern others, by whom the people will accept being governed, how to become the best possible governor” (Foucault, 2003b, p. 229). In the eighteenth century, Foucault notes that the change from the family as the central economic unit to the larger population as central to the economy (and the statistics used to describe and manage the population) resulted in our current era of governmentality.

The population is the subject of needs, of aspirations, but it is also the object in the hands of the government, aware, vis-à-vis the government, of what it wants, but ignorant of what is being done to it. Interest as the consciousness of each individual who makes up the population, and interest considered as the interest of the population regardless of what the particular interests and aspirations may be of the individuals who compose it. (Foucault, 2003b, p. 242)

Through interpretive discourse analysis informed by Foucault’s genealogy, much can be determined about how lives are governed, often without the explicit knowledge of those being governed. For Foucault, government exercises its power through “a ‘conduct of conducts’ and a management of possibilities” (Foucault, 2003c, p. 138). According to Foucault, our conduct is governed by any attempt to shape our actions (our ways of conducting our lives), so that “government” would include all policy agents in multiple contexts (e.g., politicians, doctors, speech-language pathologists, audiologists, parents and guardians, teachers, the children

10 I am influenced here by Goodley & Roets who encourage a theory of disability drawing from Braidotti’s work, in which subjectivity is “uncertain, productive, and moveable” (2008, p. 250).
themselves). In this sense, governmentality exceeds state political and economic structures. Often this ‘conduct of conducts’ takes the form of bio-power, “the organization of power over life,” through disciplinary control of the body and population regulation (Foucault, 1978, p. 139).

Bio-power came with the era of governmentality due to the subjugation of bodies via the development of disciplines (e.g., schools, workshops, barracks) and population control (e.g., public health, birthrate, migration) (Foucault, 1978). There are now a multitude of disciplines governing various specific aspects of bodies, while also constructing people’s thoughts and actions more broadly. For example, speech, language, and hearing are governed by the medical disciplines of speech-language pathology, audiology, and otolaryngology, as well as government institutions such as the Infant Hearing Program and Cochlear Implant Programs. I am interested in how such programs contribute to the construction of parental choice, while exerting bio-power over parents and their deaf children. As this interest is related to how deaf children are governed through language, into particular forms of language, this research also relates to critical language policy research as a study of language governmentality.

Foucault’s conceptual framework has been used in both disability studies research (e.g., Douglas, 2010; Edelist, 2015; McGuire, 2016; Titchkosky, 2003b; Tremain, 2015; 2005) and critical language policy research (e.g., Creagh, 2016; Flores, 2014; Heller, 2011; Pennycook, 2002; 2006). Foucault’s concepts of governmentality and bio-power have been useful in examining how disabled bodies are made subjects of disciplinary control in efforts towards normalization. Sullivan (2015, p. 41), for example, examined how rehabilitation practices for people with spinal cord injuries create a “docile paraplegic body-subject” whose function was to become a governable, productive body, and Hughes (2015, p. 82) suggests that bio-power is responsible for the creation of disability through “the medical management of people with
impairments.” The importance of language to governmentality has led critical linguistic theorists to propose “language governmentality” which “challenges the state-centric view of language policy and seeks to examine the multitude of social institutions and practices that intersect in the formation of governable ethnolinguistic subjects” (Flores, 2014, p. 2). The idea of “language governmentality” reiterates the importance of how language is conceptualized and how language is expected to be used (Flores, 2014), and is particularly relevant for examining how parents, and hence their children, are governed into language.

The relationship between power, truth, and knowledge as theorized by Foucault provides a way for me to conceptualize how the IHP can enforce its repressive view of sign language amidst conflicting Deaf/Hearing discourses. The concept of bio-power leads me to suggest that the bodies (and minds) of deaf children and the decisions made by their parents are managed by professional service providers through audiological, surgical, and linguistic disciplinary control, which are in turn managed by a certain way of thinking about disability and deafness in society. Tremain writes, “governmental practices should be understood to include…normalizing technologies that facilitate the systematic objectivization of subjects as deaf, criminal, mad, and so on, and techniques of self-improvement and self-transformation” (2005, p. 8). The IHP first identifies (i.e., objectifies) children as deaf or hard-of-hearing subjects, and then promotes the use of normalizing technologies (e.g., hearing aids, cochlear implants, auditory-verbal therapy, speech-language pathology) so that deaf children can work towards transforming themselves, with the aid of service providers and family members, to become more like hearing, speaking people. Sign language-as-problem is an extension of the ideology that deafness is a problem in need of (re)habilitation through the use of such normalizing technologies.

In a previous theoretically informed study of the CI Program at SickKids in Toronto, I examined how governmentality and the relationship between power, truth and knowledge fostered the
development of the program (Edelist, 2015). My genealogical analysis demonstrated how the CI Program stakeholders conceptualized deafness as a problem to be normalized through advances in technology and medical knowledge, while alternate discourses in support of sign language and Deaf culture were discounted as ‘untruths’ (Edelist, 2015). This analysis of the CI Program allowed for an understanding of how certain knowledges regarding deafness and language came to be known as truth by the program, demonstrating the hegemony of medicine, science, and normalization, while opening up possibilities for counter-discourses. My dissertation research broadens the scope beyond the CI program at SickKids to the discourses that support Ontario’s Infant Hearing Program more generally. In the following chapters, I closely examine discourses of deafness and language to better understand how meanings of deafness are represented by the IHP and understood by parents, and how such discourses govern the options and services provided.

To get deeper into the actualized meanings these discourses represent, I examine how the IHP’s language policy informs social action through the production of a particular form of choice, and how families experience the representations of deafness and language within the texts. An interpretive discourse analysis informed by Foucault’s genealogy, and the governmentality and bio-politics that such analysis bring to the forefront, provide a “history of the present” that can demonstrate how the IHP exerts disciplinary control over deaf children, their families, and the service providers who work with them. It is important to note that power is a productive, creative force that intertwines with knowledge to shape human behavior, and that families and children are not simply docile bodies that are acted upon, but active agents in the production of meaning. In restricting sign language, the disciplinary power of the IHP produces meanings of deafness and language that combine with the developing knowledges of parents and children to shape their actions. IHP texts not only demonstrate disciplinary control of the body, but they are
embedded in and inform the social practices of those with whom they come into contact. This inter-relationship between text and social action demonstrates the material effects of discourse.

Dorothy Smith’s concept of the social, which “directs a focusing of sociological attention on how people’s activities are coordinated” (Smith, 1999, p. 6) allows me to extend my analysis to include an examination of how parents position themselves and their children in relation to the meanings produced and disseminated by the IHP. Although my method is an interpretive textual analysis and not Smith’s method of institutional ethnography, her concept of the social assists me in applying Foucault’s governmentality to the material effects experienced by parents (notably mothers). I am interested in both what the texts tell us about the meanings of deafness and language within society, and how these meanings make it easier for parents to choose spoken language over sign language. Unlike Smith, rather than focusing on the material coordination of activities, I take an interpretive approach informed by hermeneutics and phenomenology. This analytical approach is influenced by Titchkosky:

I am following a sociological tradition of inquiry that holds that understanding how people interpret (live in) their world is an important arena for social inquiry. So, in texting our lives and reading those texts resides interpretive acts through which existence is made, and made meaningful. (Titchkosky, 2007, p. 35)

Text can therefore be considered a form of social action. I take the stance that actions are inseparable from the textual meanings that inform them, and examine how parents make meaning from the IHP texts, and how those meanings then inform the decisions they make for their children: the actions taken by parents depend on the meanings they attribute to their child’s diagnosis of deafness, which can also be understood as an aspect of language governmentality.

An assumptive reading of IHP texts as objective sources of information that simply circumscribe procedures and standards for the delivery of hearing screenings, audiological
assessments, and communication services, conceals how the texts enact their meaning of
deafness. The texts ‘do’ other than provide objective information about deafness and language
to parents; IHP texts divulge much about what kind of information can be understood as
‘objective’ and how language and deafness are organized and conceptualized in our society.
Titchkosky (2007) notes that texts enter our lives by organizing issues of concern as well as
‘normal’ ways to be concerned or worried about such issues. I am interested in how IHP texts
enter the lives of deaf children and their parents by organizing the concern of the possibility, and
perhaps also the assured diagnosis of deafness.

IHP texts constitute the ‘deaf subject’ a certain way; however, the way in which those texts get
interpreted by various actors and are then acted upon varies. The power-knowledge-truth
evident by one’s interpretation of the text alone does not constitute the deaf subject; this
constitution is a complex active process with multiple players. My textual analysis may provide
one interpretation of an over-arching nexus of power-knowledge-truth, but how those texts are
taken up by parents and service providers may result in different interpretations of meaning,
based on and leading to different lived experiences. As Titchkosky explains,

…any one text does not merely represent a reality, but is a creative or productive
power within the reality it helps to constitute. Complicating matters further, all
textual productive power occurs in relation to other texts and in relation to a
variety of readers whose lives have been entered by text. (2007, p. 31)

In addition, the texts both represent and perpetuate broader social discourses about disability and
normality; they demonstrate how deafness has been interpreted while at the same time shape
how a deaf existence continues to be interpreted and made meaningful. In critical theoretical
linguistic terms, examining this language governmentality can reveal the productive power of
the meanings of language.
I also draw on Judith Butler’s (1993) understanding of how things are made to matter both as meaning and materialization as a way to conceptualize the interplay of text and lived experience in such ‘mattering.’ Butler explores “a reformulation of the materiality of bodies” in relation to the cultural construct of “sex” (1993, p. 2), whereas I consider how deafness is culturally constructed (via the regulated construction of choices made by parents of deaf children) through the interplay between discursive representations and the materialization of deafness.

Construction is understood not as an independent act but “as a process of materialization that stabilizes over time to produce the effect of boundary, fixity, and surface we call matter. That matter is always materialized has, I think, to be thought in relation to the productive and, indeed, materializing effects of regulatory power in the Foucaultian sense” (Butler, 1993, p. 9 original italics). Deafness (and language) then, can be understood by how they have come to matter to parents within a normative order of hearing. Although my research is focused on how parents interpret the IHP’s meanings of language and deafness to make decisions on behalf of their pre-linguistic children, it should be acknowledged that the children themselves are also continually active in the interpretation of their own subjectivity.

### 2.2 Research questions

Past research on Ontario’s IHP and CI programs has demonstrated the programs’ exclusive focus on spoken language to the detriment of sign language, while suggesting alternative discourses to advocate for the inclusion of sign language (Cripps & Small, 2004; Edelist, 2015; Snoddon, 2009). Little research has yet been done to examine how represented meanings of deafness and language allow these discourses to proliferate in the first place, how these meanings influence the choices parents must make, and how they create subjectivities for deaf children. I have considered how Deaf/Hearing cultural dichotomies are used to support the
“right choice” of spoken language over sign language (Edelist, 2016), but believe there is more interpretive work to be done to analyze what gives meaning to these various discourses around deafness and language. In addition, understanding the IHP’s policies and practices as language governmentality, provides a stark example of the influence that language policies have in shaping the lives of people affected by them.

My research has thus been guided by the following questions:

1. What deaf subjectivities are assumed within the ways that government funded programs in Ontario (Infant Hearing Program, Cochlear Implant Programs) and national professional organizations (Speech-Language and Audiology Canada; Canadian Paediatric Society) present childhood deafness? In other words, how do these programs of assistance (re)present what it means to be deaf?

2. How do the meanings of deafness represented by the programs privilege audition and oral language while making sign language appear unimportant or even dangerous?

3. What are the underlying meanings on which different representations rely?

4. How do parents respond to competing discourses of deafness and language (including their own understandings) to make choices for their children?

5. How do ethno-cultural-linguistic differences and concomitant disabilities affect how deafness is presented to and understood by parents?

These research questions have led me to an understanding of how representations of deafness and language create meanings for deaf children in Ontario through the construction of parental choice. Examining the meanings that are created and circulated allow for the questioning of assumptions about the habilitation of childhood deafness, including whether these assumptions
result in the integration of deaf children into hearing society, or if they become placed in the margins of both mainstream hearing society and the Deaf community, into a vast space somewhere “in-between” (Titchkosky, 2003a).

2.3 Research design

My research seeks a sociological understanding of how deafness and language are made meaningful by the IHP, such that my focus is therefore on examining social relations rather than processes or outcomes. My interest lies in how IHP texts produce meaning, and how parents make sense of those texts as part of their experience with the materialization of their child’s deafness. There are two components to my research design that I bring into conversation with one another as part of my analysis: 1) an interpretive discourse analysis of IHP textual material and 2) an interpretive analysis of parental interviews. The methods used for each of them are outlined below.

2.3.1 Textual analyses of IHP documents

To understand the socio-cultural and political history of the Infant Hearing Program and other related government-funded programs, I adopt a Foucauldian genealogical analysis of the different discourses governing the ways in which deafness and deaf people have been represented in Ontario from the introduction of Ontario’s Infant Hearing Program (IHP) in 2000 to the present. My analysis takes on a hermeneutical dimension by examining how meanings of deafness and language are represented within these discourses. Such an interpretive discourse analysis allows for the discovery of what discursive regimes reveal about how meanings of deafness are socially organized; how texts affect readers’ conceptions of deafness, and how these conceptions of deafness influence parents’ experiences of their child’s deafness. My research includes in-depth textual analyses of position statements, fact sheets, research articles,
policy and procedure documents and informational/promotional materials related to interventions for deafness and deaf education produced by the Ontario government, and provincial and national speech-language pathology and audiology associations, as well as associations for parents of deaf children. Data sources are listed in Appendix B.

Information regarding IHP services was found by searching through the websites of the Ontario government, as well as hospitals and clinics that provide IHP services. Often these websites linked to other relevant website sources as well, such as websites for the regional IHP offices, resulting in a snowball effect for the data collection from online sources. I stopped collecting online information after saturation of information was achieved (i.e., no new information was being discovered). Information regarding services provided by professional, parent, and advocacy associations was also found by searching through the respective websites. The bulk of this data collection was completed between May 2015 and February 2016, prior to beginning parent interviews. I revisited some of the main websites in early 2017 to check if any information was added or changed. Where there were significant changes, they were reflected in my analysis. Textual information obtained from online sources were saved in a computer file and printed. The source of the text (with author name when available), webpage, date of download, and the context in which they were written were recorded on the printed copies, which were maintained in a file.

When analyzing the texts, I began by considering some key questions, such as: Who developed the texts and who was the audience? What was the socio-political history in which the texts were situated? What knowledges were validated as truth and what knowledges were discredited? How so? How were the three communication options presented in the texts? Were the three options presented equally? What did the texts repress and what did they produce? How was choice produced through the texts? What power relations were evident in the texts? What kinds
of information were included and excluded (e.g., audiological specifications, hearing technologies, communication choices, resources)? How were sign language and Deaf culture represented in the texts? What assumptions were made about language? What assumptions were made about deafness?

Thinking through these questions in relation to the content of the texts, the complexities of the manifest and latent content related to parental choice became apparent; the IHP’s stated policies regarding parental choice were at odds with the discourse about hearing, language, and deafness within the texts. The meanings of language and deafness presented in the texts pointed to a ‘right’ way to be deaf and hence ‘right’ decisions regarding hearing technologies and communication modality. After analyzing an abundance of different texts as noted above, I decided to direct most of the focus of my analysis to those texts that are materially available to parents, providing a bridge between my textual and interview analyses, as parents could describe their experiences with those texts.

Whereas past research in deaf education tends to exclude ethno-linguistic minorities and participants with additional disabilities, I sought out such differences to examine how they intersect with representations of deafness. Such inclusion is important, as not all families of deaf children in Ontario speak English or ASL as their first language, reflective of Ontario’s, and particularly Toronto’s, ethnic and linguistic diversity. The cultural-linguistic diversity and diverse physical and cognitive embodiments that must be addressed in health care situations and in regular hearing classrooms therefore also applies to deaf children and their families, adding further complexity to how deaf students are taught in spoken English. My textual analysis therefore also includes consideration of how the IHP documents address children with additional disabilities, and families who speak languages other than English in the home.
2.3.2 Semi-structured Interviews

2.3.2.1 Participants

After receiving Research Ethics Board approval in December 2015, I conducted semi-structured interviews with 12 Ontario based parents of deaf and hard of hearing children, aged one to ten years, to gain an understanding of their experiences in navigating the expectations and normative assumptions inherent in the IHP, their understanding of what it means to be deaf and what it means to have language, and how they came to make language and hearing technology decisions for their children. The main inclusionary criteria were that the families lived in Ontario and were either currently receiving IHP services or had received services within the last few years. I welcomed participants of varied ethnic backgrounds and who used languages other than English in the home. I also aimed to include participants with different technology and communication experiences (parents who have children with hearing aids and/or cochlear implants as well as parents with children who use sign language with or without hearing technologies). Deaf children with disabilities are often excluded from research about language, but I included such families as some deaf children have additional disabilities (although there is a paucity of research in this area) (National Deaf Children’s Society, 2012) and I felt it important to allow all parents the opportunity to share their experiences. Participant information is listed in Table 3 below.

11 Ethics approval was obtained by the University of Toronto Social Sciences, Humanities and Education Research Ethics Board (REB) on December 11, 2015, protocol reference #32416. Renewal for another year was obtained on November 22, 2016.
<table>
<thead>
<tr>
<th>Participant and location</th>
<th>Age of Child</th>
<th>Diagnoses</th>
<th>Technology</th>
<th>Language</th>
<th>IHP services</th>
<th>Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lauren</td>
<td>Natasha</td>
<td>4.5 years</td>
<td>Profound sensorineural hearing loss; identified at 6 weeks of age</td>
<td>Bilateral CI at 13 months</td>
<td>Spoken language, some ‘baby signs’; ASL begun at 2.5 years</td>
<td>Previously: AVT (CI Program); HVP</td>
</tr>
<tr>
<td>Jasleen</td>
<td>Nayan</td>
<td>6 years</td>
<td>Profound sensorineural hearing loss; identified at 22 months</td>
<td>Bilateral CI at 24 months</td>
<td>Spoken language, some signs (TC)</td>
<td>AVT; HVP</td>
</tr>
<tr>
<td>Vicky</td>
<td>Sam</td>
<td>10 years</td>
<td>Profound sensorineural hearing loss; auditory neuropathy; Deaf/blind, cerebral palsy</td>
<td>Unilateral CI at 5 years</td>
<td>Spoken English, ASL, tactile; understands some speech, uses signs expressively</td>
<td>AVT; ASL</td>
</tr>
<tr>
<td>Chelsea</td>
<td>Ben</td>
<td>3 years</td>
<td>Moderately severe to severe sensorineural hearing loss</td>
<td>Hearing aids at 8 months</td>
<td>Spoken English; ASL added at 2.5 years</td>
<td>AVT; ASL; HVP (every two weeks)</td>
</tr>
<tr>
<td>Vivian</td>
<td>Julia</td>
<td>6 years</td>
<td>Severe-profound bilateral progressive sensorineural hearing loss; identified at 18 months</td>
<td>Hearing aids at 2 years; Unilateral CI at 5 years</td>
<td>Spoken language, ‘baby signs’ before diagnosis</td>
<td>AVT</td>
</tr>
<tr>
<td>Participant and location</td>
<td>Age of Child</td>
<td>Diagnoses</td>
<td>Technology</td>
<td>Language</td>
<td>IHP services</td>
<td>Education</td>
</tr>
<tr>
<td>--------------------------</td>
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<td>-----------</td>
</tr>
<tr>
<td>Priya In person (home)</td>
<td>Arinan 6 years</td>
<td>Severe-profound bilateral sensori-neural hearing loss Diagnosed at 3 months</td>
<td>Bilateral CI at 11 months</td>
<td>Spoken English and Tamil</td>
<td>AVT from infancy until 'graduated' from AVT at 3 years HVP once a month until school-age</td>
<td>Grade 1 mainstream class with no support Mainstream Kindergarten with itinerant support Preschool for hard of hearing children</td>
</tr>
<tr>
<td>Angela Skype Emily Tyler</td>
<td>Emily 4 years Tyler 2 years</td>
<td>Emily: Profound bilateral sensorineural hearing loss (connexion 26 genetic mutation) Tyler: Moderate (connexion 26 genetic mutation)</td>
<td>Emily: Bilateral CI at 9 months Tyler: Bilateral hearing aids</td>
<td>Spoken English and Cantonese</td>
<td>Emily: AVT, then SLP every other week Tyler: AVT every other week, HVP every other week Some ‘baby signs’</td>
<td>Emily: Mainstream JK no direct support (itinerant teacher for equipment support) Tyler: Home based daycare</td>
</tr>
<tr>
<td>Michelle Skype Sarah</td>
<td>Sarah 7 years</td>
<td>Mild to moderately severe high frequency sensorineural hearing loss</td>
<td>Bilateral hearing aids</td>
<td>Spoken English</td>
<td>SLP until discharged from IHP</td>
<td>Mainstream grade 3 with FM system (Itinerant teacher for equipment support) Problems getting needed support at school</td>
</tr>
<tr>
<td>Heather Telephone Wyatt</td>
<td>Wyatt 2 years</td>
<td>No auditory nerve on right; moderate to moderately-severe on left Diagnosed at 2 months, Not a candidate for CI</td>
<td>Unilateral hearing aid at five months</td>
<td>Spoken English, gestures (watch his body language)</td>
<td>HVP since 9 months Private SLP until IHP-funded AVT</td>
<td>Childcare centre full-time PT and OT for “physical issues”</td>
</tr>
<tr>
<td>Participant and location</td>
<td>Age of Child</td>
<td>Diagnoses</td>
<td>Technology</td>
<td>Language</td>
<td>IHP services</td>
<td>Education</td>
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<tr>
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</tr>
<tr>
<td>Melissa Skype</td>
<td>Beckie</td>
<td>Profound sensorineural hearing loss</td>
<td>Bilateral CI at 15.5 months</td>
<td>Spoken English</td>
<td>Funded SLP available, but parents pay for private AVT as no funded AVT is provided in their area</td>
<td>Small home daycare</td>
</tr>
<tr>
<td></td>
<td>18 months</td>
<td>Diagnosed at 3 months</td>
<td>(CI Program would not implant until after 1 year)</td>
<td></td>
<td></td>
<td>Every other week AVT works with daycare provider</td>
</tr>
<tr>
<td>Rebecca Skype</td>
<td>Thomas</td>
<td>Moderate-severe and Severe-profound sensorineural hearing loss</td>
<td>Hearing aid at 1 year</td>
<td>Spoken English</td>
<td>Previously: Biweekly AVT with SLP trained (but not certified) in AVT</td>
<td>Daycare for “therapeutic” reasons two mornings a week</td>
</tr>
<tr>
<td></td>
<td>3.5 years</td>
<td>Cerebral palsy</td>
<td>Unilateral CI at 2.5 years</td>
<td></td>
<td></td>
<td>Looking for other non-IHP funded communication options (e.g., PROMPT, AAC)</td>
</tr>
<tr>
<td></td>
<td>Diagnosed after many ABRs then a CEP test at 1 year</td>
<td>(Offered bilateral but only did one side)</td>
<td></td>
<td></td>
<td>Currently: Pay for private AVT, as no funded AVT in their area</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>HVP</td>
</tr>
<tr>
<td>Courtney Skype</td>
<td>Sydney</td>
<td>Mild-moderate; and Moderate-severe sensorineural hearing loss</td>
<td>Softband device at 18 months</td>
<td>Spoken English</td>
<td>HVP began at 3 years</td>
<td>Private school for junior kindergarten</td>
</tr>
<tr>
<td></td>
<td>4 years</td>
<td>Aural atresia</td>
<td></td>
<td></td>
<td></td>
<td>In daycare from 10 months old</td>
</tr>
</tbody>
</table>
All the participants were mothers, and all the children used some form of hearing technology. Only one participant reported no strong feelings about the IHP; ten parents noted they wanted to participate in the study to share problems with the services provided by the IHP in the hopes of improvement, and one parent participated to share positive experiences. In terms of linguistic diversity, one family spoke English and Cantonese in the home, and another spoke English and Tamil; no families I interviewed were fluent in ASL. Despite reaching out to various organizations who distributed my recruitment letter, including Provincial Schools for the Deaf and Silent Voice, no Deaf parents contacted me and only one participant had a child who was learning sign language at a Provincial School. Recruitment procedures are outlined in the following section. Two children had additional diagnoses (cerebral palsy; blind/deaf and cerebral palsy) and another had received occupational therapy and physical therapy for undefined motor issues. My analysis considers how additional disabilities may influence parental experiences with the IHP and the ways in which deafness and language are presented and understood.

2.3.2.2 Participant recruitment

Participants were invited through my contacts in the Deaf community (Ontario Association of the Deaf, Deaf Culture Centre, Silent Voice) and the auditory-verbal community (VOICE) to reach parents with varying opinions and experiences. Silent Voice is an organization that provides services and resources to Deaf people and their families, and is responsible for providing ASL services to children and families serviced by the IHP (http://ihp.silentvoice.ca). The Ontario Association of the Deaf advocates on behalf of Deaf Ontarians (https://www.deafontario.ca), and the Deaf Culture Centre showcases the culture, language and arts of the Deaf community (https://deafculturecentre.ca/deaf-culture-centre/). VOICE for Deaf
and Hard of Hearing Children provides supports and resources to advocate for deaf and hard of hearing children to learn to listen and speak (https://www.voicefordeafkids.com).

I sent emails between April and June 2016 to my contacts in these organizations, many of whom were already familiar with my research, and requested they forward on a recruitment letter (letter of invite) to potential participants on my behalf (Appendix C). Those organizations forwarded my email to service providers as well, and I was contacted by teachers of the d/Deaf (including from the Bob Rumball Centre for the Deaf), auditory-verbal therapists, and speech-language pathologists, who also shared the recruitment email with their clients. In addition, I emailed the Ontario chapter of Hands and Voices, a support organization for parents and caregivers of deaf children regardless of the chosen communication modality, and they sent out a recruitment email to their parent members. I also emailed contacts that worked in deaf education, including those who work in the Toronto District School Board’s (TDSB) Deaf and Hard of Hearing Program, and teachers at the Provincial Schools for the Deaf. My TDSB contacts were not able to send the recruitment letter out on my behalf due to internal ethics procedures, and I decided to forego this line of recruitment, as the timeline to go through TDSB’s ethics review was prohibitive. My recruitment letter was distributed to parents by a couple teachers in the Provincial Schools.

I was only contacted by one parent within the first few months of participant recruitment and therefore asked my contacts to send out my letter again in early September 2016. I also posted a notice on my personal Facebook page in July 2016 to try and recruit more participants, including families who speak languages in the home other than English and whose child has additional disabilities. One participant was obtained through a Facebook contact, the other 11 were obtained from the emails that had been sent out.
When a potential participant contacted me by email, I answered any questions they had about the project and sent them more information about my research, if requested. I also obtained preliminary information from them, including the age of their child, hearing technologies and communication method(s) used and their general geographical area. If either they or I had further questions that were not easily answered via email, a preliminary telephone conversation was arranged. Fourteen parents emailed me to indicate interest in participating, and I interviewed the 12 parents who followed-up with me to schedule an interview date.

2.3.2.3 Interview logistics

Interviews took place between June and November 2016, with most interviews in September and October 2016, at locations mutually determined with each participant and the researcher to ensure participant comfort and confidentiality. Such locations included participants’ homes, local cafés, and a private room in a library. For the six participants that lived outside of the Greater Toronto Area (GTA), interviews were conducted remotely over Skype or FaceTime. For convenience, one participant within the GTA also requested a Skype interview; however, due to technical difficulties the interview was conducted over the telephone. At the beginning of each interview, I reviewed the interview consent form (Appendix D) with the parent, and obtained informed consent. For virtual interviews, I emailed the consent form to the participant and requested they contact me if they had any questions about the content before the interview. Participants emailed a signed copy of the consent form back to me in advance of the interview.

Interviews lasted around one hour, with the shortest interview being 52 minutes, and the longest interview lasting one hour and fifty-six minutes. At the conclusion of each interview, participants received a $25 Chapters/Indigo gift card as a token of appreciation of their time.
The gift card was sent electronically to participants for virtual interviews, and a physical gift card was given to participants when the interview was in-person.

The interviews were semi-structured, and I followed an interview guide with open-ended questions to give parents the opportunity to share information that was important to them and that reflected their personal experiences with the IHP (Appendix E). The questions focused on the parents’ understandings of deafness and language, parents’ descriptions of their experiences with the IHP, particularly around screening, diagnosis, and intervention choices, and the factors that parents deemed relevant in their decision-making. Following each interview, I wrote field notes detailing my subjective experience with the interview, including notes on my interaction with the participant, body language cues, and other relevant information I considered important that may not have been captured on the audiotape.

Interviews were audiotaped and transcribed verbatim by the researcher and pseudonyms were used for participant anonymity. The names of service providers were removed from the transcripts, as were service locations, with the exception of the three Ontario hospitals with pediatric Cochlear Implant Programs. As there are only three CI Programs in Ontario with many children implanted each year, participant anonymity was not compromised by the inclusion of this information. This allowed me to better understand the implicit policies of each CI program and to get a sense of whether the London and Ottawa programs prohibited sign language in the same way as the Toronto program. After the interviews were transcribed, the transcripts were emailed to the participants who were given the opportunity to review the transcript and make changes if desired. Two participants requested that minor changes (additions, removals or substitutions) be made to their transcript. One other participant made significant changes to the transcript, both in content and style which resulted in a more formal written account rather than a verbal account. This participant agreed that both the original and revised transcripts could be
used in my analysis; the original transcript reflected a more natural conversational interview and kept the original meanings intact, and the revised transcript included additional information.

2.3.2.4 Interview analysis

The interpretive analysis of interview transcripts began by considering how parents made sense of the meanings of deafness and language, and determining commonalities and/or inconsistencies throughout the interviews related to parents’ recalled experiences with the IHP. Questions similar to those asked of the textual analysis were considered in the analysis of the transcripts, with a focus on how parents made sense of hearing/deafness and language in relation to the choices they made for their children. Key questions I considered during the interview analysis included: What kinds of information were included and excluded in the parents’ discussion of their IHP experience (e.g., diagnosis, audiological testing, hearing technologies, communication choices, available resources, etc.)? What was most salient about their IHP experience? How did the parents speak of sign language versus spoken language? How did parents speak about their deaf child? How was Deaf culture discussed? What assumptions did the parents make about language? What assumptions did they make about deafness? Did parents consider the three communication options equally? How did parents feel about the information the IHP provided regarding deafness and language? Were parents satisfied with their decisions? Did parents think their children were satisfied with their decisions?

Informal analysis began during transcription, when I began to consider the most salient information provided by each parent in relation to the choices they made for their children. After transcription, I read each transcript closely, making notes in the margins and highlighting sections of interest. I then read through the transcripts and notes again, and developed a document with a list of recurrent topics and specific examples. Some topics were pre-
determined by my interview questions (meanings of language, meanings of deaf/hearing, language and technology choices), whereas others were found to recur throughout the transcripts. Topics and sub-topics identified from the interviews included: time (waiting time, time commitments); parental pressure (parent as therapist, parent versus doctor/therapist opinion, parental stress); IHP support (lack of information and emotional support); funding/finances (bureaucracy, cost of hearing technologies and private therapy); education; Deaf/Hearing culture; screening; hope; and parental self-improvement. For my dissertation, I focus on the topics explicitly related to meanings of language and deafness, and parental choice, while also drawing on inter-related categories. Parental choice, for example, was closely tied to meanings of language and deafness, and the interviews demonstrated how choice was influenced by time commitments, the supports and services provided by the IHP, conceptions of Deaf and Hearing culture, and hope.

Although the initial screening process was reported to be similar by each participant (the presentation and experience of screening is the topic of Chapter 4), the interviews revealed inconsistencies in later service delivery within and across regions. Indeed, the rules for service provision were a source of frustration for many parents. In addition to the IHP’s presentation of the screening, diagnostic, and treatment process, there were many additional socio-cultural factors that affected how parents reacted to the diagnosis of deafness and continue to react to daily experiences with their deaf child. My interview analyses therefore reflect wider societal conceptions of deafness, language, family, culture, inclusion, and the role the IHP had in assisting parents navigate the options available for their children amidst these cultural conceptions.
2.3.3 Between text and lived experience

The final step in my analysis was to examine the relationship between the results of the textual analysis and the results of the interview analysis. With the interpretive discourse analysis, I examined how meanings of deafness and language were represented in the IHP documents. Through parental interviews, I explored parents’ experiences with the IHP and examined how deafness and language were meaningful to them and how they came to make their decisions. In comparing the meanings of deafness and language represented in the IHP texts versus the parents’ understandings, I considered questions such as: Did ‘being deaf’ and ‘having language’ mean the same to parents as was interpreted in the texts? How were these interpretations the same or different? In other words, did my interpretations of deafness and language from the texts reflect the parents’ interpretations, or were there differences? How did parents make sense of the information provided to them by the IHP amidst their own conceptions of deafness and language, to make decisions for their children? This movement between text and experience is required to demonstrate an interpretive relationship between discourses of deafness and language and how parental choice gets constructed amidst these discourses, while understanding they are embedded within wider societal discourses of normalization and language standardization.

I completed an initial analysis of the IHP documents before beginning the interview process and then revisited the documents after a preliminary analysis of the interviews. There was therefore a back and forth movement between IHP text and parental accounts of their lived experience, so that one analysis was always informing the other. This movement allowed the significance of the meanings behind parental actions to remain at the forefront of my analysis, by acknowledging text as social action. The movement between IHP text and lived experience also allowed me to consider how the documents could be read in relation to the topics identified in
the interview analysis. Using the theories of Foucault and post-structural feminists, and inspired by Titchkosky’s use of such theories within disability studies, I examined how governmentality and bio-power as read through text, intersected with the experiences of deaf subjectivity – how deafness is made to matter in a particular way; how deaf subjectivities are imagined by the IHP and parents, and how such imagining constrains how deafness may be legitimately experienced.

In the following section, I review existing literature that takes a critical view of the IHP and language planning for deaf children in Ontario, as well as research that questions assumptions of language and deafness within deaf diagnostic and habilitation practices in other geographical locations. I also discuss what my research adds to this existing literature. Past research on parental perspectives in Ontario tends to focus on parental decision-making regarding cochlear implants and specific factors that lead to the decision to make the cochlear implant choice easier, rather than parental experiences of the meanings of language and deafness they encounter while making decisions, and hence were not reviewed here.12

2.4 A critical view of the IHP

There is very little research that examines the policies and practices of Ontario’s IHP from a critical perspective, but those that do provide empirical evidence of the policy’s effect on families. Snoddon (2008) outlined the systematic barriers that families of deaf children in Ontario face in learning American Sign Language (ASL), including the requirement of children with cochlear implants (CI) to undergo auditory-verbal therapy (AVT) at two of the three

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12 See Johnston et al. 2008, and Fitzpatrick, Jacques, & Neuss, 2011. These studies focus specifically on parents who chose cochlear implants for their child and how to make this choice easier for parents. My consideration of parental choice is different, as I am interested in how parents come to make their decision (whatever it may be), in light of how deafness and language are made meaningful to them.
Ontario CI centres. For her doctoral dissertation, Snoddon (2009) conducted ethnographic research of parents and children involved in the American Sign Language (ASL) Parent-Child Mother Goose Program, a program designed to foster emergent ASL literacy skills in young deaf infants and children. Her research described the difficulties faced by six families who navigated the regulation of ASL access imposed by the IHP, and how the Mother Goose Program provided a counter-discourse to the medicalization of deafness.

Cripps and Small (2004) prepared a case report to advocate for ASL funding and services for deaf children in Ontario. In their report, they provided numerous examples of unjust and discriminatory governmental practices that promoted spoken language while prohibiting sign language learning for deaf children. For example, although ASL/LSQ have been recognized by the government as languages of instruction in Ontario, as of spring 2005, the Ontario government stopped the provision of core funding to support deaf infants’ learning of ASL/LSQ. They also noted that hearing parents often enter the IHP with a natural bias for spoken language, and are not given any information about the benefits of sign language. Most disconcerting are the quotations from parents who tried to access ASL services only to have them denied by the IHP, providing evidence of the routine denial of funding for sign language support once a child receives a cochlear implant (Cripps & Small, 2004).

Most of the literature on language policy in relation to sign language tends to take either a human rights perspective by focusing on the usefulness of national and international human rights legislation to advocate for Deaf culture and sign language (e.g., Batterbury, 2012; De Meulder, 2014) and the right of deaf children to access sign language based on innate bi-lingual needs (Paul & Snoddon, 2017), or an educational language policy perspective to analyze how educational language policy influences the use of sign languages in education (e.g., Cummins, 2014; Hult & Compton, 2012; Swanwick, 2010). Aside from reproaching audism,
i.e., “the hearing way of dominating, restructuring, and exercising authority over the deaf community” (Lane, 1992, p. 43), most articles on sign language policy and planning do not explicitly address ideologies of deafness and language, nor do they consider the effect of the policies on deaf subjectivities. Small and Mason (2008) outline how four areas of language planning relate to ASL in Deaf education in Ontario. The first dimension discussed, “attitude planning,” is directly related to ideologies of deafness and language, and the authors note the systems developed in the 1970’s should be considered “‘method of communication’ planning” (2) rather than language planning, to reflect the focus on English-based communication systems (e.g., Total Communication). Small and Mason propose that attitude planning is the most important factor impacting all other areas of language planning, and that the attitude of audism creates a conception of ASL as inferior to English and negatively affects the degree of government support for bilingual-bicultural education, resulting in an emphasis on mainstreaming deaf students without any access to ASL. Attitude planning is described as “powerful and insidious, and exerts the greatest influence over either maintaining the status quo, or creating destructive or constructive change in bilingual education” (2008, p. 3).

According to Small and Mason, audism is the negative attitude that causes the repression of sign language as “those responsible for language planning are unaware of their own audist views or the profound negative impact of those attitudes” (2008, p. 3). Although audist ideologies are recognized as sustaining the current educational language policies for deaf children, how audist attitudes proliferate in Ontario is not addressed. In addition, as Small and Mason focus on attitude planning within education and a “cultural linguistic perspective of a minority linguistic group deserving of Sign Language as their birthright” (2008, p. 1), the intersecting ideologies of deafness, disability, and language and how the medicalization of deafness is both a product and a perpetrator of ideologies that lead to the repression of sign language in education are not
explicitly considered. It is logical, and likely necessary, to work within an ASL/Deaf culture versus spoken language/Hearing culture binary, as their argument is in support of an oppressed minority group advocating for the promotion of Deaf culture and the right to use sign language. I do not wish to deny the importance of advocating for the rights of Deaf people through promoting Deaf culture and sign language. However, my dissertation research is conducted on the margins and addresses the rights of all deaf children and their parents. Therefore, I move away from the dichotomy between ASL/Deaf culture and spoken language/Hearing culture and acknowledge the complicated role of culture and identity issues for both hearing parents and their deaf children. I suggest this research from the margins is necessary to consider how the meaning of deafness is constituted in ways other than, and in addition to, either/or cultural linguistic arguments.

My research examines how these audist attitudes circulate and affect language opportunities and deaf subjectivities by examining how deafness and language are represented within the medical discourse of Ontario’s Infant Hearing Program. Before deaf children are old enough to go to school, communication decisions have already been made for them; educational policies reflect the ideologies of wider society and decisions made in infancy and early childhood. Sign language in education policy therefore relies on the wider language policy of standardizing speech and language to fit the majority language hearing and speaking norm. It has also been argued that advocating for sign language in education relies on the same normalizing and standardizing discourses that seek to exclude it. Corker argues that “language standardization [whether of a majority or minority language] is a form of institutionalized oppression” and that a focus on sign language rights perpetuates oppression for those who do not use the standard sign language (2000, p. 459). Corker’s argument stems from her personal experiences as a deaf person. She suggests disability politics advocate for inclusive language rights for all disabled
citizens, rather than exclusive sign language rights for Deaf people (Corker, 2000). I would suggest that one could advocate for both sign language rights and language rights for every disabled person; one need not preclude the other. Similarly, Schriempf (2009) promotes communicability as a goal for meaningful communication rather than a focus on articulate speech as the determinant for who gets to be heard as a human. She considers speech to be one of many protheses to communication, along with signs, text to speech processors, and other forms of alternative and augmentative communication. Schriempf’s analysis also reveals a fluidity of deaf subjectivities and no ‘right’ way to be deaf: how deaf subjectivities are defined and experienced depend on who you ask and at what point in time you ask them.

The fluidity of deaf subjectivities is exemplified in Fjord’s comparison of pediatric deafness diagnostic practices in the U.S. and Denmark. In the U.S., Fjord found deafness to be interpreted and treated as a “tragic disability” diagnosed by physicians and audiologists with no personal experience with d/Deaf people, deaf education, sign language or Deaf culture (2010, p. 81). She found the threat of deafness to U.S. citizenship was based on “a peculiarly US mythos about ‘us’ and ‘them’ as embodied and biogenetic sameness or difference,” resulting in the importance of hearing technologies and auditory-verbal therapy, along with much work on the part of the deaf child and parents, to ensure integration of deaf children with the hearing majority (Fjord, 2010, p. 82). Fjord’s finding is reminiscent of the nationalist thinking of the early U.S. oralists that normalized spoken language while pathologizing sign language and deafness. In Denmark, however, the medical pathologization of deafness was resisted in favour of creating

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13 An example of how advocating for sign language in education uses linguistic normalizing and standardizing discourses is the development of an ASL curriculum in Ontario, which includes learning benchmarks to monitor student development in academic ASL skills and literacy (Small & Mason, 2008). The development of an ASL curriculum demonstrates the practical side of advocacy – following the established ‘rules’ is necessary for student learning and accountability in a bureaucratic system that relies on standardized educational assessment.
environments that would result in “happy, good children,” which in turn was thought to have positive impacts on the society (Fjord, 2010, p. 75). Members of the diagnostic team in Denmark used Danish Sign Language (DSL) and hearing parents were encouraged to learn DSL, at the expense of the state, resulting in the majority of parents desiring bilingual signed and spoken/written Danish education for their children (Fjord, 2010). The policies and practices of Ontario’s IHP seem to therefore be more similar to U.S. diagnostic practices than those in Denmark.

Fjord’s analysis exemplifies how what is included and excluded within discursive regimes and diagnostic practices shapes conceptions around deafness, language, and therefore treatment options:

The presence or absence of various sorts of cultural expertise at diagnosis entirely shaped not only the descriptive narratives offered to hearing parents about what the deafness of their child signified within their society but also the significations, prescriptions, and proscriptions attached to the national signed language and pediatric cochlear implants. (Fjord, 2010, p. 69)

Fjord’s research demonstrates how medical practices in different countries represent and produce various meanings of deafness and language, thereby enacting different language policies, different family experiences, and different subjectivities for deaf children. These alternate meanings illustrate the socio-cultural construction of deafness, language, and medicine, illuminating the potential for a "Third Space of Deafness" and the possibility for a change of attitudes.

Bhabha (1994) contends the revelation of cultural meanings found by examining this Third Space (where cultural difference is articulated), accomplishes something other than the reproduction of opposing cultural binaries. In addition to multiple meanings of deafness and language across cultures, there are many deaf people, hard of hearing people, and hearing
children of Deaf adults (CODAs), who inhabit various shifting audiological and cultural “in-between” spaces. Bhabha considers cultural dichotomies a consequence of historical processes and “the effect of discriminatory practices” rather than as an essentialist origin of conflict between cultures (Bhabha, 1994; Huddart, 2006). The Deaf culture/Hearing culture dichotomy for example, may exist due to historical events based on an audist Hearing response to deafness and sign language, that created (and continues to create) the divide. Deaf culture therefore opposes and resists Hearing culture (and vice versa), due to these historical, discriminatory practices, rather than due to the unavoidability of conflict based on an essentialist difference between Deaf and Hearing people. Acknowledgement of a Third Space of Deafness, the fluidity of identity, culture, and language and the many different ways to be deaf, could assist the IHP in understanding the importance of presenting deafness and language to parents in a more positive and comprehensive manner that acknowledges and even embraces difference.

2.4.1 Parental perspectives and meanings of deafness

In her dissertation research, Mauldin (2012a) conducted an ethnographic study examining the lived experiences of professionals and families at a Cochlear Implant Clinic in the United States. My research differs in that her focus was on how the CI process created meanings, rather than delving into the meanings themselves. Mauldin’s research revealed that: the CI process produced a CI community that considers deafness a condition to be overcome and made irrelevant by CI; mothers are socialized into a pathological view of deafness; the CI does not solve deafness but “generates new social organization and social patterns in relation to it” (p. 217); the neurological discourse around CI, especially contradictory notions of neuroplasticity, encourages and maintains linguistic divisions; and CI professionals are not literate in Deaf culture. Citing Siebers, Mauldin argues for incorporating the body and responses to it into research, and using and critiquing techno-scientific discourse to focus on the practices
surrounding CI: “It is time to look at the shifting boundaries and gray areas between the medical and the social, the embodied and the discursive” (p. 230). Corker suggested a similar reconceptualizing of deafness “within a postmodernist, poststructuralist framework which gives equal credence to both discursive practice and materialism” (1998, p. 74). In my dissertation, I heed their advice and focus on both how the IHP creates meanings through discourse, and the material effects that such discourse, and the medical practices they represent, have for deaf children and their families.

