Access for Deaf people: Perceptions of the NDIS client experience

Catherine Treloar

M.Ed. (Applied Linguistics)

Department of Educational Studies

Faculty of Human Sciences

Macquarie University

Presented as part of the requirement for the degree of Master of Research

May 7, 2018

This thesis is completed as part of the requirements of Master of Research degree

Word Count: 21,462 (excluding Abstract)

TABLE OF CONTENTS

List of Figures

ABSTRACT

In Australia, the National Disability Insurance Scheme (NDIS) seeks to ensure that people with a disability can access the supports they need to live well and flourish. In its most recent report, the NDIS acknowledged that it needs to improve the client experience; particularly for those clients who are members of culturally, and linguistically diverse groups. There is limited knowledge available regarding the NDIS client experience of signing deaf people—people who use Australian Sign Language as their primary language. This research explores signing deaf people's experiences when accessing the NDIS to obtain a service package. Taking an ontological view, an Interpretative Phenomenological Analysis (IPA) approach was adopted where members of the Sydney signing Deaf community participated in a focus group and discussed their experiences in accessing the NDIS for a service package. The focus group's discussions were interpreted from Auslan, and then transcribed into English, which was subjected to qualitative analysis using NVivo. While all participants indicated that the provision of information by NDIS of independent access, through Auslan was adequate—though lacking depth of detail; all also noted that the NDIS's staff awareness and knowledge of signing deaf people's life experience was an obvious area for development. This study can contribute to improving the quality of the service of the NDIS by identifying factors that can enhance the NDIS client experience for signing deaf clients.

Keywords: access, equity, life experience, NDIS, signing deaf, Auslan

DECLARATION

I certify that the work in this thesis entitled "Access for Deaf people: Perceptions of the NDIS client experience" has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree to any other university or institution other than Macquarie University. I also certify that the thesis is an original piece of research and it has been written by me.

Any help and assistance that I have received in my research work and the preparation of the thesis itself has been appropriately acknowledged.

In addition, I certify that all information sources and literature used are indicated in the thesis.

The research presented in this thesis was approved by the Macquarie University Human Research Ethics Committee: 5201701020

Catherine Treloar

Student number: 45016968

7 May 2018

ACKNOWLEDGEMENTS

CHAPTER ONE: INTRODUCTION

This chapter begins with an introduction to the research project. The aim of the research topic is stated, and the nature of the research is expanded. To support the main aim, three supporting research questions are presented. Next, an overview of the approach and design of the study is provided. Following this, a list of definitions for key terms is given. To provide background knowledge, and further understanding of the research topic, the primary language of signing deaf people, Auslan, is introduced. Following on, the NDIS is introduced; its introduction by the Australian government as a major policy reform, and its role in providing for people experiencing disability. The Hearing Impairment client group of NDIS is then introduced—noting that signing deaf people form a client group within the NDIS's Hearing Impairment client group. The experiences of the participants of the study are discussed, describing the processes that they have been involved in while accessing the NDIS to obtain a service package as clients of the NDIS. Finally, the value of exploring the perceptions of the experiences of signing deaf people who have been through the process of obtaining a service package, and its contribution to the field, is stated. The following chapter presents a Literature Review to provide the context, which will inform the study.

Aim and nature of the research.

This study explores signing deaf people's perceptions of their experience after they have accessed the NDIS to obtain a service package. The research takes an ontological view, adopting an Interpretative Phenomenological Analysis approach to gain insight into the perceptions of their experience.

The main research question is:

What are the perceptions of signing deaf people's experiences in obtaining an NDIS service package?

The three supporting research questions are:

1. How do signing deaf people find out information from the NDIS?

2. What is the experience of signing deaf people in finding information and obtaining a service package from the NDIS?

3. What are the perceptions for the signing deaf people of their experience of trying to obtain a service package from the NDIS?

The adoption of an Interpretative Phenomenological Analysis (Ngulube, Mathipa & Gumbo, 2015; Smith, Flowers & Larkin, 2009) provides an approach that allows the researcher to attempt to gain insight and, through interpretation, understanding of the participants in the study in relation to the participants' experiences (Pietkiewicz & Smith, 2014; Smith et al., 2009).

The participants of this study accepted the invitation to join a focus group for the purpose of sharing their lived experience in accessing the NDIS to obtain a service package. Their responses about their experience, and perceptions of their experience, were the focus of the investigation. For this study, to facilitate the interpretative nature of the analysis the data obtained is viewed by the researcher through the lens of an awareness of signing deaf people; their historical and current contexts. However, the evidence is always grounded in the information of the participants' actual account of their own view of their own experience (Pietkiewicz & Smith, 2014). Further discussion about the role of IPA occurs in Chapter 3, Theoretical Framework. An approach to the study that also informed the research was a model that functions as a conceptual framework to approach the evaluation of equity of access in the health services sector. The Levesque et al. (2013) conceptual framework of healthcare access served as a relevant perspective from which to approach the data as it focuses on the interface between a health system and the population that is attempting to access the system (Levesque et al., 2013). The framework is relevant to this research as this thesis concerns equity of access to the NDIS for signing deaf people. The NDIS relates to health because it offers support for health outcomes, and it considers health and wellbeing as being key aspects in the provision of support to its clients (NDIA, 2017b).

Key Terms

deaf/Deaf

In Australia, people who have hearing loss and use Auslan as their primary means of communication usually choose to be identified as 'deaf' or 'Deaf' (the capital 'D' indicates alignment with a cultural minority). These people rarely use terms such as 'hearing impaired' or 'hard of hearing' to refer to themselves.

Auslan

Australian Sign Language; the natural sign language of the signing deaf people of Australia.

Lived experience of disability

A person's own experience of living with a disability or having a close relationship with someone with a disability, e.g. a family member or partner (NDIS, 2017a).

NDIA (National Disability Insurance Agency)

The NDIA's core role is to implement the National Disability Insurance Scheme (NDIS) (NDIA, 2017a).

Service Plan/Service Package

The NDIS refers to this as a Service Agreement: a written agreement worked out with the participant, stating their goals and needs, and the reasonable, and necessary supports the NDIS will fund for them. Each participant has their own individual plan (NDIS, 2017a). For this study, Service Plan and Service Package are used to represent Service Plan because these are the terms that are used by the participants in the context of their experience.

LAC (Local Area Coordinator)

Local Area Coordinators are local organisations working in partnership with the NDIA, to help participants, their families, and carers access the NDIS. LACs will help participants write and manage their plans, and also connect participants to mainstream services, and local and community-based supports (NDIS, 2017a).

Background to the study

Australian sign language, Auslan, is the recognised language of Australian deaf people who choose to use sign language. Deaf people who use Auslan consider Auslan to be their primary language. Australian signing deaf people use Auslan to access the information and services that they need.

In 2016, the National Disability Insurance Scheme (NDIS) of Australia commenced its general rollout under the management its managing body, the National Disability

Insurance Agency (NDIA). The initial steps towards the development of the NDIS commenced in 2010, when the Australian government commissioned a public inquiry by the Productivity Commission into the development of a new national disability care and support scheme to support people who were living with disability (Productivity Commission, 2011). At that time, disability support provisions in Australia were considered to be "inequitable, underfunded, fragmented, and inefficient and give people with a disability little choice" (Productivity Commission, 2011, p. 5). The task of the Commission was to recommend a scheme that would support people with a disability and their families and provide benefits for the community as a whole. In 2011, the Commission presented its report recommending the development of the National Disability Insurance Scheme (Cth, 2013). The funding of the scheme was to become a national responsibility, similar to the existing national health insurance system (currently known as Medicare) (Cth, 1973). An independent Commonwealth statutory authority, the National Disability Insurance Agency (NDIA), was to administer the NDIS. Central to the planning and implementation of the NDIS was to be the concept of individual choice, whereby people living with disability or their guardians "could choose how much control they wanted to exercise" (Productivity Commission, 2011, p. 30). It was anticipated that the NDIS would provide for about 460,000 Australian citizens under the age of 65 and living with a permanent, significant disability, and that those participants would be provided with the reasonable and necessary supports they need to live an ordinary life (NDIS, 2018). Having commenced its regional trials in 2013, the NDIS is currently (as of 2018) into its second year of rollouts across the various states and territories – with the completion of the rollout expected to be achieved by the end of 2019 (NDIS, 2018). Signing deaf people are included in the scheme within a group titled the Hearing Impairment group. Members of this group are defined as disabled because they experience disability due to the lack of access to communication through their primary language, Auslan, which they need to access the information, and services, they require to live a life like everyone else.

In the wider community, signing deaf people access information and services through the provision of Auslan interpreters; live or through video platforms; or through translation services e.g. through teletypewriter (TTY). The NDIS has worked in consultation with various client groups to ensure access to services is provided by NDIS in a manner that is suitable and effective for each particular client group.

To date, the NDIS has assisted access to information for signing deaf people through the provision of Auslan in the following ways: Auslan information videos on the NDIS website, English captions on website videos, translator services such as TTY, and live Auslan interpreting services via Skype. Information sessions are also provided in Auslan through the regional Deaf Societies and Deaf community groups. In addition, Auslan is listed as one of the languages that can be used to access some sections of the NDIS website.

A specific process is involved when a potential participant with a disability seeks to obtain a service package from the NDIS. From the initial investigation, which is most likely accessed through the internet, to the first meeting with the Local Area Coordinator (LAC), the signing deaf client must follow the processes of 'the system'. There are various functional processes involved in the participant's application to obtain a plan. These include writing up a plan, presenting a proposed plan, negotiating a plan, accepting a plan, and requesting a review of a plan. All of these require various skills and are necessarily dependent upon successful communication throughout the whole process to obtain a plan.

While the NDIS has provided access to information for its signing deaf clients through Auslan, there is little information available about the experience for the signing deaf client, and in particular their client experience in accessing the NDIS to obtain a service package. This study investigates this situation and adds to current knowledge by exploring the perceptions of the experiences of signing deaf people who have accessed the NDIS. It will provide insight into the access experiences of this group, which also relates to the wider signing deaf population who may choose to become clients of the NDIS. The results of this study will contribute to the understanding of the signing deaf client experience.

This chapter provided an overview of the thesis by introducing the research question and the supporting questions of the study. To show how the research question is to be addressed, the approach and method for the study were outlined. A background to the study was presented to provide the context for the research presented in this thesis. A Literature Review will follow in the next chapter to provide the context for the thesis, and to also provide understanding of the need for an ontological view to this research study.

CHAPTER TWO: LITERATURE REVIEW

I will begin by introducing the people of the signing Deaf community of Australia, their language, Auslan, and its recognition within the Australian setting. I will explain that while this group shares some characteristics similar to other culturally and linguistically diverse groups, there are significant differences. The legal recognition of signed languages will be discussed—highlighting the impact of sign language recognition on the lives of the people who depend on access to information through their signed language. The importance of the provision of interpreters to ensure the realisation of rights to access through Auslan will be explained. To provide a context in relation to the concept of disability, I will summarise some of the notable disability models, ethnic models and frameworks that have been introduced and promoted over the past forty years. These frameworks will provide a contextual background for the experiences of signing deaf people and their communities.

