Looking Beyond Discussions of Medical and Social Models: A Critical Qualitative Examination of deaf Health Disparities

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BPsycSci (Hons)

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Abstract

There is strong empirical evidence, from Australia and internationally, that people living with hearing loss or deafness experience substantial challenges to accessing health services, resulting in poor health. Despite evidence demonstrating the success of hearing technology for correcting hearing losses and deafness, health disparities between hearing people and people living with hearing loss or deafness continue. Empirical work in the area of deafness is contextualised by ongoing theoretical discussions of the medical and social models of disability and, by extension, deafness. Despite consensus among theorists, even among those who are living with a disability themselves, that the medical model is restrictive, it is clear that this model continues to shape research priorities and dominant practices and ideology in society. While social models of disability/deafness tend to be favoured among theorists and discussed as preferable to the medical model and inclusive of the lived experiences of deafness, academics continue to debate and refine the social models of deafness. These debates largely remain theoretical as there is limited empirical work that has explored how these models, and related discourses, operate within society.

Located within a social constructionist framework, this thesis provides a reflexive account of how I explored ways that deafness is constructed within Australian society and how these constructions contribute to the health disparities between hearing people and people living in Australia with hearing loss or deafness. The aims of this thesis are two-fold, (1) to explore how people living with hearing loss or deafness construct experiences of deafness and how these constructs relate (if at all) to theoretical discussions of disability or deafness; (2) to examine how health professionals construct experiences of treating clients living with hearing loss or deafness. These aims are achieved in two separate studies. The first is a mixed methods study of an online forum with people living with hearing loss or
deafness and the second, interviews with health professionals who have treated clients living with hearing loss or deafness.

Chapter 1 is an outline the structure of the thesis, describing both the research problem and my position as the author. In Chapter 2, I introduce social constructionism and the tensions that exist between this framework and positivism, and how these frameworks have shaped the thesis. Building on this, I provide an overview of the research methods implemented in the thesis. In order to contextualise the research presented in this thesis, information relevant to deafness and the Australian context is discussed at length in Chapter 3. Chapter 4 and 5 are a review of the literature relevant to how deafness has been studied in the past. This review covers deafness as a socially constructed phenomenon and critiques the empirical evidence pertaining to the health-related quality of life, health knowledge and barriers to accessing health that people living with hearing loss or deafness experience. Chapter 5 then provides a short discussion of why not everyone wants their deafness or hearing loss cured. In combination, these chapters provide the necessary information and theoretical positioning for the reader to understand the impetus of the research presented in this thesis and the context within which it was conducted.

Chapter 6 presents a reflective explanation of how and why I developed an online survey and forum for people to discuss their experiences of living in Australia with hearing loss or deafness. As an innovative method of enquiry, this chapter includes an in-depth discussion of the challenges I negotiated as the researcher for this study. Following this, I present a discursive analysis of the 24 forum users’ posts, whereby a discourse of deafness as abnormal was identified. Building these findings, Chapter 7 presents an inductive thematic analysis of 18 interviews with health professionals who have provided health services to clients living with hearing loss or deafness. In response to the identification of an overarching theme of hearingness as privileged, I provide a brief review of the literature on privilege and
oppression, along with a reflexive account of how this analysis represented a shift and clarification in my knowledge and understanding of the research problem described in Chapter 1. In closing, Chapter 8 provides a summary of the empirical, methodological, theoretical and practical contributions of this thesis. I present the argument that while health systems in our society continue to value and assume hearingness the health disadvantages experienced by this population will remain, regardless of the successes of hearing technology. I discuss the role and importance of reflexivity as it relates to the production of knowledge in this thesis, particularly as a hearing researcher, and consider future empirical directions for work in this area.
Declaration by Author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Publications During Candidature

Peer-reviewed Journal Articles:


Conference Presentations Relevant to this Thesis:


Ferndale, D., Watson, B. & Munro, L. (November, 2013). Online research with the deaf. Annual Conference of the *University of Queensland’s School of Psychology Research Higher Degree Day*, Brisbane, Australia.


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Ferndale, D., Watson, B. & Munro, L. (December, 2012). Discourses disabbling and disabling discourses. Australian Institute for Psychology, Brisbane, Australia

**Publications Included in this Thesis**


Incorporated into Chapter 5.

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Contributions by Others to the Thesis

Contribution was made by Doctor Bernadette Watson and Doctor Louise Munro to Chapters 5, 6 and 7 as outlined above. Doctor Bernadette Watson also contributed to the overall design of this program of work and the revisions of each chapter of this thesis. Doctor Louise Munro contributed to the overall design of this program of work, the revisions for Chapter 4 and the final revisions of each chapter. Paul Jackson contributed to the design of the online forum for Study 1 and Neil Wood, Naida and Rachel Byrnes contributed to the translation and videoing of the materials used on the forum in Study 1. Doctor Alexandra Gibson and Doctor Britta Wigginton contributed to the analytical process and discussions for Study 1.

Statement of parts of the thesis submitted to qualify for the award of another degree

None.
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Australian and New Zealand Standard Research Classifications (ANZSRC)

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111799 Public Health and Health Services not elsewhere classified 25%

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Setting the Stage

This chapter provides a description of the research problem, outline the structure of the thesis including how each chapter and publication contributes to the thesis, and the purpose of the reflexive diaries that are included throughout the thesis. Owing to the inclusion of published manuscripts, a brief clarification of any presentation anomalies is provided. Lastly, I make clear how my own epistemological and personal positions have shaped the research presented in this thesis.

Description of Research Problem

People who live in Australia with a hearing loss or deafness continue to experience poorer health and insufficient access to health services and information (e.g., Chia et al., 2007; Dalton et al., 2003; Gopinath et al., 2012; Harmer, 1999; Hogan et al., 2001; Hogan, Shipley, Strazdins, Purcell, & Baker, 2011; Pollard & Barnett, 2009; Steinberg, Sullivan, & Loew, 1998). A considerable amount of empirical research has investigated the disadvantage people living with deafness or hearing loss experience. Researchers have predominantly explored the relationship between hearing technology (e.g., cochlear implants), language acquisition and educational success (and therefore intelligence and ability to access and comprehend language). Reviewed and critiqued in Chapter 5, much of the research that exists, adopting a positivist framework and quantitative methods, focuses on measuring/quantifying deafness and the disadvantage this group experiences and how deaf individuals can change to improve their health and access. Researchers have used postmodernist frameworks and qualitative methods to explore the barriers people living with hearing loss or deafness experience when accessing health services and information. Various recommendations to improve access and services have been suggested by researchers. However, recent research demonstrates that the identified health disparities continue to be an issue.

1 Throughout this thesis, I use the phrase “people living with hearing loss or deafness” to encompass all types of deafness and hearing loss, recognising and encompassing the diversity and fluidity of experiences within this population; this is discussed further in Notes on presentation anomalies.
Disability theorists (e.g., Corker & French, 1999; Thomas & Corker, 2002), in the relatively new field of disability studies (Shakespeare, 1998), continue to debate constructions of disability and impairment and how they relate to medical and social models of disability (discussed in Chapter 4). Although it remains dominant in society, the medical model of disability (and deafness) has been problematised as oppressive and limited within these debates. Previously, social models of disability have separated out impairment (physical impairment) from disability (located in the social context) however, this continues to be deliberated. Debates over the social model of disability are further complicated by the Deaf culture. Discussed in Chapter 4, deafness and Deaf culture represent a unique category which bridges discussions of disability and ethnic/linguistic minorities.

While some progress has been made in developing our understanding of disability and achieving rights for people living with disability, progress is hindered by the continued dominance of the positivist approach to knowledge in Western society, and a lack of empirical evidence to support postmodernist approaches to disability studies. In this thesis, I address the lack of attention that has been given to the social context in which people with hearing loss and deafness live; how infrastructure, language use and systems shape the (health) experiences of people living with deafness and hearing loss. As such, this thesis explores how deafness is negotiated at a discursive and societal level within a health care context.

**Structure of the Thesis and the Research Papers**

This thesis is comprised of eight chapters which contribute to a cohesive story presented in this thesis. It is impossible to read and cover everything on this topic in one thesis. As such the focus of this thesis is to present a unique contribution to the field of research but also to put this research into context by demonstrating the genesis of my thinking as it occurred throughout the research process. This is achieved through the inclusion of reflexive talk
throughout the thesis in the form of publications and journal entries. The reflective journal entries, included throughout this thesis narrate, and make transparent, the development of the thesis. Each of the entries, based on notes taken at the time and written retrospectively, is presented in numerical order. They guide the reader through my journey of developing my interest in deafness, epistemological and ontological position and the ethical, practical and institutional dilemmas I negotiated in the research context. Providing contextual information that would otherwise not be visible, the journal entries represent an additional unique contribution to knowledge.

Chapter 1 is an overview of the thesis. This chapter provides a description of the research problem explored in this thesis and a summary of the structure of the thesis. As published manuscripts are included in the thesis, Chapter 1 also includes notes of presentation anomalies. In the final section of Chapter 1, I explain my interest in the area of deaf research in Journal Entry 1 and discuss the epistemological and personal reflexivity that informed the production of data and findings presented in this thesis.

Chapter 2 provides background to the framework and methods employed in the thesis. The overarching framework that has guided the thesis is discussed; elaborating on the tension between positivism and social constructionism and how it has shaped the thesis. A brief description of the general research methods, ethical considerations, statistical tools and data management is also provided. The specific details of the methods used in each study are elaborated on in the chapters relevant to each study.

Chapter 3 introduces the reader to the context of living with a hearing loss or deafness. The purpose of this chapter is to make clear the diversity and complexity of the population of people living in Australia with hearing loss or deafness. As such, this chapter covers information regarding population estimates, audiological information, hearing and visual technology and language. Building on this information, the various philosophical
perspectives on deafness\textsuperscript{2} and key terms are discussed. The Australian context is also discussed; specifically health services and information, health professional training and education and the geographical landscape.

Chapter 4 is a review and discussion of the literature relevant to the theoretical debates surrounding constructions of disability and deafness. Building on this, Chapter 5 is an in-depth review of how deafness has been studied in the past, specifically in relation to health related quality of life, health knowledge and barriers to accessing health services. Chapter 5 includes a letter to the editor, published in the \textit{Australian and New Zealand Journal of Public Health}, which describes an incident in Australia that acted as a catalyst for this thesis (see Appendix A1 for details).

Chapter 6 marks the beginning of the research process. Comprised of two journal entries and two publications, it presents an exploration of how people living with hearing loss or deafness talk about and understand deafness and hearing loss (Study 1). This chapter begins with Journal Entry 2. Drawing links between my position as the researcher (Chapter 1), conducting research in the Australian context (Chapter 3) and the history of research on deafness(Chapter 4 and 5), Journal Entry 2 outlines the (ethical) dilemmas I faced when considering how to design and conduct Study 1. The first publication in this chapter, published in \textit{Qualitative Research in Psychology}, provides a reflexive account of my experience designing and using an inclusive online forum to conduct research with people living with hearing loss or deafness (see Appendix B1- B7 for study materials). Journal Entry 3 provides a reflexive account of the challenges I negotiated completing the discourse analysis of the online forum data. The second paper, published in the \textit{American Annals of Deaf}, presents the findings of a discursive analysis of the online forum posts of 24 Australian adults living with hearing loss or deafness (see Appendix B8 for summary report of the

\textsuperscript{2} The term deafness is used to collectively refer to the physiological aspect of hearing loss and deafness.
findings made available to the community). Specifically, this paper presents a discussion of how deafness was constructed as abnormal in the posts of the forum users and the negatively valued identity position people living with hearing loss and deafness hold within this discourse. The findings from Study 1, led me to question how such discourses are perpetuated within society and what role, if any, health professionals have in reproducing the *deafness as abnormal* discourse.

Building on a concern for how deafness is constructed within society, Chapter 7 presents an analysis of how health professionals, who have treated clients living with hearing loss or deafness, talk about and understand deafness (Study 2). This chapter includes two journal entries, a paper under review and a brief introduction to the literature on the topic of privilege. This chapter begins with Journal Entry 4; drawing links between my position as the researcher (Chapter 1) and conducting research in the deaf context (Chapter 3). This journal entry discusses the methodological and ethical dilemmas of conducting interviews with a marginalized population, using a visual language and working with an interpreter. Following this, Chapter 6 presents a thematic analysis of 18 interviews (anonymised and transcribed verbatim) with allied and medical health professionals, which is currently under review at *Disability and Society* (see Appendix C1 – C4 for study materials and summary report of the findings made available to the participants). The findings of this analysis demonstrated that health professionals are operating within (and limited by) a health system that inherently privileges hearingness, and oppresses deafness. A brief introduction to the literature on privilege is provided to contextualize the development of my thinking and how the process of discovering/identifying hearingness as privileged has revolutionised my thinking, which is explained in Journal Entry 5.

The final chapter in this thesis, Chapter 8, brings together the empirical, methodological and theoretical contributions of the previous chapters. The aims, findings and
practical implications of this thesis are synthesised in this chapter. Drawing on the findings of this thesis, in Journal Entry 6, I recount my experience attending the World Federation of the Deaf conference and discuss the ways in which I was challenged through this experience. Drawing on my experience at the conference and the findings and practical implications of this thesis, directions for future empirical and theoretical work are discussed. Lastly, I reflect on the ways reflexivity has facilitated a deeper understanding of the research process and the creation of knowledge and how the inclusion of journal entries has allowed me to reflect on the ethical nature and practical usefulness of this thesis.

**Notes on Presentation Anomalies**

The chapters and published papers presented in this thesis have not been written or published in consecutive order. While included here as one cohesive narrative, the published papers included in this thesis have been tailored to the particular journal’s audience and preferred formatting style. As such, the challenge has been producing thesis chapters that are not repetitive, and standalone publications that provide the necessary information for the journal reader. Throughout the thesis (chapters and publications), the phrase ‘people living with deafness or hearing loss’ is used to imply that we are not actively separating out people according to any audiological criteria or specific deaf identity, recognising and encompassing the diversity and fluidity of experiences within this population. Where specific research that is not my own is being reported or discussed, I will use the terminology as it is reported in the published paper.

In order to reflect the co-contribution of the authors in the publications, I will use the term ‘we’ when I referring to work that has been published. The term ‘I’ will be used when referring to ideas related to published work but was not included in the publication.

The publications presented in this thesis are the accepted (submitted) author manuscripts, and have been submitted (or published) in four different journals. Consequently,
there are stylistic anomalies. The referencing and formatting conventions of the American Psychological Association (APA) 6th Edition are primarily adopted within this thesis. Notable exceptions are:

- In Chapter 5, the publication titled *Hearing loss as a public health matter – Why not everyone wants their deafness or hearing loss cured* follows the conventions recommended by the International Committee of Medical Journal Editors, known as the Vancouver Style.

- In Chapter 6, the publication titled *Creating deaf-friendly spaces for research: Innovating online qualitative enquiries* follows the conventions of the Harvard style.

- In Chapter 6, the publication titled *A discourse of ‘abnormality’: Exploring discussions of people living in Australia with a deafness or hearing loss* and in Chapter 7, the publication titled *An exploration of how health professionals understand experiences of hearing loss and deafness* both follow the conventions of the American Psychological Association, as specified by the Journal.

**Positioning the Author in the Current Research**

Young and Temple, broadly situated within an ethnographic approach to reflexivity, explain that “researchers who adopt epistemologies other than those concerned with trying objectively to capture reality view language as helping to create as well as to describe social worlds” (2014, p. 132). As Willig (1999, 2008), situated within psychology and social constructionism explains, reflexivity requires researchers to acknowledge their own contribution to the construction of meanings throughout the research process. This process also reinforces the notion that it is impossible to conduct research that is removed from our own perspectives and experiences. Willig further explains there are two types of reflexivity, epistemological and personal. Epistemological reflexivity requires us to question the assumptions (about knowledge and the world) that we (or others) have made during the
course of the research. Personal reflexivity, as Willig describes, “involves reflecting on the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research” (2008, p. 10). The decisions I (and we) make throughout the research process “mediate what is known, how it is known and who is seen to tell” (Young & Temple, 2014, p. 130). In this section I make clear the epistemological and personal reflexivity that informed the production of data and findings presented in this thesis. I will begin with a journal entry which details where I began my journey both with deafness and as an academic and how I began to question the underlying assumptions of my positivist training.

**Journal Entry 1 - A tale of Two Worlds**

**January 2011-February 2012**

After completing my Bachelor of Psychological Science at the University of Queensland in 2010 and knowing only that I was interested in health psychology, I lacked any career direction and began exploring different experiences that could inspire some direction. At the time, I had been working at a part time job and became friends with a woman, who also happened to be deaf. In the spirit of trying new things and wanting to be able to communicate with my friend, I looked into learning sign language, I later learned is correctly named Auslan (Australian Sign Language).

Having no expectations about these Auslan lessons and with the support of a friend, I enrolled in an 8 week introductory course offered by one of the Deaf organisations. Looking back on the decision to learn Auslan and enrol in this course, everything fits into place. Only 5 people had enrolled. Two were myself and my friend, there was a gentleman and also two women; one a woman who worked for Queensland Health and the second an army psychologist.

**Rule one, turn off your voices.**
At the start of the course we were provided with a working booklet which detailed information about Auslan, the Australian Deaf Community, Deaf Culture and some myths and facts about deafness and people living with a hearing loss or deafness. Reading through this information was eye opening. This idea that there were people, everyday people, who exist in this whole other world where deafness is not perceived as a disability was completely new to me, and intriguing. I wondered how this world had remained so well hidden from me.

The course continued and each week I learnt more about this Deaf world and became more captivated by Auslan as a beautiful, expressive language. Halfway through the course, the class was practicing using Auslan having conversations. I was telling the woman who worked for a Government Health organisation and the military psychologist that I had recently graduated with a Bachelor of Psychological Science and was trying to find a career direction to which they suggested I could do research in the area of deafness. Following up on their suggestions I started to look for research articles on deafness and found that there was a lack of research in psychology and in particular in health. As I was reading an article the thought occurred to me, how do deaf Australians call emergency services? Realising that in the year 2011 Australians living with a hearing loss or deafness did not have adequate or equal access to emergency services I had to ask myself why don’t they? Following on from these light bulb moments I acquired a supervisor and embarked on my PhD journey in November 2011.

**The learning curve.**

In the early phases of my PhD, I was reading an empirical article which described the poor health realities that individuals living with a hearing loss or deafness endure. My first reaction was to discern a way to improve their health knowledge and access
to health. Given my undergraduate background in quantitative methods and positivist framework, this seemed the most obvious solution to improve the health realities of Australians living with a hearing loss or deafness. Although I had become disillusioned with the notion that ‘controlled’ experiments were able to measure and define a phenomenon, that there was one truth, at the time, I had not given much thought to my epistemological position. Having not been exposed to alternative epistemological and ontological frameworks, I was not sure what to do with this dissatisfaction.

In January 2012 I began to reassess and develop my thinking and my ‘solution’ to deaf health when I volunteered at the Australian Deaf Games being held in Geelong. Communication at the games was largely in Auslan and I had the opportunity to meet and befriend volunteers, athletes and organisers, both hearing people and people living with a hearing loss or deafness. Through this experience, it quickly dawned on me that disability is not necessarily within a person but is also in the environment; as a hearing person, with limited sign, in a room full of signing deaf people, I began to understand myself as disabled.

After talking with my PhD colleagues and my supervisor, I set about reading and reflecting on different ontologies and epistemologies, considering how they matched up with my experiences and developing understanding of the world and how they applied to the health realities faced by people living with a hearing loss or deafness. A social constructionist approach was the conclusion of my reflecting. Moving forward from this point, I continued reading and began to question whether the assumptions the researchers had made and the knowledge the researchers were obtaining was contributing to the very health disparities that they had identified.
Author’s history and biography

In this section I explicitly acknowledge the personal and political values and perspectives informing this thesis. The knowledge presented in this research has been co-constructed between myself, my supervisors and the people who participated in the studies, and is located within a specific time and place. The purpose of this reflexivity section is to provide the reader with the context to understand how my own history and biography have shaped the research.

I am a hearing person and my entire family is hearing. Prior to working at a previous part time job I had never had any personal, meaningful experience with deafness or hearing loss. I began this project with a genuine and organic interest in the world of hearing loss and deafness, understanding it to be a population of people hidden and marginalised by society. I recognise myself as a member of numerous groups privileged by society (young, white, educated, heterosexual, able-bodied, cisgendered and hearing) and as having never been explicitly or personally oppressed for any group with which I identified. I was aware that never having personally experienced being a member of an oppressed social category, and as being a member of social categories that occupy positions of power in society (e.g., white, able-bodied, hearing), I would face challenges in building trust and rapport with people who are living with hearing loss or deafness. The challenges that I have faced are discussed in the journal entries included throughout this thesis and in-depth in Chapter 6.

Throughout the process of this research it has been challenging negotiating my identity as a hearing person and as an academic. As a hearing person who does not have a natural connection to the world of hearing loss and deafness, it has been challenging establishing trust and credibility with people who are living with hearing loss or deafness. As an academic, it has been difficult to establish rapport and trust with health professionals in a context where health professionals have been criticised in published research for contributing
to the barriers people living with deafness or hearing loss experience when accessing health care.

As a hearing researcher I have frequently felt like an outsider. In the context of doing research in the hard of hearing and deafness sector I have constantly been aware of the historical relationship between people living with hearing loss or deafness and hearing researchers (Pollard, 1992; Thumann & Simms, 2009) and ongoing tensions between differing philosophical approaches (e.g., medical and social). I am also aware that as a hearing and able-bodied woman, I am unable to share the fundamental experiences of living with a hearing loss or deafness while working as or receiving treatment from a health professional in Australia. Similarly, as an early career researcher and as someone who does not practice as a health professional, I am unable to share insider knowledge and experiences of working within the Australian health system.

To manage people’s potential mistrust towards myself, a hearing researcher (e.g., assumption I value hearing over deafness), I chose to be open about my position as a highly educated, hearing woman. I explained my genuine interest in listening to everyone’s story and actively positioning people living with hearing loss or deafness as experts in the lived experience and future of deafness. I was also continually mindful of historical (yet continually relevant) events and relationships between people living with deafness or hearing loss and hearing people; enacting a respect for the lived experience of deafness and hearing loss, Deaf culture and Auslan. In addition to attending academic related events and activities (e.g., conferences, workshops), throughout my candidature I have continued to attend various deaf social events (formal and informal) and learn Auslan (both formally and informally). Participating in this combination of activities has facilitated the development of epistemological position, research skills, values and beliefs.
Conclusion

In this chapter I have described the research problem, detailed the structure of this thesis (including the published papers), explained the formatting and referencing of this thesis and outlined my position as the author. The information I have presented in this chapter serves as a guide for the reader, to not only contextualize the thesis, but the research discussed here within. Chapter 2 builds on this foundation, explaining in thorough detail the background of the framework and methodologies employed in this thesis.
Chapter 2

Methodology .................................................................................................................. 16

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Methodology

While a social constructionist framework has been adopted in this thesis, at times both positivist and social constructionist philosophies have informed the research process. The purpose of this chapter is to clarify the tensions that exist between positivist and the various social constructionist philosophies. Within this chapter I also explain the realism/relativism debate, positioning myself within critical realism. While discussed in detail in the specific research chapters, an overview of the research methods, ethical considerations, statistical tools and data management is also provided in this chapter.

Positivism and Social Constructionism

Following a definition of positivism and social constructionism, I discuss the discord that exists between the two philosophies and how they have informed the research presented in this thesis. The ontological and epistemological differences between modernist and postmodernist frameworks underscore the tension that exists between positivism and social constructionism. Positivism is informed by the assumption that there is a pre-existing truth or ‘reality’ that is discoverable; through continued experimentation and measurement, we can observe ‘reality’ and simply develop descriptions about it. (Lyons & Chamberlain, 2006; Murray & Chamberlain, 1998; Ponterotto, 2005). Resting on the assumption of the ‘average’, positivist research seeks to quantify phenomena with a sample of people that are representative of the larger population, and generalise the findings to this larger population (Ponterotto, 2005). In contrast, social constructionism is informed by the notion that knowledge is co-created between people and located within social and historical contexts (Burr, 2003; Lyons & Chamberlain, 2006; Murray & Chamberlain, 1999). Consequently there are multiple interpretations of any phenomena which will vary across time. Social constructionist research does not make claims about truthfulness, rather ‘usefulness (Burr,

3 Single quotation marks are used to indicate terms that are problematised.
The robustness or truthfulness of positivist research is measured through claims of objectivity, reliability and validity (Willig, 2013). In contrast, social constructionist research, not claiming truth, emphasises the co-construction of knowledge between the researcher and the participant and determines rigour through trustworthiness, credibility and reflexivity (Burr, 2003; Willig, 2013). Within the broad sub-discipline of (critical) health psychology, social constructionist researchers have turned to considering how ‘facts’, situations and ideas are constructed and used in language; how “various discourse have served to legitimise oppressive and unjust social relationships” (Lyons & Chamberlain, 2006; Murray & Campbell, 2003, p. 233). Psychology has a strong tradition of research and knowledge based in positivist assumptions (Gergen, 1985). The emergence of social constructionism within the discipline of (health) psychology represents a significant challenge to the normative position of positivist knowledge, and it is this challenge, and the competition for ascendancy, that has contributed to tensions between the two approaches taken to knowledge and research in psychology (Parker, 1998a; Kuhn 1962 as cited in Terre Blanche & Durrheim, 2008).

**Social Constructionism: How it has Informed the Thesis**

The beginning of this thesis journey also marks my introduction to social constructionism, and qualitative methods of research. In this section I discuss social constructionism, how it relates to deafness and where I situate myself within the various forms of social constructionism. Social constructionism is not a unitary paradigm (Edley, 2001). There are nuanced forms that exist side by side (Edley, 2001; Parker, 1998b). However, across the various forms, social constructionism calls us to question our assumptions about how the world appears to be and to locate ‘knowledge’ within, and as produced by, specific cultural and historical contexts; to acknowledge that our descriptions and understandings of the world sustain certain forms of appropriate social action, and exclude others which in turn inform power relations relating to what is permissible for different people how others should be
treated (Burr, 2003). Within this framework, language is thought of as a form of social action, and most importantly, that language has practical consequences and restrictions and obligations ensue (Edley, 2001). As Vivien Burr (2003) explains, social constructionism, with its many branches, is informed by four tenets rather than one precise definition. These four tenets, which I discuss here, refer to adopting a critical stance towards taken for granted knowledge, the historical and cultural specificity of knowledge, knowledge is sustained by social processes and knowledge and action go together.

Deafness as a socially constructed phenomenon (discussed in detail in Chapter 4) is evidenced through reflecting on how knowledge and understandings of deafness are historically and culturally located. Such that people living with deafness were (and to some extent are still) historically referred to as the ‘deaf and dumb’ and believed to be uneducable; where now there exists two universities (National Technology Institute for the Deaf within Rochester Institute of Technology and Gallaudet) which provide educational opportunities that meet the learning and language needs of people living with deafness or hearing loss. Deafness as socially constructed is also illustrated in the Martha’s Vineyard community (Scheer & Groce, 1988) where a large number of individuals born with profound congenital deafness resulted in a linguistic adaptation of the island community such that the majority of the hearing population became bilingual (English and sign language).

Contradicting the notion of an absolute truth (positivism), a social constructionist framework does not focus on the nature of people or society. Rather the focus is on processes, the dynamics of social interaction and considering how phenomena or knowledge is achieved by people in interaction. Knowledge is therefore something people do together (Burr, 2003, p.9). How something is constructed (represented in society) “brings with it implications for the way we treat people” (Burr, p. 18). I raise here the issue of realism and relativism as deafness and hearing loss are physically experienced and have physical implications.
**Realism and relativism.**

Realism posits that an external world exists independently of our representations (e.g., perceptions, thoughts, media and language; Lyons & Chamberlain, 2006; Nightingale & Cromby, 2002). As this reality underpins our representations, we can, to some extent, gain knowledge about this reality (Burr, 2003). Relativism, in opposition to this, asserts that this reality, if it exists, is inaccessible to us; “That there is no way of apprehending world outside of language…language operating as the medium through which we come to understand or know the world” (Edley, 2001, p. 437). Our various representations of the world therefore, cannot be judged against ‘reality’ and one account is no truer than another (Burr, 2003).

Taking a realist position, I do not attempt to deny the existence of a material world. Rather I recognise that once people talk about, signify or represent the material world then we have entered the discursive world and thus social constructions. Our perceptions and sensations, as volatile and changeable, do not mirror reality, rather they reference the real world in some way; our perceptions and sensations are not produced entirely through our symbolic systems (e.g., language; Burr, 2003, p.95). In line with Liebrucks (2001), there is a distinction between ‘things’ of the material world, that are subject to the laws of natural science and independent of human thought and language, and ‘things’ that are the subject matter of psychology which are socially constructed. In agreement with Willig (1999), I adopt a critical realism stance which posits that the things we observe and experience are “generated by underlying, relatively enduring structures” (p.45) which explains why some explanations for making sense of structures and events are more likely than others. Parker (1992) also explains how the physical and social environment structure our actions such that the way physical spaces are physically and social organised imposes constraints on what is possible to do and say. This type of reality exists outside of discourse and provides a structure for understanding the world through discourse. Thus reality does not only consist of
embodied experiences but also the properties and organisation of the physical and social environment. Burkitt (1999) argues that ‘reality’ is not a constant, but ever changing, both discursively and practically constructed by people (and organic evolutions of the natural world).

As Burr (2003) explains, defining illness and disease, more than identifying pathology, is a social matter which involves the interpretation of our experience within a particular cultural context of assumptions, norms and values and the economic structure of our society. Power relations are also of importance. Embodied ‘deficiencies’ are only identifiable when such a person is required to live in an environment that has been designed to suit the needs and activities of others. For example, consider the height of kitchen benches and wheelchair height. I adopt a critical stance within this thesis, not to condemn the choices of people in relation to the communication and technology choices or to devalue past research but rather to raise awareness of the assumptions underlying the theory (research evidence) and practice of the dominant ‘schools of thought’ which in 2015 remains positivism and the medical model of deafness (e.g., oralism and implantation; discussed in Chapter 4). In adopting a social constructionist framework in this thesis, I question what is often taken-for-granted knowledge; specifically, the endeavour to ‘correct’ deafness, and make transparent how dominant ways of thinking are sustained by social processes and favour certain forms of social action and knowledge over others and inform power relations.

Adopting a social constructionist framework necessitates an acknowledgement that the research I conduct in this thesis is co-produced between myself and the people who I have consulted with and who have (and will) volunteered to participate. The various identity positions that I occupy, as outlined in Chapter 1 and make transparent throughout this thesis, shape assumptions that I hold (consciously and unconsciously) which in turn inform the research questions I formulate, how I ask them and how I interpret the responses to my
questions. Through the research process that I present in this thesis, I have co-produced ‘knowledge’ that is relevant for the people who participated in my research studies and to the current historical and cultural context.

**Research Methods**

In Chapter 6, where I discuss Study 1, I adopted a pragmatic parallel mixed method approach. I employed quantitative methods in the survey component of this study for two reasons. The first was to collect large scale demographic data as way of investigating the relationship between a range of demographic variables, to explore the complexity and diversity that exists within this population. The second reason was that the quantitative survey provided a functional way of collecting, while maintaining the anonymity of, the demographic data of the online forum users. I employed qualitative methods as a way of analysing how knowledge was co-produced by the forum users and myself as the forum administrator. Where quantitative methods can limit responses, qualitative methods do not involve making a priori assumptions, and, furthermore, the purpose is to ‘open up’ responses. In this way the use of qualitative methods contributed to creating an accessible study, which allowed for a diverse sample of people to share their experiences. For this study, rather than impose my own definitions of hearing loss, deafness and deaf identities, I asked participants to self-identify. Self-definition empowers individuals to define themselves rather than fit within narrow, rigid and prescribed definitions. Self-definition also offers useful insights into how constructions of deafness are sustained and evolve. Owing to insufficient sample size, I was unable to use appropriate statistical analyses to explore the relationships between various demographic variables. Consequently, this is not included in the thesis. The study presented in Chapter 7 employed purely qualitative methods, for the same reasons outlined above. Semi-structured interviews were used to collect the data and an inductive thematic method of analysis was used to analyse the transcripts.
Ethics and Consent

All research was approved by the University of Queensland, School of Psychology ethics committee. As will be discussed in detail in both Chapters 6 and 7, I provided participant information in English and where appropriate, Auslan (approved by a native Auslan user). There are no conflicts of interest in the thesis and no organisations or participants received any remuneration or in-kind participation rewards or incentives, participation was voluntary.

Statistical Tools and Data Management

In Chapter 6 the quantitative data was collected through Qualtrics software and descriptively analysed with the assistance of SPSS software. Where quantitative data were missing in Chapter 6 it was included in all relevant analyses. Missing responses were not removed because only descriptive analyses were conducted on the data and missing values can provide useful insights into descriptions of the sample. Where quantitative data were incomplete (e.g., Qualtrics recorded a response but no items were answered) these responses were removed from the data set. As these incomplete responses contained no data, removing them did not impact our ability to understand or gain useful insights about the sample. The qualitative data in both Chapter 6 and 7 was recorded and transcribed verbatim by myself, stored in password protected files on secure computers. Where a participant used Auslan, their responses were translated into spoken English by a para-professional Auslan/English interpreter, and the interpreter’s audio recording was transcribed. The transcripts were analysed manually with the assistance of Microsoft Excel and Word.

Conclusion

In this chapter I have explained the tensions that exist between positivism and social constructionism. I have explained how I orient myself within social constructionism and position myself as a critical realist with the realism/relativism debate. A brief summary of the research methods, ethical considerations, statistical tools and data management issues was
also provided. Building on this introduction to the research, in the next chapter I introduce the background information relevant to deafness and hearing loss and the Australian context that is necessary to contextualise the research presented in this thesis.
Chapter 3

Contextualising the Research

Deafness and Hearing Loss: What You Need to Know

Statistics

Classifications of Hearing Loss

Measuring and diagnosing hearing loss

Hearing and Visual/Tactile Technology

Early Intervention and an Introduction to Language

Signed or manual communication

Australian Sign Language

Alternative communication systems

English and bilingualism

The role of interpreters

Deaf education

Key Terms

Deaf Culture

History

The Australian Context

Health Services and Information

Health Professional Education Training and Professional Development

Geographical Landscape: Access and Community

Conclusion
Contextualising the Research

The purpose of the chapter is to provide the specific context(s) to this research project (historical and geographical). I outline background information about the population(s) of Australians living with hearing loss or deafness and the Australian context. I discuss information about the size of the population(s) of people living with hearing loss or deafness, audiological classification information, technology, language acquisition and use, key terms and Deaf culture. Following this I describe the Australian context(s) in relation to the health services and the geographic landscape. In combination, this information builds an understanding of complex phenomena that is deafness and contextualises how the thesis project was informed.

Deafness and Hearing Loss: What You Need to Know

Statistics

There have been several estimates since the 1990’s, of the number of Australians living with permanent (rather than transient) hearing loss or deafness. Each attempt varies in their estimate due to differences in their definitions of deafness. The two most commonly cited estimates were proposed by Hyde and Power (1992) and Johnston (2004).

Hyde and Power (1992) investigated how many deaf\(^4\) people used Auslan. Their inclusion criteria consisted of people who identified themselves as deaf, and people who identified as ‘signing deaf’, those who relied on sign language for everyday communication. These criteria did not include people who identified as having a level of hearing loss but did not rely on signed language for everyday communication. Their investigation calculated an estimate of 15,400 deaf people who use Auslan in Australia. Comparatively, Johnston’s (2004) estimate is considerably smaller.

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\(^4\) As per Chapter 1, the terminology used here reflects the terminology used by the authors.
Johnston (2004) made the link between level of hearing loss and likelihood of relying on a signed language as a preferred mode of communication. He acknowledged the role of hearing technology such as hearing aids and the mainstream education of deaf children in decreasing the number of signing children. As such, Johnston’s estimate of the Deaf population of Australia only includes those who are native signers, those who have signed since birth or early childhood, excluding those who learn signed language later in life.

Relying on the number of children enrolled in schools for deaf, numbers of children fitted with hearing aids and neonatal screening prevalence rates, Johnston estimated a minimum signing deaf population, with a profound to severe hearing loss, of approximately 6,500 individuals.

Both these estimates need to be considered in a broader context. This context includes the understanding that level of hearing loss does not necessarily dictate communication preferences and neither level of hearing loss or communication preference are static. Hearing ability can deteriorate across the lifespan and communication preferences can change between daily contexts and the across the lifespan (e.g., Skelton & Valentine, 2003).

The Australian Bureau of Statistics (ABS) census from (2006) estimated the size of the Australian signing population to be just 7,146 people (5,537 using Auslan specifically; ABS, 2006; see Appendix D1). The 2011 Census data estimated the size of the same population to be 9,935 people, with 8,405 using Auslan specifically (ABS, 2011; see Appendix D1). This estimate is based on one question, ‘Does the person speak a language other than English at home?’ The derived estimate based on this question should be used with caution for several reasons, but particularly because it specifically refers to language use in the home (where majority of deaf people are born into hearing families), to the exclusion of language use outside of the home (work, friends). Other reasons include that it does not
account for language proficiency, provide an explanation as to why Auslan is not used at home, or indicate intentions or motivations to use Auslan at home.

The largest estimate was proposed by Access Economics (2006) who released figures that suggest 1 in 6 Australians was living with a hearing loss or deafness in 2006. Given the population of Australia at that time, Access Economics suggested there is an estimated 3.55 million adults (over 15yrs of age) in Australia with hearing loss (based on “worse ear”). Their estimate was not limited by severity of hearing loss, type of hearing loss, use of technology, education or communication preference.

Underlying each of these estimates of population(s) size is the notion that importance, relevance and justification for change are determined by the number of individuals impacted by disadvantage. In combination, these estimates highlight the heterogeneity and complexity inherent within defining and measuring deafness and hearing loss. Although they may have been included in the estimates summarised here, people living with hearing loss or deafness and additional co-morbidities (e.g., blindness, intellectual impairment etc.), people living with age-related hearing loss or people living with transient experiences of hearing loss (e.g., related to otitis media) are not specifically discussed. In the next three sections, which cover classifications of hearing loss, technology, and language, I explain the heterogeneity of this population(s). This explanation is relevant to understanding the various challenges I negotiated in conducting inclusive and accessible research.

Classifications of Hearing Loss

According to Paul and Whitelaw (2011), hearing disorders or hearing losses can be broadly classified into exogenous and endogenous. Exogenous disorders are those caused by disease, toxicity, accident or injury resulting from noises or damage to the auditory system. Comparatively, endogenous disorders are those that occur as a result of genetics. As the
anatomy of the ear and the transduction of sounds are not focal to this research but provide useful background knowledge, they are discussed in the Appendix D2.

There are two main types of deafness, conductive and sensorineural. Conductive hearing loss refers to a hearing loss produced by a blockage or abnormality in the external ear or an abnormality in the middle ear which results in sounds reaching the cochlea (where sound energy is converted into electoral signals to the brain) being quieter than they should be. Common problems include structural abnormalities, perforation of the ear, build-up of fluid, chronic infection (e.g. otitis media) or the stiffening of the ossicles (bones in the ear). In the case of conductive hearing loss, the cochlea may or may not be functioning.

Sensorineural hearing loss is the result of a malfunctioning cochlea (the most common cause), or auditory nerve, or both. Sensorineural hearing impairments are generally not medically reversible. Other types of deafness include mixed, central and progressive deafness. A mixed hearing loss refers to the concomitant occurrence of conductive and sensorineural hearing loss. Central deafness refers to damage to the nerve pathways of hearing within the brain resulting in an impaired perception of auditory information. However, this type of hearing loss is extremely rare. Progressive deafness is the progressive worsening of the levels of hearing.

Measuring and diagnosing hearing loss.

As Paul and Whitelaw (2011) explain, audiologically, hearing loss or deafness is grouped into five categories: slight (27-40 decibels [dB]), mild (41-54 db), moderate (55-69db), severe (70-89db) and profound (>90db). An individual’s hearing threshold is indicated using an audiogram. An individual’s pure tone average is designed to chart hearing sensitivity, reflecting an individual’s abilities to detect speech information.

There are a number of tests used to diagnose and measure hearing loss and deafness. One of particular note is the national Australian newborn hearing screening scheme that has
been gradually rolled out across the country since the early 2000’s. The newborn hearing screening scheme is a government funded system which ensures all new born babies’ hearing is tested at, or shortly after, birth. The introduction of this system has meant that hearing loss is being detected earlier than ever before and parents are afforded the opportunity to make decisions earlier about communication options for their children and providing appropriate developmental stimulation.

There are countless combinations of causes, types and levels of hearing loss which allow for a wide range of experience of deafness. Adding to the diversity of this population is whether people make use of corrective hearing technology and how much access to sound this technology provides to each individual. It is important to note that not everyone derives the same level of ‘benefit’ from using any particular hearing technology (i.e. one person may derive more benefits and access to sound from a hearing aid than another person who wears a hearing aid).

**Hearing and Visual/Tactile Technology**

Hearing technology refers to technology which is purpose built to improve hearing ability or access to sound. Typically prescribed by health care providers, a number of options are available. These options include hearing aids, cochlear implants and Frequency Modulated (FM) systems. Each of these devices (discussed in Appendix D3), while improving access to sound, has its own functional, social and financial limitations and it is important to note that none of these devices facilitate or restore a persons’ hearing ability to that of a hearing person. Hearing technology and the empirical research supporting its development, is largely informed by the medical model of disability and deafness (see Chapter 4) and positivism (see Chapter 2). The focus is on correcting or returning the individual’s hearing ability as much as possible rather than looking at ways in which systems (e.g., work places, building design) can change to meet the divergent needs of people living with hearing loss or deafness.
People living with hearing loss or deafness also make use of visual/tactile technology. The term visual/tactile technology refers to equipment that makes living as a deaf or hard of hearing person in a hearing world more safe, comfortable and convenient. Some examples include flashing lights (for door bells and phones) and vibrating alarms (e.g., smoke alarms or clocks) and visual communication technology (e.g., captioning). Technology can also refer to kinds of environments. Environmental considerations for deaf people include open-plan houses with good sight-lines, the shape of tables and lighting (deafau.org.au). Each of these environments promotes the use of vision rather than relying on sound, creating an inclusive space.