In an article based on her dissertation research, Mauldin (2012b) employed a critical realist model to “describe realistically the meanings that deafness and the CI have for parents and professionals” (2012, p. 532). She found that there are anticipatory structures in place that work to shape parental behavior and increase compliance. The first anticipatory structures function to reduce parental resistance to follow-up services after the first newborn hearing screening test is failed, followed by inter-institutional structures that ensure parents are trained and monitored in the early intervention of their children, with a focus on “good listening and auditory training” (p. 536). The social relations that develop in this process create a cochlear implant community framed by a medicalized understanding of deafness. This CI community puts the onus for a child’s CI ‘success’ on the efforts and actions of parents so that “decisions and their consequences are embedded in cooperating contexts” (Mauldin, 2012, p. 539).

It is important to note the parents Mauldin interviewed all had children with CI for at least three months and were “considered highly compliant by the clinic staff” (2012, p. 533); the CI clinic did not grant her access to parents who were still in the process of making a decision regarding CI for their child or parents who were considered non-compliant. Mauldin’s data was therefore limited to a very specific group of parents from one CI clinic, and highlights the social relations constructed by interactions between professionals and “compliant” parents only. The
experiences of parents who perhaps did not subscribe to this medicalized framing of deafness, or were not considered compliant by the clinic, were absent. To avoid this issue, I conducted my research independent of the IHP and CI clinics and interviewed parents who had varying experiences and had made a range of decisions with regards to hearing technologies and communication modalities. In this way, I could analyze how parents with different conceptions of language and deafness take up the meanings ascribed by the IHP.

2.4.2 Disability studies in rehabilitation and critical qualitative health research

Scholarship by rehabilitation professionals taking a critical view of rehabilitation practices is growing (Gibson, 2016; McPherson, Gibson & Leplege, 2015). Such scholarship is most evident in the rehabilitation fields of occupational therapy and physical therapy (e.g., Critical Physiotherapy Network, 2018; Gibson, Nixon & Nicholls, 2010; Magasi, 2008a, 2008b). For example, in a comprehensive re-thinking of rehabilitation, Gibson promotes a “post-critical” approach to rehabilitation that “consolidates key premises from critical and postmodern scholarship” to question the hegemony of scientific positivist research and thinking within medicine and rehabilitation (2016, p. 4). As Gibson states,

The common features of post-critical approaches sketch out a set of ready-to-hand ideas for rehabilitating rehabilitation. They highlight the importance of historical analyses in revealing how contemporary practices grew from assumptions that build upon other assumptions, and how “things could be otherwise.” Power, politics, and ingrained discourses orient practices and, while we can never fully escape these contingencies, revealing their logic is a powerful tool for effecting meaningful change. A post-critical lens thus suggests alternative areas of inquiry, new ways of producing knowledge, and different ways of examining common issues in rehabilitation. (Gibson, 2016, p. 9)
As noted in the foreword, Abrams considers these post-critical approaches to be “disability studies of rehabilitation” (p. vii). These post-critical approaches however are central to all disabilities studies scholarship; they are just being specifically applied here within rehabilitation. That rehabilitation professionals have begun to pay attention to disability in new ways and to question the representations of disability typically put forward by their professions, is an indication that the work of disability studies scholars and activists is beginning to create change in health practices, with the potential to shift power relations between disabled people and health professionals. Although the use of post-critical approaches by rehabilitation professionals is a positive indication of change within rehabilitation, such thinking is still marginal; the biomedical model remains central and continued work is needed for disability studies to be a regular component within rehabilitation training programs and clinical practices.

There is very little critical qualitative research incorporating disability studies within speech-language pathology (SLP) specifically, and none that I could find within a Canadian context. There has been some critical research on how disabled youth who use augmentative and alternative communication (AAC) experience and understand inclusion (Teachman, 2016). Although Teachman is an occupational therapist, AAC falls under the purview of both disciplines. Using a “critical dialogical methodology” adapted from the theories of Bourdieu, and Bakhtin, Teachman found the youths in her study “work to position their selves as included” within a constrictive social system that privileges ‘normal’ bodies while oppressing and separating out disabled bodies despite the intent of “inclusion” (Teachman, 2016, p. 48, p. 173 respectively). Teachman suggests the understanding of inclusion be re-conceptualized so different ways of being are accepted, rather than “included” in a way that only serves to “marginalize and silence disabled youth” (p. 169).
Beyond Teachman’s critical research on the experiences of disabled youth who use AAC, critical examination of SLP practices in Canada seems limited to advocating for culturally sensitive practices (Peltier, 2011), while the assumptions inherent to the profession go largely unquestioned. Yu and Epstein (2011), examined how SLP students at one U.S. university conceptualized developmental communication disorders, and the SLP’s role in working with children with developmental communication disorders at various points throughout two courses in the Communications Disorders Program. Student conceptualizations were examined through reflection essays written at the start of the course (the baseline), after learning content presented within a traditional medical approach, again after learning about the social model of disability and discussing different representations of disability, and finally after conducting a case study analysis where they were provided with multiple sources of information about a child to consider how different everyday interactions affect communication. The authors found the students’ conceptualizations of disability changed depending on how and what they were taught.

At baseline and after ‘traditional’ medical approaches to teaching, most students held a medical orientation to disability; this number dropped after discussion of the social model, while the number of students with a social orientation increased. After the case study, the number of students with a mixed orientation (both medical and social) increased, which the authors suggest points to a tension between medical and social models when applied to clinical situations. A similar pattern was found with the conceptualization of the SLP’s role, although more students held a mixed orientation throughout (Yu & Epstein, 2011). This study demonstrates the importance of teaching student clinicians about different representations of disability to encourage reflexive engagement with their own conceptions of disability and a consideration of communication problems as social rather than being a solely individual concern. The need to explicitly discuss how social context can affect communication, an inherently social
phenomenon that cannot occur in isolation, demonstrates how deeply entrenched the field of SLP is within a medical framework.

Although not specific to disability, Stella Ng’s research in health professional education promotes the inclusion of social scientific theories and qualitative methodologies in audiology education and health professional education more generally (Ng, 2013; Ng, Bisaillon, & Webster, 2017). Ng has also researched reflexivity in audiology and suggests that “critical reflection can be useful for bringing taken-for-granted assumptions and situations into light and for identifying and navigating ethical dilemmas and systemic challenges” (Ng, 2012, p. 122).

Although not suggesting that quantitative methods or technology be abandoned, Ng nonetheless proposes that audiologists consider different epistemologies and values, citing “aural/oral versus sign language approaches to habilitation” as one area requiring critical reflection (2012, p. 129). I return to a discussion of health professional education in the final chapter (Chapter 7).

My dissertation research provides an example of how speech-language pathologists and audiologists can critically examine taken-for-granted policies and practices and consider what those practices ‘do’ aside from (re)habilitating hearing, speech, and language. In my preliminary research of deaf educational practices in Ontario, I discovered there are speech-language pathologists and audiologists who do not subscribe to a Deaf/Hearing dichotomy, but who must nevertheless work within the constraints of a system that relies on this dichotomy. I spoke with SLPs and an audiologist who thought sign language could be beneficial for deaf children, but who had to work within a system that did not support the use of sign language. I have also heard anecdotes of SLPs and auditory-verbal therapists who use signs with their deaf clients, even while working on listening and spoken language. There are therefore rehabilitation professionals who question the ‘rules’ and provide services based on the needs of the child rather than the needs of the profession. With more critical research informing practice, researchers and
clinicians can be well-situated to work towards Gibson’s stated goal of “rehabilitating rehabilitation” (Gibson, 2016, p. 9).

Before proceeding with my analysis, I must first address how I conceptualize deafness and disability in my research. In the next chapter, I explore the different ways that deafness and disability have been theorized in the past and discuss how my research makes sense of d/Deaf and disability and my decision to take a disability studies rather than Deaf studies or rehabilitation sciences perspectives. Terminology used in my analysis is also defined and discussed.
Chapter 3

3 Deafness and disability: Diversity in defining

During these last few years as a disability studies scholar, I have come to discover that disability studies is an academic field of study not well known outside of academia, or even outside of disability studies. Most people I encounter think I study disability in a medical or rehabilitative framework, especially those who know of my past profession as a speech-language pathologist. Friends tell me of people they know who also work in the field of disability (not disability studies): people who work with children with developmental disabilities, or who study genetic conditions or provide genetic counselling, or work in ‘special’ education. Admittedly, I was not familiar with disability studies until my search for a suitable doctoral program, and if it had not been recommended by a Deaf person, I may not have even considered it, as I knew from my ASL classes that Deaf people did not typically identify as disabled. Documenting the many different epistemologies and ontologies of disability that ground assumptions about ‘disability studies’ could be a worthwhile future project in understanding meanings of disability in academia.

At this point, I provide an understanding of the meanings of deafness and disability relevant to this current project, as these understandings affect how Ontario’s Infant Hearing Program (IHP) policy makers and service providers, cochlear implant (CI) stakeholders, and parents of deaf and hard of hearing children, come to make sense of the relationship between audiological deafness and disability while creating deaf subjectivities. In this chapter, I examine the different epistemological and ontological relationships between deafness and disability in existing literature and explain how a disability studies perspective grounds this particular research project.
3.1 Disability studies

Disability studies is an interdisciplinary field of study which brings together different methodologies and philosophies that question dominant conceptions of what it means to be disabled and non-disabled, or ‘normal,’ as these relate to what it means to be human. There are ongoing deliberations regarding the extent of the usefulness of the social model of disability (discussed in the following section), how impairment should be conceptualized, and how much importance should be placed on material versus discursive considerations, which add to the rich diversity within the field. Despite this theoretical diversity, disability studies scholars hold a common belief that disability is socially and politically constructed and hence question normative views of disability (Davis, 2013; Titchkosky & Michalko, 2009). Disability studies critique individual or medical conceptions of disability as personal tragedy that limit disability to being a problem that must be solved, while acknowledging there are multiple ways to conceptualize disability (Titchkosky & Michalko, 2009). In the West, the solution to disability typically involves medical professionals employing various genetic, bio-technological, surgical, pharmacological, and rehabilitative procedures to ‘fix’ the ‘problem,’ or to enable participation in ‘normal’ activities with ‘normal’ people. Disability studies seek to question taken-for-granted conceptions of disability and this push to normalize, and to bring the experiences and opinions of disabled people to the forefront of any discussions of disability. The disability movement and the social model of disability supported the gathering of scholars and activists into organizing the field of disability studies.

3.1.1 The social model of disability

The social model of disability, a phrase coined by Michael Oliver in the United Kingdom in the 1980s and based on the work of the Union of the Physically Impaired Against Segregation
(UPIAS), initiated a way of thinking about disability from a social relational view, rather than an individual view based on the personal tragedy theory of disability. The UPIAS was established to address the oppression the founders experienced as institutionalized disabled people: “In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society” (UPIAS, 1976, p. 14). Within the social model, using the distinction first made by UPIAS, impairment (e.g., paralysis) is distinguished from disability to indicate that physical impairments in and of themselves do not cause disability (Oliver & Barnes, 2012). Disability is instead defined as resulting from discriminatory or inappropriate actions regarding impairment and is therefore located within society. For example, a society that is structured to only accommodate people who walk is disabling to those who do not walk. Rather than conceiving of disability as an individual deficit that should be diagnosed and treated within a biomedical model, the social model posits that it is society that is disabling.

Over the years, the social model has been applied more broadly to understand how disabilities other than physical disabilities are conceived and structured in society (Oliver & Barnes, 2012). Although the social model has received various criticisms, some of which Oliver has addressed, and it has been acknowledged that it “is a simplified representation of a complex social reality,” the social model was instrumental in initiating a social relational view of disability which empowered many disabled people and led some health professionals to reflect on their conceptions of disability (Oliver & Barnes, 2012, p. 23). The social model of disability

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14 Oliver and Barnes (2012) summarize the criticisms against the social model, and Oliver (2009) provides a comprehensive discussion about the criticisms and what the social model was intended (and not intended) to accomplish.
also led to the social model of health more broadly and a recognition that health is not just defined by individual factors, but social determinants such as working and living conditions which are outside the control of individuals (Mikkonen & Raphael, 2010). The intent of the social model to shift “attention to disabled people’s common experiences of oppression and exclusion and those areas that might be changed by collective political action and social change” (Oliver & Barnes, 2012, p. 22) was instrumental in considering health care systems and rehabilitation practices from a critical perspective, and in organizing disability studies as a field of study in opposition to the study of disability. In the following sections, I examine how the concepts of medicalization and normalcy further shaped my understanding of disability studies.

### 3.1.2 The medicalization of deafness

In *Birth of the Clinic*, Foucault (1973) follows changes within medical practices leading up to the time of modern positivist medicine at the end of the eighteenth century. By tracing the development of the medical clinic and the patient-doctor relationship with its focus on the gaze, Foucault demonstrates how the practice of examining dead bodies led to a change in medical discourse and practice. Rational thinking was born when death became viewed as “*embodied* in the *living bodies* of individuals” instead of as imbued with moral judgements (i.e., death as evil) (Foucault, 1973, p. 243, original italics). Medical discourse became based on what was apparently observable; disease was described and made seeable and knowable through description. This gaze was extended to include the other senses of touch and hearing along with sight in the nineteenth century. The historical processes that Foucault reveals led to a certain language used to describe human bodies and disease, and the general movements of life, that now constitute how humans organize our existence through the discourse of medical science: “Western man could constitute himself in his own eyes as an object of science, he grasped himself within his language, and gave himself, in himself and by himself, a discursive existence,
only in the opening created by his own elimination” (1973, p. 243). Foucault’s historical examination of medicine and the changes that led to current clinical practice demonstrates how the medical sciences, along with the unquestioned rationality and supposed truth of medical science, have been culturally produced.

Since the ‘birth of the clinic,’ an increasing number of bodily and social processes have come under a medicalized gaze, such as reproduction and childbirth, and notably for this dissertation, hearing, speech, and language. Conrad describes medicalization as “defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to ‘treat’ it” (1992, p. 211). Hearing, speech and language have become medicalized on all counts, falling under the purview of otolaryngologists, audiologists, and speech-language pathologists. The medicalization of deafness (and the field of otology) began at the start of the 19th century with Jean-Marc Itard, the appointed physician for the first publicly funded educational institution for deaf students in Paris. Consistent with medicine’s new gaze, the students at the Paris Deaf Institute became ‘objects of science’ while Itard worked on “the study of deafness and how to make normal those children who could not speak” (Quartararo, 1999, p. 243). Itard developed the first classification system to indicate different degrees of deafness, and performed various, often invasive and painful, experiments in his attempts to find a cure for deafness (Lane, 1992; Quartararo, 1999). Despite years of research, including a compilation of observations of past doctors as well as his own experiments, Itard did not find a cure. He did, however, continue to work towards teaching deaf students to speak, connecting the oral method with a medical approach to deafness and setting the stage for physicians’ involvement in the teaching of deaf students (Quartararo, 1999).

Today in Canada, physicians are not directly involved in the education of deaf students, although they do generally support teaching deaf children to listen and speak. The medical
approach to deafness sustained by Ontario’s healthcare system, including otolaryngologists and Cochlear Implant Programs, support auditory-oral language development and continue Itard’s quest for a cure, bolstered by advances in technology. The ear trumpets that Itard used with his students in the 19th century gave way to hearing aids which amplified sound, and later to cochlear implants which could give access to sound when amplification could not. The development of technologies that allowed for the observation of internal bodily structures previously only observable at death, first x-rays, then computed tomography (CT) and Magnetic Resonance Imagining (MRI), gave doctors more information about structural causes of deafness. Despite these technological advances, they do not provide a cure for deafness; when hearing technologies are removed, deafness prevails. The search for a cure now also extends the medical gaze to molecular levels of biology such that hereditary genes responsible for deafness have been identified.15 There is a close relationship and tension between the search for a cure and the elimination of people with ‘deaf genes’ being born deaf, as prenatal genetic testing may lead to the option of pregnancy termination in the case of a fetus with a genetic mutation. Genetic testing reveals the bio-political eugenic danger in searching for a cure for non-life-threatening bodily differences, towards the goal of compliance with normalcy.

15 Numerous genes have been identified, yet there is no clear causal link in many cases: “To date more than 70 genes and more than 2,000 causal variants have been implicated in NSHL [Non-syndromic hearing loss],” yet “genetic diagnosis for NSHL is particularly challenging given limited phenotypic variability and extreme genetic heterogeneity” (Shearer et al. 2014, p. 446;445). Shearer et al. note that “incorrect classification of genetic variants...is a systemic issue in human genetics,” likely influenced by differences based on ethnicity (2014, p. 446). Variations in the connexin 26 gene have been found to account for most cases of NSHL (Genetics Home Reference, 2017).
3.1.2.1 Normalcy

Itard and the oralists that followed thought the only way for deaf people to integrate into the majority society was to become more ‘normal.’ This concept of the norm was a significant development in the 19th century that contributed to the medicalization of previously non-medical problems. Prior to the development of the normal distribution curve by early statisticians, Western societies upheld a concept of the ideal human body that was mythological and not meant to be attainable. The statistician Adolphe Quetelet, was the first to develop the concept of the ‘average man’ by applying the error curve (previously used by astronomers) to the measurement of human features (Davis, 1995). This error curve displays most of a population falling within a defined norm (of whatever feature is measured), with outliers falling outside the norm. Sir Francis Galton, a contemporary of Alexander Graham Bell with whom he shared eugenicist inclinations, changed the name of the measurement to the normal distribution curve (also called the bell curve due to its bell shape) and used it to rank traits, rather than simply average them. This resulted in the fourth quartile outliers (those to the far right of the mean) being considered superior (e.g., traits such as taller height or increased intelligence which Galton thought would improve the human race), whereas outliers in the first quartile (those to the far left of the mean) were considered inferior in relation to the norm (Davis, 1995).

Standardized assessment measures, including those used by speech-language pathologists today, are all based on Galton’s interpretation of the normal distribution. Standardized tests compare the abilities of individuals in relation to the norm so that scores falling one standard deviation or more below the mean are interpreted as below average, undesirable and in need of therapeutic interventions. The further below the mean, the more ‘deviant’ the score. The comparison of human attributes to a norm supports disciplinary control and bio-power and is pervasive throughout modern Western society. Along with the modern medical scientific gaze and
advances in technology, normalcy provides the foundation for the continued medicalization of
deafness, and disability more generally.

Becoming aware of the hegemony of normalcy has had a profound impact on how I interpret the
world and my work within disability studies.\textsuperscript{16} As a speech-language pathologist, I regularly
assessed people and provided therapy based on comparisons to ‘normal’ speech and language.
Although as a clinician I modified assessment procedures when needed to gain qualitative,
rather than quantitative/standardized information about a person’s speech and language skills, I
did not question the idea that there was indeed a normal standard. The concept of normal has
become so ingrained in our society that it permeates all aspects of our lives from birth to death.
Infants are subjected to multiple norm comparisons within minutes of birth (e.g., length, weight,
head circumference) and throughout childhood pediatricians and other health service providers
and parents compare children to one another in multiple ways (e.g., physical growth and
development, speech and language development, social development, educational achievement,
psychological development). Comparisons to the norm continue throughout the lifespan (e.g.,
physical appearance, body shape, sleeping and eating patterns, social relations, employment and
income). As a disability studies scholar, I recognize the norm organizes Western society, but
consider it a construct we have created rather than the ‘true’ representation of reality.

The pervasiveness of the concept of normal, along with disciplinary control of the population,
conceal how what science defines as normal has been socially constructed. The Diagnostic and
Statistical Manual of Mental Disorders (DSM) provides an example of how social institutions
construct normalcy. The DSM-5 is a culturally-derived text that defines and classifies human

\textsuperscript{16} My awareness of the hegemony of normalcy was due in large part to Lennard Davis’s (1995) book, “Enforcing
Normalcy: Disability, Deafness, and the Body,” particularly Chapter 2, “Constructing Normalcy.”
mental disorders. There have been five editions since the DSM was first published in 1952, with the latest DSM-5 published in 2013 (American Psychiatric Association, 2017). With each edition, diagnostic criteria were modified and disorders were added, removed or reorganized, as conceptions of normality have shifted. For example, in past editions there was a bereavement exclusion for depression; however, bereavement is no longer an exclusion over concern that major depression may be left untreated. Depression following the death of a loved one can therefore now be medically treated (Pies, 2014). This is an indication of how pharmaceutical treatment is becoming mainstream even for ‘normal’ psycho-emotional processes.

The social construction of deafness and language also differs over time and place. For example, between the late 18\textsuperscript{th} century and early 20\textsuperscript{th} century, a large proportion of the population of Martha’s Vineyard, a small island off the coast of Cape Cod, was deaf. Both hearing and deaf islanders communicated with each other using manual signs, which many islanders assumed was the case in all communities as it was the unquestioned norm on the island (Groce, 1980). The majority of marriages on the island were between deaf and hearing people, a reflection of how deaf and hearing people blended together as one community: “the Deaf on Martha’s Vineyard were not a distinctive ethnic group; instead, they conformed to the dominant ethnicity, they were almost totally assimilated – to a society that valued them and used their language” (Lane, Pillard & Hedberg, 2011, p. 105). In contrast, during the 19\textsuperscript{th} century, deaf people in mainland USA\textsuperscript{17} were gathering together to promote the formation of Deaf people as a distinct group, different from hearing people. As more people began to marry outside of the island, the

\textsuperscript{17} Thomas Brown, a deaf man from New Hampshire was instrumental in organizing deaf people together and was the first president of the deaf organization, the New England Gallaudet Association of Deaf-Mutes (Lane, Pillard & Hedberg, 2011, p. 95).
number of deaf people decreased and eventually disappeared by the early 1950s, as did the use of the island sign language (Groce, 1980).

Unquestioned relations to normalcy provide ways to categorize and make sense of the world, and the way societies categorize things tells us much about how people make sense of the world and the power relations involved in doing so. As Titchkosky notes, understanding and critiquing normate culture provides a new way to conceptualize disability: “What Disability Studies offers the academy is a disciplined way to study and confirm normate culture, and it puts forward the possibility that the values and epistemological assumptions of ‘normalcy’ can be inserted into the world in a new way” (Titchkosky, 2009, p. 56). Disability studies question the taken for granted status of the normate and encourages a re-examination of what it means to be a normal human.

Deaf culture and Deaf studies demonstrate how contesting normate culture can empower and strengthen a marginalized group of people. Deaf studies and disability studies share this common goal of emancipation from the restrictions imposed by normate culture; however, disability studies are not universally accepted as a field of study appropriate within Deaf studies. The most obvious reason may be due to Deaf culture eschewing any association between deafness and disability; signing Deaf people often do not identify as having a disability, but

18 Rosemary Garland Thompson defines the “normate” as a culturally produced representation that allows an identification of oneself as a definitive human being (1997, p. 7). Disability then is the culturally produced representation of embodied difference.

19 Deaf studies originated in the 1970s “to develop a body of knowledge about its [Deaf Culture’s] ways, values, literature, politics, arts, and history. That is, Deaf Culture needed Deaf Studies to articulate, explore, and promote the phenomenon of Deaf culture, both to the hearing world and to Deaf individuals themselves” (Bauman 2008, p. 3). Bauman (2008) notes that now that Deaf culture is established and accepted, the scope and relevance of Deaf studies may be widened and the focus can include questioning “what it is about Deaf Culture that is valuable to human diversity” (p. 3). Ladd (2003) provides a comprehensive examination of the history of Deaf culture in the UK and US and examines how different theories can be used to explain Deaf culture.
rather use a different language and have a different worldview than speaking hearing people. Corker notes that deaf people “may also feel excluded from the disability movement because the movement is seen to reflect this [phonocentric] world-view in the way in which it is socially organized around phonocentric language ‘norms’” (Scott-Hill, 2014, p. 89). In other words, disability studies operate within the majority spoken language and reflect a hearing worldview, rather than a Deaf worldview. In the following section, I explore these tensions between disability studies and Deaf studies and examine different epistemologies of deafness and disability.

3.2 Deaf, deaf…disability?

Whether being deaf is considered a disability depends on how one defines disability and how one defines deafness. For example, the medical establishment frames deafness as a problematic disability requiring a medical solution; a deaf diagnosis is considered a personal tragedy requiring professional services to ‘fix’ the problem. Rather than framing deafness as an individual disability, Deaf culture embraces a Deaf worldview and sign language so that being deaf is not considered a problem, but rather a different way of experiencing the world. In Deaf culture, Deaf may be separated from disability with the result being that disability is still considered a problem, just not a problem applicable to Deaf people. Although Deaf people may not personally identify as disabled, there are economic programs that result in a disabled identity in a bureaucratic sense. For example, the audiological diagnosis of deafness may qualify Deaf people for Canada’s disability tax credit (DTC), where disability is defined as an economic disadvantage. In the chapters to follow, I examine how the IHP presents meanings of deafness, and how parents make sense of their child’s diagnosis and make decisions on their behalf. Lived experience with deafness demonstrates how boundaries between deaf and disability are blurred
and how difficult it can be for parents to maneuver amongst conflicting meanings of disability, deafness, and language. First, it is necessary to examine how these conflicting meanings of d/Deaf and disability have been addressed in past literature.

In Ontario, deafness has been considered a problematic disability since before the opening of the first provincial school for the Deaf, The Ontario Institution for the Deaf and Dumb, in Belleville in 1870 (Carbin, 1996). The school fell under the mandate of the Department of Prisons, Asylums, and Public Charities, and the early institutions for deaf education included the word “asylum” in their name (e.g., Connecticut Asylum for the Education of Deaf and Dumb Persons; London Asylum for the Deaf and Dumb). Their inclusion as an asylum (the word also used to label psychiatric institutions at that time), branded deaf children as children in need of specialized assistance following a charity model of education. 20 In a notice announcing the building of the Belleville Institution in the American Annals of the Deaf and Dumb, J.B. McGann, the founder of the school, used much disability rhetoric in his description of the new building location and described deaf children as needing assistance to approach the status of human. He described the physical location of the building in detail and noted that the beauty of the countryside along with the majestic building would “accomplish enduring good and more lasting benefits on a large number of our fellow creatures who labor under the ‘crushing calamity’ of deaf dumbness” (McGann, 1869, p. 249, original quotations). Similar to Bell’s discourse, McGann places deaf children not quite on par with other humans. McGann also expressed gratitude to the citizens of Belleville who “of every grade in society are widely

20 The first school for the deaf, the American Asylum for the Deaf and Dumb, was founded by Thomas Gallaudet in the interest of providing moral and religious guidance to those less fortunate. Such paternalistic benevolence was common among wealthy Protestants in Canada and the U.S. (Valentine, 1993). An asylum could also perhaps designate a safe space away from normal society members.
known for benevolent efforts to mitigate distress and the evils which afflict humanity” (McGann, 1869, p. 251). To be deaf was to have an evil affliction that caused distress and required benevolent efforts from hearing speaking citizens.

Although the terms used have changed, the idea that deaf children suffer a “crushing calamity” and must become like ‘other children’ remains, and the significance of ‘becoming hearing’ is now firmly entrenched and taken for granted with the development of hearing technologies. As I will demonstrate in the following chapters, this taken-for-granted becoming is evident in the IHP’s focus on spoken language over sign language. It is also evident in the way the director of the SickKids CI Program promotes cochlear implants for children as giving them the opportunity to become educated, productive adult citizens (Brown, 2011; Ferguson, 2011; Artuso, 2011). Deafness is framed as a barrier to the possibility of full citizenship, with education and employment (only attainable if one is hearing and speaking) considered central to becoming a productive citizen. The promotion of hearing technologies and related services that go along with them are central to this ‘becoming,’ demonstrating how normalcy and capitalism interweave within a nationalist society to medicalize deafness.

This medicalized view of deafness contrasts with a Deaf view, in which being deaf is not considered a problem, but rather a unique experience of life that brings deaf, sign language speaking people together into a distinct socio-cultural-linguistic group. Deaf culture directly opposes the medicalization of deafness by celebrating a Deaf, signing way of life. Deaf culture therefore dissociates from a medical view of deafness and the representations of deaf as tragic disability; in Deaf culture, there is nothing to be fixed as deafness is not a disability. This eschewing of any relationship between Deaf and disability, particularly disability as a social construct rather than individual deficit, has been questioned by scholars in both Deaf studies and disability studies (Burch & Kafer, 2010; Corker, 1998; Lennard, 2008). There continue to be
debates about the applicability and value of disability studies within Deaf studies, with some sug-
suggestion that disability studies can strengthen the advocacy work of Deaf scholars and
activists. I present some of this literature below, beginning with work that separates Deaf
ontologies from disability, followed by work that questions how deaf and disability can be of
benefit to Deaf studies. I would like to reiterate that I am not debating the existence and
importance of Deaf culture or Deaf studies, or proposing how deaf people should identify. The
purpose of this chapter is to examine some of the history and tension between Deaf studies and
disability studies and to explain my choice of working within disability studies for this research.

One of the most well-known North American advocates of Deaf culture is Harlan Lane, a
Lane vehemently argues against a disability construction of deaf people (1992, p. 21). Lane
presents Deaf people as a linguistic minority group and to be deaf as “a different way of being”
rather than as disabled; however, in doing so, he presents many negative connotations of
disability as defective. Lane discusses how paternalism, audism, ethnocentricity and profitability
all lead to hearing domination of deaf people. He works to develop a well-defined description of
a deaf child (e.g., what they need, how they feel, what their true nature is) and makes the
assertion that all deaf children by birthright belong to Deaf culture with ASL as their mother-
tongue. Further promotion of an essentialist Deaf identity is evident in his use of the phrase
“medicalization of cultural deafness” (p. 208) rather than medicalization of deafness. Although
this separation of Deaf from disability and arguments for a Deaf identity from birth are in
response to oppressive audist practices and are meant to promote engagement with Deaf culture
and the learning of sign language, such extreme compartmentalizing excludes many people from
the Deaf category and presents assumptions of what it means to be a ‘true Deaf person.’ Oral
deaf people who sign are effectively erased from Deaf culture, or even from any ‘real’ identity.
Lane also presents hearing parents as the problem, rather than providing information in a way that may assist parents in understanding their child better, which may encourage them to learn about Deaf culture and sign language. In my opinion, Lane advocates for Deaf culture in a way that excludes many people (including deaf disabled people and racialized deaf people\textsuperscript{21}) and his rhetoric counters meaningful and productive collaboration between Deaf people, parents, and medical professionals.

Lane directly tackles the relationship between deaf and disability in his book chapter, “Do Deaf People Have a Disability” (2008). Drawing from the work of Foucault, Lane provides an overview of how the concept of disability arose when the state began to control the health of the population in the 18th century, using norms to categorize, and disciplines to regulate and rehabilitate with technologies of normalization, all with the goal of producing productive citizens. Lane defines disability as a “classification of a physical, behavioural, or mental difference from the norm that is attributed to biological causes in a particular culture in a given era, as a result of the interventions of interested parties” (2008, p. 281). After unpacking the meaning of disability as socially constructed, Lane then does the same for “deaf.” Lane argues that deaf has been made into a problem as a disability that needs fixing, when it is instead a social problem caused by audism, and he uses the social model of disability to negate deafness as disability (rather than to negate deafness as an individual problem). Lane presents arguments

\textsuperscript{21} Within Deaf studies it has been acknowledged that the definition for admission into Deaf culture is not universally agreed upon resulting in the precarious position of many people in the margins (e.g., hearing children of Deaf adults; late deafened people who learn sign language later in life; parents of Deaf children). Deaf culture has also been critiqued for being representative of white Deaf people while excluding other minorities (there have been similar critiques of disability studies). I refer the reader to the introduction of Bauman’s (2008) edited volume for a discussion of how “newer conceptualizations of Deaf identity seek to find ways to avert the dead end of identity politics and instead forge a broad construction that encompasses the myriad ways of being d/Deaf, yet while maintaining some critical features that distinguish the existential state of being Deaf from other identities” (p. 13). See also chapters in De Clerck & Paul’s (2016) edited volume for exploration of what it means to be deaf from many viewpoints, with a focus on sustaining sign language for deaf learners.
about why it is inappropriate to label Deaf people as disabled, effectively equating disability with personal tragedy, contrary to the purpose of the social model of disability which opposes an individual personal tragedy model of disability. Lane (2008) narrowly interprets the social model to demonstrate how deafness is socially constructed as a problem, while keeping disability entrenched as an individual problem.

Lane’s arguments for “disowning the disability label” insinuate that the negatives of such a label are appropriate for disabled people, but not for Deaf people (2008, p. 285). In arguing for a purely cultural-linguistic model of Deaf, similar to his past work, Lane excludes many people and perpetuates negative attitudes towards and the oppression of disabled people, while presenting an argument for a separation between deaf and disability based on his own interpretations of what it means to be Deaf and what it means to be disabled, although he is neither. Where do non-able-bodied deaf people fit into this dichotomous relationship between Deaf and disability?

Contrary to Lane, Baynton (2008) argues that the cultural model of the Deaf community, although important for Deaf studies and Deaf pride, does not completely explain deaf experiences. Baynton’s main argument is that differences in the experience of the sensation of hearing (i.e., a different sensory world) between deaf and hearing people cannot be explained by culture, “Deaf people are different from hearing people in ways other than cultural,” and he proposes that the social model of disability fills the many gaps left by the cultural model (p. 294). Baynton addresses the difficulty Deaf people have with being labeled as disabled and argues this difficulty actually aligns with disability theory, which rejects the medical model of disability and considers disability a product of oppression. He provides compelling arguments for the alignment of Deaf people with disabled people rather than with ethnic minority groups, including: similarities in the rights and services demanded; cooperation in the development of
the Americans with Disabilities Act; education demands; differences in anatomical structures between parent and child; and the medicalization of difference.

Baynton also argues there is no reason one cannot identify as both Deaf and disabled, “‘Disability’ describes a particular kind of relationship between a majority and minority, between socially constructed notions of normality and deviance. ‘Culture’ describes a set of values and beliefs within a group…It is not necessary to say that Deaf people are either a cultural group or disabled. It is entirely possible to be both” (2008, p. 298, original italics). He also succinctly explains how the difficulty Deaf people have in identifying as disabled is a misinterpretation of what disability means within the social model:

Thus when disability activists claim that Deaf people are in the same boat with them, they do not mean to suggest that Deaf people are afflicted with a defect that ought to be fixed or eliminated, or that they are not whole, or that something is wrong with them, as Deaf people often seem to assume. Rather, they mean that Deaf people have a sensory difference from the majority that requires a different way of life; that the majority hearing population often tries to obstruct or thwart that way of life, or at the least does not make reasonable accommodations for it; and that the hearing majority thereby disables Deaf people. (Baynton, 2008, p. 301)

Recognizing the benefits of both a cultural model and disability studies, and that someone can be both Deaf and disabled without compromising a Deaf identity, Baynton promotes “disability solidarity” and the collaboration between similarly oppressed groups towards a common purpose of resisting and disrupting systemic oppression (2008, p. 309).

Corker (1998) provides a comprehensive theoretical examination of the interactions and tensions between deafness and disability, with acknowledgement of her own positionality within, between, and outside both groups. Corker posits that essentialist notions of deafness and disability create an unrealistic, simplistic binary that ignores commonalities between the groups
and influences ideological and cultural frameworks that result in social fragmentation. Drawing on Derrida, she suggests a “both/and” process of meaning and representation rather than “either/or” to achieve social change through diversity, while cautioning against total relativism. By bringing together different theories of “simultaneous and multiple oppressions” (p. 50), and attending to the middle ground between various dichotomies rather than essentialist notions that exclude, Corker promotes the breaking down of socio-cultural boundaries.

Corker also points out many shortcomings of the social model’s application to deafness, including the omission of language and discourse, and suggests reconceptualizing “within a postmodernist, poststructuralist framework which gives equal credence to both discursive practice and materialism” (1998, p. 74). I understand this as a call to consider deafness and disability not as binary notions that exclude, and that how we talk about (and how we talk within) deafness and disability is just as important as how deafness and disability materialize in society, for understanding the social construction of deafness. Another way to understand giving “equal credence to both discursive practice and materialism,” is Judith Butler’s dual meanings of “to matter,” where “to matter” can mean both “to mean” and “to materialize” (Butler, 1993, p. 32). Butler’s dual meanings of ‘mattering’ will be discussed further in the following chapter in relation to how deafness is made to matter.

Lane’s, Baynton’s and Corker’s arguments represent Western conceptions of disability and deafness that may differ from how deafness and disability are conceptualized in the Global South. Rashid (2010) writes of her personal experiences of deafness and disability as a deaf person in Nigeria and the United States and how class, race, culture, and gender identities intersect with deafness and disability in defining identity. Rashid discusses how the different perceptions of disability across countries demonstrate how disability is socially constructed, and makes the important point that Deaf cultural identity is not universal. Based on her experience,
Western Deaf culture focuses on “higher order” issues and a distinct Deaf culture which is distanced from disability; whereas in Africa, survival is the main issue and deafness and disability are inextricably linked. Rashid’s (2010) experience of multiple fluid identities leads her to caution against focusing solely on language when considering deaf identities, as the impact of other influences on identity must also be acknowledged.

The importance of considering the intersectionality of multiple fluid identities for every individual is also evident in Friedner’s (2010) work, where the normative homogeneity of “Global Deafness” is questioned. Friedner’s (2010) exploration of how women involved in a New Delhi Deaf women’s organization are positioned, and position themselves, in both public and domestic spaces, points to a fluidity between overlapping identities rather than one identity (e.g., Deaf) taking precedence for these women. Friedner’s analysis highlights conceptions of family, identity, and belonging as being heterogeneous and fluid amongst different cultural groups, and even different individuals who share a culture.

Although intersecting identities such as race, class, culture, and gender are all involved in identity-making, in North America, language has been a key focus within deaf educational practices and within Deaf culture. The mode(s) and method(s) of communication development a family chooses for their deaf child (based on their economic, political, socio-cultural circumstances and the meanings they attribute to deafness and language), determine which type of classroom in which type of school a deaf child will attend, and shapes how that child comes to understand themselves as a deaf person. Although there seems to be a clear boundary between deaf people who speak and Deaf people who sign, with oral deaf people representing a medical view rather than a cultural-linguistic view of deafness, boundaries are blurred and deaf subjectivities may change over time. For example, many oral deaf people choose to learn sign language and become involved with Deaf culture as older teens and adults (Punch & Hyde,
Mcilroy is one such deaf person and he proposes a “DeaF” identity to represent this fluidity between deaf and Deaf to avoid a dichotomous essentialization of identity. Mcilroy and Storbeck describe this bicultural DeaF identity as “separate from both deaf and Deaf communities but also reaches within both communities as the social context requires” (Mcilroy & Storbeck, 2011, p. 506).

Issues with identity are key to understanding how deaf, Deaf and disability can be conceptualized differently by different people. This dissertation is not a study of identity-making, but rather an examination of how deafness and language are made meaningful by the government program that has first contact with parents of deaf children, and how these meanings shape parental choice about communication options, which can then influence how these children come to understand themselves. How people identify as deaf, Deaf and/or disabled is not what I am after here, but rather the meanings that get attributed to deaf and Deaf and how those meanings are taken up by parents of newly diagnosed deaf children. To do so, I work within disability studies to question normative views of deafness and language, and consider such questioning congruent with Deaf studies: “Deaf and disability studies invites us to expand our understanding of what it means to be human, and in so doing, it clarifies the ways that issues like access, stigma, empowerment, and community are shared between and within diverse groups” (Andersson & Burch, 2010, p. 196).

3.3 Notes on terminology

3.3.1 deaf/Deaf

The discourse of d/Deaf that one uses signals cultural-linguistic and political views of what it means to be deaf. As noted previously, capital “D” Deaf typically signifies a cultural-linguistic
identification with Deaf culture. However, there is no consistent use of d/Deaf that has been agreed upon by all Deaf studies scholars. As Wrigley notes, “the dichotomy of ‘d/D’ is so crudely drawn that, while initially useful, it now serves to silence the full range of d/Deaf people’s experiences. It also plays into a strategy of domination by pitting Deaf people against deaf people as these labels are actively policed” (1996, p. 55). Kusters, de Meulder and O’Brien (2017) outline how the initial use of “D” Deaf was meant to signify the sociocultural experience of being deaf without making any dichotomous identity assumptions about “d” deaf, and that there is a move away from the use of the “d/D” distinction in research. The authors note, “This dichotomy is, in fact, an oversimplification of what is an increasingly complex set of identities and language practices, and the multiple positionalities/multimodal language use shown is impossible to represent with a simplified binary” (np).

Some authors acknowledge the fluidity between d/Deaf/disability by not settling with any one notation system. For example, Burch and Kafer deliberately use both “deaf and disability studies” and “Deaf and Disability Studies” as they note that, “To settle on a single format would be to answer, or to be seen as answering, long-standing questions about naming and ideology” (2010, p. xv). Other authors make a political statement by using Deaf to refer to all deaf people. For example, Snoddon (2009) follows Cripps’ convention of consistently using “D” Deaf to signify Deaf culture as the birthright of everyone born deaf (or who became deaf in childhood) regardless of d/Deaf cultural identification. Those in medical fields (i.e., outside of Deaf studies), maintain a medical understanding by using “deaf” to refer to all deaf people.

Recognizing the politics tied up in naming, I do not wish to make presumptions about how infants and children diagnosed as deaf or hard of hearing according to audiological testing will culturally identify themselves. Therefore, in my analysis of the IHP, I use lower case “d” deaf to signify the audiological diagnosis rather than cultural membership (i.e., my use of deaf does not
assume cultural membership within the hearing community, but rather only the audiological diagnosis). I use upper case “D” when referring specifically to Deaf people and Deaf culture. My use of deaf instead of Deaf is not meant to negate Deaf culture, but to represent audiological deafness at the time of diagnosis and early intervention, before a child comes to understand cultural meanings of “d/Deaf.” This is consistent with Roots who states that young children “are always ‘deaf’ because it is assumed they have not yet been enculturated one way or the other” (1999, p. 20).

My use of ‘deaf’ also maintains consistency with the IHP’s use and meaning of deafness, which is primarily concerned with diagnosing and treating audiological deafness. This is not to say there are no cultural or political meanings attached to the IHP’s discourse (i.e., the IHP may very well be assuming cultural membership within the Hearing community). The IHP’s omission of Deaf discourse is relevant to my analysis of how meanings of deafness are represented by the IHP and will be discussed in the following chapters. I use ‘deaf” to signify the audiological goals and practices of the IHP, and deaf as an audiological diagnosis. Similarly, I use lower case “h” hearing when referring to the audiological status of hearing, and upper case “H” Hearing when referring to a cultural category of Hearing people (in opposition to Deaf).

I also use the noun “deafness” throughout this dissertation, yet acknowledge that deafness is often interpreted by Deaf people as representative of a negative, medical view. I use it merely as the noun form of the adjective ‘deaf’ to describe an audiological diagnosis, and prefer deafness as a more neutral term than the IHP’s term of “hearing loss” which is discussed in the next paragraph. Paddy Ladd (2003) proposed the term “Deafhood” as a positive term to replace deafness, but as Deafhood makes a political statement about Deaf identity, I use deafness and not Deafhood when I am referring to an audiological diagnosis. Again, my use of deaf and deafness is not meant to be a political statement in denial of Deafhood or Deaf culture, but a
representation of the audiological diagnosis as this pertains best to my research topic. My use of these typical medical terms does not mean my personal views align with a medical view of deafness, but rather reflects the terminology used by the IHP and is necessary to demonstrate how the IHP’s discourse reflects a socio-political-linguistic climate of normate culture.

The IHP uses the terminology of “hearing loss” throughout various texts including those directed at parents. “Hearing loss” is a description of deafness from a hearing person’s perspective and reflects a biomedical model of deafness; it is not used within Deaf culture. Although I do not agree with this term, I use the terminology of “hearing loss” when necessary throughout my analysis to avoid confusion and to maintain consistency with the wording used by the participants or within the textual material I have collected. I do not consider hearing loss an appropriate term for people born deaf as they did not ‘lose’ their hearing in the same way that a hearing person may lose their hearing at some point. For people born deaf, it is not a loss, but a way of being. The use of this terminology is one way the IHP medicalizes deafness and presents negative connotations of deafness that reflect a hearing person’s understanding rather than a Deaf person’s understanding. Labelling children as having “hearing loss” runs counter to Wrigley’s suggestion that “The parents need to focus on the strengths of their child’s difference, rather than understanding it as a loss” (Wrigley, 1996, p. 22). The way this terminology frames parents’ understanding of deafness will be discussed in more detail in Chapter 4.

3.3.2 Hard of hearing or deaf

The precise audiological diagnoses of the children of my participants are not important for my research, as I am interested in how the IHP represents language and deafness and parents’ experiences with the IHP; the children’s latest audiograms to confirm hearing status were therefore not considered relevant and were not obtained. Although general hearing status is
included in my participant information (Table 3), I attempt to avoid categorizing children based on hearing status throughout my analysis. I generally refer to the children as “deaf,” or “deaf and hard of hearing,” except when it is relevant to the analysis to differentiate between the two, as how hearing loss and communication are discussed with parents may differ depending on the diagnosis. My research is focused on the interaction between parent and program and the meanings of language and deafness that are circulated, rather than individual children and their diagnoses. IHP texts and parents’ experiences with them can tell much about how deafness and language are made meaningful, which in turn delineate how deaf subjectivities come to be imagined.

Typically, ‘hard of hearing’ is used to refer to children whose audiological diagnosis is mild to severe and who can hear sounds with amplification. Most hard of hearing children use hearing aids and learn spoken language. Children whose audiological diagnoses are severe to profoundly deaf and whose hearing is not increased with hearing aids, are often referred to a Cochlear Implant Program to determine cochlear implant (CI) candidacy. The controversy between Deaf/sign language versus Hearing/spoken language is most applicable to severe to profoundly deaf children who do not typically learn spoken language without CI and/or intensive therapy.