Broadening the view, I will then describe the social, and cultural changes that have influenced the lives of signing deaf people—from a global and a local perspective. I will outline the rise of the Deaf Rights movement and the resulting impact on identity formation for signing deaf people at group and individual levels. Coupled with this movement was the development of knowledge about natural sign languages and how the study of such languages—and the resulting new status afforded to them—led to the rise of the academic field of Deaf Studies. Moving towards the present, referencing the maturation of the field of Deaf Studies and the evolution of identity theory, I will introduce the view that new perspectives were required—a need to adapt—and introduce the notion of intersectionality to the view in order to provide perspective on all that is happening in the diverse lives of deaf people and to clarify the existing, and developing, tensions of social power. To this end, I will introduce and discuss the emerging ontological framework that, through focusing on the lived experience of the individual, better reflects signing deaf people's lives.

I will then briefly discuss the way in which deaf people's access to goods and information has developed, highlighting the innovations and practices that enable access, as well as the specific challenges that confront signing deaf people—in particular, the concerns regarding access to information through digital formats.

To provide context, I will refer to research into the lives of signing deaf people in their efforts to access health services, noting some of the barriers they face when accessing healthcare information, and services. This will lead to the focus of the current investigation, where I introduce the NDIS—its inception, focus, and delivery as it relates to the various client groups that it aims to serve. To conclude, I will orientate the discussion towards the signing deaf clients of the NDIS, signalling the gap in the literature to date and the need for a more focused view of signing deaf people's perspectives on their own experiences when accessing the NDIS.

Signing deaf people in Australia

Australia has a very diverse population; there are at least 300 reported languages other than English used in Australian homes (ABS, 2017). In the most recent census, 10,112 people self-reported as using Auslan in the home (ABS, 2017). Auslan is the natural language of the signing deaf people of Australia—organised around similar grammatical rules to other spoken languages and providing the same expressive capacity (see Johnston & Schembri, 2007). Currently, Auslan is recognised in Australia as a community language, and the people who use Auslan are identified as members of a cultural and linguistic group (Australian Dept. of Employment & Training, 1991; Lo Bianco, 1987). Although many Auslan users consider themselves as sharing many characteristics of culturally and linguistically diverse (CALD) groups for the purposes of language classification, a significant difference between Auslan users and members of CALD groups lies in the fact that members of other CALD groups gradually gain better access to a range of services through English because they are supported in learning English as their 'target language'. In comparison, Auslan users will always need to have access to information in their own language, Auslan, through Auslan interpreters, irrespective of their English proficiency (Deaf Australia, 2018a, 2018b). Many countries have legally recognised their signing deaf communities' languages, affording them the status of official language. The way in which governments grant rights, through the recognition of their sign languages at a national level, reflects the ways in which countries accept or neglect the role of these languages and their role in linguistic and cultural diversity (De Meulder, 2015; Schiffman, 1996). Of the 193 Member States of the United Nations, 41 have legally recognised their sign languages. Australian signing deaf people, through

their representative peak body, Deaf Australia, aim to see the legal recognition of their language, Auslan, by the Australian government in the future (Deaf Australia, 2018b).

By way of comparison, the New Zealand government granted official status to the New Zealand Sign Language (NZSL) in 2006 (McKee, 2006). It has been acknowledged that legal recognition of NZSL has added moral leverage and increased the profile of signing deaf people in their interactions with the state, and within the wider society (McKee, 2011). It must be noted, however, that in addition to the legal status granted to a sign language within a country, the impact of such can only be measured in terms of the "symbolic impact" that, in the case of signing deaf people, takes place in their own lives in their reliance on their language for access to their wider community (Daoust, 2017, p. 451). The value of policies that are developed at the 'grass roots' level by those who are most involved, the signing deaf people, can be more practical, and more effective, than a 'top-down' approach in language policy (Reagan, 2010).

Sign language interpreting

Regardless of the improved national status of signed languages—whether 'recognised' or 'official', depending upon the actions of the particular government of a country—the availability of sufficient numbers of qualified sign language interpreters is central to the realisation of the rights of signing deaf people in a country, so that signing deaf people can access information in their specific sign language in a wide variety of settings (Deaf Australia, 2015; McKee, 2011; Reagan, 2010). Witko, Boyles, Smiler and McKee (2017), in a recent study investigating the quality of access to healthcare for signing deaf people in New Zealand, noted that interpreters can play "a critical role" in ensuring patient comprehension of medical information, which "underpins compliance with medical instructions" (p. 54). The Australian government, in meeting its responsibility under the United Nations Convention on the Rights of People with a Disability (UNCRPD, 2006) and Australia's *Disability Discrimination Act 1992* (Cth), provides access for Auslan users through Auslan interpreters. Currently, under the Act Auslan interpreters are provided to all signing deaf people for medical and health professional appointments (Department of Families, Housing, Community Services and Indigenous Affairs, 2005). The NDIS includes some support for the provision of Auslan interpreters for deaf signing people who access the NDIS and who obtain a service package.

The lives of signing deaf people in context

Focusing on the social and cultural context in which signing deaf people live informs us about their lived experience. A retrospective view of the events and developments affecting the lives of deaf people—that is, how they were viewed by others, and how they viewed themselves—will provide a summary of the background. To understand the concept of disability, it is necessary to consider the various approaches that have existed in the past. An awareness of these meanings in their related contexts provides an understanding for today's context.

Models of disability

The development of theoretical models that have defined disability reflects the multifaceted nature of disability (Mitra, 2006). During the nineteenth century, the concept of disability was framed by a medical or individual model—built upon the notion that disability was caused by illness and marked by defects—which 'tragically' impaired the ideal of the 'perfect' human being (Shakespeare, 1993). Anyone whose body varied from the statistical norm was deemed impaired (Davis, 2013; Thomas, 2004). In effect, the impairment was the focus, and the problems that were experienced, due to the impairment, were interpreted by society (Söder, 2009).

In 1975, 'heated' discussions were held between the then-controlling Disability Alliance in Britain and the then-newly formed Union of the Physically Impaired Against Segregation concerning the rights of the physically impaired (Finkelstein, 1975). In 1983, in talking of these discussions, reference was made to a 'social model of disability' (Oliver, 1986) which was then adopted; this model built upon the concept that disability is centrally structured by society, resulting in social oppression, inequality and exclusion (Charlton, 1998).

The social model of disability recognises the social barriers that restrict the activities of people who have bodily impairments (Oliver, 1986; Thomas, 2004). The model's success was due to its attempt to remove the physical and social barriers that disabled people experienced. The result involved organising a society in which non-disabled people had increasingly to adapt to sharing an environment that was also designed for others (Finkelstein, 1981). This required society to think about, and remove, the societal obstructions that faced people who were living with an impairment (Baylies, 2002). The

social model of disability became the basis upon which collective disability consciousness developed (Oliver, 2013). Thirty years after its adoption, Oliver reflected that he didn't plan for the social model to be a theory, nor a perspective; rather, he aimed to allow the provision of insight not only into how to solve disabling problems but, even more so, to encompass those problems around culture and attitudes (Oliver, 2013).

The human rights model of disability is an extension of the social model of disability (Degener, 2016a). The human rights model moves from an anti-discrimination approach to a more rights-based approach wherein all rights are considered to encompass "political, and civil and economic, and cultural rights" (Degener, 2016a, p. 5). This model is built upon a foundation of moral principles and values, which underlie the concepts of fundamental, unconditional rights for all people irrespective of health status or level of functioning (Degener, 2016a). This paradigm shift is seen as being a more inclusive approach than the social model of disability because it "compels societies to acknowledge the value of all persons based on inherent human worth, rather than basing value on an individual's measured functional ability to contribute to society" (Quinn et al., 2002, p. 77). This perspective focuses on the goal of "preserv[ing] that which provides for individual flourishing and modify[ing] that which is not" (Stein, 2007, p. 77). The human rights model of disability is the basis of the Convention on the Rights of People with Disabilities (UNCRPD, 2006), which states that its purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (UNCRPD, 2006, Art.1). As Degener (2016b) states, "the CRPD is a codification of the human rights model of disability" (Degener, 2016b, p. 49). Australia ratified the UNCRPD in 2008 and in the development of a National Disability Strategy (Cth, 2012) viewed the CRPD as "unique in that it is both a human rights instrument and a development instrument which aims to redress the social disadvantage of people with disability" (Cth, 2012, p. 16). The National Disability Strategy was set up to "ensure that the principles underpinning the CRPD are incorporated into policies and programs affecting people with disability, their families and carers" (Cth, 2012, p. 16). The Disability Strategy informed the guiding principles in development of the NDIS (Cth, 2013).

The capability approach, developed by Sen (1992), is best explained as a moral framework proposing that social arrangements should be evaluated primarily according

to the extent of freedom people have to promote or achieve the 'functionings' that they, as individuals, value (Alkire, 1998). This approach views disability as something that can be recognised as resulting from the interaction among an individual's personal characteristics, available resources and the environment (Mitra, 2006). Thus, the capability approach considers the advantages and disadvantages experienced by individuals in society, emphasising the social, economic and environmental barriers to equality (Burchardt, 2004).

Through the lens of the capabilities perspective, the disadvantage experienced by people with a disability is best viewed in terms of a deprivation of the opportunities that have been made inaccessible. Central to the capability framework is the notion of freedom—the autonomy to make choices, not conforming to a set idea of normality— which, when achieved, results in the opportunity for every human being to live a flourishing life (Burchardt, 2004). A model that closely represents an understanding of disability under the capability approach was developed by the World Health Organization (World Health Organization, 2001). This model, The International Classification of Functioning (ICF), represented an integration of both the medical and the social models (Kusters, De Meulder & O'Brien, 2017; Mitra, 2006; World Health Organization, 2001). The model can be described as a biopsychosocial model of disability wherein a health condition gives rise to impairments impacting activity, and participation activity, within contextual factors (Altman, 2001). One criticism of this model is that it does not focus on the rich and complex description of what people are able to do, and be, within their own contexts (Burchardt, 2004; Nussbaum & Sen, 1993). Instead, the use of questionnaires and indexes to 'assess' how the respondents are prevented from carrying out a range of day-to-day activities—what are deemed to be 'normal' activities—can be limiting because the measures tend to focus on the barriers presented to the individual (Burchardt, 2004; Nussbaum & Sen, 1993).

Breaking away from the concept of abled and disabled, it has been proposed that we are all impaired to varying degrees, which breaks down the binary notion of 'the normal' and 'the disabled' (Thomas, 2004). However, in spite of this binary notion, Thomas believes that there remains a divide between those who acknowledge that disabled people are socially disadvantaged and those who see them as oppressed. The latter argue that the social exclusion is what realises disability. Thomas signals the foundations

of the concept of 'ableism' as being similar to concepts such as sexism, racism and homophobia. Thomas concludes that a "social relational understanding of disability provides a firm foundation for an enriched sociology of disability, deploying a range of theoretical perspectives" (Thomas, 2004, p. 581).