In summary, I have described the various types of hearing loss and how it is audiologically measured. I have also discussed the technology that is available to facilitate access to the hearing world. Already when considering this information, it can be seen how experiences of deafness can be diverse and complex. The aetiology of deafness and use of hearing technology (amongst other social factors), particularly in relation to early onset deafness or hearing loss, frequently informs a person’s language acquisition and or preference (e.g., Allen & Anderson, 2010; Kumar et al., 2008). However, as I will discuss below, language acquisition introduces another layer of diversity and complexity into experiences of deafness and hearing loss. I now discuss language acquisition and the various signed languages in Australia.

**Early Intervention and an Introduction to Language**

Much of the effort in ‘managing’ hearing loss is focused on early detection, early intervention and the subsequent promotion of language acquisition. The premise underlying early intervention is that children who are born with or acquire a hearing loss or deafness, usually born to hearing parents, will not have sufficient access to sound to develop a spoken language, nor will they have ready access to sign language models. Early intervention is a
broad term used to refer to the diverse range of intervention services offered which facilitate the development or acquirement of a language. An examination of a systematic review of the literature on early intervention for children with permanent hearing loss conducted by Kumar and her colleagues (2008) revealed that a significant portion of the funding, information, services and research focuses on programs targeting corrective hearing technology and verbal language acquisition (rather than sign language or bilingual programs).

A similar review for adults who were born with or lost their hearing during childhood or early adulthood, has to my knowledge, not been conducted. However, mode of communication for adults ranges from only using spoken language through to only using native sign language with most people using varying mixes of spoken and signed language with varying levels of comprehension. This diversity is in part due to generational differences in educational and language philosophies, which I briefly discuss later in this chapter (and in Chapter 4), exposure to accessible language during critical periods, and in part due to the fund of information deficit (Fischer, 1999; Hauser, O’Hearn, McKee, Steider, & Thew, 2010; Pollard & Barnett, 2009). The fund of information deficit refers to the lack of incidental learning opportunities that are available in Auslan (or visually supported communication modalities) for deaf children to experience. For example, a common experience known as ‘dinner table syndrome’ describes experiences of social isolation where hearing family and friends converse with each other at home or in the school playground in a spoken language where the conversation is inaccessible to people living with hearing loss or deafness (Foster, 1989; Glasner & Miller, 2010; Hauser et al., 2010). Owing to the conversations being inaccessible, people with hearing loss or deafness have less frequent incidental learning opportunities.

For children with a hearing loss or deafness, exposure and full access to language during critical periods informs their subsequent ability to develop a native language (Fischer,
Exposure and access to language can be shaped by a complex combination of causes, level and type of hearing loss, the language(s) used at home, and access to (and ‘success’ of) language models, access to sound through hearing technology and early intervention programs. There is evidence to support the notion that exposure to language(s) (spoken or signed) and language experiences during childhood greatly informs a persons’ capacity to learn language(s) throughout life (e.g., Mayberry, Lock, & Kazmi, 2002; Mayberry & Lock, 2003). Consequently, there is considerable variation in language (spoken and signed) skills within the population(s) of people living with hearing loss or deafness. Within the research context it is challenging for researchers to be able to accommodate the diverse communication preferences and abilities of the population(s) and this can be a limitation to some of the research. In the next section I introduce and define the various language and modes of communication most commonly used by people living with hearing loss or deafness (see Appendix D4 for further information). The information I present here is relevant to understanding the factors that relate to accessibility which I needed to consider when designing and conducting the research that I present in this thesis.

Signed or manual communication.

Signed languages are visual-spatial languages with their own structure, syntax, vocabulary and grammar. Signed languages are unique to each country and can be referred to as manual forms of communication. As they are entirely separate from spoken languages signed languages are considered languages in their own right. There are a number of different English-influenced types of signing behaviours which bridge the gap between Auslan and English (Johnston & Schembri, 2007). However, because they are manually coded versions of spoken languages they are not considered languages, rather modes of communication.
Australian Sign Language.

Recognised by the Australian Federal government as a community language, the native sign language of the Australian Deaf community is known as Auslan (coined by Trevor Johnston in 1980); which is a blend of the words Australian Sign Language (Cornes & Napier, 2005; Dawkins, 1991; Johnston, 1989). As Johnston and Schembri (2007) explain, there are two major dialects of Auslan in Australia, northern (used in New South Wales and Queensland) and southern (used in all other states). The differences between the dialects are noticeable in that it is clear which Australian state or territory an individual comes from but not so noticeable as to seriously interfere with communication (Johnston & Schembri, 2007). Fingerspelling is a key component of signed languages. Auslan employs a two handed alphabet (Johnston & Schembri, 2007). Proper nouns and names of people are finger spelt and when there is no sign equivalent of an English term.

As Johnston and Schembri (2007) explain, as with all languages, Auslan is a living language. Auslan is continuing to develop in response to advances in access to in areas such as health resources, communication, technology and social networking. Current efforts to maintain the passing on and continued development of Auslan include Auslan being taught in courses run by different Deaf organisations around the country and accredited Technical and Further Education (TAFE) institutes. Children born to Deaf, signing parents typically have Auslan as their native language and there are also a small number of schools for the children living with hearing loss or deafness spread across Australia, which teach Auslan as part of the curriculum and predominantly communicate via Auslan.

Alternative communication systems.

Australiansian Signed English, also known as signed English, is not a language but rather is a visual representation of English including grammar markers like “ing” and “ed” (Deaf Children Australia, 2012). Fingerspelling is used to help create exact replications of English
words using visual language. Signed English was developed in the 1970’s mainly by hearing educators who were concerned that teaching deaf children to sign would inhibit their speech development (Komesaroff, 2003; see Chapter 4) and is still used today.

Home sign is another visual communication system. Home sign is typically used by an individual living with hearing loss or deafness to communicate with their hearing family members. Home sign is the use of idiosyncratic signs, develop by, and unique to, each family usually with a small vocabulary and not much grammar (Johnston & Schembri, 2007). Home sign is also often used by families to communicate with a family member with a severe delay in language development or developmental disorders, for example, Autism. Other alternative communication systems include Makaton and Pidgin Signed English (see Corker, 2000; Deaf Children Australia, 2012; Pray, 2004).

**English and bilingualism.**

According to researchers and professionals (e.g., Deaf Children Australia, 2012; Power & Hyde, 2002; Vermeulen, van Bon, Schreuder, Knoors, & Snik, 2007), the ability to comprehend and communicate using English is influenced by a number of factors and as such varies greatly from one individual to another. The amount of residual hearing and or ability to benefit from hearing aids, use of assistive hearing technology and speech therapy, type of education, and type of communication used at home are just some of the factors that have role in facilitating a child’s ability to comprehend and communicate using English. The level of influence each factor has on an individual’s ability to communicate using English continues to be researched and debated. However, developments in screening and hearing technology has meant that hearing loss is detected much earlier in a child’s life and a systematic review of the literature on early intervention for permanent hearing loss suggests that as a result children are better enabled to make use of their residual hearing and develop their speech and auditory abilities (Kumar et al., 2008). Lip reading is also a skill that people
living with hearing loss or deafness may develop over time to facilitate their ability to communicate with spoken English. However, it largely relies on guesswork and requires considerable practice. Bilingualism refers to people who are fluent in a native sign language and spoken language (Mayer & Leigh, 2010).

In the above section I discussed the various modes of communication that people living with hearing loss employ, and emphasised that there is considerable variation in language preference (often more than one) and ability. Language skills add to the considerable heterogeneity and complexity of people living with hearing loss or deafness that was discussed earlier. As a consequence of the mix of language preference and ability, conducting research that accommodates these diverse language skills, that is accessible, is challenging. Interpreters have a particular role is facilitating communication and therefore accessible research. I will now briefly discuss the role of interpreters.

The role of interpreters.

Auslan/English interpreters facilitate access to communication between Deaf individuals who communicate with signed language and hearing individuals in any setting (Australian Sign Language Interpreters’ Association, n.d.). In Australia there is an accreditation system in place administered by the National Accreditation Authority for Translators and Interpreters (NAATI; Napier & Rohan, 2007; see Appendix D4). NAATI does not require interpreters to have additional qualifications to work in specialised areas (e.g., mental health). This is problematic as specialised settings such as specific university courses, health care settings and job interviews require more prior knowledge of the subject and specific knowledge of Auslan and in some cases requires new vocabulary to be created through the collaboration of the interpreters and Deaf community.

Keeping up with the new language demands and the increasing number of requests for interpreters is challenging. A whole issue in itself is the few places in Australia which offer
TAFE and university courses for Auslan, which in turn limits the number of people qualified to obtain NAATI accredited interpreting qualifications. This in turn limits the number of qualified Auslan/English interpreters qualified to meet the demands of signing communities of Australia and new government policies such as the National Disability Insurance Scheme which implies improved access to interpreters.

As Napier and Rohan (2007) note, the high prevalence of unqualified interpreters is problematic because the quality of the interpretation cannot be guaranteed. The implications of poor quality interpreting can have serious consequences, particularly in a health setting. For example, poor interpretation of instructions on when and how to take medication prescribed by a GP could have serious negative health outcomes for the patient if the medication is taken incorrectly. When working with this population, and employing interpreting services, it is important to consider not only the communication preferences of an individual and their level of skill but the interpreter’s experience and language skills.

**Deaf education.**

I briefly discuss here the education of Deaf and hard of hearing children as it relates language preference, skill and development. Currently there are a number of options and combinations of educational instruction in Australia. Education setting choices are segregated, congregated or integrated. Instructional approaches include oral education, Total Communication (synonymous with simultaneous use of spoken English and Signed English) or bilingual education (Komesaroff, 2001). It is also important to note that a child’s setting and instructional approach is likely to be inconsistent across their schooling career as parents may struggle to find appropriate education settings to suit the changing needs of their child which is both affordable and a reasonable distance to travel on a daily basis. Teachers of the deaf and specialist aids (e.g., Auslan Language Models) are an added resources in mainstream
programs used to support children where they are deemed to require additional support (Hyde, Stein, & Hjulstadt, 2006).

Although, there are several education options available, informed by a philosophical and social interpretation of inclusion (Hyde et al., 2006), the majority of children are educated through mainstream schools (Hyde et al., 2006; Jenkinson, 1997; Komesaroff, 2001, 2005). While there are educational options which support different learning abilities within mainstream programs (e.g., deaf units) many of these programs foster the development of a normal hearing identity and speech. Compared to mainstream education options, there are comparatively fewer schools which offer an Auslan/English bilingual program, and considerably less teachers available who are proficient in Auslan (Komesaroff, 2005).

Bilingual approaches to the education of Deaf or hard of hearing children use a natural signed language as the primary language of instruction; which provides a basis for the development and transition to the majority spoken language (Komesaroff, 2001; Mayer & Leigh, 2010). Bilingual programs are typically underpinned by principles which value the language and culture of the Deaf community; emphasising equal opportunity and realising the language and learning potential of Deaf and hard of hearing children (Mayer & Leigh, 2010).

While it is not within the scope of this thesis to comment on the research evidence informing the education of children living with deafness, it should be noted that although estimates vary, researchers frequently report graduating students’ reading comprehension skills at a primary school level (Vermeulen et al., 2007).

Language acquisition and comprehension is a hugely important ‘issue’ in the area of deafness and is one that continues to be researched and debated. The purpose of this section was to add another layer of diversity and complexity that needs to be understood and considered when working with the population of people living with hearing loss or deafness.
Additionally, this section serves to contextualise the barriers people are confronted with when accessing health services and information which is discussed in Chapter 5.

Thus far I have described the population(s) of people living with hearing loss or deafness as heterogeneous and complex. In addition to the various causes, types and levels of hearing loss, there is variation in the use of, and benefit derived from, technology and language use and ability. Developing an understanding and appreciation of this diversity has informed the design and analysis of the research presented in this thesis. Moving away from the dominant, positivist approach to deaf research, my approach to the research has been to explore and acknowledge the complexity of this population(s); using a social constructionist lens and qualitative methods as a means of emphasising the multifarious contexts within which experiences of deafness occur (Mertens, 2010). In the next section I provide a description of the terms that more frequently used to refer to people living with hearing loss or deafness.

**Key Terms**

To understand the context of deafness and the issues around being deaf, it is important to be familiar with a number of terms frequently used in the deaf sector which include, but are not limited to, hearing, hard of hearing, aurally impaired, hearing impaired, deaf and Deaf. A combination of both audiological information (cause, level and type of loss, hearing technology and language preference) and the personal meaning an individual attaches to their hearing loss (related to theoretical models of deafness discussed in Chapter 4) is used to determine how an individual identifies with deafness (Israelite, Ower, & Goldstein, 2002; Jambor & Elliott, 2005). These terms are both used by, and to refer to (and define), people living with hearing loss or deafness. The use of these terms is productive in that they facilitate the development of a shared understanding of what is being discussed. However, the use of these terms also risks reducing the complexity of this population, de-individualising
people and their experiences. Some key terms (and the factors used to define these terms) are also problematic in that may be underpinned by assumptions that reproduce hearing and spoken language as ideal. For example, the terms pre-lingual and post-lingual are synonymous with pre-spoken language.

Factors that are frequently referred to by researchers in the identification process include: age of onset, identification and amplification, type of education and educational experiences, language acquisition, parental hearing status and contact and interaction with other deaf adults and the Deaf community (Israelite et al., 2002; Jambor & Elliott, 2005; Nikolaraizi & Makri, 2005). However, the personal meaning an individual attaches to their hearing loss can fluctuate in response to daily context (e.g., work, home) and life events and thus their deaf identity can vary over time (Skelton & Valentine, 2003). This fluidity contributes to the challenges associated with trying to define and quantify population of people living with deafness or hearing loss and understand their needs (discussed earlier in this chapter). The following descriptions of the different deaf identities are not definitive but rather describe the typical characteristics of people who subscribe to each particular identity.

People with a hearing loss who identify themselves as hard of hearing or hearing impaired are people who typically do not identify as being deaf (or Deaf). Most likely, they are people who have acquired their hearing loss later in life after they have developed a spoken language (Access Economics, 2006). As such, with the assistance of hearing technology, their preferred mode of communication is typically oral. People who acquire their hearing loss later in life are also commonly referred to as ‘post-lingually’ deaf (they have already developed a primary [spoken] language). The hearing loss is often the result of exposure to loud noises, accidents or the aging process (Access Economics, 2006; Johnston & Schembri, 2007).
The terms aurally impaired and hearing impaired are *politically correct* terms used to refer to both deaf and hard of hearing people as a single category. However, this term is often negatively received by the Deaf community as it can be interpreted as a subtle reference to them as being less capable than they actually are or makes them appear as dysfunctional (Leigh, 2009). Exemplifying the personal meaning attached to a deaf identity, for others the term hearing impairment is not an issue as they view hearing impairment as fact. Deaf or hard of hearing persons may also reject this term as it does not recognise a distinction between Deaf, deaf and hard of hearing.

In this thesis, the term deaf is a general term referring to everyone who has any level of hearing loss and identifies themselves as deaf. People who identify as deaf are typically ‘pre-lingually’ deaf, that is, deaf before they acquired a [spoken] language (Access Economics, 2006). Mode of communication within the deaf population ranges from only using spoken language through to only using native sign language with most people using varying mixes of spoken and manual communication. The mode of communication used by deaf individuals can change over time depending on the person’s life experiences. People who identify as deaf do not necessarily have knowledge of, or a perceived need to know Auslan. Assumptions should not be made about how a person who identifies as deaf will communicate.

Use of the term ‘Deaf’ refers to people who identify with Deaf culture, sometimes referred to as the Deaf community, which is discussed in further detail in the next section. Within the Deaf community, deafness is not seen as a disability but a different way of living. Deaf people are proud to be deaf, share experiences and values and have a number of traditions which they celebrate (Johnston & Schembri, 2007), as such they are denoted with a capital ‘D’. As mentioned earlier, Auslan is a symbol of pride within the Deaf culture and is
the preferred mode of communication. Typically ‘pre-lingually’ deaf⁵, members of the Deaf community have varying levels of hearing loss and language proficiency (signed languages, English). Use of hearing aids and cochlear implants has become increasingly more common and more accepted within the community which has had an impact on levels of proficiency in Auslan and written and spoken English (Christiansen & Leigh, 2009, 2004; Fayad & Elmiyeh, 2009). In the following section I briefly introduce Deaf culture to illustrate the final layer diversity complexity of the population of people living with hearing loss or deafness (see Appendix D5 for further discuss of Deaf culture).

**Deaf Culture**

The Australian Deaf community is a unique and complex (minoritised) culture within Australia with its own values, customs, humour, and voice. Auslan is the primary language and, as noted above, is a symbol of pride within the community. Deaf people view deafness as normal and it is not something they seek to cure. As a culture they are united by a common political goal to preserve sign language, in particular through the education of Deaf children (Ladd, 2005). The Deaf community is made up of a diverse range of people. Unlike most hearing ethnic and cultural minorities, the majority of culturally Deaf Australians are not born into the Deaf culture and consequently the Deaf language and culture is not passed on from parent to child (Johnston & Schembri, 2007). Deaf individuals from hearing families typically learn Deaf culture and Auslan from other children or from adults outside the family (Johnston & Napier, 2010).

There are also a number of culturally acceptable behaviours which differ from hearing culture. Some of these behaviours include touching another person on the arm or shoulder to gain their attention, standing or sitting further apart and opposite each other to have a conversation, using direct and abrupt language, consistent eye-contact, and thumping on

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⁵ Children who are born deaf or with hearing loss, who are born into Deaf families would meet the definition of ‘pre-lingually’ deaf. However, they are likely to develop Auslan as their first language in the same way hearing children born to hearing parents acquiring a spoken language (Johnston & Schembri, 2007).
tables and floors to get people’s attention (Deaf Australia, 2010). While these behaviours would be understood as somewhat rude or aggressive in hearing culture, they are perfectly acceptable and normal in Deaf culture (Deaf Australia, 2010). These behavioural differences between hearing and Deaf culture often result in miscommunications between the two cultures and underpin the role of interpreters.

There are a number of customs in the Deaf community (see Appendix D5) which are also relevant for facilitating effective communication between hearing and Deaf people. One in particular is the establishing of credibility within the community. Greetings within the deaf community include personal details which are used to establish where a person ‘fits’ in the Deaf community and whether they are acceptably ‘deaf’ (Deaf Australia, 2013). As the community is relatively small and close knit it is easy to establish the connections between people and determine their credibility within the community. In light of the history between the Deaf and hearing world, establishing credibility is particularly important for hearing people coming into the Deaf community.

History.

Deaf Australians have their own unique history, a history separate from that of hearing Australians. Deaf history is typically transmitted horizontally, from Deaf adults outside their immediate family (Hauser, O’Hearn, McKee, Steider, & Thew, 2010; McKee, Schlehofer, & Thew, 2013). Deaf history includes significant places such as street lights in certain areas, schools and clubs (Deaf Australia, 2013). Stories of persecution, suppression of sign language and attempts to cure deafness date as far back as the 19th century; incidents largely perpetrated by hearing people and hearing society are important elements of Deaf history.

The development of Cochlear Implant (CI; see Chapter 3 for definition) technology is also a significant part of Deaf history. The introduction of CIs was met with severe criticism and rejection by the Deaf community. In extremes, CIs were seen by Deaf people as a form of
genocide towards deaf culture, perpetrated by hearing people (Sparrow, 2005). Although some members of the Community continue to reject CIs, there has been a gradual acceptance by Deaf organisations and individuals who are now more receptive and accepting of peoples’ choice to have a CI (Christiansen & Leigh, 2004; Fayad & Elmiyeh, 2009).

The history of Deaf culture equally include stories of empowerment. Most recently, in 2014, Drisana Levitzke-Gray, a young Deaf woman, was named the Young Australian of the Year in recognition of her work advocating for diversity and Deaf Gain (Australian of the Year Awards, 2015; Bauman & Murray, 2009). Beyond the scope of this thesis, but relevant to the history of Deaf culture internationally, is the ‘Deaf President Now’ campaign at Gallaudet University in 1988 (Gallaudet University, 2016), the formal recognition of the native sign language in various countries (e.g., New Zealand Sign Language in 2006; New Zealand Parliament, 2006), and the work of the World Federation of the Deaf which has consultative status with the United Nations (United Nations Educational Scientific and Cultural Organisation, 2016).

Discussions of, and terms related to Deaf identity and culturally affirmative identities are complex, contentious and continue to be developed and debated. The concept of Deafhood, a term coined by Dr Paddy Ladd in 1993 (Ladd, 1993), a Deaf researcher and activist, represents a turning point in Deaf history. As Ladd and Lane (2013) explain, the concept of deafhood was coined in response to the need to represent the process of recovering Deaf identities within the broader cultural and political history of the Deaf. The concept of deafhood compasses “the examination of individual Deaf identities and Deaf potential … the recovery and reconstruction process of Deaf communities” (Ladd & Lane, 2013, p. 570). Where the term ‘deafness’ holds negative connotations for what it is to live with hearing loss or deafness, deafhood is harnessed as a positive term and describes a journey of self-actualisation (Ladd, 2003).
Respecting and understanding Deaf culture and the history of deafness is important contextual information for this thesis. As a hearing person undertaking research in this area, I needed to be sensitive to the Deaf culture and deaf history in how I conducted myself as a hearing researcher, developed my research questions and conducted and reported my research.

Through the discussion of key terms and the history and associated complexities of the Deaf culture, I have provided the necessary information for the reader to develop an understanding of deafness and hearing loss both generally and specifically within Australia. In summary, attempts at defining and measuring the number of people living in Australia with hearing loss or deafness have been inconsistent. Our efforts to understand deafness and hearing loss need to incorporate complex combinations of factors such as the aetiology of deafness, use of technology, language preferences and skills and the fluidity of deaf identity (including Deaf culture). The social context within which these factors and experiences occur also need to be considered. The following section further addresses the health and geographical context within which this research was conducted. In combination, this information builds an understanding of complex phenomena that is deafness and contextualises how the thesis project was informed.

**The Australian Context**

Within the western world (and indeed within a global context) Australia is a unique landscape and nation. I discuss here various elements of the Australian context specific to deafness and health that sets Australia apart from other Western countries. This discussion further serves to highlight the research problem identified in this thesis and justify exploring how deafness is negotiated at a discursive and societal level. First I detail the availability and accessibility of health services and information and the financial provisions that are made for linguistic diversity. Following this I report on how deafness is incorporated into the education and
training of health professionals and the accessibility of cultural and public information/media. Finally, I briefly describe the distinctive geographical landscape of Australia and how this shapes access and connections.

**Health Services and Information**

Generally in Australia there is limited availability of ‘deaf friendly’ health services and professionals and restricted and delayed access to health information. Conversations with health professionals and people living with a hearing loss or deafness and a brief internet search demonstrates that we have few qualified health professionals who are deaf or hearing impaired themselves or are fluent in Auslan. There are a small number of qualified counsellors dispersed around Australia who are deaf or hearing impaired themselves (communicating either orally or via Auslan), a hearing general practitioner who advertises Auslan skills, two speech pathologists who advertise Auslan level 2 skills and an audiologist who has a hearing impairment. The lack of health professionals who share the same language, culture or auditory experiences has been identified by researchers as a barrier to people living with hearing loss or deafness accessing services (see Chapter 5).

There are few health services in Australia that either promote themselves as ‘deaf friendly’ or were set up to provide services for people living with hearing loss or deafness. For example, Queensland is the only state or territory in Australia to have a service specialising in deafness and mental health. The majority of the health services that are ‘deaf friendly’, that is, they are set up knowing people living with hearing loss or deafness may need to access their service, are heavily focused on early intervention as opposed to community health services (e.g., dentistry, psychology, physiotherapy).

Considerable achievements have been made in terms of language provision. Since 2005 the then named Department of Families, Housing Community Services and Indigenous Affairs (now Department of Social Services) has funded the National Auslan Interpreter
Booking and Payment Service (NABS). This service provides accredited Auslan interpreters to deaf Auslan users (child and adult) free of charge when they attend private medical consultations. Although an extensive range of health services are covered by the NABS, medical consultations that occur in hospitals are not covered by the NABS. Furthermore, the provision of Auslan interpreters does not service the needs of people who do not communicate via Auslan.

Access to health information (e.g., disease outbreaks, vaccinations, reproductive health) in a ‘deaf friendly’ format (e.g., captioning or Auslan interpreted) is largely funded by and facilitated through the various state and national deaf organisations. Several organisations have undertaken the task of translating health information and concepts into Auslan and visual tools. However, as this information is distributed ‘second hand’ by these organisations, it is generally delayed. Furthermore, as the adaptation and distribution of this health information tends to be a state based rather than a unified approach, the general absorption of this information into the deaf population can be fragmented and subject to misinformation; and this is reflected in the literature reviewed in Chapter 5. To put this delay or fragmentation into context, the hearing population is able to have immediate access to health information delivered via static advertisements, television and radio, overhead conversations, public address announcements and information on the internet where the same information is not provided in an accessible format for people living with hearing loss or deafness. This discrepancy in access to information contributes to the fund of information deficit mentioned earlier in this chapter (Hauser et al., 2010; Pollard & Barnett, 2009). While there is health information, services and professionals available in ‘deaf friendly’ formats there are still extensive discrepancies in the accessibility and availability of information and services. These discrepancies are informed by professionals’ access to education, training and professional development opportunities.
Health Professional Education, Training and Professional Development

Within Australian there are increasing opportunities for health professionals (practicing and in training) to access training and education on deafness and hearing loss. However, inclusion of this training is not standardised across training programs and professions. Based on my tertiary education, experiences and conversations with tertiary educators, few tertiary programs assume deafness and hearing loss as a part of our community and therefore include some level of content to their provisional students about how to treat clients/patients living with deafness or hearing loss.

An internet search of ‘Australia University deaf’ returns several links with information for enrolling students, School of Education courses which include content related to deafness and information for university staff teaching students living with hearing loss or deafness. This search suggests that there is a willingness and scope to incorporate more information and training around deafness and hearing loss. However, this willingness is yet to extend beyond the faculty of humanities and social sciences (i.e. School of Education and School of Linguistics) to the health and behavioural sciences, business, economics and law. Experiences of deafness are generally not reflected in health training and education content outside of courses specific to hearing ability such as audiology and speech pathology (e.g., social work, psychology, physiotherapy etc.). Consequently, (hearing) students often graduate with little awareness of the need to seek out additional training in the area of deafness and hearing loss. Furthermore, the lack of expertise available to teach students how to adapt their skills and knowledge to treat clients living with hearing loss or deafness and the lack of content reflecting experiences of living with deafness may act as disincentives for high school graduates (living with deafness or hearing loss) to enter health careers.

The requirement for provisional health professionals to complete supervised practice may also be a considerable disincentive for people living with hearing loss or deafness to
build a career in health care. There are likely considerable challenges (e.g., financial, equipment, location) for universities and program co-ordinators to provide suitable placement opportunities for students living with hearing loss or deafness. More than this, there is likely insufficient support available for the student during the placement and limited placement supervisors willing and able to fulfil the role of supervising and mentoring a trainee living with hearing loss or deafness. In combination the education and training programs available reinforce the lack of available health services and professionals.

There are several options for qualified professionals to access professional development training in treating clients living with hearing loss or deafness. Many state based and national deaf organisations offer workshops for people to learn about deafness and general training on how to adapt this knowledge to professional practice. However, disincentives such as, not understanding they need additional training, the high cost of the course and missing a day (or more) of work for which they may not be compensated may prevent health professionals from accessing these professional development courses.

In Australia, deafness is not widely recognised in our training and education programs as an important and diverse element of our society that requires additional training. There are considerable disincentives which prevent both hearing people and people living with hearing loss or deafness from seeking additional training or considering a career as a health professional. In turn, this contributes to the lack of ‘deaf friendly’ health services and professionals and the dissemination of accessible health information. The resulting disadvantages experienced by people living with hearing loss or deafness are further compounded by the unique geographical landscape of Australia.

**Geographical Landscape: Access and Community**

Australia offers a unique geographical landscape unlike any other country. However, this landscape shapes the development and connectedness of the Australian Deaf community and
population of people living with hearing loss or deafness. The population of Australia is spread across the country’s enormous landmass. This is particularly important when considering the time and cost associated with travel around Australia which is in turn relevant for understanding how the population of Australians living with deafness and hearing loss are able to physically and digitally interact.

Unlike many other countries (e.g., UK and United States of America), Australia has ‘pockets’ of deaf people spread around the country, in urban and rural areas. The geographic landscape of Australia makes it particularly costly (time and money) for deaf people to travel to one another and to physically spend time together. Consequently, many people can feel isolated, particularly in rural communities for example, being the only deaf person in town. Furthermore, given the Australian landscape, resources (e.g., qualified health professionals, early intervention programs, hearing aids) are scattered across the country, typically located in capital cities. It is often the case that families or people who live in rural areas will need to drive for several hours to see an audiologist and have their hearing aid fitted. As such, the geography of Australia creates a range of challenges (particularly in accessing health resources) for people living with deafness and hearing loss that do not exist as pervasively in other Western counties.

Developments in technology have facilitated access to resources around the country (e.g., Telehealth; Wilson & Wells, 2009). In particular, online and visual technology facilitates access to early intervention and education programs for deaf children (McCarthy, Duncan, & Leigh, 2012; McCarthy, 2012). However, there are some barriers to accessing telehealth or telepractice services and lingering preferences for face-to-face interactions, either with the practitioner or interpreter (e.g., Hughes, Hudgins, & MacDougall, 2004; McCarthy et al., 2012). The unique Australian context, as I have outlined in this section,
contextualises both the identified research problem and the considerations that were involved when conducting the research discussed in this thesis.

**Conclusion**

In this chapter I have provided background information about the population of Australians living with hearing loss or deafness. This background information included estimates of the size of the population, audiological information, technology, language and education, key terms and Deaf culture. In combination this information constructs deafness and experiences of living with hearing loss or deafness and complex and diverse. Further contextualising experiences of deafness and the research presented in this thesis, I set the scene for the Australian context. Specifically, I have discussed the current availability and accessibility of health services, professionals and information and how education and training programs for health professionals likely contribute to lack of accessible and available professionals and services. Lastly I have described the unique Australian geographical landscape and how this shapes experiences of hearing loss, deafness and Deaf culture. In combination this information illustrates the intersection between the medical, audiological and social context that informs the lives of people living with hearing loss or deafness. In the next chapter I review how deafness has been studied in the past and empirical research related to deaf health.
Chapter 4

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Deafness as a Socially Constructed Phenomenon

The history of deafness (as an audiological state) is replete with conflicting ways of understanding deafness that have, and continue to, compete for recognition as ‘truth’ (Baynton, 2006). Within a social constructionist framework (Burr, 2003) ‘truth’ and knowledge is constructed between people and this knowledge, the ways we commonly understand the world (e.g., categories and concepts we use), is historically and culturally specific. In this chapter, I review and discuss how deafness has been historically constructed. This discussion prefaces a review of how deafness has been studied in the past which is presented in Chapter 5. The focus of this chapter is to demonstrate how meaning is created through the cultural and historical specificity of ‘knowledge’. Illustrative of the historical and cultural specificity of knowledge, Lane (2006) and Burr (2003) provide numerous examples of how various phenomena (e.g., alcoholism, childhood, sexuality, and disability) have been redefined across time and the implications of these changing definitions. The ways in which society understands a phenomenon such as deafness determines what these terms mean for the social majority, and how people who are identified as members of these groups are treated with the subsequent problems they face (discussed further in Chapter 5).

Constructions of Deafness

Deafness (as an audiological experience) can be thought of as communication disability. That is, deafness is audiological variations which relate to a person’s ability to communicate in the dominant, oral, mode of communication. Many theorists and academics have discussed and debated over how disability and deafness can and should be constructed. Discussions of disability and deafness are located in both modernist and post-structuralist frameworks. I will discuss the dominant competing constructions of deafness; the medical model of deafness, the social model of deafness and deafness as a linguistic minority. For each of these models I will outline how the model relates to broader theoretical constructions of disability and the
underlying ontological assumptions, how these constructions relate to one another, the strengths and limitations of each model and how deaf education has been or is informed by these models.

Locating discussions of deafness within the topic of disability is a contentious issue for people living with hearing loss or deafness and for academics (who sometimes, are also living with a hearing loss or deafness). To cautiously simplify a complex and on-going issue, there are some people who do not identify with constructions of deafness as a disability (a medical disability or social disability) and therefore discussions of deafness should not be related to disability. Simultaneously, there are others who strongly identify with experiences of deafness as a medical disability and therefore deafness should be included in discussions and policies related to impairment and disability. These two agendas are at odds. In this chapter I will deconstruct this issue and explain how it has influenced the research conducted and reported in this thesis.

**Medical model of deafness.**

The medical model of deafness aligns with a modernist and positivist ontology and epistemology. Deafness is a category of disability, defined as a physical sensory impairment and communication disability that is tested and measured against ‘normal’ hearing levels (see Davis, 2006 for an extensive discussion of constructions of normal). Corker and Shakespeare (2002) explain that a modernist ontology is “founded on assumptions about the unity of humanity, the individual as the creative force of society and history, the superiority of the West, the idea of science as truth and the belief in social progress” (p.2). Central to the premise of modernism is the rational and independent (i.e., able-bodied) person and meta-narratives that are built on ‘either/or’ binaries. Meta-narratives refer to grand theories that attempt to give totalising meaning or a universal truth to events and phenomena (Corker &Shakespeare, 2002). Modernism is also underpinned by capitalist values which prescribe
the endless search for profit and capital accumulation and is complicit in the continuation of social inequalities and systems of privilege and power (Corker & Shakespeare, 2002).

Despite the ideology of scientific enlightenment and progress, people perceived to not meet the modernist ideal of the rational independent person (i.e. non-disabled person) remain oppressed.

Medical/scientific interventions (e.g., surgery, hearing aids, cochlear implants,) are necessary to simulate or return to ‘normal’ hearing levels and target the acquisition or maintenance of a primary spoken language. For children, early intervention is based on the premise that the earlier the hearing impairment or deafness is identified the earlier intervention can occur, maximising the potential for the child to develop a primary language. Within this model, deafness is perceived and classified using the typical deficit meta-narratives of disability such as deviance, lack and tragedy, all of which are inferior to ‘normalcy’ (Corker & Shakespeare, 2002). Within modernism, meta-narratives legitimise extant knowledge and cultural and social institutions (Corker & Shakespeare). Scientific and medical knowledge, informed by positivism, is used as evidence to support the truthfulness of the medical model and to explain and treat deafness.

As Siebers (2006) comments, the medical model situates disability (the disadvantage experienced from impaired hearing) exclusively in individual bodies and strives to cure them by particular treatment, isolating the patient as diseased or defective. Medical model thinking seeks to count the number of people with impairment and reduce the complex problems experienced by people living with disability to issues of medical prevention, cure or rehabilitation (Shakespeare, 2006). As such, medical interventions largely target an individual’s audiological skills and social interventions, implemented through education institutes and programs, to ‘correct’ the resulting communication ‘disability’. The objective
of social interventions is the acquisition or maintenance of a primary (spoken) language and obtaining communication skills.

**Critiques of the medical model of deafness.**

The medical model of deafness has received considerable criticism from theorists, academics and people living with deafness in recent decades. Extrapolating from Corker and Shakespeare’s (2002) critique of the medical model of disability, the meta-narratives of the medical model of deafness similarly position individuals living with deafness as separate from and inferior to ‘normalcy’. More than this, what is considered ‘normal’ is specific to social, cultural and historical contexts. Within the medical model, what is normal can only be defined by that which is abnormal; and through the use of science to justify what is ‘natural’ and therefore what needs to be corrected.

The current construction of normal, as Davis (2006) explains, is informed by statistical measures of humans, the mean or average, and has consequently led to attempts to reduce deviation from the norm through the use of assistive technology and the emphasis on oral communication rather than sign language promotion. Positivist approaches to treating and researching deafness serve to reinforce this construction of normal. In this way the medical model of deafness, and the research informing the treatment of deafness does not sufficiently address the social context within which deafness is experienced (e.g., stigma of difference; Campbell, 2009). It can also be said that the medical model is oppressive towards a group that already experiences considerable marginalisation in the community. People living with hearing loss or deafness already encounter disadvantages when they are trying to access information and community services. Within the medical model, people living with hearing loss or deafness are encouraged to use their personal resources (time, money) and risk their physical and psychological health to purchase and use assistive hearing technology in order to have equal access to basic services and information. The social model broadly
situated within postmodernism and poststructuralism, focuses on addressing the disability that is socially created (e.g., barriers to accessing services) and less attention on correcting the physical impairment.

Social model of deafness.

The social model of disability emerged from the Union of Physically Impaired Against Segregation (UPIAS); a small group of people identifying as disabled who united together and rejected the liberal and reformist campaigns of mainstream disability organisations (Oliver, 2009). Key to the social model of disability, is that impairment is distinguished from disability (the former is individual and private and the latter is structural and public). The term impairment refers to the embodied physical condition, where the term disability is used to refer to the restriction of activity that occurs when social structures, environments and attitudes fail to incorporate the needs of people who are living with impairment (Oliver, 2009). There are many different models of disability which relate to variations of the social model (Oliver, 2009).

Unlike the medical model which centres on an ‘average’, within social models of disability more flexible definitions of ‘normal’ human being can be adopted (Lane, 2006). Social models prescribe the acceptance (rather than the denial) of impairment and removal of disability, shifting moral responsibility onto society rather than the individual. Advances in social justice rather than medicine are therefore prioritised and required to minimise the disability experienced by people living with disability. In this way, people are able to legitimise claims of social oppression and advocate for the removal of barriers in society rather than ‘treating’ the individual. However, Oliver (2009) cautions that the social model does not reject the usefulness of individually based intervention (e.g., medicine, rehabilitation, education).
Extrapolating from the social model of disability, within the social model of deafness
the physical/sensory hearing impairment is not denied but rather the disability that is
experienced is located in social and physical structures. Such that, the social and institutional
structures of the hearing world exclude (and therefore oppress) people living with hearing
loss and deafness. In this way deafness is not an individual problem but a social problem. The
social models of disability and deafness are situated within postmodernism and
poststructuralism.

As Corker (1998) explains, “postmodernism challenges the idea that there can be an
ultimate truth about reality which can be discovered through thought and reason” (p222). In
this way, Corker (1998) argues, social models of disability and deafness operate within
postmodernism, rejecting the modernist notion of an ‘ultimate truth’ that informs the focus on
individuals in the medical model of disability and deafness. Postmodernism is further
characterised by pluralism (existence of multiple and various context-dependent ways of life)
and individuation (increased number and segregation of roles available to or forced on
individuals; Corker, 1998). Related to pluralism, poststructuralism which deals with language
and discourse, is also an integral part of postmodernism.

Sensitive to the complexity of the social world, poststructuralism, as described by
Corker and Shakespeare (2002), argues that subjects, rather than autonomous creators of
themselves or their social worlds, are embedded in a complex network of social relations.
Social relations they explain, “determine which subjects can appear, where and in what
capacity”, subjects are constituted in and through specific socio-political arrangements (p.3).
The main premise of poststructuralism is that meaning can never be fixed, that human
discourses are constantly evolving and creating new meanings (Corker, 1998). As language
and meaning are linked, explanations of the social world are created and sustained in the
linguistic spaces between people, rather than inside people (Corker, 1998). Poststructuralist
frameworks shift away from meta-narratives and general theories to local narratives and pragmatic strategies.

The Deaf community is commonly used as an example of the social model (and the linguistic minority model, discussed in the next section). Subscribing to the social model of deafness, the Deaf community has been (somewhat) effective in shifting the focus away from the physical capabilities of the hearing organs, to the challenges faced that result from disabling environments, institutions and cultures (e.g., people who are hearing are unable to communicate with Auslan users). One particular example of this success is the introduction of bilingual deaf education in Australia.

_Critiques of the social model._

In recent history, theorists have questioned the relevance of the social models of disability. Shakespeare and Watson (2001) suggest the social model is used by some activists and academics to view the world in black and white. The social model, then has become a framework that is not easily challenged; through the simplicity of the model, organisations and people’s actions are reduced to whether they focused on barrier removal or medical intervention. In this way, both the medical and social model can be seen to reduce the complexity and intersectionality of people’s lived experiences. Shakespeare (2006) further suggests that because the social model strongly disowns the medical model, it risks neglecting impairment as an important aspect of people’s lives. Shakespeare’s further criticisms of the social model include that it is hard to distinguish between the impact of impairment and the impact of social barriers and the utopia of a barrier free world is very difficult to operationalise (e.g., natural world such as mountains, beaches, sunsets, birds will remain inaccessible, opposing/incompatible needs for different impairments and practical/resource constraints). Rooted within poststructuralism, which prescribes that people are embedded within complex networks of social relations which determine who can appear,
when, and in what capacity, Corker and Shakespeare (2002) problematise the social model as promoting “the agency of disabled people in achieving their own liberation” (p3).

In defence of the social model of disability, Oliver (2009) has responded to some of the criticisms of the social model. Oliver refutes the claim that the social model ignores embodied experiences of impairment, claiming the social model is not about the personal experience but rather the collective experience of disablement. Oliver further contests criticisms that the social model is reductionist, failing to account for the intersection of various marginalised identities. He claims that rather than the social model not being able to cope; analysts have not yet applied the social model to areas of racism, sexism and sexuality. Oliver is particularly defensive of the social model suggesting that far less time should be spent criticising and talking about the model and more time should be spent applying and using the model in practical contexts. In the disability sector, the medical and social models of disability are the two dominant models. However, in the deaf sector there is a third dominant construction, specific to Deaf culture, which bridges the social model and minority groups.