3.4 Conclusion

As a hearing person with no familial ties to the Deaf community, I have positioned my work within disability studies with the understanding that disability studies and Deaf studies share a common desire to question normate culture and what it means to be human. Although I situate my work within disability studies, theoretical understandings and literature from Deaf studies inform the pursuit of my research interests. My research is not a study of Deaf culture or deaf people, but rather a study of how a governmental program systemically organizes what it means
to be deaf and what it means to have language, and how such organization interacts with the decisions parents of deaf children must make regarding hearing technologies and communication modality. The critical component of disability studies is well-suited to the line of questioning I take in my research, which is also applicable within Deaf studies. As Yerker Andersson conveys in a conversation with Susan Burch, “Challenging the assumptions behind discrimination, recognizing the social and cultural construction of ‘deaf’ and of ‘disability,’ and adding new meaning to concepts of identity are signature characteristics of both fields. At the core, scholars in both fields question the way people judge one another and what those viewpoints mean” (Andersson & Burch 2010, p. 195).

My alignment with disability studies does not negate the importance of Deaf culture; a Deaf worldview is simply not the frame of reference for my research. As a hearing person who previously worked as a speech-language pathologist, my research takes a critical view of the biomedical response to deafness as reflected in the policies and practices of the IHP. I have spent the past few years ‘making the familiar strange,’ examining speech-language pathology and audiology and the more general medical response to deafness through a critical lens. My research queries systemically entrenched normative views about what it means to be deaf and what it means to have language, and seeks to demonstrate how such views impact the way options are understood by parents of young deaf children. I now turn to these questions in the next few chapters.
Chapter 4

4  Making deafness matter through worry

Throughout these next chapters I will use the Infant Hearing Program’s (IHP) wording of “hearing loss,” with the recognition that such terminology leads to an unquestioned conceptualization and categorization of deafness as a “loss.” This terminology is consistent with a medical view of deafness and describes the function of hearing (or not hearing) from the perspective of a hearing person rather than a deaf infant, who may never have had any hearing to ‘lose.’ The IHP’s seemingly innocuous use of the words “hearing loss” effectively demonstrates how the meanings of bodies that do and do not hear are materialized through text. I argue that these materialized meanings, how hearing and not hearing are made to matter through text, organize and regulate the social actions of IHP professionals, parents, and children. The focus of this chapter is how the conceptualization of hearing as loss is made to matter to parents of babies who may or may not be (or be becoming) subjects of such a “loss.” These potential subjects of loss comprise a large part of the population, as almost all Ontario parents are subject to the IHP’s process of hearing screening upon the birth of their baby.

Since Universal Newborn Hearing Screening (UNHS) has become an ordinary part of the birth experience for Ontario parents, parents’ first experience with their babies’ hearing and communication development is likely through texts, rather than shared lived experience with their child. The IHP’s goal is to screen at least 95% of babies born in Ontario, and follow-up with at least 95% of infants referred (Canadian Working Group of Childhood Hearing, 2005, p. 83). Between April 2003 and March 2015, over 1.5 million babies underwent Stage 1 screening (refer to Figure 1 below). Since 2006/2007, over 130 000 babies have been screened each year (Children and Youth Services, 2016). The Canadian Infant Hearing Task Force (CIHTF)
conducted a study on each of the province’s services for early hearing detection and intervention, and ranked Ontario’s IHP as, “Good (coverage needs improvement but excellent program),” with over 90% of babies born in Ontario being screened (CIHTF, 2014). For example, in the 2014/2015 fiscal year, out of approximately 141,888 births, there were 131,836 babies screened (93%) (Children and Youth Services, 2016; Statistics Canada, 2017). Although Ontario has an average high rate of screening, a special report by the Canadian Association of Speech-Language Pathology and Audiology (CASLPA) entitled, “Speech, Language and Hearing Services to First Nations, Inuit and Métis Children in Canada, with a Focus on Children 0 to 6 Years of Age,” indicates there are areas in northern Ontario that seem to have a low rate of screening and follow-up, although no specific details are provided. As of 2010, UNHS was being adapted for Indigenous children in Ontario, as there were gaps in follow-up services for First Nations newborns screened in hospital at birth, but who lived in remote Northern Ontario communities. In addition, First Nations communities in northern Ontario often have very limited (if any) access to IHP services such as AVT and SLP (CASLPA, 2010). The IHP’s UNHS is therefore a far-reaching program with most Ontario babies being screened, but with inequitable access to services depending on geographic location. Figure 1, depicting the number of babies screened per year, follows on the next page.
This chapter is based on the analysis of documents the IHP shares with parents during the screening and assessment process, and the reported experiences of parents during these first points of contact. There are, of course, many other documents from the early planning stages of the IHP, the implementation of the program, IHP protocols and guides, information from the websites of the regional offices, and association position papers, that lie behind the IHP’s first contact with parents. Some parents may have been aware of the IHP and the screening protocol before the birth of their baby, as much information is accessible via the Ministry of Children and Youth Services website and the websites of the twelve regional IHP offices. All this background material produces meanings of deafness, communication, and language within a certain political and bureaucratic context that informs not only the program, but also the material presented to parents. Of particular interest in this chapter are those texts that mark a first point of in-person contact between the Infant Hearing Program and parents.

Within the first 24 hours of a hospital birth, or within days of a community birth, the IHP screener approaches parents to obtain approval for the screening test. The hearing screening is performed “by hospital nurses or by specially trained screeners from the community” (Mount
Parents are told the importance of hearing screening for their baby’s future healthy development, consent is obtained, the screening test is completed, and parents are given information pamphlets specific to their baby’s screening result. Through the texts of this first contact, along with the physical act of the screening procedure, parents may begin to think about and even act on their children as ‘subjects of hearing,’ or more consistent with the IHP’s terminology of loss, ‘potential subjects of hearing loss.’ They may also begin to think about and act on their children as ‘subjects of developing speech and language,’ or ‘potential subjects of speech and language problems.’ The screening texts (both the information provided verbally at the time of screening and information pamphlets parents are given after screening), therefore provide a logical place from which to begin analysis, as the verbal and written information provided to new parents organize meanings of hearing, communication, and language as well as the relationships between parent and infant and service providers right from the time of birth. As such, the texts themselves need to be considered as a form of social action (Titchkosky, 2007, p. 26).

As social action, the screening texts do more than simply provide information to parents about the screening procedure. To consider what else the texts are doing, I draw from Dorothy Smith’s method of “writing the social.” Like Smith, I begin with “a sense of problem, of something going on, some disquiet, and of something there that could be explicated” (Smith, 1999, p. 9). The moment of disquiet that frames my analysis is quite literally a ‘problem’ that is encountered in the IHP’s discourse of “hearing loss.” To be clear, the problem I sense is not the identification of a child’s hearing levels, but how such identification is organized and represented by the IHP. Throughout the screening and assessment process, parents are introduced to the potentiality of their infants having a hearing loss and all the meanings such a loss conjures, and all this even before experiencing how their infant reacts to them and to the world. While experiencing the
newness of the birth of a baby and all the physical, emotional, social, and financial changes that may accompany a baby’s birth, the IHP’s screening process ensures that parents attend to the functioning of their newborn’s ears. The hearing screening process turns complex parent-infant communications and mutual understandings into an orchestrated act of deciphering, to regulate hearing and language development, “Under the hegemonic control of the medical model, disabled persons are deciphered but not understood” (Titchkosky, 2003a, p. 162). This act of deciphering is grounded in a culturally-established normative idea of what it means to hear and have language.

We are brought into the world as the consequence of other people’s words and deeds, and our beginning in the world is marked first and foremost with what those others have already begun, already thought, and have already understood. We come into the world as subjects of others’ interpretations of our naked physical existence. (Titchkosky, 2003a, pp. 163-164)

The materialization of deafness as loss through text represents a medical interpretation of the physical existence of deafness. This materialization informs and regulates parental (and professional) actions, regardless of whether or not embodied deafness will become part of the family’s lived experiences. In creating these meanings that regulate social action, parent-child relationships are organized, and deaf subjectivities are created.

How deafness is made to matter, is manifest both in the meanings of deafness and language embedded in the texts, and in the materialization of an identified “hearing loss.” As explained by Judith Butler, “To know the significance of something is to know how and why it matters, where ‘to matter’ means at once ‘to materialize’ and ‘to mean’” (1993, p. 32). From the outset, deafness is made to matter through text as loss (where “to matter” means “to mean”), and in the discovery of the small percentage of children whose ears do not pass the test (where “to matter” means “to materialize”) (Butler, 1993, p. 32). Beginning from the sense of disquiet around
hearing loss, in this chapter, I examine how deafness and language are made to matter to parents, both through text and with the materialization of hearing loss, and how the IHP texts coordinate and govern parent-child-professional relations.

The IHP carefully scripts the way information is shared with parents about the hearing screening procedure and about the result of their baby’s hearing screening, to ensure protocol is followed and hearing loss is presented a certain way to manage parental action. As noted in an IHP protocol and support document, “What the screener says and does after any successful screen has a strong effect on the family’s state of mind and subsequent behaviour” (Hyde & Derbyshire, 2013, p. 11). Screeners (who could be nurses or community members) must undergo training to learn how to use the screening equipment and perform the screening via “a standardized approach” (Ontario Ministry of Children and Youth Services, 2013). There is a training video on the Mount Sinai website (also available on Vimeo), “Communicating with Parents: Sample Scripts for Each Pamphlet,” which demonstrates how the screener should approach parents about the hearing screening, and how the different screening results should be communicated to the parents (http://www.mountsinai.on.ca/care/infant-hearing-program/accurscreen-training-videos). After the screening and a verbal explanation of the result, the screener gives the parents a pamphlet which contains information specific to the screening result obtained. The possible screening results are: pass; pass at risk; refer to a second screening; or refer to diagnostic audiology. The post-screening information pamphlets are available in many different languages and can be accessed on the Ontario Ministry of Children and Youth Services website (http://www.children.gov.on.ca/htdocs/English/topics/earlychildhood/hearing/moreinfo.aspx). The pamphlet covers are depicted in Figure 2 below, and the full pamphlets can be found in
Every parent in Ontario is expected to get one version or another of both the verbal screening script and the information pamphlet, within days, or often hours, after birth.

Both spoken texts (verbal information provided to parents by the screener as exemplified in the screening scripts) and written texts (information pamphlets given to parents after the screening), comprise the texts of this chapter’s analysis. The ‘screening scripts’ and ‘information pamphlets’ will be referred to together as the ‘screening texts’ throughout my analysis. These screening texts were developed specifically for parents, following the implementation procedures documented in the many IHP texts that support their generation. Recall the goal of the IHP is to screen all babies at birth (or soon after), to identify the 3-4 out of 1000 babies that are expected to be deaf from birth, and to provide supports and services to deaf and hard of hearing babies and their families across Ontario. Such a government initiative resulted in resource documents, implementation documents, training manuals and protocols that guide the implementation of the program from a bureaucratic standpoint. There are also information documents and journal articles that explain the services of the IHP to health professionals and
the public. The screening texts (the verbal screening scripts and the information pamphlets for parents), comprise the information that is presented directly to all parents in Ontario and to which I now turn. Throughout this chapter, I also include parents’ recollections of their experiences with the screening process recounted to me during interviews, to further illustrate how deafness is made to matter.22

Throughout the remainder of this chapter, the screening texts are described and analyzed, working from the “pass” result through to the “refer to diagnostic audiology” result of screening. By “writing the social,” I carefully consider how the information given to parents after each screening result make language and hearing loss meaningful in a way that informs social action by governing aspects of parent action and parent-child interactions. In a discussion of Foucault’s work on the history and organization of scientific discourse, McGuire notes, “Biomedical knowledges-and the positivist sets of procedures and practices generated by these knowledges-so often tell us how things are, what things are, and who we are” (2016, p. 71). In addition to telling us how and what deafness is and who we are in relation to deafness, these biomedical knowledges tell us how to behave when confronted by deafness or its possibility. In this way, the IHP screening texts demonstrate how the IHP exercises power via a form of governmentality, “a ‘conduct of conducts’ and a management of possibilities” (Foucault, 2003c, p. 138). The chapter concludes with a discussion of how the materialized meanings of hearing and hearing loss, speech, communication, and language presented in all the pamphlet versions and screening scripts, and as experienced by parents, organize parental worry as a governmental social action while defining the subjectivities of deaf and hard of hearing infants.

22 I conducted semi-structured interviews with 12 Ontario based parents of deaf and hard-of-hearing children, aged one to ten years, who use or had recently used IHP services. A comprehensive description of my participants and interview procedures can be found in Chapter 2.
4.1 Pass result: No reason for concern…at this time

The screening result obtained by most babies is a “pass” result and no further testing is required. Although these parents are not expected to have any further involvement with the IHP, the communication of the pass result is still scripted and parents nonetheless receive a pamphlet. Whatever else this pamphlet does, it is involved in providing a textual rendering of meanings of hearing (loss) and language that are widely circulated in society and reflective of how language and deafness are made meaningful by the IHP. The sample screening script for communicating the pass result to parents reassures parents there is no problem with their baby’s hearing, and differentiates their baby’s hearing from those who do not get a pass: “We got a pass result which means both ears are great. I’m going to give you a copy and a pamphlet, it just says everything is OK” (Sinai Health System, 2012). In communicating the ‘good news’ there is a judgement being made that a baby with a hearing loss does not have “great” ears, and that everything may not be OK; hearing loss is presented as a problem these parents do not need to worry about.

Parents are also told by the screener to “give us a call” if they ever have any questions or concerns as “there’s lots of great follow-up services,” but it is unclear from the script why parents would need follow-up services if their baby’s “ears are great” (Sinai Health System, 2012). The accompanying pamphlet provides the information not given in the verbal script. The pamphlet, “Your baby has passed the newborn hearing screening,” informs parents that even though their baby “passed,” the worry is not quite over yet: “He or she is able to hear in both ears at this time” (Ontario Ministry of Children and Youth Services, 2014b, italics added) (http://www.children.gov.on.ca/htdocs/English/documents/earlychildhood/hearing/passed-screening/Passed-Screening-EN.pdf; Appendix F). As well as signaling that hearing loss can develop over time, “at this time” was likely added to protect the IHP from potential legal action
if a child does have an identified hearing loss at a later date; regardless, hearing loss is presented to parents as a continuing potential problem. The pamphlet warns parents their baby may develop hearing loss as they get older, and a checklist of speech and language milestones is provided so parents can keep watch to ensure language is developing normally. Hearing loss is therefore presented to parents as something that requires vigilant monitoring for any deviance from normal speech and language development.

The pamphlet instructs parents to closely monitor their baby’s speech and language development to watch out for potential hearing loss: “Pay attention as your baby grows.” As these babies will not be monitored by the IHP, it is up to the parents to perform this function.

A few babies may develop hearing loss as they grow older, so it is important to pay close attention to your baby’s development. The first months and years of a baby’s life are very important for developing language: Undetected hearing loss is one of the causes of delayed language development. Delayed language development can lead to behaviour and emotional problems and later to problems in school. (Ontario Ministry of Children and Youth Services, 2014b)

In addition to ‘paying attention,’ the pamphlet tells parents they are important in helping their child learn speech and language. Not only must parents monitor development, they should actively and deliberately assist in development. Placing this explicit responsibility on parents sends the message that babies who do not follow the milestones may have a hearing loss, or they may have inattentive parents who did not do all they could do to “help their baby learn language.” Either way, unmet milestones signal that the babies do not have a ‘natural’ and ‘normal’ communicative relation to others. Parents are therefore being monitored for how well they help their baby learn, while also being expected to monitor their baby’s learning.

Although babies with normal hearing do not require the services of the IHP, they do require “help” from their parents: “Most babies have no problem learning language, especially if they
get a little help” (Ontario Ministry of Children and Youth Services, 2014b). Parent-child interaction is reduced to serve the function of helping with language learning; parents are to keep their child’s speech and language development on track, and to obtain professional help if it goes off the rails. Similarly, the sense of hearing is presented as being necessary to, and having the sole purpose of language learning. Language is presented as something to learn, with assistance, and something to be monitored. By focusing on the importance of monitoring language milestones for signs of hearing loss and emphasizing the need for continual speech and language surveillance, the importance of language as communication between parent and child is lost. While warning parents that any delays in the milestones could indicate a hearing loss, the pamphlet also informs parents that even babies with normal hearing could have problems with speech and language and they should access help if the milestones are not being met. As these babies will not be monitored by the IHP, their parents become the first line of defense against unidentified hearing loss and/or delayed speech and language development.

Some suggestions for how parents can help are listed in the pamphlet and are shown in Table 4 below. The suggestions are made to seem as if they come directly from the babies and toddlers rather than professionals: “Babies/toddlers like it when you…” (Ontario Ministry of Children and Youth Services, 2014b). Both the milestones and the helpful suggestions normalize and standardize speech and language, as there is an assumption that all babies and toddlers learn the same way and like the same things. This unquestioned assumption that “normal” speech and language follow a particular pattern and timetable, and that all babies and toddlers like the same kind of specific interactions, calls to mind Haraway’s “god-trick” (Haraway, 1991, p. 189). Such god-tricks present ideas as if they just ‘are’; an objective knowing of “seeing everything from nowhere,” so that the “knower” (i.e., science, medicine) is hidden behind a position like that of an all-knowing god (Haraway, 1991, p. 189). Presenting speech and language milestones in this
manner hides their professional construction. The speech and language of infants and children have been observed, documented, studied, normalized and standardized to create these milestones, but the pamphlet presents them as ‘truth’ attributed to the children. The milestones have become accepted fact for all children, rather than recognized as being developed from research on infants and children who learn language according to an already preconceived idea of what is normal, or what is valued as important skills to learn. The history behind the development of the milestones is erased in favour of an objective presentation.23 The pamphlet tells parents there is a normal way for language to develop and a normal timeframe for it to develop within.

Table 4. “Babies/toddlers like it when you…”

<table>
<thead>
<tr>
<th>Babies like it when you:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Get down to their level so they can see your face. This tells them that you’re interested in what they’re doing and saying. It makes it easier to interact with you.</td>
</tr>
<tr>
<td>• Repeat the sounds they make. Babies enjoy making noises, and like it when you imitate them over and over.</td>
</tr>
<tr>
<td>• Sing and laugh, especially when you are feeding, bathing, and changing them. Remember to talk to your baby throughout the day about things you do and see – “Mommy’s putting on her coat”, “That’s a big truck”.</td>
</tr>
<tr>
<td>• Tell them the names of the objects they are looking at and playing with. Babies are interested in exploring and learning about new things, and like to hear what things are called.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Toddlers like it when you:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Let them touch and hold books while you point to and name the pictures.</td>
</tr>
<tr>
<td>• Use real words instead of baby talk – “give me” instead of ta ta or “water” instead of wawa.</td>
</tr>
<tr>
<td>• Take the time to listen to them – they want you to hear all of their new sounds, words and ideas.</td>
</tr>
</tbody>
</table>

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23 Erica Burman’s post-structuralist research provides a history and critique of developmental psychology by examining its socio-political context and effects (e.g., Burman, 2016; Burman, 1998). Burman addresses language specifically in Part 3: “Developing Communication” of the third edition of “Deconstructing Developmental Psychology” (2016). This section examines how language development has been conceptualized and the power relations evident in the scientific discourse of standardized language development (2016, pp. 183-232).
• Give them simple directions to follow – “Go find your red boots”.
• Use lots of different words when you talk to them – opposite words like up/down, in/out; action words like “running”, “splashing”, and descriptive words like “happy”, “big”, “little”, “clean”, “dirty”.
• Encourage them to play with other children – at the library, play groups, park.

Source: Ontario Ministry of Children and Youth Services, 2014b

In what seems to be an attempt to be “family-centred” and to ensure parents in Ontario who are not fluent in written English receive the information about the screening results, the pamphlets are available in multiple different languages. These translated pamphlets are important for non-English speaking/reading parents to access information about screening; however, the milestones seem to be direct translations of the English milestones and the suggestions given reflect a Westernized worldview more appropriate for white, middle-class parents than those of diverse ethnicities or lower socio-economic status. In this way, the milestones and suggestions reflect a language policy that normalizes English speech and language, as well as cultural norms (e.g., eye contact, pointing, and specific activities and expectations for parent-child interaction), calling into question the purpose of the translated pamphlets. That is, the translated milestones in the pamphlets work to normalize non-English speaking families into a Westernized worldview, rather than to reflect their cultural-linguistic practices.

The information in the pamphlets for anything other than a “pass” emphasizes the unlikelihood of the baby having a hearing loss (therefore no reason to worry), while at the same time warning parents that an undetected hearing loss could lead to delayed language, which could lead to behavioural and emotional problems, which could lead to problems in school (some reason to worry). These pamphlets present the possibility of dire consequences to impart the importance of continued screening and assessment, while the emphasis on the unlikelihood of a hearing loss alleviates concern over those potential dire consequences. The next few sections examine how...
parents are governed to follow through with further screening and assessment by a particular presentation of deafness and language in the screening texts.

### 4.2 Pass at risk result: No reason for concern…but there is a risk

Some babies who pass the screening but are categorized “at risk,” get a “Pass at risk result.” According to IHP procedure documents, “at-risk” babies include those who spent more than 48 hours in the Neonatal Intensive Care Unit (NICU) and are at risk for progressive hearing loss (Ontario Ministry of Health and Long-Term Care, 2001). Oxford Dictionary defines risk as “a situation involving exposure to danger,” or “the possibility that something unpleasant or unwelcome will happen.”

Using the word “risk” for the potential of hearing loss presents hearing loss as an unpleasant, dangerous, unwelcome medical problem to be concerned about, and the child-at-risk “comes to represent the potential for loss” (McGuire, 2016, p. 131). The pamphlet outlines those risk concerns as relating to language, behaviour, emotional health and school success.

The sample script for “Giving a pass at risk result” informs parents that, “Baby passed, everything’s OK…but because of the risk factor we do want to check again” (Sinai Health System, 2012). Like the pass result, “everything’s OK,” suggests that everything may not have been OK if the baby had not passed. According to the script and the pamphlet, a baby who

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passed the screening but is deemed at risk will be monitored with a follow-up screening (to be arranged by the IHP at the “appropriate time”) and parents are expected to also closely monitor the baby’s speech and language development for any signs of hearing loss. The IHP monitors hearing directly with a follow-up screening, and parents are expected to monitor hearing indirectly by diligently monitoring speech and language development as indicators of a potential hearing loss.

As there is a “risk” of hearing loss, “…a small chance that a hearing loss may develop over time,” the pamphlet for babies at risk emphasizes the importance of finding a hearing loss early to mitigate the negative effects that may arise from unidentified hearing loss (Ontario Ministry of Children and Youth Services, 2014c). As this “at risk” group is more likely to develop hearing loss than the “pass” group, and the IHP wants to ensure parental follow-through with subsequent screening, there is information in the pamphlet about the benefits of early identification. The pamphlet informs parents that finding the hearing loss early means services can be accessed early:

> When hearing loss is found early there is more time to take advantage of all the services that are available. Most deaf and hard of hearing children whose hearing loss is identified early, and who receive the support they need, will have the same chance to develop language skills as other children their age. (Ontario Ministry of Children and Youth Services, 2014c)

The pamphlet informs parents there are many services available to help with learning language, and parents must use these services, beginning as early as possible, for their child to have a “chance” of developing language like ‘normal’ children, and “most [other] deaf and hard of hearing children.” If the parent does not follow the IHP’s recommendations, their child may be one of the few deaf and hard of hearing children who do not have the same chance to be like other children, since as the above quote indicates, “most” participate in the chance to be like
others. The risk of not identifying the hearing loss early enough for the baby to have the same chance as hearing babies is used to induce parents to continue with screenings. The risk of not getting early needed language support makes the small chance of hearing loss an urgent concern.

It is significant that “chance” has both negative and positive meanings within the pamphlet. For babies at risk, there is “a small chance that a hearing loss may develop over time,” but finding out early will give these children access to services and “the same chance to develop language skills as other children.” This duality of chance works to induce parents to access the services, both the screening services and follow-up audiology and speech and language services if needed. Parents are told to worry - but not too much, just enough to go for the testing - about the potential risk of hearing loss, but not to worry if there is a hearing loss, because finding it early and getting the needed support mitigates the problem of delayed language development, if supports are utilized. The duality of chance as risk and chance as opportunity provides an interpretive frame on deaf subjectivity. The materialization of hearing loss is established as both something to be feared (which is already based on the assumption parents will interpret hearing loss in a negative way) and something that can be fixed, producing meanings of deafness that manage parental action. That is, parental action is managed through conflicting meanings of “chance,” which then manage the assessment and interventions their baby will receive, all while maintaining hearing loss as a risk worth worrying about. The IHP’s assertion of bio-power, “the organization of power over life,” seeks parental cooperation in the identification and treatment of any possible hearing loss (Foucault, 1978, p. 139). Within this duality of chance, it is difficult to consider hearing loss as anything other than loss or a problem in need of fixing.

As the pamphlet compares deaf and hard of hearing children with “other [hearing] children their age,” language skills seem to refer specifically to spoken language skills. This assumption is
further supported by the use of “speech” along with “language” throughout the pamphlet. Speech and language are described as both potential developmental concerns that may arise from hearing loss AND as indicators for potential hearing loss. Screening may prevent speech and language delays through early identification of hearing loss; but if screening does not ‘catch’ the hearing loss, then speech and language delays may indicate there is a hearing loss. Language can serve as an indicator, making it seem as if the hearing loss is the main ‘problem,’ but the potential for delayed language is also presented as the main reason for identifying hearing loss early (so that language problems can be prevented). This circular relationship between speech, language, and hearing presented in the pamphlet, places the focus on spoken language development. From the beginning of the screening process, there seems to be no consideration (implicit or explicit) that language development could refer to anything other than spoken language development. What can be imagined as language and communication is precisely governed by how the IHP presents information to parents via the pamphlets.

As with the pass result, the sample script in the training video for the pass at risk result encourages parents to compare their child’s speech and language development with the checklist: “As long as he’s meeting the checklist then everything is great, if you ever find that he’s not meeting the checklist then give us a call anytime” (Sinai Health System, 2012). Language is again conceptualized as a process that follows a certain developmental sequence and timeframe. ‘Normal’ (as defined by the milestones) speech and language is “great,” whereas deviations from the checklist indicate all is not great and help may be needed. As noted by Gibson, Teachman and Hamdani, “Developmental norms always and already construct disabled children as failed children, as those who require interventions in the hopes that they can approximate the normal as closely as possible” (2016, p. 80). In this way, the developmental checklists in each
pamphlet construct deafness (and/or non-normative speech and language) as failure to be habilitated by the IHP.

4.3 Refer result: Unlikely reason for concern

4.3.1 Passing as the goal of screening

When the baby does not pass the hearing screening, and does not have any risk factors, they are scheduled for a repeat screening in a couple of weeks and parents are told a hearing loss is unlikely: “We didn’t get a pass today…it doesn’t mean that there’s a hearing loss…” (Sinai Health System, 2012, italics added). Parents are told that waiting a couple of weeks can give time for any fluid or debris in the ears to clear “so we can have a better chance of passing” (Sinai Health System, 2012, italics added). The act of passing is presented as a collaboration between the screener, the infant, and the parents, with a pass result the goal of the test, and perhaps the goal of the program. There is no mention by the screener of what happens if the baby does not pass the second screening. This avoidance of the possibility of another refer result along with the judgement that a pass is the desired outcome, presents hearing loss as an unthinkable problem that is connected to a professional “we” who do not want or expect the problem to materialize.

The paradox of hearing loss being presented as unthinkable within a program whose purpose is to identify hearing loss, demonstrates how hearing loss is only included as an excludable type (Titchkosky, 2007).

A deep provocation lies in the fact that the very ways that disability is included in everyday life are, also, part of that which structures the continued manifestation of disabled people as a non-viable type. It is, for example, provocative to think about how disability is both excluded and included simultaneously in the
interstices of our lives, or included as an excludable type. (Titchkosky, 2007, p. 5)

The IHP’s screening of over 90% of babies born in Ontario includes deafness in the everyday lives of newborns and parents (and hospital staff, and IHP professionals), yet at the same time, deafness is excluded as a possible outcome of screening. The possibility of permanent childhood hearing loss is the justification for screening, yet the very condition that makes the screening necessary is presented to parents as an inconceivable outcome during the screening process when the child receives a refer result. Making deafness unthinkable in this way is reflective of society’s desire for normalcy, and it makes habilitation (i.e., making a deaf child to hear and speak) the only acceptable action in response to a deaf diagnosis, should there be one, in order to recover normalcy. Other ways that deafness is included as an excludable type will be discussed throughout the chapter.

Babies who do not pass the screening and have identified risk factors bypass the second screening and are referred directly for a hearing assessment with an audiologist (“Refer to diagnostic”). The demeanour of the screener on the training video was notably different when delivering this result. She slowed down her speech and looked empathetic and concerned, while still informing parents that, “it doesn’t mean there’s a hearing loss” (Sinai Health System, 2012). The screener did not mention the milestones checklist for this result, although it is included in the pamphlet.

The pamphlet for the ‘refer to diagnostic result’ is titled: “Your baby needs a hearing assessment” (Ontario Ministry of Children and Youth Services, 2014d) (see Appendix H). The pamphlet has been replaced as of May 3, 2018 with a link to a webpage that includes information about a new “expanded hearing screen” that includes a “hearing loss risk factor blood spot screen”
pamphlet informs parents again that, “Most babies who receive a refer result have normal hearing.” The pamphlet briefly describes the testing that will be done, the right time to do the testing and how to prepare the baby for the test. The possibility of hearing loss is mentioned for the first time in this pamphlet, but babies with hearing loss continue to be presented as the rare exception, “Most babies are found to have normal hearing. If your baby does have a hearing loss, the audiologist will direct you to the services and supports that are available to help you and your child” (Ontario Ministry of Children and Youth Services, 2014d). Hearing loss is presented as a problem, a rare anomaly in need of help in the form of professional services and supports. There is no other information given in the pamphlet about hearing loss or what supports and services are available, only that if identified, such services will be necessary.

The lack of further information about supports and services, along with a focus on the likelihood of normal hearing, marginalizes the very people the screen is set up to “help” (“most babies…” versus “if your baby…”). In reassuring parents their babies will likely have normal hearing, what is said about the babies who do have hearing loss? Babies with hearing loss seem like an afterthought, included only for their potential to be normalized with biomedical supports and services. Titchkosky explains, “Disability needs to be manufactured and included as an exclude-able type if current governing conceptions of the normal citizen, normal participant, and normal worker are to be maintained” (2007, p. 151). Parents come to the screening process already

26 On the newer webpage, this information is re-worded to remove the direct comparison to “normal” hearing: “Only a small number of babies are found to have hearing loss” (http://www.children.gov.on.ca/htdocs/English/earlychildhood/hearing/your_baby_needs_hearing_assessment_phase_1.aspx). Instead of comparing their child to “most” babies, the parent whose child has a hearing loss becomes one of the small number. This wording does not outright exclude hearing loss as much as the original wording; however, hearing loss continues to be represented as unusual and out of the ordinary.
familiar with a governing conception of deafness as problem which the screening texts maintain. Through the way information is presented in the pamphlet, babies with hearing loss are an excludable type, briefly mentioned only in reference to the IHP services that can assist them in becoming ‘normal.’

As with the pass and pass at risk pamphlets, the refer pamphlet includes developmental milestones so parents can “pay close attention to your baby’s speech and language development” to catch any “problems with speech and language development” as they may be “a sign of hearing loss” (Ontario Ministry of Children and Youth Services, 2014d). Parents are therefore placed in a position as screener for their child’s potential hearing problems while awaiting the audiological assessment; they are to compare their child’s development with the ‘normal’ developmental milestones in the pamphlet for clues as to whether their child may be deaf. Such expectation of ‘paying close attention’ demonstrates in a material way, how our society would have us monitoring ourselves and our children. Although parents are expected to pay close attention, how parents are intended to act on any observations of problems is not made clear at this point. Such paying attention seems to serve the purpose of preparing parents to answer questions about their child’s development at the diagnostic audiology assessment, to provide the audiologist with more information about how the possible hearing loss is manifest. For children referred to audiology assessment then, the demand for parents to pay attention seems to be for the benefit of the audiologist in making their possible diagnosis.

As will be discussed further in the following section, two parents I interviewed became concerned about their child’s hearing at this point and began to “pay close attention” for signs of hearing loss, whereas most parents assumed their child would be one of the “most babies” with normal hearing, and subsequently did not give the upcoming audiology assessment much thought. The IHP’s management of parental worry is therefore experienced differently by
difference parents. I now examine parental experiences with the screening process, before turning to an analysis of the texts presented to parents upon the identification (diagnosis) of hearing loss.

4.3.2 Parental experiences with screening

Through parental interviews, I discovered how parents make sense of a diagnosis of hearing loss and that the IHP’s representations of deafness and language at the time of screening restricts the possibility of sign language as a legitimate option for communication between parent and infant. I interviewed 12 mothers of 13 deaf and hard of hearing children from 18 months to 10 years of age. Five had recently been discharged from the IHP or were about to be discharged, eight were four years old or younger and still receiving services. Unlike most research with deaf and hard of hearing children, I included parents of children who have other disabilities such as deaf/blind and cerebral palsy, and two of the families spoke a language other than English in the home. A comprehensive description of my participants and interview procedures can be found in Chapter 2.

In general, parental reports of the screening process were consistent with what was described by the IHP screening texts. When asked to tell me about their experiences with their child’s hearing screening, most parents, without prompting, recalled that the screener told them not to worry about the failed screening because it was most likely due to fluid build-up in the ears. For example, Rebecca27 was not present for her son Thomas’s screening as he was in the Neonatal Intensive Care Unit (NICU) at the time. She recalled the NICU nurse telling her about the refer

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27 Pseudonyms are used for all parent participants and their children.
result when she came into the NICU the day after screening: “I wouldn’t worry about it, a lot of kids fail their newborn screening test and it’s not a big deal, they have fluid, they have like embryonic fluid in their ear” (Rebecca, mother of Thomas). Vivian reported that she was told her daughter did not pass the screen because of the amount of blood and mucous in her ears, and she was not referred for a second screen, “’Oh well she’s just full of mucous don’t worry about it,’ and away they went and we never heard from them again” (Vivian, mother of Julia). In Vivian’s case, the screener assumed the refer result was due to mucous and did not follow the IHP protocol to refer for a second screening to assess the potential risk of hearing loss. Before being told it was likely fluid in the ears, Angela, mother of Emily, recalled the screener thought there may have been a problem with the machine or technician error and Emily was sent to a different clinic for the second screening test. Similarly, Heather reported the screener presented the refer result as surprising and unusual, and repeated the test right then to be sure the result was accurate.

All the parents told me the screener reassured them a refer result did not mean there was a hearing loss. Even though Courtney’s infant, Sydney, had aural atresia, a physical indicator that lower hearing levels were likely, she too was told the refer result did not necessarily mean hearing loss. This discourse continued after the second screening done a few weeks later, as parents stated they continued to be told that a second refer result was likely due to fluid in the ears. For example, Heather told me she was stressed about other health issues her son was experiencing at the time of the second screen and recalled being visibly anxious when Wyatt received another refer result. Looking back, she thought the screener had tried to reassure her and ease her anxiety by telling her it could just be a “false positive” or due to fluid in the ears.

Reassuring parents to have them come back for the second screen without being too worried exemplifies the emotional component of what Mauldin has termed “anticipatory structures”
which are used by professionals “to encourage and maintain compliance” (Mauldin, 2016, p. 28). As Mauldin explains, “Anticipatory structures are persons, practices, and protocols in the clinic that are already in place and are triggered by a particular event and deployed to reduce parents’ resistance to medical interventions” (2016, p. 28). I would add that some anticipatory structures, such as reassuring parents of the unlikelihood of deafness throughout screening, also act to reduce professional angst: such managing of parental worry in turn makes parents easier to manage. These anticipatory structures are in place in the IHP under the belief that managed worry will help to ensure parents follow up with the second screening and diagnostic audiology if needed, without causing undue alarm. It is likely the screeners themselves do not consciously consider how deafness is being excluded, after all, they work within all-encompassing governing conceptions that already exclude disability, and are following IHP protocol. Although downplaying the potential of hearing loss reflects the quantitative aspects of screening and diagnosis, as many infants who are referred to diagnostic are not deaf or hard of hearing, it also reflects a paternalistic view common within biomedical discourses, that parents would not be able to ‘handle’ the potentiality of hearing loss at this point. It also in turn reflects a biomedical view of deafness, and disability more generally, as something negative that must be ‘handled.’

As well as governing parental action, the IHP’s anticipatory structures manage parental worry, while letting parents know that continuing with assessment is the right thing to do with their worry, in a way that makes a deaf diagnosis an excludable type.

Many of the parents I spoke with recalled feeling reassured when they were told hearing loss was unlikely and they were therefore not worried when their child failed the first screening, an indication that parents may have been worried had hearing loss been likely (i.e., parents come to the screening already with their own negative notions of disability). Some parents began to worry when their infant did not pass the second screening, although continued assurances that
their child’s hearing was likely normal decreased parental worry. For example, Melissa told me she did not even consider Beckie could have a hearing loss, as she was told the second screen was likely failed again due to fluid in the ears, and she felt she entered the audiology appointment unprepared for the outcome.

They just kind of tell you, ‘Yeah it’s pretty common, it’s usually fluid, don’t worry about it.’ So we honestly didn’t, like I really didn’t think, I thought, ‘oh yeah, it’s fluid not a big deal,’ it didn’t even cross my mind that it could be more than that…there was no thought in our mind[s] that she couldn’t hear us.

(Melissa, mother of Beckie)

Similarly, Angela told me, “They never really brought up the potential that hey, this could be hearing loss.” Priya however recalled panicking when her son did not pass the second screen despite the screener’s reassurances, and she began to pay attention to his responses and noticed he did not respond to sounds.

With the exception of Priya and Heather who were concerned after the second refer result, the IHP’s discourse worked to reassure parents their child likely did not have hearing loss. The IHP accomplished their goal of ensuring parental follow-up while keeping parents calm and not causing stress, but it did so by making deafness an unthinkable outcome. Parents were reassured not because deafness was presented as an acceptable way of being, but because they were told their child likely did not have hearing loss.28 Presenting deafness as unthinkable alleviated anxiety only because it was assumed that such a diagnosis would cause anxiety; that is, the IHP’s presentation of deafness as unthinkable worked to reassure parents because deafness (and disability) are already established as negative things in society. Parents therefore expected to

28 That parents followed through with assessment despite not expecting the diagnosis the assessment was meant to identify, demonstrates how the bio-power of medical imperatives can inform social action.
come out of the audiology appointment being told their child did not have hearing loss, but when that did not happen, they then faced what had been presented (and already thought of) as the worst possible outcome. How the parent participants came to make sense of the materialization of deafness at diagnostic audiology testing (and after deafness had already been made meaningful as an unthinkable outcome) is explored in section 4.4.1 below, and a more detailed discussion of the management of worry follows in section 4.5. I first examine the IHP texts that are shared with parents at the time of diagnosis.

4.4 Hearing loss identified: No concern, help is available

The pamphlet titled, “Your baby’s hearing: Does your child have a hearing loss?” (Ontario Ministry of Children and Youth Services, 2014e) explains the need for several hearing screenings and tests, how hearing is tested, why it is important to test at an early age, and what happens if a hearing loss is identified, including a summary of the services provided after identification (http://www.children.gov.on.ca/htdocs/English/documents/earlychildhood/hearing/hearing/Hearing-EN.pdf; Appendix I). Hearing loss is referred to as a “hearing problem” in the first line of the pamphlet. This pamphlet provides more detailed information about hearing than what is provided in the other pamphlets (e.g., there can be different types and degrees of hearing loss). The pamphlet informs parents that the audiologist will complete a hearing test and will “explain the details of the hearing loss” including:

The type of hearing loss; the sounds your baby can hear; the sounds your baby may not hear or have difficulty hearing; how the hearing loss may affect speech and language development; the types of hearing technology that could help your baby hear; support services made available to you by IHP, including access to a FSW who can provide counselling and support and help you find other resources
you or your child may need. (Ontario Ministry of Children and Youth Services, 2014e)

The “details of the hearing loss” include much more than an explanation of the physical hearing loss; deafness has already been understood as a problem and the pamphlet makes it clear that a child with an identified hearing loss (and their family) will need support services and resources to deal with the problem. Deafness as presented in the pamphlet is something testable, quantifiable, medically knowable and a cause of speech and language problems, making deafness a problem in need of hearing technology and other supports and services. The focus on sounds, how speech and language could be affected, and helping the baby to hear, assumes that parents will want/should want their child to learn spoken language. There is an inherent assumption of the superiority of spoken language simply by omitting any mention of sign language in the main section of the pamphlet, even though many IHP documents purport to present information about communication options to parents in an unbiased manner (Ontario Ministry of Health and Long-Term Care, 2001, p. 6).

In addition, as the pamphlets indicate the audiologist is the professional who provides all the information about hearing loss and speech and language development to parents at the time of identification, a neutral discussion of spoken language versus sign language does not seem possible. Regardless of any well-meaning intent to be unbiased, it can be argued that neutrality is not possible, and is not a reasonable expectation; an audiologist would not present sign language as an option in the same way they would provide information about hearing technologies and auditory-verbal therapy. The professional bias of IHP service providers will be further addressed in the following
chapter, along with a problematization of the IHP’s policy that information should be provided in an unbiased manner.

The middle section of the pamphlet asks, “Why is it important to identify a child’s hearing loss so soon after birth?” (Ontario Ministry of Children and Youth Services, 2014e). Rather than an inclusive answer explaining the importance of identifying a hearing loss in relation to access to language, the answer focuses on the exclusive importance of hearing to learn to communicate. The focus on hearing rather than language further demonstrates the IHP’s emphasis on the importance of hearing technology and spoken language, significantly affecting how deafness and language are made meaningful. The absence of hearing is made to be the most important factor affecting communication; hearing and communication are tied together in a way that makes non-verbal communication (or communication that does not rely on hearing) to be irrelevant. “Most babies are born ready to hear their parents’ voices and the sounds of the world around them. Babies with hearing loss have the same need to communicate as babies with normal hearing” (Ontario Ministry of Children and Youth Services, 2014e). These two sentences are a notable formulation of what hearing is supposed to mean: babies with hearing loss will not be able to communicate like hearing babies since they cannot hear, although such communication via hearing is still important to them. The bio-political rendering of the duality of chance is evident again here. With the small chance of hearing loss now confirmed as reality, the IHP texts present hearing as important for communication such that early intervention is assumed to include hearing technologies to ensure the child has “the same chance to develop [spoken] language skills as other children” (Ontario Ministry of Children and Youth Services, 2014c).

Although it could be argued that “need to communicate” does not disregard manual communication and sign language, the first sentence describes hearing babies and how they are
ready to hear sounds, and the second sentence describes a need to communicate, inextricably linking hearing and communication together. In addition, hearing parents may not be familiar with sign language, and would not automatically think of sign language as fulfilling a “need to communicate” in the same way they would automatically think of spoken language as fulfilling this need. Therefore, this text seems to produce and disseminate a certain knowledge that babies with hearing loss will need to first gain access to hearing to fulfill the need to communicate, and that communication refers to spoken language. Such an argument is further supported by the repeated mention of hearing technology, and the simultaneous lack of mention of sign language in this section of the pamphlet.

This answer to the question of why it is important to identify hearing loss soon after birth is a social action that orders the meaning of hearing and communication as well as the relations between the subjects of hearing’s absence (both the infants and the parents) and other people. Hearing babies are ready to be present to others and to have others presented to them. Babies that do not hear are not “born ready.” There is an ordering of hearing as necessary to be ready for communication, placing the onus on the baby who was not born ready to “get ready” and conform to the norms of hearing society, rather than on considering hearing society as “not ready” to communicate in ways that would be meaningful to a deaf baby. Parents and infants are made subjects of the absence of hearing and communication, and hence subjects of the technologies that can allow for hearing and communication, with the assistance of the IHP.

Although the onus is placed on the baby to conform to hearing society, the rest of the answer to the above question in the pamphlet puts the focus on IHP professionals rather than the baby and family. The “we” that was apparent in the screening script reappears and exemplifies the duality of chance; now that “we” did not get the pass result and “we” identified a hearing loss, “we” can now work together to solve the problem: “Identifying hearing loss as soon as possible helps IHP
professionals working with your family ensure family-centred services are in place to provide your child with the opportunity to develop language and communication skills” (Ontario Ministry of Children and Youth Services, 2014e). Hearing loss also therefore means “work”; work for the professionals and work for the child and family to make the child (who was not born ready) to become ready to hear. The irony of early identification to help “IHP professionals” while in the same sentence stating the importance of “family-centred services” calls into question who is being “helped” and what is meant exactly by “family-centred services.” Many of the IHP texts state the importance of family-centred services with no clear definition of what makes services “family-centred.”