Baylies summarises the process of disablement most succinctly, stating:

> What is recognised as impairment or as a disability varies across cultural contexts, but societies are also implicated in fundamental ways in the creation, maintenance and the intensification of impairments, and in translation into the experience of disablement. (2002, p. 726)

Activism by signing deaf people

During the first half of the twentieth century, there was a "hunger for equality among deaf people"—and by 1965, "change was everywhere" (Humphries, 2014, p. 58). The focus of their new-found activism involved efforts to move away from the oppressive medical model, which had controlled their lives, particularly in relation to their education (Kusters, De Meulder & O'Brien, 2017). Reflecting on this period, Humphries (2014) noted the 'tumultuous' times of the 1970s and 1980s in the United States, when signing deaf people considered themselves as oppressed because their natural language, American Sign Language (ASL), was not recognised by the government and other relevant authorities. As a consequence, deaf people believed they experienced discrimination due to their lack of access through their language, which impacted upon their ability to function in a hearing world in the dominant language—English (Humphries, 2014).

We know that, throughout history, whenever deaf people have come together and formed communities, natural signed languages have developed. Communities have been noted in Ancient Greece, and numerous examples of other communities in various countries have also been described in the literature (Johnston & Schembri, 2007). The 1960s signalled the birth of signed language linguistics, which provided a sophisticated description of signed languages (Stokoe, 1960). There was now proof that signed languages were fully fledged languages with complex structures deserving academic scrutiny (Kusters, De Meulder & O'Brien, 2017; Stokoe, 2005). During this period, amid the dynamic period of the civil rights movement, there was a contagious atmosphere with many cultural and linguistic minorities 'finding their voice' to fight the oppression

they believed their respective communities faced. The signing Deaf community joined this movement for the same reasons (Bauman, 2008).

Deaf Studies in academia- its early development

In the 1970s, the academic field of Deaf Studies commenced within universities, predominantly in the United States and Britain. During that early period, much was discussed and developed towards the recognition of sign language rights and identity politics (Humphries, 2014; Humphries et al., 2013). At its early stage of growth, researchers—often belonging to various disciplines—approached Deaf Studies as a research focus within their own discipline. Some of these included cultural studies, linguistics, applied linguistics, disability studies, education, sociology and anthropology (Fernandes & Myers, 2010). In the 1980s, scholars of Deaf Studies focused on the development of the study of sign language rights, Deaf culture and Deaf community (Kusters, De Meulder & O'Brien, 2017; Schiffman, 1996). The importance of the use of signed language, and the social discourse concerning its use, has been asserted to be a vital element impacting deaf people's self-perception and the construction of deaf cultural identity (DeMeulder, 2015; Humphries, 2014; Reagan, 2010; Trovato, 2013).

During the eighties, there was a focus on seeking recognition for the signing Deaf community and use of their language in their lives. There was a perceived need to challenge oppressions; the dominant practices that were negatively impacting the life being experienced by deaf people (Ladd, 2003). During this time, identity theory informed researchers. Identity theory heralded the importance of the formation of one's identity to the successful development of one's sense of wellbeing. This theory provided the academic justification for the struggle that was being played out in the lives of deaf people (Erikson, 1968; Waterman, 1992). It was during this time, through the use of the term 'Deaf culture', that a great sense of pride, and an affirmed sense of identity, was experienced by signing deaf people (Humphries, 2014).

During the mid to late 1980s, the cultural-linguistic model of deafness supplemented the social model of disability, while continuing to challenge the medical model (Padden, 1989; Padden & Humphries, 1989). At that time, society was expected to adapt to the communicative needs of the group of signing deaf people. There was an expectation that society should be aware of—and accommodate—this now identified, specific

cultural group; a group not to be identified as disabled yet with the distinction of being the Deaf cultural group (Kusters, De Meulder & O'Brien, 2017; Ladd, 2003). To further identify the cultural, signing deaf group during this period, the marker of the capital 'D' was used to identify its members as being of the Deaf culture; a cultural construction, as distinct from other deaf people so named according to their medical circumstance: their hearing impairment (Woodward & Horejes, 2016).

During this period of ethnic identification, 'markers' were put forward to which the Deaf culture could refer and promote in order to support their positioning (Smith, 1986). To this end, Deaf Studies academics set about identifying the Deaf culture by listing the histories, behaviours and artefacts that delineate this specific group (Padden & Humphries, 1989). To help explain how deaf people develop identities related to Deaf and hearing societies, there was a searching for social identity models (Maxwell-McCaw, Leigh & Marcus, 2000). The Deaf culture reached such a precise state of description that a Deaf Identity Development Scale was developed to gauge the process of identification of those who identify as being part of the signing Deaf community (Glickman, 1993).

Bicultural deaf people

During the mid-nineties, researchers began to acknowledge that deaf people lived in various situations, and their skills in their identity-making were being forged by the experiences, and contexts in which they were living (Grosjean, 1996). Researchers were investigating how the notions of Deaf culture were actually being constructed; 'how' the culture was being 'done'. What were people of the Deaf culture actually doing in their lives; their shared language, and shared experiences (Turner, 1994). Turner's proposal was a development away from the 'features of membership list', as proposed five years prior, to a more enriched approach (Padden & Humphries, 1989). It was thought the acculturation process—what was really happening for deaf people—was indicating that deaf people were, in fact, bicultural. The development of the Deaf Acculturation Scale (Maxwell & Zea, 1998) provided yet another measurement of this newly identified cultural classification. The reality was that deaf people were living in two worlds; one of the culturally and linguistically 'Deaf World' (Lane, 1995), and the primary cultural world of hearing people, which used English (Fitzgerald, 1993; Grotevant, 1992; Lane, 1995; Powell-Williams, 2017; Woodward, 1997).

A social identity paradigm was proposed whereby deaf people through social mobility could identify as culturally hearing or culturally Deaf or bicultural (Bat-Chava, 2000). As adaptive and interesting the lives of these bicultural people appeared to be, researchers were sceptical of the additive benefits of biculturalism believing that the navigation of such, and the variance in identity caused a state of tension in the individual as they attempted to cope with the negotiation between the often-competing beliefs, and values of each culture (Padden, 1996; Powell-Williams, 2017). Over the years, the academic view of identity formation development had matured to a point where most researchers supported the view that—though ever-evolving and 'crafted' within our lives—our identity is shaped by how we view ourselves, what happens to us and how others see us (Bat-Chava, 2000; Breivik, 2005; Grotevant, 1992; Hintermair, 2008; Leigh, 2009; Nikolaraizi & Hadjikakou, 2006; Thayer-Bacon, 1997). Scholars acknowledged that people who identify as deaf work and toil with their identity in a reflexive manner, finding that there are, in fact, many ways of being deaf (Breivik, 2009; Carty, 2006).

The Deaf group's diversity

Moving into the new century, with its evolving social dynamics, there was interest in the ongoing flux of how deaf people identify themselves. In response to these observed dynamics, there was a call for the deconstruction of existing paradigms, and post-modernist views were adopted. Notions of an 'ethnic minority', a special 'deaf world' (Lane, 2005), and 'deaf way' (Erting, 1994) were criticised for being rigid and potentially leading to the marginalisation of those who weren't deemed to fit into the group (Davis, 2007). Research indicated that the formation of deaf identity goes beyond the oversimplified binary conceptualisation—of the lower case 'deaf' or capital 'Deaf' of Deaf community identity—which began to be seen as anachronistic, allowing for only the medical and social models respectively, where one views being a deaf person as either a disability or a cultural difference (Kusters, De Meulder & O'Brien, 2017; McIlroy & Storbeck, 2011).

The time had arrived for a widening of views on the development of deaf identity to allow for recognition and acceptance of a fluidity in identity-making whereby deaf people can negotiate the cultural space between these two models (Breivik, 2005; Leigh, 2009). This complex work for deaf people has been described as "a quest that is bound up with the

acceptance of being deaf while 'finding one's voice' in a hearing-dominant society" (McIlroy & Storbeck, 2011, p. 494).

It was commented that there was a need for a more analytical lens on the complex phenomena that were the real lives of deaf people in the new millennium. Following the lead of other researchers in the field of rights and discrimination there was a call to resist the pattern of the single-view analysis, compartmentalising the lives of people. Rather, the recommendation was to place those who are marginalised, for whatever reason, in the centre so as to observe the total intersectionality of the person's life (Crenshaw, 1989; Kusters, De Meulder & O'Brien, 2017). By attending to intersectionality, Deaf Studies scholars believed that they were better able to gain perspective, and understand the importance and the meanings "of variables such as nationality, gender, ethnicity, religion, migration status, educational background, disability, and class in deaf-deaf interactions and in deaf signers' everyday interactions with hearing people" (Kusters, De Meulder & O'Brien, 2017, p. 12). The complexity of describing deaf people's identity was at the forefront for those attempting to identify and theorise about identity formation; a way that encompasses the many ways that deaf people live (Fernandes & Myers, 2010). Leigh (2009) summarised the complex reality of deaf identity as perhaps involving a 'multiplicity of identities', each linked to time and space, language and communication.

Revision of the term 'culture'

Following the discussion by Deaf Studies academics about the need for a more 'analytical lens', a new period emerged calling for the specific labels of the past to be revised. The use of the term 'culture' was being questioned as to its adequacy: its ability to adequately reflect the disablement that deaf people live with (Baynton, 2008). Since 2005, the concepts of Deaf culture, community, and identity have been further explored and it has been suggested by some that the concept of identity politics should be minimised (Davis, 2007).

Although the Deaf community, described as a culture with its own ethnic identity, was, no doubt, a powerful and effective political, and cultural force in its day, some thought that deaf people might be more appropriately supported by an identification within the social model of disability. The latter provided an explanatory context to enable the sharing of one's own life experience, explaining the need for interpreters, aids and

supports to enable access to a world through their own language (Kusters, De Meulder & O' Brien, 2017).

Today, in the Australian setting, although signing deaf people who use Auslan are considered to be part of a culturally and linguistical diverse (CALD) group, a new perspective has been called for, representing the politics of identity for people disabled—a 'bottom-up' approach to shed light on the lives of people and focus on the self-understanding, experiences and practices confronting disabled people in their everyday life (Breivik, 2009).