**Linguistic minority model.**

Related to the social model of deafness, within the linguistic minority model, deafness is not a disability rather a linguistic minority community identifying as Deaf culture (discussed in Chapter 3). Advocates of the linguistic minority model contend that deafness is in no way a disability; within their own community there is no impairment or disability to overcome (Lane, 2006). Advocates of this model prioritise and fight for the recognition of their native language and subsequently the recognition of their distinct culture (Lane, 2006). As Gleason (1991) commented, minority group status is associated with a certain amount of moral power, and greater potential for grievances to be recognised as legitimate. For example, through reconstructing their identity as a minority, marginalised groups are able to challenge the
power of dominant groups and constructions of ‘normal’ (e.g. ableism, hearing, heterosexuality etc.).

Advocates of the linguistic minority model face challenges equating Deaf culture with ethnic/linguistic minorities. The issue lies within the passing down of language and culture from parent to child (discussed in Chapter 3). As Lane (2006) explains, generally children are identified as members of language minority when their native language is not the language of the majority. However, most children living with deafness are born to hearing families who are usually unable to model spoken language (or Auslan) for their child. Consequently, there are those who argue that the child’s language and culture is in principle that of their parents, while others, advocating for the linguistic minority model, argue that the child’s native language (primary language) should be Auslan and they should be a part of Deaf culture. However, such a view idealises a context where hearing parents, aware of linguistic minority constructions of deafness, want to, are able to, or have the means (money, connections, local classes) to teach their child sign language. The involvement of health professionals (e.g., surgeons, speech therapists, audiologists) in the diagnostic (and treatment) process, and how they construct deafness, also contributes to the challenges of promoting Deaf culture and Auslan. Health professionals are heavily involved with parents throughout the ‘early intervention’ process that begins with diagnosis, usually from the Newborn Hearing Screening Test (Bailey, Bower, Krishnaswamy, & Coates, 2002). As will be discussed in Chapter 7, health professionals have a heavy influence on parents, who are new to deafness, and the decision making around early intervention (Kluwin & Stewart, 2000; e.g., Li, Bain, & Steinberg, 2003; Matthijs et al., 2012).

Despite the success of the Deaf community receiving recognition of their language as a community language (Dawkins, 1991), constructions of deafness as a linguistic minority, comparable to ethnic/linguistic minorities continue to be challenged. Lane (2006) explains,
for example, that Deaf people cannot learn spoken English as a second language as readily as other minorities. Similarly, subsequent generations of Deaf people have the same level of difficulty learning English, where second and third generation immigrants are able to learn English easier than previous generations. Furthermore, Auslan is not typically passed on from previous generations but rather by peers and associates. Lane also explains that Deaf people share significant similarities with people with disabilities. For example, both must negotiate the challenges of social stigma and both struggle with ‘troubled-person industries’ (e.g., healthcare) for control of their destiny. Moreover, it is largely through the combined forces of the Deaf and the people living with hearing loss that funding, resources and services have been implemented.

The struggle for resources and support is a difficult issue for advocates of the linguistic minority model and Deaf culture. Despite being at odds with the concept of deafness as an impairment, in order for Deaf advocacy organisations and groups to receive funding they frequently need to subscribe to the medical and social models of deafness. At an individual level, in order for Deaf people to gain employment (and access to their workplace) they must similarly subscribe to the medical and social model. The medical, social and linguistic models of deafness have, and continue to, shape deaf education in Australia. Through a brief review of this history it can be seen how competing constructions of deafness have informed the diversity of the population of people living with hearing loss or deafness that was reviewed in Chapter 3.

**Language and education in Australia.**

The first schools for the deaf were established in Sydney and Melbourne in 1860 (Crickmore, 1995). According to Stevens, Smitt, Thomas & Wilson, (1995), at the time, the ‘manual method’ (sign language and finger-spelling) was used to instruct students. In 1880 an international meeting of teachers of the deaf known as the Milan Congress, saw the teachers
of the deaf vote for the use of the ‘pure oral method’ (i.e. speech and lip reading; known as oralism) and for the ban of the use of sign language in schools. It is important to note that only one deaf person was among the 164 delegates at the meeting. The education of children living with hearing loss or deafness and the landscape of Deaf culture around the world were significantly changed due to the outcome of this meeting. Remaining the dominant mode of education well into the 20th century, oralism has impeded the passing on and natural development of native sign languages by younger generations (Komesaroff, 2001).

Baynton’s (2006) review of metaphorical constructions of deafness in the 19th century contextualises the events that occurred at the Milan Congress. Baynton explains that until 1860s deafness was commonly described as an affliction that tragically isolated a person from the (hearing and English-speaking) Christian community. The remedy for this affliction during this period was the use of sign language (known as “manualism”), which was widely used and well respected. Beginning in the 1860’s, Baynton explains that in the United States, deafness started to be redefined as a medical condition that results in people being isolated from the (hearing) general community. According to Baynton, the oralist movement, born out of this reconstruction of deafness, was underpinned by the belief that the exclusive use of oral methods of communication would lead people living with deafness or hearing loss to better assimilate into the general (hearing) community.

Signed English, the production of literal signing produced in English word order (see Chapter 3), was developed in Australia in 1970 (Komesaroff, 2003). While Signed English is a step away from pure oralism, according to Komesaroff, Signed English was developed by committees mostly comprised of hearing educators and it lacks the syntactical and grammatical features of a full language (Johnston & Schembri, 2007). Total Communication a term coined in the late 1960’s, refers to the simultaneous use of spoken English and Signed English (Power, 1998). Again challenging the pure oral method, total communication calls
for the use of a variety of approaches including signs. However, according to Stewart (1992), native sign languages are rarely considered and English remains the targeted language.

A pivotal point in the deaf sector, in particular for Deaf culture, was the introduction of Auslan/English bilingual-bilcultural deaf education which was suggested in the 1970s (Komesaroff, 2003; Power, 1998) and established during the 1990s (Komesaroff & McLean, 2006). A bilingual education involves the use of two languages to provide instruction and content, in this case via Auslan and English (Branson & Miller, 1993). Advocates for this approach, according to Power (1998), argued that sign language (Auslan) is the natural language of the Deaf and should be preferred as the first language of children living with hearing loss or deafness, and English should be taught as a second language via reading and writing (Branson & Miller, 1993). Despite the introduction and advocacy support for bilingual education, Komesaroff (2001, 2003) illustrates how oral methods of instruction have had considerably more support than manual methods. As Komesaroff and McLean (2006) explain, Australian schools are not required to provide instruction using Auslan nor do they require teachers to be fluent in Auslan for registration or employment purposes.

A landmark court case in Australia in 2005, Hurst and Devlin v. Education Queensland, generated much needed discussion around ‘reasonable adjustment’ and the provision of Auslan interpreters in schools (e.g., Dickson, 2006). A learning and development – Auslan project has been introduced by the Queensland Government which funds the provision of Auslan language models in the classroom for students living with hearing loss or deafness (Department of Education and Training, 2014). It is unclear how the provision of Auslan language models has altered the landscape of the education of children living with hearing loss or deafness in Australia in the long term. However, according to Komesaroff and McLean (2006) and Komesaroff (2003) children living in Australia with hearing loss or deafness continue to be predominantly educated using English in mainstream classes and
Signed English remains a prevalent form of manual communication used by teachers of children living with hearing loss or deafness (Komesaroff & McLean, 2006; Komesaroff, 2001).

In line with Branson and Miller’s (1993) compelling argument for oral/mainstream education to be viewed as symbolic violence, Baynton explains how deaf education is predominantly informed and controlled by people who are hearing (e.g., parents, educators). Moreover, it is important to question what is considered evidence for educational success and how success is measured. Relying on controlled samples and statistical relationships between factors (e.g., audiological information, school test scores) informed by hearing standards may narrow our definition and understanding of success and deafness and hearing loss. Keeping in mind that as educators and researchers continue to debate which language of instruction is preferable, children continue to progress through the education system experiencing (and graduating with) less than equal access to academic and social knowledge and resources.

Understanding the history of education in Australia illustrates how constructions of deafness and hearing loss shape policy and practice and have practical implications for the outcomes for people living with hearing loss or deafness. The match between the individual and the education philosophy at the time has long term consequences for the linguistic, social, employment, psychological and relationship outcomes of people living with hearing loss or deafness (Power, 1998).

**Discussion**

It is impossible to escape dominant constructions of deafness. However, we need to acknowledge the historical and current context within which they are being employed and the implications of a reductionist approach to understanding deafness and hearing loss. We also need to recognise that these dominant constructions are not free from socio-political contexts. There are many deaf, hearing impaired, Deaf, hearing technology and visual technology
organisations and professional services (e.g., schools, interpreters, audiology, speech pathology) that espouse any one of these constructions of deafness. Each of these stakeholders’ has an economic interest in the ‘success’ or ‘truthfulness’ of the construction of deafness to which they subscribe (see Lane, 2006). As Corker (1998) explains, culturally embedded discourses shape and constrain experiences [of disability or deafness] within specific socio-cultural, political, geographical and historical contexts and are reinforced by and interpreted through social practices and social structures. Acknowledging the various stakeholders interests and the discourse operating in society is important within a post-structuralist framework, working with plurality of experience and meaning, such that the actions (linguistic and physical) of some may oppress others.

There is a general assumption, as Lane (2006) explains, that people living with moderate hearing loss or those who are late deafened tend to associate with the disability construction of deafness. In comparison, people living with early on-set and or profound deafness tend to associate with the social model of deafness or the linguistic minority construction of deafness (Deaf culture). As a consequence of the research undertaken in this thesis, I take the view that such general statements oversimplify the diversity and subsequent complexity that is associated with the experience of living with deafness or hearing loss. Corker and Shakespeare (2002) believe that existing theories of disability both modernist and poststructuralist are insufficient. Medical and social models seek to explain disability universally, and consequently create meta-narratives that exclude important dimensions of disabled people’s lives and their knowledge. Corker and Shakespeare consider the range of impairments and the different ways they impact on individuals and groups over their lifetime and the intersection of disability with other social categories (e.g., gender, race, class, sexuality) and how notions of embodiment are challenged through impairment to illustrate the insufficiency of meta-narratives. Discussions of the models of deafness similarly seek to
create multiple meta-narratives of deafness which I similarly argue oversimplify important dimensions and intersections of people’s lives.

I also argue, as has Skelton and Valentine (2003), that how a person makes sense of their deafness is not necessarily fixed, across contexts and across time. For instance, an individual may identify as linguistic minority, as a member of the Deaf culture, and reject the notion that they are disabled. However, in a workplace they may need to conform to workplace adjustment policies which may use language that constructs deafness as a medical condition and require them to provide detail of the disability (impairment) they experience. In this situation, an individual must subscribe to and reject both constructions of deafness. Further to this, there is endless information that an individual can draw on to inform their understanding of their own and others deafness. This information can include age of onset (pre or post-‘lingual’), level of hearing loss (which depending on their aetiology can change), communication skills and preference, family demographics (education, age, hearingness, siblings, income, citizenship etc.), education experiences (available options, deaf unit, language of instruction etc.), social networks (friends, colleagues, residential community etc.) and use of hearing technology. As such, how an individual or group of individuals understand their deafness should not be inferred from audiological information and communication skill and preference alone (as is common practice for researchers).

While it is impossible to escape these constructions of deafness entirely, it is possible to identify the mechanisms through which they are reproduced. For most people who interact with living with deafness or hearing loss, their journey begins with the health system. The health system is where a parent or individual seeks initial guidance, confirmation, information and support when they recognise ‘something is wrong’. The diagnostic process produces and reinforces a medical construction of deafness (where medical professionals are positioned as the experts). Diagnosis is the trigger that sets people on a path that requires
them to constantly negotiate their deafness in a society that values and assumes hearingness. For example, diagnosis triggers discussions of appropriate intervention. For children, early intervention informs formal education (and social relationships) which in turn informs employment (and financial resources) to lifestyle (and physical and mental health). For older adults, intervention can inform employment (or loss of) and affect lifestyle. Consequently, understanding how deafness is constructed within the health context and health system is the focus of this thesis.

Conclusion

In this chapter I have reviewed and discussed the dominant constructions of deafness demonstrating how each model has, and continues to, compete for recognition as ‘truth’. I have illustrated how despite the criticisms of the dominant constructions of deafness, they have shaped the lives of people living with hearing loss or deafness (e.g., education). With an understanding of the dominant constructions of deafness and the criticisms of these constructions, I am able to critique the research literature on deaf health. In the following chapter I demonstrate how these dominant constructions of deafness have shaped our knowledge of deaf health.
Chapter 5

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How Deafness has Been Studied in the Past

Building on the review and discussion of the dominant constructions of deafness in the previous chapter, this chapter provides a comprehensive review of the previous and current (national and international) literature on deaf health. This chapter concludes with a letter to the editor published in the *Australian and New Zealand Journal of Public Health*, which describes an incident in Australia that acted as a catalyst for the thesis. I use the term ‘deaf health’ here to refer to the literature on health related quality of life, health knowledge (e.g., mental, physical, disease, reproductive) and health access. The literature reviewed here was identified through a broad and iterative search process using both the University of Queensland library search tool and Google Scholar. Initial search terms were broad (e.g., ‘deaf AND health’) and through snowballing techniques and identification of key authors and papers, additional search terms were identified (e.g., deaf AND quality of life; deaf AND access AND health; deaf AND health knowledge; d/Deaf AND cancer etc.). A critical appraisal of this literature coincided with my introduction to and immersion within postmodernist and social constructionist theories. That is, I questioned the assumptions that appeared to be underpinning the literature that I had reviewed and identifying common patterns across the literature. This process led me to identify how researchers have typically adopted a positivist framework and comparative approach to measuring deaf health. I will demonstrate how, through taking up this position, research exploring ‘deaf health’ inherently assumes a corrective focus which emphasises ‘hearingness is best’ and reinforces deafness as a deficit and is a mechanism by which medical constructions of deafness are reproduced.

As a note to the reader, throughout this review it will become clear that generally within the literature there is a lack of consistency in the use of various terms such as deaf, hard of hearing, hearing impaired, disability and impairment and this will be discussed as a critique of the literature. It is also important to acknowledge that my use of terms such as
‘disability’ and ‘impairment’ is determined by current common understandings of these terms. Operating within this abstruse terminology and a post-structuralist framework, I have adopted an understanding that a person’s identity is fluid. Specifically, people hold numerous identities and that any one identity held by an individual at a time is relevant to that context (physical and social location), the people they are with and the purpose of their interaction/being.

**Deaf Health**

There is general agreement within the research field of ‘deaf health’⁶, that people living with hearing loss or deafness are more likely to experience noticeably poorer health related quality of life and have poorer health knowledge than people who are hearing (e.g., Hogan, O’Loughlin, Miller, & Kendig, 2009; Hogan et al., 2011; Li et al., 2014; Margellos-Anast, Estarziau, & Kaufman, 2006; Orsi, Margellos-Anast, Perlman, Giloth, & Whitman, 2007; Pollard & Barnett, 2009; Steinberg, Wiggins, Barmada, & Sullivan, 2002; Theunissen et al., 2014; Wake, Hughes, Poulakis, Collins, & Rickards, 2004). As I will illustrate, much of this research is informed by assumptions that align with positivism. It is important to acknowledge, that while people who are living with a hearing loss or deafness are disadvantaged, people who acquire a hearing loss later in life negotiate challenges separate to those experienced by people who are born deaf or acquire deafness or hearing loss early in life. And separate again from people who experience deafness or hearing loss related to age.

I do not contest that people living with hearing loss or deafness experience considerable disadvantages accessing and benefiting from the Australian health system and that this has consequences for their health related quality of life and health knowledge. However, adopting the lens of social constructionism, I do problematise that the majority of published research, that falls under the broad term of deaf health, appears to have been

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⁶ The term ‘deaf health’ is used to encompass all people who experience living with any level of deafness or hearing loss.
underpinned by assumptions that speak to positivism and the medical model of deafness (as discussed in Chapter 4). The majority of deaf health research adopts a comparative approach with a ‘corrective focus’ and this knowledge is presented as truth. From a poststructuralist perspective, this is problematic, as the production of this knowledge reproduces dominant meta-narratives of deviance and tragedy with deafness and hearing loss as separate from and inferior to ‘normalcy’ (hearing). Constructions of deafness and hearing loss as inferior to hearing continues to be embedded with social relations which perpetuate specific socio-political arrangements which in turn inform who can appear where, and in what capacity (Corker & Shakespeare, 2002).

Using considered examples, I will illustrate how research that appears to be informed by positivist and medical model assumptions, inherently reinforces ‘hearing as ideal’ and deafness as a deficit and that this is problematic to the Deaf, and hard of hearing, cause. I use examples that are both international and specific to Australia from the areas of health related quality of life (mental and physical health), health knowledge (general and specific health conditions) and risk behaviours.

**Health Related Quality of Life**

A broad range of topics in relation to health related quality of life among deaf and hard of hearing population(s) have been covered including mental health, self-image, obesity, health care utilisation and the role of hearing technology. Across these topics, researchers have focused on children, adolescents, middle age and older adults to varying extents and have mostly focused on people who are living with a mild to profound, bilateral hearing loss. The majority of the research has reported that level of hearing loss (and associated impairment) was negatively correlated with health related quality of life; such that the greater the level of hearing loss the poorer their health related quality of life and that access to hearing was associated with greater quality of life (e.g., Chia et al., 2007; Cohen, Labadie, Dietrich, &
Haynes, 2004; Dair, Ellis, & Lieberman, 2006; Dalton et al., 2003; Gopinath et al., 2012; Hogan et al., 2001; Hogan, O’Loughlin, Miller, & Kendig, 2009; Hogan, Shipley, Strazdins, Purcell, & Baker, 2011; Shakespeare & Watson, 2001; Werngren-Elgström, Dehlin, & Iwarsson, 2003). I will review some examples of health related quality of life research in detail, highlighting the findings and critically reflecting on the assumptions underpinning the aim or method of the paper.

A limited number of studies have explored health related quality of life in Australia. Hogan and his colleagues (2009) explored the health impact of hearing disability on older people (55 years and older) in Australia. They compared data collected by the Australian Bureau of Statistics (Survey of Disability, Ageing and Carer SDAC) and responses to the SF-12 quality of life survey (Ware, Kosinski, & Keller, 1995, 1996) against Australian population norms (Avery, Grande, Taylor, & Australia, 2004). They concluded that older Australians with self-reported hearing disability have poorer physical and mental health scores, compared with (hearing) population norms. In a separate study focused on children, Hogan and his colleagues (2011) conducted a cross sectional analysis of the impact of hearing loss using the Longitudinal Study of Australian Children (LSACs). Children aged 4-5 years with identified hearing loss, when compared with children without hearing loss, were found to have elevated prevalence of emotional and behavioural difficulties as a consequence of reduced receptive language skills.

Several studies explored health related quality of life in cochlear implant populations. One study by Huber (2005) examined the subjective health related quality of life of young Austrian’s (age 8-16 years) with cochlear implants. Huber reported that this study was based on the evidence that deaf children benefit from cochlear implants (in relation to oral language and integration into mainstream schools) and the subsequent general view that these children had a good quality of life. It is important to note that 15 children were excluded due to
reading comprehension difficulties. Huber found that the health related quality of life of the children aged 8 to 12 was significantly below the standard for hearing children, where children aged 13-16 were within the (hearing) norm. It is unclear how the exclusion of the 15 children, whose English comprehension skills had not clearly/sufficiently benefited from the cochlear implant, would have altered the findings of this study. As the author acknowledges, the findings of this study can only be generalised to a narrow range of the heterogeneous cochlear implant population. There does not appear to be explicit acknowledgment that reading comprehension, rather than the cochlear implant or deafness, is associated with quality of life.

In the topic of health related quality of life, there were few studies that focused on culturally Deaf population(s). Gerich and Fellinger’s (2012) study focused on the effect of social networks (size and composition) on the quality of life for middle to older aged members of the Deaf community in Austria. Gerich and Fellinger found that larger (deaf) social networks were associated with a higher quality of life. Participants with larger deaf networks were also more likely to maintain larger hearing networks and this bicultural network composition did not have any particular positive effect beyond that found for the size of the deaf network. Gerich and Fellinger do not argue that a bicultural network is more desirable or required for positive health and the exploration of a bicultural network is not problematic. Rather, that the same exploration is yet to be explored, to my knowledge, within hearing populations; how does a bicultural network involving Deaf people effect the quality of life of hearing people? While Buaman and Murray’s (2009) concept Deaf Gain, which refers to the sensory and cognitive diversity that people living with deafness contribute to the greater good of humanity, is gaining legitimacy within the Deaf community and Deaf studies, there is little evidence that it has been taken up beyond ‘Deaf studies’. I use Gerich and Fellinger’s study here to illustrate how assumptions that hearingness is best and deafness as a
deficit continue to remain dominant; that Deaf Gain is yet to influence research beyond ‘Deaf studies’.

Li et al. (2014) was interested in the prevalence of and risk factors for depression among adults in the United States with hearing loss. After controlling for age, sex, race/ethnicity, lifestyle characteristics and selected health conditions, Li et al. found that compared with people who self-reported “excellent – good hearing”, people who reported anything greater than “a little trouble hearing” (>20dB bilateral loss) had higher rates of depression (particularly for women). The authors claimed an association between hearing impairment and depression such that “hearing impairment … can impose a heavy social and economic burden on individuals, families, communities, and countries. Hearing impairment tends to isolate people from friends and family because of a decreased ability to communicate” (p.E5). Such a conclusion is problematic, as it locates the aetiology of the depression in their biological hearing impairment, removing their experience from their social context. Li et al. do not discuss in their article how experiences of depression may be associated with the (in)action of family and friends or lack of resources, equipment and support available for people living with hearing impairment to access or facilitate their continued participation in the workforce, hobbies and social events. In support of this critique, two separate studies by Fellinger, Holzinger, Sattel and Laucht (2008) and Hallberg, Hallberg and Kramer (2008) found that quality of life cannot be predicted from audiometric data (degree of deafness) data.

As examples of the research focused on the health related quality of life, I take issue with the unquestioned, reductionist and or comparative method that is frequently adopted and the overtly quantified medical construction of deafness. Within the literature that I reviewed that focused on health related quality of life, researchers frequently compared their findings against population norms, normative standards or hearing counterparts, reproducing either/or
binaries and meta-narratives of deafness as deviant, lacking, tragic and inferior to ‘normalcy’. Such comparisons are underpinned by the assumption that hearing is ideal and hearing experienced in any other way is a deficit to be corrected. Such comparisons appear unquestioned in the literature reviewed here and inform efforts to correct or reduce the difference between the two populations; these efforts are commonly linked to medical interventions. As has been discussed, within a social constructionist lens deafness has multiple possible constructions whereby no one construction is more real or true than another. However, in the health related quality of life deaf health literature it is commonly constructed as a medical deficit.

This thesis contends that constructions of deafness as a medical deficit (only) are problematic. Medical constructions of deafness offer definitions of deafness that remove the experiential element of deafness. In the health related quality of life literature, hearing impairment was typically quantified according to medically defined levels of loss, measured in Hertz and decibels, and was both required to be permanent and bilateral to meet participation requirements. This narrow definition decontextualizes experiences of deafness, excluding the diversity of deafness/hearing loss as it is in the population (i.e. assumes that people who meet those criteria have an entirely different experience from someone with a unilateral profound hearing loss and that person does not experience similar difficulties accessing communication or resources). For example, in Huber’s (2005) research, participants were excluded due to their comprehension skills. The practice of using narrow and quantified definitions of deafness serve to establish a threshold to determine the level of ‘tragedy’ and separation from ‘normal’ people that people with hearing loss or deafness will experience. This is further emphasised by the deaf health literature that reports the ‘success’ (return to ‘normal’ functioning) that people with cochlear implants and hearing aids experience and benefit from (not reviewed here). Furthermore, within our society, medical
knowledge, qualified medical practitioners and academics occupy an empowered position within our Western society. As such, being published in these peer reviewed academic journals, constructions of deafness as a medical condition remain dominant within society.

As mentioned at the beginning of this chapter, across the literature there is a lack of consistency in the use of the term deaf, hearing impaired and hard of hearing. Although the authors of the literature I have reviewed here defined the population to which they were specifically referring, typically using medical quantifications of deafness, these definitions were not consistent across studies (see e.g., Fellinger et al., 2008; Gerich & Fellinger, 2012; Hallberg et al., 2008; Li et al., 2014). Defining these terms according to medical quantifications is also problematic due to these terms also being used to refer to complex ‘deaf identities’. Both hearing people and people living with hearing loss or deafness commonly use the terms listed above to identify themselves or others, to refer to a broad range of experiences such as communication preference, accommodation needs and education. The use of these terms in interchangeable contexts where the meaning is changed is troublesome from a poststructuralist perspective; As Corker (1998) explains, language and meaning are linked and explanations of the social world are created and sustained in the linguistic spaces between people. This critique of the health related quality of life deaf health research can similarly be applied to the deaf health literature on health related quality of life knowledge, discussed below.

Health Knowledge

A considerable amount of research has investigated and found that deaf individuals, particularly those who communicate predominantly through signed language, have insufficient health knowledge. In particular, health literacy (Pollard & Barnett, 2009), mental health (Steinberg, Sullivan, and Loew 1998), and specific health conditions including cancers (Folkins et al., 2005; Orsi et al., 2007; Sacks et al., 2013; Sadler, Gunsauls, et al., 2001;
Two studies examined the health knowledge of Australians living with hearing loss deafness. Kleinig and Mohay (1990) administered a health knowledge questionnaire (written English or via Total Communication) to both hearing and hearing-impaired high school students. Their comparison revealed that hearing students had superior health knowledge over their hearing-impaired peers. Wollin and Elder (2003) similarly found that 13 Australian Deaf women’s knowledge about mammograms and pap smears (obtained via interviews with interpreters) was incomplete. Wollin and Edler comment that most Deaf women, similar to hearing women, knew that mammograms are a preventative strategy but half of the Deaf women did not know which age to begin having them.

As an example of more general health knowledge, Pollard and Barnett (2009) measured the health literacy of 57 highly educated, signing and oral deaf adults using a modified Rapid Estimate of Adult Literacy in Medicine (REALM; written or in American Sign Language, ASL). They found that this sample of adults had low health literacy compared with the normative expectations of hearing REALM respondents. Interestingly, some basic health words commonly used by clinicians and researchers were challenging for the participants. For example words such as obesity, incest and constipation were frequently not understood by participants, even by those who held a college degree. Pollard and Barnett (2009) suggest that health knowledge is not associated with intelligence.

Margellos-Anast et al.’s (2006) face-to-face interviews with ASL proficient Deaf adults found that compared with the general hearing population, almost half could not identify any of the most common symptoms of a heart attack or stroke. Mental health knowledge has also been found to be insufficient. Interviews with 54 deaf adults, conducted
by Steinberg, Sullivan and Loew (1998) concluded these adults had a large variation in their ability to recognise mental health terms in English. Terms such as psychosis and obsessive-compulsive disorder were particularly problematic. Further, these participants were found to have likely learned their mental health knowledge from deaf friends and family; which is typical of Deaf cultures. These two studies illustrate the ineffectiveness of health education campaigns and health promotion for people living with hearing loss or deafness whose primary language is sign language.

Within the health knowledge literature, researchers have tended to focus on people living with hearing loss or deafness who use a signed language. This focus is conceivably informed by the inherent assumption that these population(s) are likely to be the most disadvantaged by their primary mode of communication being a signed language (and one that is not well supported within broader (hearing) society), limited English comprehension skills, poor education outcomes, and the fund-of-information deficit. The focus on these population(s), may facilitate the lack of attention that is given to the population of people who have grown up with a hearing loss or deafness and despite being raised orally and educated in mainstream schools, also do not have sufficient English comprehension skills to benefit from mainstream spoken English health information. While some researchers are careful to ensure their research is accessible via range of communication options (e.g., Pollard and his colleagues), the dominant focus of research conducted on health knowledge focuses on people living with hearing loss or deafness who use a signed language. This focus, risks decontextualising the complexity of living with a hearing loss or deafness in a society that values and assumes hearing. People, particularly those living with hearing loss or deafness, are not easily categorised into strictly defined labels.

A comparative approach to examining the health knowledge of people living with hearing loss or deafness was also evident in the health knowledge research (e.g., Kleinig &
Mohay, 1990; Margellos-Anast et al., 2006; Pollard & Barnett, 2009). However, the researchers consistently concluded and discussed the need for health knowledge to be taught and delivered in formats (e.g., sign language, through interpreters) that are more accessible to people who communicate via visual languages. They also discussed the need for (hearing) health professionals to be more aware of Deaf culture and the communication needs of people living with hearing loss or deafness (e.g., Margellos-Anast et al., 2006; Steinberg et al., 1998, 2002; Wollin & Elder, 2003). It should be noted however, that the researchers rarely noted or considered in their research papers the barriers (e.g., cost, time off work, availability of workshops) that health professionals face when attempting to implement their recommendations, who is responsible for driving/overseeing the implantation of these recommendations. Additionally, researchers rarely questioned that public health knowledge and campaigns assume a hearing culture and a hearing audience in the first place; that English health campaigns are not concurrently produced in Auslan. Linked to low rates of health information, there has been some research interest into whether people living with hearing loss or deafness are more likely to engage in risk behaviours.

Risk behaviours that have been explored within deaf health research include drug, alcohol and tobacco use (Barnett & Franks, 1999; Barnett et al., 2011; Berman, Streja, & Guthmann, 2010; Roberts & Mugavin, 2007), obesity (Barnett et al., 2011; Dair et al., 2006), suicide (Barnett et al., 2011) and sexual behaviour (Gomez, 2011; Joseph, Sawyer, & Desmond, 1995). Predominantly conducted within the United States, the majority of research has focused on signing deaf populations. This is probably in response to the identified lack of health knowledge and recognition of the barriers to accessing health information and services. The findings of this collective category of research have been mixed. When compared to ‘hearing counterparts’ authors have found some risk behaviours to be higher
(e.g., obesity, suicide, intimate partner violence, HIV and ‘risky’ sexual behaviour), some lower (e.g., smoking) and some with no difference (e.g. drugs and alcohol).

The findings of risk behaviour research are particularly concerning considering the lack of health resources (professionals who also live with hearing loss or deafness or are competent in sign language and culturally relevant mental health assessment tools) available in Australia (see Munro, Knox, & Lowe, 2008). It is also interesting to note, that where risk behaviour (e.g., smoking) experiences of people living with hearing loss or deafness are compared against hearing populations, the same comparison is rarely made in return. This absence in the ‘general’ smoking literature illustrates how deafness, as a part of our community, is not reflected in research that is designed to be generalised to the broader population. Where terms such as ‘general population’ and ‘broader population’ are used to imply or refer to the population of people who are hearing, hearing as the ideal norm or the benchmark is reinforced.

There was also a considerable lack of collaborative approaches employed in the research reviewed here. Only a minority of researchers reported in their article whether they adopted a collaborative approach (collaborated with people living with hearing loss or deafness) to design their study or analyse their data. One example in the risk behaviour literature was Barnett et al.’s (2011) study. In their study, “Deaf and hearing researchers and community members worked collaboratively to develop a linguistically and culturally appropriate survey…” Collaborative approaches to research create opportunities for health priorities to be determined in meaningful ways by people living with a hearing loss or deafness (rather than being informed by hearing people’s agendas, as has been enacted in the past, see Chapter 4) and is an important element of challenging dominant ways of thinking informed by the hearing majority.
Summary

In this section I have summarised and critiqued two large areas of research in deaf health; health related quality of life and health related quality of life knowledge. Across the two areas and the diverse range of topics that have been researched within the area of deaf health, people living with hearing loss or deafness are consistently compared against a (hearing) population norm. Researcher’s constant use of comparative approaches to deaf research (where the same comparison is rarely applied in reverse) reproduces deafness as deviant and lacking where being hearing is idealised and ‘normal’. This is problematic as it has implications for explanations of the social world and social relations between people living with hearing loss or deafness and hearing people which determine who can appear where and in what capacity (Corker & Shakespeare, 2002; Corker, 1998).

As I discussed earlier, the use of terms such as hearing impaired, deaf and hard of hearing in deaf research is also problematic. These terms are both used to label participants based on their audiologically defined level of hearing loss and to refer to fluid identities which incorporate complex combinations of information pertaining to an individual’s social context. In some studies participants self-identified their ‘deaf identity’ or their level of hearing loss while in others the researchers categorised their participants according audiological definitions or categories. Although these terms provide useful assumptions or indicators about a person’s level of hearing ability/Deaf Gain and their communication preferences, it is difficult to justify the generalisations of the research findings. The use of these terms risks generalising experiences and disregarding the diversity of experience that exists within this population. The use of audiometric definitions of these terms also serves to reproduce constructions of deafness as a medical condition and as a deficit. Additionally, the inconsistent, and in some cases undefined, use of these terms makes it difficult to compare and synthesise the findings of this body of research. Despite these criticisms, I recognise that
currently there is no ideal alternative to using these terms. In the following section, I review and discuss the empirical literature that has identified the barriers people living with hearing loss or deafness experience when accessing health knowledge, resources and practitioners.

Health Access and Quality of Life

In line with the social model of deafness, a considerable amount of research has identified the barriers people living with hearing loss or deafness face when accessing health knowledge, resources and practitioners. This research is utilised to argue for, and has informed, the adaptation of some ‘mainstream’ health resources into ‘deaf friendly’ (captions, signing, visual) formats. However, as I will discuss, this research is also problematic as it frequently locates the issue or disability within the individual. This problem is largely an issue with semantics rather than intent, and reflects culturally reinforced discourses of individual responsibility. Following a brief summary of the findings in this area of research, I will demonstrate how these barriers or the recommended solutions are frequently constructed as an individual problem rather than a problem located within the resources themselves or in broader society. The majority of the research investigates the barriers experienced by people who communicate through signed language, this will be discussed as a limitation. A broad range of barriers have been identified which I will classify into communication barriers, interpreter issues and health professional attitude.

Communication.

Any published research that relates to the challenges experienced in relation to a person’s ability to express and to understand the communication of others is included under the heading communication. Various studies from the United States and United Kingdom report that poor communication is a frequent occurrence between hearing health professionals and deaf patients (Alexander, Ladd, & Powell, 2012; Harmer, 1999; Iezzoni, O’Day, Killeen, & Harker, 2004; Royal National Institute for the Deaf Great Britain, 2004; Steinberg et al.,
2002). Difficulties in communicating due to not sharing a common language often result in the use of qualified interpreters or more frequently, the use of family members as interpreters, lip-reading and or writing notes (Ebert & Heckerling, 1995; Iezzoni et al., 2004; Sadler, Huang, et al., 2001). However, as many researchers have outlined, each of these strategies is less than optimal and can compromise patient health.

The use of qualified interpreters is specific to people who communicate through a signed language. While employing the services of an interpreter is an ideal option for effective communication (Harmer, 1999), having this third person in the room raises issues of privacy (and rapport building) for some people. Sadler, Huang et al.’s (2001) focus groups and interviews with Deaf adults found that these individuals’ sense of privacy or willingness to discuss intimate issues, which is important for a health professional-patient relationship, can be disrupted by the presence of an interpreter. Additionally, some Deaf individuals have reported that they fear interpreters will break their code of ethics and gossip about their health issues with other interpreters or with members of the Deaf community (Harmer, 1999). In the common absence of interpreters (see next section), health professionals and patients rely on family members (including children) to interpret. However, this can be problematic, as Sadler, Huang et al. (2001) suggest this third party person can interfere with the patient’s sense of privacy and communication of intimate problems (Harmer, 1999).

Lip reading, which is largely guesswork, is most effective between people who have had repeated experiences communicating with one another. Consequently, the reliance on lip reading in health care interactions is not sufficient in a health professional-patient setting (Sadler, Huang, et al., 2001). Reported by 26 deaf and hard of hearing adults interviewed by Iezzoni et al. (2004), the effectiveness of lip reading is limited by people speaking quickly, turning away, bowing their head, or facial hair, all relatively unnoticed behaviours in verbal interactions. These interviews also revealed that deaf and hard of hearing adults experience
communication difficulties during physical examinations and procedures, whereby they were not aware of what was happening or why and the health professional was hidden from view by screens (Iezzoni et al., 2004). The use of note writing is also problematic (Harmer, 1999) largely because it assumes a certain high level of written English comprehension (Alexander et al., 2012; Bat-Chava et al., 2005, see Chapter 3) and can also be complicated by the use of awkward or abbreviated English (Sadler, Huang, et al., 2001).

Given the importance of communication between health professionals and patients (Markides, 2011; Stewart, 1995), the identification of communication barriers is particularly concerning. Researchers have found that poor health professional-patient communication has important implications for the health practices of people living with hearing loss or deafness. Such that, poor communication has resulted in their avoiding going to see their general practitioner, abandoning efforts to explain themselves in appointments, feeling unclear about their condition or their treatment plan, incorrectly following medication instructions, being less likely to ask for additional information and being less likely to check the accuracy of their understanding (Iezzoni et al., 2004; Royal National Institute for the Deaf Great Britain, 2004; Sadler, Huang, et al., 2001).

**Interpreter issues.**

The use of interpreters is commonly considered the most effective way of facilitating communication between a signing Deaf person and a hearing person (Harmer, 1999; MacKinney, Walters, Bird, & Nattinger, 1995; Middleton et al., 2010). However, as alluded to above, the use of interpreters is not without issues. In this section I briefly discuss the barriers to accessing health that are specifically related to the use of interpreters. Interpreter availability and cost can be a barrier to deaf health. Harmer (1999) suggests that health professionals in the United States may not know how to book interpreter services, who is responsible for paying for the interpreting service or how to work with the interpreter.
(Steinberg et al., 1998). Despite the introduction of the National Auslan Booking Service, this issue likely extends to the Australian health professionals.

Incorrect use of interpreters is also cited as a barrier to health. Iezzoni et al. (2004) outlines how some health professionals inappropriately communicate with the interpreter, giving them eye contact, rather than the deaf patients. Interpreters who are not specifically trained in medical sign language may not able to accurately interpret information for the patients and affect the patients’ ability to understand the information. As discussed in Chapter 3, despite being regulated by the NAATI there is no requirement that interpreters will have any additional qualifications (medical, law, health) to their interpreting qualification (Cornes & Napier, 2005).

Further to this, as Cornes and Napier (2005) discuss, there is limited mental health terminology in Auslan due to the lack of Deaf people working as professionals in the mental health field. The use of interpreters in mental health settings is further complicated by the emotional impact on the interpreter and the potential for role confusion to affect the therapeutic alliance between the therapist and patient (Cornes & Napier). While interpreter services are essential for effective communication between health professionals and patients where one uses sign language, there are still difficulties associated with the use of interpreters which act as barriers to deaf health.

**Health professional attitude, knowledge and availability.**

Health professional attitude has also been noted as a barrier to health for deaf individuals. Deaf adults interviewed by Iezzoni et al. (2004) reported that physicians’ fundamental assumptions about deafness lacked an appreciation of the totality of deafness and their patients’ lives and health concerns. This included a lack of respect for their intelligence, motivation and desire to be involved in their own health care. This lack of appreciation served to undermine the patient-professional relationship.
As noted in Chapter 3, availability of ‘experienced’ health professionals in Australia is limited and this is noted as a barrier to health. This lack of training is particularly concerning as research has shown people living with hearing loss or deafness prefer to communicate directly with health professional rather than through an interpreter (Steinberg et al., 1998). Furthermore, people living with hearing loss or deafness experience equal if not greater rates of anxiety, depression and psychosis (e.g., du Feu & McKenna, 1999; Kvam, Loeb, & Tambs, 2007; Rogers et al., 2013; Sheppard & Badger, 2010) and there are differences and difficulties involved in diagnosing and treating deaf patients (including a lack of empirically validated measures of psychopathology for Deaf people; e.g., Cornes, Rohan, Napier, & Rey, 2006; Munro, Knox, & Lowe, 2008; O’Hearn & Pollard, 2008). Glickman (2007) explains that language patterns of mental health patients are frequently examined as indicators of thought disorders and that there are complications diagnosing thought disorders in patients living with deafness or hearing loss where language dysfluency may be the result of language deprivation rather than an indicator of mental illness. In combination, this literature demonstrates that the lack of available health professionals’ with the appropriate attitude, knowledge and skills to treat people living with hearing loss or deafness is a considerable barrier to accessing health services and information.

**Addressing barriers.**

The studies reviewed here offer suggestions to reduce the barriers to health care that people living with hearing loss or deafness experience. These suggestions frequently include the translation and creation of health information about various topics (e.g., cancers, cardiovascular information, HIV) into visual materials that are both captioned and presented in native sign language (Bat-Chava et al., 2005; Harmer, 1999; Sadler, Gunsauls, et al., 2001; Steinberg et al., 2002) and the creation of health education workshops to provide information and “psychoeducation” to people living with hearing loss or deafness (Cornes & Napier,
2005). Suggestions also included the need for health professionals to be cognizant of their role and responsibility to be aware of and accommodate the language needs of their patients and to ensure their patients understand all the health information that they discuss (Bat-Chava et al., 2005; Ebert & Heckerling, 1995; Steinberg et al., 2002). Other suggestions include the need for interpreters to obtain additional training for specialised settings, self-advocacy skill development for people living with hearing loss or deafness (Harmer, 1999; Steinberg et al., 2002) and culturally sensitive prevention and targeted intervention strategies (Sadler, Gunsauls, et al., 2001; Steinberg et al., 2002).

Many of these recommendations address the barriers that have been identified and will contribute to improving the physical and mental health and health knowledge of people living with hearing loss or deafness. However, many of these recommendations operate at an individual level and do not challenge the notion that people living with hearing loss or deafness continue to rarely be considered in the development and distribution of health knowledge and disease prevention and treatment and training of medical and allied health professionals. For example, suggestions often call for existing materials and information to be translated but do not suggest or inform how future materials and resources should be provided in Auslan and captioned prior to distribution. Moreover, researchers suggest that health professionals should be more cognizant of their responsibilities (on top of what is already a demanding and time poor profession). There is rarely any discussion of how training and education programs should be required to incorporate deaf awareness training into their mainstream education programs and professional development requirements. Nor is there discussion about who is responsible for developing and overseeing these changes. Iezzoni et al.’s (2004) study was the only study reviewed here that incorporated environmental/system level changes, suggested by the Deaf participants, into their recommendations. Participants’ suggestions included installing light signals for fire
emergencies, reviewing automated telephone menus, installing lights to signal various actions in varied contexts (breathing instructions in radiology) and vibrating pagers in waiting rooms. In targeting changes to the environment, the participants locate the disability in the environment rather than in individuals (hearing or deaf).