The only mention of sign language in the pamphlet is on the last page under “What is a Communication Development Plan?” The pamphlet explains that the Communication Development Plan is a written document outlining the decisions made by the parents based on information provided to them by professionals: “Your IHP audiologist, speech-language pathologist and other professionals will provide information to help you make decisions about your child’s communication development” (Ontario Ministry of Children and Youth Services, 2014e). Note there is no mention of Deaf adults as providers of information; speech and hearing professionals are given sole responsibility for providing parents with information about communication options. As “fully informed choice” is an IHP principle, it is therefore presumed that professionals will fully inform parents about all options, and the input of Deaf people is not needed. However, professionals who centre their work on assessing and treating hearing, speech, and spoken language problems would know more about normalizing hearing, speech and language than about sign language and Deaf culture. Both groups hold their own opinions on communication, yet the hegemony of normalcy results in the IHP favouring professional opinion over subaltern opinions. In the following chapter, I argue that hearing, speech, and
language professionals are inherently biased towards communication development strategies that focus on hearing, speech, and spoken language, and as these are some of the first professionals who provide parents with information, parents do not become “fully informed” as they do not receive unbiased information from the IHP. The bias of speech and hearing professionals towards a spoken language approach to communication, yet the provision of information regarding communication options to parents by these professionals, is an indication that the IHP’s principle of providing fully informed choice should be problematized and reconceptualized.

There is also a difference in the wording of services related to speech and language, and services related to manual communication, in the pamphlet. Services specifically related to hearing and speech development are worded as services to help the baby learn: “learning to listen; learning to use voice to communicate,” whereas sign language and manual communication are presented as devices to be used similar to hearing technology: “use of hearing technology; use of a signed language; use of manual communication and gestures” (Ontario Ministry of Children and Youth Services, 2014e). The term “use of” insinuates those services are supplementary to learning language; they are something to ‘use’ rather than something to ‘learn.’ This subtle difference in terminology works to govern parents toward a spoken language approach, whether intentional or not.

There is a lone sentence in larger font on the back page of the pamphlet that leaves parents to ponder a final statement: “Parents are important partners” (Ontario Ministry of Children and Youth Services, 2014e). This sentence situates the health professionals as the experts in control of the children’s hearing, speech, and language, while telling parents they are important partners to the professionals. From my experience as a speech-language pathologist, I recognize this as a tactic to engage parents who may otherwise expect the professionals to ‘fix the problem.’
Stating the importance of parents as partners holds the parents accountable for their child’s development, as well as the professionals. However, while attempting to engage parents, the status of the professionals as those in ultimate control is reinforced, and in the context of the pamphlet, may be interpreted as condescending.

4.4.1 Parental experiences with diagnosis – something to worry about…

The inclusion of hearing loss as an excludable type (an unthinkable, unwanted outcome) throughout the screening process, leaves those parents whose babies are identified as having a hearing loss unprepared for the diagnosis. The parents I spoke with reported that when they received the diagnosis by the audiologist, they were completely unprepared for the outcome; they were expecting to come out of that appointment being told their child could hear normally, as this is what they were led to believe, and wanted to believe, during the screening process. Upon discovering their child did indeed have hearing loss, parents recalled many feelings including: shock, sadness, uncertainty, anxiety, devastation, disappointment, a sense of loss, guilt and grief. Although the IHP intended to prevent undue stress and anxiety during screening, the reassurances of the unlikelihood of a deaf diagnosis throughout screening meant these parents upon diagnosis were now faced with the unthinkable problem of deafness.

Throughout the screening process, the diagnosis of hearing loss is established as an unlikely negative outcome, and when given the diagnosis, the presentation of deafness as a problem continues. Melissa recounted the audiologist reviewing a parent questionnaire she had filled out (one reason that ‘paying attention’ is necessary), “She just kept saying, ‘oh that’s not normal, oh that’s not normal,’” (Melissa, mother of Beckie) leaving her with a feeling of incompetence as a parent. Upon reflection, Melissa thought perhaps this was done purposely to prepare her for the possible diagnosis, “I don’t know if it was her way to be able to make you start to realize there
was something more wrong so that when she told you that there was, it wasn’t all of a sudden out of nowhere that this was being dropped on you” (Melissa, mother of Beckie). Angela recalled the audiologist frowning when giving them the diagnosis, “I remember the audiologist coming out frowning and she said, ‘Oh you know unfortunately your daughter didn’t pass, she has profound hearing loss,’ and that was a big blow” (Angela, mother of Emily). Angela then worked to make sense of the diagnosis, questioning if it was due to fluid or wax or was something that Emily, would outgrow. Angela asked the audiologist if she’d be “OK” with hearing aids, and was told, “’No, she’ll likely be a cochlear implant recipient’ and referred us on to SickKids.” Courtney recalled the audiologist being apologetic and presenting her daughter’s hearing loss as something to be sorry about.

In general, parents recalled that the diagnosis (whether deaf or hard of hearing) was presented as (and understood as) an unfortunate outcome that was not normal and not wanted, something wrong, consistent with the way deafness was presented throughout screening. This negative presentation of deafness as problem and the parents’ emotional reactions to the materialization of deafness, had a couple of the parents retrospectively empathizing with their audiologists. Melissa told me she felt sorry for the audiologists who must deliver such tragic news to parents, “I can’t imagine having that as my job, to give parents that news” (Melissa, mother of Beckie). Rebecca recalled how her son’s audiologist was fantastic, but that “It just kind of sucked that she had to be the one to tell me, ‘oh that nurse was wrong, like that this is a serious issue,’ but as far as being a good person to deliver that news, she was excellent” (Rebecca, mother of Thomas). Melissa and Rebecca’s thoughts for their audiologists reflect how devastated and unprepared these parents were to receive the ‘bad news’ their children had hearing loss.

The IHP’s presentation of the diagnosis of deaf as an unthinkable failure affected how parents emotionally responded to the diagnosis and their actions and decisions after the diagnosis.
Rebecca’s son Thomas had many health issues at birth and stayed in the NICU for over a month. Rebecca was shocked at the time of diagnosis since she was told that many children who do not have hearing loss fail the screening and her son had other health issues occupying their minds during the time of screening. She felt she was given misinformation about the screening and was not prepared for a diagnosis of hearing loss:

We had a lot to deal with when Thomas was born because he almost died on me twice in five days, but um, just there was a lot going on so we had a lot of other things to worry about and we weren’t concerned about his hearing, when apparently we should have been. So, getting that kind of misinformation and then having the audiologist tell me, “No this is a big deal,” I was kind of in a little shock at that point, because I thought like all the bad news we’re going to get we’ve gotten so we’re dealing with that, but to get another “no this is not good,” it was like, “oh shit here we go again” sort of thing, so, ya. That wasn’t good. (Rebecca, mother of Thomas)

Melissa recalled being caught off guard and was distraught and cried when the audiologist told her that Beckie had permanent profound hearing loss. The audiologist responded by telling her there were things that could be done so she would be fine, “She’s just like reassuring me that there’s lots of options and like, she’s still going to be fine, and you know there’s technology and there’s, you know there’s just lots of different things that we could do” (Melissa, mother of Beckie). Priya told me it was very difficult for her to find out her son was deaf, and that they had a difficult time accepting it; they did not tell their friends until Arinan got his cochlear implants activated when he was one year old. Heather recalled Wyatt’s first audiology appointment being one of the most stressful periods of her life. As Lauren expressed, “They do the newborn hearing screening and they fail. They do the second screen, they fail. And then you have the diagnosis of deafness and ‘I’m so sorry.’ So, it’s right from the get go, as a parent, your child’s a failure. There’s no positive in it” (Lauren, mother of Natasha).
After making deafness matter to parents as a negative outcome by establishing the diagnosis of deaf as something unlikely and unwanted, most parents were then left on their own to ponder what the materialization of deafness at diagnosis meant for their child (and to them). After diagnosis, most parents reported they had to wait a significant amount of time to get an explanation of the diagnosis or any information or support from the IHP. Although the IHP has procedures in place for parents to meet with an otolaryngologist and a Family Support Worker (FSW) soon after diagnosis, many parents told me they were given little information by the diagnosing audiologist and were not told next steps. The parents I spoke with waited weeks to months before seeing the FSW after diagnosis.

Melissa had already done research, decided on a spoken language only approach and advocated for her daughter to get services before meeting the FSW, “I think I knew more about hearing loss at that point than she did. I still don’t fully understand what her role even is” (Melissa, mother of Beckie). As Lauren noted, “it’s a long process to get the stuff started, so, they need to give parents something in the beginning” (Lauren, mother of Natasha). Vivian described her quest for answers as being frustrating and anxiety-provoking. She found the audiologist did not have the time or patience to answer her questions at the time of diagnosis and she recalled waiting six weeks for a follow-up appointment to ask her questions. Even then, the audiologist dismissed her questions as her not accepting the diagnosis when she was trying to understand it,

I asked her my questions, she would give one word answers, she would roll her eyes, she’d be like “listen, you’re just going to have to accept it. I know you don’t want to accept it, but you have to accept it.” And I’m like, “it’s not about not accepting it, I’m trying to like understand. (Vivian, mother of Julia)

Vivian described being “shell-shocked” at the diagnosis, and wanting to understand what it meant for her daughter, and the audiologist was not sensitive to her needs. She did not meet with a FSW until six months after diagnosis, “And I don’t think that any of the services along the
way helped to kind of alleviate our fears, or to answer our questions, or to predict our questions” (Vivian, mother of Julia). Many parents reported feeling they had to do their own research to make sense of their child’s diagnosis as answers were not forthcoming from the IHP. Parents also felt there was a lack of emotional support and little understanding that parents may need immediate assistance in understanding and dealing with the diagnosis.

During screening, IHP texts work to purposely disregard the possibility of a deaf or hard of hearing diagnosis to manage parental concern and ensure parents continue with screening and assessment. However, it seems that upon diagnosis, the IHP’s reassurances that they will be providing services do little to ease parental anxiety, as those services are not available right away. Once a diagnosis is confirmed, the family becomes part of the system and the IHP’s focus seems to shift from the parents’ emotional state to putting services in place by the six-month goal. This combined lack of emotional support (which is at least in part made necessary due to the IHP’s presentation and parental understanding of deafness as failure) and the time lag between diagnosis and any explanation of the diagnosis or supports and services that the IHP will provide to them, resulted in many of the parents doing their own research and deciding about communication modality for their child before even meeting with the IHP’s FSW and learning about what services would be available to them. How parental choice is constructed through the meanings of deafness and language presented by the IHP and the services that are offered is the topic of the following chapter.

Parents are guided to do the screenings and assessment and are told the importance of beginning intervention early, yet once diagnosed they must wait to find out about next steps from the IHP. Although the IHP may meet their goal of beginning intervention by six months of age, the parents I interviewed felt that any amount of time between diagnosis and further service was a suspended state of questioning and worry. Presented as an unthinkable problem that requires
supports and services from the IHP, even a few weeks delay in getting information about the diagnosis and finding out what supports and services will be available to them resulted in parental stress and worry about what deafness means to them and their child. At diagnosis, parents understood something was wrong but did not quite know what exactly was wrong and what (or if something) could be done to make it right; deafness went from an unthinkable diagnosis to *their* child’s diagnosis. This resulted in much parental stress over what the diagnosis meant for their child.

With the managing of parental worry prior to diagnosis, deafness only became thinkable when it materialized. This management limits the number of distraught parents the IHP screeners (who are not audiologists, but trained community members or hospital nurses) will have to encounter. The behaviour of the screeners themselves is managed to ensure parents cooperate along the way to the audiological assessment. As explained in a screening protocol and support document, “From the initial contact through to the completion of screening, the screener’s behaviour, style and tone can have a major effect on the family’s cooperation, giving of consent, satisfaction with the screening experience and adherence to follow-up instructions” (Hyde & Derbyshire, 2013, p. 5). The managing of parental worry is therefore also a management of the chain of command – the audiologist is the professional deemed most qualified to manage parents’ response to deafness.

It is important to point out that most of the parents interviewed talked about their child failing the screening tests, even though the IHP uses the discourse of “refer.” During interviews, a couple parents governed their own language use by noting that they kept saying “fail” when they should be saying “refer.” The IHP calls a failed screening test a “refer result,” yet parents whose children were identified as deaf and hard of hearing, understood it as their child having failed the test. For example, when recalling the results of screening, Melissa said, “They just
said that she got a refer, which we later learned refer probably means the same thing as fail” (Melissa, mother of Beckie). It can be interpreted then that the IHP’s use of the term “refer” instead of “fail” serves as an anticipatory structure that manages parental worry rather than to genuinely represent deafness as something other than failure. To present the possibility of deafness as something other than a problem, much more needs to be attended to than terminology.

4.5 Discussion: Wondering about worry

To wonder about the shape of worry seems to me to be a rare challenge. It is interesting that in our knowledge-based, technologically driven, capitalist times we are encouraged to linger as little as possible with the advent and form of worry. Ordinarily it is no one’s concern that the experience of worrying about embodiment might be more than a call for solutions to symptoms of problems. (Titchkosky, 2007, p. 109)

The pamphlets given to parents and the parents’ experiences with screening and assessment demonstrate how the IHP attempts to ensure compliance with screening, assessment, and speech and language monitoring, by organizing parental worry. My analysis thus far has led me to consider how this organization of worry (about hearing, speech, and language) does more than ensure parental compliance with hearing screening and assessment and the monitoring of their children’s speech and language. Parental compliance is needed for the IHP to meet their objectives which include: “screening of all newborns by one month of age”; conducting audiometric assessment on babies with a ‘refer’ result by three months of age; and beginning intervention, if needed, by six months of age (Ontario Ministry of Children and Youth Services, 2014a). The goal of getting all babies screened and assessed within a narrow timeframe is meant to ensure that those 3 or 4 out of 1000 children who will have hearing loss from birth are
identified and receive the necessary supports. In attempting to meet these goals, meanings of language and hearing are governed through worry, and are produced and widely distributed, not just to families of deaf and hard of hearing infants who end up using the services of the IHP, but also effectively to almost every parent in Ontario.

Parents are induced to attend follow-up screenings and hearing assessments with their baby through a carefully balanced manipulation of worry; the IHP uses the psychological matter of worry as a tool in the governance of parents. This presentation of what parents should and should not worry about constructs meanings of language and hearing (loss) and contributes to the creation of deaf and hard of hearing children’s subjectivities. When a child receives a refer result after screening, the fear of potentially delayed speech and language due to (the very slight risk of) hearing loss is used to have parents agree to further screenings and assessments, while at the same time they are reassured that, in all likelihood, their baby’s hearing will be normal, with no mention that their hearing could be other than normal. Parents are informed that hearing screening and follow-up hearing assessments mitigate the risk of speech and language delay, because if their baby does have hearing loss and it is identified early, needed help will be available right away. While the possibility of dire consequences (behavioural and emotional problems and problems in school stemming from language delays caused by hearing loss) is used to impart the importance of screening, the emphasis on the unlikelihood of a hearing loss alleviates worry about those dire consequences. This combination of chance and worry is a bureaucratized gamble, well-managed to lead to the desired result of making deafness a problem that parents can manage with hearing technologies and spoken language, for their child to become more like a hearing, speaking child.

Although the main purpose of the IHP is to identify babies with hearing loss as early as possible, the repeated assurances in the pamphlets of the unlikelihood of hearing loss seems to focus on
the parents of infants who do NOT have hearing loss, while excluding those who do. The identification of these few children is the main objective of the IHP and the purpose of the screenings, yet the discourse of screening emphasizes that these children are the problematic, unwanted, exceptional cases. In addition, the severity of the potential ‘problem’ of hearing loss is emphasized through the push for everyone to be screened. By focusing on the rarity of hearing loss and its negative impact on speech and language, parents of babies identified with hearing loss are made aware their baby is not like “most babies”; they receive the message their baby is not ‘normal.’ The subjectivity of a deaf or hard of hearing baby is created before the baby is even identified as such. Hearing loss is framed from the beginning of the IHP process as a negative outcome, with negative consequences, a risk that must be monitored. The negative presentation of hearing loss and language delay as risk produces entirely different meanings of deafness and language than had the information been presented in a more positive manner. As Titchkosky notes, “Worry is a form of social action informed by the meanings a culture enacts for and on embodied experience” (2007, p. 109). Being told not to worry about a failed screening due to the unlikelihood of hearing loss sets up the materialization of deafness as a valid worry, a worry that can then be placated through actions to fix it. Cultural representations of hearing (loss), speech, and language, are represented in the way worry is governed and the way parents are governed through worry.

4.5.1 Disciplining the family

For parents whose babies “pass” the screening, they can feel relief with the assurance of normality, that everything is fine. There was a very slim possibility their baby had a hearing loss, which if left unidentified, could create problems with language development. The IHP introduces this worry to all parents, to ensure parents will consent to the screening. For most parents, a pass on the screening test can subsequently alleviate the immediate worry of hearing
loss. However, this reassurance may be short-lived, as parents are then told hearing loss could develop over time, and speech and language problems could become apparent; thus, some degree of worry must still continue. Worry now functions to ensure parents will monitor their children’s speech and language development to catch such potential problems as soon as possible.

Recall Titchkosky’s suggestion that, “the experience of worrying about embodiment might be more than a call for solutions to symptoms of problems” (2007, p. 109). In this case, parents are made to worry about the potential future problems of hearing loss and language delay so they will seek solutions (i.e., contact the IHP for assistance) to appease their worry. Through worry, the IHP governs parent-child interactions in an attempt to ensure that hearing, speech, and language proceed according to standard socio-linguistic norms. The IHP therefore does more than provide needed services to babies identified with hearing loss; the IHP asserts bio-power over all Ontario parents and infants that participate in screening, supported by the medicalization and standardization of hearing, speech, and language.

With a pass result, the surveillance of infant language development shifts from the disciplinary power of the IHP to parents, so that parent-child relations “become ‘disciplined’ … which have made the family the privileged locus of emergence for the disciplinary question of the normal and the abnormal” (Foucault, 1977, p. 216). The disciplining of the family again calls into question the meaning of “family-centred,” a central tenet of the IHP. Parents are told how to watch for signs of ‘the abnormal,’ any deviation or delay from the norm, and to seek professional assistance if ‘the abnormal’ becomes apparent. This disciplinary surveillance reinforces the social construct of standardized speech and language and reflects an overarching language policy: there is only one right way to speak and one right way to learn language.
4.5.2 Alleviating the ‘problem’

What about the families whose babies do have an identified hearing loss? These parents have reached the point most parents end up not having to worry about; they are the parents that must move past worrying about the possibility of hearing loss, to worrying about ‘what to do now?’ After establishing hearing loss as an unlikely concern and an unimaginable outcome of assessment, the IHP pamphlets shift the focus of parental worry from the potential of hearing loss, to the possible solutions to hearing loss. Upon identification, the IHP attempts to alleviate the parental worry that has been created, by emphasizing the supports and services available to assist with hearing and communication development. This is the flipside to the potential language development problems that accompany unidentified hearing loss: the hearing loss has been identified early, consequently, language problems can now be avoided. Even though their baby does not have ‘perfectly normal hearing,’ there is little need to worry as something can be done; the IHP is there to help: “This worry is abated somewhat since it is thought that medical, rehabilitation, or other forms of professional intervention can make these abnormalities normal or, at least, as normal as possible” (Titchkosky & Michalko, 2009, p. 5). However, the urgency of the concern created by the IHP’s presentation of hearing loss does not alleviate parental worry upon the materialization of deafness, but rather has parents anxiously searching for information while waiting for the IHP to meet its goal of delivering intervention by six months of age.

The proposed solution for infant hearing loss is to take advantage of the supports and services offered by the IHP, but as Titchkosky (2007) notes, the organization of parental worry does more than seek solutions. The worrying has been organized within a medical model of hearing, speech, and language, producing meanings of hearing loss as risk, and language as something to be monitored and normed. There is nothing good about being deaf imparted during screening;
hearing loss is made to matter as the unthinkable, problematic outcome. As Lauren, noted, “There’s no positive in it.” Lauren suggested a more positive presentation of the diagnosis could have changed her reaction to it, “To have that support there going not ‘I’m so sorry that this has happened to you’ but ‘congratulations because now you’re on a different journey,’ maybe might have changed my mindset a little bit” (Lauren, mother of Natasha). The only positive outcome conveyed by the IHP is that the IHP professionals can now help the ‘identified’ child hear and learn language. In limiting the outcome to the need for supports and services, deaf children and their families are presented as consumers of normalizing services and the disciplinary control shifts back to the IHP professionals. There is no possibility presented that perhaps the families would not want to be normalized, or may not be worried about solutions, as could be the case for Deaf parents.

There are many ways the texts work to frame worry: worry enough to consent to screening and assessment, but don’t worry too much as in most cases babies have normal hearing; there is nothing to worry about now, but there could be later; worry enough about later so you are sure to monitor baby’s speech and language; don’t worry if baby has a hearing loss, because help is available. All of this worrying organizes the relations between parent-child and parent-professional, while creating subjectivities for deaf and hard of hearing children, as well as children whose speech and language does not follow the standardized norm, through the meanings of hearing, speech, and language produced and disseminated by the texts. Through worry, parents are governed to think of deafness as a negative outcome (which is successful because deafness is already widely conceptualized as a problem), but one that can be remediated through testing, waiting on professional (re)engagement, and eventually through using hearing technologies.
In this chapter, I have focused on the texts that are shared directly with parents during the IHP screening and assessment process and demonstrated they present negative meanings of deafness, which govern parental worry to ensure compliance with screening and assessment while hierarchizing spoken language over sign language. In the following chapter, I turn to an analysis of professional position statements and IHP development and implementation documents to gain an understanding of the political and bureaucratic contexts in which these pamphlets were developed. The following textual analysis, combined with an exploration of parental experiences after diagnosis, allow me to delve deeper into meanings of deafness and language and to examine their material effect through their construction of parental choice.
Chapter 5

5 Constructing parental choice

It is the policy of the Infant Hearing Program that parents of babies identified as deaf or hard of hearing will have access to unbiased information on all methods of communication available to their child. It will be the decision of the parents as to what method(s) of communication their child will use and it will be a fully informed choice.

Parents will be provided with counseling and support as they adjust to the knowledge that their child is deaf or hard of hearing and go through the decision making process to choose a communication method. They will be provided with information on all methods of communication and on the various stakeholders that represent the different communication options. (Ontario Ministry of Health and Long-Term Care, 2001, p. 6)

In Chapter 4, I demonstrated how the texts of the Infant Hearing Program (IHP) screening procedures produce normative meanings of hearing, speech, and language that work to govern parental worry and action. This chapter is an extension of that analysis, where I examine how other IHP and related documents and procedures organize meaning and social action for parents, specifically related to decisions about the type of interventions their child will receive. This analysis demonstrates how the IHP constructs parental choice through the way meanings of deafness and language are presented to parents and the type of services that are offered. I begin the chapter by considering how the IHP’s policies and procedures reflect the underlying principles of rehabilitation and medical professional organizations. The principles endorsed by Speech-Language and Audiology Canada (SAC) and the Canadian Pediatric Society provide a socio-political context important for the interpretation of IHP texts, as audiologists are the professionals that tell parents the result of diagnostic audiology testing and are the first to discuss their options with them, and speech-language pathologists provide therapy. In addition, pediatric otolaryngologists assess children and provide a formal diagnosis before any treatment
is begun. After establishing the position of the professionals that provide IHP services, I then consider how IHP texts construct parental choice by exploring how parents perceived the communication options they had for their children. The chapter concludes with a discussion of how the deaf/hearing and sign language/spoken language binaries presented by the IHP can be deconstructed through parental experience.

5.1 Professional position statements

Audiologists and speech-language pathologists in Canada are regulated health professionals governed by provincial regulatory colleges of which they must be members in good standing to practice in their respective province (e.g., the College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO)). There are also provincial and national associations audiologists and speech-language pathologists are encouraged to join to support their professions, although membership is not mandatory. Speech-Language and Audiology Canada (SAC) is the national association “that supports, promotes and elevates the professions of our members and associates…Through this support, we champion the needs of people with communication disorders” (SAC, 2018). SAC promotes the professions, offers national clinical certification upon passing an exam, and offers opportunities to learn from and connect with others in the profession. SAC also provides professional resources, including position papers on both universal newborn hearing screening (UNHS), and cochlear implants (CI) in children. How the professions of audiology and speech-language pathology are represented by the association provide much information about the ideologies that frame professional practice and how speech, language, and hearing are made meaningful. In this section, I focus specifically on how professional associations present language and hearing in the context of deaf children, as this relates to the meanings of language and hearing that frame the practice of the professionals who
provide services within the IHP. The Canadian Paediatric Society is also included in this analysis, as infants identified as deaf or hard of hearing must be assessed by an otolaryngologist before treatment begins, and as pediatricians are regularly involved in the medical and developmental care of infants and young children.

SAC (previously CASLPA) first developed a position paper in support of cochlear implants in 1995 and updated their position paper in 2006. A review and update of the original position paper was stated as necessary because “the evolution of technology and the compilation of empirical data have clearly demonstrated the efficacy of these devices in allowing children with bilateral severe to profound sensorineural hearing loss to develop oral communication skills” (CASLPA, 2006, np). The 2006 position paper provides: a rationale for SAC’s position on cochlear implants in children; recommendations to ensure CI provides the possibility of “improved access to sound and oral communication”; and background information about CI, candidacy information, and outcome expectations (np). A brief analysis of this position statement provides information about how audiologists and speech-language pathologists are expected to promote CI for deaf children while demonstrating how meanings of language and deafness present spoken language as the only desirable language outcome.

Throughout the position paper, there are repeated references to cochlear implants being of benefit and improving “auditory-only speech understanding” (i.e., the understanding of speech without lip-reading or manual gestures or signs). This can be understood as a ‘progression’ from the earlier days of CI when they were promoted as improving the accuracy of lip-reading. The repeated mention of “auditory-only speech understanding” can be interpreted as SAC’s support of the use of auditory-verbal therapy, or another speech-language therapy program that does not include the use of manual signs or sign language. This is further reinforced by the association’s recommendation that “cochlear implantation be followed by a comprehensive (re)habilitation
program emphasizing the development of listening skills within a communication context with a focus on oral communication” (CALSPA, 2006, np). Although the text acknowledges there is significant variation in individual outcomes after CI, this is later followed by a claim that despite this variability, “all cochlear implants have been shown to be effective in improving auditory-only speech understanding” (CASLPA, 2006, np). It is evident that SAC considers the primary benefit of CI to be an improvement in auditory-only speech understanding (no matter how significant the improvement may be), rather than access to sound. Cochlear implants are therefore supported by SAC in such a way to make sign language irrelevant and counterproductive to the focus on auditory-only speech understanding.

There is no explicit mention of what SAC’s official position is with regards to sign language and cochlear implants, but as sign language is absent from the position statement, it is made irrelevant by its exclusion and the focus on “auditory-only.” The only reference to Deaf culture is a cautionary statement that “hearing professionals should be familiar with the position and concerns of the Deaf culture to provide counselling to parents, older children and adolescents on the cultural, educational, and psycho-social issues surrounding cochlear implantation” (CASLPA, 2006, np). The information is presented as necessary for reactive counselling, rather than for proactive educational purposes to assist parents in deciding whether to agree to a CI for their child. The “position and concerns” and “issues” that Deaf culture has with CI are presented as important to know to provide counseling in support of CI and spoken language; knowledge of Deaf culture and sign language in and of themselves is not presented as important to learn about, thereby situating cochlear implants in direct opposition to Deaf culture.

The position paper provides the association’s opinion in support of CI for children based exclusively on the possibility of improved auditory-only speech outcomes. How deafness is experienced by the child is disregarded and overruled by the push to develop listening and
speech skills with the CI. Deafness is presented as a problem the CI can and should ameliorate, but with no attention given to the child who would receive the CI and the ways deafness may define their unique way of being in the world. This is demonstrated by the mention of only quantitative factors related to outcomes:

Factors which may affect outcomes [of auditory-oral speech understanding] include: duration of hearing loss, amount of residual hearing, age of identification and intervention, age at implantation, status of the cochlea/cochlear nerve, other medical conditions and degree of involvement in a (re)habilitation program post-implantation. (CASLPA, 2006, np)

There is remarkably no mention of a deaf child; the outcomes relate to how deafness and the medical treatment of deafness affect the cochlear implant, rather than how the child may relate to and respond to the technology.

Michalko’s (1999; 2002) concept of estranged-familiarity is valuable for theorizing how SAC makes deafness disappear. As a blind man, Michalko conceptualizes blindness as an aspect of his estrangement from the sighted world, a world within which he must live and become familiar. He is therefore both estranged from and familiar with the sighted world, “strangeness and familiarity become ironically harmonized in their reformation as ‘estranged familiarity’” (Michalko, 1999, p. 109). (Re)habilitation, however, works to validate familiarity and eliminate estrangement; one’s sensory experiences and internal subjectivities are dismissed and devalued while being taught how to live and experience the sighted world (Michalko, 2002). SAC’s position paper on CI makes a deaf child’s estrangement of deafness irrelevant through its focus on auditory-only; estrangement is expected to disappear through habilitation into an exclusive familiarity with the hearing world. Michalko notes the danger in devaluing one’s sensory experience is that one’s sense of self may become lost in this familiarity of the expectations of normal sensation. SAC’s position paper on CI therefore makes deafness, and the deaf child,
disappear. How deafness is made to disappear for parents when their child becomes a CI candidate is discussed further in section 5.3.2 below.

SAC’s position paper in support of Universal Newborn Hearing Screening (UNHS) in Canada (2010) further demonstrates a professional bias towards spoken language for deaf infants. The position paper provides: a rationale for supporting UNHS; recommendations about what should be included in a UNHS program; and background information on permanent childhood hearing loss (PCHL) including communication outcomes, the importance of early auditory stimulation, and UNHS as a standard of care in other countries. In the position paper, SAC states “the overall goal of early detection is to identify PCHL and initiate intervention for auditory and communication development” (2010, p. 20). Furthermore, “extended periods of auditory deprivation have a significant impact on the overall brain development and sensory integration of the child” (SAC, 2010, p. 2). With a focus on auditory deprivation rather than language deprivation (either spoken or signed) that can occur from unidentified hearing loss, SAC presents hearing loss itself, rather than the identification of hearing loss, as the unquestionable problem. That is, the value of UNHS is considered to be the identification of hearing loss to prevent auditory deprivation (with hearing aids and cochlear implants), rather than to begin teaching the child a visual-based sign language. In addition, moral assumptions are being made that deaf people without hearing technologies are ‘auditorily deprived’ and have poor sensory integration and brain development. According to this text, the ‘right’ way to be deaf is to have hearing technologies provide access to sound so the child can develop to their full potential. Deafness is only considered as a deprivation to be fixed and spoken language as the only way to develop the brain, once again demonstrating the hegemony of normalcy within these professions and their intent to remove any deaf estrangement.
The association’s support of spoken language for deaf children is further clarified in the background section of the paper, where it is stated that the underlying premise of UNHS is the importance of early identification to ensure early auditory stimulation (which is necessary for developing a child’s auditory potential), and the development of “speech, language, cognitive and psychosocial abilities” (SAC, 2010, p. 3). Early identification is therefore presented as important to ensure the early use of hearing technologies for the development of auditory-oral language, and with that, cognitive and psychosocial abilities. Within this text, communication is equated with spoken language supported by hearing technologies: “coupled with advances in hearing aids and cochlear implants, UNHS has improved the outcomes for communication development for children with all degrees of hearing loss” (SAC, 2010, p. 4), effectively eliminating sign language and other non-verbal modes of communication as viable and desirable options for deaf children.

The rhetoric of parental choice prevalent throughout IHP documents is not apparent in either SAC’s UNHS or CI position papers, and the necessity of auditory-oral language development for deaf children is not questioned or presented as a choice amongst others. With the professions’ obvious promotion of spoken language, how audiologists and speech-language pathologists can provide “unbiased information” regarding the use of hearing technologies and communication modalities to parents, as per IHP policy quoted at the start of the chapter, requires interrogation. Again, sign language and Deaf culture are notably absent from both position papers; there is no mention of how early identification could mean early access to the Deaf community and a chance for the family to learn sign language while their child is an infant. Associating UNHS with early use of hearing technologies to improve deaf children’s communication prioritizes spoken language over sign language and situates UNHS exclusively within a medicalized frame. These position papers demonstrate how audiologists and speech-
language pathologists enter into relationships with parents of newly identified deaf children with professionally sanctioned guidelines against the use of sign language.

In supporting their professions, SAC narrowly interprets the benefits of UNHS and CI in a way that supports the normalizing work done by audiologists and speech-language pathologists, rather than in a way that supports deaf children’s use of any communication modality. The IHP’s supposition that an audiologist can and will fully inform parents by presenting unbiased information at the time of diagnosis neglects what is obvious: audiologists’ work depends on treating hearing loss, not fostering a relationship between an individual’s deaf estrangement and the familiarity of the hearing world, and not teaching sign language. Audiologists are well trained in how to treat deafness from a medical perspective and how hearing technologies can improve access to sound, which can improve speech development. Audiologists are not provided the same level of training in Deaf culture and sign language or other communication methods. Even if there were the intent to provide unbiased information, I question the possibility that these professionals, who work within a medical model of hearing, can do so. Instead, for parents to make a well-informed decision, they would need both information about hearing technologies and spoken language development, and information about sign language and Deaf culture from people who have the appropriate knowledge and experience, including those who live with the estranged familiarity of deafness, rather than assuming that neutrality is possible or necessary. The importance of presenting information in a way that recognizes the ongoing socio-political debate about signed and spoken language, rather than focusing on “unbiased information” will be addressed in Chapter 7.

The Canadian Paediatric Society also has a universal newborn hearing screening (UNHS) position statement which focuses on the negative effects of auditory deprivation at a cortical level, and functional effects in terms of speech, language, psychosocial, cognitive, and reading
abilities (Patel & Feldman, 2011). This UNHS position statement also supports cochlear implants:

Cochlear implants, along with oral language habilitation, have transformed the hearing and language potentials of severely and profoundly deaf individuals, enabling highly functional language development. Current recommendations for eligible children are bilateral implantation between eight and 12 months of age, coupled with auditory oral therapy. (Patel & Feldman, 2011, p. 303)

Unlike the SAC text, the Canadian Paediatric Society position statement is more aligned with IHP documents, as it states that habilitation strategies could take the form of “oral and gestural communication, or a combination of both,” and that families need to receive objective information regarding options and outcomes (p. 303). However, what is meant by “objective information” can be questioned, as the next sentence states,

With the advances in hearing aid and cochlear implant technology, along with early intervention, functional oral communication and mainstream education are realistic goals for many hearing-impaired children. Thus, in North America, the development of spoken language is the primary objective of almost all English-based programs for hearing-impaired children. (Patel & Feldman, 2014, p. 4)

By stating the importance of giving parents objective information, but then discussing spoken language outcomes while not mentioning sign language, “objective information” (which is presented as value-neutral information on all communication modalities) is not provided within the position statement itself. This calls into question the concept of objectivity as a sensible goal, considering that what is known as objective is only that which fits the primacy of medicine and science, and does not necessarily incorporate the complexity of communication in people’s lives. In this position statement, the Canadian Paediatric Society is demonstrating a moral imperative that “functional oral communication and mainstream education” should be the
“objective” goals for all deaf children, effectively eliminating any information about sign language as objective, thereby discounting sign language as an acceptable option.

Mackinnon (1989) discusses how objectivity is reflective of the norm - she specifically addresses objectivity in relation to the norm of men’s point of view within the legal system, resulting in female perspectives not being included as reasonable. “It [objectivity] legitimates itself by reflecting its view of society, a society it helps make by so seeing it, and calling that view, and that relation, rationality. Since rationality is measured by point-of-viewlessness, what counts as reason is that which corresponds to the way things are” (Mackinnon, 1989, p. 162). In the case of “objective information” about communication modalities, objectivity can be considered to reflect the norm of hearing and spoken language. In recognizing objectivity as value-laden and reflective of normalcy, the social construction of parental choice can be better understood. This assumption of imparting value-neutral objective information to parents, which is not value-neutral at all, affects the services the IHP makes available to parents, how parents are told of the services, how parents make decisions, and how parental choice is evaluated as rational or not.

Again, as the professionals work within a medical system that promotes spoken language and has normalcy as its goal, it is difficult to imagine those same professionals would (or should) provide information on all communication options equally to parents. Deafness is objectively considered a problem due to the hegemony of normalcy, and this taken-for-granted objectiveness of deafness-as-problem corresponds with what is considered to be the objective solution of hearing technology and spoken language. This understanding of the medical construction of objectivity is important to comprehend how the IHP can purport to provide “unbiased information on all methods of communication,” yet still favour spoken language over
I have shown how the meanings of language and hearing within professional position statements make deafness matter only as a problem to be solved with hearing technologies and a spoken language approach, and provide the context within which medical and rehabilitation professionals enter into relationships with parents of newly identified deaf children. For the remainder of the chapter, I examine parents’ experiences in making their ‘informed choices’ and how these recalled experiences relate to my analytic interpretations of IHP policy and procedure documents. The way parents perceived the options provided depended upon what the parents discovered during their own research on childhood deafness, and the preconceived notions they held about deafness and language, including their experiences throughout the screening process. In the following sections, I analyze the material effects of the IHP texts on parents and their children by examining how parents came to make the decision of cochlear implants for their children, and how the IHP’s different communication options were presented to and understood by parents. Parental experiences with the IHP demonstrate how the IHP’s policy to fully inform parents about each communication option was experienced by parents as value-laden, with the most value placed on spoken language.

5.2 The ordering of parental experiences of decision making

As soon as a child has been diagnosed as being deaf or hard of hearing, a social worker should be made available to support the family. This individual must be completely unbiased in terms of choices for communication. The main purpose of this individual will be to support, counsel and assist the family; and to serve as a short term case coordinator to ensure that they receive all the information on
communication options and meet with all the stakeholders that represent those options…
Each area should have a team of experts that would be available to meet with families of newly identified deaf and hard of hearing children. Many of these individuals will be volunteers from stakeholder organizations and others will represent various programs providing supports and services. The make up of each of these resource teams may vary from area to area, but every effort should be made to provide access to parents of children who use sign language; parents of children who use oral language; parents of children who are bilingual/bicultural; deaf/hard of hearing adults who sign; deaf/hard of hearing oral adults; deaf/hard of hearing bilingual/bicultural adults; different programs or agencies that provide the various methods of communication. (Ontario Ministry of Health and Long-Term Care, 2001, p. 17)

The above quote from the Local Implementation Support Document produced by the Ontario Ministry of Health and Long-Term Care in May 2001, explicitly states the IHP’s intent to provide unbiased information to parents on all communication methods to assist in their decision making, demonstrating an implicit acknowledgement of the historical manual-oral controversy and how they attempt to overcome it by fully informing parents. The document indicates parents should be given “access to parents of children who use sign language…parents of children who are bilingual/bicultural; deaf/hard of hearing adults who sign; deaf/hard of hearing bilingual/bicultural adults; and different programs or agencies that provide various methods of communication” (Ontario Ministry of Health and Long-Term Care, 2001, p. 17). However, there is no indication in the document as to how this should be accomplished, or how they intend to ensure the social workers are “completely unbiased,” or how that would even be possible. On the contrary, the bulk of the document contains bureaucratic information, detailed screening procedures and audiological protocols, with no guidelines given on how to implement
sign language services, and no protocols to ensure other communication systems and information on Deaf culture and sign language are shared with parents.

In addition, the wording of “stakeholders” points to different people having a stake in the different communication options and reflects a tension between the different people that advocate for different communication methods. The term stakeholders implies there are different people and organizations who benefit from the various communication methods; these are people who have a stake in the different options so that information provided on communication method seems to be about what is best for these stakeholders rather than what is best for the child. This is a red flag indicating the various communication methods for deaf children continue to be a contentious issue for the IHP, rather than a seamless service of options provided to deaf children and their parents (as appears in the above quote). Indeed, the repeated reiterations of the need for an unbiased presentation of options is itself an indicator of the biases within the IHP and the antagonistic debate between spoken and signed language.

The experiences of the parents I interviewed demonstrate how the IHP’s policy of providing unbiased information to parents so they can make a fully informed choice regarding communication modality is not (and cannot be) fully realized in the IHP’s current practices. The policy quoted at the opening of this chapter presents communication and language as apolitical and parents as arbiters of their child’s method of communication.

It is the policy of the Infant Hearing Program that parents of babies identified as deaf or hard of hearing will have access to unbiased information on all methods of communication available to their child. It will be the decision of the parents as to what method(s) of communication their child will use and it will be a fully informed choice. (Ontario Ministry of Health and Long-Term Care, 2001, p. 6)

However, this policy is at odds with the meanings of language and deafness presented throughout IHP texts and professional position papers and as experienced by parents. As
examined in the prior section, the meanings of language and deafness presented in professional position papers demonstrate that language is anything but apolitical, and that despite the IHP’s stated intent to provide unbiased information to fully inform parents, bias is unavoidable within the current practices of the IHP (and the medical establishment and society more generally) which situate objectivity only in relation to normalcy. Rather than parents making fully informed choices, I argue that the IHP constructs parental choice in such a way as to produce children who will become culturally Hearing, English-speaking governable citizens, when the children are judged to be physically and cognitively capable of such becoming. Choice is constructed through the ways the IHP presents meanings of deafness and language, guiding parents toward the ‘right’ choice of hearing technologies and spoken language, thus supporting a capitalist economy through reliance on medical technologies and therapies that purport to fix disability. To demonstrate the material effects of text as social action and how parental choice is constructed, it is necessary to examine parental experiences with IHP support after diagnosis, how deafness and language were meaningful to parents, and how parents came to make choices regarding hearing technologies and communication modality for their child.

Parental experiences with the IHP differed depending on several inter-related factors including: the geographical region of service; the practices of the diagnostic audiologist; the role of the Family Support Worker (FSW) and how soon she met with the parents; their child’s candidacy for CI; and the funded services available in their region. Following from the problem of deafness presented to them during screening, understandings of the meanings of deafness and language differed amongst parents which also affected the choices they made and continue to make for their children. For many parents, especially those whose children are now older, how deafness and language matter to them has changed over time.
Recall that during screening, hearing loss was presented as an unthinkable outcome; all the parents who went through the screening process expressed shock upon the diagnosis of hearing loss. These meanings of deafness as problematic, unwanted, and unthinkable presented to parents by the IHP contribute to parents being unprepared for their child’s diagnosis of deafness. This shock of now having to think about what deafness means for their child made it difficult for many parents to fully understand and process information about their child’s hearing loss and communication modality options. For some parents, the shock of diagnosis was compounded by not receiving enough information from the audiologist at the time of diagnosis.

The various inter-related factors resulted in parents receiving information in different ways and hence having different experiences in the period at, and following, diagnosis. When parents were given information about their options, whether by the audiologist or FSW, some parents felt information was presented in a consciously unbiased manner, sometimes to such an extent that parents were frustrated with the lack of robust information about their child’s hearing loss. These parents felt as if the professionals were restricted in the type and amount of information they could provide; they seemed to put the IHP’s policy of providing unbiased information into action by simply not providing detailed information. This response to the IHP’s call for objectivity could reflect an understanding that it is impossible for an audiologist to avoid bias about what to do about hearing loss; a reflection of a struggle to remain unbiased amidst bias and not knowing how to handle it. Other parents felt like they were pushed towards a spoken language only approach right from diagnosis and were given no information about sign language, whereas other parents chose a spoken language approach right away, often before meeting with the FSW, and did not want to even receive information about sign language or the dual option.
The experiences of parents referred to CI Programs exemplifies how the intent to provide unbiased information about different communication options may not be borne out in practice. An ‘objective’ presentation of options within a normalcy-based system shows itself as a decidedly moral presentation of options most fitting a hearing society. As the majority of children in my study were severe to profoundly deaf and had cochlear implants, my analysis begins with how parents came to decide on cochlear implants for their child and how this decision related to communication modality.

5.3 The “choice” of cochlear implants

Eight out of thirteen children in this study had cochlear implants (CI). All the parents of children who were candidates for CI chose to get CI for their child. In other words, there were no children of my participants who were candidates for CI and did not have a CI at the time of my study. Four children were diagnosed by three months of age and received their CI between 9 to 15 months, and one was diagnosed in infancy and had other disabilities but was not implanted until five years of age after being adopted. One child was diagnosed with profound unilateral hearing loss at four months and was assessed for CI candidacy but was not a candidate. One child had a progressive hearing loss diagnosed at 18 months and received a CI at five years; one child was diagnosed at 22 months and received a CI in the United States at 24 months to bypass a waitlist in Toronto, and one child who also has cerebral palsy received a definitive diagnosis at one year of age and was implanted at two and half years of age.

Three of the parents of children diagnosed with severe to profound hearing loss before four months of age recalled being referred to the CI Program before meeting with the FSW and two parents met with the FSW before going to the CI Program. Lauren recalled meeting with the FSW soon after diagnosis but she seemed to only become aware of sign language as a
communication option when the home visiting teacher services began when her daughter, Natasha, was six months old. Angela also met with the FSW soon after diagnosis, but recalled the teacher of the deaf later providing more information about communication options than did the FSW. Two of these parents were also referred to SickKids without being explicitly told they were being referred to the CI Program to determine their child’s candidacy for CI. When children were deemed potential ‘good candidates,’ the process towards CI and spoken language began unbeknownst to some parents and before other communication options were even presented to them.

The parents’ experiences suggest the system is set up to move infants quickly through a diagnosis of profound hearing loss, to candidacy for CI, to AVT, to CI surgery, particularly when the infant was deemed to be a ‘good candidate.’ The process happened so quickly that Heather and Priya were not even aware their children were referred to the Cochlear Implant Program, “I had no idea yet that it was specifically about a cochlear implant, so, I don’t know I think sometimes they treat parents like they’re kids” (Heather, mother of Wyatt). Parents knew they were being referred to SickKids, but not that the referral was specifically for the CI Program. Heather had just thought they were going to SickKids as their ENTs are specialized “to see if your child has significant hearing loss” (Heather, mother of Wyatt). Priya also did not know her son was referred to the CI Program until the audiologist at their first appointment at SickKids told her so. For parents whose children were not considered ‘good candidates’ the process towards getting a CI was slower: Vivian, whose daughter Julia was diagnosed with a progressive hearing loss at 18 months, asked about a CI as a possible option for two years before Julia was implanted; Rebecca’s son, Thomas, who also has cerebral palsy was implanted at age two and a half; and Vicky’s son Sam who is deaf/blind and has cerebral palsy, was implanted at
The experiences of parents whose children were not good candidates and how meanings of deafness and language intermingle with disability will be discussed in Chapter 6.