Cultural processes involving deaf people: a new perspective

To further develop the concept of Deaf cultural identity, Humphries (2008) informs us that deaf people have always known about their lives, and that perhaps they should not allow others to inform them about what their culture is. Referring to the early days of talking about culture, he states: "At first, it was mostly hearing people who articulated our story in the language of culture… hearing people reporting what they had learned from us" (2008, p. 36). He calls for a focus on the cultural processes that are in existence—what's really happening in the lives of those of the culture; the lives of the deaf people. "Put simply, we need to move from 'How are we different?' to 'How are we being?'" (Humphries, 2008, p. 41). Viewing culture as a process addresses the potential problem of 'square-pegging' people's identities (Turner, 1994). This new perspective was not only looking beyond culture, but also building upon this to share 'the significance of living this life in a different sensory world'—the visual world (Baynton, 2008, p. 295). The concept of 'Deafhood' was introduced by Ladd (2003), who proposed that the reality for deaf people is that they live their lives in a visual reality as a point of difference compared those who embrace 'hearinghood' and 'hearingness' (Hauser et al., 2010). A concept was suggested whereby deafness is 'reframed' to be viewed, as it is experienced by signing deaf people, as 'deaf gain'; deafness is to be valued in terms of its intellectual, creative and cultural benefits, recognising the physical and cognitive differences as a vital aspect of human diversity (Bauman & Murray, 2009; Bauman & Murray, 2014). To recognise the ways of life for signing deaf people, there is a call to look at Deaf ontologies—deaf people's ways of being—to illuminate how deaf people understand themselves within their world (Kusters, De Meulder & O'Brien, 2017).

Access to a range of services for signing deaf people

As citizens, people use their language to access the life around them and participate in all that life has to offer—to live the so-called 'good life' (Piller, 2014). Recent innovations in technology have undoubtedly improved the lives of deaf people. In Australia, innovations have included captioning in English; the provision of telephone relay services in both English and Auslan; video platforms to improve contact through Auslan; and increased global contact through social media, all of which have had a positive impact. When discussing the life of a person living with a disability, we need to think about the context of life as a citizen in one's local community as well as a global citizen in the 21st century. In its Digital Report (2016), the World Bank states that public services and government information are increasingly migrating to the internet, which makes access an important topic from the standpoint of public policy (World Bank Group, 2016). The transition to an all-digital communications environment and the digital 'switchover' of public services brings to the fore the need to rethink access as a goal of public policy (National Archives of Australia, 2015; Sourbati, 2012).

The ubiquitous presence of information and communication technologies (ICTs) has meant that access to information and goods through ICTs is necessarily a focus of public policy. Web accessibility has focused on large organisations, commercial enterprises, nonprofit organisations (NPOs), and governments and their agencies. There is a reliance upon governments to enact laws that require web accessibility and impose a duty to ensure that government departments, and their agencies, are good role models in making their websites and services accessible to all citizens and users, including those with disabilities (Ellis, Goggin & Kent, 2015). In the Australian setting, the Digital Continuity Policy 2020 plays a key role in supporting the government's digital transformation initiatives and driving e-Government (National Archives of Australia, 2015). Goggin and Newell (2007), while acknowledging that a market-driven approach and self-regulation are desirable, concede that guiding, custodial and directive roles are also required of our standards-setting bodies, regulatory agencies and government.

The digital divide for signing deaf people

The digital divide is an expression that describes the gap between those who have digital access to the services, and the information and services they need, and those who don't.

Access is assumed to be achieved through a computer or a device, and through the possession of the relevant skills required to effect meaningful activity (Ellis et al., 2015). Abascal et al. (2015) comment that there is disagreement between those who see disability technology as 'assistive' and the now more widely accepted view of such technology as part of everyday life for all.

Those who are not participating in online activities are at risk of becoming members of what has been termed the 'digital underclass'. It has been noted by researchers that non-user populations have become more concentrated in vulnerable groups. In effect, the disabled—being members of a vulnerable group—are having the benefits of the digital age 'neutralised' as far as they are concerned. There have been calls to employ "[e]ffective interventions aimed at tackling digital exclusion, and individual experience with the internet " (Helsper, 2017, p.1).

The promotion of the principles of Universal Design, which call for the design of products that can be used by the greatest number of users, is at the forefront for accessibility engineers. The implementation of web content accessibility principles has been encouraged by initiatives such as the Web Content Accessibility Guidelines (WCAG, 2005). There is a call to better monitor and enforce compliance with WCAG in relation to responsibilities under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Easton, 2012). Universal design is sometimes invoked for the generalisation of access for disabled groups, although; the idea that an overarching approach to accessibility design will necessarily cater to the specific needs of individual groups is contested by researchers such as Abascal, Barbosa, Nicolle, and Zaphiris (2015).

For signing deaf people's efficient use of ICTs, there is a need for researchers and designers to attend to people who communicate 'differently', which necessarily requires a shift in how we understand communication (Alper et al., 2015).

Making progress on the issue of digital exclusion

The term 'digital islands' has been used to refer to the various smaller groups of people that exist between the divide: the people of linguistic minorities (Abascal et al., 2015). Ellis et al. (2015) warn of the tension that exists between the need to design for universal use and the need to understand, address and support the often-contradictory needs and

expectations of specific groups and individuals. Ellis et al. (2015) celebrate the friction that exists between disability and the dispositions of technologies, viewing them as a rich source of social action, ideas and reflections that open up into the larger problematic of political beings, participation, justice and technologies, framing these against a broader horizon' (p. 14). Helsper (2012) calls for researchers to 'unpack' the offline aspects of exclusion and define clearly which elements characterise digital exclusion. Ellis et al. neatly summarise the situation, stating: "Disability justice involves a shake-up and reimagining of democracy itself; the same is true of technology too" (2015, p. 23).

Research on the issue of access to healthcare information

Researchers are being guided by the challenge of contextualising research into studies of digital access for specific groups of people (Helsper, 2012). Signing deaf people have unique cultural and linguistic characteristics that affect their healthcare experiences (Kuenburg, Fellinger & Fellinger, 2016; Steinberg et al., 2002). The focus on contextualised research has led to a more informed approach to research, with researchers seeking to understand the factors that impede access for signing deaf people. For example, it is often stated that many deaf people have inadequate English literacy skills. However, informed researchers note that the lack of English literacy skills can be attributed to the challenges that face educators in teaching deaf children, and the resulting impact upon deaf students and adults in their continuing endeavour to improve their English language literacy skills. Consequently, when signing deaf adults attempt to access a wide range of services through written English, a language that is not their primary language, their limited English literacy skills, which are a result of the effects their past educational experiences, often negatively impact their access to information (Clark et al., 2016; Marschark et al., 2005; Mayer, 2007; Mayer & Trezek, 2014; Power & Leigh, 2000).

Another contributing factor affecting access to healthcare is a lack of a general health knowledge base and specific health literacy, which is compromised for signing deaf people because they are underexposed to incidental learning as a result of being excluded from 'overheard' conversations, radio broadcasts, and background stories and information about general health due to the lack of access in the wider community, through their signed language (Bat-Chava, Martin & Kosciw, 2005; Joseph, 1993; Pollard & Barnett, 2009; Steinberg et al., 2002; Ubido, Huntington & Warburton, 2002). The

importance of a well-developed healthcare knowledge base and associated healthcare literacy skills is viewed as vital for a full life. It is acknowledged that limited skills in health literacy, for any citizen, necessarily adversely affect a person's health, and are one of the strongest predictors of a person's health status (Komaric, Bedford & van Driel, 2012; Lytton, 2013; Nutbeam, 2008; World Health Organization, 2013).

Researchers have been investigating how, for signing deaf people, inadequate English literacy skills, limited health knowledge and specific health literacy are associated with poor healthcare access and outcomes (McKee & Paasche-Orlow, 2012; Napier & Kidd, 2013; Witko et al., 2017; for a comprehensive discussion, see Naseribooriabadi, Sadoughi & Sheikhtaheri, 2017). In the U.S. health system, it has been suggested by some researchers that signing deaf people who identify as Deaf ASL users are—like other people from minority linguistic groups—viewed as disenfranchised (McKee & Paasche-Orlow, 2012). There is a call by researchers for "health literacy and limited English proficiency researchers to work together to understand how culture, language, literacy, education, and disabilities influence health disparities and health outcomes" (McKee & Paasche-Orlow, 2012, p. 7).

The NDIS

In Australia, the National Disability Insurance Scheme (NDIS) promises to deliver services for people with disabilities to support their independence—their social and economic participation in their society (Cth, 2013). This social reform seeks to enact Australia's compliance with the United Nation's Convention on the Rights of People with Disabilities (UNCRPD) (UNCRPD, 2006). Under the scheme, people who have a disability that affects their ability to live a full life can become clients of the NDIS and access the products and services they need to manage their everyday life, increase their participation in society and enhance their quality of life (NDIS, 2017b). The NDIS services a total of fourteen client groups, each with its own characteristics and profile.

The Hearing Impairment group is one of the client groups supported by the NDIS. The Council of Australian Governments (COAG) provides independent quarterly reports on the performance of the NDIS. Currently, over 140,000 people have accessed the scheme (COAG, 2017). The NDIS acknowledges that, in order to provide a person-centred

approach to the provision of support to its clients, participants need to be treated as 'experts' in their lives (NDIS, 2016b, p. 23).

The most recent report from COAG indicated that the implementation of the scheme has involved the management of some tension between the speed of rollout and the quality of participants' experiences (COAG, 2017). In response to concerns regarding the participant experience, the NDIA reviewed its participant pathways to improve this aspect of the scheme. Following consultation with members of the various participant groups, the NDIS Pathway Review resulted in recommendations to improve the client experience (NDIA, 2018). Since the commencement of the rollout, there have been investigations by researchers resulting in recommendations as to how the NDIS can better understand the various client groups and their participants' unique profiles. Participants with intellectual disability as well as those with psychosocial disability have been represented in these discussions (Dowse et al., 2015; Smith-Merry et al., 2018).

Of the Hearing Impairment group, over 3,600 people held approved plans as at the time of the last quarter report (see Figure 1). This figure represents 3% of the total client group's population (COAG, 2017). Within the Hearing Impairment group, there exists a group comprising people who identify as signing deaf people, who use Auslan as their primary language. This 'Auslan users' client group can be described as a group that includes clients who share some of the characteristics of members of CALD groups; that is, they use a language other than English as their primary language in the home. As a group within the Hearing Impairment group of the NDIS, the Auslan users' client group has a specific client profile.

1.2 Primary disability of active participants with an approved plan

Disability	Number of participants	Proportion
Intellectual Disability	38,071	29%
Autism	37,383	29%
Psychosocial disability	9,007	7%
Cerebral Palsy	6,891	5%
Other Neurological	6,062	5%
Developmental Delay	5,917	5%
Other Physical	5,285	4%
Acquired Brain Injury	4,280	3%
Hearing Impairment	3,662	3%
Visual Impairment	3,129	2%
Other Sensory/Speech	2,757	2%
Multiple Sclerosis	2,638	2%
Global Developmental Delay	1,697	1%
Spinal Cord Injury	1,580	1%
Stroke	1,535	1%
Other	561	0%

■ Number of participants   Proportion of participants

Figure 1. Numbers of participants with a plan from various disability groups End Dec. 2017 (Source: COAG, 2017, p. 10)

For Auslan users who plan to access the NDIS in order to live their 'good life', success is dependent upon successfully accessing the NDIS. To better meet the needs of the various client groups, the NDIS consults with peak bodies and community groups representing the various groups. For the Auslan users' client group in NSW, the NDIS works closely with the Deaf community's representative bodies (Deaf Australia, 2015; The Deaf Society of NSW, 2018).