Further to this, the body of research that examines barriers to health care is largely explored from and informed by people living with hearing loss or deafness, specifically those who identify as Deaf or predominantly communicate using signed language. While this is important, there is a lack of published research that explores whether health professionals or systems (e.g., hospitals, clinics, and disease prevention organisations) experience difficulties reaching and treating deaf populations. The absence of this knowledge suggests that health professionals are unaware, do not perceive a problem or do not understand how they contribute to the barriers. A search for research evidence revealed that comparatively fewer studies have examined the barriers people living with deafness or hearing loss experience from the perspective on non-specialist health professionals (Thomas, Cromwell, & Miller, 2006).

**Health professional perspective.**

The few studies that explore health professional’s experiences of treating patients living with hearing loss or deafness conclude that health professionals are aware of and experience difficulties. Ebert and Heckerling (1995) in the United States found that despite knowing that sign language should be the initial method of communication, physicians frequently communicated with their patients through lip reading and writing notes. Also in the United States, Ralston, Zazove, and Gorenflo (1996) found that physicians reported greater difficulty communicating with and different attitudes towards deaf patients. They were not able to determine if these differences impacted the quality of care the physicians provided their deaf patients. Neither of these studies problematised the poor communication practices they
identified or suggest that they contribute to the disadvantages people living with hearing loss or deafness experience. It is also not clear if the physicians in these studies were provided with skills training or information on how to improve their communications strategies.

One study in the United Kingdom by Thomas, Cromwell and Miller (2006) conducted focus groups with non-specialist (in the area of deafness) community mental health teams which are sometimes involved in providing care for Deaf people with serious mental health problems. Participants in the focus group discussed feeling ill equipped (knowledge, resources, language) to provide effective treatment to patients living with hearing loss or deafness and that this was impacting negatively on their clinical competencies. The recommendations offered by the authors, while constructive, are reactive to the challenges the health professionals identified. Comparatively less attention is given to suggestions that require change at system, policy and reform levels (e.g., mandatory training courses and professional development, minimum language requirements, service provision).

A small number of studies have implemented deaf awareness interventions in health professional student populations (e.g., Hoang, LaHousse, Nakaji, & Sadler, 2011). These interventions mostly involved an experiential intervention. Two separate studies by Matthews, Parkhill, Schlehofer, Starr and Barnett (2011) and Thew, Smith, Chang, and Starr (2012) implemented role reversal interventions with first-year undergraduate students in pharmacy and medicine respectively. The interventions require students to engage with local deaf community members in scenarios where the community member’s role play as the health professional using signed language and the student as the hearing patient. Both studies concluded that the role reversal interventions were an effective method of teaching students about communication competency and cultural awareness. The limited research that has investigated the health professional’s perspective and tested interventions suggests that the barriers people living with hearing loss or deafness experience are not one-sided.
Summary

People living with hearing loss or deafness face considerable barriers when accessing health information and services. Extending beyond issues with communication differences, people experience difficulties accessing qualified interpreters and challenges negotiating health care professional attitude and skills. The limited research available also suggests health professionals are somewhat cognizant of their lack of training and skills to treat and communicate with people living with hearing loss or deafness. Many researchers have begun to address some of the identified barriers, largely focusing on adapting already available health knowledge into Deaf and hard of hearing friendly formats. There is some research evidence that demonstrates how increasing professionals’ awareness of and training in deafness improves their ability to work with and treat their deaf patients. While identifying and addressing these barriers is important for improving health outcomes for this population(s), I question how social processes and constructions of deafness which remain largely unchallenged create and sustain these barriers.

Conclusion

Through critiquing the literature on deaf health, I have illustrated that researchers have typically adopted a positivist framework and comparative approach to measuring deaf health, assuming a corrective focus which emphasises ‘hearing as best’ and deafness as a deficit. From a social constructionist perspective I have discussed the assumptions underpinning this research as problematic because it has implications for explanations of the social world and social relations between people living with hearing loss or deafness and hearing people which determine who can appear where and in what capacity.

In this chapter I have also reviewed and discussed the empirical literature that has identified the barriers people living with hearing loss or deafness experience when accessing health services and information. Researchers have identified that people living with hearing
loss or deafness experience communication barriers, interpreter issues and challenges negotiating health care provider attitudes and skills. While this research has been somewhat effective in the generation and adaptation of mainstream resources into Deaf and hard of hearing friendly formats, it has had limited success in bringing about changes at an environment, system, policy and reform level. Illustrative of on-going competition between the dominant constructions of deafness and how this shapes the social world and social relations, this chapter concludes with a letter to the editor published in the *Australian and New Zealand Journal of Public Health*, which describes an incident in Australia that acted as a catalyst for the thesis.
Hearing Loss as a Public Health Matter - Why Doesn’t Everyone Want Their Deafness or Hearing Loss Cured?

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“it [deafness] is a scourge in our world but it can be almost completely eradicated…”

Following national and international media coverage of the 2011 Telstra Business Awards, members of the Australian community expressed their views on the alleged words, quoted above\(^1\), and the sentiment expressed in the acceptance speech of the recipient of the Woman of the Year award. Interestingly, not all members of the community shared the same view. Our focus is not on the quote itself but the public responses to it and importantly, what can be learnt from these responses.

Definitions and understandings of disability, deafness included, have largely focussed on the individual and the medicalisation of their ‘disabling’ condition\(^2\). From a medical understanding, disability is a bodily impairment and defined as a negative variation from the norm\(^3,4\). Subsequent interventions are informed by the expertise of medical professionals\(^4,5\), focusing on returning individuals to an approximate norm\(^4-6\). Agreeing with both the sentiment of the speech and an individualised approach, one online reader\(^7\) posted, “... She said she wants to get rid of the "scourge" of deafness, not kill deaf people. As a deaf man if I had a chance to rid people of deafness I would” (Tony, 2011).

Challenging the medical model of disability, the emerging area of disability studies focuses on an array of social definitions and theoretical models of disability\(^4,8\). Theoretical models of disability concentrate on the discriminatory social reactions to physical differences or the ignorance of the effects of difference rather than the physical differences themselves\(^3\). Within the area of disability studies, impairment is defined as lacking part or all of a limb, or having a defective limb, organ or mechanism of the body\(^5\); preferring the term disability to refer to society at large not accommodating the physical difference\(^3\).

In line with this view of disability as external to the individual\(^5,6\), one reader of Charlie Swinbourne’s (a Deaf journalist) online blog\(^9\) commented “Is this the resurrection of Hitler or what? Nothing wrong with being deaf, its people like her [Telstra Business Woman of the Year recipient] that is the problem, assuming what is best for us, the deaf community. It is society, not our deafness, that disables us, …” (Christof Niklaus, 2011).

The original acceptance speech and subsequent responses to the speech illustrate the diversity, and polar extreme views on deafness and hearing loss. It is this diversity which is
often overlooked in discussions around hearing loss as a public health concern (e.g.10), instead there is a tendency to oversimplify hearing loss and deafness and the people who are living with hearing loss or deafness. A comment posted by one reader of the Australian Broadcasting Corporation’s Ramp Up blog11 clearly sums up the complexities of ‘fixing’ or managing hearing loss or deafness, as he describes the distress he experienced while learning to hear with a cochlear implant.

…I used to go to the extenstive[sic] oral/aural early intervention program when I was younger...I first got my cochlear implant less than five years ago, and to my parents, it is a gift from the god. But to me, I suffered. … I work[sic] so hard to concentrate to my teachers all day. At the end of day, I would switch off my cochlear implant because I was so much in pain listening hard to the teachers… All what my parents want was to see me hear and speak... (Connor Arthurs, 2011)

It is clear from responses to the online media coverage of the incident that the choice of words used in the acceptance speech1 was provocative to a diverse group of people highlighting the contentious and ongoing issues surrounding hearing loss and deafness and the roles of culture and medicine. It is clear responses to ‘curing’ hearing loss and deafness are not as obvious, one-sided or straightforward as perhaps previously thought. While disability researchers discuss the theoretical models of disability as being theoretically distinct 4, we argue that these models oversimplify the complexities of this population without understanding how people living with a hearing loss or deafness subscribe to, resist or negotiate these models.12 To improve our understanding, and prior to implementing population based interventions, people who have the capacity to effect change need to recognise the diversity of views that people living with a hearing loss or deafness inevitably express. This would be step towards ensuring the voices of people who are living with hearing loss or deafness are included in the public health decisions that are made on their behalf.
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Chapter 6

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Journal Entry 2 – The Researcher’s Dilemma

February 2012 – April 2012

At this point, having volunteered at the Deaf Games in Geelong and talked to different people about their experiences and about my research, I started to question how, if it all, I as a hearing person with minimal experience in deafness should go about doing this research. It was (and still is) apparent to me that there are some people who believe that hearing people should not or cannot be successful at conducting research with Deaf people; “How can hearing people research something they can never fully appreciate?” As I reflected on this dilemma I was considering the history of Deaf research and whether I am capable of taking on the challenging task of negotiating the diversity of views held by people living with hearing loss or deafness.

Historically, hearing researchers have had a prominent and considerable role in using empirical evidence to depict people living with deafness or hearing loss as “deaf and dumb”. This history has directly contributed to creating a distrust of hearing researchers and a tenuous relationship between people living with deafness and hearing loss, particularly people who identify as Deaf, and hearing people. As I considered this history I started to reconsider my goal to improve the health knowledge of people living with deafness and hearing loss and their access to health services. When I reflected on the research papers I had read I realised that researchers rarely report how their research was informed by people living with hearing loss or deafness or whether they collaborated community representatives. Puzzled by this realisation I wondered why this was the case. I wondered what gives me the authority or power to come in and decide what research needed to be done, how it should be done and who could use the findings. Maybe it’s more about asking
what people living with deafness and hearing loss believe is the problem and what needs to change. So I began to think about how I can use my position and power as a researcher to give a voice to people living with deafness or hearing loss. Whether this is the best alternative I’m not sure.

My conversations with people living with hearing loss and deafness and hearing people about their experiences, deafness and hearing loss and my research have been very insightful but also confusing. The information I got from these conversations doesn’t quite match what’s happening in the research (research questions, methodologies, participants etc.). The research seems to oversimplify what is actually quite a complex area; perhaps necessarily? At the same time I appreciate the difficulty of working with a population of people where, at one end people want to reduce their physical hearing impairment and at the other end people do not want to reduce or alter their deafness, with most people somewhere in between. However, I have begun to question the usefulness of delineating one group of people from another and the rigid criteria that are used to create this delineation. I questioned how I, a hearing researcher, am going to be able to ‘do right’ by groups of people who are not dissimilar (negotiate common challenges) but who are also fundamentally different.

As I began designing my first study for this thesis, implementing these realisations and new directions was quite challenging. Particularly when I considered the pragmatics of how I can achieve all of this within the context of meeting the requirements for a Doctorate of Philosophy and the resources (funding, equipment, language skills and knowledge) that I had.
Creating deaf-Friendly Spaces for Research: Innovating Online Qualitative Enquiries

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In this paper we provide a reflexive account of the first authors’ experience of designing and using an inclusive online forum to conduct research with people living in Australia with deafness or hearing loss. We reflect on the personal, institutional, pragmatic and ontological influences on the project and how we managed these influences when they conflicted. In recounting this experience we highlight the productive and restrictive aspects of doing research with deaf Australians in a university context and “online”.

Keywords: deafness, online qualitative enquiry, reflexive, forum, visual language

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While online methods have been employed in a number of populations with a health focus (e.g., Im & Chee, 2012), researchers have not fully explored the full application of online methods with the population of people living with deafness. The following is a reflexive account of the first author’s experience of designing and using an inclusive online space to conduct research with people in Australia living with deafness. We discuss the values and assumptions we brought to the research and make transparent how they shaped the project.

In reviewing the literature we were struck by the lack of published research in Australia exploring how deafness is constructed by people living with deafness and that adopts a participatory approach to research. This gap informed our decision to adopt a participatory approach in our research and was the catalyst that led us to using an online forum to explore how deafness is socially constructed.

The use of an online forum facilitated access to a diverse sample of deaf participants with varying language preferences and skills without needing to privilege one language over another. However, we found that web-based methods can also be restrictive, particularly in relation to anonymity as Australian Sign Language (Auslan) is a visual-spatial language using hand and facial gestures. Following a brief description of the study and the participants, we begin this reflexive account by contextualising the project with respect to our epistemological position, the historical and socio-political context, and our own positions as researchers. Thereafter, we critically reflect on the process and challenges we negotiated in designing the project, developing the materials, recruiting participants and running the forum. We conclude this discussion by highlighting the productive and restrictive nature of using an online method in a university setting and the use of visual languages in research, problematising the research and publishing process. The findings of this research will not be discussed in this paper.
The Study: Background

This study was a part of the first author’s larger PhD project. This project was approached from a social constructionist perspective (as per Burr 2003), which allows researchers to capture the diverse experiential aspects of deafness and to acknowledge the importance of language, positioning and power (we discuss the rationale for our choice in epistemological and ontological framework later). While we do not deny the material, physical reality of deafness, the focus of this project was exploring how experiences of deafness, in an Australian context, are socially constructed.

An important consideration of qualitative and social constructionist approaches is to locate the study within the socio-cultural context in which it is produced. Significant for our study is the long history of negative portrayals of deaf people as unintelligent, inferior and disabled as this history continues to shape the relationship between hearing researchers and deaf persons today (Graybill et al., 2010; Thumann & Simms, 2009; Pollard, 1992). Interventions are aimed at assisting deaf people to attain (ideal) hearing standards (e.g., health knowledge, literacy, education achievement, mental health,) and qualitative approaches have largely focused on language development rather than exploring social constructions of deafness. Taking advantage of the movement towards greater acceptance of qualitative methods and social constructionist frameworks in Australian psychology, we sought to develop our project in collaboration with the population of interest, which actively facilitated equal access to information and rather than compare or intervene, learn and understand about experiences of deafness.

Several socio-political events at the time of data collection also contextualise our project (Mauthner & Doucet, 2003). Data collection began shortly after the 2011 Telstra Business Awards in Australia (Carty, 2011), a prominent incident within the deaf world. It is alleged that deafness was compared to polio in the acceptance speech of an award recipient, a
prominent figure in the industry (Carty, 2011). This alleged comparison conflicts with how some people (e.g., Deaf community members) understand the experience of deafness and this incident fuelled the tension that has long existed in the deaf world, between the different philosophies for responding to deafness (e.g., aural versus manual communication)\textsuperscript{ii}.

Tensions were high following this incident providing an opportunity for discussion and change (e.g., Author 1 et al., 2013). Shortly after the awards incident a natural disaster in Australia, the Queensland 2011 floods, represented a rare occasion where interpreters were employed to interpret live official television broadcasts of the disasters. This unprecedented access to live information and obvious presence of interpreters brought deafness and the need for improved and equal access to information to the attention of the Australian public.

Finally, the awareness of deafness was further raised by the Australian parliamentary and popular discussion of the proposal for a National Disability Insurance Scheme (see National Disability Insurance Agency, n.d.).

**The Study: Aims and procedures**

The aim of this study was three-fold: to explore how people living in Australia with deafness construct their experiences (e.g., draw on or resist medical constructions of deafness), to highlight the importance of and incorporate Auslan into the study and to explore ways of addressing issues of power between hearing and deaf people in the research context. As will be discussed, our aims were informed by the limitations of previous research.

Defining deafness is a difficult task that needs to go beyond audiological differences, acknowledging the meaning(s) attached to these audiological differences. For our study, people living in Australia, aged 18 years or over who identified as having any level of hearing loss or deafness, after completing a short survey, were asked to discuss their experiences of living with deafness using an online forum. Online forums refer to internet discussion sites where forum users can discuss specific topics and interact with other users.
through posting a series of messages (Im & Chee, 2013; Im & Chee, 2012). Of the 118 people who completed the survey, 22 participants ranging in age from 20 to 81, chose to participate in the online forum. The forum was active from May 2012 through until January 2013. Using snowballing (Braun & Clarke, 2013), participants were continuously recruited during this period, through various organisations and relevant community groups using online advertisements.

Including any legal adult who self-identified as living with any level of hearing loss was a conscious decision. This decision was informed by an awareness of the complexities surrounding deaf identity and fluid nature of these identities. We were also interested to explore the differences and similarities in how people living with deafness construct their experiences. For example, how do people who are born deaf but raised orally (as hearing), or people raised orally who later identify as culturally Deaf construct their deafness?

The primary research questions were posed to the participants in the form of ‘topics’ (e.g., “What is your experience of having a hearing loss or being deaf/Deaf? – Positive or Negative – Why?”, “How have your experiences shaped your choices in life: e.g. hearing aids, cochlear implant; part of hearing or Deaf world; willing to go to the doctor; view of hearing people etc.”). All study information, including the menu options, was available in written English and Auslan videos. Participants were able to use both forms of communication on the forum. Computer generated forum login details provided anonymity on the forum for the participants.

Participants selected a topic and posted their responses to the question by beginning a new thread, which participants could title themselves, or continue an existing thread. Ferndale encouraged participants to post their own responses to the questions and respond to posts from other participants. Several threads within each topic were started.
In line with the iterative nature of qualitative research and participatory approaches, the following is a discussion of how we (re)conceptualised and (re)negotiated our positionings as researchers and the design on the project.

**Negotiating research-participant positioning**

Ferndale was the lead researcher on this project with supervision from Watson and Munro on research methods and the specifics of working with the deaf community. Watson has experience with both qualitative and quantitative methods and her work focuses on communication in health. Munro has experience working with deaf clients and conducting research with Australians living with deafness. We consciously avoided adopting a disability framework as we were aware of the historical relationship between hearing researchers and deaf persons and the dynamic nature of deafness, specifically deaf identity.

Ferndale is a young, hearing, postgraduate student, whose first language is English. Her age is salient because the participants were typically older than 30. Although Ferndale’s hearing is a prominent difference between herself and the participants, her position as PhD student is something deaf Australians are less likely to have experience with and is therefore a potentially notable difference from their perspective. While English is her first language, she has been learning Auslan as a second language which was made clear to the participants on the forum. Her openness about her second language abilities may have contributed to developing rapport with the participants who also share similar experiences of using English or Auslan as a second language (Deaf Australia, 2013b; Deaf Australia, 2013a; Fischer, 2009). These points of similarity and differences have shaped the design of the project, her interaction with the participants and the production of discourses on the forum (Burr, 2003).

This project is also the product of Ferndale’s academic and personal biography as suggested by Mauthner and Doucet (2003). Similar to Mauthner’s experience (Mauthner & Doucet, 2003), Ferndale came from a positivist psychology background. Disenchanted with
this framework, she adopted a social constructionist framework to explore how ways of understanding deafness are socially constructed and to be critical of assumptions surrounding deafness (e.g. abnormality; Burr, 2003). Despite explicitly rejecting a positivist framework, she felt intellectually caught between the two frameworks during the process of conceptually and physically designing this project as these two frameworks offer opposing ontological and epistemological positions (Burr, 2003). This conflict played out when making decisions about how visible and how active she should be on the forum, and is discussed further on.

Ferndale negotiated multiple conflicting positions throughout this project. In light of historical conflicts between hearing and deaf people (Leigh, 2009; Branson & Miller, 2002), she came to believe, during the process of this project, that she should never position herself as an expert in the experience of deafness and as such actively positioned deaf people as experts in deafness. While actively positioning herself as a ‘deaf’ novice, she also occupied the position of a researcher intending to collaborate with and provide a forum to invite the voices of this traditionally marginalised group.

As an early career researcher, Ferndale was restricted by the institutional requirements of a PhD where there is an expectation that she has the lead role on all research activities and must demonstrate a level of responsibility for designing, conducting and reporting research (The University of Queensland, 2011). Managing these identity positions was further complicated as Ferndale negotiated her positions as both an expert and novice in designing and managing the forum; to our knowledge, a new method in the area of deaf research. She found it difficult prioritising her position as a ‘deaf’ novice as it conflicted at times, with her role as lead researcher and her development of theoretical knowledge of deafness and the institutional requirements of a post graduate degree (Baker-Shenk & Kyle, 1990). How she negotiated these conflicts is discussed.

**Negotiating the Design of the Project**
In designing and developing the project we had several priorities: to decide the purpose of the project, developing and maintaining a neutral position (with regards to the different responses to deafness), creating an inclusive space, and recruiting a diverse sample. These priorities were informed by the first author’s firsthand experience communicating with people who are living with deafness, the existing research in the area of deafness, and the gaps in this research.

**Reconceptualising the purpose of the project.**

Initially the purpose of our project was to do research that was informed by and conducted with people living with deafness and that would effect changes in their lives that they wanted to see happen. However, given my identity (as hearing person) and the context (living in a world that values hearing over deafness), continual, broader reading of the literature on social constructionism, ableism and deafness informed our awareness that this approach reproduced power relation that continue to marginalise the deaf population. This awareness informed Ferndale’s decision to consciously position herself as a novice in the lived experiences of deafness and position all people living with deafness as experts in experiences of deafness.

Furthermore, given the history of research on deaf people and how it has shaped relations between deaf and hearing people (Baker-Shenk & Kyle, 1990; Branson & Miller, 2002; Leigh, 2009; Pollard, 1992; Thumann & Simms, 2009), it was important to us that the participants were not treated like “guinea pigs” (Baker-Shenk & Kyle, 1990). Following this, informed by participatory research (Cornwall & Jewkes, 1995), our priority shifted into making this a collaborative project that was informed by the expertise and needs of people living in Australia with deafness.

During the process of negotiating the purpose of this project, we intended to involve deaf Australians in the project as much as possible (Baker-Shenk & Kyle, 1990). However,
this was not as successful as intended. Similar to the realities of participatory research (see Cornwall & Jewkes, 1995) and collaborative research with deaf populations (see Baker-Shenk & Kyle, 1990), practical restrictions including the financial cost of assistive communication (e.g. interpreters, captioning), institutional time and qualification restrictions, and difficulties finding deaf Australians with the interest, time and skills to be involved in the project shaped the way we followed through on intentions.

**Researcher participation and visibility.**

An awareness of the historical relationship between deaf people and hearing researchers (Pollard, 1992; Thumann & Simms, 2009) and ongoing tensions between differing philosophical approaches (e.g., medical and social) to deafness shaped our intentions to minimise Ferndale’s influence as a highly educated, white, hearing woman. We were aware that appearing to favour one philosophical approach over another may reinforce undesirable historical relationships and limit the diversity of people who chose to use the forum. As Ferndale is hearing, minimising her influence became connected to visibility. We needed to negotiate how visible she, as a hearing person and as a researcher, would be on the forum. Informed by literature on the topic of deafness and deaf research and her personal experiences with people living with deafness, Ferndale was aware of the potential mistrust towards her as a hearing researcher based on assumptions about her philosophical positioning valuing hearing over deafness. Transparency was employed to address potential mistrust and she openly discussed her education, hearing ability, participation in the deaf world and her respect for deafness, Deaf culture and Auslan (Baker-Shenk & Kyle, 1990; Fischer, 2009). To establish herself and the project as neutral, we avoided choosing our own restrictive definitions of deafness and encouraged any Australian who identified as living with any level of hearing loss or deafness to participate. Furthermore, during recruitment we contacted organisations irrespective of their philosophical positions.
Online as an inclusive space.

Inclusivity in terms of communication and participants was also a priority. Effective communication between the participants and the first author was important. Given that English or Auslan may be a second language for some participants we anticipated a variety of language preferences and skills. We were also aware that, being a second language, low English literacy is common for adults living with deafness (Fischer, 2009; Power & Leigh, 2000). As such, we needed to ensure the questions we asked and the modes of delivery were easily and equally accessible. Additionally, it was important to provide a means for the participants to respond to the questions and fully participate in the forum using their preferred language. We felt that online methods provided us with the capabilities to efficiently and effectively cater to these diverse communication needs without privileging one language over another.

We considered a number of factors both practical and socio-political, in making the decision to conduct the project online. It was a lack of funding for face-to-face interpreters and travel across Australia, time management and interpreting considerations that largely shaped our decision. We were aware that if participants chose to post videoed responses in Auslan, we would need to employ an interpreter to interpret their responses. However, this would be significantly less costly than employing an interpreter for multiple participants in traditional face-to-face interviews. Our decision was also shaped by the reality that the participants are real people with busy lives and the practicalities of organising times and places to conduct interviews or focus groups, with interpreters and captioning, when we did not have appropriate facilities. In using an online forum, participants were free to talk on the forum at a time that was convenient to them. Consistency in interpreters was also a practical concern in terms of managing variation of interpreting style and level of experience (see Wallin & Ahlström, 2006). An additional consideration is that interpreters would need to be
reflexive about their position and role in producing the discourses that would be subsequently analysed, a further cost for the interpreters’ time (Temple & Young, 2004).

These practical concerns speak to the socio-political factors that were also considered in our decision. The use of interpreters can be problematic, particularly in the context of a discourse analysis (the analytic method we employed) where the focus is on production of language with a hearing researcher. While loss of integrity occurs in any translation, it is particularly evident with sign language as it is a translation from spatial/visual to oral/written; there is no written form of Auslan. One possible solution would be for deaf researchers to do research on deaf topics rather than hearing researchers. This solution is problematic due to the sparcity of researchers who are also deaf (Woodcock et al., 2007); and as English remains the dominant language in a Western context, hearing people require research to be translated to English in order for them to understand it. Consequently, there are no easy answers, only compromises as to how best to translate sign language to English with minimal loss of integrity.

**Encouraging a diverse sample.**

We were interested in exploring the diversity (or lack thereof) in experience and constructions of deafness as such, encouraging a diverse range of participants from all around Australia to contribute to the forum was another priority. Perhaps informed by latent positivist assumptions about generalisation, we wanted to capture the varied experiences of deafness and explore the differences and similarities between contexts. Given the Australian geographic context and that deaf communities are small and widely dispersed around the country, experiences of deafness are likely to differ between geographical contexts (e.g. medical and social support, access to education). The use of online methods facilitated the recruitment of a national sample within our time and funding restrictions. Diversity encompassed factors such as age, gender, State or Territory of residence, education type and
attainment, city versus country living, employment, communication preference, level of hearing ability, use of assistive hearing technology and deaf identity. We knew that our sample would be limited to people who were comfortable using the internet and as such we anticipated our project would attract a younger sample. However the mean age of the sample was 53 years.

The establishment of these priorities informed the development of the materials for the project.

**Development of Materials**

Given the priorities outlined, the following is a discussion of how these played out in reality. After receiving ethical clearance for the study, Ferndale contacted local deaf friends, deaf contacts and hearing people who work closely with the deaf community for feedback and suggestions on the project and the drafted materials. Seven people agreed to give feedback via email and face-to-face. Maintaining our neutrality, the seven assessors came from a variety of backgrounds in relation to deafness. Some were deaf and some hearing, some had hearing and some had deaf family, they had various communication experiences and preferences, diverse ages, education and employment.

Ferndale explained the purpose of the study and asked the assessors to provide feedback on the draft materials. The feedback provided was positive and the changes suggested were minimal. However, institutional (ethical and university) requirements conflicted with some of the feedback offered. Where conflict occurred, she prioritised institutional and ethical requirements above the feedback of the assessors. For example, several of the assessors commented that while they believed the level of English was appropriate there was too much detail in the participant information. While she agreed, all of the information included was required by the ethics department and so could not be removed.
Where there was no conflict, the assessors’ feedback was fully implemented, for example questions were altered (answer options added or wording changed).

In line with participatory research (see de Koning & Martin, 1996; Martin, 1996) and Baker-Shenk and Kyle's (1990) discussion of research with deaf populations, we intended for this feedback process to distinguish us as different from previous research and give the study credibility, as a study with deaf Australians not on deaf Australians. Through consulting with a diverse sample of assessors we sought to minimise the power imbalance between the deaf participants and Ferndale as a hearing researcher. However, there is a privilege in being hearing that is inherent in living in a hearing society and the institutional requirements (ethical and institutional PhD requirements) restricted our ability to effectively fully involve deaf people in the design of the project.

Following this consultation process, three deaf, native Auslan users helped translate the materials into Auslan and were Auslan models on the website. A collaborative approach was taken to the translation process. The first author used her knowledge of Auslan (Fischer, 2009) and worked with the native Auslan users to come to a mutual understanding of the questions and an accurate translation of this meaning. She was also filmed explaining the participant information and the website menu options in Auslan which were displayed on the website. Although time consuming, this process was necessary for three reasons. First, because as visual information is particularly important and preferred for sign language users (Jambor & Elliott, 2005), the author intended for her visual presence to help build rapport with the participants and demonstrate her commitment to the language and the culture. For example, she included a short section in the participant information where she actively positioned deaf Australians as experts in deafness and herself as hearing and as a novice in experiences of deafness and keen to learn. Second, we aimed to ensure the materials were appropriate and equally accessible to a wide population of deaf Australians. Third, this
collaborative approach served as a visible way of representing the important role and input of deaf Australians in the project. We intended for this collaboration to further reinforce that this project was with deaf Australians.

During the development of the materials for this project we negotiated a number of challenges, compromised on priorities and managed conflicting identity positions. Using web-based methods was productive for us in that it enabled us to create an inclusive, visual space and encourage a diverse sample of participants. The design of our project was restricted however, by institutional requirements, time, money and the lack of researchers who are living with deafness. We continued to negotiate these challenges in the recruitment of participants and running of the forum.

**Recruitment and the Running of the Forum**

Recruitment was facilitated by various organisations who advertised the project in their newsletters and on their websites. One large organisation, which is accessed by a significant portion of Australian families with deaf children, declined to advertise the project, citing unaligned research priorities, and this may have limited the diversity in our sample of participants.

We initially decided Ferndale would monitor the forum and not be involved in forum discussions. This decision was informed at the time, by the author and her assumption that by being less involved as a hearing researcher, the participants would feel more comfortable conversing on the forum. In response to minimal interaction between participants within the threads in the first weeks for the forum, we decided that as lead researcher, Ferndale would have an active role in the forum to encourage greater repeated activity in the forum. This decision was overtly informed by social constructionist values and recognition of the role of the researcher in constructing discourse (Burr, 2003). She encouraged participation by posting follow-up questions to the original poster within 24 hours of the original post. These
follow-up posts typically thanked the participant for their post, posed a follow up question related to the content in the participant’s post and in some instances invited additional discussion from other forum users. Monitoring and participating in the forum also helped her determine saturation.

When responding, Ferndale was mindful to use the same terminology as the original poster in order to remain neutral and unbiased. For example, if the participant used the term hearing impaired, the she responded to their post using the term hearing impaired. She was careful to position herself as hearing and not as an expert, in line with her belief that people living with hearing loss and deafness are the experts with respect to their lived experiences.

Ferndale also monitored all the posts to check that they were not abusive or discriminatory to any named individual or organisation. Her responsibilities as forum moderator, a position of power, conflicted with her priority of positioning the participants as experts in experiences of deafness and herself as a novice. She acknowledged this conflict by informing the participants that they were able to contact her with any concerns about activity on the forum. She only had one incident, where by a participant contacted her asking her to black out identifying information they had accidently put in their own comment which might be harmful to an organisation’s reputation. She complied with the participants’ wishes and blacked out this content. No other issues were brought to the attention of the authors.

The Opportunities and Shortfalls of a deaf Friendly Online Forum

We found an online forum was productive in providing us with a financially and time effective method of addressing our research questions while meeting our priorities; developing and maintaining a neutral position, creating an inclusive space and recruiting a diverse sample. Face-to-face, paper based and telephone methods, in this context, would have been inappropriate or financially costly and time consuming, linguistically restrictive, or introduced analytical complications (Temple & Young, 2004). Further to this, an online
forum builds a sense of community in a way that survey’s and interviews do not. Given that ‘community’ is a key value in Deaf culture (Deaf Australia, 2013b), this sense of community could have had a positive impact on deaf participation.

The use of an online forum was also productive in that it facilitated the recruitment of a geographically, and therefore experientially diverse sample of participants from Australia. However, as half the sample reported being tertiary educated and only four participants were under the age of 40 we may not have successfully captured the age and educational diversity that exists within the population of people living with deafness in Australia. This is important as we are aware of the differing generational experiences of deafness in relation to privileged philosophies, availability of services and access, development and experiences of technology (e.g. hearing aids and cochlear implants) and opportunities for education and employment (Leigh, 2009)

An online forum also enabled us to accommodate the diverse linguistic preferences of the sample of deaf Australians. The flexibility of online forum software and video technology provided us with the capacity to include both Auslan and English throughout the site. It should be noted that although the website and original project materials were purposefully designed to be as inclusive and accessible as possible, the participants’ forum posts and the Ferndale’s forum posts were not made available in Auslan. We did not anticipate that this may have excluded participants whose primary language was Auslan from both contributing to the forum and interacting with the first author and the other participants. However it may explain why, although we provided an option for participants to post responses in Auslan (via a recorded video), the participants chose not to use this option instead opting to post comments in written English. The preference for written English may also be attributed to the age of our sample and their oralist education (Branson & Miller, 2002), limited internet and computer skills or concerns for their anonymity. Participants who choose to participate using
their native sign language in a forum context would need to forgo their anonymity with the researcher and fellow participants. The participants’ privacy would be further compromised by the need to hire an interpreter to translate their response to English. Accessibility and inclusiveness can be addressed by considering whether the population has access to the necessary technology and providing basic, step-by-step ‘how to’ guides. However, the use of signed languages in research introduces privacy concerns and can discourage deaf people from participating in research, and participate using their native sign language.

As English speakers, the use of visual languages in research was the most challenging aspect of this study that we negotiated. However, what we learned in this process can be applied to similar populations such as, culturally and linguistically diverse populations who use verbal languages, small and geographically diverse samples (physically hard to reach communities) and cultures which value experiences of community. This reflexive process has highlighted for us, the broader, complex issue of sign languages in research. Although the resources for participants to communicate via their preferred native language, which for some is Auslan, are available, analysing and publishing sign languages in academia remains problematic. As English is the dominant language in a Western context, visual-spatial languages such as Auslan are required to be translated into English. As Temple and Young (2004) discuss, this translation from sign language to written English is problematic in terms of analysis as aspects of visual languages such as space, tone and emphasis are lost.

In the context of our project, English is our first language and we lacked the knowledge, expertise and resources to appropriately translate, transcribe and analyse Auslan data (Fischer, 2009). We also did not have access to any researchers whose first language is Auslan to analyse the data in its original form. And as we did not record participant contact information, we also would not have been able to contact the participants to provide them with an opportunity to be involved in the translation process (Temple & Young, 2004). Low
literacy levels in the deaf population further complicate a collaborative translational process, as we risk highlighting deficits and further marginalising deaf people in research.

Resolving these complex issues around the use and analysis of sign languages in research are not easily resolved and require compromise and negotiation on behalf of the researcher. However, they speak to larger systemic problems. Characteristic of the invisibility of people living with deafness and their difficulty accessing information and resources, few researchers have given consideration to issues such as anonymity and how to analyse languages which have no written form (Fischer, 2009). More than this, there is currently a lack of researchers whose native language is Auslan and who have the skills and experience to conduct qualitative analyses of sign language. There is little incentive to rectify this situation as academic journals do not commonly facilitate the publication of empirical work in sign languages. It is difficult for people living with deafness to be involved in research and establish a career in research when published research work is not accessible to them in their native language. We recognise producing and publishing academic work in minority languages such as Auslan is a costly exercise, however, equal access to knowledge is a large step towards achieving equality between hearing and deaf people.

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1 We recognise the diverse terminology used to discuss living with a hearing loss or deafness and the implications of the various terms. In this context, we use the term ‘deafness’ to encompass all types of deafness and hearing loss, including people who use sign language as their first language to simplify complex issues around deaf identity.

2 Aural approaches to communication promote the use of residual hearing and hearing technology to develop lip reading skills and spoken language comparatively manual approaches encourage the use of sign language (Eleweke & Rodda, 2000).

3 We would like to clarify that 119 people completed the survey and 24 people contributed to the forum data (either online or via hard copy). However, in this paper we only discuss the survey/forum respondents who participated online.

4 Deaf culture, sometimes referred to as the deaf community, is similar to an ethnic minority. It is a network of people who share a language (e.g., Auslan), a history of common experiences, customs, values, and beliefs (Deaf Australia2013b).
References


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As I collected data on the forum I continued to explore social constructionism and what that meant for my ontological and epistemological position. I was also reading about qualitative methodologies, considering how my ontological and epistemological position would inform how I would conduct a discourse analysis of the forum data. The result of all this reading and thinking was feeling lost, like I’m feeling around in the dark trying to figure out how to do “good” research.

Through reading texts on the subject of qualitative methodologies and discourse analysis, my understanding is that there is not one correct way of doing an analysis but also that there are wrong ways. Beyond that, I found very little guidance from texts.

Conducting research within a School and culture where positivism is the norm and unquestioned only added to my confusion. It was challenging finding the formal mentorship, training and support (beyond what my supervisors could offer) to develop my knowledge and skills. I was fortunate to find support in two PhD colleagues who were able to offer guidance, some informal training and support. Seeking additional information and guidance about how to go about analysing the data from the forum, I found reading reflexive accounts of qualitative research informative. Researchers such as Natasha Mauthner, Andrea Doucet and Susan Morrow have published articles which detail their experiences of shifting from one epistemological and ontological position to another and learning new qualitative methodologies. Their accounts reassured me that that feeling lost and overwhelmed is common.
The initial stages of analysing the forum data helped me to realise that I was working with complex data. Not only is the data asynchronous, there are inconsistencies in the language used by the forum users and how much they contributed to the forum, there are unanswered questions and there wasn’t an opportunity to clarify responses with forum users. These realisations only added to my feelings of confusion.

... As I progressed further into the discourse analysis, it was difficult to undo four years of intense positivist training. There were times where I became overwhelmed by the data and trying to keeping track of my thinking which oscillated between positivism and social constructionism. However, I was able to recognise when this was happening and through persistence, I was able to realign my thinking. Having the opportunity to discuss the analysis with my co-authors/PhD supervisors and colleagues throughout the analytic process was helpful for developing both the analysis and my skills.

Although the analysis, being my first, was particularly challenging and drawn out, I developed my own skills and knowledge and produced a rigorous analysis of the online forum data.
A Discourse of ‘Abnormality’: Exploring Discussions of People Living in Australia with a Deafness or Hearing Loss

Danielle Ferndale, Louise Munro, & Bernadette Watson

Abstract
Adopting a social constructionist framework, we conducted a synthetic discourse analysis to explore how people living in Australia with deafness construct their experience of deafness in a society that assumes and values hearing. We developed an online forum to facilitate access and communication to the widely dispersed and linguistically diverse population of people living with deafness. In the current analysis, we discuss the productive and restrictive effects of the emergent discourse of deafness as abnormal and the rhetorical strategies mobilised in people’s accounts: fitting in, acceptance: permission to be different and needing to prove normality. The use of these strategies was productive such that the forum respondents were enabled to reposition deafness as a positive, socially-valued identity position. However, the use of these strategies reproduced the need to manage deafness as an individual concern, disallowing any exploration of how society and infrastructure could be altered to create spaces for people living with deafness or how deafness could be reconstructed as socially valued. We conclude by discussing the implications of this construction.

Keywords: Deafness and Hearing Loss, Discourse Analysis, Discourse of Abnormal

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The current study is situated within ongoing theoretical debates (e.g., Corker & French, 1999; Thomas & Corker, 2002) about constructions of disability and impairment and how they relate to both medical and social models of disability. There is limited empirical work that has explored the discourses that operate within society and how people living with deafness draw on, resist and negotiate these discourses. Consequently, the impact of such discourses continues to be largely invisible and, therefore, risks maintaining a disadvantageous status quo. In this paper, we discursively explore how people living in Australia with deafness and hearing loss discuss and construct their experience of deafness.

In light of Australia’s size and population distribution and that deaf communities are small and widely dispersed throughout Australia (Willoughby, 2014), we used an online forum to overcome the practical restraints of distance and communication with this population. This forum was created as a space for respondents to share and discuss their experiences of living with deafness in Australia, providing insight into how constructions of deafness are shared and are different.

Within a social constructionist framework (Burr, 2003), we adopted a synthetic approach to discourse analysis (Wetherell, 1998) to analyse the online forum responses of people living with deafness. Whilst we recognise the material, physical experiences of deafness, our interest is in the constructive (and restrictive) power of language and its paradoxical relationship with the speaking subject (Billig, 1991; Burr, 2003; Wetherell & Edley, 1999). Taking the perspective that people are both the products of and the producers of discourse (Priestley, 1999; Wetherell & Edley, 1999), we are interested in how the forum users drew on discourses to construct different versions of reality. In this way, we were interested in how the forum users positioned themselves within, and are positioned by, available discourses (Davies & Harré, 1990); and on a rhetorical level, the strategies people
used to negotiate these discourse in relation to their own lived experience (Burr, 2003; Davies & Harré, 1990; Lafrance, 2007).

**How Deafness Has Been Studied in the Past**

Bodily impairments, such as audiological impairments, have historically been targets for intervention rather than sources of socio-political change (Grue, 2011). Current psychological approaches to deafness frequently target early intervention best practices with a focus on closing the ‘gap’ between people living with deafness and hearing standards (e.g., intelligence, personality; Paatsch & Toe, 2014; Pollard, 1992). Researchers also frequently use fixed characteristics (e.g., age at onset, level of hearing loss, communication preference and hearing technology use) in addition to the medical and social models of deafness to define deafness and explain how people identify with deafness (their own and others). Inconsistencies in the use and definition of terms (of deafness), and therefore population samples, mar the effectiveness of this approach. The dominant focus on interventions also reinforces binary constructions of deafness. Galvin (2003, p. 7) explains binary oppositions as “the practice of defining what is “normal” against that which is “other”. In the context of deafness, hearing is defined as normal when it is measured against deafness as abnormal. Myers and Fernandes (2010) suggest that from a Derridean perspective, binary oppositions cannot be neutral as one term of any opposition is always privileged. As Corker and Shakespeare (2002) suggest, Derrida also claims that through trying to break out of a binary (e.g., through positive or proud disability identity), binaries are reproduced. Though largely operating on an individual level, targeting changes in the individual, interventions also reinforce experiences and bodies outside the ‘norm’ as inherently bad.