The referral of profoundly deaf infants to CI Programs before parents have met with the FSW, or being told at the diagnostic audiology appointment their child would likely need CI, as was Angela’s experience, sets parents on a path towards a spoken language only approach to communication before they are fully informed about other options. In addition, as it is assumed parents have chosen auditory-oral language when they choose CI, the CI Program undertakes no responsibility to tell parents of other communication options. On the contrary, some parents told me they were instructed not to use signs with their child, and that they had to commit to a spoken language only approach for their child to be considered a candidate for CI. For the few parents who were not explicitly forbidden from signing, signs were considered something parents could learn on their own – support for learning sign language was not offered by the IHP until parents started advocating for those services for their children. The decision to get CI is therefore inextricably linked to a decision for a spoken language approach to communication, and parents understood their choice to get a CI was also a choice to focus exclusively on spoken language and not sign language. Some of the parents wholeheartedly agreed with this stipulation, whereas others questioned why they should limit their communication to spoken language.

As outlined in Chapter 1, cochlear implants provide a way for some deaf people, who would otherwise not have access to sound through hearing aids, to access sound as digitized signals and learn to interpret the meaning of those sounds to understand and produce spoken language. Before CI, severe to profoundly deaf children often learned sign language and became part of Deaf culture in schools for the Deaf, as learning spoken language is very difficult without hearing spoken language. Recall also that the vast majority of deaf children are born to hearing
parents who are not fluent in sign language; this was the case for all of the parents who contacted me about the study. The decision to get a CI for their child was very much tied up with the parents’ decision to have their child learn spoken language, as the CI was considered the only way their child had of accessing sound and learning spoken language, demonstrating the predisposition that hearing parents have toward the normative order of hearing and spoken language. This predisposition that hearing parents have towards spoken language contributes to the acceptance of the IHP and CI Programs ‘objectively’ presenting cochlear implants as the ‘right’ choice.

As cochlear implants were the only way their child would have access to sound and learn to speak, many of the parents of profoundly deaf children who were candidates for CI told me they felt that getting a CI was not really a choice, but rather their only option. CI was considered a necessity, because hearing and spoken language were considered necessities. For some parents who felt they had no choice but to get a CI for their child, sign language was not considered an option, not just because the CI Program made it a condition to not use sign language, but also because the parents wanted to focus exclusively on spoken language. As Priya noted, “I didn’t have any option. I already decided that sign language was not my option. Since I have the option of having the cochlear implant, I didn’t have any option [need] for sign language.” Priya met with the FSW after her referral to the CI Program at SickKids and she recalled the FSW speaking to them about their options for communication:

They asked whether you want your son to be oral or you want to go for the sign language, and I said no for the sign language. I was very strong in communicating [to] him with the [spoken] language. I wanted him to be oral, so I wanted to go with the cochlear implant. So, they explained [to] us, they said it’s your choice. From the start, I said I wanted him to be oral. (Priya, mother of Arinan)
Upon discovering their son was a candidate for CI, Priya recalled being told, “It’s your choice. You can choose one, or two, or nothing.” Priya told me numerous times the IHP and CI Program told her she had options and it was her choice. Nevertheless, she did not feel there was a choice to be made, as spoken language together with CI was the only option that made sense to her for her son; the other options were not even a consideration. Priya’s choice upon the presentation of her son’s problem of deafness, was to not consider all the communication options, but to choose the one option she thought would give her son the chance of fitting within the normative order of hearing and communication. Priya did not recall discussing sign language, or both sign and spoken language with the FSW since she had already decided on CI and was not interested in any other option. She did recall the auditory-verbal therapist telling her that doing both spoken and sign language at the same time was not a good idea.

Choosing the CI was also not a difficult decision for Lauren (mother of Natasha), “To me, it was she’s going to, she’s going to hear. That was it. I didn’t know anything else.” Upon further reflection, Lauren told me she was not given any options, “Looking back at it, I wasn’t given choices, I was told.” In Lauren’s experience, getting hearing aids and then a CI for her child automatically meant starting AVT, “because I’m now going the technology route, it’s speech and spoken language.” Lauren had the choice of getting CI or not, but by choosing CI, she did not have any communication option except to teach her child spoken language. This restriction of sign language was so severe that she was told Natasha would be removed from the CI program if they used signs. In further describing her decision to get bilateral cochlear implants for Natasha, Lauren explained how the CI Program tries to implant children before one year of age so that, “By the time she reaches school age, she will be the same as all her peers in hearing and spoken language. Well, that sounds fantastic as a new parent, doesn’t it!.” The assertion that her child would be the same as hearing peers made getting CI an easy decision, demonstrating
the strong pull the possibility of normalcy had on Lauren’s decision. Based on her lived experiences with her daughter over the last four years, Lauren felt the CI Program provided false hope regarding expectations for speech and language development, and she questioned what was meant by “the same.” How the meanings of language and deafness, and notably normalcy, have changed over time for Lauren and some of the other parents will be discussed in Chapter 6.

Melissa made her decision for CI based on consideration of what she thought would provide her daughter Beckie with the most opportunities for the future. When making the decision regarding CI, she told me they thought that if spoken language was possible for Beckie, then that is what they would want. They did not consider other options once she was found to be a candidate for CI. For Melissa, CI and spoken language “would just give her so many more opportunities, and so, we just felt like it was not even a question, that if she could learn to hear and speak that’s what we would do.” Melissa understood being deaf without learning to hear and speak as limiting her daughter’s future opportunities in life.

Angela was presented with the possibility of CI for her daughter, Emily, at diagnosis when she was six weeks old, and recalls being hopeful that she would be a candidate. Like Lauren, Angela recalled the CI Program telling her, “she should be able to understand speech without difficulty and that because she’s getting implanted so young, that the neuroplasticity would be great and that within five years she’d be fine, so. That’s what they said, within five years that she would be fine” (Angela, mother of Emily and Tyler). When asked what the CI Program meant by “fine” Angela elaborated, “I think that her spoken language would be fine, her auditory skills would be fine, her language skills would be fine, speech, things like that, that she would be well integrated within school and peers five years post implantation,” so that “fine” was equated with ‘normal.’ Like Lauren’s experience, the CI Program’s assertion that speech and language would be on par with hearing peers by school age (i.e., speech and language would be ‘normal’).
reassured Angela that cochlear implants were the right choice. Angela felt choosing to get bilateral cochlear implants for Emily was an easy decision to make, despite briefly questioning the decision when they thought perhaps she did hear something with her hearing aids.

One of the issues Blume determined from his comprehensive account of the development of cochlear implant technology, was how the “‘momentum’ of the technology,” led to its largely unquestioned uptake by professionals and parents (Blume, 2010, p. 196). “As a source of status, legitimacy and profit” for CI stakeholders, and framed as medical progress taken up by the media as a miracle cure for deafness, the CI provided (and still provides) hope to parents (Blume, 2010, p. 196). The urgency of the need for early implantation to ensure future benefit (i.e., the learning of spoken language) and parental hope for such benefit, brought parents on board as political advocates to help secure the needed health care resources to support the technology. Blume posits that the strong momentum behind the technology leads to parents not considering alternatives for their deaf children, “Despite the doctrine of informed consent to which all now play lip service, the social dynamic of momentum leads inevitably to a situation that excludes precisely the informed and reasoned choice that the doctrine requires” (2010, p. 196). Blume’s account provides some explanation as to how the IHP could have informed consent as a guiding principal, but one that is at odds with parental experiences of obtaining information about their options. I would add that a guiding force behind the momentum is society’s view of deafness as a problem to be eradicated. If deafness and the use of sign language were not considered problematic, then there would not be the same push for such technology. As CI is understood as the only choice for the possibility of normal speech and language, other options are not even contemplated, and it is accepted as reasonable and objective to only offer (and for parents to only consider) cochlear implants as an option; the
choice of CI is considered an objective decision, as it suits society’s ideals of how a deaf child should hear and speak.

Although they all went to the same CI Program, and Angela’s daughter is only six months younger than Lauren’s daughter, Angela’s experience with sign language was different from Priya, Lauren, and Melissa. Angela did begin learning baby signs when her daughter was an infant and she felt she had been given information about the different options and was not prohibited from teaching Emily signs while she waited for her CI, although the IHP did not offer her sign language services. This difference in experiences could suggest that parents are given different information depending on which audiologist or FSW they meet, and/or depending on what kind of questions the parents ask. How parents choose communication methods, whether their child has CI or other technologies, is addressed in section 5.4 below.

5.3.1 Choosing cochlear implants after infancy

The decision-making experiences of parents whose children received cochlear implants after they were two years of age were different from those who were implanted in infancy. Vicky threatened legal action to advocate for Sam to receive CI and to expedite his surgery after adoption at four years of age. Vivian tried to obtain information about CI for her daughter Julia for almost two years before beginning the CI process and found getting a CI a difficult decision to make. Rebecca also found it difficult to decide to implant Thomas.

When asked if choosing to get a CI for Thomas was a difficult decision to make, Rebecca responded, “It was brain surgery, I didn’t want this, absolutely not.” It took many months of different audiological tests to get a firm diagnosis for Thomas. After diagnosis, Thomas used hearing aids for a while, but when they did not seem to give access to sound, he was referred to the CI Program. Rebecca told me she had many questions for the CI Program she wanted
answered before deciding, but found the CI Program not forthcoming with information. She sought out information on her own and spoke with a family member who is an otolaryngologist to help her decide. Ultimately, they chose to get Thomas a cochlear implant as it seemed the only thing they could do for him, “my child needs to hear and speak, right, so we had to do something” (Rebecca, mother of Thomas). Despite her worry over the surgery, Rebecca chose to get a CI for Thomas as it was the only option that could give him hearing and spoken language.

Vivian recalled the decision to get a CI a difficult decision to make. At the time of the interview, she told me she knew it was the right decision as Julia could now hear and speak, but at the time of deciding, she had struggled with it. Vivian found the IHP and CI Program were not forthcoming with support; she would have liked to have more information from the IHP while they were trying to decide, including information about the politics of CI and advice for how to deal with the political issues. For example, Vicky recalled another parent asking her if she was alright with changing her child forever without her consent and this weighed heavily on her mind. Whether the CI would result in ‘normal’ hearing, speech and language for Julia was unknown; the CI program did not give Vivian such assurances since Julia was not an infant at the time her candidacy for CI was determined. In retrospect, Vivian concluded that a CI was the right decision as Julia could now hear and speak.

As Vicky adopted Sam when he was four, she was not involved in the decision making regarding CI when he was an infant. Vicky told me Sam’s social workers decided not to pursue cochlear implantation for Sam as an infant, but rather decided to let him choose if he wanted CI when he was older. To Vicky, this decision removed choice from Sam, “If you don’t do the cochlear implant, there isn’t a choice to be had, because it doesn’t work later on” (Vicky, mother of Sam). Vicky chose to get a CI for Sam when he was adopted and advocated for an expedited surgery since he had already gone four years without CI. More details about Vicky’s
experience with the IHP and CI Program are examined in the following chapter. Vicky also advocated for sign language services beginning before Sam moved in with them; she and her family had weekly lessons in the home to learn sign language before Sam arrived. Vicky’s approach to decision making was to do all they could to help Sam communicate and figure out what worked best for him, rather than deciding on one or the other, and she took a legal rights-based approach to obtain services. Sam’s other disabilities and his age at the time of adoption seemed to have made it easy for Vicky to decide to focus on improving their communication through whatever technology and modalities were available to him, rather than striving for ‘normal’ speech and language.

When children were deemed ‘good candidates’ for CI, their parents were told to expect they would hear and speak by school age, which made the decision to get cochlear implants relatively easy. When the child had other disabilities or a CI was being considered at a later age, parents had a more difficult time making the decision, as they were not given the same assurance by the CI Program. For cochlear implant stakeholders then (specifically professionals with stakes in the CI Programs), the value of cochlear implants corresponded with the best opportunity to learn spoken language, which increases the chances of showing CI ‘success’; the provision of access to hearing (regardless of expected language outcome) was not the main goal. Based on this presentation of the benefit of cochlear implants and as the examples above demonstrate, the difficulty parents had in deciding about CI was linked to how likely the CI would result in normal spoken language development, rather than access to hearing for any non-linguistic reasons. That is, the access to hearing provided by CI was considered a benefit for the purpose of developing spoken language, not for access to hearing as a benefit in and of itself.
5.3.2 Removing deafness: A discussion of CI and the (re)disappearance of d/Deafness

As discussed in the previous chapter, the IHP’s screening texts made deafness matter as an unwanted, unthinkable outcome; deafness only became thinkable when it materialized as a diagnosis. By making deafness unthinkable, deafness was made to disappear in the IHP’s screening texts, and then after appearing as a diagnosis, the discourse of CI makes deafness disappear again. As IHP screening texts present deafness as unusual, unwanted, and unthinkable, parents are in shock when their child receives the unexpected diagnosis of deafness (i.e., when deafness materializes or appears). The possibility of learning to hear and speak offered by cochlear implants mitigates parental anxiety about their child’s profound deafness, and deafness once again becomes unthinkable through its expected disappearance. At the time of considering CI, the thought that their child could hear and speak like ‘normal’ was of paramount importance to all participants. How the child experiences their deafness, or their inside-view (Michalko, 2002), or the child’s immediate need for communication may be disregarded, as CI offers a fix for the child to eventually become like their hearing peers by removing the estrangement of deafness.

When a child is found to be a candidate for CI and implantation happens around one year of age, parents were told that access to hearing and therefore spoken language and a ‘normal’ life would now be possible. Once CI was known as a possibility, deafness, and Deafness, again became unthinkable as the child was thought of as becoming like a hearing child. Since parents are told their child will hear and speak like their hearing peers by school age, there is no need to think about their child as being deaf and no need to consider sign language. However, the unthinkable
deaf diagnosis does not literally disappear – despite the rhetoric, CI does not cure deafness – but deafness is thought of as an estrangement that can be removed if the technology is used.

Making deafness unthinkable serves to ensure parents will choose technology that may allow their child to hear and speak, while in turn making Deafness unthinkable and transforming deaf estrangement into hearing familiarity. As discussed in Chapter 1, cochlear implants have been touted as a ‘miracle cure’ in the media (Murray, 1989; Socha, 1992) and have been promoted as devices that can increase productivity and make deaf people contributing citizens to society (Sheppard, 2011). Cochlear implant stakeholders present CI as devices that make it possible for deaf children to become like hearing, speaking people and productive members of society, while situating sign language and Deaf culture as unnecessary and even harmful. This makes the espousing of the benefits of cochlear implants and spoken language to be considered an unbiased presentation of information, whereas any promotion of Deaf culture and sign language are considered biased as they do not support what is ‘objectively’ known as a deaf child’s path to normalcy.

Parental desire for their deaf child to be like them, to speak their language, to be ‘normal’ and lead a normal life, supports the disciplinary control of the IHP and CI Programs and exemplifies how bio-power and governmentality are multi-layered. The decision to get a CI is also a commitment to do normalizing work, work that must be done by service providers, but also by parents and their children, with the goal of shaping a deaf child into a hearing, speaking person familiar with (and familiar to) the hearing world. Michalko describes this work as dispensing with the estrangement of disability (deafness in this case), “The ‘rehabilitation’ of estrangement amounts to treating it as the result of a ‘defective’ physiology… and to remedy this ‘defect’ through rehabilitation’s version of ‘work’. Thus, the only thing to be done with estrangement – the view from the inside – is to dispense with it” (Michalko, 2002, p. 181). Parents are governed
through their desire to fix their child’s deafness and the hope brought by the CI, which in turn
exerts bio-power over the parents and children through a regiment of continued CI calibrations
and audiological testing, AVT and/or SLP, including much work done by the parents and
children themselves to create this hearing, speaking, ‘normal’ deaf person, while dispensing
with any deaf estrangement and hoping for its disappearance. In this way, the “bias” towards
spoken language and cochlear implants is naturalized as the rational, objective way to think of
deafness, leading to the only rational, objective thing to do with deafness.

5.4 Sign or spoken: It’s one or the other, you can’t have both

Children who are born deaf or hard-of-hearing or at risk for developing hearing
loss in early childhood will be identified and will be offered services and
supports to assist them and their families in the development of communication.
According to the choices made by the family, children identified as deaf or hard
of hearing will be assisted in the acquisition of the communication skills needed
for performance of daily activities and for personal and social sufficiency at
home and at school. (Ontario Ministry of Health and Long-Term Care, 2002, p. 2)

A dichotomous relationship between spoken language and sign language, with spoken language
as the right choice and sign language as the wrong choice also makes a Deaf way of being
unthinkable. The parents I spoke with seemed to think the choice given to them by the IHP was
a choice between services in sign language and no hearing technology (and no spoken
language), or hearing technology and exclusively spoken language. The parents who did recall
being told about a dual option (both sign and spoken) did not recall being told how this option
would work or what services the IHP would provide to support this option. This presentation of
choice creates a dichotomous relationship between sign language and spoken language and
between the professionals and stakeholders that advocate for each. This dichotomous
Lauren explained how she felt she was not given an option of both spoken language and sign language when Natasha became a candidate for CI,

If she was going to have cochlear implants, I was to speak to her. And that was it. I wasn’t allowed to sign with her…But you know, to not have that support from doctors, and we’re told it’s only this way, I wasn’t given a multitude, the only options I was given was if she’s implanted it will be spoken [language] and listening, if she’s not implanted, then you’ll have sign language. So, it’s clear cut.

It’s one or the other, that’s it, you can’t have both. (Lauren, mother of Natasha)

Melissa also had no recollection of a dual approach being presented to her as an option, only sign language versus spoken language. Melissa recalled when the teacher of the deaf through the Home Visiting Program (HVP) came to work with Beckie, she signed when she spoke. Melissa and her partner however did not want her to sign as they wanted a verbal approach for Beckie. The HVP teacher told the parents a sign language instructor could come into their home to teach them sign language, but the parents understood this as focusing on sign language rather than spoken language and they did not want that for their daughter. They discontinued the HVP services after a month because they felt like the teacher was pushing sign language on them.

Melissa explained why they discontinued the HVP services,

I don’t really know that anyone specifically presented a combined approach as an option, I felt like it was more like two paths, like two different options…it was almost like pulling us in so many different directions at the same time, like she [teacher of the Deaf] was saying one thing, and our AVT was doing another thing, and it just felt good to be on the path that we wanted to go down and be able to focus on that. (Melissa, mother of Beckie)
Melissa had said they had already done their own research and gone to the CI Program and made the decision for the spoken language approach and CI before they met with the FSW who presented different options for services. They would have considered sign language a good option only if spoken language (via CI) was not going to be possible.

Melissa’s experience with the different IHP services created an impression that spoken language and sign language were diametrically opposed to one another. The HVP teacher signed while she worked with Beckie and encouraged the parents to access ASL services in the home. Conversely, their AVT told them to focus on auditory-oral language and not to sign. Melissa’s experience demonstrates how different stakeholders have different, sometimes opposing (and notably biased), opinions on what is best, and parents may feel overwhelmed by being caught in the middle of two seemingly dichotomous ways of doing things. This feeling of being pulled in different directions made it easy for Melissa to focus on what was considered the best option and most familiar to them (spoken language) while eschewing sign language as unnecessary.

Vivian ended up getting advice regarding communication modality from their family doctor who only had limited experience with deaf children. Vivian recalled her advising them to make a decision in line with Hearing culture:

I actually got more guidance from my family doctor who was like, “do not go Deaf culture, go spoken culture,” she said that she [the doctor] has some teenagers that are deaf and she said without fail they go through a very, very difficult time. Now, that could just be her experience, I don’t know, I’m sure there’s deaf teenagers who have a perfectly good time, but when you only get one piece of information from one person, you don’t know which way to go. And IHP did say you can do this, this, or this, what do you pick? And I said, well I think we’re picking you know [spoken] language acquisition, because that’s what we all do and I want her to be part of us and our family and they said OK then you have to do AVT. (Vivian, mother of Julia)
Vivian noted the IHP did give them a choice of options, but did not give them enough information to make a fully informed choice. Without comprehensive information given by the IHP, parents turned to other sources. All the parents I interviewed did their own internet searches for information and some asked other health professionals whom they knew. Parents therefore also encountered meanings of deafness and language from sources outside the IHP, many of whom ascribed negative meanings of deafness, representative of how deafness and disability are thought of within Hearing culture.

Heather’s son ended up not being a candidate for a CI as he did not have an auditory nerve, but Heather reported she and her husband did not seek out any information about other options aside from spoken language, as they wanted their son to learn spoken language exclusively. Like Melissa, Heather expressed her annoyance with the FSW for even telling them about sign language as an option, as they wanted their child to speak; sign language was not thought necessary to become fully informed. Heather described their decision for an exclusive spoken language approach,

"None of us know sign language or have hearing loss ourselves, so in terms of him learning only sign language, like I just thought it would be too isolationist for him. And then in terms of like a combination, of speech and sign language option, I didn’t really, I mean I felt like in terms of like we only have so much energy to do things. It was better to just try and focus on speech rather than trying to pursue multiple avenues unless it was really necessary. (Heather, mother of Wyatt)"

Heather’s concern that sign language would be isolating for Wyatt exemplifies how hearing parents make decisions from a h/Hearing point of view. Hearing parents imagine sign language as isolating their child from the hearing world and from the hearing family, rather than imagining how sign language could give their child the opportunity to learn a fully accessible language and provide a visual modality for experiencing their deaf estrangement. This fear of
sign language demonstrates the importance of providing parents with information from, and the opportunity to meet with, Deaf children and adults to help parents understand a Deaf point of view. Heather was also concerned that a combined approach would be too taxing on their resources, as they only had so much time and energy to work with Wyatt, providing an indication of the work that is expected of parents and children, and further supporting the dichotomy between spoken language and sign language.

Angela felt like the teacher of the deaf and the FSW presented information about communication options equally, but she and her husband were more biased towards spoken language and hence did not consider teaching Emily sign language exclusively, although they did want her to learn both ASL and spoken language. Angela was told by the FSW and teacher of the deaf that the SickKids CI Program would not like it if they signed with Emily, but when she met with the SickKids audiologist and the AVT she found out they were agreeable to them signing. When asked if she was offered services for both AVT and sign, Angela replied, “That would have been amazing. No, they did not offer that.” Although Angela was not prohibited from signing, the IHP did not offer services to support the learning of sign language. The lack of offered services for sign language despite the option of a dual approach seems to lead parents to interpret their options as between sign only or speech only. When the dual approach was presented to parents, it was presented as something that would be tolerated, but not supported with the provision of ASL services.

Vivian recalled the FSW telling her she had the option for sign language, spoken language or both, but information about services was only provided for either AVT or sign, not both.

I do remember her distinctly saying you have a choice, do you want to go sign language, do you want to go like mixed, or do you want to go auditory…mixed would just be like, you could learn, you could use the baby signs that you’ve
been using…But that was the only option that I remember not being well explained. It was basically just pick this one or this one. (Vivian, mother of Julia)

Vivian understood the dual option to be permission to use baby signs that she had learned when Julia was an infant, before she was diagnosed. Although a dual approach of oral and visual modes was presented as an option, there were no IHP services offered to support that choice. Vivian would have liked the option of both spoken and sign language for Julia, but she understood them as being mutually exclusive as this was how she recalled the FSW presenting them to her.

Vivian told me she was warned by the FSW that sign language services mean voice-off and no talking, which she perceived as taking communication away from herself and Julia:

> There was a group called Silent Voice that Julia could go to like some camps and activities and parents’ and kids’ programs for signing if I wanted to go that route, but that they were pretty rigid about the no-talking thing, and that’s really scary for a hearing family to say like I’m going to take my kid somewhere where she can’t communicate with me at all in the way that we’re used to communicating. And it’s unfortunate because it really sets up this like, it’s either this or it’s that, and I wish that there could have been some of both, because I think it’s really valuable to learn sign language and be able to communicate in that way. (Vivian, mother of Julia)

Vivian’s impression of available sign language programs was negatively influenced by the way they were presented to her by the FSW. A meeting with a Deaf person involved in the Silent Voice program and/or with parents of signing Deaf children would have provided the opportunity to learn about sign language and Deaf culture and the reasons for the voice-off policy.

Vivian was also put off by an encounter she had with a Deaf woman who ran a program in sign language, as she would not communicate with Vivian without an interpreter. Vivian thought the
woman had been inflexible and rude to her when she approached her to learn about the program, even though an interpreter would have allowed for a clear exchange of important information. The woman may have had a rude manner towards Vivian, but Vivian’s interpretation of inflexibility suggests a lack of knowledge about sign language and Deaf culture and an uncomfortableness being a majority language speaker in a minority language situation. Vivian’s experience highlights the importance of parents having the opportunity to meet one-on-one with signing Deaf people and to learn about sign language programs from Deaf people instead of from a Hearing FSW who may perhaps inadvertently present the programs in a negative way. There is also a need for the IHP to reconceptualize how parents and children can be supported in choosing the dual option of sign language and spoken language for it to become a practical option.

Without an understanding of bilingual-bicultural education and how a child can learn both sign language and spoken language, the strict voice-off policy of such programs adds to the perceived dichotomy between spoken and sign language approaches: spoken language means no sign, and sign language means no spoken language. Although necessary to learn the language, voice-off policies may alienate some hearing parents who may worry their child will learn a language the parents do not know, or that the parents themselves will have difficulty learning a visual language. For some of the parents I interviewed, sign language was considered a threat to parent-infant communication and the unity of the family. There seems to be a fear that learning sign language in a voice-off environment will inhibit the use of spoken language; an unfounded fear considering that deaf children in hearing families spend more time surrounded by spoken language than sign language. Without IHP assistance in place to provide a comprehensive plan for the dual approach, including information about sign language and Deaf culture from Deaf
people, it is understandable that parents feel caught between what are presented as two non-compatible communication systems.

5.4.1 Communication options for hard of hearing children

Although hard of hearing children are expected to learn spoken language as they can usually access sound through hearing aids, some of the parents I spoke with wanted to find out about other options. Michelle’s daughter Sarah had failed two screenings but passed a third screening as a baby with no further follow-up. Sarah was later identified as having mild to moderately severe high frequency hearing loss after she began elementary school, and she now uses hearing aids. The FSW met with them soon after diagnosis to tell them about available services, but Michelle told me they were left on their own to figure things out as there were no further FSW appointments (the parents were told to call if needed). At the time of diagnosis, they did not know if Sarah’s hearing loss was progressive and they wanted information about other language options. Michelle described looking through the information given to them by the FSW and her experiences enquiring about sign language:

There was really no information about sign language or anything, because a lot of my friends would say “well, are you going to learn sign language?” And I found it really odd that no one was talking to you about it. And I called (FSW) and I just said, like you know I just don’t know what is going to happen with my daughter, should I learn sign language? And I remember she was just kind of like pause, and then she just kind of explained that it is a bit of a contentious issue with sign language, and I don’t remember how I ended up getting resources, maybe she pointed me in the direction of something, I can’t remember. But I got the impression that she almost wasn’t able to talk about it. I was just looking to make an informed decision, because I just wanted to keep the door open, and so I remember that just kind of being taboo almost to talk about. (Michelle, mother of Sarah)
The presentation of sign language and Deaf culture as unthinkable was Michelle’s experience although her daughter used hearing aids and not cochlear implants. Whether sign language was “taboo” because her daughter was hard of hearing and was expected to access and learn spoken language with hearing aids, or whether sign language was off-limits in a more general sense is not clear. What is evident is the precarious positioning of sign language as the ‘wrong’ choice.

Courtney’s daughter, Sydney, has aural atresia (narrowing of the ear canal) and is hard of hearing. Courtney recalled being told by the FSW that their options were between SLP, AVT or sign language, although they ended up getting speech-language pathology services without really learning about the other options. When recalling how the options were presented, Courtney said, “I really feel like it was never laid out like here’s your option for sign, and here are people to contact… I don’t feel like the options were laid out super well.” Courtney told me she taught herself some basic signs to help Sydney communicate, as the IHP provided no assistance with learning sign language other than a book of basic signs. After a year of SLP, which was supportive of them using signs, Sydney had not yet learned language so they decided to switch to AVT, although they weren’t sure of the difference between SLP and AVT as it wasn’t explained well to them. Courtney recalled the AVT telling them not to sign with Sydney, “Our AVT person actually told us we can’t do sign and we shouldn’t do the teacher for the Deaf program because they will only sign” (Courtney, mother of Sydney).

Courtney received conflicting information about sign language from different professionals. The SLP supported the use of sign language whereas the AVT prohibited signs and even told the parents not to access the Home Visiting Program teacher because the AVT was concerned she would use signs with Sydney. The AVT presented speech and sign as mutually exclusive and influenced the parents’ decision to not access other services for their child. Courtney later found out the HVP was a school readiness program and the teacher would communicate with the child
using sign, speech or both depending on what the parents decided. She described how spoken
language and sign language were presented as dichotomous,

The one thing I do feel like, I don’t know if it’s the Infant Hearing Program or
just in general out there, it’s very one or the other, and so like our AVT person
said, if you’re going to have someone come to the house and do sign or whatever,
then they won’t allow her to talk, or you know vice versa, if we’re going to do
AVT then you’re not doing sign, so it’s very cut and dry. (Courtney, mother of
Sydney)

When asked if she wanted to say anything else at the end of the interview, Courtney came back
to the dichotomy between sign and speech as a problem they encountered, “that disconnect
between you have to choose one, like you have to choose that you’re either signing or you’re
speaking, so that was kind of an issue that I had.” Courtney went on to say that it seemed as if
the disconnect was changing a little as AVT is no longer available in her area, just SLP, and that
you could “do whatever works for you and not as much cut and dry” (Courtney, mother of
Sydney).

Chelsea was thankful her son Ben could use hearing aids to access sound, “because Ben is in the
moderate to severe range it was just sort of like a given that he would wear hearing aids” and
learn spoken language. She recalled there not really being a discussion about hearing
technology, but rather being told what to do by the audiologist, “this is his hearing level and so
you know hearing aids will help him and this is what you do now” (Chelsea, mother of Ben).
Chelsea was relieved Ben had access to sound and that they did not have to consider whether to
get him cochlear implants, as she was aware of the arguments for both CI and for Deaf culture.
When Ben was two and a half and not yet talking, Chelsea inquired about sign language and was
able to access biweekly sign language services. Chelsea encountered no resistance with
accessing both AVT and sign language services, although she had to be proactive about asking
about sign language; the option for this service was not simply offered to her. Chelsea’s path to
learning ASL will be discussed in the following chapter.

The IHP presents a dichotomy between spoken language and sign language with AVT or SLP
services being offered as a matter of course while restricting sign language services and placing
the dual option in a precarious position. On the surface, deaf versus hearing may seem
categorically meaningful as opposite sensory experiences necessary for the IHP to provide their
services. However, a deconstruction of the deaf/hearing binary demonstrates the normative
underpinnings that support the binary (and the IHP’s services) and the many meanings and
experiences that make it otherwise. In the chapter’s conclusion to follow, I discuss how the
deconstruction of the deaf/hearing binary demonstrates how the IHP’s presentation of the
meanings of language and deafness construct parental choice and make the dual option
inaccessible.

5.5 Discussion: Deconstructing the language binary

My description and analysis of the interaction between the IHP program, professionals, and
parents demonstrates there is a disconnect between the IHP’s stated intent to provide
communication options and unbiased information about those options to parents, and the
meanings of language and deafness presented to and as experienced by parents. Although the
IHP may have the intent to fully inform parents by offering them “unbiased information” about
their options for communication, the meanings of deafness and language interpreted within IHP
texts dichotomizes spoken language and sign language making them mutually exclusive and
endorsing spoken language as the ‘right’ choice. The Ontario IHP is not the sole authority on
childhood deafness; it is a provincial program working within a society that already ‘knows’
deafness as a problem, and its meanings of deafness and language are representative of how deafness is problematized on a wider scale.

In a paper addressing the large global public health concern of hearing impairment, the World Health Organization assumes the best treatment for a deaf child is the combination of hearing technologies and habilitation to learn spoken language, “Early detection of hearing loss and early use of hearing aids or cochlear implants are critical for the development of speech, language, and communication skills in children with hearing loss” (Duthey, 2013, p. 19). Unlike the IHP which has an unfulfilled policy of neutrality, the WHO explicitly supports technology and spoken language as first choice treatments for hearing loss:

> Several devices such as hearing aids, cochlear implants, middle ear implant can be used to amplify sounds or help people hear better. Alternatively, when none of these devices can be used, sign language and speech reading remain an alternative to help people to communicate and lead a life as normal as possible. (Duthey, 2013, p. 33)

Speaking a language other than the majority language is not considered of benefit to society, or not even considered by the WHO as a language, but a way to help people communicate. The WHO sets up hearing technologies as giving the possibility of a normal life, while sign language is an “alternative” to help people “lead a life as normal as possible.” This widely accepted conceptualization of deafness and what to do about it informs the practices of the IHP. In Chapter 7, I suggest that to sincerely educate parents of different communication options, the IHP must first acknowledge the historical (and ongoing) debate between manual/sign and oral/spoken language that made their policy of providing unbiased information so important in the first place.

The material effect of the IHP’s bias towards spoken language (disguised as objective neutrality), is apparent in parental experiences of the IHP’s practices. For example, at diagnosis,
audiologists (professionals who subscribe to a medical view of deafness and promote hearing technologies and spoken language) are the first people to provide parents with information, and all the FSWs who met with the parents I interviewed were h/Hearing, and only one FSW brought a Deaf person to meet a parent (Vicky); this was after Vicky had specifically enquired about sign language before adopting Sam. In addition, sign language services were not offered to parents when they chose spoken language, even if they enquired about sign language, making the dual approach an impractical option not supported by the IHP.

The presentation of deafness as an unthinkable, unwanted outcome of screening that can result in developmental problems (e.g., speech, language, cognitive, behavioural problems) that must be rectified by hearing technologies and early intervention, creates a foundation for the IHP’s framing of services towards the normalcy of spoken language, which is supported by how deafness is commonly problematized by health organizations and society more widely. This foundation is bolstered by the professional responsibilities of IHP service providers, as the profession of audiology medicalizes deafness and audiologists are the first people to provide parents with information. Speech-Language and Audiology Canada supports universal newborn hearing screening and cochlear implants for children in a way that dismisses Deaf subjectivities and sign language, so that audiologists have a professionally sanctioned bias towards spoken language approaches to communication for deaf children, as does the Canadian Paediatric Society. Moreover, upon diagnosis, the referral of profoundly deaf children to CI Programs (which support an exclusive auditory-oral approach) before parents are given comprehensive information about all their child’s communication options, guides parents towards an exclusive spoken language approach.

What makes it important for the IHP to state the policy of providing parents with unbiased information so they can make fully informed decisions, while at the same time leading them
towards a spoken language only approach to communication? Although the IHP may have had the intention to fully inform parents of different communication options in an unbiased manner, this policy could also be interpreted as nothing more than a gesture of acknowledgement of the historical controversy between the use of spoken versus signed language in deaf education. In short, the policy could be considered a token policy to appease Deaf people and other advocates of sign language and bilingual-bicultural education. The assumption of objectivity in the way information is provided to parents along with the power of the medical knowledge-truth of what deafness means and what to do about it, allows the IHP to surreptitiously lead parents towards hearing technologies and spoken language.

The expectation that parents will make a fully informed decision also puts full responsibility on the parents for any decisions made and the outcomes resulting from that decision, fitting nicely with what is expected of citizens in a neoliberal nation, all while concealing the ordering of hearing that is already (and always) being done within society and within the IHP. Parents are made to seem as if they are completely in charge of their child’s future with full responsibility for their decisions, as the involvement of the IHP in ordering those decisions is obscured by the hegemony of normalcy. The need for unbiased information is an implicit acknowledgement that there is bias to overcome, but without any meaningful attempts to address the bias in a way to ensure parents do indeed receive comprehensive information without being led toward one option more than another.

Even though the IHP offers a “dual option,” the IHP makes deafness and hearing meaningful as opposite states of being while presenting sign language and spoken language as incompatible with each other (and spoken language as the ‘right’ choice), so that in practice, the dual option is not a realistic choice for parents. Although situated in opposition to one another, following the philosophy of Jacques Derrida (1974; 1978), deafness and hearing (and also sign language and
spoken language) cannot exist without the other. “Derrida is concerned with ways of thinking about how meanings are established, specifically that meanings are organized through difference in a dynamic play of presence and absence” (Corker & Shakespeare, 2002, p. 7). Following this thinking, the meaning of something is defined by both what it is and what it is not, so that presence and absence organize meaning; binary terms such as deafness and hearing therefore need each other to be meaningful – the significance of what it means to be hearing or what it means to be deaf is only made meaningful through the other. As Corker notes, “though we may see ‘deaf’ on the one hand and ‘hearing’ on the other, since this view is legitimated in the dominant culture, we cannot claim they are unrelated any more than we can suggest that ‘society’ and ‘individuals’ are [unrelated]” (1998, p. 41). This interplay of the absence and presence of deaf and hearing is apparent in IHP texts and in how deafness and hearing materialize throughout assessment and treatment.

The IHP and the associations that support the professionals that work within the IHP, present the absence of hearing and the concomitant absence of spoken language as the danger in deafness. However, hearing technologies provide access to hearing so that hearing becomes materially present in deafness, and deafness is made to (temporarily) disappear. Even though deafness is seemingly made absent through technology, the biological presence of deafness remains; hearing technologies make deafness disappear only in as much as there is something to be made to disappear in the first place: deafness becomes absent, while also remaining present.

This movement of the absence and presence of deafness is a social action that governs both parents and their children; parents and infants continue to be subjects of the absence of hearing and subjects of the hearing technologies that can make deafness seem to disappear and spoken language a possibility. Hearing aids and cochlear implants do not provide a cure for deafness; deafness only appears absent when the hearing technology is at its optimal functionality. When
the technology is broken, turned off, requires calibration, or is taken off (e.g., for sleeping or swimming) deafness reappears. This is not to say deafness is not always present in some way to the deaf person themselves, but rather, that an individual’s experience of deafness can be disregarded by the h/Hearing professional/parent/teacher/communication partner. Although the IHP presents deafness and hearing as binary opposites to make it easy for parents to choose spoken language, they are always experienced in tandem. Cochlear implants and AVT attempt to remove the estrangement of deafness; however, this estrangement cannot be fully removed as a deaf or hard of hearing person will always ‘hear’ the world differently and must find their place as a deaf person in the hearing world. If we consider a child as being neither deaf nor hearing (rather than either deaf or hearing), perhaps we can allow for possibilities other than normative assumptions that result from the either/or binary.

Parental experiences with their children demonstrate this binary is not as oppositional as it seems. The line between being deaf and being hearing is not always clear, nor are the associations between hearing/Hearing (lower case deaf) and spoken language and between Deaf and sign language, as strong as they are made out to be. Difficulty obtaining definitive diagnoses for their children, sometimes due to progressive hearing loss, additional disabilities, or late diagnoses; hearing technologies not resulting in spoken language despite the child’s access to hearing; the necessity of non-verbal cues to aid communication (e.g., interpreting body language and facial expressions, using gestures and signs) in the absence of spoken language during infancy and beyond, all indicate the complexity of the separation between deaf from hearing and sign language from spoken language. However, the IHP’s presentation of a d/Deaf versus h/Hearing binary, the offering of services that support spoken language but not sign language, societal conceptions of deafness and language, and parents’ own normative expectations for their children, guide parents to initially choose spoken language as the ‘right’
choice. The IHP intends this choice to be a fully informed choice, yet some parents often come upon different information later leading to a questioning of this choice and the realization that it was not fully informed.

Parents may begin to question the hearing/deaf binary after experiencing their child’s (absence of) hearing with them; meanings of deafness and language may change. To demonstrate how the construction of parental choice is a multi-layered ongoing process, I now turn to further discussion of how deafness and language matter (both as meaning and materialization) to families serviced by the IHP, and how such ‘mattering’ changed over time for some parents as their knowledge of deafness changed.
Chapter 6

6 The different knowledges of deafness

For if I am confounded by you, then you are already of me, and I am nowhere without you. I cannot muster the “we” except by finding the way in which I am tied to “you,” by trying to translate but finding that my own language must break up and yield if I am to know you. You are what I gain through this disorientation and loss. This is how the human comes into being, again and again, as that which we have yet to know. (Butler, 2004, p. 49)

In Chapter 5, my analysis demonstrated how the Infant Hearing Program (IHP) constructs fully informed parental choice in a way that presents spoken language as the ‘right’ choice. This directing of parents towards an exclusive spoken language approach occurs despite the IHP’s policy of providing unbiased information about communication modality options to parents. What is considered “unbiased information” is tied up with a medical knowing of objectivity, such that what is considered objective or unbiased is informed by medical knowledge-truths about deafness and language. In this chapter, I explore the complexities of how deafness and language are made to matter by the medical language industry,29 and how parents may challenge these imposed institutional and societal meanings as language and deafness materialize in their day-to-day lives with their children.

The chapter begins with how parents of deaf children with additional disabilities experienced the services of the IHP and cochlear implant (CI) programs and an analysis of the significance

29 As noted in Chapter 1, I use the term “medical language industry” to describe a capitalist industry within the medical-industrial complex that medicalizes deafness and language. This medical language industry includes cochlear implant manufacturers, otolaryngologists, audiologists, speech-language pathologists, auditory-verbal therapists, researchers, and manufacturers, publishers and distributors of assessment and treatment materials, all of whom contribute to the medicalization of both deafness and language, and whose services intend to produce normalized hearing, speaking, ‘good’ citizens.
of them not being considered ‘good candidates’ for CI. The experiences of parents whose children were not deemed good cochlear implant candidates versus those who were ‘good candidates’ demonstrate how the interests of medical technology stakeholders informs how both deafness and language are ‘known’ in a society that values and economically relies on biomedical science and technology. I then examine how a limited ‘diagnostic knowing’ based on the medicalization of deafness and the power-knowledge-truth of IHP and CI Programs influences parental decision making, followed by an examination of how some of my parent participants questioned the knowledge-truth presented by the IHP and CI Programs as they came to know their child outside of a purely medical framework. These parents rethought their own conceptions of deafness and language and the decisions they were initially guided to make by the IHP, as they gained lived experience with their child. Judith Butler’s quote at the opening of this chapter describes a process of coming to know another that allows an understanding of how a parent comes to know their deaf child, “I cannot muster the ‘we’ except by finding the way in which I am tied to ‘you,’ by trying to translate but finding that my own language must break up and yield if I am to know you” (Butler, 2004, p. 49). This chapter explores how parents come to know their child relationally and to make decisions based on interactions rather than a knowing of deafness and language removed from any personal experiences of becoming.

6.1 Power-truth-knowledge and the non-ideal deaf child

The parents of profoundly deaf children who were deemed ‘good candidates’ went through the process of cochlear implant (CI) candidacy and surgery relatively quickly. The parents of infants not deemed good candidates had different experiences and the path to CI took longer. In some cases, this may have been due to caution around implanting an infant without fully understanding what was happening in their auditory system, but for others, additional
disabilities seemed to have slowed down the process. These differing experiences raise the question of who the IHP and CI Programs are set up to benefit, and the place deaf children have in a technology-promoting capitalist system.

Vicky adopted her son, Sam, when he was four years of age, and he had yet to learn language. She told me that when Sam was around one year old, the community hospital recommended he be screened for CI candidacy, but his social workers decided to let him make that decision when he was older. Vicky’s understanding was that since he did not get cochlear implants, the IHP dropped his file and put him under the purview of the deaf/blind residential program as he is blind and has cerebral palsy as well as being deaf. When Sam joined their family, Vicky advocated for Sam to receive a CI by taking a legal-rights based approach, that is, by citing Ontario’s disability and discrimination legislation and the IHP’s negligence in not providing him any language services when he was an infant. Vicky felt this approach was necessary to expedite the CI process for Sam, as the CI Program was not keen on implanting him based on the assumption of possible cognitive disability. Because he was already four years old, deaf/blind with motor issues as well, and did not receive the necessary services to assist him learning language when he was younger, Sam was not considered a good CI candidate. This gatekeeping of potential CI candidates raises the question of how the benefit of CI is defined and by whom; CI is promoted by stakeholders and the media as a cure to the problem of deafness, but one that is only acceptable to potential ‘good candidates’ insomuch as these good candidates have the potential to have good spoken language outcomes.30

30 Another issue this gatekeeping raises is that of the potential medical risks of cochlear implantation. CI’s are not without possible surgical complications, and the hesitancy to implant children judged less likely to learn spoken language can be considered a risk-averse, protective measure. The problem that I raise here, however, is how the risk of CI is determined based on spoken language outcomes, which can be considered most harmful to good candidates, or not good candidates, depending on one’s viewpoint.
Rebecca’s son Thomas, who has cerebral palsy, received a definitive diagnosis of moderate to severe hearing loss in one ear, and severe to profound hearing loss in the other ear at one year of age, after many months of testing to confirm the severity. Rebecca reported Thomas was also diagnosed with auditory neuropathy, which she understood as fluctuations in hearing, or hearing without making sense of the sound. Thomas used hearing aids for a while and cochlear implants only became a consideration when the hearing aids did not seem to provide him with access to sound or lead to spoken language, as Rebecca did not want the surgery unless necessary. The IHP (i.e., the diagnostic audiologist and the otolaryngologist) did not refer Thomas to a CI Program upon diagnosis, unlike the severe to profoundly deaf children in my study who did not have additional disabilities. Thomas received his CI at two and half years of age.