Australian signing deaf people consider that they are disabled because they experience a lack of access to information, and a limited range of services, through their primary language: Auslan. For the signing deaf clients of the NDIS, their perceptions of their experience in accessing the NDIS will provide a clearer focus on the possible existence of disablement as part of their client experience. This insight will provide direction for development so that access can be assured to allow these NDIS clients to access the supports they need to live an ordinary life (NDIS, 2017b).

CHAPTER THREE: THEORETICAL FRAMEWORK

Introduction

This chapter starts by explaining the benefits of the adoption of theoretical frameworks; their role in a qualitative study—specifically in this study—and how they can be used to gain insight into the perceptions of experiences of signing deaf people's access to the NDIS. Then the theoretical frameworks, the lenses through which this study are viewed, are described. A brief description of Interpretative Phenomenological Analysis (IPA) (Smith, 1996) will be given along with a justification of its adoption as an approach to this study. Then, the relevance of models that evaluate access to health systems will be explained. Finally, the Andersen (1995) and the Levesque et al. (2013) conceptual frameworks used in health systems to evaluate the equity of access for populations will be explained and the relevance of the Levesque et al. access framework to this study justified.

The purpose of theoretical frameworks

A theoretical framework informs the research by providing a system—a way of approaching the research, according to various assumptions, beliefs and concepts available to the researcher (Ngulube et al., 2015). The framework shapes the study, influences the methodology to be selected and facilitates a plan for the study that is well grounded in the literature (Creswell, 2007; Creswell & Plano Clark, 2007). For this study, a theoretical framework is viewed as being "the lens through which we conceptualize a research question" (Carpiano & Daley, 2006, p. 564).

A theoretical lens for this study

This study explores the lived experience of signing deaf adults, specifically, when they accessed the NDIS to obtain a service package. It concerns the meaning that has been ascribed to that experience by these people, which is reflected in their language about the experience, and their perception of that experience. The analysis concerns their reflection, their language and their form of expression of their reflection (Liamputtong, 2010b). The planning of this research has allowed the researcher to commence the investigation while already possessing "assumptions, a worldview, the possible use of a

theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem" (Creswell, 2007, p. 37).

This study adopts a phenomenological approach to the analysis of the data, which is an appropriate stance from which to commence the approach to the methodology. Phenomenology is grounded in the works of the philosopher Edmund Husserl (1927), who was concerned with the careful examination of human experience (Smith et al., 2009). Husserl's student, Martin Heidegger, developed the concept of 'Dasein', which is a word that directly translates into 'there-being' (Heidegger, 1962/1927). Heidegger was concerned with the person in context, and the interpretation of such, which allows for the incorporation of the work of hermeneutics—the theory of interpretation.

We might characterise Husserl as primarily concerned with what can be broadly classified as experience, and the perception of the experience. In contrast, Smith posits that "Heidegger is more concerned with the ontological question of existence itself, and with the practical activities and relationships which we are caught up in, and through which the world appears to us, and is made meaningful" (Smith et al., 2009, p. 16).

Our understanding of experience is guided by the works of these philosophers, among others of the period, who have led us to see that such an understanding

> invokes a lived process, an unfurling of perspectives and meaning, which are unique to the person's embodied and situated relationship to the world. In IPA research, our attempts to understand other people's relationship to the world are necessarily *interpretative*, and will focus upon their attempts to make *meanings* out of their activities and to the things happening to them. (Smith et al., 2009, p. 21)

For this study, in moving to the analysis of the data, an interpretative approach is appropriate. In fact, it is the interpretative aspect of the analysis that most closely meets the demands of this research project. When using IPA, the task of the researcher is to 'collect' and 'represent' the concerns of the participants. However, this is seen to be an oversimplification of the potential of IPA (Larkin, Watts & Clifton, 2006). The process becomes more complex as the researcher approaches the data from a perspective enriched by his or her knowledge of the underlying structures and the relevant contexts that may shine some light as to the context of the situation for each participant (Pietkiewicz & Smith, 2014).

There are two distinct phases in using IPA. The first phase relates to the 'first account'. In working with the first account, the researcher accepts that participants' accounts of their experiences are necessarily 'accounts' of their own experience and, therefore, already interpreted. Then, there is the aspect that the account is necessarily constructed by both the participant *and* the researcher—their necessary interaction influences the retelling of the 'narrative' of what happened; the story of the experience (Smith et al., 2009). This engagement between the researcher and the participant impacts upon the reality of the reflection of the experience because of the way the story is elicited and how it is represented (Metcalfe, 2013). So, in fact, the 'first-person account' is always interpreted to some extent. However, the task is to produce an informed description that "tries to get as 'close' to the participants' views as is possible" (Larkin et al., 2006, p. 104).

The second phase relates to the interpretation by the researcher. In the second stage, a "more overtly *interpretative* analysis, a 'second-order account,' which positions the initial 'description' in relation to a wider social, cultural, and perhaps even theoretical, context " (Larkin et al., 2006, p. 104; emphasis in original). It is this relationship to the context of the participants, the 'life in context' of each signing deaf participant, that makes IPA the most appropriate approach to this research task, in order to get as close as we can to understanding signing deaf people's experiences, and their perceptions of their experiences, when they accessed the NDIS to obtain the supports and services that they believe they need to live like everyone else.

Conceptual frameworks from the healthcare sector

The healthcare sector is necessarily concerned with equity of access for its patients and clients to the services and information that it offers. The NDIS is related to the healthcare sector because, when it provides support for its clients, it includes supports for clients' health and wellbeing. Researchers have identified that equity of access to healthcare services can be compromised at many levels, impacting the health outcomes for individuals and people belonging to vulnerable groups, such as migrants, those with limited English and those who live with disability (Comino et al., 2012; Fiscella & Shin, 2005; McKee & Paasche-Orlow, 2012; Memon et al., 2016; Overs et al., 2017; Tomlinson et al., 2009). Other studies have specifically investigated the access to healthcare experience for members of CALD groups, where the focus is often a combination of

factors impeding access to health services for these people (Wechkunanukul, Grantham & Clark, 2016).

Some researchers have hailed the suitability of IPA as a qualitative methodology of choice in healthcare research because through the use of IPA they can engage with the patient in a dialogue and attempt to capture the lived experience of the patient in context (Biggerstaff & Thompson, 2008; Oliveri & Pravettoni, 2017).

The Andersen conceptual framework

The Andersen conceptual framework of access to and use of health services is an effective framework that researchers can use to enable analysis of different categories of access (Aday & Andersen, 1974). The framework was designed to provide measures of access "to discover conditions that either facilitate or impede utilization" (Andersen, 1995, p. 4). The framework has evolved since its development in the 1970s. The original model was elaborated in the 1980s and 1990s, representing a pathway of access whereby primary determinants, such as the characteristics of the population, are noted, leading to intervention in relation to a health behaviour, such as use of health services, and to health outcomes, including perceived health status and consumer satisfaction. The framework attempts to visualise the 'fit' between the demand side (the user) and the supply side (the provider). The emerging model has been adapted to include the multiple influences that impact upon the patient as the they move towards realised health outcomes (Andersen, 1995). The longevity of this model is a testament to its application. Researchers looked at numerous qualitative perceptions about barriers to access to health services for migrants and used the Andersen framework of access for its analysis (Agudelo-Suárez et al., 2012). This framework, in turn, has informed the development of the Levesque et al. framework, which is used by many researchers of equity of health access today (Levesque et al., 2013).

Levesque et al. access framework

The Levesque et al. access framework (2013) was informed by the previously described Andersen framework. This model focuses on the 'interface' between the demand-side and the supply-side determinants of access.
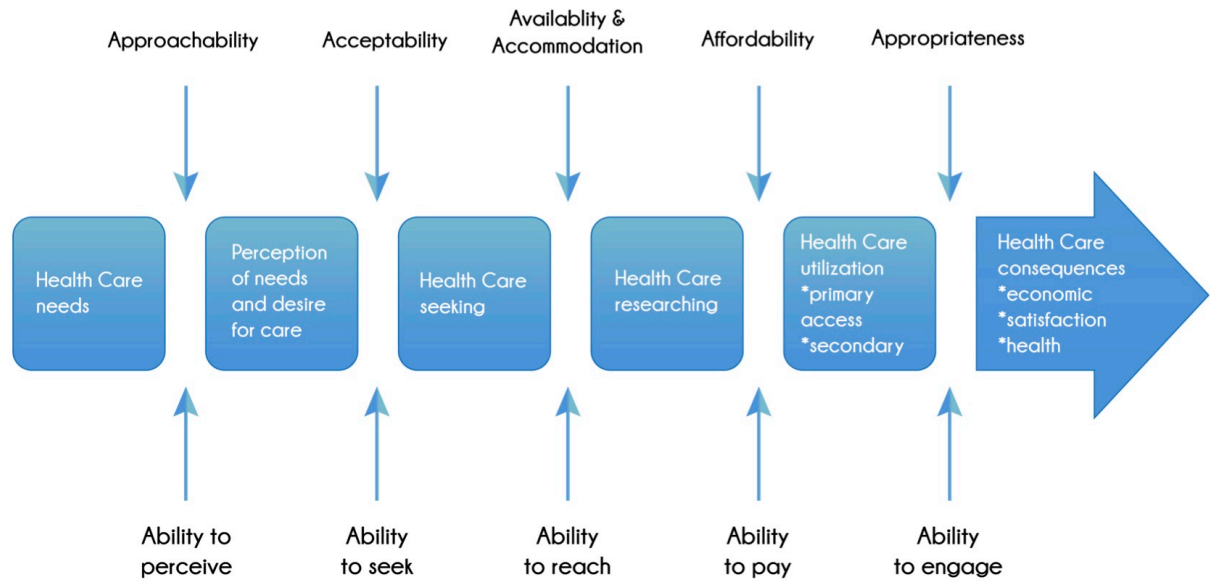
Figure 2: The Levesque et al. access framework (Source : Levesque et al., 2013)

The framework shows five dimensions of accessibility of services, seen at the top of the model: Approachability, Acceptability, Availability and Accommodation, Affordability, and Appropriateness, which relate to the corresponding characteristics of the person seeking access, and there is an interaction between the characteristics of the person and the dimensions of accessibility to generate access. The key to this framework is that there is an 'interaction' and a 'generation' between the supplier and clients to achieve access. In addition, there is a clear visual representation of the requirement for the provider to respond to the characteristics of the population "to ensure the people's capacity to use the services" (Levesque et al., 2013, p. 7). One study was conducted into the innovations that have been developed for equity of access to primary healthcare for vulnerable populations (Richard et al., 2016). The framework was adapted for another study into the access to treatment for tuberculosis (Tschirhart, Nosten & Foster, 2016). It is the view of these researchers that the use of IPA may complement this conceptual framework to allow researchers to get to the centre of the engagement process between the provider, and the client during access relations. The combination of the two frameworks as forms of reference is suitable for this study.