In line with social models of disability (Shakespeare, 2006), socio-political change refers to adapting social, structural and environmental factors to meet the diverse needs of
the community, rather than changing the individual. In line with Corker and French's (1999) views on disability theory, through understanding and recognising bodily impairments as diverse, it can be seen how society can be (socially and structurally) altered to support the diverse needs of the people who make up the community. Studies of communities such as Martha’s Vineyard demonstrate how experiences of deafness are a socially constructed phenomenon (Scheer & Groce, 1988). Another instance of this criticality is the identification of discourses, such as the disability as abnormal discourse, whereby disability is reproduced as marginalised (Grue, 2011). These examples are reflected in research and theory that considers the ways in which society contributes to constructions of disability (e.g., Brueggemann, 1999; Corker, 1999; Hindhede, 2012) have considered.

**Constructions of Disability (deafness) as Abnormal**

Shaped by historical ideals and practices (i.e. Eugenics; Davis 2006), people who fall outside socially defined concepts of normal are categorised as deviant, socially constructed as disabled or abnormal (Davis, 2006). Within the disability as abnormal discourse, undesirable abnormalities, such as audiological impairments, need to be reduced or repaired through practices which allow them to be or appear to be ‘normal’ (Davis, 2006). In the context of deafness, the oralist movement, informed by the ideal that all deaf people should be able to learn to communicate orally and assimilate into the hearing world (Baynton, 2006), best represents contemporary ‘normalising’ practices. A review of the literature on deafness (e.g., Kumar et al., 2008; Yueh, Shapiro, McLean, & Shekelle, 2003) suggests that the emphasis on corrective (intervention) approaches to deafness continues to inform research priorities.

Some deaf individuals have collectively constructed a Deaf culture which is embodied through a common language, and shared values, norms and experiences. Repositioning deafness as a cultural identity, allows for the meaning of deafness to be
understood in relation to ethnic and/or linguistic minority cultures rather than within a hearing/deaf binary. The adoption of a Deaf identity allows this group to take advantage of the moral power and greater potential for grievances to be recognised as legitimate (Gleason, 1991). For example, through reconstructing their identity as a marginalised minority groups, they are able to challenge the power of dominant groups and constructions of ‘normal’ achieving socio-political change. Similar responses where shared norms, values, lexicon, and cultural commonalities contribute to “identity” over and above the more visible binaries can be seen in various marginalised ethnic minority cultures and in the Lesbian, Gay, Bisexual, Transgender and Queer communities who have (and continue to) faced persecution informed by religious and medical constructions of sin and mental health. In this vein, people who identify as Deaf are a heterogeneous group, not defined by fixed characteristics such as level of hearing loss or age at onset. Further to this, not all people living with a hearing loss or deafness identify with Deaf culture (Rogers, Evans, Campbell, Young, & Lovell, 2014).

We assert, as others have done (e.g., Skelton & Valentine, 2003), that deafness is a unique embodied and social experience, bridging discussions of disability, culture and the marginalisation of difference. While fixed characteristics are frequently used in research, we are assert that identity is fluid (Hindhede, 2012; e.g., Skelton & Valentine, 2003). The invisibility of deafness both enables and, at times, requires people to continually negotiate their identities as hearing, disabled, and deaf within daily contexts and across their lifespan (Hindhede, 2012; Skelton & Valentine, 2003). Through the invisible nature of deafness, the availability of and need to manage multiple identity positions, deafness is distinguished as a complex experience. Contradicting dominant binary constructions of deafness (e.g., medical/social; hearing/deaf; Deaf/deaf), this complexity, and the social context within which it occurs, has not always been sufficiently recognised in past research. As such,
before introducing the current study we briefly summarise the current socio-political context within which our study took place.

**Socio-Political Context of Deafness**

In Australia, deafness is far less visible in the hearing world than it is in similar Western countries. Australian television does not facilitate access to information and current media (e.g., televised news programmes) via sign language interpreters or consistent captioning. Recent natural disasters in Australia, the Queensland 2011 floods, the 2013 New South Wales Bushfires and the Queensland 2015 cyclone Marcia, represent a new trend where interpreters have been included in official television broadcasts of the disasters, providing unprecedented access to live information.

The implementation of the Government funded National Auslan Interpreter Booking and Payment Service (NABS) in the last decade has improved access for deaf Australians to private health care. Using the NABS service, Australians who use Auslan are able to receive free interpreting services for private health care appointments. The upcoming implementation of the National Disability Insurance Scheme (aimed at improving access to funding for health and support services; National Disability Insurance Agency, n.d.), and how the needs of people living with deafness would be serviced within this scheme have been the focus of recent discussions in the community.

A lack of critical discursive work on disability, and specifically on deafness (Grue, 2011), reinforces the need to explore how people in Australia living with deafness construct experiences of deafness. There is a spectrum of models and discussions that surround the population of people living with deafness which serve to reduce and simplify experiences of deafness. The current study does not seek to replicate the more common “data reduction” approaches from large samples but rather to broaden and deepen our understandings of deafness from a smaller sample (Morrow, 2005). Our study recognises the social-political
context within which deafness occurs, namely a society that values and assumes “hearingness” (see Morrow, 2005). In presenting the findings of our study we aim to maintain and represent the complexity of the experiences of 24 people living with deafness within the Australia socio-political context. In this paper we explore the online forum responses of people living with deafness focusing on how deafness is constructed, and how it maps on to, if at all, dominant theoretical discussions of the medical and social models of disability and deafness.

The Current Study

Participants

Following institutional ethics clearance, people currently residing in Australia aged 18 or over who identified as having any level of hearing loss or deafness completed a survey on their hearing loss and could also participate in an online forum. Of the 119 people who completed the survey, 24 people ranging in age from 20 to 81 chose to participate in the online forum (two chose to respond to the forum topic questions via mail/email, they did not interact on the forum). The people who completed the survey (and the people who subsequently participated on the forum) were recruited from around Australia through word of mouth and online advertisements in various newsletters and websites for national and state-based organisations and community groups related to the field of hearing loss and communication. When asked to choose between Deaf, deaf, hearing impaired, hard of hearing or hearing, the majority of the sample identified as hearing impaired and as having experienced deafness since early childhood. The majority of the sample also used spoken English as one of their preferred modes of communication. Table 1 illustrates the diversity in the forum respondents’ background and experiences. We do not know why the 95 people who also completed the survey did not choose to participate on the forum. However,
conventional wisdom would suggest that time-factors are a perennial issue for survey participants.

The Online Forum

A combination of pragmatic and sampling factors informed our decision to take the study online. An online forum facilitated a more diverse (language preference and location) sample of people while minimising time (e.g., travel) and financial (e.g., travel, interpreter, captioning) costs. The online forum was developed in consultation with several people connected to the population of people living with deafness and was specifically designed to be as inclusive as possible (see Ferndale, Watson, & Munro, 2015). For example, the content of the website was available in both written English and videos of Australian Sign Language (Auslan) and respondents had the option upload a video of their response in Auslan (no participant opted to do this; for an in-depth discussion of the process of designing and implementing this study and how it was shaped by practical, logistical and financial factors see Ferndale, et al., 2015).

Procedure

People interested in participating in the study were instructed to use the link to the website provided on the study advertisements or contact the first author. The home page of this website provided and directed the participants to read the participant information (provided in both English and Auslan). A link to the demographics survey was supplied at the bottom of the participant information, clicking on the link was considered as participant consent. In accordance with the Ethics proposal, no personal information was recorded. Following the completion the demographics survey, the participants were provided with a unique computer generated username and password to access the online forum. The participants who chose to participate in the forum accessed the forum from the menu options on the home page of the website. The forum users were able to select a topic on the forum (each topic was an open-
ended, neutral research question posted by the first author) and post their responses to the question by beginning a new thread which they could title themselves or continue an existing thread. Several threads within each topic were started. Participants were encouraged to post of the forum as little or as much as they liked and to post responses to other participant’s posts. As the moderator, the first author participated in the forum by posting additional open-ended follow up questions to the forum users’ responses and inviting additional discussion from other forum users. The forum was active from May 2012 to January 2013, during which time recruitment was ongoing. The decision to stop recruiting and close the forum came after a substantial period of no activity on the forum. The content posted onto the forum is the focus on this paper.

**Analytic Process**

Guided by Wetherell’s (1998) synthetic discourse analysis and Morrow’s (2005) discussion of quality and credible qualitative research, the first author began by copying the content (including the mail/email responses) from each thread into separate Word documents and removing irrelevant information (e.g. IP addresses). The first author read through the data initially in order to gain familiarity. Owing to the use of non-standard English⁵ (typical where English is a second language) in several responses on the forum, the interpretation of some posts was sometimes ambiguous. Without the opportunity to clarify with the original poster, typographical errors in the data were not corrected and the first author used her best judgement and experience with sign language users to interpret the content of the posts. In the second reading of the data the first author, guided by the research question, “how do the forum users talk about deafness and their experience of deafness”, identified patterns of responses, recurring phrases and metaphors used to describe experiences of deafness. The first author distinguished patterns of responses by noting the rhetorical strategies the forum users used (such as ‘accepting their deafness’) and how these had certain discursive
functions and implications for their accounts (Lafrance, 2007). Using an Excel file, these patterns and phrases were coded in a third reading of the data. The first author clustered these codes into the following themes, ‘coping’, ‘acceptance’, ‘difference and belonging’, ‘ab/normal’, ‘milestones’, ‘medical and social’, ‘support’ and ‘ability not disability’. The first author refined these codes using an iterative process of checking the similarity and differences within and across patterns of responses (Morrow, 2005). In subsequent readings of the data the first author paid particular attention to identifying power relations in the forum users’ responses and whose interests were best served by prevailing definitions of deafness and disability (Edley, 2001).

This process led the first author to identify a discourse of deafness as abnormal. The presence of this discourse was not assumed prior to this point. The data was re-read by the first author to identify instances where the deafness as abnormal discourse was drawn on, negotiated and resisted by forum users and also to explore the discursive strategies they employed; drawing on Davies and Harré (1990) positioning theory to examine the ways in which the forum users positioned themselves and people who are hearing. To minimise the effect of the first author's views on the analysis she engaged in reflexive practices throughout the research process, including posting neutral questions and encouraging people to post different experiences (Morrow, 2005). To maintain rigour, each author read and independently coded the data where instances of abnormal discourse had been identified (Morrow, 2005).

**Analysis and Discussion**

**Overview of Themes**

Through exploring the forum user’s accounts of living in Australia with deafness, we identified a discourse that we labelled deafness as abnormal whereby deafness is constructed as abnormal and hearing as normal. Within this discourse deafness is produced
as a negatively valued identity position. We discuss the three rhetorical strategies we identified, *fitting in, acceptance as permission to be difference* and *the need to prove normality*, which the forum users drew on to manage the negatively valued identity position they expressed as people living with deafness. To begin, we first discuss the discourse of *deafness as abnormal* and how it was mobilised in the forum user’s talk, this is followed by an exploration of the three rhetorical strategies. Excerpts which most clearly illustrated the concepts we identified were selected from the range of possible excerpts available in the data.

**Constructing Normal When You Are Different**

In analysing the forum responses we found that the *deafness as abnormal* discourse was mobilised in the respondents’ forum posts, regardless of their deaf identity. In their accounts, several forum users’ responses oriented to *deafness as abnormal* by either problematising constructions of [hearing as] normal, as shown below, or constructions of deaf as different (Excerpt 3).

*Excerpt 1.* Along with regular Speech Therapy classes and my mother’s insistence that I go to a “Normal?” State School to make sure I can communicate with “Normal?” People around me, I gradually began to take in what I was being Taught in my Primary and Secondary School Days! *Justin (HI)*

*Excerpt 2.* Social situations were extremely stressful, so to look as if I was ‘normal’ I created my own party trick. I’d ask question after question after question, understanding about 10 percent of the conversation before moving away. I was terrified I’d bump into that person again. *Catherine (HI)*

*Catherine* I can relate to your party trick. I use it myself. By dominating a conversation I know that the topic is and can communicate or appear to be communicating. It’s important for me to be seen as intelligent. *Tom (HI)*
Justin and Catherine use contradictory talk in their accounts. Although they orient to normal as problematic, through the use of quotation marks, ‘to look as if I was ‘normal’’, they also describe engaging in normative practices, such as creating their ‘own party trick’, to pass as hearing and avoid being detected as different. Through practices of passing, Justin, Catherine and Tom are positioned as disempowered in their everyday contexts, ‘I was terrified I’d bump into that person again’. These excerpts are examples of a broader pattern we identified in the data, where the fear of being, or identified as different reproduced notions of deafness as abnormal and ‘abnormal’ individuals as needing to adapt their own behaviour to pass as normal. As shown below, there were instances on the forum where forum users’ constructed difference as subjective and shaped by context. However, illustrating that efforts to break out of binary have the effect of reproducing the binary, challenging ‘deaf as different’ reproduced normal as ideal.

Excerpt 3. Parents were deaf and I didn’t feel ‘different’ whilst growing up, was immersed within the deaf community/culture. Janet (deaf)

Deafness as abnormal is challenged in Janet’s response through the use of quotation marks and constructing difference as subjective, ‘I didn’t feel ‘different’’. Difference as subjective is legitimised in Janet’s account through constructing context, such as parental hearing ability and cultural immersion, as opposed to the physical hearing deficit, as shaping experiences of difference. Through problematising ‘different’ and constructing difference as subjective, Janet is empowered to reposition herself as not different within her social context. However, this also has the effect of reproducing normal as ideal and as an empowered identity position. John’s account, as shown below, is unique in that hearing as normal is not challenged or problematised nor is deafness as abnormal.

Excerpt 4. Now that I accept myself for who I am, I no longer have to strive to be normal […] I always considered myself part of the hearing world because I didn’t
want to be different. But accepting that I am hard of hearing and embracing the Deaf world has opened up many new and wonderful possibilities. John (HoH)

In his response John positions normality [hearing] as something that he must achieve and something that is difficult to attain, ‘no longer have to strive to be normal’. While normal [hearing] is positioned as ideal in his account, ‘I didn’t want to be different’, John positions himself as empowered to accept his difference [hard of hearing]. John constructs this process of acceptance as liberating, as having ‘opened up many new and wonderful possibilities’ of being a hard of hearing person.

Respondents oriented to the deafness as abnormal discourse in their accounts through problematising constructions of [hearing as] normal or deaf as different, and embracing deaf as different. Constructions of deafness as abnormal were further reinforced by the forum users’ use of overlexicalisation throughout the forum.

*Overlexicalisation: Signalling a deviation from social convention.*

Overlexicalisation refers to the repetitious use of quasi-synonymous terms which create a sense of ‘over-completeness’ (Fowler, Hodge, Kress, & Trew, 1979; Fowler, 1991; Teo, 2000; van Dijk, 1991). According to Teo (2000) and Fowler et al. (1979), the use of overlexicalisation is characteristic of disempowered identity positions such that, repeated and pervasive instances of talk which identify the way in which a person ‘differs’ from the norm serves to separates them from our community. Overlexicalisation was evident in forum users’ descriptions of people, particularly children, such that references to deaf people were consistently prefaced with their hearing status (e.g., ‘deaf’, ‘Deaf signing pupil’, ‘Deaf student’, ‘people who are Deaf and hard of hearing’, ‘Deaf consumers’), whereas the ‘hearingness’ of hearing people was not elaborated on.
The use of overlexicisation, as shown in Excerpts 5 and 6, also reinforces hearing as normal such that where the forum users did not signify the hearing status of hearing professionals, they did for professionals who are living with deafness.

*Excerpt 5.* Im a deaf [health profession] and have met clients who are relieved to found someone who can sign and who understands their culture and unique needs.  
*Laura (Deaf)*

*Excerpt 6.* I has been my experience personally and work-based that professionals have a very limited knowledge of Deafness and hearing-impairment. […] I believe more Deaf/hearing-impaired people need to be given the opportunity to study in professional areas and professionals need to conduct some of their training in Deaf/hearing-impaired services.  
*Sally (HI)*

The use of overlexicalisation in these excerpts constructs professionals who are deaf as deviating from social convention and reinforces hearing professionals as ‘normal’. Laura, identifying as a ‘deaf [health profession]’, is positioned as deviating from the norm however, she reconstructs this position as helpful, ‘clients are relieved’, legitimising her claim through drawing on shared experiences and culture. Deafness is further repositioned as normal in Laura’s comment through the lack of indication of the clients’ hearing status. Although the expertise of [hearing] professionals is challenged in Sally’s response, deaf as a devalued identity position is reinforced through ‘Deaf/hearing-impaired people’ being positioned as passive and disempowered, needing ‘to be given the opportunity to study in professional areas’.

Denoting people as either deaf or hearing is productive in that it provides immediate information about a person’s likely experiences and needs. However, it reinforces binary constructions of deafness and hearingness, oversimplifying the diversity of lived experiences of deafness. The motivation to identify people as hearing or deaf may have been
facilitated by the first author being a hearing person and the research context. However, consistent patterns in how the respondents denoted people constructed deafness as deviating from social expectation, reproducing hearingness as a cultural norm (Fowler et al., 1979; Teo, 2000).

**Identity Repair Work.**

Through challenged constructions of normal and different (see Excerpts 1-3), deafness is produced as a negatively valued identity position. We now we turn to a fine-grained analysis of the rhetorical strategies the forum users drew on to manage this negatively valued identity position. We identified three main rhetorical strategies, *fitting in, acceptance as permission to be different and the need to prove normality.* We discuss the productive and restrictive effects of these rhetorical strategies, illustrating how efforts to challenge their negatively valued identity reproduce the binary of normal [hearing] and abnormal [deaf] (Corker & Shakespeare, 2002; Hindhede, 2012).

**Fitting in.**

Several forum users described their efforts to *fit in,* into either the hearing or deaf world, further emphasising *deafness as abnormal* and the need to adjust. Efforts to *fit in* were often equated with the mastery and modes of communication (e.g., picking up banter and nuances of speech, Auslan, lipreading etc.). In the excerpt below, Samantha recalls the difficulties she had *fitting in* in both the hearing school she attended and the deaf school.

*Excerpt 7.* I went to a deaf school (cued speech) in mornings, and a hearing school in afternoons – a terrible set up for me socially as I was finding it hard to fit in, Deaf – I had trouble fitting in because I did not sign as my parents wanting the best for me, did cued speech successfully and viewed Auslan as dumbed down version of communication the deaf did not relate to me as I spoke more than I signed and I was also 2 years ahead of the deaf school academically, I was a cued speech student and
still am. I didn’t fit in a hearing school very well either, partly because I was part time student, and other reason was I was still learning to talk […]. Deaf people mostly not all, are straightforward, blunt or “literal” in the way they communicate. They don’t have the nuances of a speech like hearing people do. How do I know? mum told me, my hearing husband told me and I learnt that from them and I was able to fit in a hearing world better […]. I also have this unhappy dislike, hearing people banter then laugh, I would miss the gist of the joke and I ask ever so politely and warmly, ” sorry to bother you, what was that?” the reply which I really hate is ” oh don’t worry its not important”. Do NOT say that! I am left out! Thank you! ah well. My family is guilty of that at times. I had the opportunity to turn tables around, I had deaf friends over for dinner, my parents were taking part, we had a joke and mum asked what was that. I thought about it but I am too soft – I said “yeah you know I did think to say ” dont worry its not important” but I guess you are trying to fit in”, so I explained the joke. My mum had the impact and ever since she would be more honest. Samantha (HI)

Samantha orients to the deafness as abnormal discourse, drawing a comparison between deaf and hearing, describing ‘Auslan as a dumbed down version of communication’, her deaf school as academically behind (her hearing school) and deaf people as lacking the nuances of hearing people’s speech. Through describing her efforts to fit in to the hearing world, learning ‘the nuances of speech’, Samantha is positioned as rejecting her devalued identity position as a hearing impaired person. Despite her efforts to ‘fit in a hearing world better’, Samantha is positioned in her response as on the periphery of both worlds through describing contexts, such as when ‘hearing people banter’ where Samantha is left out. Although Samantha positions herself as empowered, requesting people to reiterate what was said and taking the opportunity to ‘turn tables around’, she reinforces
hearing people as empowered when they (continue to) deny her access to the conversation and this is something that she has learnt to tolerate, ‘ah well’. Penny, in Excerpt 8, also describes her efforts to “fit into the hearing world” and positions herself on the periphery of both the deaf and hearing world.

Excerpt 8. I am a profoundly deaf person. I have been forced to try to fit into the hearing world, but I am not happy. My mother did not want to learn Sign language and did not want me to. Hearing aids did not work for me and so I was forced to become a lipreader. I had extensive speech therapy. Almost the only use for my lipreading is for people to give me instructions and orders at my employment. I don’t fit into conversations. When I try to fit in with other Deaf, I cannot read Auslan, and feel left out there as well. My employer has refused to change their selection criteria for their full time vacancies to enable me to apply for those jobs. I am in a position where I am forced to work at times and hours (Saturday and nights) that no body else wants, and have been in it for 25 years. I don’t feel appreciated enough, even though they would find it hard to replace me if I retired. I feel the hearing world should make changes, both in attitude and work. Penny (deaf)

Through the use of repetition in her response (e.g., ‘forced’), Penny is positioned as disempowered, and the choice to fit into the hearing world is constructed as not her own choice, ‘forced to become a lipreader’ because her mother ‘did not want to learn Sign language and did not want’ her to either. Penny constructs her efforts to fit in (e.g., hearing aids, ‘extensive speech therapy’) as unsuccessful, ‘almost the only use for my lipreading is for people to give instructions and orders’. Through describing her unsuccessful efforts to fit into spoken and Auslan conversations Penny is able to justify why she feels ‘the hearing world should make changes’ for deaf people to fit in. However, deafness as abnormal is reinforced through this claim and hearing people are put in a position of power.
Speakers utilise the rhetorical strategy of *fitting in* to describe their efforts to manage their difference [deafness], ‘I was able to fit in a hearing world better’. By being ‘seen’ to be trying to be hearing (e.g., ‘I learnt that [nuances] from them and I was able to fit in a hearing world better’) the forum users’ avoid being ‘devalued’ because of their deafness; however, it also has the effect of silencing their needs as a person living with deafness (e.g., ‘[…] hearing people banter then laugh, I would miss the gist of the joke […] the reply which I really hate is ”oh don’t worry its not important”. Do NOT say that! I am left out!’). Efforts to *fit in* reproduce deafness as abnormal and position deaf people as responsible for fitting into the hearing world. While Samantha constructs *fitting in* as valuable, providing her with access to social support, cultural knowledge and information and equal opportunity, Penny constructs unsuccessful efforts to *fit in* as problematic, limiting her access to knowledge and opportunities (e.g., ‘I don’t fit into conversations.’). Both Samantha and Penny position themselves as agentic in *fitting in* but as disempowered by their efforts not being accommodated or supported by their [hearing] family, friends and employers. Through describing her lack of success fitting in, Penny positions hearing people as restricting her success and the hearing world as responsible for making changes, ‘in attitude and work’. In the context of this forum, the forum respondents’ use of *fitting in* as a rhetorical strategy serves to reproduce deafness and ‘managing’ deafness as an individual responsibility. This restricts opportunities for social-political change whereby this responsibility can be shared between the members of society and the infrastructure of that society.

**Acceptance as permission to be different.**
The rhetorical strategy of *acceptance* was utilised by the forum users to give themselves permission to be different, to normalise difference. This permission to be different, as seen in the excerpts below, is emphasised as both important and a conscious choice.

**Excerpt 9.** It is important for families with Deaf children to show love, acceptance and support towards their Deaf child/children. *Simon (Deaf)*
Excerpt 10. I think in a nutshell a parent needs to know that deafness is not necessarily a barrier to a good quality of life, but it does require extra support. Possibly the most important thing a parent can do is work with the child and nurture that child’s strengths without projecting their own ideals onto the child. There has to be an acceptance that the child may never hear or speak as they do. This is especially true of children who learn sign language as their primary means of communication. 

John (HoH)

In both accounts, acceptance is constructed as necessary and [hearing] family members, particularly [hearing] parents, positioned as responsible for accepting that their child is deaf, ‘possibly the most important thing a parent can do’. In their talk acceptance is tied to accessing support, ‘deafness is not necessarily a barrier to good quality of life, but it does require extra support’. In the forum responses [hearing] parents and the forum users themselves were positioned as being in a position to accept deafness. In their responses, Simon and John (Excerpt 10) both position hearing parents as the gatekeepers for giving permission to children living with deafness to be different. In Excerpt 4 and 11, John and Lisa position themselves as accepting of their own deafness, as opposed to deafness in general. In Excerpt 4, John’s use of acceptance allows him to both defend his decision to ‘no longer strive to be normal’ and justify his acceptance as enabling him to embrace the Deaf world which ‘has opened up many new and wonderful opportunities’. Lisa similarly constructs acceptance as a ‘freeing experience’, as shown below.

Excerpt 11. I have become much more tolerant since finding I had hereditary hearing loss. I am adopted and had no idea. Before that I saw hearing loss as a great embarrassment, but now I just see it as something some people have, like others have severe arthritis. Lisa (deaf).
Initially seeing ‘hearing loss as a great embarrassment’, Lisa reinforces constructions of _deafness as abnormal_. Lisa describes the cause of her deafness as hereditary, simultaneously constructing hearing loss as something beyond her control and normalising experiences of deafness. Within her account, Lisa is positioned as resisting constructions of _deafness as abnormal_ (e.g., ‘now I just see it [deafness] as something some people have’). It is noteworthy that Lisa compares her ‘difference’ with another physical impairment, ‘...like others have severe arthritis’ as opposed to other differences that are not constructed as impairments or disabling, for example, hair or eye colour. Through this comparison whereby difference is reconstructed as normal and normal is positioned as ideal, Lisa is able to maintain a valued identity position as someone who ‘has’ deafness but is not necessarily defined by their deafness (e.g., it just something people have).

While John (Excerpt 4) and Lisa construct acceptance as a ‘freeing experience’, the use of _acceptance_ in their accounts reinforces _deafness as abnormal_, as something that needs to be acknowledged or addressed. In the context of the forum, ‘acceptance’ was mobilised in relation to accepting deafness as different and limiting (e.g., Excerpt 14). Acceptance of deafness in a broader, sociocultural sense was not discussed.

_The need to prove normality._

The respondents mobilised _the need to prove normality_ as a strategy to challenge the negatively valued identity position they hold as a person living with deafness. The respondents describe engaging in practices which emphasise their ability to overcome the limitations of deafness and participate in practices which demonstrate [hearing] normality. As shown below, Tom and Rita describe their ability to engage in practices which serve to demonstrate that deafness did not get in the way of their life.

*Excerpt 12.* In [international country] I went to hire a car and I struggled to hear what I was being asked even in English. So one helpful lady waiting for her car
repeated what I was being asked. Then she said to me are you sure you should be driving? I replied most DEFINITELY

Later I was speaking to another Australian who asked my why do you want to try to drive in [international country] on the other side of the road with all the tensions frustration and danger associated with driving overseas. My answer was to explain that I need to prove I can overcome these challenges because of my hearing impairment. **Tom (HI)**

Tom challenges constructions of deafness as abnormal by drawing on the rhetorical strategy of *the need to prove normality*. Tom constructs being able to drive overseas as something [hearing] people are able to do and he therefore must prove that he is able to do the same. Although it is unclear who Tom must demonstrate his normality to, in his account Tom is positioned as actively responsible for proving his abilities. Rita similarly uses *the need to prove normality* to justify her educational successes, reinforcing constructions of deafness as abnormal, as shown below.

*Excerpt 13*. I come from a hearing family, where I am the only Deaf person, and I have defied all odds the world have thrown at me. I am the first person in my family to graduate with a Bachelors degree, and will be starting my postgraduate studies next year. My family could not have been more prouder of me than they are already! I do not let my deafness to get in the way of my dreams and I have had to show the world what I am made of and what I am capable of. **Rita (Bicultural)**

As the only deaf person in her family, Rita positions herself as empowered and equally capable succeeding where her deafness should have got in the way, ‘I have defied all the odds’. Through drawing on the deafness as abnormal discourse, being ‘the only Deaf person’ in her hearing family, Rita is able to construct her success in the hearing world (e.g., the completion of a Bachelor’s degree and starting postgraduate) as extraordinary
achievements and demonstrate her ‘normality’. Interestingly, both Tom and Rita describe practices that are not specifically related to hearing ability (e.g., international driving, university education). The respondents’ use of these practices is productive in that people living with deafness are normalised (humanised) and the focus is on their ‘normal’ abilities. While deafness as abnormal and the need to prove normality are not challenged in their responses, constructions of normal are modified to include people living with deafness.

Tom and Rita mobilise the need to prove normality to challenge constructions of deafness as limiting, they do this by emphasising their ‘normal’ abilities. In Excerpt 14 John discusses his need to prove normality in the past and how this strategy was both productive and limiting.

Excerpt 14. You mention that advocating for yourself was draining and took up a lot of your time - what effect did this have on how you think of youself and your experience of having a hearing loss? Ferndale

That's a very interesting question admin [Ferndale]. I think once I had to start advocating for myself, I experienced a major shift in my self identity. I had grown up all my life striving to be ‘normal’ and showing that I can do things just as well as, if not better than a hearing person. I am guessing that is a fairly normal response for anyone who has a disablity and has struggled with feelings of inadequacy. But when I started advocating for myself I had suddenly taken on a new identity that accepted my deafness. This was both helpful in that it allowed me to finally ask for help, and unhelpful - accepting my deafness meant "giving in" to it. John HI

As John highlights, proving normality can be a trade-off between being seen to be normal and being able to ‘ask for help’. Challenging abnormality by showing that you can ‘do things just as well as, if not better than a hearing person’ is constructed in John’s response as a useful and common strategy for people who have a disability, ‘fairly normal
response for anyone who has a disability and has struggled with feelings of inadequacy’. However, *the need to prove normality* is also constructed as denying the limitations of deafness, ‘accepting my deafness meant "giving in" to it’ and preventing access to support, ‘allowed me to finally ask for help’.

Although the respondents position themselves as actively responsible for proving their ‘normality’, it is important to note that across the forum responses it was unclear as to whom the respondents are demonstrating and proving their normality to, ‘I do not let my deafness to get in the way of my dreams and I have had to show the world what I am made of and what I am capable of”. We argue that it is through constructions of *deafness as abnormal* that deafness is seen as limiting and people who are living with deafness are positioned as needing to demonstrate and prove their normality.

**Conclusion**

Across responses, the forum users oriented to the *deafness as abnormal* discourse where people living with deafness occupy a negatively valued identity position while ‘normal’ hearing people occupy a position of power. In the context of the forum, constructions of *deafness as abnormal* were reinforced through respondents either challenging constructions of ‘normal’ or deafness as ‘different’. Additionally, the use of overlexicalisation on the forum reproduced binary constructions of deafness as deviating from social expectation and hearingness as a cultural norm. Illustrative of the ubiquitous nature of this discourse, we could not identify a counter narrative in the forum responses to the deafness as abnormal discourse. For example, there were no instances of Deaf Gain, a reframing of deafness ‘as a form of sensory and cognitive diversity that has the potential to contribute to the greater good of humanity’ (Bauman & Murray, 2009, p. 3).
Occupying a negatively valued identity position within the *deafness as abnormal* discourse, three rhetorical strategies were utilised in the responses on the forum; *fitting in, acceptance as permission to be different*, and *the need to prove normality*. Several respondents described their efforts to *fit in* to either the hearing or deaf world. Where these efforts were often unsuccessful, respondents repositioned the responsibility for their ‘failure’ to fit in onto hearing people while *acceptance* was mobilised as a strategy for respondents to give themselves permission to be different. Reproducing *deafness as abnormal*, several respondents emphasised acceptance as important and as a conscious choice. Respondents utilised *the need to prove normality* strategy to emphasise their ability to overcome the limitation of deafness and demonstrate their normality.

In line with a Derridean perspective (Corker & Shakespeare, 2002), the forum respondents’ attempts to resist the *deafness as abnormal* discourse (e.g., challenging deaf as ‘different’ and proving normality), rather than alter the discourse, had the effect of reproducing deafness as abnormal. The rhetorical strategies mobilised within the forum users’ responses work at an individual level (e.g., deaf people must fit in, deaf children must be accepted by their hearing parents) rather than challenge deafness as abnormal at a societal level. Despite all the striving to be normal, efforts to fit in and prove normality, educational achievements and successful ‘party tricks’ and international driving, the forum users still needed to engage in identity work to either defend their identity as not abnormal or accept their abnormality.

In opposition to the notion that fixed characteristics (e.g., age at onset, level of deafness) inform how a person constructs experiences of deafness (e.g., medical or social), our findings suggest that people living with deafness negotiate constructions of deafness as abnormal regardless of their specific demographic characteristics. Also that constructions of deafness are not readily limited to medical and social models. This finding lends support to
the notion that disability and impairment are not readily separated and current proposed models of deafness (e.g., social and medical models), may oversimplify experiences of deafness and contribute to creating an unhelpful division within this broad and diverse population.

Our findings illustrate that experiences of deafness extend beyond efforts to regain physical hearing ability into efforts to manage a negatively identity position. Medical efforts to reduce or repair deafness do not specifically or sufficiently acknowledge or address this aspect of deaf experiences. Rather than develop models of deafness which oppose one another, perhaps our efforts should focus on developing a model of deafness which captures and maintains the complexity of what it is to live with deafness (of any level, type etc.) in a society that values and assumes hearingness.

Our exploration of this discourse within the context of our online forum is limited by our hearingness and the positions from which we conducted this analysis. Experiences that are afforded to us as hearing people combined with our varying experiences with deafness and deaf communication and language have shaped the design, implementation and analysis of this study (e.g., as hearing researchers we specifically decided to consult with community members during design of project, and have knowledge of both English language and linguistic devices and Auslan). Further, the experiences recounted on the forum may have been influenced by the forum user’s own recall bias. However, our focus was not on the specific instances recalled but rather the language used to recall and make meaning out those experiences. Due to the design of our study we were unable to contact forum user’s to encourage or remind them to respond to posts on the forum. This limited our ability to clarify the forum user’s responses and also to involve them in the data analysis process. Furthermore, ethical, practical and logistical issues, which informed the design of the study, may have discouraged people from participating using sign language, limiting the depth or
diversity of experiences discussed on the forum. While the current study is not designed to
genralise to larger populations, we acknowledge that a larger sample size may have
revealed more diversity and possibly uncovered discourses such as “Deaf Gain” (see
Bauman & Murray, 2009). As such future research efforts might focus on adapting the
design of the current study, recruiting a more diverse sample and identifying more diverse
discourses.

**Practical Implications for Practitioners**

As we have illustrated in this paper, responses from participants in the current
research demonstrate the *deafness as abnormal* discourse continues to shape people’s
understandings of deafness, and in doing so oversimplifies what is considered ‘normal’ or
‘abnormal’ regarding people’s hearing abilities. Without reflecting on and changing how
deafness is discussed within society, institutes for education and training programs
(particularly for health practitioners), opportunities for social action will remain under
explored. As such, there needs to be more published, accessible work exploring and
illustrating the diversity of experiences of deafness so that practitioners have corpus of
information to refer to when training or treating people living with deafness. The
information can be made accessible through the implementation of educational workshops
on working with and treating people living with deafness within educational institutions and
workplaces.

When providing services to clients living with deafness, practitioners should be open
minded about deafness and acknowledge the diversity of lived experience of deafness. We
suggest that in the first instance it is helpful to take time to understand what deafness means
to the client. In considering the negatively valued identity position people living with
deafness hold, practitioners should consider and discuss with their clients, ways to re-frame
deafness as socially-valued. Where health practitioners might focus on deafness as the
primary ‘problem’, we suggest that they move the focus from the individual (e.g.,
acceptance, fitting in) to the client’s social context and encourage them to explore how the
context and the people in it can change to accommodate their needs. We also suggest that
trainees and practitioners take up opportunities to be in contact with people living with
deafness.

The respondents in this study were seen to negotiate the *deafness as abnormal*
discourse in various ways, through the use of rhetorical strategies, so as to reposition
themselves in positive, socially-valued ways. However, this discourse remains so
entrenched that it can be difficult for people to resist it entirely. While managing deafness
continues to be constructed as an individual concern, people living with deafness will
continue to occupy a devalued identity position. Further, this construction disallows any
exploration of how society and infrastructure could be altered to create spaces for people
living with deafness or how deafness could be reconstructed as socially valued. Through
reflecting on and engaging with the discourses that surround deafness both empirically and
critically, we will be able to identify and take up opportunities for social action which can
create a world that is equally accessible to all members of society.
References


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iii Denoted by a capital ‘D’, Deaf culture, sometimes referred to as the Deaf community, is similar to an ethnic minority. It is a network of people who share a language (e.g. Auslan), a history of common experiences, customs, values and beliefs (Deaf Australia, 2013)

iv Participants self-identified as either deaf, Deaf, hard of hearing, hearing impaired or hearing. We note the forum users’ ‘deaf identity’ in the excerpts

v Referring to bilingual’s use of standard English; For many native sign-language users English is a second language (Channon & Sayers, 2007)

vi All excerpts are directly copied from the forum. We use […] to denote text we have removed from participants’ posts, for the purpose of being concise.
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Journal Entry 4 – Interpreters and Interviewing

March 2013

During the course of the online forum, a forum user contacted me via email to say that she would be happy to discuss, in more detail and face-to-face, her experience as a Deaf Auslan user and allied health professional. Because of financial constraints, I explained to the forum user that I would be unable to interview her face-to-face but she agreed to do the interview via Skype with a professional interpreter.

Her interest gave me the impetus to speed up the process of developing the materials for interviewing health care professionals and obtaining ethical clearance. As I went about designing and developing the materials and processes for the interviews I was also considering that for some interviews I would need an interpreter. I found that standard interview guides and articles about interviews don’t usually discuss how to go about conducting interviews where one person communicates with a visual language and the other uses a spoken language. One paper I found, Bogusia Temple and Alys Young’s (2004) reflexive article, was particularly informative.

From being involved in and reading about sign language and Deaf culture, I was aware that interpreters not only interpret (not, translate) what is being communicated, but they are also a bridge between two cultures, one Deaf the other hearing. While interpretations are highly informed by the skill, knowledge and experience of the interpreter, they are just that, an interpretation of what is being said. At that point in my PhD journey I was able to combine my knowledge of interpreting, working with marginalised groups and social constructionism to understand how the interpreter would contribute to the construction of knowledge in
the interview. Temple and Young’s paper was particularly helpful in providing a guide for conducting rigorous research that involves a visual spatial language and interpreters.

As I worked through the process of developing the interview materials and organizing the interview itself, I became acutely aware of the complexities of using online methods of communication and needing the services of an interpreter. I have grappled with issues of anonymity and privacy and the potential for scheduling conflicts and technical issues to interfere with process and quality of the interview. It didn’t help that the interview was my first ever research interview.

To address the issues of privacy I checked with the interview participant she was comfortable with the interpreter I booked and reassured her that no-one was able to overhear the interview or have access to the recording. I installed recording software to make sure I had an audio-visual recording of the Skype interview. I met the interpreter prior to the interview to work through the interview guide to make sure she understood the meaning of the questions that I was going to be asking. And I also debriefed her about the importance of privacy and anonymity.

... Overall the interview went well. Unfortunately, I found out that the recording software was limited by the ‘less than optimal’ internet and Skype connection we experienced on the day. This made it difficult to transcribe the verbal content of the interview and to check it against the visual recording. The interview participant also commented that she was dissatisfied with the Skype interview process, preferring to be face-to-face. Due to the poor recording, and to reassure the participant about how her responses were interpreted/recorded, I provided her with a copy of the transcript to comment on and clarify any ‘inaudible’ sections.
The experience of interviewing a person who communicates using a visual language made apparent to me three things. First, that there are very few resources (books, articles, people) available who have the experience with, and knowledge of, qualitative methodologies to conduct research with visual languages and populations of people living with hearing loss or deafness; specifically, how to analyse (e.g., thematically, discursively) visual languages with and without interpreting them into English. Second, that there are limited academic journals which publish academic research in visual, signed languages. Third, there is not much by way of incentives in Universities and academia to encourage people who communicate via signed languages to learn research skills and to take up a career in academia.

The rest of the interviews, coincidentally with only hearing health professionals, were also been a learning curve for me. I adapted my interviewing skills as I progressed; refining my listening skills, learning how and when to ask follow up questions, the best way to introduce the research and purpose of the interviews and ways of building rapport.

As I began the process of transcribing the interviews I came across the issue of knowing how to translate the verbal use of “deaf” to the written use. By that I mean, often during the interview the professionals would use the word deaf and during that conversation we seemed to have an unspoken, shared understanding of who we were referring to. However, when it came to transcribing that meaning I found myself restricted by pre-determined meanings of terms like ‘deaf’, ‘hearing impaired’, ‘hard of hearing’ and the ethical and methodological constraint of adding meaning to the transcript that was not explicitly confirmed or spoken by the participants. I don’t believe this to be an issue that is restricted to myself or to this
study; rather that it reflects a broader issues of terminology and socially constructed meaning that is socially and historically specific.
An Exploration of how Health Professionals Understand Experiences of Hearing Loss and Deafness

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Abstract

In response to the commonly accepted notion that people living with hearing loss or deafness commonly experience poor access to health information and services and subsequently experience poor health related quality of life, we question how these health disparities continue to exist in modern society in light of broader technological and communication developments. We investigate this question according to the perspectives of 18 health professionals practicing in Australia. Through an inductive thematic analysis, we identified an over-arching theme, which we labelled hearingness as privileged, and three sub-themes that pointed to the ways in which participants accounted for the quality of health services available to deaf clients within Australia. In light of our analysis, we discuss how the health system in Australia inherently privileges hearingness and how to move forward from here, including how acknowledging hearingness as privilege can be linked with social action, offering practical suggestions for health professionals.