Vicky and Rebecca’s experiences with the IHP and CI Programs were different from the other parents in the study whose children were deemed good candidates. Vicky threatened legal action against the IHP for discriminating against her son. Rebecca did not have to advocate for her son in the same way; however, Thomas’s referral to the CI Program came later than other infants with profound hearing loss who were referred right after diagnosis. The ‘good candidates’ were referred to the CI Program at diagnosis or soon after; they still wore hearing aids before getting their cochlear implants, but the process was expedited as they were being assessed for CI candidacy while wearing the hearing aids. Rebecca also told me her auditory-verbal therapist (AVT) asked permission to videotape Thomas so she could show other professionals that kids like Thomas (presumably non-verbal children with cerebral palsy and hearing loss) can benefit

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31 Auditory neuropathy describes a disorder of the function of the auditory nerve in the presence of normal outer hair cell functioning in the cochlea, and which often presents as difficulties comprehending speech sounds (Starr et al., 1996).
from therapy and learn to understand spoken language even if they do not use spoken language to express themselves. That the AVT felt a need to show others Thomas was learning language is an indication that non-verbal children and/or children with disabilities may be passed over for certain services due to inaccurate assumptions of incompetence and ‘poor outcomes.’

When a child is assessed for CI candidacy but found not to be a candidate, the choice about cochlear implants is made for the parent, as the CI option is removed. For example, Heather’s son Wyatt was found not to have an auditory nerve making him ineligible for a CI, and he used a hearing aid in his other ear for a moderate to moderately-severe hearing loss. Heather described her experience after finding out Wyatt was not a candidate for CI, “Once we found out that Wyatt was not a candidate, we kind of entered like a weird kind of zone for a little bit until they figured out what to do with us.” Heather found it difficult to access services for Wyatt once he was removed from the CI Program, as he did not qualify for funded speech-language pathology services (SLP) or AVT even though he was completely deaf in one ear. If he had an auditory nerve and did get a CI, he would have received AVT. Heather was also frustrated with the lack of services for Wyatt due to seemingly arbitrary and illogical rules that differed depending on the geographical region they resided within. Heather felt Wyatt was forgotten until his hearing levels dropped below the threshold, and even then, it took some work to get him services, “it took a fair bit of effort to get him back in the system again to get rechecked, ‘oh yeah your hearing is worse you’re below our magic cut off, you can get therapy now’” (Heather, mother of Wyatt). The provision of AVT or SLP for children with CI but not for Wyatt, who had a moderate to moderately-severe loss in his ‘better ear,’ and no hearing in his other ear, again raises the question of who, or what, the services are meant to help, the cochlear implant industry, or the child.
The rules encountered by Heather, and Vicky’s experience trying to get a CI for Sam, make the rules for service delivery seem such that the CI technology and its success is of more importance than support for the child’s language learning. This may seem like a rather cynical interpretation, but one that is important to consider due to the material effects such rules have for the parents and their children. There is a notable absence of any reference to the personhood of a deaf child in IHP documents; policy and procedure documents focus on the relationship between the auditory system and technology. The rules that govern service delivery in each regional centre provide guidelines for the IHP’s treatment services. As well as being delimited by the availability of individual service providers, these rules are based on a medical knowing of deafness that measures auditory systems and how they may be improved to increase the likelihood of spoken language development.

This biomedical knowing of deafness overlooks the personhood of the child, making it easy to structure services around what is needed to support the technology (i.e., to provide services that may lead to optimal outcomes with technology) rather than to support all deaf children (regardless of which, or if, any technology is used) in learning language. Because the IHP is part of a wider socio-medical system that relies on standardized measurements of bodies around which medical services are framed, the danger in narrowly focusing guidelines for best practices on statistical numbers about discrete bodily systems (e.g., auditory system) and how they interact with technology goes unnoticed. Health care professionals may have the best interest of deaf children in mind when developing such guidelines; however, these ‘best interests’ are framed from a medicalized hearing point of view, which demonstrate an ableist and audist understanding of deafness.

Like most government services, there is also a cost-benefit analysis to determine who should receive health technology and related services. Aside from the medical reasons that could rule
out any benefit to CI, there are certain children assessed to be worthier of the government’s investment in technology and follow-up services. This judgement to provide CI as soon as possible to good candidates (i.e., those likely to learn spoken language) aligns with statements made by the SickKids CI Program director that cochlear implants produce productive citizens32 (Brown, 2011; Ferguson, 2011; Sheppard, 2011); those children who fit the criteria of having the potential for ‘successful’ CI outcomes are the ones that may demonstrate the efficacy of cochlear implants for continued government funding. This is not to say there should not be a thorough examination to ensure safety and that the cochlear implant will provide access to sound before performing surgery, but an appeal to the IHP and CI Programs to consider benefits other than the learning of spoken language, and what their processes tell us about how we make deafness meaningful for both good candidates and not-so-good candidates.

I am not trying to promote the use of cochlear implants, or suggest more deaf children should be implanted. Rather, I suggest that presenting options to parents based on the presumed likelihood of their child developing spoken language restricts their options and has material effects on the children and their families, as the opportunity for deaf children to learn both spoken language and sign language is restricted and the inner ‘voice’ of the child (i.e., personhood, or deaf estrangement) is disregarded. The IHP and CI Programs carefully construct communication decisions parents must make based on assumptions of how the child will learn language, and are influenced by the services and technologies offered during diagnosis and for some children, after CI candidacy has been determined. Along with the diagnosis of deafness, other factors that are ‘known’ about a child influence the technology and services they are offered. In the next

32 See Chapter 1, section 1.6, and Chapter 3, section 3.2 for prior discussion about the SickKids CI Program director’s comments in local media.
section, I introduce a theoretical discussion about how parents initially make decisions based on the knowledge of diagnosis, and all that goes along with such diagnostic knowing.

### 6.2 Knowing the diagnosis of deafness

As outlined in Chapter 1, Ontario’s Infant Hearing Program (IHP) is organized around universal newborn hearing screening (UNHS) to identify infants and young children with “hearing loss” and ensure they receive supports and services during infancy and early childhood. With early identification and service provision, the anticipated outcome for deaf and hard of hearing children is “normal” language development. My analysis thus far has shown how the IHP governs parent-child relationships from infancy to achieve this desired outcome: parents are told about hearing loss, and about how their infant does not hear and what must be done for the child to learn to hear and speak despite their deaf diagnosis. Most of the parents in my study learned something of their child’s diagnosis well before three months of age, and profoundly deaf infants who were deemed ‘good candidates’ were referred to a Cochlear Implant Program by the time they were three months (or even younger). These parents recalled that their children began auditory-verbal therapy (AVT) or speech-language pathology services (SLP) and received hearing aids by three to four months of age, well within the IHP’s goal of beginning intervention prior to six months of age. The IHP’s goal of beginning intervention prior to six months ensures their treatment plan for early language development is in place, but it also requires parents to decide on a course of action for language development for their young infant based on a very limited way of knowing their child, influenced by a highly structured medicalized and bureaucratized diagnostic and treatment protocol that relies on dominant societal constructions of disability and deafness.
My analysis has shown how parents make decisions for their child based on what their child’s
diagnosis (or diagnoses) means to them and how they react to it, as well as ‘expert’ advice given
to them about the diagnosis and how to remedy it, within the context of the IHP structure, as this
intersects with the particularities of the family’s socio-economic life. The child’s future then, is
decided based on what is ‘known’ about their diagnosis, rather than on what is yet to be known
about the child. This medical discourse of diagnosis is based on the “clinical gaze” (Foucault,
1973), what can be observed and what is therefore known about the ear and the process of
hearing. For children diagnosed in infancy, the diagnosis precedes any deliberate
communication on the part of the child and occurs after only a short period of a lived
relationship between infant and parent. However, parents of profoundly deaf infants are
expected to decide whether their child will learn spoken language or sign language, only
knowing the clinical gaze of the deaf diagnosis (and of any other additional diagnoses) but not
yet knowing their child. With this lack of experience with lived deafness and without yet
coming to know their child and how deafness and communication (and the world in general) are
experienced by them, parental decisions are grounded in a hope for normalcy, and decision
making is made easy by the CI Program’s assurances to ‘good candidates’ that their child would
be ‘normal’ by school age. The societal hegemony of normalcy supports the medical framing of
the diagnosis and makes what is ‘known’ about cochlear implants and language powerful
incentives for choosing technology and a spoken language-only approach, when that option is
provided.
The literal meaning of the word diagnosis is “to know thoroughly,” but what exactly is known? The IHP assumes this medical knowing of deafness provides the most important information about a deaf child; deafness as an observable condition and what to do about it comes to define the infant’s subjectivity and parent-child inter-subjectivity. Diagnostic knowing defines subjectivity in a literal sense of how parent-infant communication is structured – after all, the diagnosis is the reason parents must decide on communicating with their child one way or another – and in how children come to be known as deaf. This medical knowing of a child’s auditory system and what can be done to ‘fix’ it, becomes a knowing of how that child can and/or should communicate. Although hearing speech sounds is necessary for learning spoken language, there is nothing inherent in what is known about a child’s auditory system to precisely predict how that child will develop language, with or without hearing technology.

This medicalization of deafness and language is an example of Ivan Illich’s (1977) observation that medical professionals are considered the unquestioned authority, in this case of a deaf child’s language development. As Illich notes, “The dominant professional provides jury or legislature with his own and fellow-initiates’ global opinion, rather than with factual self-limiting evidence and specific skill” (1977, p. 22). In other words, promoting an exclusive spoken language approach for ‘good candidates’ is a moral assumption based on medical opinion and values, rather than so-called medical facts; the clinical gaze does not allow for a prediction of future language development. For example, not every deaf child with CI or hearing aids becomes fluent in spoken language, yet diagnostic knowing is presumed robust enough to

33 The word diagnosis as used in medicine today stems from the Greek word “diagignoskein” meaning to discern or distinguish, or literally as “to know thoroughly.” It comes from the root *gno- meaning “to know” and the prefix dia- meaning apart, or thoroughly. Diagnosis then is a way of thoroughly knowing a condition isolated from other factors, including how that condition might be experienced. (https://www.etymonline.com/word/diagnosis)
tell parents all they need to know about their child, and about how their child should learn and communicate.

Through diagnosis, parents are made to know their child prior to the ongoing process of getting to know their child, and prior to getting to know themselves in relation to their child. However, this diagnostic knowledge and the meanings of deafness and language presented along with it, may get disrupted as parents develop a relationship with their child (i.e., get to know them). Butler’s theorization of how one defines oneself in relation to another describes the process that parents may go through, “…finding that my own language must break up and yield if I am to know you. You are what I gain through this disorientation and loss” (2004, p. 49). As the child (and the parents) grow and relationships develop, parental knowing expands beyond the diagnosis, and what deafness means to them and their child may change. At diagnosis, the child’s deafness is framed as an individual deficit that can create problems for the individual deaf child, which would also create problems for the parents, educators, and others in society with whom they come into contact.

As parents come to know their child relationally, they may search for other ways beyond an individual diagnosis to understand and respond to their child’s social communication needs. This searching for information and services beyond a diagnostic way of knowing can be considered a form of resistance to the way parent-child relationships and deaf subjectivities are governed through the bio-power asserted by the IHP (and the medical establishment and society more generally). I now turn to an analysis of how parents may come to disrupt the prescribed diagnostic knowing of their child.
6.3 Getting to know you: The disruption of diagnostic knowing

As discussed in the previous chapter, the parents of profoundly deaf infants in my study understood that getting a cochlear implant (CI) was the only way their children would have access to sound and learn spoken language. The decision to get a CI was linked to an exclusive auditory-oral approach and an expectation for normal hearing and language by school age. Similarly, as hard of hearing children are generally expected to be able to access sound and auditory language with hearing aids, they are therefore expected to be able to learn spoken language. As parent-child relationships develop throughout infancy and childhood, the expected future discussed at diagnosis or during CI candidacy may become an unexpected present; normalcy (in the form of spoken language) may not appear as anticipated. Deciding on a spoken language approach when an infant is too young to intentionally communicate is a theoretical decision grounded in a desire to normalize deafness for the future. When a deaf child begins to require more than the basic communication needs of infancy, this expected normalization may not be plausible in practice.

At diagnosis and the period following diagnosis, deafness and what to do about it (note the absence of the child here – deafness is discussed as something that occurs separate from a person) is guided by ‘expert’ opinion. Parents ultimately make the decision about communication modality and hearing technologies as they must give consent for the use of hearing technology or participation in therapy, but they are guided to do so by professionals who adhere to a medicalized framing of information. Hearing parents want their child to hear and speak; once parents disclose this to the IHP, the experts tell them how to make their child hear and speak by focusing on spoken language. According to IHP guidelines, this decision regarding communication and hearing technology is to be made by three months of age, and therapy is
expected to start before six months of age, while parents are just starting to get to know their infants. These decisions shape parent-infant interactions, as a commitment to auditory-only communication means parents are expected to interact with their child in specific ways that promote listening and speaking, rather than overall communication.

The knowledge of diagnosis assumes more than a naming of a medical condition. Alongside knowledge of the child’s auditory system (based on the clinical gaze), there is also the knowledge of what it means to be deaf and how it should be treated to approximate normal hearing, speech, and language. Or, if the diagnosis (and/or additional diagnoses) are assumed (known) to make an approximation to normal unobtainable, then alternative and/or augmentative communication systems may be considered. The diagnosis and how deafness and language are made meaningful in relation to the diagnosis, structure the decisions parents make. Decisions about how a child will be encouraged to communicate are based on how language and deafness are meaningful for parents, during the time immediately following diagnosis. As will be exemplified below, for many of the parents I interviewed, their communication priorities and choices changed as they got to know their child after diagnosis, and depending on how their child responded over time to the technologies and therapies that were provided. These new ways of knowing their child disrupted the clinical gaze and often resulted in active resistance to their previously assumed ‘right’ choice as defined by the IHP and CI Programs.

Parents come to realize their child is still deaf after getting a CI, as they cannot hear in certain situations (e.g., when the CI is off at bedtime and while bathing and swimming or when it is malfunctioning). Some parents also found their child was not just like ‘normal’ by school age; they had different ways of communicating that did not fit the standard expectations for spoken language development. How parents think about deafness and language as their child becomes older therefore may change; what is known about deafness becomes integrated with what is
known about the child rather than being a discrete diagnosis only known in the realm of expert opinion. These other ways of knowing, beyond deafness as an observable condition, are neither acknowledged nor encouraged by the IHP; parents are not given any information or tools to comprehend that their other more interactive and personal ways of knowing deafness are even there, let alone valid.

Lauren’s daughter, Natasha, was implanted with bilateral CI when she was 13 months old and Lauren was told to focus exclusively on spoken language and to not sign with Natasha. When Natasha was two years old and not yet talking, Lauren sought other communication options. Through the teacher of the deaf from the Home Visiting Program (HVP), she became aware of bilingual-bimodal education, met Deaf people and decided she no longer wanted to restrict Natasha to an exclusive spoken language approach. The CI Program had told Lauren how to communicate with Natasha based on her diagnosis and the decision to get cochlear implants. After getting to know Natasha, this spoken language only approach did not seem adequate to foster parent-child communication. Nevertheless, Lauren received resistance from the IHP when she tried to access services based on her new knowledge that her daughter needed to communicate in ways other than auditory-oral. Lauren described her difficulty accessing sign language services when Natasha was two years old and not yet speaking,

When I went to SickKids and they put us on the Cochlear Implant Program, which again is a very long process, I was told not to use any sign language with her, because when she’s implanted, she will eventually, through audio-verbal therapy, by the time she’s school-aged she’ll be the same as all the rest of her peers. So, there was no communication almost pretty much for the first year of her life. Now looking back do I think that had a negative impact on her, yes, I do. It wasn’t until she was probably about two years old, so she was implanted, we started with AVT, her speech wasn’t progressing, at all, at two and a half years old I started [sign language services] with the Home Visiting Program through
IHP. And I had to fight for it because in our area you’re only allowed to have one or the other. So, you’re only allowed to have either AVT or sign, you can’t have both, so I had to fight for it. (Lauren, mother of Natasha)

Lauren accessed funded sign language services after a six-month battle with the IHP, demonstrating the IHP’s resistance to parental requests for services that defy an exclusive auditory-oral approach. Lauren’s battle also demonstrates how parental persistence for alternate services can challenge the power relationships of the CI Program and hold the IHP accountable to provide the communication options they outline in their policy. I should note that Lauren was the only parent I interviewed who had decided to send her child to a provincial school for the Deaf, and Natasha was therefore the only child in my study who was on the path to becoming bilingual in English and ASL.

Although she was happy with the decision to teach Natasha sign language, Lauren summarized the difficulty hearing parents have with choosing to immerse their child in the Deaf community. Without resources to help parents learn sign language fluently, it is difficult for parents to become part of the Deaf community that embraces their child. At the time of our interview, Lauren’s funded sign language services were about to end as Natasha was in kindergarten at a Provincial School for the Deaf. After a year of school, Natasha’s signing was progressing faster than Lauren’s, and Lauren needed more support to learn ASL fluently. Lauren’s experience trying to access ASL services for Natasha and the limited support she received in learning ASL has not made it easy for the family to become fluent in sign language. When IHP services end at age six or earlier, parents are on their own to continue learning ASL; it is up to the parents to pay for lessons through the Canadian Hearing Society or the Bob Rumball Centre for the Deaf, if they want to continue learning.
Lauren explained why learning ASL was important not just to Natasha, but to her as well,

I hear from a lot of friends of mine that are Deaf, that growing up, if they had hearing parents a lot of them never learned sign language, they didn’t want to learn, so the child is not included, doesn’t feel included within the family because you have a parent that’s not speaking their language, and I don’t want to be that parent. I want to be very inclusive in her life and now within her community, because now she is a part of the Deaf community. It’s hard. (Lauren, mother of Natasha)

Lauren got to know Natasha in a different way than was expected by the CI Program and found it was difficult to receive services to support this different way of knowing beyond the exclusive spoken language approach required for CI recipients. Although she ‘won’ the fight in accessing ASL services for Natasha, the services provided were not adequate for her to become fluent in ASL, which is especially important for parents whose children attend a Provincial School for the Deaf as their majority expressive language becomes ASL.

Jasleen’s son Nayan had passed his newborn hearing screening and was not designated “at risk,” so he did not require any follow-up. Jasleen noticed when her daughter was born a year later, she responded to noise and spoken language very differently than Nayan. Suspecting that he may have not been hearing everything, she took him for audiological testing. After he had seen a few different audiologists that reported his hearing was fine, he had an Automated Brainstem Response (ABR) done that revealed he was indeed profoundly deaf. With this diagnosis of profoundly deaf at 22 months, the family moved to the United States for Nayan to have bilateral CI surgery there to avoid what they were told would be a six month wait in Toronto. Since Nayan was 22 months old and had already been without access to sound, Jasleen and her husband wanted to take quick action to get him what he needed to learn spoken language. Jasleen did not recall the audiologist discussing their options at diagnosis, leading her and her husband to quickly do their own research; they did not wait to meet with a family support
worker (FSW) before deciding on a course of action. Jasleen’s husband learned about cochlear implants and although Jasleen had misgivings and “protested it until the day of surgery,” they went ahead with cochlear implants. Although they had decided on CI, Jasleen was thankful she had taken baby sign classes (for hearing children) with Nayan when he was an infant, and as soon as he was diagnosed as profoundly deaf, she arranged for that teacher to come and teach her basic signs to assist their communication with him.

Since Nayan’s CI surgery, they have been searching for a school for him. They looked at many different schools in the U.S. and were content with a School for the Deaf; however, at Nayan’s three-year check-up they asked the ENT his opinion about the school and he told them they would be doing Nayan a disservice to put him in a sign language environment since he has cochlear implants and needs to be surrounded by spoken language. Reflecting, Jasleen said “Not knowing Nayan at all, he says this to me,” explicitly stating the discrepancy between this medical knowing of cochlear implants and relational knowing of a person. However, they acquiesced to the doctor’s advice, “We’re like, OK, yeah, he’s right, he’s the doctor, you know, he’s gotta be right, Nayan has cochlear implants, Nayan talks;” and did not put him in the School for the Deaf (Jasleen, mother of Nayan). Although Jasleen’s experience was with a CI Clinic in the U.S. and not Canada, her experience exemplifies the powerful influence professionals and medical knowledge can have on parental decision making. The family had searched for and found a School for the Deaf with a bilingual-bicultural environment; however, the doctor recommended a spoken language only environment since Nayan had cochlear implants, putting the parents in a position to once again search for what they felt would be an appropriate school, that would also satisfy the doctor’s requirements.

The family came back to Toronto when Nayan was three and a half years old to pursue educational options that include both sign and speech, as they were not satisfied with the
available options in the U.S. When they met with a FSW upon returning to Toronto, they were not offered sign language as an option, although they did have a teacher from the Home Visiting Program (HVP) work with Nayan. Jasleen was just getting in touch with Silent Voice (the agency that provides ASL services to the IHP) regarding sign language instruction at the time of our interview, when Nayan was six years old, and they were continuing to search for the right school for him. Jasleen was conflicted between following the advice of the professionals and doing what she thought seemed right for her child and family. Despite being told by the CI Clinic not to use sign language with Nayan, they did use signs: “I don’t care, I did what works. They weren’t the one who came home with him flipping out because he couldn’t use spontaneous expressive language” (Jasleen, mother of Nayan). Nayan’s behavior and their parent-child connection was at odds with the professional directives. Jasleen also had reservations about speech-language pathology therapy (SLP) because of Nayan’s response to it,

Even this morning I spoke with a speech path [SLP] and asked, you know, is this working? Is this something he needs? Are we putting unnecessary pressure on him, because speech [therapy] is the hardest thing for him and he completely hates it, but he does it. He sits there and he does it. But I can see how hard it is. (Jasleen, mother of Nayan)

Jasleen continued the service in the hopes he would be able to express himself verbally and have conversations with hearing peers.

Jasleen described a conflict around wanting Nayan to hear and be ‘normal’ and wanting to accept him for who he is; this was part of the struggle she had with cochlear implants. She

34 Although the doctor told them not to enrol Nayan in a bilingual-bicultural School for the Deaf, Jasleen told me that the oral-only school for kids with cochlear implants did not accept Nayan as he also uses signs to communicate. The spoken language/sign language dichotomy parents and their deaf children are subjected to is therefore evident in the U.S. as well as Canada.
expressed guilt in hoping that, in addition to allowing him “to hear to be safe” the CI would allow him to “join his peers in the hearing world” (Jasleen, mother of Nayan). She described how they are now “bringing to him what he needs” instead of taking an auditory-oral approach without sign language as recommended by the professionals. Jasleen’s family’s struggle with choosing certain communication modalities and therapies that may support them demonstrates the complex inter-relationships between communication partners, as well as how difficult it can be for parents to challenge the dominant medical approach to deafness, both in terms of literally challenging the advice of the doctors, and in terms of challenging their own ideologies. Jasleen wanted Nayan to learn ASL, but she also wanted him to learn speech even though it is difficult for him, because the family is a hearing family that speaks. Jasleen struggled with doing what was best for Nayan while also considering the needs and wants of the family and his place within it, all of which happen within a certain cultural understanding of deafness and language propagated by expert opinion, revealing the difficulties that hearing parents may have in committing to a sign language approach.

Jasleen’s experience demonstrates a constant process of getting to know her child and getting to know herself in relation to her child, and discovering his preferred methods of communication, while using that information to make education decisions. Her experience exemplifies how it can be difficult for parents to make decisions for their child in the midst of receiving conflicting information (from different professionals, online information and their own experiences with their child), especially when expert opinion is at odds with what feels right to the parents. Parents (and everyone else in society) are conditioned to trust that medical professionals have more knowledge than lay people, and more knowledge than the different groups of people who receive medical treatment. As what falls under the realm of medicine has expanded into everyday life (e.g., communication, learning), it may be difficult for parents to challenge
medical opinion about typically non-medical issues (e.g., education), as they may feel their own opinions lack validity under the purview of science. Once parents decide to challenge medical opinion regarding what to do about the condition of deafness as experienced by their child, they may then encounter the difficulty of accessing services they think would be most appropriate. What parents know about their child may change over time, and they may recognize a need for a variety of communication modalities, yet the services offered continue to dichotomize spoken and sign language within a hearing cultural milieu.

Vicky spoke directly of not knowing her son at the time they had to make decisions on his behalf, when he first became part of their family at four years of age:

    In some respects, it was kind of a horrible experience because we didn’t have, we didn’t know our kid at all by that point. Like, I know my kid well now, but at the time, we were making major decisions for him and we had no idea, we didn’t really know anything about him at all. We maybe had a week and a half under our belts of being a parent. (Vicky, mother of Sam)

Vicky ‘knew’ a lot of information about Sam from his case file, yet she spoke of not really knowing him. They had yet to develop a relationship with one another, representative of how knowing someone is more than knowing a diagnosis or what a professional has written about them in a case file. This awareness of not yet knowing Sam on an interpersonal level, yet knowing he had not received services to help him develop language, led Vicky to advocate for Sam to receive every communication option available to them. In addition, as she had a law background and had time to research their options before Sam came to live with them as a four-year old, Vicky could take a proactive approach; she had the time, education, and resources to do her own research on communication modalities and meet with professionals to discuss available services before Sam moved in with them. This positioning led her to be assertive in getting what she felt Sam needed from the IHP, without being swayed or intimidated by medical
opinion. Vicky’s reliance on what she thought was right contrasted with the parents I interviewed who faced the shock of an unexpected deaf diagnosis at infancy, as they experienced more reliance on the IHP’s professional guidance.

Courtney described how she struggled with getting conflicting advice from experts telling her and her husband what to do for their daughter Sydney’s hearing and communication, and how they were just getting to the point where they felt comfortable making their own decisions based on what they felt was right, whether a certain professional agreed or not. Sydney had no hearing technology for 18 months as aural atresia meant that hearing aids would not improve her access to sound, and the audiologist provided no other option. They tried both SLP, with a therapist who was supportive of using manual signs, and AVT, with a therapist who “told us we can’t do sign and we shouldn’t do the teacher for the deaf program because they will only sign.” When Courtney found out about a softband device that could conduct sound through the mastoid bone (bypassing the ear canal) without surgery, she had to “push, push, push for it because nobody really told us about it.” This seemed to be a turning point for them in realizing the knowledge of the IHP professionals was not absolute, “I think we were swayed a lot of the time from people that said, no this is what you should be doing, and now I kind of, I’m like, no we’re doing what is working for us and not feel, you know, bad about our choices” (Courtney, mother of Sydney).

Chelsea had been interested in ASL since before she had children and she therefore considered teaching Ben sign language when they found out he was hard of hearing. However, the IHP did not tell Chelsea she had any options aside from spoken language support for Ben, and ASL was not mentioned in any of the pamphlets she was given. Despite her interest in ASL, Chelsea decided to focus on spoken language in the beginning as she was not offered sign language services and she had read that sign language would interfere with speech development.
I remember reading an article that said learning sign language could delay their speech, whether or not that’s true, who really knows, but I believed it at the time, and thought I want to get my son talking first, so we’ll do you know, the weekly AVT first, and then add it in once he’s talking, we can start adding in some ASL. My son’s speech never did come along as we expected it would, so I started learning sign with him as a way to help him with his frustration because he was two and a half and still not talking and very frustrated because he had a two and half year-old brain that wanted to tell us things. (Chelsea, mother of Ben)

The diagnostic knowledge that hard of hearing children can access sound with hearing aids means they are expected to learn spoken language without any need for ASL. “Because Ben is in the moderate to severe range it was just sort of like a given that he would wear hearing aids” (Chelsea, mother of Ben). The parents of hard of hearing children in my study were not explicitly offered sign language services or even told they were available.

Chelsea told me that when Ben was “two and a half and still not talking and very frustrated” she noticed a poster for Silent Voice in the AVT’s office. She asked the AVT about Silent Voice, then asked to be referred, and managed to arrange for a teacher of the Deaf to teach her and Ben sign language every other week. Although Chelsea accessed the services without resistance from professionals, she noted that the services were not openly offered to them, she had to be proactive about getting them. Chelsea also paid to take ASL classes in the community and she has found that it has improved their communication. She regretted not signing with Ben from the beginning, “I just wish I had started the ASL sooner but again you know I read a stupid article that said it would delay his speech right?” (Chelsea, mother of Ben).
Although Chelsea was aware of and had an interest in ASL, the information she had easy access to through the IHP and VOICE\textsuperscript{35} (the VOICE website is where Chelsea read that “stupid article”), supported an exclusive spoken language approach. It was easy to find information in support of spoken language as powerful organizations like VOICE promote hearing technologies and spoken language and provide access to information that seems to support this approach.\textsuperscript{36} Chelsea made the decision to not include signs with Ben at the beginning based on what is ‘known’ as truth, yet Chelsea’s experience with Ben over time indicates that what is typically represented and understood as truth is reflective of socio-political constructions that frame deafness and language in ways that support spoken language and the medicalization of deafness, while discounting alternate truth-knowledges that support sign language.

6.4 Discussion: The ‘fight’ against IHP/CI power-truth-knowledge and the ‘right choice’

Organizations such as the IHP, CI programs, and Voice for Hearing Impaired Children, are organizations which reflect and uphold a medicalized view of deafness, where deafness is

\textsuperscript{35} VOICE for Hearing Impaired Children is a large parent advocacy organization based in Toronto that actively supports and advocates for auditory-verbal therapy and an exclusive spoken language approach for deaf children (http://www.voicefordeafkids.com). VOICE is supported by SAC and has a partnership with the Teacher of the Deaf Program at York University.

\textsuperscript{36} The research studies available on the VOICE website compare children with cochlear implants who are educated in Oral Communication classrooms (OC) with those educated in Total Communication classrooms (TC), not children who use sign language versus spoken language (Geers et al., 2011; Moog & Geers, 2003). Although beyond the scope of this thesis to address in detail, there are many problems with using such studies as evidence against early sign language learning. Briefly, one problem is children with CI in TC classes are often those who did not do well in OC classes, so it cannot be assumed that the TC classroom caused the poor outcomes. Another is TC classes use various visual supports along with spoken language (they are not sign language classrooms). Therefore, studies that do not explicitly examine the effect of early sign language use on spoken language have been inappropriately used to support an exclusive spoken language approach. However, studies that do show evidence that early sign language use supports later spoken language development are not provided to parents.
sought to be normalized through a purely spoken language approach to communication. These organizations make a social issue (both in terms of the social construction of deafness and the social nature of communication) seem as if it were ‘just’ a medical issue to be dealt with a certain way. As this medicalized view fits in with society’s expectation of fixing disability, the knowledge they impart is often understood as factual truth. Although the IHP has a policy to provide unbiased information to parents to allow them to make fully informed choices, IHP pamphlets and parental experiences indicate that spoken language is presented as the de facto ‘right choice.’ As spoken language is the societal norm, supporting a spoken language approach for deaf children is not recognized by the IHP as showing bias towards spoken language; it is the objective ‘normal’ that is to be expected, making it the unquestioned right choice. However, the IHP seems to be careful in how sign language is presented to parents, to ensure that no bias is shown towards a visual approach to communication.

In addition, professional medical authority is held in high regard and assumed to be objective: “The very expertise, being socially legitimated, makes this judgement seem morally neutral” (Zola, 1977, p. 64). While seeming morally neutral, the IHP therefore continues to emphasize an approach that is already hegemonically accepted and taken for granted (known) as the normal and hence right way to communicate, whereas the visual approach, that does not fit into the normal way of communication and is not known by parents, is neglected. The onus is therefore on parents to learn about and decide if they want to pursue sign language as an option. This decision to pursue sign language is frequently made against powerful professional advice, and is often followed by a fight to obtain paid services (and/or a willingness to pay for ASL classes); the decision is made difficult by the subaltern position that sign language holds within the IHP and within Hearing society.
The IHP tries to mitigate the power of professional opinion by making fully informed choice and unbiased presentation of the options central principles of the program. These principles make it seem as if the professionals could present unbiased information about all the communication options to parents, and parents then have full autonomy in choosing the option(s). However, as discussed in the previous chapter, simply stating the neutrality of the professionals does not make it so; what is known as objective, unbiased information follows an already medicalized framing of deafness. Speech-language and hearing professionals inherently support hearing technologies and a spoken language approach, and only one parent in my study (Vicky) met with a Deaf person through the IHP as she made it clear she wanted to teach Sam sign language from the beginning. All the family support workers (FSW) the parents met with were hearing and Deaf people were not included in meetings with the other parents. Without an opportunity to meet with Deaf people, and instead merely telling parents they have an option of sign language within a setting that is otherwise completely immersed in Hearing culture, sign language and Deaf culture remain in a subaltern realm of alternate knowledges not fully embraced by the IHP, and outright eschewed by CI Programs.37

When parents must make decisions soon after diagnosis, they look for information to help them decide what to do regarding language choices for their child, and they make such decisions based on the diagnosis and what is ‘known’ about their child’s hearing, particularly what professionals tell them. Over time, parents come to know their child and how they communicate, and make further decisions based on what they have learned about their child rather than based on their diagnosis (or diagnoses). What deafness means for the child begins to

37 For further discussion of power-knowledge-truth within a cochlear implant program in Toronto, see my genealogical examination of the CI Program at The Hospital for Sick Children in Toronto, http://dsq-sds.org/article/view/4312
take precedence over what deafness means for the parent based on the diagnosis and all that goes along with it. With this ongoing process of knowing, the needs of the individual child and the parent-child relationship become important factors in decision making, rather than the diagnosis and the assumed right choice of spoken language leading the way. If parent-child communication becomes hindered as the child grows, there may be a shift in the types of knowledge parents consider most important: whatever the child needs to communicate in the present time may become paramount, rather than what they are assumed to need for an idealized future version of a hearing, speaking child. In a sense, the development of the child and lived experience together disrupts what is considered normal; expectations of normal hearing and normal speaking as an ideal may be put aside to ensure parent and child foster a communicative relationship.

This modification of expectations as the parent-child relationship develops (along with the relationship the child has with the world and other people in their world), shifts the focus from the child’s individual deafness to the social-relational aspects of deafness, demonstrating in a material way, how deafness is a social issue rather than an individual issue. Deafness is not forgotten, but becomes meaningful in ways other than medical. For some parents, this shift has them considering the estrangement of deafness and how their child experiences the world as a deaf person, rather than insisting they learn how to become fully familiar with the hearing world to the detriment of their deaf estrangement. This coming to know their child as a social being with their own unique way of experiencing the world through sound, disrupts the knowing of the diagnosis and the influence of the expert opinion that came from that diagnosis. Although diagnostic knowing leads parental decision making in ways that attempt to remove deafness, when the child’s need to communicate becomes paramount in the preschool years, deafness as a diagnosis becomes of less importance than deafness as a way of being and part of family life
(which can be very different than clinical life), which can lead to an acceptance of deaf estrangement. However, parental acceptance of deaf estrangement still happens within a setting dominated by medical ways of knowing, resulting in some parents having to ‘fight’ for services that do not medicalize deafness and language. The significance of the need for parents to fight for services (and how they should not have to fight) will be addressed in the next chapter.

Parents of children who had more of a complicated diagnostic presentation, such as those children with additional disabilities or whose deafness did not fit neatly into an easily recognizable diagnostic category, were not presented with options in the same way as those whose deafness was considered ‘fixable.’ For these parents, diagnostic knowing did not provide enough information for them to make decisions based solely on their child’s diagnosis, as the recommendations from professionals were not as specific. The IHP and CI Program interactions with the families of children who were not considered to be good candidates for CI, or who presented with complicated diagnoses presumed not easily ‘fixed’ by CI or hearing aids, reveals how the meanings of deafness are defined within a socio-economic system that works to promote technology and the professional services that support that technology. When a deaf child is assumed to not have a good chance for a successful CI outcome (i.e., to develop spoken language), the rush to implant and the insistence on a spoken language approach may be reduced.

This critical interpretive analysis of parental experiences with the IHP demonstrates that the medical response to ‘fix’ deafness is not as straightforward as it may first appear. Although first based on the knowledge of diagnosis and a desire to ‘help’, what to do about deafness is also tied up with the promotion of technology and which children are expected to become spokespeople for the technology (people who can literally ‘speak’ about what the technology
This fixing of deafness does not seem to be for hearing in and of itself, but for how access to hearing can allow for the learning of spoken language: deafness is a (spoken) language problem so when cochlear implants are not expected to fix the language problem, the implanting of CI becomes less urgent. Technology is at the centre of IHP services: primarily the screening and assessment technologies, as well as hearing aids for hard of hearing children and cochlear implants for severe to profoundly deaf children.

Technology that is less common and less profitable may not be pursued to the same degree as more popular technologies promoted by service providers. Not all service providers receive financial compensation for promoting specific technologies, but some in more powerful positions do gain financial benefit. For example, SickKids only implants children with cochlear implants from the Cochlear Corporation, and the current director of the SickKids CI Program holds the inaugural chair in Auditory Development Research funded in perpetuity by Cochlear Corporation. He also serves on the speaker’s bureau for the Cochlear Americas Corporation (Ear implant problems rare, 2011; Wolter et al., 2016). Although likely working in what he considers to be the best interest of deaf children, the director also has a vested interest in implanting children and demonstrating the benefit of the technology. In addition, if a child has no CI to support, such as Wyatt’s case after leaving the CI Program, speech-language services may not be provided to the same extent as if there was technology to support. Children who are

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38 An example of how CI recipients may become spokespeople for CI and CI Programs is a 2011 Canadian Broadcasting Corporation news series promoting the 1,000th cochlear implant procedure performed at SickKids. Two young adults who had received implants as children were interviewed about how much they have been able to accomplish in life because their implants allowed them to hear and speak, the insinuation being that they would not be so successful and happy without the implants and spoken language (Sheppard, 2011). This is a modern example of a long history of educators/professionals using ‘successful’ deaf children to publicize their approach/technology for the purpose of receiving funding (Blume, 2010; Mackay Institution for Protestant Deaf-Mutes and the Blind, 1885).
implanted receive services to support the CI technology,\textsuperscript{39} whereas children who require
technology that is less common and does not have the same level of financial and professional
promotion (e.g., the softband technology that Sydney did not get until 18 months of age), may
not be supported in the same way.

How deafness and language are made meaningful depend on an interplay of cultural norms
within a capitalist society and have material effects for deaf children and their families.
Professionals make judgements about the best course of action after weighing multiple factors
that may affect the child’s learning of spoken language (which is often taken as the ultimate and
only goal). How options are presented to parents depends on the expectation of a child reaching
this ultimate goal. The push for spoken language and technology to support it is reduced when
the expected speech-language outcomes are not favourable, such as when there may be other
reasons aside from hearing that can affect the goal. When spoken language is not the expected
outcome, more communication options are considered acceptable and are made available to the
children. ‘Good candidates’ are given access to technology that can give them access to sound.
However, this “chance to develop spoken language” may result in the removal of opportunities
to learn other methods and modes of communication. As Gibson notes, “Paradoxically, in
working toward helping people live better lives, rehabilitation risks limiting possibilities and
potentials when it adopts a too narrow notion of what constitutes a good life” (2016, p. 43).
When spoken language is the expected outcome and deemed necessary for a good life, the
potential of sign language is limited.

\textsuperscript{39} It should be noted that not all parents reported receiving funded AVT after their child received their CI. Both
Melissa and Rebecca lived outside the greater geographical area surrounding the three CI Programs and they pay
for private AVT as they were offered funded SLP services (with SLPs who did not have much experience with deaf
children) but not AVT, as there were no IHP-funded AV therapists in their area.
On the other hand, deaf children with other disabilities may not be given the same chance to learn spoken language like hearing children, as they may not be given the same access to the technologies that could give them this chance. However, they may instead have the opportunity to access different modes of communication without the same spoken-language only restriction placed on good candidates. There is an intricate system organizing the gatekeeping of different services based on professional judgements of which deaf children may, or may not, become like hearing, speaking people, resulting in a hierarchy of normalization. Whether a good candidate or not, there are limitations placed on families and their children based on judgements being made by people and programs who benefit in some way from those decisions.

How parents are made to know their child as having the problem of deafness upon diagnosis is closely tied to how deafness and language are made meaningful by the complex intra-action of multiple facets of the medical language industry in which they (and all other families in Ontario) are immersed. How parents of deaf children come to know their child (and their child’s ‘problem’) within their first year is dictated by the diagnostic information given, the technologies that are (or are not) offered, and the communication options and related services that are (or are not) offered. All these offerings, including who is offered what and when, demonstrate the ordering of hearing, disability, and language orchestrated within a hierarchical socio-economic system whose purpose is not just to serve individual deaf children and their families, but the financial interests of those whose professions depend on the technologies and the normalizing work of the medical language industry. This system is the framework of cultural norms that precede our becoming, “The ‘I’ who cannot come into being without a ‘you’ is also fundamentally dependent on a set of norms of recognition that originated neither with the ‘I’ nor with the ‘you.’” (Butler, 2004, p. 45).
The parent-child relationship and their coming to know each other is inextricably linked to how deafness and language are presented by the IHP and delimited by wider societal norms. As parents come to know their deaf child, the dependence of this mutual becoming on the “norms of recognition” may shift, resulting in a ‘fight’ or ‘struggle’ between the parents and their own expectations of normalcy. Parents engage in critical reflection when they question their taken-for-granted assumptions and the expert opinions that fostered those assumptions and governed the way they interact with their children. If parents then decide they would like to use sign language with their child, or would like to consider a bilingual-bicultural educational environment, there is a further ‘fight’ with the IHP and/or CI Program; a fight against the hegemonic medical way of knowing deafness and the institutions that support such a way of knowing.

The fight begins when new knowledges present themselves to parents and they begin to question decisions that are based solely on diagnostic knowledge. The symbolism of the fight and how it materializes can be understood in terms of Foucault’s trifecta of power-knowledge-truth (Foucault, 2003c; 2003d). What is taken for granted as ‘truth’ (by society, medical professionals, and parents), is what is known from a scientific/medical understanding of deafness set within a system of power relations. These power relations are structured such that scientific institutions (IHP, CI Programs) exercise power by governing the actions of parents in a way that upholds this ‘truth’ of deafness. “‘Truth’ is linked in a circular relation with systems of power that produce and sustain it, and to effects of power which it induces and which extend it – a ‘regime’ of truth” (Foucault, 2003d, p. 317). The IHP’s regime of truth is what allows hearing technologies and spoken language to remain the assumed ‘right’ choice for deaf and hard of hearing children who are expected to be able to learn to speak.
Foucault (2003c) insists when there is a relationship of power, freedom must also be present. Freedom becomes apparent when parents actively challenge the medical ‘truth’ of deafness, and when children unwittingly challenge the ‘truth’ by not conforming to expectations (‘good candidates’ do not always meet parental and CI Program expectations for spoken language development). Although parents are governed towards making certain decisions for their deaf children, and children are then in turn governed to learn to hear and speak, the children’s communication and language development do not always conform to the outcomes expected of such governing. With their children’s conduct challenging expected outcomes, parents may then challenge the IHP’s regime of truth, and fight to obtain services that do not necessarily fit within the medical truth of deafness.

This fight or struggle parents often referred to is therefore a fight between the hegemonic medical knowing of deafness and alternate knowledges of deafness. It is not simply a fight between different groups of people (e.g., Deaf people/culture versus Hearing people/culture or parents/family and professionals/program) or a struggle to access services, but a fight between the actual experience of deafness and how deafness is typically conceptualized and hence ‘treated’ as a condition to be fixed. It is a fight for recognition that there is a person attached to the deafness, with their own personal experiences and way of living with deafness; a recognition that ongoing relationships with others cannot always flourish when the development of those relationships is limited by how deafness is conceptualized and deaf bodies are governed.

In the concluding chapter to follow, I discuss possibilities for the re-imagining of deafness and propose the IHP has the opportunity to fight along with parents rather than against them to broaden deaf subjectivities. In fighting against a purely medical understanding of deafness and language, and offering services that acknowledge deaf experiences, the IHP can meaningfully transform life experiences for deaf infants and their families. I now turn to the final chapter in
which I summarize and synthesize key points from my analysis and provide suggestions for rethinking how deafness and language are made to matter.
Chapter 7

7 Re-constructing parental choice by re-imagining deafness

In this dissertation, I have examined the many ways language and deafness are made meaningful through text and lived experience in Ontario, and how parents come to make choices for their deaf and hard of hearing children. I situated my research within disability studies to question normative assumptions about speech, language, and hearing, and the meaning of fully informed choice, to understand how meanings of disability, hearing, and language can shape the way communication options are presented to and understood by parents. Through interpretive analyses of Infant Hearing Program (IHP) documents and parental interviews, my research demonstrated how the IHP frames deafness as an unexpected problem that can be remedied with the IHP’s services, specifically through the use of hearing technologies and spoken language services. The IHP’s normative assumptions, which are reflective of assumptions held by the wider society, construct parental choice by presenting deafness as an unthinkable and undesirable outcome of screening and spoken language services as the ‘right’ way to deal with this unexpected outcome. However, my analyses also showed that how the IHP deals with the outcome of deafness differs depending on whether a child has additional diagnoses and whether they are assumed able to learn spoken language.