To summarise this chapter, the value of theoretical frameworks has been explored and frameworks that relate to the approach to this study have been identified. The theoretical frameworks include firstly, IPA (Smith, 1996), because its interpretative function relies on a theoretical context for the analysis and, for this study, the historical, and contextual

lives of signing deaf people is the theoretical grounding. In addition, the studies into equity of access to health services are relevant to the background context of this research because they often extend to research on various populations, including those with limited literacy, people living with disability and members of CALD groups. The equity of access domain is related to this study because the signing deaf clients of the NDIS are seeking equity of access to the NDIS for the provision of health and wellbeing supports as part of their NDIS service package. Developing on an understanding of the issues associated with equity of access to health systems for various populations, the Levesque et al. access conceptual framework also relates to this study since it takes into account the dynamic nature of the conceptualisation of access to healthcare and the engagement between the supplier/provider of the information and services, and the client.

The next chapter will describe the methodology used for this study into the perceptions of experiences of signing deaf clients in relation to their access of the NDIS.

CHAPTER FOUR: METHODOLOGY

This chapter reiterates the aim of the study in order to provide an orientation to the methodology of the research project. The chapter then describes and justifies the chosen research methodology for this thesis with a description of the chosen approach of analysis: Interpretative Phenomenological Analysis (IPA). Following on, a detailed account of the planning and execution process of the research is provided. The account will include information about the adoption of a focus group method for the collection of data. Further information about the participants, the recruitment method and relevant ethical concerns will be provided. The research procedure will then be described. To conclude, an explanation of the data analysis will be provided.

The aim of the study

This study explores the perceptions of the experiences of clients of the NDIS who are signing deaf people—specifically, their experiences in accessing the NDIS to obtain a service package.

Design and approach to the study

This study adopts a qualitative design, taking an Interpretative Phenomenological Analysis (IPA) approach. Qualitative design provides in-depth and rich information about participants' personal perspectives and their subjective meanings (Johnson & Christensen, 2017). Researchers who adopt a qualitative approach are interested in the quality and texture of the experience of the participant, and in the meanings the participants themselves attribute to events (Willig, 2013).

A phenomenological approach is concerned with the study of experiences; what it is to be human and, in particular, to be human in relation to the things that matter to us and " which constitute our lived world " (Smith et al., 2009, p. 11). Furthermore, and notably relevant to this study, a phenomenological approach allows us to draw conclusions as to our reality based on a number of variables, including that of socio-cultural diversity, which is the contextual reality for many people within our community (Spinelli, 2005).

Interpretative Phenomenological Analysis: theoretical orientation

IPA "draws upon the fundamental principles of phenomenology, hermeneutics, and idiography" (Pietkiewicz & Smith, 2014, p. 8). IPA represents an interpretative commitment to understand the experiences and concerns of participants; to contextualise, and 'make sense' of the participants' claims (Larkin et al., 2006). For the purpose of interpretation, the attention to the hermeneutics involved, expressed by the participants, necessarily deals with the interplay of tradition, language, dialogue, experience and context (Freeman & Given, 2008). There is, therefore, a focus on how the participants perceive, and express themselves about, objects and events.

IPA has been selected for the analysis in this study because there has been a call for researchers, within the field of Deaf Studies and beyond, who are researching deaf people to address research questions through the use of theoretical approaches that capture information from the perspective of the individual; attending to the lived experience of the individual, the individual in context (Baynton, 2008; Hauser et al., 2010; Kusters, De Meulder & O'Brien, 2017; McKee et al., 2012).

IPA may appear an essentially simplistic approach, a simple 'describing of events and experiences'. However, IPA can be a powerful method of analysis because the careful execution of the analysis introduces a paradoxical capacity for complexity in its development to an interpretative or conceptual level (Biggerstaff & Thompson, 2008; Larkin et al., 2006).

Method of data collection

A focus group design was chosen as a suitable method of data collection for this study. Focus group design involves the organisation of a discussion group that is designed to obtain "perceptions on a defined area of interest in permissive, nonthreatening environment" (Krueger, 1994, p. 6). Focus groups are considered suitable for IPA because IPA researchers are concerned with obtaining rich, detailed, first-person accounts, and focus groups allow for multiple descriptions at the one sitting. However, there is a need to ensure that the participants are able to discuss their own personal experience in sufficient detail and intimacy, despite the presence of the group (Smith, 2004). Furthermore, focus groups are considered to be appropriate for vulnerable groups of people because the group work "ensures that priority is given to the respondents'

'hierarchy of importance': *their* language and concepts, *their* frameworks for understanding the world" (Kitzinger, 1994, p. 108). According to Liamputtong (2011), focus groups can provide a neutralising effect on the imbalance of power between the researcher and the participants, which is very appropriate for this research study because signing deaf people have had to address imbalances of power throughout their lives (Dunn & Creek, 2015).

This research concerns the exploration of perceptions about experiences of this group of NDIS clients; an area that has not been explored to date. It is important that an informed understanding about the experiences of this group is developed. The use of a focus group permits the researcher to disclose aspects of understanding that often remain hidden in other methods of data collection (Liamputtong, 2010a). The nature of the question being researched can influence the decision as to whether to use focus groups for IPA or not; for example, if the question has an immediate and applied perspective, the focus group provides a starting point to then perhaps develop further studies (Smith et al., 2009).

The topic for this research explores an immediate and relevant perspective concerning the client experience of signing deaf clients of the NDIS. The perceptions of this client group could meaningfully inform future studies that could capture more participants, which could positively influence the impact of this, and future, research and the development of the NDIS.

Participants

The sample for this study was recruited from the signing Deaf community in Sydney. Participants for this study were included in the study if they were deaf adults between the ages of 25 and 65, who used Auslan and considered Auslan to be their primary language, and had been successful in obtaining an NDIS service package. Four participants were successfully recruited and participated in the focus group. For the purposes of IPA, to achieve a suitable environment, it is considered that 'four to five is a good size for a focus group' (Peek & Fothergill, 2009; Smith et al., 2009, p. 73).

Recruitment

Recruitment was carried out through the Deaf Society. Working with known community networks ensures commitment through trust, allegiance and advocacy (McKee et al., 2012). Initially, the researcher met with a senior staff member at the Deaf Society. This first meeting was organised at the commencement of the research project planning. The purpose of the meeting was to instigate contact and commence the development of rapport with the staff members of the Deaf Society. The researcher, through contact with the senior staff member, ensured that updates about the progress of the project were communicated and, importantly, built upon the established rapport with the Deaf Society. Once the concept for the study was developed, the researcher contacted the society and was referred to a staff member who would be responsible for liaising with the researcher regarding the recruitment and the logistics of running the project. The recruitment was advertised through the Deaf Society's news system, The Deaf Herald, which is a video released monthly with news announcements that are signed in Auslan (see Figure 3). The Deaf Herald is distributed on the Society's website and translated into written English at the bottom of the screen. The inclusion details were provided in the advertisement (see Appendix 1). The offer of a $50 gift card by way of appreciation for the investment of their time was advertised. Prospective participants were invited to contact the researcher via email or to leave their details with the Deaf Society. Staff members of the Deaf Society promoted the research project during the performance of their duties with clients at the Society. Once the participant had contacted the researcher and indicated a desire to participate, the researcher then replied by email with three questions to ascertain eligibility. The three questions asked were: Are you deaf? Do you use Auslan as your primary language? Do you have an NDIS service package? If the respondents replied 'yes' to all of the questions, they were emailed details of the planned focus group.

Figure 3: Image of recruitment video which was produced in Auslan and written English

Ethical concerns for the participants

Ethics approval was granted for this research project by the Macquarie University Ethics Committee: Approval no. 5201701020

There were no major risks associated with this project. The project was deemed to be straightforward and low risk. The benefits for the participants included a sense of satisfaction at representing the signing deaf client group of the NDIS; that through participation they might feel that their experiences, and perceptions of their experiences, were being 'heard'; and that the outcomes of the research might contribute to the provision of better access and an improved NDIS client experience for signing deaf people.

Concerns relating to consent and the right to withdraw, participant anonymity and engagement

Communication in Auslan, through an Auslan interpreter, was done to ensure understanding for all participants concerning completion of consent forms and the explanation of participant anonymity, as well as the right to withdraw at any time. This information was re-stated at the commencement of the focus group discussion.

The Auslan interpreter was accredited by the National Accreditation Authority for Translators and Interpreters (NAATI), which demands adherence to a strict code of conduct regarding privacy and respect for clients, and this helped to ensure participant anonymity.

For the purpose of assuring anonymity during audio recording and transcription, the interpreter used participants' names when identifying their input on the audio tape to ensure clear and inclusive communication throughout the discussion; however, the names were removed prior to transcription and replaced with numbers. The participants were invited to contact the researcher during an identified month following the research to learn of the findings of the study.

Research procedure

The research procedure involved a series of processes planned to ensure that the research project ran smoothly so that the research questions were able to be addressed. Once the research participants had been recruited, the researcher developed and maintained contact with the participants throughout the lead-up to the focus group date. The focus group was held in the evening in a meeting room at the Deaf Society. The consent forms were interpreted through Auslan and then signed. The provision of anonymity through the deactivation of names prior to transcription was explained. The purpose of the focus group was explained to the participants and the expectations of the participants were stated. The participants were advised, once again, that they could withdraw at any time throughout the running of the focus group discussion. During the focus group discussion participants were invited to respond to the questions and prompts that were designed to elicit answers to the research questions.

The focus group discussion (including the interpreter's voicing of Auslan responses) was audio-recorded using an iPhone recording application on the researcher's personal iPhone, and also on an Olympus portable digital voice recorder. At the completion of the focus group, the participants were asked if they were feeling well and whether any concerns that might have been raised had caused concern for them. If they had indicated that they had concerns, the researcher was prepared to refer them to appropriate services. Participants were thanked for their time and presented with a $50 gift card as a token of thanks for the donation of their personal time. The following day, the researcher emailed the participants individually to convey a personal expression of gratitude for their interest, time and involvement.

Research instruments

The instrument used in the focus group was developed to provide the stimulus to encourage discussion and to elicit responses. The responses were expected provide insight about the experiences of the signing deaf clients of the NDIS in their efforts to secure a service package, and their perceptions of their experience. The instrument was a list of questions, with supporting prompts to be used as a reference for the researcher during the focus group discussion. This included a lead-in statement thinking about getting information about the NDIS.

The three overarching questions and their supporting prompts were:

1. How did you find out information about the NDIS?
    a. Internet website, brochures, Deaf Society, family, friends?
2. Tell us about your experience? Did you find information that you needed?
    a. Was it what you needed?
    b. Enough information?
    c. Compare experiences from the start to now?
    d. How is it going now?
3. Tell us about your perceptions of your experience.
    a. How did it make you feel?
    b. How do you feel about it now?