Keywords

Community and public health; health care disparities; health care professionals; hearing / deafness; interviews, semistructured

*This article has been submitted for review at Disability and Society.*
People living with hearing loss or deafness commonly experience poor access to health information and services (e.g., Iezzoni, O’Day, Killeen, & Harker, 2004; Pollard & Barnett, 2009; Thomas, Cromwell, & Miller, 2006) and subsequently experience poorer health related quality of life than the broader (hearing) population (e.g., Chia et al., 2007; Gopinath et al., 2012; Hogan, Shipley, Strazdins, Purcell, & Baker, 2011). Although these findings are widely reported and drive current research priorities aimed at the deaf population, we question how these health disparities continue to exist in modern society in light of broader technological and communication developments. Through an exploration of how health professionals talked about and understood deafness, we identified that the Australian health system privileges hearingness and oppresses deafness. In light of these findings we discuss how to move forward, particularly in relation to how acknowledging hearing privilege can be linked with ‘social action’ and what social actions looks like in reality (Eckert & Rowley, 2013).

Privilege (and Oppression)

Privilege (and oppression) is a complex phenomenon blurred by the terms advantages and disadvantages. As Johnson (2006) explains, the term privilege is reserved for instances where something (e.g., respect, membership, access, or rate of pay) is systematically allowed for some and denied to others based on their membership in a social category(s). Members of social categories that are privileged (e.g., male, heterosexual, white, non-disabled) have the cultural authority to make judgements about others, to define reality and have prevailing definitions of reality fit their experience (Johnson, 2006). Members of privileged social categories are granted the presumption of superiority and social permission to act on that presumption without having to worry about being challenged, to move through life without being marked in ways that identify you as an outsider (Johnson, 2006; Campbell, 2009). Oppression refers to the systematic barriers and forces, not of one’s own making, that lead to
the devaluing of ‘the work, experiences and voices of members of marginalized social
groups’, because of the social category they are a member of (Bailey, 1998, p.106).

We are careful not to deny the advantages that people (regardless of their social
memberships) have earned. As Bailey (1998) argues, all privilege is advantageous but not all
advantages count as privilege in the same way that all oppression counts as harm but not
everyone who is harmed (disadvantaged) is oppressed (Bailey 1998). We are also careful to
distinguish that being in a privileged category (e.g., male\(^7\), hearing) which has an oppressive
relationship with another category (e.g., female, deaf) is not the same as being an oppressive
person who behaves in oppressive ways (Johnson, 2006). However, if we are going to be a
part of the solution to oppression, as members of privileged categories we must be mindful of
how our continuing participation in oppressive systems allows oppression to continue
(Johnson, 2006).

Unrelated to population size, privilege is systematically created and culturally
reinforced through legislation, public policy, informal expressions of speech, stereotypes,
aesthetic judgments and media images (Bailey, 1998). Known as the ‘luxury of
obliviousness’, one of the key attributes of privilege is that mechanisms of privilege remain
invisible to those who benefit from them (Johnson, 2006; McIntosh, 1986). Benefitting from
the luxury of obliviousness, members of socially valued categories (e.g., heterosexual, white,
male, able-bodied) are encouraged to attribute their success wholly to merit and remain
unaware of the privilege the system has conferred on them (Bailey, 1998; Pease, 2010 p. 8).
Termed ‘civilized oppression’, we are socialized into processes of oppression that are
normalized in everyday life and embedded in cultural norms and bureaucratic institutions;
consequently, many of these practices are habituated and unconscious (Harvey, 1999; Pease,
2010). Johnson (2006) explains, privilege is also perpetuated through ‘paths of least

\(^7\) We acknowledge that the examples of privileged social categories we have included here, such as the male
social category, may serve to reinforce the privilege of those categories; however, they also serve the purpose of
explicitly recognising the power relations that exist between particular social categories.
resistance, courses of action we take to avoid negative consequences (e.g., mild disapproval to the loss of one’s livelihood, physical violence and death).

The majority of research and literature focused on the concept of oppression is concerned with changing how ‘the oppressed’ think and act and how these groups reproduce their own oppression (Pease, 2010). Comparatively less attention has been given to how systems privilege the interests of dominant groups and members of the privileged group reproduce the oppression of others, and to critical examination of how systems allow inequalities to continue be accepted as the norm (Pease, 2010). We define systems here as ‘something larger than ourselves that we participate in’ for example, workplaces, families, schools, religious organisations (Johnson, 2006 p. 83). Rather than assign blame to any one individual or group of individuals, we emphasize how privilege is sustained within Western societies.

**Audism.** Much of the oppression literature focuses on the social categories of race, gender, class, sexual orientation and ableism (e.g., Campbell, 2009). Here, we focus on the social category of hearingness, repositioning it as a form of, but separate to, ableism. Although there are many parallels, deafness is a unique social category because it bridges theories and discussions of ethnic minorities (e.g., Deaf culture) and disability (e.g., hearing impairment); it does not fit neatly within either. Exploration of the oppression of people living with hearing loss and deafness has been ongoing (e.g., Bauman & Murray, 2009; Bauman, 2004; Eckert & Rowley, 2013). A particularly important development was the coining of the term Audism by Humphries in 1975, which refers the notion that ‘one is superior based on one’s ability to hear or behave in the manner of one who hears’ (as cited in Bauman, 2004, p. 240). Audism extends to the judgment of deaf people’s intelligence, success and happiness based on the ability to use the language of the hearing culture and the application of hearing standards, behaviours and values onto deaf people (Humphries as cited
in Bauman, 2004). In the current article we explored how health professionals interact with their clients in clinical and health care workplace systems. Specifically, we were interested in how health professionals talked about and understood deafness. The findings build on explanations and evidence of audism and how social systems privilege hearingness. We use the term hearingness to refer to the social category of hearing and to discuss instances where systems privilege hearing ability.

**Method**

*Participants*

Following institutional ethics clearance, the first author interviewed 18 health professionals practicing in Australia. The health professionals were recruited through the authors’ existing professional contacts and via word of mouth. Recruitment strategies (flyers, word of mouth) specifically targeted medical and allied care providers who have had or would potentially have interactions with deaf clients by asking, ‘What is your experience of working with clients living with a hearing loss or deafness?’ We purposefully sought professionals from a variety of health professions (e.g., nursing, counselling, dietetics, physiotherapy and so forth) with varying degrees of experience to obtain perspectives from a wide variety of professions and experience levels. The diversity included in this sample shifts the focus from one particular profession and from individuals onto the broader health system.

For reasons of confidentiality the professionals were given a pseudonym and categorized as either allied health professionals (as defined by Allied Health Professions Australia, n.d.) or medical professionals (Australian Institute of Health and Welfare, 2013). The sample of professionals included four medical professionals and 14 allied professionals, one professional identified as Deaf (17 identified as hearing). The majority of the professionals were located in Queensland. The professionals’ level of experience with deafness ranged from limited to extensive experience with seven professionals currently
working in a service specifically set up for clients or families living with hearing loss or deafness. The years of experience as a practicing professional ranged from four years to more than 20 years.

*Interviews*

The first author conducted semistructured interviews (face-to-face or phone) using spoken English or via Skype with a para-professional Auslan/English interpreter. Prior to starting recruitment, the interview schedule, drafted by the first author, was finalized (e.g., questions added and refined) through consultation with three people who identify as living with hearing loss: a Doctor of Philosophy, Masters student and a carpenter/teacher. The final interview guide included general questions such as interest in their field of expertise and the training they received. More specific questions included asking them to describe their understanding of deaf identities (e.g., deaf, hearing impaired, Deaf), how they communicated with their clients and whether they felt adequately trained. Where appropriate, the first author responded with follow up questions to encourage the professional to expand on their response. Prior to the interview each professional was provided with participant information and they provided consent to be interviewed either via email or verbally.

We acknowledge that people who acquire a hearing loss later in life negotiate some challenges separate to those experienced by people who are born deaf or acquire hearing loss early in life. However, the real world experience of health professionals is that they see the full range of hearing loss and deafness in their clients rather than one pre-determined sub sample. Through asking about the professionals’ experiences with clients living with hearing loss or deafness we were able to maintain the complexity and diversity of experience for both the health professionals and the population of people living with hearing loss.

All interviews, conducted between March and December 2013, were audio recorded (and for one interview video recording using Callnote software) and transcribed verbatim by
the first author. The transcripts indicate pauses and laughter. Where the interview was conducted in English and Auslan (via Skype) through the services of a professional level interpreter, the audio from the interviewer and the interpreter was transcribed and analyzed. As one interview was conducted in the participant’s primary language of Auslan and was interpreted into English, the first author provided the participant with a copy of their interview transcript with an opportunity to comment on the English interpretation of their Auslan response. The first author made corrections to the transcript in response to the participant’s comments. All interviewees were given the opportunity to read their interview transcript and provide any comments on the transcript where they felt necessary. As a result minor edits were made on three transcripts; the remaining interviewees indicated that they were happy with the transcript or chose not to comment. No additional comments to what was said in the interview or removal of any content was permitted during this process.

**Analytic Process**

Situated within a social constructionist and critical realist framework, the interviews were analyzed using a latent level, inductive thematic method, established by Braun and Clarke (2013), as such the authors did not have pre-determined concepts. The first author systematically read through each interview transcription and over readings developed descriptive codes from the transcripts (e.g., role as, interest in profession, insight into deaf experience, therapy techniques, qualified as, need for services, deaf as health professionals). As she coded each interview, codes were added and refined. Using these descriptive codes, the first author created a ‘code matrix’ in Microsoft Word for each participant and copied excerpts from the transcripts into the code matrixes. She went through the code matrix of each participant interpreting the excerpts, identifying themes and subthemes. From each code matrix the first author built on and refined the themes and subthemes, which led her to identify an overarching theme we labelled hearingness as privileged, see below for an
overview of the identified themes and sub-themes. To establish rigor, the second and third author read the code matrix to check themes and sub-themes and the first author re-read the code matrixes to identify how the health professionals oriented to the identified themes. We acknowledge that we are hearing researchers and we are not exempt from the privileges of our hearingness and this is acknowledged in this analysis we present here.

Reflexivity

Within qualitative methods, rigor is established through contextualizing the role and position of the researcher. As a young, hearing, female postgraduate research student whose first language is English, the first author was mindful of how her identity positions and how these might shape the interview experience and her interpretation of the data. Although she is tertiary educated in the field of Psychology, she has never worked as practicing medical or allied health professional. This might have made it difficult for her and the professionals to develop sufficient rapport based on shared familiarity and shaped the jargon the professionals used in their responses. However, tertiary education was a shared experience and point of similarity between herself and the professionals. Aware that the professionals' knowledge and experience of deafness would vary, the first author took care during the interviews to ensure the professionals did not feel judged and could feel free to say they did not have an answer. These points of similarity and differences have shaped her interaction with the health professionals and what was (and not) discussed in the interview and how the data were subsequently analyzed. The first authors interpretation of the data was also informed by her conversational level Auslan skills and her ongoing participation in both the hearing and deaf world (e.g., formal and informal community events and social connections).

Interpreter Reflexivity

The interpreter was first accredited by the National Accreditation Authority for Translators and Interpreters as a para-professional Auslan/English interpreter in 2004, gaining her
professional level accreditation in the same year the interviews were conducted. The interpreter has been involved with the Deaf community and worked in the deafness sector with Auslan users since 1990, holding a variety of positions in social welfare and community development. The majority of her work is in the health sector, enhanced by the fact that she has many years of personal and professional experience in this field. The interpreter has previous experience in research interviews, skype interpreting and qualitative research paradigms. These experiences inform her interpreting skills, giving her a unique insight and understanding of the language and culture of Deaf people.

Results

Overview of Themes

Through exploring the professional’s accounts of working as health professionals with deaf clients, we identified an over-arching theme that we labelled hearingness as privileged whereby deafness is constructed as being a disadvantage and hearingness as advantaged. Within this theme, we identified three sub-themes in which participants accounted for the quality of health services available to deaf clients within Australia (not good enough, doing the best we can and, it could always be better). In the context of the broader, albeit unspoken, notion that hearingness is privileged, the professionals described the available health services within Australia as not good enough. However, through relating their efforts to do the best they can the professionals were implicitly absolving their own responsibility in changing (and participating in) a larger system that privileges hearingness, describing how the situation could always be better. To begin, we first discuss the overarching theme of hearingness as privilege and how this features in professional’s explanations of the current quality of health services, followed by an exploration of the three sub-themes.

Hearingness as Privileged
In this section we discuss how privilege and oppression were constructed in the professionals’ explanations of the quality of health services. In addition, we show how professionals negotiated instances where they recognized hearingness as privileged. Professionals were specifically asked to comment on the services (health and general; specific to deafness and wider community) that are available to deaf people in the community. The professionals’ awareness of hearingness as privileged varied and this is made clear throughout the analysis. It tended to be that professionals with more (quality) personal or social experience with deafness were more aware of the various privileges of hearingness.

The professionals constructed health services as disadvantaging deaf consumers in terms of access and legitimacy. Access refers to occasions where all things being equal, people living with deafness might have restricted or limited access to services/information simply because of their deafness (e.g., health education and information based on empirical evidence relevant to Deaf culture and deaf experiences). Legitimacy refers to situations when legitimacy is denied or not recognized because of deafness (e.g., Auslan not recognized in policy and funding and achievements celebrated because of their deafness and not because of merit). Highlighting the lack of qualified professional services available for people who are deaf, Neil (hearing medical professional) discusses the difficulty he experienced as a health professional seeking additional health services for his client:

Neil: um (6) I suppose with our deaf consumer we want to do some in depth counselling and that’s been a struggle for us as a team to a um to organize that to get a psychologist who can who is who is um experienced in working with a deaf consumer . . . . We have arranged it but it has took [sic] us some time um (3) I don’t think there’s a team we’re aware of (2) where to go.
Neil discussed the delays his client experienced in accessing mental health support as being because of the lack of qualified and experienced professionals who can effectively treat a deaf client. Neil’s experience, echoed by several professionals, highlights the disadvantage deaf people experience in accessing health services. All things being equal (cost of services, scheduling conflicts) a hearing client at Neil’s service would not experience the same delays in accessing support, nor the limited range of professionals to select from. Sarah’s comment, ‘I thought how can the deaf people see a [allied health professional] that does not use their language or understand their culture and ways of living’, highlights the importance of having access to professionals who share fundamental life experiences (culture, language).

Sarah also described instances that reflect a denial of legitimacy. She reflected that it is difficult for qualified allied health professionals, who are also deaf, to get paid employment in their profession. Adding that hearing counsellors have rarely sought her expertise to treat their clients who are also living with deafness or hearing loss. Felicity’s (hearing allied health professional) comment, which was similarly voiced by several professionals, demonstrates hearingness as privileged within ‘wider community’ services:

Felicity: I think even if you’re just accessing front line services, if you go into an emergency department it’s unlikely you’re gonna meet somebody who can sign there let alone understand that you have an entirely different culture and that your language isn’t just fluttering your eyes it’s got real syntax and grammar. I think it’s not really understood to that degree and it’s not appreciated.

Sarah and Felicity’s responses highlight the privilege we experience as hearing people in being able to access any number of health services and variety of health professionals in our primary language at times that are convenient to us. Felicity also recognizes the legitimacy spoken languages receive where the same is not applied to natural sign languages,
‘isn’t just fluttering your eyes’. Felicity’s account is particularly interesting in light of her extensive prior international experience working with deaf clients and socializing with Deaf colleagues. In the instances below Felicity describes how systems, not specifically set up to serve the deaf population, inherently disadvantage deaf clients:

Felicity: . . . if you’ve never worked with deaf people before then you just take an interpreter along and you ask the same questions and people automatically expect the interpreter to change the words to make it understandable and not realize that they’re changing the meaning of what they’re saying

. . . this [community] service [where she works] is just geared up to think about how do you get out of a room quick if someone’s going to hit you, not how do you make sure that your body’s square on to the person that you’re talking to and you know, what is appropriate eye contact, how would that influence you [professional assessment] if somebody was really kind of really intently looking at you

Interviewer: yeh, which is normal for a deaf person

Felicity demonstrates how hearingness is privileged at an individual level and at a system level. At an individual level, professionals operating within community services assume hearingness in how they interact with their clients. However, the professionals are working within a system that prescribes hearing centered way of operating, through the physical structure of their workplace (e.g., room set up) and the ‘treatment’ processes (e.g., ideal length of face-to-face time with clients).

When discussing the quality of health services it was common for the professionals to describe instances where they recognized hearingness as privileged and, for the hearing professionals, had to negotiate their privilege. Although reactions to a group’s privilege being identified are typically negative (aggressive, defensive; Johnson, 2006), this was not always
the case with the professionals we interviewed. We briefly discuss the various ways the professionals negotiated their privilege as hearing people and professionals. One such response by Tina (hearing medical professional), below, normalizes variability:

Tina: I guess, in terms of the community in general, all of us have variance. So it’s not just limited to whether your deaf or hearing impaired or small “d” deaf … So there are challenges which are over and above what the average person might face in the course of their life. So I believe that in general it’s still pretty tough for a lot of people who are deaf.

Commenting that variance extends beyond an individual’s hearing capabilities, Tina is normalizing variance and this has the effect of accounting for the privilege she receives (e.g., as a hearing person). Tina suggested that where hearing people have privilege they might experience variance in other social categories and therefore be denied privilege in another way (e.g, gender, race, sexual orientation see Johnson, 2006). Following this qualification, Tina acknowledged that for a number of people access to opportunities (educational and work) are challenging and ‘over and above’ what the average (hearing) person might experience. Tina’s use of the phrase ‘average person’ is an example of an informal expression of speech which serves to maintain hearingness as assumed and normal and deaf gain as abnormal.

Lucy (hearing allied health professional) recalls the uncertainty she experienced about being able to communicate with her client:

Lucy: . . . and also I mean when he ah I guess it’s quite judgmental of me but when I first saw him I thought “oh gosh, how’s this gonna go? this isn’t going be very successful” but he had used all of those strategies [iPad, typing] to make communicating easier for him.
Exemplifying the luxury of obliviousness, Lucy’s experience demonstrates how we (as hearing people) can operate in society without having to think about our communication (and any barriers), or the communication of others; until we are confronted with a communication incongruity. Being suddenly confronted with her inability to communicate with her client through her preferred methods highlights that where a deaf person must frequently consider how they will communicate with a hearing professional, and the onus is on the deaf person to adapt, hearing professionals rarely do the same. Hearingness as privileged is evident in how health systems (e.g., hospitals) are set up (e.g., lack of on-site interpreters). Where (deaf) staff and patients cannot operate within the system, the system remains unchallenged and rather the (deaf) individual is expected to adapt to the system.

The health professionals’ explanations of the quality of health services included an identified lack of access, denial of legitimacy, assumed hearingness and instances which required the professionals to negotiate their privilege as hearing people. These explanations highlighted how the professionals participate, and have to negotiate working, in a health system which privileges hearingness. Within the hearingness as privileged theme, we identified three sub-themes in which participants accounted for the quality of health services available to deaf clients within Australia, which we now discuss.

Not Good Enough

This sub-theme comprises the various ways the professionals constructed the health services (including their own) as not good enough. The majority of the professionals commented on the inadequacy of the services and therapy tools that were available to them, highlighting that people living with deafness and hearing loss were disadvantaged in their profession. Services that were classified as not good enough covered interpreters, professional’s prior
training/experience, therapeutic tools and assessments and availability of appropriate resources/services available, which we will discuss below.

Interpreters are commonly accepted as the most effective means of facilitating communication between a person who communicates through sign and a person who communicates via spoken English (see Harmer, 1999). Several professionals commented on the poor workplace procedure and support for interpreters, lack of access to interpreters and interpreter qualification requirements (e.g., mental health qualification). In the excerpt below Rachel (hearing allied health professional) recalled her experience of working with interpreters, who lacked context specific experience and qualifications, and the lack of support in place within her workplace to facilitate the interpreter’s ability to perform her role effectively:

Rachel: … I spoke to my manager about it, about that the interpreter didn’t want to work with this client anymore and she said she wasn’t getting adequate sup um debriefing. So it was suggested that I provide debriefing to the interpreter, which I don’t feel comfortable doing because it kinda breaches yeh boundaries. And it just became a bit messy and it wasn’t my role to provide debriefing to an interpreter that’s the role of the manager.

According to some of the health professionals, insufficient access to interpreters resulted in preventing or delaying access to timely treatment, where hearing people do not experience the same delay. Rachel’s experience highlights how health systems, which assume hearingness, create resistance for health professionals trying to address the needs of their deaf clients.

When we discussed prior training we were interested in the standardized training that was provided at a qualification level or recommended for professional development. We
discuss it here within the sub-theme of ‘not good enough’ because it exemplifies hearingness as privileged; in qualification training and knowledge foundations. The majority of professionals commented on having little to no prior experience prior to commencing their current role. Most professionals who worked in a service specifically available for the deaf population said they received on the job training prior to treating any clients. Where the service was open to the wider community, professionals did not receive any prior training, nor was prior knowledge or experience, with deafness listed as a job requirement. The professionals did not explicitly discuss their training, or lack thereof, as problematic. Some professionals commented on seeking out and funding their own training. Sarah was an exception here, as Sarah received her qualification from an international institution which provided training in a setting where hearingness was not privileged.

The lack of recommended and inbuilt training speaks to the epistemic nature of hearingness as privileged. We argue that deaf people, as a part of the community, are not sufficiently reflected in the training health professionals receive prior to having their qualification conferred. Such that hearing professionals working in community services are rarely encouraged or required to consider the needs of deaf clients and how they might differ from the needs of their hearing clients. The training they receive, to treat the ‘average’ (hearing) client, reinforces hearingness as privileged, systematically disadvantaging people, including those living with deafness.

Where therapeutic tools were discussed in interviews, the professionals believed either that the tools available were generally adaptable to the deaf population or were extremely inappropriate. Therapeutic tools typically referred to risk assessment tools. These two responses are typified in Kirsten (hearing allied health) and Isabelle’s (hearing allied health) comments:
Kirsten: I mean, I guess I’m aware that not all psychometric assessments work on all populations of people. So it applies very similarly to the deaf population as well, because the risk assessments that we’re using are structured professional judgment tools aren’t actually, that I’m aware of, you know, utilized for research purposes on a deaf population and therefore normalized on that population.

Kirsten’s response was echoed in several interviews, usually by professionals who have limited experience with deafness (professional, social and personal). The professionals commonly cited their ‘informed’ expertise to adapt the tools to their clients and this was sufficient for diagnosis or treatment. We problematise the term informed as some professionals volunteered that they were not overly knowledgeable on deafness or experiences of deafness. Some professionals did not discuss the lack of specific tools as disadvantaging their deaf clients.

Isabelle’s comment ‘but I also, I’m a bit scared of that because a lot of the tools we use obviously, are extremely inappropriate for deaf people. So yeh so um so it’s a tricky role’ illustrates the response of professionals who believed that therapeutic tools are extremely inappropriate. Isabelle’s response is illustrative of the endemic nature of hearingness as privileged and the path of least resistance. Despite working in a service providing specialized services for the deaf population, Isabelle described having limited viable alternatives to using therapeutic tools she believes, as a qualified professional with extensive personal and work experience with deafness, are ‘extremely inappropriate’ for her client base. We address in the discussion workable alternatives health professionals can engage in to challenge the system.

In addition to the lack of appropriate therapeutic tools, several professionals commented on the lack of available, appropriate, services and professionals (also discussed in Excerpt 1). Sarah, one of the few qualified allied professionals, who is also deaf, discussed
the limitations of using Skype to treat clients who live in another area of the country. Her experience highlights the privilege we have as hearing people, that we can access any of several qualified allied professionals, from a range of disciplines and specialties, in a local area (and other locations) using our preferred language, whether we access the service in person, on the phone or via email. Not only is the deaf population disadvantaged by the number of qualified professionals available, but they a disadvantaged by location of the few available experienced professionals. As Auslan is a visual language, people who communicate using sign language use visual mediums (in person and/or video communication affected by internet connection).

In recognition of the lack of access deaf people have to the same services hearing people are able to access, Tina discussed her interest and work in improving access to services. Tina’s response to her privilege as a hearing person is interesting because it differs from typical responses to privilege which are often defensive (e.g., Pease, 2010). Tina discussed the need to change systems, health services, in contrast to changing individuals. In addressing the lack of accessibility, Tina addresses the issue by working with representatives (individuals who operate within the oppressive systems) from various stakeholders to make changes within the system.

Across the interviews with professionals (hearing and deaf), in community and deaf specific services, we identified a general recognition that health services, as they stand, are not good enough. The systems they operate in largely serve to maintain the hearingness as privileged and disadvantage deafness. In response to this recognition, many of the professionals commented on their efforts to manage the disadvantage, often constructing their efforts as doing the best they can.

*Doing the Best We Can*
We recognize the professionals we interviewed operate within specific work, and broader community systems and as such we continue to focus on the systems as inherently problematic rather than blame the professionals as individuals. Within this sub-theme we discuss how the professionals managed the identified inequalities in relation to access to communication, prior knowledge or training, therapeutic tools and available resources, all of which illustrate the notion that they are doing the best they can. Each professional discussed communication and how they negotiate access to ‘mutual’ comprehension in communication exchanges. They each negotiated this topic differently and we considered their responses in light of the professionals’ apparent experience with deafness and depth of understanding of visual languages and communication exchanges. Illustrated in Neil’s comment, professionals with limited experience with deafness tended to acknowledge the need for an interpreter, or at the very least acknowledged the need to ensure they spoke clearly to facilitate lip reading; but rarely acknowledged how some of their efforts are inherently problematic and operate on an individual level rather than challenge processes at a systems level:

Neil: I don’t sign and he uses um . . . his own sign that he grow[sic] up in the family home . . . I need to go an find paper all the time so we can we can communicate . . . I think my accent somet [sic] really difficult for him to pick up . . . the consumer and the clinical team (3) um tend to communicate using paper or um he, as I said, he can lip read to a certain extent. If we have anything that such a clinical review or um, if we had a um a meeting, whether there were other clinicians who we didn’t know, we would always book an interpreter through the [organization].

In his talk, Neil discusses the various methods of communication they practice at his workplace to communicate with their deaf client. Although an interpreter is booked for clinical review meetings (or with unknown clinicians) this access to communication is not
discussed as necessary or wanted in any other context. This could be for many reasons, the client’s preference, cost and availability of interpreters, but this does not address the notion that the system does not inherently meet the communication needs of this deaf client. Although we cannot make any claims here, we think it is important to consider how a client’s preferences have been shaped by his/her experience of living in a world that privileges hearingness.

Where the interviewer queried the limitations of some communications practices with Oscar (hearing medical professional), rather than challenge the system within which he works and taking the path of least resistance, he commented that he accepts the risks of the communication practices he uses. However, his laughter might indicate a level of discomfort with these risks:

Oscar: um some are some are excellent lip readers but they miss a lot and some you have to write things down um either on an iPad or a piece of paper or some other method some you have to explain to them through a family member ah or through a translator interpreter if they’re signing in particular

Interviewer: are you ever concerned that um when you are explaining things that import coz obviously you know it’s medical procedures and things that they might miss or misunderstand important information?
O: yes. yes yes and it happens all the time (laughs).

By not problematising the unearned disadvantage his clients experience, Oscar’s various efforts to communicate with his deaf clients are constructed as doing the best he can. It is a fair response to ask ‘what else could Oscar being doing’. As we will discuss later, challenging the system is an immensely difficult task and a long term solution. Making efforts to adapt on an individual level is only half of the solution and without challenging the
privilege that is inherent within the system, hearingness as privileged is perpetuated. A few professionals (generally those with more experience) commented on working with each client to facilitate the most effective communication practice for that client. For instance Tina commented, ‘It’s about working out what strategies can be used in terms of asking them what things are successful’.

As illustrated in Zanthe’s (hearing allied health professional) comment, many of the professionals, when discussing their background training, discussed their efforts as doing the best they can, ‘I think it’s a good base discipline to come from I think it’s a highly specialized area and there’s a lot of knowledge you need to acquire and I’m still acquiring.’ Zanthe is able to justify her knowledge base by explaining that even though she is qualified, the combination of the health sector and population she works with creates a ‘highly specialized area’. At an individual level, many of professionals indicated a willingness to learn new skills and to adapt their professional practices (with the assumption that this will be self-driven and funded).

Isabelle’s recollection of a recent experience where she was required to adapt the phrasing of a therapeutic tool for a client living with deafness, because of the lack of alternatives, is illustrative of a broader pattern across the interviews of professionals doing the best they can with the tools available:

Isabelle: the client that I had today um has been [condition] in the past and I had a suspicion that there was some trouble um so I actually did a risk assessment today on her I pulled the tool that I was meant to use off the system um it had no meaning to in if I was to ask her the exact questions on the list it would have it wouldn’t have been meaningful for her so I elicited I elicited um (1) responses to the questions but I didn’t use the questions on the tool to come to the same conclusion as to um what level of risk she was in terms of [condition] so it’s adapting.
Isabelle’s experience demonstrates how efforts to adapt the system to accommodate the needs of deaf clients operate at an individual level, addressed on a case by case basis. Comparatively, change at a systems level, where hearingness is not assumed and resources are purposefully developed and implemented, minimizes the need to keep readdressing the issue with each client. Change at a systems level was discussed by some professionals, in the sense that they recognized it was needed but it was not discussed in a concrete way.

In light of the professionals’ recognition that the current quality of services is not good enough, some professionals qualified these limitations by demonstrating that the services were doing the best they can, as illustrated in Grace’s (hearing, allied health professional) comment, ‘It’s just about resources not about the actual program the way it’s set up, if they had half as many referrals they’d offer a brilliant service.’ Grace’s comment again reflects the invisibility of the system and how it is problematic. Through focusing on the lack of resources and the subsequent capability of the staff (rather than expanding the service), Grace is able to represent both the program and the staff as doing the best they can with what they’ve got.

In response to the acknowledgement that access to and capabilities of services are not good enough, many of the professionals constructed their efforts and their services as doing the best they can. Typical of becoming aware of privilege (e.g., Pease, 2010), many of their responses focused on effort and change at an individual level, rather than at a systems level. However, through constructing their efforts as doing the best they can, little attention is subsequently required to be given to how the system is required to change. When the professionals were asked to consider the applicability of changes at a systems level, many of them echoed the sentiment that it could always be better, and cited being constrained by the system.
It Could Always be Better

In response to discussions about the quality of health services not being good enough, Ferndale discussed, with each professional, different ideas for changes at system level. These ideas included whether training programs should have explicit training on how to treat deaf clients and whether a qualified deaf person could work in the professional’s health field. Ferndale intended for these questions to elicit conversations about change at higher, system level. The sub-theme it could always be better consists of the various responses and subsequent discussion about change at system level. In analyzing the professionals’ responses we discuss four main patterns that emerged from their talk: the system as constraining; whether change is warranted; the value of health professionals who are deaf; and suggestions to do better. In extrapolating these patterns, we show they relate to the over-arching theme of hearingness as privileged and highlight the importance of the dynamic between individuals and systems (Johnson, 2006).

Throughout the interviews, and in particular when discussing ideas for change at a system level, many of the professionals made reference to the system as constraining change at an individual level. Again, according to Johnson (2006), this is typical of responses to privilege such that we are socialized to see privilege as located within individuals and to overlook the privilege inherent within the system, and the dynamic relationship between individuals and systems. The following two excerpts are illustrative of the professionals’ positive response to the introduction of training specific to treating deaf clients in tertiary education programs and their reservations or knowledge of how education institutions (systems) will likely constrain the possibility to add information related to deafness. Sarah in particular, in the second excerpt, drew on her own experience to demonstrate the lack of opportunity for deaf Australians to study at a postgraduate level and for people to study mental health within a deaf population:
Zanthe: definitely yeh but it’d probably be postgraduate [level] because I don’t know that there would be room for that in an undergraduate program but certainly yeh some kind of diploma, potentially.

Sarah [interpreted]: I just feel lucky [comparing her international tertiary education experience with opportunities in Australia] when many deaf have missed out [on] valuable mental health study but here in Australia there’s actually not very much [opportunity to study], it’s much more difficult here in Australia.

Sarah’s fortune at being able to take the opportunity to study and gain a qualification at an international institution is illustrative of the lack of accessibility to Australian educational institutions for people with similar career goals. Her response suggests that the life experience of deafness, and deaf people as part of the population, are not sufficiently reflected in the teaching of mental health in Australian programs. We would argue that such a gap in health teachings perpetuates hearing practitioner’s obliviousness to the needs of their future deaf clients, enabling hearingness as privileged to prevail. Feelings of being constrained by the system extended to discussions about the use of therapeutic tools. When discussing inappropriateness of therapeutic tools and possible ways of doing better (e.g., using tools developed for and normed on deaf populations), many of the professionals often cited being unable to do anything differently because of being constrained by the system, specifically by a lack of access to funding:

Rachel: and also we have a lack of funding (laugh) . . . like I’ve gone up through channels and like tried different people around the organization and it’s just we have a bucket of money for interpreting different languages but they don’t see sign
language as a different kind of language as a country like they see it as something different so we I can’t use that bucket of money.

Demonstrating hearingness as privileged, verbal languages are automatically recognized as languages where visual languages, such as Auslan, are not provided with the same recognition. Going on to explain that she was able to access interpreting services through other obscure channels, Rachel’s account is an example of the path of least resistance. Such that, rather than challenge the system (seek to change the rules of the ‘bucket of money’) where Rachel would have faced considerable resistance (e.g., potentially lose her job and source of income), she chose to go around the system believing she was not in a position to do otherwise. Through Rachel’s well intentioned actions, people who communicate via verbal languages remain privileged where people who communicate via visual languages remain disadvantaged and the issue remains an individual problem.

Comparative to Rachel, Oscar resists identifying the system as problematic, instead locating the need for change with deaf individuals:

Oscar: um there are gaps but they’re relatively minor you should focus on the positives they really do have access to fantastic services um they’re well subsidized, they’re freely available ah they’re generally adequate. The problem is that their expectations of these services are ridiculously high and it sometimes um ah gives them the wrong perception of ah the services that they’ve received they don’t think it’s good enough um so yeh so I think that’s part of the problem but there’s certainly a lot of resource ah which is available for them.

Similar to Oscar’s account above, many of the professionals challenged the idea that changes at a system level (for increasing access to services for deaf clients) were warranted.
One of the ways in which professionals sought to challenge the need for system level change was by citing the number of (deaf) clients they see to infer the size of the population as not large enough to warrant change. For example, Simon commented, ‘When I look at the number of people that I work with who have serious hearing issues I suppose that you couldn’t justify on one you know an FTE [Full-Time Equivalent]’ In citing the size of their client base as the justification for change (or not) the health professionals demonstrate a preference for prioritizing the continuing functioning of their respective workplace systems as they are. Despite previously detailing how support and services were not good enough, many of the professionals resisted additional, larger scale changes that would minimize the disadvantage deaf Australians experience. There were a few professionals who acknowledged the need for change as system level; they tended to be professionals with more personal and social experience with deafness:

Neil: … there is a vast component of our society who can’t hear. You know, they still need a service. So um yeh, I think it’s important that it’s addressed um early and thoroughly. I suppose yeh. How that would look I’m not quite sure.

Where the professionals discussed the need for and potential benefits of system level changes, they also highlighted people living with deafness as an element of our society. The professionals’ lack of certainty about the change and how it would play out in the ‘real world’ illustrates the immense difficulty that is associated with addressing issue of privilege at a system rather than individual level.

Operating on the assumption that deaf people have equal access to education and training programs, each professional was asked to comment on whether they thought an equally qualified deaf person could work in their professional role. The majority of the health professionals believed this would be a worthwhile and feasible option. However, this system
level change was again resisted such that most professionals automatically assumed a deaf health professional would only treat deaf patients. Kirsten’s comment is illustrative of a broader pattern identified across the interviews, ‘it would be so much easier for the deaf consumer if you had psychologist in front of you who could sign and you could just have a straight forward communication between the two of you.’ Kirsten response reflects the assumption that people living with deafness have nothing else to offer (to society) beyond what they can offer in relation to their deafness. This is demonstrative of the broader socially embedded notion that people living with socially devalued bodies have nothing to offer mainstream society (Johnson, 2006).

It was commented by some that hearing clients would struggle with communication with a deaf health professional and this was an important consideration when employing a deaf professional; usually explaining that it would be difficult for the hearing person to receive sufficient treatment and the deaf health professional was responsible for ensuring effective communication with their hearing clients. As Johnson (2006) and Pease (2010) explain, where one group is privileged over another, it is typical for the privileged group to place responsibility for change/reducing the gap with the disadvantaged group, as they are motivated to effect change where the privilege group is not motivated. This feature, evident in several interviews, is most clearly exemplified in Neil’s response below:

Interviewer: Um, do you think there’s a place for qualified deaf people to work as nurses or in nursing care units?

Neil: (1) do ya know that’s never I’ve never considered that before. (1) um you mean as clinicians?

I: yep yep.
N: (3) I suppose it would (1) this is gonna sound awful but I suppose it would depend on how well they could communicate how how well they could communicate with somebody who isn’t deaf um (4) who doesn’t know Auslan (2) um
I: coz I mean there are
N: you could use interpreters I suppose you know it could be a mirror image of what we’re doing now.

What is particularly interesting about Neil’s response, and illustrative of the luxury of obliviousness, is that he did not comment on the lack of qualification required for hearing people to communicate with, and therefore treat, deaf clients. Where hearing people are not explicitly required to be able to effectively communicate with a deaf person to be able to treat them, nor is it widely recognized as ethically problematic if they cannot, a deaf person must demonstrate their ability to communicate with a hearing person.

When the professionals recognized the disadvantage in the system, they offered alternative suggestions for changes at a system level. Acknowledging that effective communication is vital and particularly with in her profession and instead of placing the responsibility for effective communication within individuals, Lucy discussed identifying barriers more broadly and implementing strategies to address the barriers. Sarah similarly suggested employing (encouraging them into health careers) people who have grown up with deafness. However, Sarah’s response seems to oversimplify the disadvantage deaf people experience that is inherent within the education and employment systems.

After constructing the various aspects of the health services as not good enough and discussing their efforts to do the best they can, many of the professionals discussed their efforts and proposed ideas for change (e.g., tertiary training programs) as being constrained by the system. Operating within a society that functions on systems of competition and
scarcity of resources, the size of their client base was also used by the professionals to question whether additional system level changes were warranted. In this section we have demonstrated the willingness of many health professionals to minimize the disadvantages deaf Australians experience and illustrated the importance of recognizing the dynamic between individuals and systems.

Discussion

We recognize that systems of privilege and oppression and the dynamic between individuals and systems are not easily or quickly altered. However, through highlighting hearingness as privileged and how it operates particularly in the Australian health system, we take small steps toward a path of greater resistance. Through exploring the professionals’ accounts of working as health professionals with deaf clients, we identified an over-arching theme that we labelled hearingness as privileged. Within this theme we identified three sub-themes not good enough, doing the best we can and it could always be better in which participants accounted for the quality of health services available to deaf clients within Australia. Although it was commonly discussed by the professionals that the support and services available are insufficient, through describing their efforts to do the best they can, the professionals were able to justify their role in resisting additional, larger scale changes that would work to minimize the disadvantage deaf Australians experience.

The empirical findings we present here build on empirical evidence of health disparities and theory driven discussions about audism and the privileges of being (able bodied and) hearing in a society that values and assumes hearing (e.g., Bauman, 2004; Campbell, 2009; Corker, 1998). Theorists have discussed in depth, instances that demonstrate the oppression of people living with hearing loss and deafness (e.g., Eckert & Rowley, 2013) and empirical evidence supports the notion that people living with deafness and hearing loss are systematically disadvantaged in our health systems (e.g., Chia et al., 2007; Gopinath et
al., 2012; Harmer, 1999; Hogan et al., 2011). Our findings illustrate that often we are blind to how the systems we participate in are oppressive to others (Johnson, 2006; Pease, 2010) and that our actions, contributing to this oppression, are rarely malicious in their intent. Additionally, that typical of discussions about oppression and privilege (Pease, 2010), the focus is largely on individuals and groups rather than on addressing systems. We now discuss these findings in the context of bringing about system level changes, the limitations of this study and practical suggestions for health professionals.

The size of the health professional’s client base and the size of the population of people living with hearing loss or deafness was frequently cited as not sufficient to warrant changes at system levels. Within a business model and capitalist society this is a legitimate concern. Where population size is considered important, we point to Access Economics’ (2006) report which suggests that one in six Australians are living with hearing loss or deafness. Irrespective of population size, we point to recent system level structural changes, such that buildings and toilets are designed and built to accommodate diverse embodied physical needs. Furthermore, that these changes have become so embedded within our society that buildings are legally required to provide these accommodations regardless of the number of people who need to use them. We also highlight that these changes do not disadvantage the physical needs of non-disabled people. Although they are not without complications, in the United Kingdom and the United States of America, there are examples of health services where hearing and deaf people work together as colleagues (e.g., Moore, Guthmann, Rogers, Fraker, & Embree, 2009; Young, Ackerman, & Kyle, 2000) Given these considerations, population size as an argument against system level changes becomes weak and somewhat irrelevant.

Encouraging a more diverse range of people, including people with diverse hearing and linguistic abilities, into health professions is a challenging system level change to
achieve. Education institutions and training programs will need to be revised to increase the accessibility of the institution (e.g., cost, location, accessibility to the classroom) and the course content (how deafness, and similarly marginalized social groups, as a part of our community is reflected in the content). Moreover, organizations and clinics will need to recognize the value of deafness and what people who are living with deafness and hearing loss bring (beyond their deafness) to the health profession and the workplace. It is important that people in positions to effect these larger system level changes do so and people in less empowered positions continue to demand these changes occur. Various independent individuals and deaf specific organizations are trying to create opportunities to advantage people who are deaf (e.g., Hear For You, Deaf Children Australia). These individuals and small groups are typically people who have a strong connection to deafness (deaf themselves or closely connected to someone who is). However, this change is often small scale and these groups have relatively less power than hearing people, particularly hearing people in positions of power, for example health professionals, university leaders and administrators.