Furthermore, I found the IHP’s principle of “fully informed parent/guardian choice and consent” reflects medical knowledges of deafness with the repeated messaging about hearing technologies and spoken language, while making it seem as if parents are given comprehensive information to help them understand their child’s communication options in order to make an informed choice. My textual analysis demonstrated that “fully informed” did not include much information about sign language and Deaf culture (if at all), which was consistent with parental
accounts of their experiences with screening, diagnosis, and intervention. These results point to a problem with the general principal of fully informed choice and consent prevalent throughout the health care field, which I discuss further in section 7.3 below. My analysis also showed how parents may resist medical knowledges of deafness as they get to know their child beyond diagnostic assumptions, an indication that parents and their children may benefit from services that promote a wider variety of communication options from infancy, regardless of expected outcomes. In this concluding chapter, I explore ways the Infant Hearing Program can re-imagine deafness as other than a problem, and assist parents in being aware of how they think of their child’s deafness and the consequences of the communication decisions they make for their children.

My analysis of deaf diagnostic and intervention practices in Ontario demonstrates that spoken language is taken for granted as the only desired outcome for deaf children who are assumed capable of learning to speak with technologies that provide access to sound (e.g., cochlear implants and/or hearing aids). The assumed normativity of hearing technologies and spoken language as solutions to the problem of deafness make it easy for the IHP to support such solutions while disregarding other solutions, despite stating they provide parents with different options to ensure parents are “fully informed.” The IHP’s hearing-centred solutions are based on a long history of hearing people attempting to ‘help’ deaf people integrate into mainstream society by teaching them the written and spoken majority language. In more recent times, the advent and promotion of hearing technologies within a society that relies on scientific technologies for economic gain (both in the direct exchange and use of technology, and in the expected improved productivity of those who make use of the technology), has strengthened this assumption that spoken language for deaf children is attainable and desirable, while sign language is represented as unnecessary and even harmful. My genealogical analysis
demonstrates how the IHP’s ‘options’ “prevailed by ruling out others” (Scott, 2007, p. 28). By showing how alternatives have been disregarded (e.g., alternate ways of understanding deafness and disability; alternate ways of understanding language; alternate ‘outcomes’ beyond spoken language), my analysis allows for a reinterpretation of ‘how things are’ to suggest instead ‘how they could be.’ How can the IHP reinterpret what it means to be deaf as something other than a problem, to then provide services that allow deaf children many communication opportunities and the ability to discover who they are rather than presenting them (and others) with a restricted view of their deaf subjectivities?

As a government organization that has contact with over 90% of new parents in Ontario, the IHP is in a position to service deaf children and their families by challenging, rather than upholding, constraining normalizing ideologies about deafness and language. To do so, first, program administrators and service providers must acknowledge the current policies and practices of the IHP do not result in parents receiving “unbiased” information to make “fully informed choices.” This acknowledgment relies on IHP professionals reflecting on and questioning their own conceptions of what it means to be deaf and what it means to have language, the conceptions enforced by their respective professional organizations, and how these conceptions influence their practice. Once acknowledged, the way deafness and language are presented to parents, and the options provided to them, can be altered to ensure parents have the opportunity to learn about how the expectations of the various options have consequences for how they will come to know their children, and how their children will come to know themselves. After a brief explanation of the difference between access to sound and access to language, in thinking about how things could be otherwise, I present some improvements for the IHP to consider. Above all, and central to each suggestion, is the need to assist parents in knowing the possibilities for their children and providing services that foster those possibilities.
7.1 Access to sound versus access to language

In terms of the impairment paradigm, deaf children are not seen as normal, and making them normal becomes more important than allowing them to be human and facilitating their learning by whatever means. (Corker, 1998, p. 83)

There are two separate issues related to deaf diagnostic and intervention practices which the IHP currently presents as one normalizing issue: access to sound and access to language. This conflation of access is evident in SAC’s position papers as discussed in Chapter 5, in which “auditory deprivation” is stated as the concern, rather than language deprivation. It can be argued that access to sound is not needed for access to language as sign language requires no hearing or speaking, and many sign language advocates endorse sign language as the natural language for deaf people (e.g., Lane, 1992; Paul & Snoddon, 2017). The IHP currently frames the diagnoses of deaf and hard of hearing as a medical issue, where access to hearing through hearing technologies is deemed necessary for access to language. I suggest instead that the IHP may better inform parents of all communication options if the diagnosis of deaf or hard of hearing was to be considered first and foremost an access to language issue, and by extension an access to education issue. Placing the focus on communication and language rather than the habilitation of hearing could allow for a shift to services that assist families and children in developing communication systems and using the language(s) that work for them, instead of limiting children who use hearing technologies to learn exclusively through hearing and spoken language. This shift towards access to communication and language rather than hearing would reduce the ordering of hearing and the hierarchy of normalization that currently govern parental choice. Providing access to sound through hearing technologies should be recognized as necessary for teaching deaf children spoken language, but not as the only (or best) way for them to learn language and develop other linguistic-related skills (social, cognitive, educational).
Structuring the IHP around access to language would require a conceptual shift (discussed further in the following section), away from deafness as a biomedical problem requiring a biomedical solution to a cultural situation requiring a social-interactional and contextual response. This would require the provision of a wide range of communication and language opportunities, rather than the provision of limited opportunities based on how deaf children are assumed to experience the world aided by hearing technologies. All deaf and hard of hearing children and their families should be provided with opportunities to learn sign language; be encouraged to develop their own home gesture-sign systems; use augmentative/alternative communication systems; and to use whatever works to give them a way to communicate with other people on their own terms. Hearing technologies can be presented to parents as tools that provide access to sound and hence possibly to spoken language, but spoken language should not be presented as the only ‘ideal’ outcome, nor should the importance of visual or tactile modes of communication be discounted.

Placing secondary importance on hearing technologies may seem counter-intuitive and in contradiction to the medicalization of deafness which defines the education and practice of doctors, audiologists and speech-language pathologists. The difficulty stepping back from access to hearing as the ultimate goal for language development is especially salient in the discourse of neuroplasticity and the framing of deafness as a “neurological emergency” requiring immediate access to sound and auditory-verbal therapy (Dornan, 2009). I am not suggesting hearing technologies be abandoned, but rather, suggest a conceptual reframing that recognizes the medicalization of deafness without placing absolute importance on hearing technology and spoken language, as such thinking has subjugated deaf children for generations. To allow for individual development and growth, it is imperative to acknowledge that deaf children experience the world differently than hearing children, and to nourish those differences
as accepted ways of being human. The acceptance of deaf difference need not necessarily delay the use of hearing technologies for access to sound and spoken language; rather, such technologies should not be used at the expense of other ways of being deaf.

7.2 Deafness as other than failure

The IHP’s presentation of deafness as failure reflects an overarching societal understanding of deafness and disability, which is also taken up by parents as members of society, within a capitalist order that ranks people based on their productive capacity to economically contribute to society, and/or their economic burden on society. This economic-based ranking of disabled people has been critically engaged by disability studies scholars for some time now (e.g., Hunt, 1966). In a World Health Organization (WHO) paper addressing what is presented as the large public health concern of hearing impairment, hearing loss is quite literally presented as a financial problem to solve, with the solution being the living of a normal life, or as close to one as possible (Duthey, 2013). 40 The 2015 WHO Global Burden of Disease study ranks and describes degrees of hearing loss from “mild” to “complete.” Descriptions focus on the degree the person can hear someone else talking in various situations (e.g., in a quiet room, on a phone) and how well they can communicate and relate to others, with “others” presumably being hearing people who speak, and “communicating” referring to expressive spoken language (World Health Organization, 2017, p. 36). The WHO’s ranking of hearing loss is reflected in deaf education practices as theorized by Corker,

40 This WHO paper provides details on the possible causes of hearing loss, diagnostic procedures, prevalence of hearing impairment around the world, control strategies, the financial cost of hearing loss (the burden) and why the burden persists, research on pharmaceutical interventions, “products” used (where sign language is counted as a product), and available funding sources (Duthey, 2013).
If the goal of education is to enable communicative choice and freedom in social participation, it is shortsighted and arrogant to suppose that deaf children will want to communicate only with hearing people. Moreover, manipulating language in this way, particularly at the political level, creates an artificial division between Deaf and hearing impaired people and, it must be said, between the ‘successes’ and the ‘failures’ of the system. It is still the case that only the ‘most profoundly’ hearing impaired children – those who are most likely to ‘fail’ – need sign language. (Corker, 1998, p. 88)

The IHP’s presentation of deafness as failure within a culture that already frames deafness and disability as problems to be (re)habilitated with hearing technologies and spoken language, sets up the necessity of the supports and services of the IHP to fix the problem of deafness; it is a social action that puts parents on a path of searching for normalizing solutions to the unexpected problem of hearing loss.

My research shows how the IHP relies on many assumptions based on a bio-medical epistemology of deafness. The IHP assumes that: all hearing people share the same meaning of deafness as problematic; the ‘problem of deafness’ needs to be deciphered, dealt with, and normalized as soon as possible; this management of deafness can and must be done in a medicalized ‘right’ systematic and consistent way based on what is considered ‘objective evidence.’ These assumptions rely on deciphering diagnoses rather than understanding lived experience: “In standard and routine ways, the lived experience of disability becomes encoded as a series of signs and symptoms in need of deciphering by the experts of normate culture” (Titchkosky, 2003a, p. 163). Presenting these assumptions as evidence-based within a bio-medical deciphering of deafness removes cultural conceptions of deafness (both Deaf culture knowledges as well as the understanding that bio-medical knowledges are themselves culturally constructed). The power assumed in the medical knowing of deafness masks how such knowing is a social construction within a society that values normalcy, as well as biotechnology and its
economic advantages. This leaves the individual diagnosed with ‘the problem of deafness’ (as deciphered by ‘experts’) as the target of habilitation. In this way, the IHP makes a social issue seem as if it were only a medical issue to be dealt with in a certain medicalized and normalizing way.

The IHP has the opportunity to disseminate different conceptions of deafness to counter the hegemonic bio-medical and audist understanding of deafness as a problem. As previously noted, it would first be necessary for the IHP to critically reflect on how the current presentation of deafness creates limited deaf subjectivities constrained by societal understandings. How does a focus on diagnosis, assessment, and treatment limit deaf subjectivities and shape parent-child relationships? After a realization and acknowledgement of the existing constraints on deaf subjectivities, the IHP can then have a significant role in expanding societal understandings to embrace more than a medicalized Hearing point of view. This could include bringing awareness to Deaf Gain, “the unique cognitive, creative, and cultural gains manifested through deaf ways of being in the world” and the benefits of embracing human diversity (Bauman & Murray, 2014, p. xv). Bauman and Murray propose the medical framing of the term “hearing loss,” which typically refers to a deaf person’s ‘loss’ of hearing, instead refer to “the loss that hearing people experience by not being open to the benefits, contributions, and advances that arise through deaf ways of being” (2014, p. xxxviii).

The current practices of the IHP demonstrate Bauman and Murray’s alternate conception of hearing loss: the denial of d/Deaf ways of being translates into experiences of parental loss through the IHP’s focus on aural habilitation and spoken language and the way parental choice is constructed around the disappearance of deafness instead of the acceptance and benefits of deafness. I propose that through considering Deaf Gain and sharing with parents the many benefits and joys their children may experience by embracing their deaf ways of being, the
parents’ lives may in turn be enriched through new ways of experiencing the world. Introducing parents to this concept of Deaf Gain from the beginning of screening could help them understand deafness as a different sensory experience as opposed to a failure (compared to the norm of h/Hearing). A positive first impression of their child’s diagnosis was also discussed by parents in Young and Tattersall’s (2005) study, where they asked parent focus groups for feedback on a draft information packet for England’s equivalent of the IHP.

There was a great deal of discussion in all groups about the importance of setting a positive tone in the choice of language used and in the presentation of information…Hearing parents were also acutely aware of how powerful first impressions had been for them as they began to understand what deafness was and what its implications were likely to be for their family. (Young & Tattersall, 2005, pp. 68-69)

A possible outcome of screening and assessment then could be to assist parents in understanding and embracing their child’s differences and needs through a positive attitude about deafness, rather than assuming those differences need only be ‘fixed’ in a medical sense.41

One way the IHP can present deafness as something other than failure is to reconsider how screening results are shared with parents. Although the IHP presents a failed screening to parents as a “refer” result to avoid unnecessary stress and worry, my analysis demonstrated that deafness is presented as an unwanted outcome during the screening process, making deafness

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41 Introducing parents to a positive attitude about deafness and encouraging them to consider how being deaf may be experienced by their child (rather than from the hegemonic Hearing point of view), should not discount the parents’ and children’s affective experiences with deafness. For example, Michael Davidson (2016) suggests that loss should be included in the politics of deaf gain. Although writing from the view of a late-deafened person and not a parent of a deaf child, parents also experience certain ‘negative’ emotions and a feeling of loss when coming to terms with the need for different communicative interactions with their children than what was expected. Davidson suggests that we “acknowledge the lived experiences of loss, frustration, pain and embarrassment in a politics of gain” and be careful to not “deny experiential elements of complex embodiment that constitute the matrix of disability” (2016, np). My suggestion for the IHP to present a more positive view of deafness then, should be done in a way that recognizes the complexities of embodied experience, while providing parents support to consider alternate views of what deafness may mean to their child.
itself a failure. When the screening test indicates the child’s ear/ears did not respond to sound, the IHP is careful to tell parents their child had a “refer” result instead of saying the child failed the screening: “‘fail’ is never used in conjunction with a screening result because it alarms parents unnecessarily and because it does not capture the true significance of not recording an OAE [oto-acoustic emission]. If the test is done properly, less than about 5% of well babies will fail it” (Ontario Ministry of Health and Long Term Care, 2002, p. 9, italics added). The IHP uses “fail” to describe the screening result within internal IHP communications, but “refer” is used in communications with parents to manage parental worry. Parents whose children do end up having a deaf or hard of hearing diagnosis retroactively interpret their child’s “refer” result as them having failed the screening. The IHP needs to recognize that deafness is being conceptualized and presented to parents as a failed (and unwanted, unthinkable) outcome regardless of the wording used for “failed” screening results. How can the IHP assist parents in coming to understand “failure” as not the only thing to be imagined on the other side of not hearing?

I suggest the IHP critically examine how language and deafness are being constructed while trying to manage parental worry and action, and modify their protocols to remove the ‘taboo’ possibility of a deaf diagnosis. In ‘protecting’ those parents whose children can hear (those whose second screening or audiological assessment shows normal hearing) from unnecessary worry, the diagnosis of deafness is made unexpected and unwanted. The paternalistic assumption that parents cannot ‘handle’ the possibility their child may not hear is based on the likely assumption that parents already come to the screening process with a preconceived understanding of deafness as problematic. This careful manipulation of parental worry to increase compliance with screening and assessment follow-through makes the problem of deafness unthinkable. To ensure parents of infants who fail the screening receive follow-up
audiology assessment, IHP protocol states, “The key ingredients are the information system that records and flags infants requiring assessment, and a careful process of family intervention and instruction that promotes compliance yet is sensitive to family anxiety levels” (Ontario Ministry of Health and Long-Term Care, 2002b, p. 179). The IHP should consider how their “careful process of family intervention and instruction” constructs meanings of deafness, and work towards giving parents comprehensive information in an open manner, rather than in a way that is assumed to ‘increase parental compliance.’

Rather than perpetuating this negative biomedical notion of deafness and insisting on parental compliance with a biomedical epistemology, the IHP can play a role in shifting such negative connotations and help parents consider what deafness may mean to their child outside a medicalized frame. Although many infants with normal hearing (around 5% as indicated in the above quote) fail the screening because of temporary conditions such as fluid in their ears, the purpose of the screening is to identify those children who are deaf and hard of hearing, and the possibility of this outcome should be made clear to parents. Rather than presenting a deaf diagnosis as unwanted and unexpected, the IHP should make parents aware of the slight possibility of deafness, which is the reason for the screening in the first place. Being upfront with parents by explaining the meaning of a refer result (i.e., there are many reasons for not recording an OAE which are often due to conditions in the ear canal, but could also be because the baby does not hear) and the significance (services to assist with language development can be implemented from a young age; parents would be aware their child experiences the world differently and can adjust communication methods appropriately) also demonstrates respect for parents.
7.3 Fully informed choice and consent

The power held by adults in determining who each deaf child is and, therefore, who they will be and which path they will take to get there creates a situation where the ‘treatment’ matches the label, and as such education is not needs-related at all. (Corker, 1998, p. 82)

The above quotation appears in the context of a discussion of the education of deaf children in Britain two decades ago, but it remains relevant to current diagnostic and intervention practices in Canada today. The subjectivities of deaf children are constructed by diagnostic labels or knowledges instead of the individual needs of children, and the IHP’s health service providers hold a position of power as the professionals who impart information and provide services to parents. As such, the IHP has an obligation to inform parents about different communication options, and provide services that give deaf children the opportunity to learn language based on their needs.

Following from the suggestion to present deafness as other than failure, I suggest the Infant Hearing Program reconsider what it means to “fully inform” parents. After critically examining the IHP’s medical framing of deafness and recognizing the different ways of being deaf and considering Deaf Gain, the IHP would be in a better position to inform parents of various communication development options. Deaf and hard of hearing children would have better opportunities for multi-modal communication if their parents were told about communication options without constraints based on preconceived notions and expectations for the development of spoken language. Only with such provision of comprehensive information, including different knowledges of deafness and an understanding of the history of those knowledges, can parents then provide their informed consent for whatever option(s) they choose. The IHP therefore needs to consider fully informed consent as a commitment to communicate to parents
the importance of social-relational communication with their child. Encouraging multi-modalities and flexible choices that could change as parents get to know their children could also remove some of the stress that parents experience in making communication decisions for them. Parental decision-making is not as simple as it is made out to be as a choice between spoken and sign language; lived experience with their children show how parents in my study struggled with making the “right” decisions for their child. Jasleen, Lauren, Chelsea and Courtney all recalled feeling not quite right about how the IHP professionals expected them to communicate with their children, and they were all just gaining confidence in doing what seemed right for them and their child versus following the advice of the professionals.

After a discussion of informed consent below, I introduce the idea that the IHP should inform parents about the history of deaf education and the ongoing power relationships within the Deaf/Hearing debate. By acknowledging the debate, the IHP has the opportunity, and even the responsibility, to bridge the Deaf/Hearing dichotomy by also acknowledging and supporting the many ways that d/Deaf/hard of hearing may be experienced. I also suggest the IHP’s dual option of sign and spoken language be better developed as a viable option (even for children with cochlear implants); parents must be informed about the possibility for both sign and spoken language, with the appropriate services in place to support this choice.

7.3.1 Informed Consent

All health care practitioners are required to obtain informed consent before beginning any treatment, as stipulated by the Health Care Consent Act which became law in Ontario in 1996. Therefore, as regulated health professionals (governed by the Regulated Health Professions Act, 1991), physicians, speech-language pathologists, and audiologists must obtain voluntary, informed consent, “not obtained through misrepresentation or fraud” from the parents/guardians
of infants and young children before providing a specified health service (Government of Ontario, 2018, p. 8). Speech-Language and Audiology Canada (SAC) defines informed consent as,

…consent from a patient or client based on an informed choice that is the result of a process of educated decision-making. To provide informed consent, the patient or client must be provided with sufficient information about the proposed service or product, including the benefits, risks and any possible alternatives, and understand this information. (SAC, n.d., p. 8)

To ensure parents are able to provide informed consent, the IHP states parents will be provided with “unbiased information” about communication options. As shown in my analysis, what the IHP considers “unbiased” is framed within a medical understanding of deafness so that “fully informed” does not currently include comprehensive information about sign language and Deaf culture, or the potential consequences of each option.

Young et al., (2006) undertook a review project to prepare for the development of informed choice guidelines specifically for service delivery to families with deaf children in England. 42 This review was in response to many years of studies involving the unsatisfactory experiences hearing parents of deaf children had with professionals providing communication services. Many of the parents’ complaints were similar to those of the parents I interviewed, including, “provision of information that is regarded as biased, the withholding of information about particular communication options, the unequal weight given to one communication approach

42 The UK government commissioned the National Deaf Children’s Society to conduct research on informed choice for families of deaf children, to develop guidelines. Out of this research, two handbooks were developed; one for professionals and one for parents. Please refer to these two publications for the UK’s comprehensive guidelines of informed choice as relevant to families of deaf children, from both professional and family perspectives (Early Support, 2006a; 2006b).
over another, the attitudinal bias of some professionals toward particular support options” (Young et al. 2006, p. 323). Their review highlighted numerous challenges to developing informed choice guidelines for parents of deaf children, one being a problem identified within the literature reviewed. Within the literature on informed choice for families of deaf children, the authors found it difficult to separate what it means to provide informed choice from how a deaf child was conceptualized by the author(s) (Young et al., 2006, p. 324). They therefore conducted their literature search more generally, rather than focusing on studies of informed choice in relation to deaf children and their families. Thematic concepts were identified and described, and then reflected on in relation to implications for informed choice for families with deaf children. I summarize some results of the Young et al. (2006) study throughout the discussion to follow, as they are applicable to my suggestions for the IHP.

My research reveals that the phrases “unbiased information” and “fully informed choice and consent” (Ontario Ministry of Health and Long-Term Care, 2001, p. 6) are complicated social assemblages when approached through the experience of disability or deafness of one’s child. These terms work to govern parents toward a particular choice, under the guise of legislation that is meant to ensure parents have autonomy and the right to make decisions for their child. Indeed, a stated purpose of the Health Care Consent Act is “1 (c) to enhance the autonomy of persons for whom treatment is proposed….by (iii) requiring that wishes with respect to treatment…expressed by persons while capable and after attaining 16 years of age, be adhered to” (Government of Ontario, 2018, p. 4). My research suggests that the rights outlined in the Health Care Consent Act may not be upheld by the IHP in their provision of information and
services to parents, despite an intent to do so. The information provided by the IHP exemplifies “a tension between the provision of information to promote informed choice and the provision of information to promote participation in a particular activity, the benefits of which may already have been accepted as health or social good” (Young et al., 2006, p. 327). Such informed consent fits into a neoliberal system where individuals (or their parents/guardians) are assumed responsible for their own choices, while the social forces at play that construct a ‘right’ choice are hidden.

Health practitioners are responsible for informing parents about the proposed treatment, including alternatives, but the discourse of informed choice and consent makes parents ultimately responsible for the decisions made for their children. In this way, it is the parents, not the professionals, who are held responsible; it is the parents’ choices that determine how their child will develop and learn language. The system is set up such that parents are responsible if they go against professional opinion and the child does not learn language; however, if parents follow the professional’s treatment advice but the child does not learn language, the problem is situated within the child (and/or the parent), not the device or the system. To give parents and children the opportunity to choose to include alternate modes of communication and learn language in the way best suited to them, parents must first, at the very least, be made aware of those modes and the importance of allowing deaf children access to them.

43 This finding points to the messiness of the medical discourse of “choice and consent” which I touch on here, but which has been theorized and critiqued in-depth by other scholars, including the added layer of complexity involved in parents making decisions on behalf of their children (e.g., Mol, 2008; Ouellette, 2011; Showalter Salas, 2011). Annemarie Mol proposes a focus on the “logic of care” to counter the “logic of choice” that has become so prominent in health care, discussed below.
As discussed in previous chapters, by stating they provide unbiased information to fully inform parents, the IHP effectively obscures the socio-historical politics of the Deaf/Hearing debate that the provision of unbiased information about communication options is likely meant to address. Because of the assumed objective neutrality of medicine, “unbiased” is currently framed within a medical understanding of deafness – it does not mean that all modes and methods of communication are presented equally to parents, even if this was the intent. It is important for the IHP to have protocols in place to ensure parents receive, and understand, comprehensive information about all options, and before they are referred to a CI Program. At the same time, it must be acknowledged that providing comprehensive information does not guarantee parents will be “fully informed.” On the contrary, I would argue that it would be impossible for parents to be fully informed about every option and their potential consequences, as this simplifies the complex decision making process and implies a static, rather than fluid understanding of their child and their child’s communication; my research has shown how parents are in a constant process of taking in information and coming to understand their children at different points in time. A reframing of “choice” as a fluid and flexible process with an acknowledgement of the ongoing socio-political debate between signed and spoken language (and Deaf and Hearing culture) is necessary, rather than assuming parental decision making is a singular, static event.

Conceptualizing decision making as a fluid process fits with Mol’s suggestion to focus health care on a “logic of care” rather than a “logic of choice” (2008). Mol proposes shifting focus to “situations of choice” rather than who has the ability to choose. As Mol notes, by doing so “it becomes possible to show that the ideal of choice carries a whole world with it: a specific mode of organizing action and interaction; of understanding bodies, people and daily lives; of dealing with knowledge and technologies; of distinguishing between good and bad; and so on” (Mol, 2008, p. 7). This world encompassing the ideal of choice is what Mol terms a “logic of choice,”
whereas a “logic of care” describes a non-linear, relational, ongoing process that acknowledges and respects differing embodiments (Mol, 2008). In this sense, my suggestion for the IHP to reframe choice as fluid and flexible would align parental decision making in deaf diagnostic and intervention practices with a logic of care.

As part of a logic of care, I suggest the IHP acknowledge, respect, and embrace embodied deafness and the collective experiences of deaf people. To do so, it should be the responsibility of the IHP to inform parents about the historical (and ongoing) power relationships between signing Deaf people and their allies and Hearing health practitioners and educators. In addition, parents should be given information about the ‘pros and cons’ of different approaches from various perspectives, including disadvantages associated with an exclusive spoken language approach, as such disadvantages would be more difficult for a hearing parent to understand than the disadvantages of teaching a child ASL without also teaching them some form of English. This suggestion is consistent with arguments presented in informed choice literature as summarized by Young et al.:

There is … a well-developed set of arguments that draws attention to the fact that the provision of effective information to facilitate informed choice is not synonymous with information that could be regarded as neutral or merely functionally descriptive. Rather, information that is evaluative is considered essential, and in particular, information that draws attention to the various risks and benefits of particular options. (Young et al., 2006, p. 326)

Providing information about the historical oppression experienced by Deaf people and the politics of the various options, is one way to present evaluative information within a logic of care.

In addition, Young et al. (2005) examined parental perspectives on a draft information folder for parents of deaf children in the UK, and noted that parents found the information was missing
political context (i.e., it would have been helpful for parents to be aware of the communication debate). Again, this requires the IHP acknowledge their part in supporting the ‘h/Hearing’ side of the debate and consciously work towards including subaltern knowledges of deafness and language in the discourse of screening and assessment. A pamphlet providing information about Deaf history, written by a Deaf organization, could be provided to parents so they can understand the politics of their choices and what sign language and Deaf culture mean for Deaf people. Rather than presenting the IHP as an ‘unbiased, objective’ program, parents should be made aware of all aspects of the debate, and the opinions, including the reasons behind them, held by the different groups involved. By bringing the debate to the forefront and including alternate knowledges, Deaf and estranged ways of knowing may eventually be accepted along with medical knowledges of deafness.

At some point in the planning and implementation of the IHP, there seems to have been an intent to include alternate knowledges:

…every effort should be made to provide access to parents of children who use sign language; parents of children who use oral language; parents of children who are bilingual/bicultural; deaf/hard of hearing adults who sign; deaf/hard of hearing oral adults; deaf/hard of hearing bilingual/bicultural adults; different programs or agencies that provide the various methods of communication.

(Ontario Ministry of Health and Long-Term Care, 2001, p. 17)

However, unlike the well-documented standardized screening procedures and audiology assessments, there seem to be no procedures in place to ensure parents do indeed have access to deaf and hard of hearing people who communicate in ways other than (and/or in addition to) spoken language. I suggest the IHP revisit some of their earlier documents that encouraged the involvement of Deaf people, and establish a system to ensure parents do meet people who have different experiences of what it means to be deaf and have language. Many IHP documents
focus on screening and audiological protocols, but I found none that outline how to inform parents of their options to ensure they receive information from Deaf people, or parents of deaf children. At minimum, a pamphlet providing information about Deaf history, Deaf culture, and sign language, provided by a Deaf organization, should be included in the information package parents receive. Such information should be given before children begin the process of cochlear implant candidacy.

Included in this pamphlet or information packet should be information about bilingual-bicultural education and the Provincial Schools for the Deaf, to make parents aware there is an education option available that can support their child’s development of both sign language and written and spoken English or French. All the parents interviewed (with the exception of Vicky who adopted Sam at 4 years of age and knew he needed different modes of language for education, and Jasleen who wanted Nayan to have access to some form of visual communication at school) originally expected their child would attend regular spoken language classrooms in a mainstream school. Parents told me they were not made aware of bilingual-bicultural education until the teacher from the Home Visiting Program informed them (after they had chosen a spoken language approach for their child). As Lauren noted, “we’re told your child will go to the same school as everybody else. They don’t mention that there are deaf schools in our province, which you know, a lot of people don’t realize are actually out there, and they are wonderful schools.” It is important that this education option be shared with parents alongside any discussion of spoken language, and that they have the opportunity to meet parents whose children attend Provincial Schools and older teens or graduates of the program. In addition, regular school board programs for deaf and hard of hearing children should include some instruction in sign language and Deaf culture and encourage communication in multi-modalities.
Informing parents about the history of deaf education requires the IHP be open to a critical view of this history and the IHP’s own practices, while also addressing societal understandings of deafness which many parents will already bring with them to the assessment experience. The IHP has the opportunity to open up new ways of considering deafness and language to expand deaf subjectivities beyond audist limits. My research has shown that some parents decide on a spoken language only approach without even considering sign language, and not wanting to consider it; in this way some parents may not want to be informed about options that do not fit ‘normal’ cultural and linguistic expectations. Roots discusses how the fear of losing their child to a different culture factors into parental decision making: “The family may not in fact view the choice as being primarily between language modes but rather as a choice between keeping the child in the family or surrendering him/her to an unfamiliar culture with which the hearing family members can never identify” (Roots, 1999, p. 45). Roots describes the choice between sign language and spoken language as a political choice, with a spoken language only approach representing a nonacceptance of the child’s deafness, “the choice of spoken language...denies the child political power and manifests a refusal to accept his/her difference” (Roots, 1999, p. 47).

Although such denial of political power and difference may be an outcome of a spoken language choice, it is important to acknowledge that hearing parents want the best for their child, and spoken language is often considered the best choice because of societal understandings of deafness and language. This exemplifies another concern with the principle of “fully informed choice and consent,” that of how to “fully inform” a parent who does not want to be informed. As members of a society that makes deafness a problem, parents are immersed in normalized ways of thinking; the IHP can have a role in changing how deafness is conceptualized and in helping parents consider different perspectives beyond a desire for their child to develop
‘normal’ speech and language. Challenging the IHP to acknowledge and support different ways of being deaf and having language, means also challenging parents to consider their child’s deafness from a view other than a Hearing point of view, while being sensitive to other socio-cultural values held by families.

7.4 Reconsider language as open and flexible

One way to challenge normalizing assumptions of spoken language is to theorize language from a postmodern perspective. Pennycook suggests that a postmodernist approach requires a questioning of the notion of “language,” so that language is viewed as “an emergent property of social interaction and not a prior system tied to ethnicity, territory, birth, or nation” (2006, p. 67). Applying a postmodern approach to the IHP’s language policy would shift the focus to the constantly evolving social-relational aspects of communication between people instead of making deaf children learn a preconceived language in a prescribed way. In her research with youth who use augmentative and alternative communication, Teachman suggests the need for a reconceptualization of communication differences and argues that “mediated communication is no more or less ‘authentic’ than oral speech, and that embodied norms of communication have the effect of muting persons who communicate differently” (2016, p. 176). Reconceptualizing languages as unbounded, constantly evolving interactional communication systems made meaningful by exchanges between people would allow for a more flexible understanding of language that would not exclude, or ‘mute,’ those who use ‘non-standard’ methods of communication. In this way, spoken languages (and the people who use them) would be no more meaningful or important than sign languages, or other visual or tactile modes of communication.
My research shows how the CI Programs and the Ontario IHP use their authority and influence to impose limits on the languages and communication systems parents use with their deaf child(ren), based on a presentation of deafness as a negative outcome that can be fixed by IHP services. This negative medicalized presentation of deafness as a condition to be fixed, situates sign language and Deaf culture on the margins, making them inconceivable to some parents. The IHP uses the discourse of “communication options,” yet standardized (spoken) language and not communication is the current focus of services. When sign language is unthinkable and/or prohibited, the future expectation of ‘normal’ speech and language trumps the child’s immediate need for communication. Wrigley explains such language options for deaf children as an “ethic of deferring, the need to sacrifice immediate needs for the possibilities held out for the greater good” (1996, p. 211). With a reconceptualization of languages as communication systems that foster social interactions, and a commitment to “fully inform” parents by nurturing communication, along with a consideration of Deaf Gain, the IHP could instead promote social-relational communication between parent and infant rather than standardized spoken languages which defers the learning of sign language.

Rather than limiting parents and children to a spoken language only approach, I suggest the IHP offer the dual approach as the primary option for all deaf and hard of hearing children, while encouraging parents to use whatever means possible to communicate with their child. This would require the IHP move away from the dichotomizing discourse of “choice” between sign language and spoken language to allow for a multitude of (simultaneous) communication options for deaf children, more consistent with a logic of care. Shifting the focus to social-relational communication rather than discrete, dichotomous, standardized language(s) could change the meaning of language, and in turn change how deafness is made meaningful. To determine the modes of communication most suitable to the child, parents could be encouraged
to ‘listen’ to their child, rather than insisting the child always work on listening to learn to speak.

A shift away from a Deaf-sign language/Hearing-spoken language binary (with spoken language on the ‘right’ side of the dichotomy) would allow parents to explore all communication methods with their children without limiting their subjectivities to fit ‘normal’ expectations. Instituting such a shift in practice would require a significant change to the IHP’s current service delivery system. Auditory-verbal therapy (AVT), speech-language pathology (SLP), and American Sign Language (ASL) services are currently offered as separate individual services and parents can access only one or the other in a week. For example, the parents I interviewed who were receiving both AVT or SLP and ASL received spoken language services and sign language services on alternate weeks. Although intensive individual sessions could be useful for developing individualized support, one-on-one ASL sessions every other week do not provide much opportunity for parents and children to learn ASL.

One possible solution could be to offer a weekly parent-child half-day program in the community (organized through established Early Years Centres) that brings together different communication modalities in one place, to encourage a more holistic approach to language and communication. This program could happen in addition to individual therapy sessions and could include Parent-Child ASL Mother-Goose Programs for younger children and ASL story time and games for older children, in an environment that encourages both parents and children to learn and practice ASL with Deaf ASL facilitators and other parents. The ASL program could run concurrently with a group SLP session covering topics of concern generated by the parents. To be cost effective, this program could be made available to other families who receive or are on the waitlist for preschool speech and language services, if there are few deaf and hard of hearing children in the area. In addition, ASL programs could be offered to all parents through
the Early Years Centres, whether their children are deaf or hearing to foster communication development.\textsuperscript{44} As most hearing parents do not know sign language, it would be important to have an ASL interpreter available to aid conversation between parents and Deaf facilitators; parents should not be expected to converse in sign language when they are just beginning to learn the language, and Deaf facilitators should not be expected to use spoken language. A mutual understanding and respect would also be needed between service providers to create a positive environment and unified services.

By offering both ASL and SLP to groups of parents and children at the same time and place, the IHP would demonstrate a commitment to providing comprehensive services that encourage all forms of communication without prioritizing spoken language over sign language. A reimagining of language as open and flexible also means accepting that deaf children may use both sign and speech and visual/tactile modalities within the same communication exchange. Parents and children should have freedom to communicate using multiple modalities rather than either spoken language or sign language separately. Often when working towards spoken language, especially when AVT is the therapy of choice, sign language or any other visual cues are prohibited to ensure the child is developing their auditory pathways.\textsuperscript{45} Likewise, when learning ASL, teachers usually institute a ‘voice-off’ policy to optimize learning and to respect

\textsuperscript{44} Baby sign classes are popular with parents of hearing children to foster communication before babies develop spoken language, but are often taught by hearing instructors and focus on individual signs rather than language. ASL programs (rather than “baby sign”) would promote the use of sign language for both deaf and hearing children and foster an understanding of the importance of sign language and Deaf culture for deaf children.

\textsuperscript{45} The theory is the brain’s neuroplasticity could allow visual modes of communication to take over the auditory cortex, so limiting sign language would decrease competition between vision and audition for the same neural resources (Dornan, 2009; Sharma & Campbell, 2011). Mauldin (2014) notes that this battle over auditory versus visual neural resources reframes the spoken language/sign language debate into one of neurological development. This argument creates a neuroplasticity paradox, as a neuroplastic brain should be capable of adjusting to different modalities.
the Deaf teacher. However, such rules are not likely representative of how communication occurs in the child’s home, and they artificially limit the way deaf infants with hearing technologies learn to communicate; very few (if any) children are learning ASL without also learning spoken language. The rules represent the political governance of language and deaf people.

The IHP can bridge the gap between spoken and sign language by encouraging the learning of sign language and the use of different modalities for communication. Code-switching (switching between different languages or dialects, or modes of communication, in a conversation) is well-documented in bilingual speakers (e.g., Meisel, 1994; Li, 2011) and should be expected and accepted for deaf children. The IHP’s service providers should allow fluidity between language and communication modalities, so that signs are permitted during predominately spoken language exchanges, and speaking is permitted during exchanges in sign language.

Many of the parents I interviewed, even those whose children had cochlear implants and were following an exclusive spoken language approach, used multiple communication methods with their children, particularly when the CI was turned off or not functioning. Mauldin also found that “parents of children with CIs do sometimes create their own ‘gray areas’ and reject the strict divide between the two approaches to deafness” (2012a, p. 229). This is an indication that parents intuitively foster social-relational communication, even while working towards development of the standard spoken language. For example, Jasleen used baby signs with Nayan and used multiple communication methods with him as he got older; Arinan used lipreading when his CI was off; and Angela learned baby signs and used visuals to aid communication with her children. In addition, some parents became open to other modes of communication after their child did not develop spoken language as expected. For example, when Sydney was two and a half years old, Courtney decided to switch from AVT to SLP to allow for a “broader
approach of sign, and pictures and whatever else that we can get that’s going to make her feel comfortable talking and stuff.” Although spoken language was still Courtney’s end goal for Sydney, she felt alternate modes of communication were beneficial. Rebecca was considering AAC for Thomas who was learning to understand spoken language but needed alternate modes for expression, and Lauren chose to teach Natasha sign language when she was a toddler.

Lauren described how the choice between spoken language and sign language presented to her when Natasha was an infant did not reflect the many communication options she later found were available: “there are so many options out there, there’s so much out there for your child…now I’ve been open to a world that it’s not just spoken language or sign language… But those options aren’t given, until it’s too late.” Lauren’s discovery of diverse communication options when Natasha was older and her struggle trying to get sign language services for Natasha, led her to volunteer her time speaking to parents of newly diagnosed children and letting them know about bilingual-bicultural education and the communication options beyond just speaking and signing. Reconceptualizing language as open, flexible, and in constant flux, instead of standardized and static, would give greater credence to those parent-child interactions that do not involve “listening and speaking.” In turn, parents could be empowered to use whatever communication methods work to foster meaningful interactions with their children, by removing the pressure to constantly provide standard language models and expecting standard expressive language in return.

In placing importance on the development of spoken language, the IHP constrains children and their families to a very limited, standardized view of language. The IHP’s current focus is on habilitating hearing, specifically for the development of spoken language. Habilitation services therefore focus on maximizing auditory input and encouraging verbal responses, all to make a deaf child pass for a hearing child through the use of the majority spoken language. By
becoming aware of how the IHP and CI Programs contribute to the governing of language (and the governing of deaf children), this constrained view of language and the normative assumption that spoken language should be the primary focus for deaf children (whether or not they use cochlear implants), can be challenged. Deaf children who use hearing technologies are not able to hear all of the time, and should not be expected to communicate solely through spoken language. In addition, the assumption that deaf children who use hearing technologies should only learn spoken language with no need to learn sign language, situates Deaf people and others who use non-verbal communication systems as not worthy of being communication partners.

In a discussion about the difficulties legitimating the use of sign language in education for deaf children in Britain, Corker critiques the system’s conception that “only the ‘most profoundly’ hearing impaired children – those who are most likely to ‘fail’ – need sign language” (Corker, 1998, p. 88). Although it is now 20 years later, and despite progress in the acceptance of the Deaf community and sign language becoming known to hearing people, sign language continues to be considered a last resort, only for those profoundly deaf children who cannot use hearing technologies or who do not develop spoken language with hearing technologies. If the IHP were to adopt a postmodern perspective of language, the program could work to reduce the hegemony of spoken language and advocate for the acceptance of all forms of communication by all deaf and hard of hearing children regardless of hearing technology use and/or expected spoken language outcomes. Hearing children are not limited in their use of extra-linguistic communication (e.g., gestures, body movement, facial expressions); a postmodern perspective can allow for the importance of such communication features for deaf children as well.
7.5 Encourage children with CI to learn sign language and use multiple modes of communication

A postmodern perspective of language could also work to remove the dichotomy between spoken and sign language for children with cochlear implants. The cochlear implant has become the go-to solution for severe to profoundly deaf children to access sound and learn language. Currently, children who have cochlear implants in Ontario receive most of their services from one of three provincial Cochlear Implant Programs rather than the Infant Hearing Program. Families have access to a social worker from the CI Program, and have assessments and follow-up appointments with the CI Program audiologist, who also acts as a case manager until the child reaches 18 years of age (SickKids, n.d.b). CI Programs are therefore not mandated to follow the IHP principle of informing parents about all communication options, but rather assume/expect that spoken language is the communication option of choice, once CI is chosen. Providing detailed information about CI and spoken language but not sign language, is commonly presented as fostering “informed choice” about that option, yet parents may not know other options are available (Young et al., 2006). Furthermore, as reported in past research and by many of my parent participants, CI Programs discourage parents from using sign language with their children, and have told parents that a commitment to an exclusive spoken language approach is necessary for their child to be considered for cochlear implants, and to obtain successful cochlear implant outcomes.

It has become taken for granted that severe to profoundly deaf children be assessed for cochlear implant candidacy, and referrals may be made to a CI Program before the IHP’s family support worker meets with parents to discuss communication options. Two of the parents I interviewed were not explicitly told their child had been referred to a CI Program and only became aware
during the initial assessment. Some parents of deaf children therefore do not have the opportunity to learn about sign language before choosing an exclusive spoken language approach to communication. The following are suggestions based on my research for the IHP and CI Programs to consider, to improve access to sign language services for severe to profoundly deaf infants:

1. Parents should have the opportunity to meet with the IHP’s family support worker and a member of the Deaf community before their child is referred to a CI Program. Information about the socio-political history of Deaf culture, as discussed in section 7.3, should be given to parents.

2. Professionals working in CI Programs should have knowledge about non-audiological research in deaf education to understand how deaf children learn language, including studies that show the benefits of young CI users learning sign language as well as spoken language.

The current practice of instructing parents not to teach their child sign language based on research in auditory development and theoretical assumptions of neurological development may be detrimental to those children whose auditory systems do not develop as expected with the CI. In addition to restricting the development of a visually accessible language, my research has shown how limiting sign language may hamper parent-child communication; impose on parents a limited knowledge of their deaf child based on diagnostic assumptions; as well as create parental stress over the requirement to follow medical language directives, rather than allowing freedom to communicate visually with their child without fear of repercussions (e.g., denial of services or professional judgements). A narrow focus on the discrete auditory system also neglects the multitude of factors that contribute to a child’s socio-cognitive-linguistic learning. There is more to learning language than the auditory system (and there is much more to a child
than audition), and it is short-sighted of CI stakeholders to assume auditory development is the most important aspect of learning language and developing cognitive skills.

I also argue that no professional should dictate limits on how parents communicate with their children. That is not to say that professionals should not provide their opinion based on their own experience and medical knowledge, especially when they are asked for their opinion directly by parents, but that they do so only as an exchange of information with parents, rather than a directive. During this exchange of information, their ‘expert’ opinion should be presented with the clear acknowledgement that other ‘experts’ in deaf intervention may hold alternate opinions based on their own experience and knowledge.

3. CI Programs should ensure parents are aware of the political aspects of choosing a CI and CI Programs should implement a plan to counteract the historical oppression of Deaf people by embracing Deaf knowledges and sign language rather than discounting them. Parents should be aware of what the CI Program does to address and rectify how cochlear implants have contributed to this oppression.

4. Ensure that CI candidacy is determined based on medical evaluations and the expected success of the CI in providing access to sound, not moral judgements based on expected ‘success’ of the child to learn spoken language.

CI is not a medically necessary surgery in that it is not a life-saving operation. Yet my research has shown that it is considered necessary, by medical professionals and parents, as the only way a profoundly deaf child can access sound and develop spoken language. Cochlear implant teams recommend cochlear implants for ‘good candidates’ who are medically suitable for the procedure and have a good chance of developing spoken language. If spoken language is not an expected outcome, then CI is not considered necessary and may even be discouraged, making
spoken language the only worthy outcome of CI, and good candidates the only worthy CI recipients. As Blume notes, CI outcomes cannot be predicted by medical professionals, yet CI Programs have authority to decide who will benefit from an implant: “What the technology has to offer to the deaf child…cannot be assessed, measured, or predicted with the skills and the instruments of medicine alone. What is then at issue, and what needs to be questioned, is the authority of medical expertise and the scope of medical jurisdiction” (Blume, 2010, p. 171). CI Programs therefore provide recommendations that include moral as well as medical imperatives. That is, in addition to medical imperatives, recommendations for the surgery are based on expected outcomes of the CI(s) and what is considered a worthy outcome (i.e., spoken language development), even though those outcomes cannot be adequately predicted. There may be structural or medical reasons for a child not being a candidate for CI surgery (e.g., no auditory nerve, ossification of the cochlea, compromised immunity), but there are also judgements being made based on assumed cognitive and/or motor ability.