In using this instrument, the researcher was mindful of good practice in managing group dynamics during a discussion setting. Attention was paid to turn-taking,

acknowledgement of contributions and strategies to ensure group cohesiveness (Krueger, 1994).

Research analysis

The research analysis was completed in accordance with the requirements of IPA (Smith et al., 2009). For this study, the form of analysis is inductive, drawing on the data to explore the meanings and then to identify emerging themes (Duff, 2003).

IPA concerns the analysis of the actual first-person accounts of the participants. Once the accounts are collected, they are analysed in order to create themes. Through this process of abstraction, the researcher conceptualises how the words and their context within the discussion can be interpreted by relating them to various themes the researcher believes relate to the wider context of the discussion and the participants' lives (Pietkiewicz & Smith, 2014).

At the completion of the focus group, later that evening and again the following day, the audio was listened to and brief notes made. First impressions of the data were noted though not formalised until there was time for deeper analysis. The data for this study were prepared for analysis using NVivo 11. To prepare the data, the recording of the focus group discussion was sent to a professional organisation for transcription. The names were deactivated. Transcription was carried out in verbatim style. Once received by the researcher in Word document format, the transcript was imported to the NVivo software. Emerging themes were noted and thematic coding organised the information into various categories, which is the researcher's way of highlighting the parts of the data that appear to be of theoretical interest (Pham, 2018).

Figure 4: Image of analysis process - NVivo coding emerging barriers and positive themes into nodes

Figure 5: Image of NVivo coding emerging negative themes and feelings into nodes

For the analysis, themes were created by relating the data to the questions that were asked, then to the context of the discussion and the context of the meaning that they may have for these participants.

The following three questions were then used to commence coding by identifying themes:

1. How did you find out information about the NDIS?
2. Could you tell us about your experience?

3. Could you tell us about your perceptions of your experience?

The codes were first identified, quite literally, as they related to the above questions. However, in an effort to have the data further drive the selection of more informative codes, the researcher referred to the Levesque et al. (2013) access model to frame the approach to the data and its interpretation. The data were reorganised according to themes, which were sometimes more readily expressed in terms that represented some of the terms in the framework. The researcher might ask of the 'first order sample', for example, "Was this an appropriate way for this to be done? What abilities were lacking in this situation? What accommodations did the Local Area Coordinators make?" For this study, the themes focused on the participants' experiences, the interface between themselves, as those seeking the access to the NDIS, and those responsible for generating the access for them—that is, the NDIS system and its staff (Levesque et al., 2013). To complete the analysis of the data using IPA, the researcher looked at each node, reflected on the context of the discussion during the focus group, and then attempted to code further to bring together the significant themes. Once the major themes were identified, the researcher drew a visual map to assist in the understanding of the forces that were in action; the interrelationships between the major themes. By reading the vignettes of conversation relating to each theme, the researcher was able to rewrite them in terms of their more contextual meaning; the assumed meaning based on the researcher's guided knowledge (Pietkiewicz & Smith, 2014). To assist in this process, the researcher would ask of the data: "What is this saying?" "What is really happening here for this participant?" "What are their needs?" "What's happening in the process, the good things, the not-so-good things when trying to get their plan?" "What's happening when they face a barrier?" "What happens when they have a good experience?" "What seems to their reaction?" "What are they telling me about this?" "How does it appear to affect them?".

Figure 6: Visual map of major themes: needs, barriers and feelings

The next part of the analysis involved the 'writing up' of the experiences. During this more complex part of the IPA process, the researcher tells the story of what was revealed about the participants' experiences, what appeared to be happening in their life; themselves in their world (Larkin et al., 2006). This part of the process is still the analysis, yet, upon completion, forms the results.

This chapter described and justified the chosen research methodology for this thesis, Interpretative Phenomenological Analysis. A detailed account of the planning and execution process of the research was then provided. Information about the adoption of a focus group method for the collection of data was given. To provide further detail, information about the participants, the recruitment method and relevant ethical concerns was explained. To allow step-by-step understanding of the research process, the research procedure was described. To conclude, an explanation of the data analysis was explained.

The following chapter presents the research findings and the results of the analysis.

CHAPTER FIVE: RESULTS

Introduction

This chapter presents the research findings of the exploration of the experiences of signing deaf adults, and perceptions of their experiences when they have accessed the NDIS to obtain a service package. The data gained proved to be very detailed, which provided in-depth and rich information about participants' personal perspectives and their subjective meanings (Johnson & Christensen, 2017). The three overarching questions were sufficiently broad to encourage participants to recount their experiences and enrich the experience further by telling the group what they thought about the experience and, in particular, how they felt about it. The IPA analysis calls for the researcher to look for evidence of the participants making sense of their experiences, and then to attempt to capture the meanings and the lived experience of the participants (Pietkiewicz & Smith, 2014; Smith et al., 2009).

Many of the accounts of the participants' experiences concerned aspects such as challenges with finding out about the NDIS system, navigating the system, and efforts to engage with NDIS staff members. The exploration of these topics served to reveal similarities and differences in the lived experiences of each of the four participants. For these participants, the experience of accessing the NDIS to obtain a service package involved a preoccupation with having needs met. However, the initial process of planning to have their needs met, for most, proved difficult. Often, these participants' needs were not able to be met due to the barriers that confronted them, either with the system or in interacting with staff. The challenge to deal with the barriers they confronted was experienced in different ways by these people. When reflecting on these times, the participants could express their emotions about the events. The main emergent themes were: needs, barriers and feelings as evidenced by the group participants.

Need for information

This theme developed throughout the focus group session as the participants reflected on their experiences and then shared their stories. All the participants chose to recount the timeline of events from an awareness of the NDIS at its inception to the end goal of obtaining a Service Plan. During the recounts, participants all found themselves in a situation of 'needing to know' about what was happening. The need to know appeared

to grow from an initial inquisitiveness to then really wanting to get information. This theme of 'needs' appeared to be ever-present within the data. Fundamentally, it was present within a constant context of seeking to have needs met: the planning of needs, the negotiating of needs, the meeting of needs, the review and then renegotiation of needs (NDIS, 2017a). There were the resulting questions that challenged them to find out about the NDIS: What is it? What to do? How to do it? These questions continued throughout their experience with the NDIS—a system that was new, big, and a significant challenge to navigate.

However, the word 'needs' took another meaning when the word was required to reference something about them: 'their needs', the things they need so they can live like everyone else. In the NDIS glossary, this translates as 'supports' (NDIS, 2017a). Typically, most people attempt to find out about accessing a new service that they need via the internet. For many people, this is the first step in the process of getting their needs met. As one participant described their experience, "I googled the internet and went through the NDIS website. They had some information, but it's very vague. It still wasn't clear to me." Another participant explained, "So really what happened was, because I couldn't get in to register, I then went further into the internet base. It was very basic, really, because the information that was on the internet really wasn't very—with any depth. So, it was a matter of just waiting to see." Another commented, "Because it was something new it was just a case of waiting for the information to get out".

Needing to understand the system

Needing to understand the processes of the NDIS was expressed as challenging. The participants mentioned that, because information was lacking or was not clear, rumours started to circulate within the Deaf community. The participants acknowledged the role that the Deaf Society played in supporting the NDIS in offering information sessions to its community. "So, The Deaf Society actually started to give information sessions to make the comfort [sic] of the people who were listening to the rumours." Once a plan was achieved, the knowledge about the processes regarding the use of the plan, and the possibility of review of the plan, appeared to cause concern. One participant expressed confusion with the systemic processes of the NDIS: "So it took me six months to be able to prove a change in my circumstances in the fact that I needed to have access to others. I've got family, we called the NDIS, and they asked. It was really quite

weird really. Because we rang the person, we spoke to them on the phone. They just sort of said, 'Oh well, the application, just hang on, we've got it on urgent". We just sort of said, 'Yeah.'" Another participant expressed that she found government departments easy to navigate. She explained how it is for her: "You know, the government doesn't frighten me I have to say". This comment suggests that knowing how to navigate the system—having the necessary abilities and confidence—is a big part of achieving access to the NDIS. This participant offered further counsel: "You could put an appeal in, but maybe sometimes it's better to say it's a change of circumstance." Two of the participants shared their experience through their stories, which seemed to follow a familiar pattern of not understanding the review process and the fact that, if one changes plans, the remaining money is taken away. This is obviously a procedural fact that was not made clear to these participants.

The resulting confusion and sense of disappointment and frustration was evident in their accounts: "I've got no idea why they didn't tell me. When I saw the date on it and I said, 'Oh, it's backdated to January. But they never told me, and they just said, 'Well you can start using it now'. But, of course, [if] you don't use it, you lose it. So, I had so much money that just went out of my package and I couldn't use it." There was an appreciation that the implementation of the NDIS is a challenging task for the management section of the NDIS staff themselves to understand and administer: "Really, with the NDIA it's an organisation without any training in regard to the various disability sectors and everybody's new. It's a new organisation, everyone's had to fill all these seats. 'Can you do this job? Okay, well this is the criteria you follow.' You've got these people who are trying to follow a criteria [sic] that don't have the experience and they don't know. Some of them don't even have any disability experience." This comment gives a very generous perspective on the effectiveness of delivery for the NDIS. There is an evident low expectation of level of service for this participant, which may influence his perceptions of his experience. This low expectation and sense of empathy for the challenge that the provider, the NDIS, is facing is at odds with wider societal consumer expectations, and does not align with the aims of the NDIS, which state that their clients have the right to live just like everyone else (NDIS, 2017b).

This aspect of this client's perception of his overall initial experience, his engagement with the NDIS, could indicate that the level and quality of the service, in terms of the

NDIS's preparedness to deliver its service in an equitable way, could be interpreted as unacceptable (Levesque et al., 2013). Within this seemingly logical pathway of organising the fulfilment of needs, a whole other array of needs seemed to appear before them. To express these experiences, often a narrative would commence with the typical complication, within which would exist the subplot of the 'war story' of the event (Metcalfe, 2013). The stories were told in the context of the participants' deafness: their need for information through Auslan, the need to understand and be understood and, from their point of view, what it really means to be living as a deaf person.