As we do live in a society that functions on scarcity of resources, it is important to consider whether there is a reasonable expectation to change training programs and develop resources for a population that the majority hearing population believes to be small. A considerable amount of research suggests that the health disparities (and barriers) that deaf people experience (e.g., Gopinath et al., 2012; Harmer, 1999) is enough to warrant change. We also argue that, given the amount of resources, financial and otherwise, going into developing hearing technology, and the justification used to expend these resources, suggests that the disadvantages this population experiences are significant. Perhaps the resources contributing to the assessment of deaf people and progression of hearing technology could be more equally shared with efforts to adapt systems (like health professional training programs) to better accommodate a more diverse population of people. For example, rather than
adapting therapeutic tools on an individual basis, the development of and training in standardized tools would likely save time and money in these clinics in the long term.

Although our study makes an empirical contribution to discussions of audism and broader understandings of privilege, we acknowledge that the study is restricted by a lack of diversity in our sample such that, 17 of our 18 health professionals were hearing; although, this is also representative and speaks to the issues raised in this article. However, through a predominantly hearing sample we are able to explore how people living with hearingness negotiated privilege in a health context. Furthermore, this sample reflects the audiological diversity in the population of health professionals in Australia. Future empirical work could explore hearingness as privileged in other contexts (e.g., education) or further explore the recommendations we discuss below.

Our use of the term ‘people living with hearing loss or deafness’ may also be problematic in that it refers to a broad range of people and risks grouping all experiences under the same umbrella. However, the use of specific and narrow definitions we believe is potentially more risky. Specific narrow definitions lose the complexity and diversity of this broad and fluid population. Furthermore, there is not one clear, widely used definition of terms such as deaf, hearing impaired and hard of hearing. Consequently, there is a lack of consistency in the use of these terms across contexts such that, how one professional understanding or defines deaf may differ from the next professional. Moreover, through the use of ‘people living with hearing loss or deafness’ we were able to capture the diversity in the professionals understanding and experience of providing services to the full range of people living with deafness or hearing loss.

Based on our work we propose a number of recommendations. We think it is important for health professionals to consider how they can use their power to create opportunities that advantage the disadvantaged. Practicing clinicians can consider offering
work experience opportunities, mentorship to high school or university students considering a
career in their profession. Health organizations or education institutions can consider offering
scholarships to prospective students living with deafness or hearing interested in a career in
health. Training officers and lecturers can include a lecture or course which incorporates
content about deafness and how to address communication barriers. University leaders could
use student service fees to fund the addition of hearing loops to lecture halls and teaching
rooms and the costs of having campus information evenings and community events and
public lectures interpreted and captioned (regardless of the audience). When using advertising
material to promote education institutions and training programs, administrators can
specifically include content that reflects the hearing diversity in our society. The benefits of
implementing these recommendations extend to reducing unemployment, increasing client
bases, improving service satisfaction, reducing costs on the health care system (e.g.,
 improved use of the health system, rates of misdiagnosis and so forth).

We need to identify and take opportunities where we can to promote the path of
greater resistance. Taking action in the smallest of ways, such as publicly correcting anyone
who uses the phrases “deaf and dumb”, documenting the inadequacy of therapeutic tools and
challenging workplace procedures which disadvantage people who require visual
communication, can collectively bring about change in the long run. Larger scale action can
include not giving business to, or attending events that are not equally accessible to people
who have alternate sensory experiences, for example cinema sessions, concerts, conferences.
Rather than challenge only one form of privilege (Waite cited in Pease, 2010, p. 22) we
suggest people consider their actions in a broader context and make efforts to understand the
world from other people’s perspectives. Through taking these small steps as a society cultural
change can occur.
Notes
1. The phrase ‘people living with hearing loss or deafness’ is used here to refer to the population of people living with any level or type of hearing loss regardless of communication preference and skills and use of hearing technology.
2. Numbers in brackets refer to length of pauses in talk in seconds.
3. Words included in square brackets in excerpts indicate where the authors have corrected the English grammar of the Interpreter’s spoken interpretation of the professional’s Auslan response.

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Understanding Privilege

In this section I introduce key authors and readings which have informed my understanding of privilege as I have applied it to my thesis. The purpose of this section is to introduce the necessary background theory which is not discussed elsewhere in this chapter. I briefly explain the notion of privilege as it relates to oppression, how privilege is sustained within our society, typical responses to privilege and understanding the dynamic between systems and individuals.

I use the term privilege to refer to instances where things of value (e.g., respect, membership, access, or rate of pay) are systematically conferred to some people, and denied to others, based on their membership in a social category (e.g., male, heterosexual, white, non-disabled; Johnson 2006). Oppression refers to the systematic barriers and forces, not of one’s own making, that lead to the devaluing of “the work, experiences and voices of members of marginalised social groups”, because of the social category to which they belong (Bailey, 1998, p. 106). We are careful not to deny the advantages that people (regardless of their social memberships) have earned (e.g., working hard to afford to live in desirable neighbourhood). As Bailey (1998) argues, all privilege is advantageous but not all advantages count as privilege in the same way that all oppression counts as harm but not everyone who is harmed (disadvantaged) is oppressed. It is important to understand this distinction when managing people’s (typically) defensive responses to their own privilege being identified, which is discussed further on in this section (Johnson, 2006).

Privilege and Advantage

As Johnson (2006) explains, the existence of privilege does not mean that people who belong to privileged categories do not do a good job or that they do not deserve credit. It means that people who also belong to a privileged category(ies) are also getting something that is denied to other people. While maintaining they do not operate independently, Bailey (1998)
delineates privilege as unearned advantages from earned advantages. Earned advantages are strengths in the form of skills, assets or talents that benefit its possessor and which, under restricted conditions, help to advance that person. Examples of earned advantages include working hard to earn a tertiary degree, training hard to be selected for a sports team.

To present an example, in the context of disability, non-disabled people often assume people with disabilities lack intelligence and their achievements depend on their physical or mental condition. Where two people applying for a job are the same, except one is nondisabled, the person who is non-disabled is assumed to be intelligent and capable and therefore is more likely to receive the job. However, this does not deny that the non-disabled person has not worked hard to earn the job rather that the social category he belongs to (non-disabled) confers to him certain things (e.g., assumed intelligence, fit for the physical work space) that are denied to his disabled peer.

Although privilege is received by people, privilege is more about perception of belongingness to particular categories than it is about individuals. As Johnson (2006) discusses, in order to receive the privilege that is associated with a particular category (e.g., non-disabled) a person only has to convince others that they do belong to that category, (e.g., appear to be able-bodied). This is frequently discussed in the literature on various oppressed and marginalised groups as ‘passing’ (see Brune & Wilson, 2013). By the same token however, a person can lose privilege if people think you do not belong to a particular category (e.g., effeminate men).

**Systems and Individuals**

As McIntosh (1986) and Bailey (1998) describe, people are made aware of, and are usually receptive to, discussions about oppression as the product of systematic barriers and forces beyond an individual’s (their) control. However, people are typically much less aware of, and receptive to, the notion that the privilege of one group contributes to the continued oppression
of another (McIntosh, 1986). As Johnson (2006) explains, people in Western societies are socialised into seeing the world as consisting of individuals who have equal agency to make decisions and opportunity to access resources (e.g., organisations and societies are collections of individuals). As a result of being socialised into an individualist society people typically have defensive reactions (e.g., discomfort, fear and defensiveness) to an individual’s or a group’s privilege being identified (Johnson). This individualistic thinking reinforces the notion that unearned disadvantages or advantages are located within individuals (e.g., men are sexist) rather than the social categories which people end up in. Consequently we are blind to the role of systems in reproducing privilege/oppression. As Johnson argues, in order to discuss privilege (without defensiveness) we need to understand the social world as consisting of social systems and people who participate in systems.

Understanding that privilege is not something people take (or do not take) and that it does not derive from who we are or what we have done is key to being able to discuss and address issues of privilege (and oppression). Johnson (2006) posits the key to removing fault or blame from discussions of privilege is to construct privilege as maintained through the dynamic relationship between individuals and (social) systems. Specifically, to understand how people participate in particular kinds of social systems and how this participation shapes their behaviour and the consequences it produces. As Johnson posits, we are shaped as individuals in two ways, through a process of socialisation and through participating in systems through ‘paths of least resistance’.

Through the process of socialisation we learn to participate in social life and to distinguish what is considered “normal” and acceptable and what is not. Through systems we develop personal identities (race, gender, ability, class, religion etc.) and learn how identities are positioned in relation to others. Participating in systems through paths of least resistance shapes how we behave within a system and the consequences of this behaviour. Varying in
how much resistance we will run into if we try to follow them, there is any number of possible paths in any system. Resistance can take many forms from experiencing mild disapproval to the loss of one’s livelihood, physical violence and death (e.g., Freedom Riders). As individuals we frequently choose the path of least resistance even in the smallest ways. For example, when in an elevator we typically stand facing the door to avoid mild disapproval (e.g., stares). The potential for resistance has a considerable role in shaping our decisions and actions as individuals (Johnson, 2006).

While acknowledging one’s privilege and speaking out against it is important, Pease (2010) argues that it is not as simple as not participating in systems, it is impossible to relinquish privilege. To be in society requires individuals to participate in systems. However, in making privilege more visible, we make oppression more recognisable (Pease, 2010). In the next section I reflect on my experience of ‘discovering privilege’ and how this has clarified my understanding of experiences of hearing loss and deafness in the health disparities identified in the literature reviewed in Chapter 5.
Journal Entry 5 – Discovering Privilege and Coming Full Circle

Jan 2015

The process of completing the thematic analysis on the interview transcripts was simpler than the discourse analysis on the online forum data. It felt like I had had more structure and that the interview data was more straightforward. Identifying the overarching theme of hearingness as privileged was a particularly profound moment for me and for this thesis.

As I was reading through the interview transcripts I saw that a number of health professionals described living with deafness as a disadvantage. As I was pondering this thought, it occurred to me that no-one ever talks about people who can hear as being disadvantaged (for their hearingness). Continuing this thought, I realised that people don’t talk about hearing unless they are talking about it in relation to a person who does not hear; and only then do we think about how we are advantaged as hearing people. Similar remarks can be said about similarly disadvantage groups (e.g., racial) and so this isn’t something specific to deafness. Not having thought much about privilege and oppression before I remembered the expression ‘check your privilege’ but I didn’t fully understand what this expression meant. So naturally I googled ‘check your privilege’ and started reading online articles that explained what that phrase meant. As I read through the articles it wasn’t really mapping onto what was in the data. So I explored this idea further by typing in ‘privilege’ into google scholar. Johnson’s book Privilege, Power and Difference, the second listing, naturally mapped onto what I was seeing in the transcripts and my reading and thinking progressed from there.

As I completed the analysis and wrote up the manuscript for publication I started to reflect on my thinking from where I started my PhD journey to now, re-
reading the literature with this new lens and I can see how privilege and oppression was at the centre of the research problem I identified prior to starting this research.

Empirically, the evidence suggests that deaf people experience barriers to accessing health services and information and poor health. These disparities continue despite improvements in cochlear implant technology and early intervention. So why aren't they enough? In the last chapter of this thesis I propose an answer to this question, offering practical and theoretical implications and suggestions for future research.
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Considering Future Directions

The purpose of this chapter is to synthesize the empirical, methodological and theoretical contributions of the previous chapters. First I summarise the research problem addressed in this thesis and the aim of my research. This is followed by a summary of the findings from Studies 1 and 2 where I discuss the limitations of each study and the overall thesis. In Journal Entry 6, I discuss the challenges I negotiated attending the World Federation of the Deaf conference and how I have been able to make sense of my experience through reflecting on the research presented in this thesis. Following this, I present suggestions for future research which are informed by my experience at the conference and the limitations of this thesis. In this chapter I also discuss the theoretical, practical and methodological implications of this thesis. Lastly, I reflect on the ways reflexivity (e.g., the journal entries) has facilitated a deeper understanding of the research process, the creation of knowledge and the ethical nature and practical usefulness of this thesis.

Summary of Findings

Research Problem

There is substantial empirical evidence that suggests that people living in Australia with hearing loss or deafness experience poor health related quality of life, health knowledge and considerable barriers to accessing health services and information. A critical review of this empirical literature in Chapter 5 demonstrated that this knowledge is largely informed, and therefore, limited, by modernist and positivist assumptions and methodologies. Moreover, this literature serves to reinforce dominant meta-narratives of deviance, tragedy and is lacking in relation to deafness. The production of this knowledge and meta-narratives has implications for what is possible for people to say and do in society in relation to hearing loss and deafness. However, prior to this thesis, to my knowledge, there has been little empirical exploration of how deafness is constructed within society nor the dynamic relationship
between constructions of deafness and the health experiences of people living with hearing loss or deafness.

**Aim of this Research**

The overarching aim of this thesis was to explore how theoretical debates of the dominant models of deafness mapped onto how people living with deafness or hearing loss and health professionals construct deafness. The particular focus on health professionals and the health context was informed by my personal interest in health and the notion that for most people who interact with living with deafness or hearing loss, their journey begins with the health system. The health system is a crucial context where constructions of deafness would need to be negotiated and where the interaction between the social and medical model would be identifiable.

It was also the aim of this thesis to conduct ethical and (linguistically) accessible research that was guided by the needs of people living with hearing loss or deafness. This aim was informed by my critique of the literature and from my connections and experiences with people living with hearing loss or deafness. The purpose of the reflexive style adopted in this thesis was to showcase the practical and ethical dilemmas I experienced during this thesis project, contextualising the knowledge that is produced in this thesis. Additionally, the reflexive journal entries illustrate the process of how my knowledge and skills have developed during this period, also shaping the construction of knowledge, which would not otherwise be known to the reader or future researchers.

**Findings**

**Study 1.**

The primary aim of Study 1 was to explore how people living with hearing loss or deafness talk about and understand deafness using a linguistically accessible online forum. In the context of the theoretical debates surrounding the dominant models of deafness, the purpose
of this study was to analyse the talk of the forum users to identify the discourses that were used (and not used) to construct their experiences. Through a discursive analysis of the forum posts we identified the deafness as abnormal discourse such that people living with hearing loss or deafness, regardless of their self-identified deaf identity (and diverse demographic information) subscribed to constructions of deafness and hearing loss as abnormal. Within the discourse of deafness as abnormal people living with hearing loss or deafness occupy a negatively valued identity position and subsequently engage in rhetorical strategies to manage their identity as people living with hearing loss or deafness. I identified three rhetorical strategies, fitting in, acceptance: permission to be different, and needing to prove normality. Although these strategies enabled the forum users to reposition themselves in a positive and socially-valued identity position, the use of these strategies reproduced the need to manage deafness as the responsibility of the individual. Consequently, constructions of deafness as abnormal or deafness as a devalued identity position are likely not challenged or altered as a social or institutional level.

Within the deafness as abnormal discourse the binary of normal abnormal is also reproduced whereby being or becoming ‘normal’ is idealised. The rhetorical strategies mobilised by the forum users centred on their efforts to adapt and pass as normal (hearing), redefining normal or proving their normality. Within the deafness as abnormal discourse the meta-narratives of tragedy and lacking are reproduced. Furthermore, what is abnormal is defined by what is normal and this in turn reinforces a comparative approach to deafness and hearing loss. As hearingness and oral communication are constructed as normal within this discourse, research, interventions and services which speak to this agenda will be well supported in society. Comparatively, research, interventions and services which subscribe to alternative constructions of deafness are less likely to readily receive funding and support. I argue we need to question the notion that ‘hearing is normal’ and consider the implications of
this taken for granted knowledge. Through critical examination of ‘hearing as normal’ we
will be able to identify alternative ‘truths’ that offer more and varied opportunities and
access for people living with hearing loss or deafness.

Although the focus of Study 1 was on the language use of the forum users, the design
of the forum may have limited discussion on the forum. Forum users were able to post
comments in either written English or videos of Auslan or spoken English. While each
participant opted to use written English, English may have been their second language and
therefore shaped the language they used on the forum. Additionally, videoed responses
maybe have been an unattractive option as they would have compromised the anonymity of
the user. The design of the forum (and approved ethics) also limited my ability as the forum
administrator to contact users encouraging them to return to the forum and respond to follow
up questions and other forum users or involve them in the data analysis process. In
combination these limitations may have limited the depth and diversity of the content on the
forum. However, despite these limitations, we were able to recruit a demographically diverse
group of people and identify the discourse of deafness as abnormal for this group of people in
the context of the forum.

The identification of the deafness as abnormal discourse makes visible the ways in
which language, and unexamined assumptions, shape positivist research and interventions
which reduce the hearing impairment of (and therefore normalise) people living with
deafness or hearing loss. While this discourse remains prevalent, individuals living with
hearing loss or deafness will continue to engage rhetorical strategies to manage their
negatively valued identity position, impeding the development of our understanding of
deafness and hearing loss (e.g., Deaf Gain). As such, we need to question the language use
that surrounds hearing loss and deafness and why we measure people living with hearing loss
or deafness against standards that are defined by the population of people living with
hearingness. Without questioning why hearing is normal, how hearing loss and deafness can be more than an impairment and how society, institutes and infrastructure contribute to experiences of ‘disability’, the health disadvantages experienced by people living with hearing loss or deafness will continue, contributing to costs on the health and welfare systems.

The findings of this study reinforce the notion that theoretical debates (Corker & Shakespeare, 2002; e.g., Lane, 2006; Shakespeare & Watson, 2001; Siebers, 2006b) about the various models of deafness, while necessary and informative, need empirical investigation. While discourses which speak to a medical construction of deafness or a social construction of deafness may have been evident on the forum (these discourses were not identified during the course of the analysis), the identification of the deafness as abnormal discourse suggests that people living with hearing loss or deafness do not readily construct their experience according to either the medical or social models of deafness as commonly assumed in the deaf sector. The findings of Study 1 add the burgeoning literature which suggests deaf identity (development) and constructions of deafness are more complex than medical and social models prescribe, that they are context specific, intersect with other identities (e.g., gender) and people do not rigidly subscribe to one model over another (e.g., Al-Makhamreh, 2013; Kemmery & Compton, 2014; Ladd & Lane, 2013; McIlroy & Storbeck, 2011; O’Brien & Emery, 2014).

Deafness as a devalued identity position contributes to the broader theoretical and empirical literature within which identity development is discussed as socially constructed (Gergen, 2000; McEwan, 2003). Torres, Jones and Renn (2009) discuss how new(er) theories of identity (development) such as Critical Race Theory, Queer Theory and Latino Critical theory, foreground marginalised populations and the societal structures that produce and perpetuate oppression and marginalisation. The findings from Study 1 build on these theories
of identity development which have largely focused on populations marginalised based on race, sexual orientation and gender; illustrating how societal structures marginalise people living with deafness or hearing loss, either as a ‘disabled’, or linguistic or cultural minority.

The findings of Study 1 informed my approach to questioning how health professionals talked about and understood experiences of deafness and hearing loss. Based on the finding that the models of deafness do not readily map on to how people living with hearing loss construct their experience I wanted to question how health professionals, who are commonly assumed to subscribe to medical constructions of deafness, construct hearing loss and deafness. The position of power that health professionals hold within our Western society was also something that interested me, how this would shape their constructions of deafness and hearing loss.

**Study 2.**

The primary aim of Study 2 was to explore how health professionals, who have had some experience working with clients living with hearing loss or deafness, talk about and understand deafness and hearing loss. This interest was informed by my conversations with people living with hearing loss or deafness, who colloquially discussed health professionals as espousing medical constructions of deafness with a focus on correcting hearing loss. This aim is also guided by the lack of empirical research that has explored the issue of deaf health disparities from the health professional’s perspective (e.g., Ebert & Heckerling, 1995; Thomas et al., 2006). As discussed in my review of the literature in Chapter 5, the empirical research that has explored barriers to accessing health services and information is largely informed by the people living with hearing loss or deafness. Comparatively less research has explored whether health professionals recognise their contribution to these barriers, are aware of these barriers or experience barriers themselves. Consequently, I was interested to explore
how health professionals talked about and understood deafness and hearing loss and their own ability to provide health services to this population.

Through an inductive thematic analysis with 18 health professionals I identified an overarching theme labelled hearingness as privileged. Through this analysis I was able to see how the health professionals recognised that the quality of health services available to people living in Australia with deafness or hearing loss was lacking and also how they accounted for this quality. Through the talk of the health professionals I was able to identify how the health system within Australia inherently privileges hearingness and how this provides a rationale for the disparities identified in the literature discussed in Chapter 5 (e.g., Gopinath et al., 2012; Hogan et al., 2009, 2011).

Through analysing the talk of the health professionals I was able to recognise the professionals as individuals operating within a larger, restrictive, system. Colloquially health professionals are discussed as endorsing the medical model of deafness and as asserting their power to corral people into making decisions in line with the medical model. Contrastingly, most of the health professionals I interviewed discussed the gaps in their knowledge and skills related to experiences of deafness and hearing loss and demonstrated a genuine interest in wanting to improve their service delivery. However, their efforts were discussed as being limited and restricted by the health system within which they worked (e.g., lack of resources, funding and broader recognition that this is an important issue).

The findings of Study 2 are limited by the shortage of perspectives from health professionals also living with hearing loss or deafness. However, the sample of health professionals I interviewed reflects the audiological diversity of this industry. Furthermore, it speaks to the notion that the health system (and higher education, training programs) inherently disadvantage people who are living with a hearing loss or deafness who are seeking a career or employment as a health professional, or industries ‘traditionally’
dominated by hearing people which is arguably all industries (e.g., Young et al., 2000; Young & Ackerman, 2001). The scarcity of available professionals who are living with hearing loss or deafness is discussed in Chapter 5 and is recognised as a barrier to accessing health information and services.

As Johnson (2006) and McIntosh (1986) explain, a key attribute of privileged is that mechanisms of privilege remain invisible to those who benefit from them and as such we are usually unaware of the ways in which we are privileged (Pease, 2010). In this way, mechanisms of privilege facilitate the continuation of discourses, such as the deafness as abnormal discourse, which oppress or disadvantage people living with hearing loss or deafness. The identification of privilege is productive in shifting the focus off individuals and meta-narratives of tragedy and loss, onto structures and systems which contribute to deaf health disparities. As I discussed in Chapter 5, much of the literature on deaf health examines the issue from the perspective of people living with hearing loss or deafness. While this is an important viewpoint, it produces a narrow view of a very complex issue. Furthermore, it allows deaf health disparities (and barriers to health) to remain an individualised problem that needs to be resolved through individualised efforts (e.g., learn oral language, lobby for funding to develop accessible health resources).

Changes required at a social, institutional or structural level remain under-examined and largely unaddressed. Examinations of Deaf and hearing cooperative workplaces and programs of research (where Deaf and hearing people are employed equally as staff members or researchers) highlight the entrenched (oppressive) nature of Deaf-hearing relations and the complexity of addressing the social, institutional and structural factors which serve to perpetuate the privilege of hearingness and oppression of deafness (e.g., Dickinson & Turner, 2008; McDermid, 2009; Young & Ackerman, 2001). Study 2 created the opportunity for health professionals, who interact with the health system on a frequent basis, to identify the
barriers and issues they experience offering health services to people living with hearing loss or deafness. Consequently, as researchers we are able to understand how systems restrict what is possible for health professionals to do and say and how this in turn informs deaf health disparities.

The purpose of this thesis is not to represent the voice of all people living with a hearing loss or deafness or all health professions but rather to identify how deafness can be constructed by people, how deafness is positioned within these constructions and the implications this has on what people can say and do to whom and when they can do it.

Although the experiences recounted by the online forum users and health professionals are specific to the Australian context, the findings of this thesis can be applied broadly as discourses are not geographically confined nor is privilege and oppression. The findings of Study 1 suggest that despite individual efforts, people living with deafness or hearing loss occupy a devalued position within our society. The findings of Study 2 suggest that both people living with hearing loss or deafness and health professionals are operating within a health system that inherently privileges hearingness. In combination, these findings contribute to our understanding of the health disparities that have been identified within the deaf health literature. Both with the deafness as abnormal discourse and within a system that privileges hearingness, the responsibility to remove barriers, achieve normality and resist oppression is put on people living with hearing loss or deafness. While individual effort is important, wider system level changes are needed to alter dominant discourses and practices which in turn will facilitate improved access to health services and information.

Achieving wider system level changes is particularly challenging. As people cannot exist outside of systems (Johnson, 2006), it is difficult to recognise when and what systems we are participating in and how they might inherently privilege us. Upon reflection, I can see how the current thesis similarly reproduces the focus on the actions of individual people. My
research questions focused on how language is used by individuals, how deafness is discussed and understood by key stakeholders. As privilege is sustained through remaining invisible, it is easier to identify what is visible, oppression, than what is invisible, privilege. Only through completing this thesis can I reflect on and now understand how I am privileged by my hearingness, how my hearingness has informed this thesis and be aware of how systems privilege hearingness. As a participant in the system of academia I recognise the challenges of producing rigorous research that challenges the very systems within which I receive privilege. At the conclusion of my thesis journey I attended the World Federation of the Deaf conference in Turkey. In Journal Entry 6, the final journal entry, I discuss the challenges I experienced as a hearing researcher at the World Federation of the Deaf conference; adopting the notion of hearingness as privileged, I reflect on the ways I have made sense of, and learned from, those experiences.

**Journal Entry 6 – A Hearing Academic in a Deaf World**

**July 2015**

The World Federation of the Deaf conference was held in Istanbul, Turkey in July 2015. This was my first experience of the Deaf world on an international stage. There were delegates from 97 different countries who were united by a shared Deaf culture. The presentations, including my own, covered a range of diverse and important topics (e.g., education, health, developing countries). Attending presentations from key academics in the deaf sector (who also happen to be Deaf) and being surrounded by sign languages from around the world was an invaluable experience.

While my experience of attending this conference was enriching, it was also profoundly challenging in many different ways. Linguistically, not knowing international sign made it difficult for me to negotiate communicating with other
delegates. Being my first time working with multiple interpreters, my skills as a presenter were challenged. Most importantly, I felt challenged as a hearing person.

Having limited access to communication with other delegates, created a situation where I experienced (physically, mentally, linguistically and emotionally), to a limited extend, some of the challenges people living with hearing loss or deafness experience daily in the hearing world - I am careful not to claim that I know what it is to live with a hearing loss or deafness in a world that values and assumes hearingness. This experience reinforced for me, that what is normal and abnormal is socially constructed; there is nothing inherent about hearingness or deafness that is less or more than the other.

Demonstrating the socially constructed nature of knowledge, power and categories, at the conference I was an outsider. As a hearing person, not working as an interpreter, and with no Deaf family, I could feel my legitimacy within the Deaf world being questioned. I have experienced this before on a smaller scale in Australia. However, now being mindful of the privilege of hearingness, I also felt urged to account for and manage my hearing privilege. For example, as a hearing (white, middle class, western woman) person I have had easy access to tertiary education and postgraduate and employment opportunities. My privilege has afforded me the opportunity to present at this conference, potentially taking the space of a deaf person who has not benefitted from the same privileges. I found it difficult to negotiate my privilege; how to (not) act, what (not) to say. I didn’t come up with any solutions and I don’t know how well I negotiated the situation but it was a constructive challenge that has certainly left me thinking.

Overall, it was being a hearing academic in a Deaf world, where my privilege as a hearing person was being challenged, that was the most enriching experience.
It is difficult to know the balance between believing that what I have to offer is of value and expressing that, and acknowledging my status as a largely unwelcome outsider. Do I convince people of my legitimacy as a hearing person in a Deaf world (and how do I convince people without being insincere)? How can I be manage my own privilege while still having my own voice? Indeed should I have my own voice? Adding another layer of difficulty to this reflective process is considering that it is within the very nature of privilege for me not to be able to easily recognise instances of my own privilege. As such, it is difficult for me to be able to recognise how my (re)actions are informed by my responses to my privilege being denied.

I have informally discussed my experience with colleagues who experience oppression in their own lives in other ways. One suggestion is that I should focus on presenting my work to hearing audiences, encouraging them to address their hearing privilege. However, I am mindful that the Deaf community have a clear mandate that research about deafness should not be conducted without people living with hearing loss or deafness. I need to consider ways of reconciling the Deaf research mandate, with my position as an outsider, with attempts to use my position as a hearing person to help other hearing people recognise their privilege, and address privilege at a system level – and this is proving to be a challenging endeavour.

My experience attending this conference has created an opportunity for me to reflect on my experience as a hearing academic with a passion for the lived experiences of hearing loss and deafness and Deaf culture. When I consider future directions for myself as an academic there doesn't appear to be straightforward solutions to the questions that this conference has raised for me. But through sharing my experiences and disseminating the findings of this thesis (academically and within the community of people living with hearing loss or deafness), there is a space
for people to develop new ideas and strategies for addressing the way systems privilege hearingness.

**Suggestions for Future Research**

In order to build on the findings of this thesis, future research should focus on identifying how systems privilege hearingness and explore strategies to help people (particularly those who are privileged) be a part of the solution to the problem of privilege and oppression. As Johnson (2006) explains the problem of privilege and oppression is pervasive and entrenched. Being able to clearly identify the problem is key to being able to talk about it in useful ways (Johnson, 2006). People can be made aware of the problem through closer examination of the health system (e.g., hospital departments, specific professions, training courses) and the ways in which policies and procedures privilege (e.g., assume) hearingness. For instance, how the language used in government and workplace policies construct and position hearingness and people living with hearing loss or deafness. It is also important that people understand that their involvement in the removal of privilege and oppression is part of a long term, complex process of change (Johnson, 2006). As such, researchers could focus on the development of strategies. These strategies should avoid blaming but rather focus on how individuals are able to incite system level changes to bring about long term change for future generations.

As a pervasive element of our society, media and social media have a critical role in the co-construction of knowledge and the production and reproduction of discourses. In light of this, future research could also explore how deafness is constructed within lay society, particularly through media and social media. The accrual of this knowledge could inform the development of strategies to question hearing as normal, challenge constructions of deafness as abnormal and demonstrate strategies that individuals can implement in their daily lives to challenge hearingness as privileged.
Implications Arising from the Research

There are several theoretical, practical and methodological implications that can be conferred from the research presented in this thesis. The theoretical implications relate to the theoretical discussions of the models of deafness and discussions of privilege and oppression while the practical implications relate to strategies people can employ to challenge the hearingness as privileged problem. The creative online space employed in Study 1 and the reflexive approach to this thesis contributes to the methodological implications of this thesis.

Theoretical Implications

The findings of Study 1 contribute to the theoretical debate of the models of deafness (see Chapter 4). While these on-going debates are valuable they suggest there is a delineation between the medical model and social models of deafness. Often times in lay discussions, these two distinct models are used to describe how people living with hearing loss or deafness orient to their experience and understanding of hearing loss and deafness. However, in contrast to these theoretical and lay discussions, the findings of Study 1 suggest that in reality, for the forum users, constructions of deafness are not readily delineated between the models. Nor are these constructions systematically informed by predictable combinations of audiological and demographic factors. This is an important finding because it suggests that much of the deaf health literature, which investigates relationships between these factors and the language and health outcomes of people living with hearing loss or deafness, may be reducing the complexity of this population. It is also important because these findings show that the models of deafness, which are commonly used to explain and describe how people identify with their deafness or hearing loss and how a person may interact with society, may also underserve the diversity and complexity of people living with hearing loss or deafness. Consequently, these findings suggest that people who operate within the deaf sector may need to question how we understand and talk about people living with hearing loss or
deafness; that separating people according to medical and social understandings of deafness may be damaging or misleading.

The findings of Study 2 build on current discussions of privilege and oppression, establishing hearingness as a sub category of the social category of able-bodiedness. Furthermore, Study 2 creates a link between the notion of audism and hearingness as privileged. In combination this theoretical contribution helps to build a foundation to justify further research and funding to continue exploring how systems in our society privilege hearingness and developing programs to address the problem of privilege and oppression. Understanding how privilege operates within our society can strengthen our understanding and the evidence of oppression.

**Practical Implications**

The empirical research reviewed in Chapter 5 suggests that people living with hearing loss or deafness experience disadvantages accessing health services and information and this has serious implications for the health related quality of life. The findings from Study 2 indicate that health professionals in Australia from a diverse range of health fields also recognise that their training and health service, and services more broadly, frequently do not meet the needs of people living with hearing loss or deafness. Furthermore, the findings of Study 2 help to illustrate how the effectiveness of previous and current efforts to address these health inequalities may be constrained by the health system. That is, while the health system continues to privilege hearingness, the efforts of people living with hearing loss or deafness and health professionals to achieve meaningful, long term change will be constrained.

The findings of this thesis reinforce the need to shift our focus from changing individuals to addressing changes at system levels. Although change at a system level is achieved through the actions of individuals (i.e., choosing to take paths of greater resistance), it is the target of our efforts that are important (Johnson, 2006). That is, rather than focusing
on how we can change individuals, we need to individually and collectively question and challenge how we participate in policies, practices and attitudes that allow the system to continue unchanged. Suggestions about how to do this include acknowledging that privilege and oppression exists (rather than deny it), listening when someone confronts your own oppressive behaviour, identify ways of changing how you participate within a system or in other words opting to take paths of greater resistance (e.g., not laughing at jokes that derogate experiences of deafness or hearing loss; Johnson, 2006). As Johnson (2006) explains, system level changes are progressively achieved through the actions of one person which create changes in the social environment which encourage others to follow suit.

The majority of health professionals in Study 2 identified ways in which they were already or could individually improve their service to meet the needs of people living with hearing loss or deafness. However, these efforts largely focused on changes at an individual level rather than efforts to challenge the system within which they operated. They described their efforts for consistent or greater change as being constrained by the system. They also felt that the number of people living with hearing loss or deafness does not warrant taking paths of greater resistance. The findings of Study 2 provide an empirical justification for the development of programs or workshops which could provide health professionals with tips and strategies for how to balance their need to both work within and challenge the health system which privileges hearingness.

Methodological Implications

The design and method of Study 1 contributes to the growing body of research on creating and using “deaf friendly” spaces online (e.g., Jones, Goldsmith, Effken, Button, & Crago, 2010). Despite the limitations of this method (e.g., confidentiality issues with videoed responses; English literacy skills), the publication of the reflexive process of designing and implementing this method makes it possible for researchers to improve upon this method,
creating more inclusive and rigorous research methods for research with people living with hearing loss or deafness. Furthermore, my efforts to consult with key stakeholders and people living with hearing loss or deafness during the design on Study 1 and Study 2 builds on the recent efforts other researchers (e.g., Barnett et al., 2011; Jones et al., 2010) to demonstrate the importance and benefits of conducting research with and not on people living with hearing loss or deafness. This approach to research is further reinforced through my efforts to distribute the findings of these studies back to the participants and wider community in an accessible format.

The reflexive process has also highlighted the importance of building a repository of methods and skills for researchers to use when collecting and analysing data in visual languages. Currently, there is a growing body of published research and expertise available to researchers to guide the use of methodologies using visual languages (e.g., Jones & Boyle, 2011; Sheppard, 2015; Stone & West, 2012; Temple & Young, 2004; Young & Temple, 2014). A notable example is Winston and Roy’s (2015) chapter on discourse analysis and sign language. Producing rigorous research in visual languages may contribute to the demand for journals to publish articles simultaneously in visual languages or establish peer reviewed journals which publish in visual languages (there is currently only one which publishes in American Sign Language). Further to this, the availability of training and expertise in visual language research methodology (in areas beyond linguistics and education) may encourage people living with hearing loss or deafness, particularly in Australia, to consider obtaining a research qualification and beginning a career in research.

The reflexive process that I have engaged in throughout this thesis has highlighted for me, the importance of the methodological research process, and the context within which it is conducted, to be made transparent; as has become standard for researchers from critical, qualitative perspectives (e.g., Stephens, 2015) and increasingly, researchers in the field deaf
studies (Young & Temple, 2014). Researchers are constantly making informed compromises in the course of designing studies and collecting and analysing data. In my experience, as I discussed in Chapter 6, I was negotiating conflicting priorities which included the interests of people living with hearing loss or deafness, the parameters of completing a research higher degree in the School of Psychology at the University of Queensland and factors related to my own personal health, time and resources. Improving the transparency of this negotiation process will improve the accessibility and rigour of research in the field of deafness and hearing loss.

**The Reflexive Process**

The reflexive process is visible throughout this thesis, in particular through the reflexive journal entries. The inclusion of these journal entries has added to the depth of knowledge presented. Such that it has facilitated my ability to communicate the context within which this research was conducted and how the knowledge presented in this thesis has developed across time. The rigour of the findings from Studies 1 and 2 has also been strengthened through engaging in reflexivity.

The reflexive process is also congruent with both the aims and outcomes of this thesis and the increasingly common reflexive practice in ‘deaf research’ (e.g., Young & Ackerman, 2001). Through constantly engaging in reflexivity, and showcasing this throughout the thesis, I am able to illustrate the actions I have taken to ensure the research I conducted was carried out with and not on people living with hearing loss or deafness. In light of the identification of hearingness and privilege, through including the reflexive journal entries I am able to share my new found awareness of my privileged identities and how this will inform my actions as a person and as a researcher.

Through engaging in reflexivity I have strengthened my understanding of ‘knowledge’ as socially constructed. It has highlighted for me that within Australia, and in
particular within psychology, a higher value that is more readily recognised is placed on research that is positivist and quantitative in nature, than research that is not positivist and quantitative. The system of academia, key performance indicators and the publishing process prescribes what kind of research is valued and rigorous, what can be published, how it can be published and when. Research that does not subscribe to current notions of ‘science’, or rigor or the agenda of journals and funding bodies is less likely to be initiated, completed or published for wider consumption. In this way what is considered knowledge is a social construction.

The reflexive process has also highlighted for me a perpetual dilemma that I face as a hearing researcher doing research in the deaf sector, as others have also experienced (e.g., Young & Ackerman, 2001). Not only am I an outsider because I am hearing but I am a privileged outsider. There are times, when my privilege is particularly apparent, that I struggle to manage my privileged position and desire to choose paths of greater resistance. Lakritz (1995) suggests that rather than speaking for the marginalised, members of privileged groups should talk about how their lives are transformed by their experiences of engaging with the marginalised and their stories of oppression and exploitation.

In considering how my life has been transformed I am aware that I have only encountered the notion of privilege and hearingness as privilege in the later stages of my thesis journey. Thus it is difficult to articulate how listening to people’s experiences of marginalisation because of their hearing loss has transformed me personally and academically. In the first instance I have become more aware of my privileged identities. As I reflect on my position and how I operate within systems which continue to privilege my identities as hearing, white, nondisabled and highly educated, it is challenging balancing my personal interest and welfare against my new found recognition for the need to take paths of greater resistance. As an example, recently my privilege of being able to access and complete
higher education and afford to participate in events which have subsequently provided me with the opportunity to establish networks, has resulted in my being able to apply for and accept a job as a research officer for a small team that specialises in deafness and mental health. However, I am constantly aware that in accepting this job, I may have taken this opportunity away from a person living with hearing loss or deafness who has not experienced that same privilege that I have benefited from. I have found this a difficult experience to justify and accept and is something I am continuing to negotiate. One solution is to use my position to create opportunities to collaborate with a person or people living with hearing loss or deafness on a research project, using the opportunity to develop skills and provide mentorship in navigating and changing the academic system. Additionally, encouraging the recruitment of a person living with hearing loss or deafness to fill my role when I leave.

In summary, I have found this reflexive process an invaluable element of this thesis. Engaging in reflexivity has enabled me to demonstrate the progression of this thesis and my thinking, illustrate the complex context within which research decisions were made and highlight the ethical considerations involved in doing social constructionist and qualitative research with people living with a hearing loss or deafness. Moving forward in my research career, I will continue to engage in reflexivity and take opportunities to share this process in all aspects of my life.
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Appendix A1: Screenshot of articles and comments discussed in Ferndale, Watson, & Munro (2013).

**Figure 1.1.** Screen shot from November 2013 of the ABC’s Ramp Up blog article titled The divided culture of the Deaf.
Figure 1.2. Screen shot from November 2013 of the comments responding to the ABC’s Ramp Up blog article title The divided culture of the Deaf.
Figure 1.3. Screen shot from November 2013 of Charlie Swinbourne’s blog article titled Deafness isn’t a “scourge”.

Figure 1.4. Screen shot of the comments responding to Charlie Swinbourne’s blog article titled Deafness isn’t a “scourge”.
Figure 1.5. Screen shot from November 2013 of the comments responded to an article posted online for The Age in October titled Deaf group angry at comment by disabled children’s educator.
Appendix B1: Study 1 recruitment flyer

**HAVE YOUR SAY**

What is your experience of being deaf/hearing impaired or being the parent of a child with a hearing loss?
What is your experience with health care providers in Australia?

These are important questions for you to answer because you are the experts in hearing loss. In telling your story you will have an important role in improving the support, policies and funding for deaf, Deaf and hearing impaired Australians and future Australians with a hearing loss. We want as many parents, Deaf, deaf and hearing impaired Australians as we can to participate because this will give you a stronger presence and help show how big the Deaf, deaf and hearing impaired population of Australia is and how important you are - in numbers there is strength.

We want to hear about your experience of having a hearing loss and your experience with health care providers. The findings of this research will be presented back to the Deaf, deaf and hearing impaired community and to organisations who lobby on behalf these communities and other related bodies.

To tell your story you will need to complete a short survey and then go on to a forum and discuss some questions.

Tell your story by going to this web address: [http://haveyoursay.psy.uq.edu.au](http://haveyoursay.psy.uq.edu.au)

Or contact Danielle Ferndale:
Email: danielle.ferndale@uqconnect.edu.au
Twitter: @deafresearchau

Help spread the word and forward this on to friends, family and colleagues.
Appendix B2: Information about project given to community members for feedback

Deaf Health Research Project
‘Have your say: Be heard’

Hello,

Thank you for your support, time and effort in helping me with this research project. The following is a detailed explanation of what I am trying to achieve with this project and how the whole project will work. Copies of the materials that will be used in the project are at the end of the document. These materials include the information that people will read on the website before participating in my research, the survey questions they will be asked and the discussions questions that will posted in the forum for people to comment on.