There should be equal access to cochlear implants for those who are medically determined to be candidates; children with multiple disabilities should not be denied access to CI technology because of lack of expectation for spoken language development, as this limits how disabled children come to be understood as social-relational beings. Hayward et al. (2013) researched parents’ perspectives of CI benefits for their children with multiple disabilities and found parents perceived benefits other than spoken language development, including reactions to and enjoyment of environmental sounds, meaningful expressive communication in multiple modalities, improved receptive communication, perceived increase in child happiness, social connectedness, as well as improved family interactions. I must reiterate that I do not wish to push for more children to get cochlear implants, but for CI Programs to provide more equitable access to cochlear implants based on medical and not moral judgements. I acknowledge this
may not be a simple feat in practice, as the line between medical and moral has become blurred with the medicalization of so much of everyday life (Conrad, 1992; Illich, 1977; Zola, 1977).

Determining candidacy based on whether the CI would provide access to sound instead of assumptions of spoken language development, also reduces the hegemony of spoken language as an exclusive approach for deaf children with CI. This means that effectiveness of the CI should be determined by the quality of sound provided to the child, not the child’s ability to speak. Removing the expectation of normalcy would open up other communication options for children assumed capable of learning spoken language with CI, and ensure that all severe to profoundly deaf infants and children have the opportunity to be assessed for CI based on medical grounds.

7.6 Provide more intensive sign language services and supports to parents and their children

When access to language and communication become the main concern of the IHP, and all parents of deaf and hard of hearing children regardless of hearing technology are informed of and encouraged to use all modes of communication, the IHP then needs to ensure services are in place and accessible to provide support for learning sign language. Outlining exactly how parents can obtain sign language services, or both sign and spoken language services, should be part of informing parents about different communication options. A common theme for many of the parents in my study was having to fight for sign language services for their children, once they learned such services were available. To better serve all families, sign language services should be openly offered to parents so they do not have to fight for them. Without procedures to ensure parents learn about sign language and Deaf culture from people in the Deaf community, some parents may not even be aware that sign language is an option, or its importance to deaf
children. Some parents may also not be in a position to fight for services, which creates inequities between families of different means, demonstrating how social determinants may add to the ordering of hearing. For example, some parents may have more time, information, and resources than others to advocate for their children in this way. As an IHP mandate is to provide communication services, the IHP must ensure that parents are aware of the available service options, and that services are adequate to assist deaf children and their families with communication.

The IHP ASL services that parents told me about were not sufficient to foster fluency in ASL. Parents who had fought for and received funded ASL services only received one hour every other week, and only up until school age. Such limited services cannot result in either the parent or child becoming fluent in ASL; at most, the family would become familiar with some basic signs to aid communication. For example, Lauren had an ASL consultant come to their home to teach her and Natasha ASL every other week, and when Natasha began school in a bilingual-bimodal program, Lauren continued to receive instruction so she could keep learning ASL while Natasha was at school. These services were scheduled to end before Natasha turned five years old, and Lauren noted that after a year attending a Provincial School, Natasha’s ASL use had already exceeded Lauren’s capabilities. Lauren feared she would no longer be able to converse with Natasha in ASL. The “dual option” when parents can access it, is still focused on spoken language with signs used to support spoken language; even though parents are already fluent in spoken language, they receive the same, if not more, services to support this choice. ASL services should be structured to ensure parents have more access to ASL instruction, family-infant ASL instructional play groups (e.g., ASL parent-child Mother Goose Program), and accessible online services to accommodate families who live in rural areas or who are not
available during typical hours of service. Such sign language services should be made available to every parent of deaf and hard of hearing children, regardless of hearing technology use.

The IHP’s mandate to provide communication supports also means children who receive cochlear implants should have funded access to language services that help them make sense of their new auditory environment. A few of the parents indicated they pay out of pocket for SLP or AVT services due to a lack or inefficiency of services in their area (e.g., no AVT in the area, and/or access to a funded speech-language pathologist who does not have experience with deaf children). The IHP could consider providing reimbursement to parents who pay out of pocket for private therapists if there are no experienced, funded therapists in their area. Similarly, parents who pay to attend intensive ASL courses could be reimbursed by the IHP. The IHP could also assist parents in arranging parent groups and meetups to practice ASL and discuss communication methods that work for them.\(^{46}\) A few of the parents indicated that meeting with other parents was invaluable to them and provided more information than that provided by the IHP.

### 7.7 Include critical approaches to health practitioner education

Critical approaches to education … explore unexamined assumptions that are held at individual, institutional, and cultural levels of healthcare and aim to raise awareness of the conditions of the people and communities served. They question the power relations inherent in health and healthcare, and how individuals, groups, and systems may be (unintentionally or intentionally) complicit in

\(^{46}\) There is a wealth of information on the Silent Voice website, the organization that provides IHP ASL services, including different resources for learning and practicing ASL at home, and events and services for the Deaf community in Ontario. All parents of deaf and hard of hearing children should be made aware of and encouraged to use the resources available through this website (http://ihp.silentvoice.ca).
perpetuating and reproducing the current, at times inequitable, state of social conditions. (Halman, Baker, & Ng, 2017, np)

Individual health practitioners are typically trained in biomedical-based education programs within a society that devalues disability and embodied difference. As objects of science, ‘normal’ human bodies and minds are described and taught as the normalized standard, to which ‘impaired’ bodies and minds are compared. Student health practitioners (like my experience as a student of speech-language pathology as recalled in Chapter 1) are taught about how bodies and minds function, and how to help those bodies and minds that do not work ‘as they should.’ Students are generally not taught to think critically about how this information is presented or what kind of information is presented; it is taken for granted that this culturally produced medical discourse represents the ‘real’ human embodied existence. Rehabilitation professionals, like speech-language pathologists (SLP) and audiologists, are taught in education programs that support medicalized thinking, even for social-relational phenomena such as communication and language. Such medicalized thinking was apparent in my analysis of SAC’s position papers on universal newborn hearing screening and cochlear implants for children. A critical approach to health practitioner education would have students: question the taken-for-granted assumptions of their professions; consider power relationships within the healthcare system; become aware of the lived experiences of people served; and work to make the system more equitable (Halman et al., 2017).

Reflective practice is one approach that can foster critical thinking in health practitioner education. The importance of reflective practice within SLP has been discussed in the recent past, but with a focus on the general benefit to the field of SLP rather than to the people they serve (Caty, Kinsella & Doyle, 2016). Caty et al. discussed reflection as a way to independently learn new practitioner skills and cope with a changing workplace: “We propose that reflective
practice is important for S-LPs, and for the S-LP profession, because it offers opportunities for enhancing effectiveness in professional practice” (2016, p. 84). Reflective practice as discussed in this article did not include a critical approach to reflection, but rather focused on what could be learned by reflecting on past clinical experiences and sharing those learnings with students. Reflective practice was also considered helpful for developing ways to deal with “challenging interpersonal situations” (p. 85). The purpose of reflective practice was presented as individual reflection to improve clinical practice, rather than critical reflection to question why and how assessment and treatment are carried out in particular ways and the underlying thinking behind rehabilitation. There was brief mention of reflection as a way to uncover the normative standards of assumptions, but this critical view was not discussed in any detail in relation to the underlying assumptions inherent to SLP, rather reflecting individual values of the practitioner.

Stella Ng (2012) has written specifically about the relevance and importance of reflection and reflective practice for audiologists, theories not previously embraced by the profession. Ng notes that critical reflection, as theorized by Habermas, “can be useful for bringing taken-for-granted assumptions and situations into light and for identifying and navigating ethical dilemmas and systemic challenges” (Ng, 2012, p. 122). In this way, reflection can lead to action and “offers an emancipatory framework for audiologists to attend to ethical dilemmas and to advocate for systemic change and improvement” (p. 126). Ng cites the habilitation of deaf children as a specific area of audiology requiring critical reflection, thereby acknowledging the role audiologists have in the controversy around spoken language versus sign language approaches for deaf children (p. 129). I suggest that SAC critically reflect on how deaf children are presented in their position statements, and consider updating their statements to acknowledge Deaf ways of being, and sign language as a viable option for deaf children, rather than a hindrance.
Introducing critical approaches to health practitioner education, including teaching health professionals to question the assumptions within their professions and to critically reflect on their own practices, could greatly improve how services are provided by the IHP. In addition to assisting in professional knowledge expansion, critical approaches could lead to health practitioners who not only want to help people, but who do so by attending to how people want to be helped (i.e., not just a circumscribed type of help dictated by the medical gaze). As health practitioners generally enter into rehabilitation professions to help people, they must therefore consider the different ways that people may want to be helped. My research has shown that parents may want different kinds of help as they get to know their child, consistent with a logic of care.

One way to question assumptions is to welcome and value community members as sources of information – not just as exemplars for various ‘conditions’ or how SLPs have helped them, or to prepare students for how to counsel their clients, but to open the possibility for alternate ways of thinking about differences in hearing, speech, and language. Speech-language pathology and audiology training programs (as well as other health programs) should include alternate knowledges (i.e., non-medicalized knowledges) about the ‘conditions’ in which they specialize, to have a more comprehensive understanding of how people assessed as ‘outside the norm’ experience life. Understanding how a medicalized framing of rehabilitation supports the devaluation of difference is an important critical reflection for health practitioners to consider, as treatment approaches can then be expanded to consider personal lived experiences of impairment and disability. The suggestion to include alternate knowledges in health practitioner education is supported by Yu & Epstein’s (2011) study, which demonstrated how student SLP clinicians changed their conceptions of developmental communication disorders when they were
taught about the social model of disability and to consider communication problems as social rather than individual.

As stated in my introductory story in Chapter 1, as a speech-language pathology student I learned much about the aural habilitation of children and how to teach deaf children to speak, while learning nothing about why and how to incorporate sign language into therapy. What SLPs are taught about childhood deafness focuses on how hearing impairment affects speech and language development and how to provide intervention. For example, one of the courses in the University of Toronto’s Master of Health Science SLP Program is “Aural Rehabilitation” in which, “Students learn about the effects of hearing impairment on speech and language development. Intervention includes discussion of visual communication, auditory training and assistive listening devices” (Department of Speech-Language Pathology, 2018, p. 10). Visual communication is included as a discussion topic; however, sign language and Deaf culture are not specific topics, and may not even be appropriate topics for a course on “Aural Rehabilitation.” Perhaps what is needed is a separate, mandatory course to teach students about disability studies perspectives as related to hearing, speech, language, and swallowing. Such a course should include a discussion about Deaf culture and what it could mean to a deaf child to have access to sign language and Deaf culture, as told by a member of the Deaf community. A worthwhile future research project could involve examining audiology and SLP students’ (as well as SLPs’ and audiologists’) understandings of different communication methods and how they came to those understandings.
7.8 Conclusion and implications: Re-constructing parental choice/Re-imagining deafness

Universal Newborn Hearing Screening has resulted in the capacity to identify deaf and hard of hearing children in infancy. Although such early identification leads to the opportunity to implement appropriate language services from a young age to avoid language delay, the way a deaf diagnosis is presented to parents changes the way parents come to know their children, and can restrict, rather than cultivate, language development and parent-infant interactions.

Ontario’s Infant Hearing Program (IHP) relies on a system that replaces a parent’s gradual coming to learn about their child with a prescribed way of knowing their child based on a diagnosis or diagnoses. Reducing the knowledge of deafness to a medical paradigm that has a goal of making deafness appear absent, restricts the ways parents are encouraged to interact with their child, and limits how parents can imagine their deaf child’s being and becoming. This medical knowing of deafness seeks to remove deaf estrangement, yet such estrangement will always be there for the child, whether or not hearing technologies are used. The cure paradigm which supports cochlear implantation and an exclusive spoken language approach is a powerful one, so powerful that it does not recognize itself as such: parents are governed toward a spoken language approach amidst the discourse of “informed choice” so that it may seem the IHP is supportive of all communication modalities.

The IHP has the opportunity to make deaf and hard of hearing diagnoses meaningful to parents in ways that do not limit deaf subjectivities, by assisting parents in coming to understand their child (their needs, wants, personality, learning style, communication preferences, etc.), rather than governing parents into a predetermined understanding of their child from a hearing perspective that seeks to ignore their deaf estrangement. Early knowledge that an infant cannot
hear can bring awareness that the child may experience the world differently than their hearing parents; hearing parents can be encouraged to watch for how their child experiences and responds to the world and interact with them accordingly. In this way, parent-infant relations and communication may be improved by encouraging parents to “pay attention” to their child, not just their child’s audition and vocalizations.

Canadian society, along with other Western societies, values normalcy such that normalcy is a prominent guidepost that governs how people make sense of the world. By becoming aware that normalcy is a construct created as an organizational tool to categorize and govern people within a society, we can begin to think differently about deafness and disability. As Titchkosky (2009) notes, a critical awareness of normal demands or assumptions can provide an opening to think differently about what has been categorized as ‘abnormal.’ In terms of deafness, this means the typical understanding of standardized spoken languages and full sensation of hearing as normal and necessary does not have to be so. I am not suggesting deaf children only be taught sign language or non-standard communication systems, or that hearing technologies be eschewed; I am instead suggesting the IHP acknowledge there are many ways to understand what it means to be deaf and what it means to have language beyond normalizing constraints. By doing so, deaf and hard of hearing children could have the opportunity to develop subjectivities without predefined limits placed on them.

One way to affect this understanding is to offer services that take these many ways of being deaf into account, rather than using a Deaf/Hearing binary to promote spoken language and deny sign language. By considering deaf children as both d/Deaf and h/Hearing and everything in between, rather than determining services based on a categorization of one or the other (i.e., “Hearing” deaf children receive hearing technologies and spoken language, whereas “Deaf” deaf children learn sign language), the IHP can remove the dichotomizing label that leads to
oppressive practices, and instead allow every opportunity for the children to come to know who they are and all the ways they experience the world. No doctor, audiologist, auditory-verbal therapist or speech-language pathologist should have the right to limit the modes of communication a child has access to, or limit deaf subjectivities and parent-child interactions by telling parents how they should come to know their child.

7.8.1 Implications for future research

As I began working on this dissertation, the IHP was in the process of changing its ASL service delivery so that all IHP ASL services were organized by one organization, Silent Voice, an organization that was already providing services to Deaf people and their families in ASL. Silent Voice, therefore, is contracted by the Ontario Ministry of Children and Youth Services to provide ASL services to children and families serviced by the IHP (http://ihp.silentvoice.ca). A couple parents mentioned they thought changes were happening in the system to allow for more flexible services including sign language, based on what they had heard from other parents. However, the parents I interviewed who had younger children had not been referred to Silent Voice, and the Silent Voice website states that ASL services are provided to those IHP children “who meet IHP referral criteria” (http://silentvoice.ca/what-we-do/). Future research could examine how (or if) the involvement of Silent Voice has changed families’ access to sign language and/or how the meanings of language and deafness have changed.

To define my research within manageable limits, I focused my interviews on parents of children serviced by the IHP. I had originally intended to also interview IHP service providers, but this would have generated an unwieldy amount of information for one project. To get a fuller sense of how deafness and language are made to matter by the IHP, I think it is important to understand the perspectives of IHP service providers (e.g., screeners, audiologists, speech-
language pathologists, auditory-verbal therapists, family support workers). Future research, then, could ask similar questions of IHP health practitioners to determine how language and deafness are meaningful to them and how these meanings interact with the work they do with parents and children. Such research could include: screener experiences with parents; audiologists’ experiences sharing diagnostic audiology results and ongoing assessments to parents; family support workers’ experiences providing information to parents; assessment and therapy decisions made by speech-language pathologists and auditory-verbal therapists. It is important to understand how IHP service providers mesh their own conceptions of deafness and language with the expectations of the IHP, and whether their conceptions changed over time as they gained experience working with the children and their families. In addition to understanding more about how deafness and language are made meaningful and deaf subjectivities defined, such information would be useful for the IHP to improve their procedures. Similarly, I think it is also important to understand how deafness and language are meaningful to the children themselves.

My research focused on parents whose children were identified as deaf or hard of hearing and who were receiving, or had recently received services from the IHP. Future research could include the experiences of parents whose infants passed the hearing screening, and parents whose infants failed the initial screening, but were found to have normal hearing during audiological assessment. In addition to determining how effective the IHP’s procedures are at relieving parental anxiety during the screening process, this research would also lead to a better understanding of how deafness and language are meaningful to those parents whose children are not deaf or hard of hearing. In addition, despite attempts to include Deaf parents in my research, no Deaf parents responded to my call for participants. This is a gap in my research, as Deaf parents likely have different conceptions of language and deafness than hearing parents, and
they may have had different experiences with screening and other IHP services. Future research could focus on how Deaf families experience IHP services, as this could provide invaluable information for the IHP to consider in any reformulation of services; Deaf parents have both lived experience as parents of deaf children serviced by the IHP, and as Deaf people themselves. Deaf parents’ feedback about their experiences with the IHP should therefore be instrumental for the implementation of the IHP’s last two principles: “The program will be monitored and evaluated on an ongoing basis” and “The quality of the program will be continuously improved based on the evaluations” (Ontario Ministry of Health and Long Term Care, 2002, p. 2).

Finally, there is repeated mention in IHP documents of services being “family centred” with no clear definition of what is meant by it. Indeed, one of the IHP’s principles is “All services will be child and family centred taking into consideration the cultural and ethnic diversity of the people of Ontario” (Ontario Ministry of Health and Long Term Care, 2002, p. 2). Future research could examine how cultural and ethnic diversity is taken into consideration by the IHP, and how culturally diverse families, including those who may not be fluent in English, experience IHP services. In addition, most parents spoke about the amount of work and stress involved in teaching their child to speak: taking their children to many different appointments; constant work on listening and speaking at home; prioritizing on what to spend their time due to limited time and resources; hearing technology maintenance; and pressure to meet speech and language milestones. Family-centred may therefore be experienced as the family doing the “work,” not necessarily doing what works for the families. Future research could examine what the IHP considers as family-centred, and how families experience services as family-centred, or not.

This dissertation represents my expedition, as a former practicing speech-language pathologist, into disability studies. I have demonstrated how the IHP’s representations of language and
deafness construct parental choice and deaf subjectivities, whether intentional or not, in such a way as to legitimate spoken language while suppressing sign language and Deaf culture. Ultimately, one potential outcome of my dissertation research is to raise awareness amongst audiologists and speech-language pathologists about the conceptions of disability that are brought to clinical practice, and to question the assumptions about ‘normal’ speech, language, and hearing that are inherent to these professions. I hope that my research can provide the opportunity for more questioning of the assumptions made by the speech-language pathology and audiology professions. Such questioning of normalcy holds bio-medical approaches in tension with cultural approaches. I suggest that consideration of socio-cultural representations and implications within predominantly bio-medical approaches can improve health care experiences, by accounting for lived experience with disability.
References


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http://www.thestar.com/life/health_wellness/2011/03/07/province_cutting_wait_times_for_cochlear_implants.html#


www.children.gov.on.ca/htdocs/English/topics/earlychildhood/hearing/brochure_services.aspx


Ontario Ministry of Children and Youth Services. (2014c). *Your baby has passed the screening but is at risk* (Publication #019609). Queen’s Printer for Ontario. Retrieved from


Toronto District School Board. (n.d.). *Special education-hearing itinerant.* Deaf and Hard of Hearing Program. Toronto, ON.


# Appendix A – List of Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AAC</td>
<td>Augmentative and Alternative Communication</td>
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<tr>
<td>ASL</td>
<td>American Sign Language</td>
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<tr>
<td>AVT</td>
<td>Auditory-Verbal Therapy/Auditory-Verbal Therapist</td>
</tr>
<tr>
<td>CASLPA</td>
<td>Canadian Association of Speech-Language Pathology and Audiology</td>
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<tr>
<td>CBC</td>
<td>Canadian Broadcasting Company</td>
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<tr>
<td>CODA</td>
<td>Hearing Child of Deaf Adults</td>
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<tr>
<td>CIHTF</td>
<td>Canadian Infant Hearing Task Force</td>
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<tr>
<td>DSL</td>
<td>Danish Sign Language</td>
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<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
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<tr>
<td>FSW</td>
<td>Family Support Worker</td>
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<tr>
<td>GTA</td>
<td>Greater Toronto Area</td>
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<tr>
<td>IHP</td>
<td>Infant Hearing Program</td>
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<tr>
<td>HVP</td>
<td>Home Visiting Program</td>
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<tr>
<td>LSQ</td>
<td>Langue des signes du Quebec/ Langue des signes Quebecois</td>
</tr>
<tr>
<td>NICU</td>
<td>Neonatal Intensive Care Unit</td>
</tr>
<tr>
<td>OC</td>
<td>Oral Communication</td>
</tr>
<tr>
<td>SAC</td>
<td>Speech-Language and Audiology Canada</td>
</tr>
<tr>
<td>SLP</td>
<td>Speech-Language Pathologist</td>
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<tr>
<td>TC</td>
<td>Total Communication</td>
</tr>
<tr>
<td>Acronym</td>
<td>Full Name</td>
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<tr>
<td>UPIAS</td>
<td>Union of the Physically Impaired Against Segregation</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Ontario’s Infant Hearing Program Resources

Central South Infant Hearing Program
http://ascy.ca/ihp-intro/

Central West Infant Hearing Program
https://www.erinoakkids.ca/services/services/infant-hearing-services.aspx

Eastern Ontario Infant Hearing Program
http://www.pqche.com/children-family-services/infant-hearing-program/
http://firstwords.ca/hearing/

Essex-Kent Infant Hearing Program
https://connectwithus.ca/programs/ihp/

Kenora-Rainy River Infant Hearing Program
https://www.nwhu.on.ca/ourservices/ChildAndFamilyHealth/Pages/InfantHearingAndVision.aspx

London Health Sciences Centre
http://www.lhsc.on.ca/About_Us/LHSC/Publications/Homepage/Infant-Hearing.htm

Mount Sinai’s website (Many links with information about the IHP are provided here, including downloadable documents)
http://www.mountsinai.on.ca/care/infant-hearing-program

Northeastern Ontario Infant Hearing Program
http://www.nbrhc.on.ca/programs-services/mental-health-programs-services/wordplay-jeux-demots/northeast-ontario-infant-hearing-program/

Silent Voice
http://ihp.silentvoice.ca

Simcoe Muskoka Parry Sound Infant Hearing Program
https://www.simcoe.ca/ChildrenandCommunityServices/Documents/Early%20Intervention/Infant%20Hearing%20Program.pdf#search=infant%20hearing%20program

Southeast Region Infant Hearing Program

Southwest Region Infant Hearing Program
http://infanthearingprogram.com/screening.html

Thunder Bay Infant Hearing Program
Toronto Infant Hearing Program

Tri-Regional Infant Hearing Program
http://www.childdevelopmentprograms.ca/hearing/program-information/
http://www.fivecounties.on.ca/pdf/InfantHearing.pdf

Ontario Ministry of Children and Youth Services

Information about hearing screening

Services for children who are Deaf or hard of hearing
http://www.children.gov.on.ca/htdocs/English/topics/earlychildhood/hearing/brochure_services.aspx

List of Regional Infant Hearing Programs
http://www.children.gov.on.ca/htdocs/English/topics/earlychildhood/hearing/where.aspx

Ontario Ministry of Health and Long-Term Care

Public Health and Epidemiology Reports (which mention the IHP)
http://www.health.gov.on.ca/english/providers/pub/phero/phero_052600.html


Ontario Paediatric Cochlear Implant Programs

CHEO (Children’s Hospital of Eastern Ontario)
http://www.cheo.on.ca/en/audiology

London Health Sciences Centre
http://www.lhsc.on.ca/About_Us/Cochlear_Implant/

SickKids Cochlear Implant Program
http://www.sickkids.ca/CochlearImplant/What%20We%20Do/index.html
Speech-Language and Audiology Associations

College of Audiologists and Speech-Language Pathologists of Ontario
http://www.caslpo.com/

Speech-Language and Audiology Canada
https://www.sac-oac.ca

The Ontario Association of Speech-Language Pathologists and Audiologists
https://www.osla.on.ca

Parent Organizations

Ontario Hands and Voices
http://www.ontariohandsandvoices.com

Voice for Hearing Impaired Children
http://www.voicefordeafkids.com/
Appendix C – Letter of Invite

Hello,

My name is Tracey Edelist and I am a graduate student at the Ontario Institute for Studies in Education at the University of Toronto. I am currently conducting research as part of my PhD degree requirements. As part of this research, I am interested in parents’ experiences with Ontario’s Infant Hearing Program, understandings of what it means to be deaf and what it means to have language, and how parents make communication and hearing technology decisions for their child(ren). Your sharing of these experiences could lead to suggested recommendations for improvement of the policies and practices of the IHP.

I am seeking parents of deaf or hard-of-hearing children, one to ten years of age, who currently receive services or have recently received services from the Infant Hearing Program, to participate in a one-on-one interview with the researcher that will be approximately 1.5 hours in length. You will be asked to discuss your experiences with the Infant Hearing Program, including the assessment and treatment that your child received, how diagnosis was communicated to you, how communication options were presented to you, and how you made choices regarding hearing technologies and communication modalities for your child. You may choose to give as much or as little detail as you are comfortable with, or decline to answer any question. Please note that I am not in any way affiliated with the Infant Hearing Program; the interview provides a safe space to discuss any negative experiences with the IHP, and/or the opportunity to share positive experiences. Your participation and your identifying information would be confidential and anonymous.

With your permission, the interview will be recorded with a digital audio recorder. An American Sign Language interpreter will be provided if your main language is ASL. After transcription, you will have the opportunity to review the transcript of your interview and make revisions if desired.

I would greatly appreciate your participation in my project. Please feel free to contact me for more information or if you have any questions about what your participation would involve.

Sincerely,

Tracey Edelist
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Supervisor:

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Professor, Disability Studies
Department of Social Justice Education
Ontario Institute for Studies in Education of the University of Toronto
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416-978-0451
Appendix D – Interview Consent Form

Dear Parent,

The purpose of this letter is to inform you of my research study about Ontario’s Infant Hearing Program (IHP) and what you can expect if you choose to be a participant in this study. You are being asked to participate as a parent of a deaf or hard-of-hearing child who is receiving, or has recently received, services from the IHP. The researcher is not affiliated in any way with the Infant Hearing Program.

This study is being undertaken as part of my Ph.D. degree requirements. As part of this research, I am interested in your experiences with Ontario’s Infant Hearing Program; your understandings of what it means to be deaf and what it means to have language; and how you came to make communication and hearing technology decisions for your child. You are being asked to participate in a one-on-one interview with the researcher that will be approximately 1.5 hours in length. The interview will be recorded with a digital audio recorder and transcribed by the researcher. You will have the opportunity to review the transcript of your interview and make revisions if desired.

Your participation in this study is completely voluntary. Should you wish to withdraw from participation, you are free to do so at anytime. If you decide to withdraw after your interview and no longer want your interview data to be used in the research project, your audio-recording and interview transcript will be destroyed. You may choose to decline to answer any question during the interview. To show my appreciation to you for taking the time to participate in this study, you will be given a $25 Chapters/Indigo gift card at the conclusion of the interview.

Your participation in this study is confidential and measures will be taken to ensure that all information collected from interviews will remain confidential. This consent form and any other hard copies of material with identifying information will be kept in a locked cabinet in a secure location. Names and other identifying information will be removed from the transcript and pseudonyms will be used in the presentation of findings. Only this researcher will have access to the raw data. Audio files will be deleted upon completion of the research, which could take up to four years after data collection. The researcher will keep the anonymized transcripts on a secure server for potential use in future projects. If used in the future, confidentiality and anonymity of the participants will be maintained. A copy of the final thesis will be provided to you upon request. The researcher may make presentations and/or publish papers based on this research, in which case you may request to be kept informed of such happenings.

Participating in this research provides you with the opportunity to share the experiences you had with the IHP. The interview provides a safe space to discuss any negative experiences with the IHP, and/or the opportunity to share positive experiences. Your sharing of these experiences
could lead to suggested recommendations for improvement of the policies and practices of the IHP.

If you have any questions about this study at any time, please contact me at tracey.edelist@mail.utoronto.ca. You may also contact my thesis supervisor, Dr. Tanya Titchkosky, at tanya.titchkosky@utoronto.ca, should you have any concerns about this research. If you have any questions about your rights as a participant in this study, please contact the Office of Research Ethics at ethics.review@utoronto.ca, 416-946-3273.

Thank you for your participation in this research project.

Sincerely,

Tracey Edelist
Ph.D. candidate, Social Justice Education
Ontario Institute for Studies in Education, University of Toronto
Email: tracey.edelist@mail.utoronto.ca

The expectations for my participation in this study have been explained to me by the researcher. I, ___________________________________________, understand the above explanation and give consent for my voluntary participation in this research project.

Signature: ___________________________  Date: ___________________
Appendix E – Interview Guide

Interview Guide

Thank you for taking the time to meet with me. As part of my doctoral thesis research, I am interested in your experiences with Ontario’s Infant Hearing Program and how you came to make language and hearing technology decisions for your child. I will be audio-recording the interview so that I can transcribe the information later. Do you have any questions before we begin?

Background

1. Could you tell me a bit about your child?
   Personality, likes/dislikes, age, school placement, hearing technology used (if any), how you communicate with your child, how your child communicates with others.

2. Do you recall how your child was referred to the Infant Hearing Program? (Age of initial screening; subsequent testing; which professional made the referral?)

3. Can you recall how you were told of your child’s audiogram and diagnosis?
   What information were you given? Do you recall the appointments you had leading up to and following the diagnosis? Describe your thoughts and feelings throughout the process.

Parental choice

4. The IHP offers three options: auditory-verbal; sign language; both. Can you describe how those three options were presented to you, and who presented them? What information were you given about each option and how was the information presented (verbal, written, video, etc.)?
   Did you feel as if you had enough information about each of the three options? Did you think the options were adequate or would you have preferred another option for your child?

5. What do you consider the advantages and disadvantages of each of the three options?
6. Were you given the option to consider a cochlear implant for your child? If yes, when was the option of cochlear implants first mentioned to you and by whom?

Can you recall what was discussed during that conversation? Can you recall any advantages and disadvantages discussed? Expectations regarding communication modality? How did you feel when told of this option?

7. What do you recall being told about sign language, and by whom? How did you feel about sign language as an option?

8. What do you recall being told about the dual approach, both sign language and auditory-verbal? How would services be provided for both sign language and spoken language? How did you feel about this dual option?

9. Were the choices you made regarding hearing technologies and communication modality easy for you to make? What was easy and/or difficult about your decisions?

What information factored into your decision?

10. Are you and your child happy with the choices that were made? Is there anything that you would change if you could?

What has deafness meant for you and your child and your family?

11. Before your involvement with the IHP, what did you think about being deaf? Did you know anyone who used hearing aids or cochlear implants? Did you know anyone who used sign language?

12. Since your child’s diagnosis and your family’s involvement with the IHP, has the way you’ve thought about deafness and what it means to be deaf changed at all? If yes, how so?

13. What are some of the significant changes that you have experienced having a deaf child?

14. Since your child’s diagnosis and your family’s involvement with the IHP, do you think that
your understanding of “communication” or “language” has changed? If yes, how so?

Do you think of language differently than before? Is the way you communicate with your child different than the way you communicated before the diagnosis, or different from how you communicate with your other children (or with other people)? Has your experience of communication changed since the birth of your child? What is communication like now with your child?

15. Is there anything else you’d like to tell me regarding your experiences with the IHP?
Appendix F – “Pass” Pamphlet

Your baby received a pass result. Your baby passed all levels of the hearing screening. This means that they are able to hear at a normal range, which is important for their overall development.

Pay attention to your baby’s movements. If your baby moves in response to different sounds, this is a good sign. If your baby does not move or if they are less responsive, it may be a sign of hearing loss.

Your baby has passed the newborn hearing screening. Keep an eye on your baby’s movements and behaviors to ensure they are responding to different sounds.

You can help your baby learn language. Babies are able to learn language at an early age, even before they are able to speak. Here are some examples of ways you can help your baby learn language:

- Babies like it when you:
  - Smile or talk to them.
  - Sing or hum to them.
  - Call them names or use their names.
  - Give them toys or play with them.
  - Read to them.

- Toddlers like it when you:
  - Tell them stories or read books with them.
  - Sing songs.
  - Play games.
  - Talk to them.

- Some ways to help your baby learn language:
  - Use simple words.
  - Point to things and talk about them.
  - Read to your baby.
  - Sing songs.
  - Play games that involve language.

Remember, every baby is different. Some babies may learn language faster than others. If you have any concerns about your baby’s hearing, talk to your doctor or a hearing specialist.
These developmental milestones show some of the skills that mark the progress of young children as they learn to communicate. There are also some tips on how you can help your child develop speech and language skills. If your child is not meeting any of these milestones, please contact your local Preschool Speech and Language Program.

**Developmental milestones**

**By 5 months**
- Tunes to sounds of language
- Cries in response to sudden loud noises
- Makes different coos for different needs
- Smiles when you talk
- Smiles and laughs in response to your smiles and songs
- Initiates cough or other sounds - "uh uh" etc.

**By 6 months**
- Follows simple one step directions - "sit down"
- Looks across the room at something you point to
- Uses three or more words
- Uses gestures to communicate - waves "bye bye", shakes head "no"
- Gets your attention using sounds, gestures and pointing while looking at your eyes
- Brings you toys to show you
- "Performs" for attention and praise - combines lots of sounds as though talking - abides back to 
- Shows interest in simple picture books

**By 9 months**
- Responds to father's name
- Responds to the telephone ringing or a knock at the door
- Understands being told "no"
- Gets what he or she wants through sounds and gestures; for example, reaching to be picked up
- Plays social games with you, for example, peek-a-boo
- Enjoys being around people
- Babbles and repeats sounds - baba bababa, da da da

**By 12 months**
- Follows two step directions - "Get your teddy bear and show it in Grandma's"
- Uses at least two pronouns - "you", "me", "mine"
- Consistently combines two or more words in short phrases - "tasty hat", "truck go down"
- Enjoys being with other children
- Begins to offer toys to peers and imitates other children's actions and words
- People can understand his or her words 50 to 62 per cent of the time
- Words and sounds wisely and effortlessly
- Holds books the right way up and turns pages
- "Reads" to stuffed animals or toys
- Scratches with fingers

**By 18 months**
- Understands the concepts of "in" and "out",
- "up and down"
- Goes to normal body parts when asked
- Uses at least 26 words
- Responds with words or gestures in simple questions - "Where's Teddy?" "What's that?"
- Shows some pretend play with toys - e.g. baby doll or block
- Makes at least four different consonant sounds - "r", "d", "g", "l"
- Enjoys being read to and looking at simple books
- Points to pictures using one finger

**By 24 months**
- Understands the concepts of size (big/little) and quantity (big, small, lots, more)
- Uses some adult grammar - "two apples", "two helping"
- "Jumps" "up"
- Uses more than 300 words
- Uses action words - run, play, fall
- Begins to take short turns with other children
- Uses both toys and words
- Shows concern when another child is hurt or sad
- Combines several actions in play - feeds and then puts her to sleep
- Puts blocks in train and then drives train and drops blocks off
- Produces words with two or more syllables or words - "banana-nana", "bunny-land", "a vase"...
- Recognizes familiar logos and signs - stop sign
- Remembered familiar stories
Appendix G – “Pass at Risk” Pamphlet
Developmental milestones

These developmental milestones show some of the skills that help your child develop speech and language. If your child is not meeting one or more of these milestones, please contact your local Preschool Speech and Language Program.

By 6 months
- turns his or her head in response to sounds
- smiles in response to sudden, loud noises
- makes different cries for different needs – ‘(I’m hungry) ’(I’m tired)
- watches your face as you talk
- smiles and laughs in response to your smiles
- finds objects
- imitates coughs or other sounds – ‘Ah, ah, buh’

By 9 months
- responds to his or her name
- responds to the telephone ringing or a knock at the door
- understands ‘this is my toy’
- makes what he or she wants from sounds and gestures, for example, reaching to be picked up
- plays peek-a-boo
- enjoys being read to
- imitates sounds – ‘ba-ba-ba’

By 12 months
- follows simple one-step directions – ‘Sit down’
- talks across the room to something you point to
- uses two or more words
- uses gestures to communicate – always ‘bye, bye’, sometimes ‘thank you’
- gets your attention using sounds, gestures and pointing while looking at your toy
- brings toys to show you
- ‘performer’ for attention and praise
- combines lots of sounds as though talking – sounds Individual
- shows interest in simple picture books

By 18 months
- understands the concepts of ‘in’ and ‘out’
- ‘up’ and ‘down’
- points to several body parts when asked
- uses at least 23 words
- responds with words or gestures to simple questions – ‘(I’m happy)’
- demarcates some pretend play with toys – plays ‘doctor’
- makes at least four different consonant sounds – ‘m, n, g, k’
- enjoys being read to and looking at simple books with you
- points to pictures using one finger

By 24 months
- follows two-step directions – ‘Go find your baby bear and show it to Grandma’
- uses 100 or more words
- uses at least two pronouns – ‘you’, ‘me’, ‘mine’
- consistently combines two or more words in simple phrases – ‘Daddy, shake the toy’
- imitates others’ actions and talks
- can understand several words – over 50 per cent of the time
- sounds words and sounds easily and voluntarily
- reads books by looking up and turning pages
- talks to stuffed animals or toys
- pretends with crayons

By 30 months
- understands the concepts of ‘hot’ (big) and quantity
- uses words like ‘a lot more’
- uses some adult grammar – ‘two apples’
- ‘hand over’
- ‘(I’m sad)’
- ‘(I’m happy)’
- ‘(I’m hungry)’
- ‘(I’m tired)’
- ‘(It’s time to go)’
- demonstrates some pretend play with toys – ‘picks baby brother’
- makes at least four different consonant sounds – ‘m, n, g, k’
- enjoys being read to
- combines lots of sounds as though talking – sounds Individual
- shows concern when another child is hurt or sad
- combines several actions in play – feeds doll, nurse doll, put her to sleep, puts blocks in train, floods train and stops blocks off
- puts sounds at the start of most words
- produces words with two or more syllables or beats – ‘(I’m sad)’, ‘(It’s time)’
- recognizes familiar topics and signs – stop sign
- remembers and understands familiar stories

Babies like it when your:
- Get down to their level so they can see your face.
- Turn to look at them when they’re interested in what you’re doing and stop talking to make it easier to interact with you.
- Repeat the sounds they make. Babies enjoy making noises, and it’s fun when you imitate them.
- Sing and laugh, especially when you’re feeding, bathing, or changing them. Remember to talk to your baby throughout the day about things you do and see – ‘Mummy’s putting on her coat.’ ‘That’s a big truck.’
- Tell them the names of the objects they’re looking at and playing with. Babies are fascinated in exploring and learning about new things, and like to hear what things are called.

Toddlers like it when your:
- Let them touch and hold books when you point to and name the pictures.
- Use real words instead of baby talk – ‘go on’ instead of ‘do do’ or ‘go’ instead of ‘go go’.
- Talk to the toys they like to play with.
- Let them take care of their own toys.
- Give them simple directions to follow – ‘Put your toys in your boat’
- Use lots of different words when you talk to them.
- Oppose words like ‘down’ with action words like ‘up’, ‘up’ with ‘down’, and descriptive words like ‘red’ with ‘blue’.
- Encourage them to play with other children – at the library, playgroup, park.
## Developmental Milestones

These developmental milestones show some of the skills that mark the progress of young children as they learn to communicate. There are also some tips on how you can help your child develop speech and language skills. If your child is not meeting one or more of these milestones, please contact your local Preschool Speech and Language Program.

### By 6 months
- Turns to sounds of your voice
- Stares intently at objects, your face
- Makes different sounds for different needs
- Is hungry, finicky
- Watches your face as you talk
- Grasps and brings to mouth in response to your smile and laugh
- Likes clothes or other soft objects - with both hands

### By 9 months
- Responds to his/her name
- Responds to the telephone ringing or a knock at the door
- Understands being told “no”
- Takes what he or she wants through sounds and gestures, for example, reaching to be picked up
- Plays social games with you, for example, peek-a-boo
- Enjoys talking around people
- Uses and responds to sounds - imitations, babbling, sobbing

### By 12 months
- Follows simple one-step directions - “sit down”
- Takes across the room to something you point to
- Uses three or more words
- Uses gestures to communicate - waving “bye-bye”, shakes head “no”
- Gets your attention using sounds, gestures, and pointing when looking at your eyes
- Takes one toy to show you
- “points” for attention and preferred objects
- Can express lots of sounds as though taking - babies babbler stage
- Shows interest in simple picture books

### By 18 months
- Understands the concepts of “in and out”, “hit and off”
- Points to several body parts when asked
- Uses at least 20 words
- Responds with words or gestures to simple questions - “Whose baby?”, “What’s that?”
- Demonstrates some pretend play with toys - dolls, baby, E.E.
- Makes at least four different consonant sounds - “m”, “n”, “p”, “b”
- Enjoys throwing in and looking at simple books with you
- Points to pictures using one finger

### By 24 months
- Follows two-step directions - “go find your teddy bear and show it to Grandpa”
- Uses 300 or more words
- Uses at least two pronouns - “you”, “me”, “mine”
- Consistently combines two or more words in short phrases - “daddy’s car”, “truck go down”
- Enjoys being with other children
- Begins to offer toys to peers and entices other children
- Recognizes and names some familiar objects
- Points with hand to objects
- Shows interest in simple picture books

### By 30 months
- Understands the concepts of size (bigger/little) and quantity (a little, a lot, none)
- Uses some adult grammar - “two apples”, “bird flying”, “I want”
- Uses more than 500 words
- Uses action words - run, skip, fall
- Begins taking short turns with other children, using both toys and words
- Shows concern when another child is hurt or sad
- Combines several actions in play - tends to put in the flying in attic, then drives train, and drops books off
- Pulls sounds at the start of most words
- Produces words with two or more syllables or beats - “papa’s car”, “mama’s car”, “baba”, “dada”
- Recognizes familiar sounds and signs - stop sign
- Remembers and understands familiar stories

### Babies like it when you:
- Get down to their level so they can see your face. This tells them that you’re interested in what they’re doing and saying, it makes it easier to interact with you.
- Repeat the sounds they make. Babies enjoy making noises, and like it when you imitate them over and over.
- Sing and laugh, especially when you are feeding, bathing, and changing them.
- Remember to talk to your baby throughout the day about things you do and see — “Mommy’s cutting on that coaster,” “That’s a big truck.”
- Tell them the names of the objects they are looking at and playing with. Babies are interested in exploring and learning about new things, and like to hear what things are called.

### Toddlers like it when you:
- Let them touch and hold books while you point to and name the pictures.
- Use real words instead of baby talk - “give me” instead of “papa or “water” instead of “drink”.
- Take the time to listen to them — they want you to hear all of their new sounds, words, and ideas.
- Give them simple directions to follow — “Go find your red boot.”
- Use lots of different words when you talk to them — opposite words, like up-down, in-out; action words like “jumping”, “sliding”, and descriptive words like “happy”, “tired”, “happy”, “sad”.
- Encourage them to play with other children — at the library, play groups, parks.
Appendix I – “Hearing Loss Diagnosed” Pamphlet
Why does my baby need to have several hearing screens and tests?

The newborn hearing screening only shows that a hearing problem might be present. In order to diagnose the sounds your baby can hear or may have difficulty hearing, more information is needed. The follow-up testing is done by an Infant Hearing Program (IHP) authorized audiologist.

How do you test a baby's hearing?

The audiologist will test your baby's hearing in a very quiet room while the baby is sleeping. Electrodes (small cloth-like patches leading to computer connections) are placed on the baby. Soft tips are placed inside your baby's ears. Sounds at different loudness levels will be played into your baby's ears. A computer measures the hearing nerves response to the sounds. The information is used by the audiologist to identify babies who have a hearing loss, and to assess the amount of hearing loss your child may have. The test is completely safe.

My baby has a hearing loss.

What next?

After a complete hearing test, the audiologist will explain the details of the hearing loss:
- The type of hearing loss
- The sounds your baby can hear
- The sounds your baby may not hear or have difficulty hearing
- How the hearing loss may affect speech and language development
- The types of hearing technology (e.g., hearing aids) that could help your baby hear
- Support services made available to you by IHP, including access to a Family Support Worker who can provide counseling and support and help you find other resources you or your child may need.

Why is it important to identify a child's hearing loss so soon after birth?

Most babies are born ready to hear their parents' voices and the sounds of the world around them. Babies with hearing loss have the same need to communicate as babies with normal hearing. Identifying hearing loss as soon as possible helps IHP professionals work with your family to ensure family-centered services are in place to provide your child with the opportunity to develop language and communication skills.

What is the role of the Family Support Worker?

The Family Support Worker is available to assist your family. This trained professional supports families of children with hearing loss in many ways, including:
- Providing counseling support
- Helping you connect with services available for you, your child and family
- Connecting you with other parents of children with hearing loss
- Helping your family with transitions to child care and school.

What kinds of hearing technology are available for my child?

There are different types of hearing technology (e.g., hearing aids, cochlear implants, FM systems) available for your baby. Your audiologist will provide important information and work closely with you to help with decision-making regarding the use of hearing technology for your child.