As I outlined in the email, there are a number of goals I am trying achieve with this research project. The first goal is to explore deaf and Deaf Australians’ experiences of being deaf, their experiences with the health industry and how these experiences have influenced their decisions and health and well-being. Also to discuss their thoughts on the barriers they face when dealing with the health industry and what they think needs to change to improve their experiences. The second goal is to explore parents’, both deaf and hearing, experiences with the health industry and their child's hearing loss and how these experiences have shaped their choices when raising their child with a hearing loss.

To achieve these goals in the most time and cost efficient way I have decided to use an online forum. Using an online forum allows deaf persons from all around Australia to participate and have their say without me having to fly around the whole country on my small PhD scholarship and interview every single person which would take up a lot of time and a lot of resources which can be better served through the online survey and forum. However, just because it is online doesn’t mean everyone can participate. I realise there is still a language barrier that I need to overcome. In order to overcome this barrier I need the help and expertise of the Deaf community and people who work closely with deaf people on a regular basis.

One method I have come up with to get around this language barrier is to present the project materials on the website in both English (written) and Auslan (video’s). This is one particular area where I require some help. I am aware that there is a lot of variability in deaf people’s understanding of written English so I want to make sure that the written information will be understood by as many people as possible.

Keeping in mind that everything on the forum (or as much as possible) will be available in both written English and Auslan I will tell you more about the forum and how it will work. The idea is that people will go the forum website, read (or watch the Auslan interpretation) the information about the project and choose to participate. They will then click on a link which will take them to a survey. If they are a parent they will click to complete the parent survey and if they are an individual they will complete the survey for individuals. Everyone’s survey answers will be anonymous.

When a person has finished the survey, the website will create a username and password for that person. He or she can use this username and password to log on to the forums. Again parents and individuals will have their own forum. Individuals who are parents also can participate in both, but will need to fill out both surveys. When they log on to the forum the participants will be able to see and read the discussion questions and they can post their response to the questions and also see and respond to what other people have commented. I am working with a university IT person to try and make it possible for people to be able to post both written comments and video comments so that people can use Auslan to respond to the questions. I will monitor the forum on a daily basis to make sure people are being respectful and staying on topic. If people choose to post video comments their
anonymity can’t be guaranteed but all written comments can be anonymous. When the data is analysed no identifying information will be kept and everything will be anonymous in any publications.

The survey and forum will be available for comment for two or three months to give everyone an opportunity to hear about it and participate. As I mentioned in the email, to help advertise the study and get the word out I will contact Deaf organisations around Australia and other related bodies to ask if they can put a link on their website or advertise in their newsletter.

At the end of the two or three months the site will be shut down and I will begin analysing the data. Given the size of the data that I hope to collect, a research assistant will more than likely help me analyse the data. Everything will be kept secure and anonymous. Once I have finished analysing the data I hope to present it back to the people who participated, to the Deaf community and anyone else who is interested. I haven’t thought of how best to do that, so any suggestions are welcome. As this project is designed to benefit deaf people and as I mentioned in the email, organisations interested in using the data will be able to do so.

This study has been given ethical clearance by the School of Psychology at the University of Queensland (Ethical clearance numbers: 12-PSYCH-PhD-09-JS and 12-PSYCH-PhD-10-JS). Once I receive your feedback and suggestions I will make some changes and apply for an amendment to my ethics application.

Now that I have given you all the background information, below is the information participants will read before participating in the forum, the survey questions for parents and individuals and the proposed discussion questions. The Auslan version of the information is yet to organised and filmed. If you know of anyone who would like to be involved and volunteer as a video model for the Auslan information let me know and I can get in contact with them.

Any guidance or suggestions you have in relation to:

Information page: whether the information understandable, if you think I need to mention anything else, for people who are negatively affected by the forum (e.g. talking about their experience makes them sad) do you know of any professional resources they could access to help them?

The survey and discussion questions I have proposed – are they important, do you think there are other important questions to ask, are they worded appropriately, are the answer options appropriate

Participants: do you think there should be an age limit for parents to participate (e.g. their child is currently 18years old or younger) or all parents should be able to participate no matter how old their child with a hearing loss is? Do you think people will want to post video comments? Are there any groups of people you think might not be able to access the forum that I should be aware of so that I can try and find a way for them to still be involved?

Of course any other criticism, ideas and suggestions are welcome. Again, thank you for your time, effort and support. If you have any questions please email me or call me on 0433002177.
Appendix B3: Study 1 recruitment newsletter blurb

Have your Say: Be Heard. PhD research into the health and well-being of deaf Australians

With the help of some deaf individuals and Deaf community members, Danielle Ferndale, a PhD student from the University of Queensland is conducting a nationwide research project investigating first, Deaf, deaf and hearing impaired Australians’ experience of hearing loss and their experience with health care providers and second, parents’ experience of raising a child with a hearing loss.

We want as many Deaf, deaf and hearing impaired Australians as we can to participate because this will give Deaf, deaf and hearing impaired Australians a stronger voice and provide an accurate indication of the size of the Deaf, deaf and hearing impaired population of Australia and the importance of this population. This research offers you the opportunity to tell your story of being a deaf, Deaf or hearing impaired Australian. In telling your story you will have an important role in contributing to better support, policies and funding for yourself and for future Australians with a hearing loss.

The findings of this research will be presented back to the Deaf, deaf and hearing impaired communities, to organisations who lobby on behalf on these communities and to other related bodies.

To tell your story, you will need to complete a short survey which takes 5mins and then go onto a forum and answer some discussion questions and have a discussion with other participants about their experiences. All the information is available in Auslan and English.

Tell your story by going to this web address: http://haveyoursay.psy.uq.edu.au

Or contact Danielle Ferndale
Email: danielle.ferndale@uqconnect.edu.au
Twitter: @deafresearchau

Help spread the word - tell your friends, family and colleagues to tell their story and be heard!
Appendix B4: Study 1 participant information

‘Have your say: Be heard’
Information

My name is Danielle Ferndale. I am a PhD student in the School of Psychology at the University of Queensland under the supervision of Dr. Bernadette Watson. This is a survey for deaf, Deaf and hearing impaired Australians who are 18 years old and older. This survey is part of a university research study. Danielle Ferndale is the person who is in charge of this research.

With the help of some Deaf community members and people who work closely with the Deaf community, Danielle has put together this survey. Your answers to these questions will help to give deaf people a voice and help to make changes to make it better for deaf people.

You can choose to participate in this research but you don’t have to. If you change your mind and you do not want to participate anymore that is alright you are free to stop without any consequences. You do not have to give any personal identity information.

If you want to participate in this research you need to first complete a short survey. The survey asks questions about yourself. Then answer some discussion questions. Your answers will be kept private and in a password protected computer.

If you have any problems with the questionnaire you can email Danielle. If you think something is rude or offensive you can tell Danielle and talk about the issue with her. You can stop participating in the research when you want and if you don’t want your comments to be a part of the research anymore you must tell Danielle.

Because this forum is part of a research study your answers to the questionnaire and the forum questions will be copied word for word, then coded and analysed by Danielle. You will not give any personal information so everyone’s answers will be private. Once the answers have been analysed the information will be presented to deaf people who are interested. Deaf and hearing impairment organisations who advocate on behalf of deaf people might want to use some of the information to lobby on behalf of deaf people. They will only be allowed to use the information that has already been analysed by Danielle.
The forum will finish at the end of August and as soon as possible the research findings will be available for deaf people who are interested.

If you want to participate in the research and agree to your responses being analysed and reported as a part of this study please fill out the survey.

This study has been cleared in accordance with the ethical review processes of the University of Queensland and within the guidelines of the National Statement on Ethical Conduct in Human Research. You are free to discuss your participation with project staff (contactable on: 0433 002 177; danielle.ferndale@uqconnect.edu.au). If you would like to speak to an officer of the University not involved in the study, you may contact one of the School of Psychology Ethics Review Officers: Jolanda Jetten (j.jetten@psy.uq.edu.au, tel 3365 4909), Michael Phillip, (tel 3365 4496) or Jeanie Sheffield (jeanie@psy.uq.edu.au, tel 3365 6690). Alternatively, you may leave a message with Ann Lee (3365 6448, ann@psy.uq.edu.au) for an ethics officer to contact you, or contact the University of Queensland Ethics Officer, Michael Tse, on 3365 3924, e-mail: humanethics@research.uq.edu.au

Thank you
Appendix B5: Study 1 Survey

What is your Gender?

- Male
- Female

How old are you?

______________

I was born in ....

______________

I live in...

- ACT
- NSW
- NT
- QLD
- SA
- Vic
- WA
- TAS

Do you live in the city or country?

- Capital City
- Country
- Regional City
I have finished...

- Primary School
- Grade 8
- Grade 9
- Grade 10
- Grade 11
- Grade 12
- University Bachelor Degree
- Postgraduate Study
- Tafe certificate
- Apprenticeship
- Traineeship

What type of school(s) did you attend and how positive was your experience at that school (rate out of 5; 0=not very positive 5 = very positive)?

- Residential School for the Deaf
- School for the Deaf
- Mainstream Private School
- Mainstream State School
- Mainstream Boarding School
- Special School
- Never went to school

What is your Job?

______________________________
Which is your preferred mode of communication at...

<table>
<thead>
<tr>
<th></th>
<th>Spoken English</th>
<th>Auslan</th>
<th>Signed English</th>
<th>Typing on a Computer</th>
<th>Home Sign</th>
<th>Total Communication</th>
<th>Simultaneous Communication</th>
<th>Writing Notes</th>
<th>Ubi-Duo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Work</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>With Friends</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

How good do you think you are at communicating in your preferred mode of communication?

<table>
<thead>
<tr>
<th></th>
<th>Very Bad</th>
<th>Not Very Good</th>
<th>OK</th>
<th>Good</th>
<th>Very Good</th>
<th>Fluent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>With Friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
At what age was your hearing loss diagnosed?

How would you describe your hearing ability?

- Slight
- Mild
- Moderate
- Severe
- Profound

Do you use any assistive hearing devices?

- Hearing Aid
- Cochlear Implant
- No
- Other

What age did you get your Cochlear Implant?

How well has the Cochlear Implant worked for you?

- Not at all
- Not very well
- OK
- Good
- Very well
Which best describes your identity?

- deaf
- hearing impaired
- Deaf
- Bicultural/Bilingual
- Hearing
- Hard of Hearing
- Deafblind
Appendix B6: Study 1 Forum Questions

1. What is your experience of having a hearing loss or being deaf/Deaf? – Positive or Negative – Why?

2. Do you think you have reached your full potential? (e.g. in relation to work, relationships, achieving goals etc. do you think hearing people have held you back/helped you; your hearing loss has held you back/benefited you etc.)

3. What is your experience with people who work in health, including people not related to deafness e.g. doctors, nurses, psychologists, audiologists, counsellors, speech therapists? – Positive or Negative – Why?

4. How have your experiences shaped your choices in life: e.g. hearing aids, cochlear implant; part of hearing or Deaf world; willing to go to the doctor; view of hearing people etc.

5. How have your experiences shaped how you think of yourself: e.g. valuable, important, smart, worthwhile, lovable, special, different etc.

6. What do you think are some problems with doctors, audiologists, counsellors, speech therapists etc.? Why do you think they exist?

7. What do you think needs to change to make that better?

8. Do you think deaf people should fit into the hearing world or the hearing world should make changes so that hearing and deaf people can exist together?
Appendix B7: Screenshot of Forum Website

Figure 2.1. Screenshot of Study 1 forum website home page, showcasing the language accessibility of the website
Appendix B8: Summary Report Provided to Participants

Experiences of deafness and hearing loss in Australia

Danielle Ferndale
School of Psychology, The University of Queensland.

The aim of this project was to explore how people living in Australia with hearing loss or deafness understand deafness. 119 people completed the survey and 24 people then chose to respond to open-ended questions on the online forum. This report provides a summary of the survey and forum data with the interest of communicating these findings to the people who kindly participated and the wider community.
CITY VS. COUNTRY
72 people lived in a capital city. 15 people lived in a country town. 29 people lived in a regional city.

EDUCATION

Level of Education Completed

<table>
<thead>
<tr>
<th>Level</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary School</td>
<td>2</td>
</tr>
<tr>
<td>Grade 10</td>
<td>14</td>
</tr>
<tr>
<td>Grade 11</td>
<td>2</td>
</tr>
<tr>
<td>Grade 12</td>
<td>13</td>
</tr>
<tr>
<td>University Bachelor Degree</td>
<td>33</td>
</tr>
<tr>
<td>Postgraduate (e.g., Masters, PhD)</td>
<td>16</td>
</tr>
<tr>
<td>Tafe</td>
<td>21</td>
</tr>
<tr>
<td>Apprenticeship</td>
<td>4</td>
</tr>
<tr>
<td>Traineeship</td>
<td>1</td>
</tr>
</tbody>
</table>

Most Common Jobs

<table>
<thead>
<tr>
<th>Employment (e.g., teacher, lecturer)</th>
<th>Administration (e.g., clerk, assistant)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Service</td>
<td>Engineer</td>
</tr>
<tr>
<td>Hospitality</td>
<td>IT Support</td>
</tr>
<tr>
<td>Unemployed</td>
<td>Journalist</td>
</tr>
<tr>
<td>Trade (e.g., carpenter, electrician)</td>
<td>Student</td>
</tr>
<tr>
<td>Research and Science</td>
<td>Retail</td>
</tr>
<tr>
<td>Self employed (e.g., builder, retail)</td>
<td>Health worker (e.g., nurse, social worker, counsellor)</td>
</tr>
</tbody>
</table>
COMMUNICATION
People were asked how do people communicate at home, at work and with friends. People could tick as many options as they needed.

People were asked to rate their ability to communicate at home, at work and with friends.

AMOUNT OF HEARING LOSS

IDENTITY

TECHNOLOGY
What did people say on the forum?

People (10 Men, 13 Women) aged between 20 and 81 (average 53) years old commented on the forum. Most people identified as hearing impaired, with only a few people identifying as deaf, Bicultural, hearing and hard of hearing. People shared their experiences of growing up, being at school, working, travelling and being treated by health professionals. Their experiences revolved around three ideas:

1. Feeling different and the need for acceptance
2. The importance of support
3. Focus on ability not disability

1. FEELING DIFFERENCE AND THE NEED FOR ACCEPTANCE

Many people commented on the situation and things that made them feel different. Other people did recall feeling different from family, peers or co-workers. It was clear that people did not want to be different and they talked about the strategies they used to look as if they are ‘normal’. Some people said they did not feel different because of their deafness.

Here are some examples of what people wrote:

A few people said that it is particularly important for family members to show love and acceptance towards their deaf or hearing impaired child.

Here are some examples of what people wrote:

Some people also commented on the dilemma they experienced learning to accept their own deafness and what it meant for their identity and relationships.

Here are some examples of what people wrote:

“Social situations were extremely stressful, so to look as if I was ‘normal’ I created my own party trick.”

“But every Deaf Community had different ability of what they can do, it the same as Hearing people”

“There has to be an acceptance that the child may never hear or speak as they do”

“It is important for families with Deaf children to show love, acceptance and support towards their Deaf child/children.”

“Now that I accept myself for who I am, I no longer have to strive to be normal. It’s been liberating.”

“I do remember the struggle I had at hearing schools and finding my own identity as a Deaf woman at around 18 years old. Now as a 45 year old woman, I’m satisfied with what I have now”
2. THE IMPORTANCE OF SUPPORT
Many people on the forum commented on the importance of support. People talked about receiving different types of support from a range of people in their life. This included equipment which supported their ability to do their job and support from people. The importance of family support was discussed by several people on the forum. Others talked about support from their community, in their workplace and from health professionals.

Here are some examples of what people wrote:
When people commented that they had little support they often talked about having a negative experience.

Here are some examples of what people wrote:

3. FOCUS ON ABILITY NOT DISABILITY
Several people talked about the importance of and their ability to overcome the barriers they faced in their daily lives. For many, it was important that they didn’t let their deafness get in the way of their lives or happiness. People who were able to overcome the challenges they faced felt like this was an achievement for them.

Here are some examples of what people wrote:

“Growing up as a profoundly Deaf female has been positive experience for me, I was lucky to receive support from family, friends, colleagues and educators…”

“I think a supportive family is a key issue for people who are Deaf and hard of hearing…”

“I have received a great deal of help since becoming over 90% deaf through Australia Hearing with very powerful hearing aids and listening device, which has vastly improved my experience.”

“It hurts when family and friends don’t try to help enough to bridge the isolation”

“Others give ‘lip-service’ to understanding but very soon forget their good intentions… This is the same for friends and family.”

“‘different speech’ – some girls made fun of that aspect but my family always redirected me to focus on positive parts of my life – my ability not my disability.”

“I do not let my deafness to get in the way of my dreams and I have had to show the world what I am made of and what I am capable of”
Conclusion

The purpose of this project was to explore how people living in Australia with hearing loss or deafness understood deafness. The people on the forum posted comments about many diverse experiences, good and bad, challenging and encouraging. The people who were generous enough to participate in the forum described three important issues, deaf acceptance, support and the need to focus on ability not disability.

It was clear from the responses on the forum that people who experience deafness and hearing loss describe deafness as something that needs to be accepted and supported by family, co-workers and society. However, it was also clear that deafness was understood as something that is not readily accepted by people and this can have a negative impact on the experiences and opportunities for people living with deafness or hearing loss.

“There is a strong dialogue in society that says “normal” is good, that being able bodied is the best and most desirable way to be. This can be disempowering for people with a disability and is misleading because a good quality of life is not exclusive to the able bodied.”

I would like to acknowledge and thank the various individuals and organisations that were involved in and contributed to the development of this project. Thank you to the people who completed the survey and the 24 forum users for sharing their experiences with us.

About the researcher: Danielle is a young hearing woman completing her PhD Student in the School of Psychology at the University of Queensland. Danielle has been learning Auslan since 2011 and volunteered at the Australian Deaf Games held Geelong in 2012.

Danielle Ferndale
School of Psychology, The University of Queensland. June 2015

PhD Project supervised by: Dr Bernadette Watson and Dr Louise Munro

dferndale@gmail.com
@deafresearchau
HEALTH AND ALLIED CARE PROVIDERS

What is your experience of working with clients living with a hearing loss or deafness?

Your participation in this research would involve a one-on-one interview with the researcher (Danielle), to talk about your experience of working with clients who have a hearing loss or deafness. The interview will take approximately 30 minutes at a time convenient to you, via phone, Skype or face-to-face. This interview will include general questions such as your interest in your field of expertise, the training you have received and your experiences working with clients who have a hearing loss or deafness. Your participation in the interview is completely voluntary. Participation in this interview will be completely anonymous and confidential. This study forms part of my PhD research project which I (Danielle Ferndale) am conducting at The University of Queensland with Dr. Bernadette Watson and Dr Louise Munro.

If you would like more information or would like to participate please contact me

Danielle Ferndale:
Email: danielle.ferndale@uqconnect.edu.au
Twitter: @deafresearchau

Help spread the word and pass this on to colleagues.
Appendix C2: Study 2 Participant Information

Thank you for considering taking part in an interview. This study forms part of my PhD research project which I (Danielle Ferndale) am conducting at The University of Queensland with Dr. Bernadette Watson and Dr Louise Munro.

Your participation would involve a one-on-one interview with the researcher (Danielle), to explore your experience of working with clients who have a hearing loss or deafness. The interview should last between 30 and 45 minutes. If you agree, the interview will be audio/video-recorded. Recording the interview precludes the need for me to take copious notes during the interview.

Your participation in the interview is completely voluntary. At the conclusion of the interview you are able to choose a pseudonym (fake name) that I can use throughout the research to maintain your anonymity and privacy. This interview will include general questions on topics such as your interest in your field of expertise, the training you have received and your experiences working with clients who have a hearing loss or deafness. If at any time during the interview you feel uncomfortable then you are free to withdraw from the interview completely. All information relating to this study (including the tape recording) will be kept secured in a locked cabinet only accessibly by Danielle. Only myself and my supervisors will have access to the recording.

Thank you for your participation in this study.

This study has been cleared in accordance with the ethical review processes of the University of Queensland and within the guidelines of the National Statement on Ethical Conduct in Human Research. You are, of course, free to discuss your participation with project staff (contactable on: 0433 002 177; danielle.ferndale@uqconnect.edu.au). If you would like to speak to an officer of the University not involved in the study, you may contact one of the School of Psychology Ethics Review Officers, Jolanda Jetten (j.jetten@psy.uq.edu.au, tel 3365 4909), Jeanie Sheffield (jeanie@psy.uq.edu.au, tel 3365 6690), Thomas Suddendorf (tsuddend@psy.uq.edu.au, tel 3365 8341) or Alex Haslam (uqhasla@uq.edu.au, tel 3346 7345). Alternatively, you may leave a message with Ann Lee (3365 6448, a.lee@psy.uq.edu.au) for an ethics officer to contact you, or contact the University of Queensland Ethics Officer, Michael Tse, on 3365 3924, e-mail: humanethics@research.uq.edu.au.
Appendix C3: Example of Study 2 Interview Guide

**Hearing HCP’s Interview Questions:**

- How do HCP talk about deafness/hearing loss?
- What behaviours do they engage in?
- How does this shape a deaf individual’s experience of health care?

Thank you for your time this morning I really appreciate it. So as I mentioned in the participant information I emailed, I am interested in learning about your experiences of working in the area of deafness and hearing loss. Everything discussed here today is confidential. Do you have any questions before I start?

Do you mind if I use the term deaf to refer to all children and people living with hearing loss or deafness? Or what term(s) would you prefer I use?

1. How would you describe your role as an audiologist?
   a. How many consumers have you worked with (how many years)
   b. How regularly do you interact with people who have a hearing loss or deafness as co-workers or outside of your work?

2. What got you into your current field – why are you interested in audiology? **What is training or qualification?**

3. How would you describe the differences between the different deaf identities (like HI, HoH, Deaf, deaf) – if you think there are differences at all? – why do you think there are these differences?

4. How would you describe the life experiences of deaf people (education, home, work, friends, relationships)

5. Could you tell me about your most memorable positive experiences with a deaf person? – What made that experience so successful?

6. Could you tell me about your most memorable negative experience with a deaf person? – what made that experience so unsuccessful?

7. How do you communicate with your consumers? (more than one way?, Ask for example of hard to communicate and easy to communicate – how are they different; What would you do if you couldn’t communicate with your patient? What do you rely on?
   a. What is your experience working with an interpreter – help or hinder, do you know how to book/who pays for the interpreter)

8. From your experience could you tell me about your consumers’ knowledge of deafness?

   Is there anything else you would like to comment on about the things we have talked about before I move on to another topic?

9. Could you tell me about what you think about the services provided to deaf australians? Do they currently meet their needs?
10. Do you feel you were adequately trained or prepared to work with deaf people? – did you receive any specialist training?

11. Do you think training and education programs should or is there room to provide more explicit training on working with deafness and hearing loss and the psychosocial implications of living with deafness?

12. Are you aware of the Deaf Culture in Australia – what is your experience with Deaf culture and Deaf people?

13. Do you think there is a place for qualified deaf or hearing impaired professionals in your industry?

That is all my questions, do you have anything else you would like to share with me that we haven’t had a chance to talk about today?

Thank you for your time. Would you like to choose a pseudonym that I can use when writing about this research? Once I have transcribed this interview I will send you a copy of the transcript for you to look over and have an opportunity to comment on the transcription. Once I have completed all the interviews would you be interested in a summary of the preliminary findings of the interviews?
Health Professional’s Experiences of Treating Clients Living in Australia with Deafness and Hearing Loss

Danielle Ferndale
School of Psychology The University of Queensland.

The aim of this project was to explore health professional's experiences of providing health services to people living in Australia with hearing loss or deafness.

18 health professionals from Australia were interviewed. The professionals worked in a variety of allied and medical health professions.

This report provides a summary of the interview data with the interest of communicating these findings to the professionals who kindly participated and the wider community.
Who Participated

<table>
<thead>
<tr>
<th>Gender</th>
<th>Years of Experience</th>
</tr>
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<tbody>
<tr>
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<td>Least</td>
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<td>Female</td>
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<table>
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<td>QLD</td>
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<tr>
<td>Allied</td>
<td>Ear Nose Throat Specialist</td>
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<tr>
<td></td>
<td>General Practitioning</td>
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<tr>
<td></td>
<td>Physiotherapy</td>
<td>2</td>
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</tr>
<tr>
<td></td>
<td>Dietetics</td>
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<tr>
<td></td>
<td>Pharmacy</td>
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<td></td>
<td>Audiology</td>
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</table>

<table>
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<th>Community vs. Specialised Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
</tr>
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<td>1</td>
</tr>
</tbody>
</table>

The Interviews

The health professionals were asked to respond to general questions about their experience providing health services or treatments to people living with hearing loss or deafness. The questions included their interest in their field, the training they had received (generally and specific to hearing loss and deafness), their experiences (positive and negative) treating clients living with hearing loss or deafness. The professionals were also asked specific questions about their understanding of deaf identities (e.g., Deaf, hard of hearing etc.), how they communicated with their clients and how, if at all, they felt their training could be improved. Each professional was also asked to comment on whether they thought a qualified deaf of hearing impaired person could work in their field.

I acknowledge that people who acquire a hearing loss later in life negotiate some challenges separate to those experienced by people who are born deaf or acquire hearing loss early in life. However, the real world experience of health professionals is that they see the full range of hearing loss and deafness in their clients rather than one pre-determined sub sample. Through asking about the professionals’ experiences with clients living with hearing loss or deafness our intention was to maintain this complexity and diversity of experience for both the health professionals and the population of people living with hearing loss.
A Summary of the interviews

Most people described the health services, both general and specific to the needs of people living with hearing loss and deafness, as being insufficient.

“I thought how can the deaf people see a [allied health professional] that does not use their language or understand their culture and ways of living”

“even like in [City] like on the North side if you wanted to go to a child development service to get your child assessed or monitored it could easily be an 18mth waiting list which is pretty significant if your only 6mths old”

“I suppose with our deaf consumer we want to do some in depth counselling and that’s been a struggle for us as a team to a um to organise that to get a psychologist who can who is um experienced in working with a deaf consumer”

“I think you’re at an advantage if you live in live in a regional metropolitan centre as opposed to a rural centre”

There were also some people who described the health services available as sufficient.

“I suppose with our deaf consumer we want to do some in depth counselling and that’s been a struggle for us as a team to a um to organise that to get a psychologist who can who is um experienced in working with a deaf consumer”

There were some professionals, particularly allied health professionals who raised concerns about the validity of the therapeutic tools used in their work place.

“I mean I guess I’m aware as a psychologist not all psychometric assessments work on all populations of people so it applies very similarly to the deaf population”

“I would hope because of the nature of the risk assessment tools um that it does take does allow for the experience of a deaf person to be fully captured or as fully as possible”

“I’m a bit scared of that”

“I’m a bit scared of that as a lot of the tools are developed are extremely inappropriate for deaf people”
When discussing the training specific to treating clients living with deafness and hearing loss that they had received many of the health professionals recalled their training as being provided ‘on the job’.

“Oh no, not at all. No I had no training specific to hearing loss um in my psychology degree. Zero. Um I did health psyc and some disability stuff but nothing specific to hearing loss that I recall”

“Had I not worked with deaf people before there was no training”

“most of it I learnt on the job”

When discussing suggestions for how, if at all, training and education programs could provide more explicit training on working with deafness and hearing loss (e.g., communication, psycho social implications) most professionals responded that changes might be helpful but they weren’t sure how they could be implemented or if the size of the population warranted such changes.

“It’s really important to have training within universities for … anyone who’s going to be working in the health area you know to have a great awareness of the implications for mental health of deafness. how to work with interpreters and the need for them you know and um how to use real time captioning for the hearing impaired group”

“I think there’s room for it. Um it’s really specialised so I’m not sure where that would necessarily fit like reflecting on my training like I’m not sure where it would fit exactly”

Across the interviews, a variety of strategies were used to facilitate communication. These included the use of Auslan interpreters, skype, reading lips and writing notes.

“I’ve got one chap who comes in with an iPad and he types questions into that and then I type the answers into it”

“we’d often write notes down she would write back”

“when we were using Skype it wasn’t really helpful. I think it was actually better to have a face-to-face discussion because there’s um a lot of opportunities for drawing and you know using some role plays … Skype it was a bit limiting”

“um some are some are excellent lip readers but they miss a lot and some you have to write things down um either on an iPad or a piece of paper or some other method some you have to explain to them through a family member ah or through a translator interpreter if they’re signing in particular”
On numerous occasions across the interviews people recalled instances that they found particularly challenging in their workplace when providing services to people living with hearing loss or deafness.

“so often we’re not told even if somebody’s indigenous let alone if they’ve got hearing impairment and all that”

“I don’t think there’s um large enough access to interpreters um or enough sort of social awareness about the impact of hearing impairment especially for people who are also have other um disabilities”

“we have a lack of funding, so um we used to get an interpreter … but now we just don’t have any funding for it so we’ve like I’ve gone up through channels and like tried different people around the organisation and it’s just we have a bucket of money for interpreting different languages but they don’t see sign language as a different kind of language as a country like they see it as something different so we I can’t use that bucket of money”

“the interpreter didn’t want to work with this client anymore and she said she wasn’t getting adequate sup um debriefing so it was suggested that I provide debriefing to the interpreter which I don’t feel comfortable doing because it kinda breaches yeh boundaries and it just became a bit messy”

Across the interviews there were different ways of describing the differences between the different deaf identities (e.g., hard of hearing, hearing impaired, Deaf, deaf etc.). Most professionals were aware of the different terminology used to discuss people living with hearing loss or deafness. However, there wasn’t much consistency across these explanations.

“Hard of hearing people normally really you know grow up they might speak really well however it’s really difficult for them to follow um fluent conversation it’s really frustrating for them and it’s um not a perfect world. Um sometimes you know they’re not sure where they belong”

“It’s a complex spectrum of reactions to um hearing loss um and it’s dependent on gender and culture, age as well education, level of education as well as the degree of deafness”

“I generally say hearing impairment. If they’ve v virtually have very limited little hearing at all I’d probably then refer to them more as deaf”

“Well I see them as different cultural groups … lower case d as usually … this is maybe my stereotype of usually hearing parents with a deaf child or child with a hearing loss who um access services to habilitate their child’s hearing loss um to communicate and then there’s people in between who take elements of each but most of those families, most of the members are hearing”
Most professionals believed that there is a place for a person who is qualified and living with a hearing loss or deafness to work in their profession. Some people commented that a professional who also lives with hearing loss or deafness would be a valuable addition to their workplace or profession. Some professionals highlighted the barriers that would prevent a person living with hearing loss or deafness working as a professional in their field.

“do ya know that’s never I’ve never considered that b-fore. um you mean as clinicians? I suppose it wouldn’t this is gonna sound awful but I suppose it would depend on how well they could communicate how; how well they could communicate with somebody who isn’t deaf um who doesn’t know Auslan. Um you could use interpreters I suppose you know it could be a mirror image of what we’re doing now

“absolutely definitely. I think there are times where it might be more difficult within this type of role be-cause you’re assessing people who are often acutely unwell have limited frustration tolerance um so if you’re doing that via a third party interpreter that and to a hearing person that it could cause issues”

I think it would be very difficult um just be-cause of the you know clearly you need to be able to hear to actually examine the patient ... you can’t listen to their heart sounds or their abdominal sounds or anything like that if you’re deaf so yeh so I think that would be place significant limitations on being able to practice”

Conclusion

The purpose of this project was to explore health professional’s experiences of providing health services to people living in Australia with hearing loss or deafness. Most of the health professionals that were interviewed described the quality of health services currently available as insufficient.

The health professional’s response to the quality of health services available could be described as doing the best they can. Despite concerns with validity of current assessment tools many professionals described being able to adapt the instruments for their use. The professionals had also identified different ways of communicating with their clients which predominantly included note writing, lip reading and sometimes captioning and interpreting services.

The professionals described confronting considerable barriers when attempting to further meet the needs of their clients living with hearing loss or deafness. These barriers included a lack of funding, support from superiors and formal processes in the workplace. Some professionals felt that the size of the population of people living with hearing loss or deafness does not warrant high level changes such as adding hearing loss and deafness specific content to training and education programs.

These findings add to our understanding of the health experiences of people living with hearing loss or deafness. It can be seen that health experiences are informed by factors related to the health professional (e.g., education, awareness, prior experience, attitude etc.) and more importantly factors related to their workplace or the health system. These findings suggest that further examination of workplace policies and procedures are needed to understand how they inform the decisions and actions of health professionals.

Further findings from this study have been submitted for publication. Please contact Danielle for further information.
I acknowledge the various individuals who contributed to the development of this project and the preparation of any published material. In particular I would like to thank the health professionals for sharing their experiences with us.

thank you

About the researcher: Danielle is a young hearing woman completing her PhD Student in the School of Psychology at the University of Queensland. Danielle has been learning Auslan since 2011 and volunteered at the Australian Deaf Games held Geelong in 2012.

Danielle Ferndale

School of Psychology, The University of Queensland. June 2015

PhD Project supervised by: Dr Bernadette Watson and Dr Louise Munro

dferndale@gmail.com  @deafresearchau
### Appendix D2: Australian Bureau of Statistic Census tables

**Table 2.1** 2006 Census Data. State/Territory by Language Spoken at Home counting persons, place of usual residence

<table>
<thead>
<tr>
<th>Language Spoken at Home (LANP)</th>
<th>Sign Languages, nfd</th>
<th>Auslan</th>
<th>Makaton</th>
<th>Sign Languages, nec</th>
<th>Total</th>
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<tbody>
<tr>
<td><strong>State/Territory (STE)</strong></td>
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<tr>
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<td>14</td>
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<tr>
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<td>943</td>
<td>61</td>
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<tr>
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<td>5</td>
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<td>31</td>
<td>0</td>
<td>0</td>
<td>46</td>
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*Note*. Data Source: 2006 Census of Population and Housing; Cells in this table have been randomly adjusted to avoid the release of confidential data; LANP - please refer to the Census Dictionary for further information regarding coding issues identified when processing data; No reliance should be placed on small cells; for details on classification and associated data quality information click on the blue i-links in the table; Table generated using ABS TableBuilder; © Commonwealth of Australia

**Table 2.2** 2011 Census Data. State by Language Spoken at Home - 4 Digit Level Counting Persons, Place of Usual Residence

<table>
<thead>
<tr>
<th>LANP - 4 Digit Level</th>
<th>Sign Languages, nfd</th>
<th>Auslan</th>
<th>Makaton</th>
<th>Sign Languages, nec</th>
<th>Total</th>
</tr>
</thead>
<tbody>
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<td>Other Territories</td>
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<td><strong>Total</strong></td>
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<td>1250</td>
<td>64</td>
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<td>9935</td>
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*Note*. Data Source: 2011 Census of Population and Housing; Cells in this table have been randomly adjusted to avoid the release of confidential data; LANP - please refer to the Census Dictionary for further information regarding coding issues identified when processing data; No reliance should be placed on small cells; for details on classification and associated data quality information click on the blue i-links in the table; Table generated using ABS TableBuilder; © Commonwealth of Australia
Appendix D2: Anatomy and Transduction of the Ear

Figure 3.1. Diagram of the anatomy of the ear (Paul & Whitelaw, 2011)

As Paul and Whitelaw (2011) explain, transduction of the ear refers the process by which sound energy proceeds from the outer to inner ear and is converted into mechanical and electrical energy and neural impulses on its way to the brain
Appendix D3: Hearing Technology

Hearing Aids

The basic function of a hearing aid is to amplify sounds in the ear (Paul & Whitelaw, 2011). There are a range of different types of hearing aids, typically categorised according to where they are worn, behind or in the ear (Paul & Whitelaw). The battery life of a hearing aid is similar to that of all electronic gadgets, needing replacement roughly every fortnight (Paul & Whitelaw). The life of the battery varies with device type and condition of use with more powerful devices needing larger and more batteries (Paul & Whitelaw).

In addition to battery life there are number of concerns associated with hearing aid choice and use. These factors include lifestyle and the devices functional limitations, visibility of the device and cost. Functional limitations can include the device’s ability to function in moist or wet conditions such as during exercise and at the beach. Typically hearing aids are damaged by moisture and so cannot be worn during sport or in water. However, hearing aid technology has developed models which are water resistant, although these tend to be more expensive. Visibility is important depending on the individual’s desire for their hearing status to be visible. Cost is particularly important, especially for those over the age of 26 when the government no longer funds the cost of hearing aids (Australian Government Department of Health Office of Hearing Services, 2015). According to HearingHQ magazine, a single hearing aid can cost anywhere between $2,000AUD and $5,000AUD (HearingHQ, 2013).

Cochlear Implants

Cochlear implants replace the function of a damaged inner ear (Paul & Whitelaw, 2011). Cochlear devices are implanted under the skin with electrodes positioned in the cochlea which stimulate the auditory nerve directly to generate sound (Paul & Whitelaw). Sound information is transmitted to the implant via an external component containing a
microphone and a device which picks up and processes incoming sound (Paul & Whitelaw). Access Economics (2006) reports approximately 400 Australians receive an implant each year, children under the age of 18 make up one third of those 400 people. Children as young as 12 months and adults over the age of 80 are eligible to receive cochlear implants.

Eligibility criteria have changed over time; influential factors include audiometric criteria, developmental, social, communication and occupational considerations and reasonable expectations (Paul & Whitelaw, 2011). Key criteria include a moderate to profound loss in both ears with little or no benefit from using hearing aids (HearingHQ, n.d.). The recipient’s knowledge and understanding of CIs, their communication needs and skills, psychological strengths and weaknesses, attitude towards implantation and availability of a support network is also assessed before implantation (Paul & Whitelaw). A team of allied and medical professionals are involved throughout the implantation and (re)habilitation of CI recipients (Paul & Whitelaw. It is important to note that CIs also do not restore hearing to that of a hearing person and may not be an ideal solution for everyone, with research indicating some people, in fact, turn off their cochlear implant and do not use them (Paul & Whitelaw; Rose, Vernon, & Pool, 1996; Uziel et al., 2007)

The cost of a CI varies from country to country and between devices. To give an idea of the cost of a CI device, in 2005 the cost of a Nucleus® Freedom™ CI system was $25,070AUD (Access Economics, 2006). In Australia the costs associated with providing a CI (the surgery, device and rehabilitation) are covered by a mix of private and government health funds. On-going costs may include replacing/upgrading the speech processor or parts of the speech processor and replacing speech processor batteries. Speech processor batteries will generally need to be replaced or recharged every few days depending on CI usage. Functional limitations/considerations of the device include keeping the speech processor
clean and dry (usually cannot be worn in the water), avoiding contact sports and passing through airport security.

Although it is less true in 2015, cochlear implantation continues to be a source of tension and conflict in Australia, in particular between the Australian Deaf community (see section below) and health professionals. Some leading Deaf advocacy organisations such as Deaf Australia (this organisation has since closed) do not fully support the implantation of infants (Deaf Australia, 2006). Their position is based on ethical concerns and a lack of research.

**FM System**

An FM system is used to transmit sound from one person to another over a distance. FM systems are made up of a microphone and transmitter, worn by the speaker and a receiver which is worn by the individual who wears hearing aids, or lightweight earphones if they do not wear hearing aids (Paul & Whitelaw, 2011). These devices are particularly beneficial in environments like a classroom, where this a lot of background noise, reverberation and distance between the speaker and the listener as they improve the quality of sound reaching the listener (Paul & Whitelaw).
Appendix D4: Language

Australian Sign Language

The Australian sign language is known as Auslan is a symbol of pride within the Deaf community and is the preferred mode of communication for deaf individuals who identify with the Deaf culture (Johnston & Schembri, 2007). Auslan is a natural sign language and a language entirely separate from spoken English and is an unwritten language. Auslan is only a new name for the signed language that has grown and developed in Australia over the past 200 years (Johnston & Schembri, 2007). There are two major dialects of Auslan in Australia, north and south that are a result of the establishment of residential schools for the deaf in the mid-nineteenth century. There is certainly a need for increased support to facilitate the continued development of Auslan and sign language interpreter services.

The Role of Interpreters

Interpreters can gain accreditation through passing a NAATI exam or completing a NAATI accredited TAFE or university course. In addition to being fluent in Auslan and English, interpreters must demonstrate an understanding and competence in interpreting Code of Ethics, cultural, linguistic and social issues within the Deaf community and effectively interpret consecutive and simultaneous dialogues from English to Auslan and vice versa with minimal errors (Australian Sign Language Interpreters’ Association, n.d.).
Appendix D5: Deaf Culture

Deaf Culture: The People

As mentioned previously, hearing status is not a prerequisite for becoming a part of the Deaf community; rather it is valuing Auslan and deafness which are essential to being accepted within the Deaf community (Deaf Australia, 2013). Becoming a member of the Deaf community can happen at any point in a person’s life. While there are several ‘core’ Deaf families with several generations of Deaf individuals whose native language is Auslan, most deaf members of the Deaf community come from hearing families.

Deaf Culture: Values and Traditions

Some of the values shared in Deaf culture include respect for Auslan, viewing Deaf as normal and highly valuing Deaf babies (Deaf Australia, 2013). Introductions always include first and last names as it gives an indication about a person’s family connections and position within the community. An individual’s association with particular places, sporting or cultural organisations or the school they attended might also be included in an introduction. If a hearing person is introduced and cannot offer any of this information they might be asked about their connection with Deaf people for example, who is their Auslan teacher or if they have a deaf family member. Long goodbyes are typical within the Deaf community as it is customary for Deaf people to seek out each of their friends at a gathering and say goodbye and discuss when they next expect to meet. Given the small Deaf community, Deaf people tend to have a large number of friends and saying goodbye to each one takes a long time (Deaf Australia, 2013). There is also a humour unique to the Deaf culture that is based in the visual nature of the deaf world and Auslan as a visual spatial language.