Needing to ask for supports through the Local Area Coordinators

Often the stories centred around the actual meeting with the Local Area Coordinator (LAC), the person who plans their service package with them. It is at this meeting that the client puts forward their proposed plan and the LAC is involved in the discussion about the claims for the supports that the client has made. The participants report that when a signing deaf person meets with the LAC, the level of engagement can be less than ideal. Again, the LAC can lack knowledge and understanding about being deaf, and the implications of living as a signing deaf person. One participant shared an experience about a family she was assisting to apply for a plan. The comment reflects a lack of understanding on the part of the LAC about the specific needs of signing deaf people. The participant explains: "Because they live with hearing people, it's the assumption with the LAC that the hearing person will do everything for them. But they need to be able to see their front door and they need to know when things are dangerous, so that's what the discrepancy is. They [the friends] spoke to me and just sort of said 'The LAC told me that we didn't need it.'" This participant is very concerned about her friends, and her particular ethnic community (the Korean community). There is a sense of concern about those who are not getting the support that they should. This is even more serious for this participant as their friend has actually arrived at the stage of engaging with a LAC who, in effect, just said "No." One participant shared: "…because they had no idea about the needs of a deaf person I just sort of felt like I was wasting my time trying to explain all that." The sense of being 'at the mercy' of the 'powerful' LACs is shared with a summary of the problem as seen by one participant: "So they don't even know how to access information about the Deaf community, and yet they give recommendations that they have no idea about. So how can they say to someone, well you don't need a flashing

light, you don't need this, you don't need interpreters, you don't need to learn sign language." It is interesting that the LAC is accused of not even knowing how to access information. This appears to be quite ironic given that in the life of signing deaf people, access is usually all up to them; they are the 'doers' of accessing. In this snapshot, the responsibility for the accessing appears to be being placed on the shoulders of the LACs. The participant appears to be proposing a different expression of roles: the role of the LACs as needing to have the ability to provide their service with the appropriate awareness of and knowledge about signing deaf people.

Barriers

The second theme concerns the existence of barriers. Barriers can be obvious, or they can be subtle. During the focus group session, the word 'barriers' was not introduced or used as a prompt by the researcher; however, it appeared in the language used by the participants. Barriers, a word that is well-known to those familiar with the field of disability, is used as a metaphor to indicate a block that obstructs access. As discussed earlier, the lack of knowledge and information about the NDIS can have the effect of creating a barrier. For this theme, for these participants in this context, the word barrier holds the same meaning. However, for this study, the researcher sought to identify some meanings that are represented as a barrier, depending on the context of their use within the discussion (Smith et al., 2009). When the participants shared their experiences about the processes they followed in obtaining a service package, two main themes concerning barriers emerged: the general lack of information available to them as a consumer, and the role of the LAC.

Barriers to accessing the NDIS independently

To be a consumer means to be able to get goods and services. For these participants—and for the understanding in this research study, ideally, for someone without any complicating disabilities—a signing deaf person should be able to get access to the NDIS or NDIA and obtain information independently, without the assistance of other support people. Provided the information can be accessed through Auslan and technologies to assist access, contact could be achieved through the internet via the NDIS website (where Auslan informational videos have been uploaded) or email, by phone through TTY and/or Skype or interpreter. All the participants indicated that they

use the accommodations that the NDIS offers to meet their communication needs; however, it appears that, for the majority of these participants, the NDIS was not as welcoming and accessible as it perhaps could have been. When contact was made, the depth of detail that they needed was not available, or perhaps their own lack of ability to seek information, impeded by their lack of knowledge of the system, affected their ability to navigate the system as effectively as non-deaf consumers might. One participant shared how she responds to the information on the website when it is vague or lacks depth: "In one way that was good because I could just interpret it to suit me. So, there was enough ambiguity, enough unclearness for me to be able to say, 'Well, the way that you've written is the way that I've interpreted.'" For one participant, the key to meeting his need for information was to be successful at registering: "I could register, and with that comes more information".

The use of Auslan, as a means of accessing information, was mentioned just once during the focus group session and only in response to a question from the researcher. The researcher asked whether there was an issue about accessing information through Auslan. The response was a dismissive, "No". This was briefly explained by one of the participants who indicated that, for meetings, there was always an interpreter present: no problem. Evidently, the provision of access through Auslan is satisfactory during meetings for this group of participants, provided there are interpreters available to ensure the access in a meeting situation. However, there was the suggestion of a need for more detail and depth of information through Auslan on the website so that people could find out about things by themselves. There was a discussion about the problem of finding out what will be accepted as a support and what will not. There was one mention of confusion over the funding of interpreters: "Another example is that person didn't even get an interpreter in her budget." This seems to indicate another 'surprise' that resulted from a lack of understanding during a planning meeting.

The power of the Local Area Coordinators

The Local Area Coordinators (LACs) are the people who meet with the client to organise a service package. These NDIS representatives are viewed by the participants as holding a lot of power and, in effect, can be seen to act as the 'gatekeepers' to the supports these participants believe they need.

The barrier LACs can create can be a controlling barrier, which affects the participants in various ways: the barriers can cause delays, which result in a sense of confusion, and frustration. It appears that some LACs don't seem to know their own system: what supports can be requested and what can't. For example, "Then they, the LAC, will say, 'Oh, I don't know whether you qualify for that, I'll have to ask". So you feel like it's an endless attempt sometimes to try and have an interview. So it's an ongoing barrier, of course." One participant added, "[J]ust say I say that I have a need for … and then you were telling them, and they don't understand the specific needs. Sometimes they make the decision that it's not important." One participant summarised this concern regarding the level of understanding of the LACs: "But their knowledge is very basic, they don't understand the different … and they just have a schema of what they think that a deaf person would require. If it doesn't fit in within their schema then the deaf person misses out because it's not being considered." There was a 'hard to believe but true' moment shared by one participant: "They don't even understand about the fact that we can't hear, and we can't talk". There was agreement among the group that this can be an experience for many signing deaf people.

However, despite holding such power, it is the view of all of the participants that the LACs could be better skilled in their preparation for their role. One participant commented, "[B]efore the LACs started, it would have been a good idea that they were trained to the needs and what each disability group needed". This was then expanded upon in a quote previously noted- though, again, relevant in this context: "Really, with the NDIA it's an organisation without any training in regard to the various disability sectors and everybody's new. It's a new organisation, everyone's had to fill all these seats. Can you do this job? Okay, well this is the criteria you follow. You've got these people who are trying to follow a [sic] criteria that don't have the experience and they don't know. Some of them don't even have any disability experience." In addition to the challenge of carrying out their role, the LACs appear to lack understanding about the life experiences of their signing deaf clients, and this is impacting their ability to be accepting of these clients and to engage with them to provide access appropriately. One participant sums up the whole process of preparing and receiving his first plan: "No, when I went to the interview from [sic] the LAC it was just so heart-wrenching. You just felt like you were being ignored and it was just a protocol. Then when I got my plan, can I say, it was crap." This participant went on to explain that his ability to navigate the

system did improve. "So I'm sure with my next plan it will be better. That's my strategy, you learn from somebody else's plan and you hope that it will help your plan." One of the participants shared that she had a way of dealing with this problem: "So, I chose to ignore the LAC and I can argue my case and I'm assertive. So a lot of people don't have that confidence. So if I'm booking things and I get caught, well, then I'll take that risk. So that's a risk that I decided to take because I am self-managed. It fits my goals and I can argue that case and so I have no hesitation." This participant appears to be expressing that she has so much confidence in what she is doing that she is prepared to take a risk, because, in effect, as she states, "I can argue my case". This client is expressing to the group and the researcher that she is competent and confident. One participant shared a strategy that she has adopted and expressed her relief in finding someone in the system who could assist her, and work with her to provide the most appropriate access. "So now I've just got that new person who understands deafness, so I'm going to contact that OT [Occupational Therapist] and see whether she can come." It appears that the OT to whom she is referring had the appropriate skills and understanding to bring to the planning meeting for this signing deaf woman's needs. One solution offered by a participant to improve the situation so that signing deaf clients experience appropriate access involved recruitment practices. "I can remember a particular deaf person applied for a job for the NDIS in Newcastle. So that would have been great. They didn't get the opportunity to get in. So they didn't—and I just sort of thought, 'Well, you know, that was a deaf person who knows something about deafness.'" Here there is a contemplation, an imagining of how things could be. In her mind, the solution was quite logical, sensible, and because it didn't happen it was seen by the participant as a 'lost opportunity'.

Feelings

The next theme that was identified is feelings. Feelings can be defined as the representation of the physiological changes that occur when one is experiencing an emotion; a cognitive representation of an emotional state (Damasio, 2001; Panksepp, 1998). In the first response, emotions can include expressions of sadness, happiness, fear, anger or disgust and can be measured through observation, physiological responses and self-reported responses (Ekman, 1992; Mauss & Robinson, 2009). Feelings are reported to be the consequences of emotions, a kind of mental reminder,

and can alert and amplify the impact of a situation and thereby provide a learned response of what could be expected in a similar situation in the future (Damasio, 2001). Once an experience has passed the emotion fades; however, the feeling associated with an experience may not fade; it may continue to be recalled by the person who experienced the emotion and consequently affect future thinking, planning and behaviour (Damasio, 2000). When there is a mismatch between the expectations of a situation and unexpected information that is presented, there is reported to be a feeling of surprise and, if this feeling is ongoing, confusion occurs; the new information fails to be processed (D'Mello et al., 2014). For signing deaf people, when attempting to access healthcare services, diverse life experiences may result in feelings of confusion, misunderstanding, resentment and frustration and, ultimately, often result in avoidance of any further threat of negative emotional experiences (Sheppard, 2014). For participants in this research, when reflecting upon their experiences in accessing the NDIS, their individual perspectives will be necessarily influenced by their own context and their own lived experience as a signing deaf person (Kusters, De Meulder & O'Brien, 2017).

The participants in this focus study reflected on their experiences of obtaining a service package and shared their reflections with the group. Some participants indicated that they felt that it was a good experience, others found it challenging. Some participants referred to others they know in the community who felt too overwhelmed by the prospect of the challenge, and so didn't seek to access the NDIS. Some reported that they felt obliged to help those who felt overwhelmed or had given up on the challenge. These participants were recruited for this sample because they had successfully navigated the NDIS. They indicated that they do feel that they have improved in their ability to navigate the system. Some have adopted strategies to do so.

However, when they reflect on their experiences the feelings they shared with the group showed that some experiences were not easy, and that the feelings about some experiences are still very clear in their memories. The participants indicated that in the early months of the implementation of the NDIS, there was a general feeling of confusion, at both an individual and a community level. In the focus group, there were discussions about who got what, and the feelings reported in this exchange within the group reflected an excited 'lottery' effect: those who were the winners! "Then some people are saying,

'Well, I only got this'. Somebody else would say, 'Oh but I got more than that'. So the questions would then go around, because people were very diverse with their access and what they were getting on their packages." However, in addition to those who experienced the excitement one could look deeper into this scenario to imagine the individual feelings of those involved, perhaps feelings of disappointment, jealousy and injustice, and possibly even failure: a failure to access and navigate the system.

Some indicated that they had a feeling of responsibility to others they knew who might have been eligible for a service package but didn't appear to have the ability to engage in the process. One man told of his wife, who he believes doesn't have the abilities required to obtain a service package independently, and so he feels that he has to help her. "If it becomes too hard she won't do it, so I have to come to her rescue and try and help her and so that's not fair either." When asked how she feels about this, he replied, "She's just so used to—even with all her growing-up years, she's always encountered barriers, and so she just sort of knows already. She's very disappointed, but that's been her life. So it makes life a bit easier for her so that she doesn't feel like she's encountering barriers all the time. So, if I assist her it just makes things a little bit more smoother." There were others who felt responsible for their partners or friends if their ability to access the NDIS was hindered through other cultural factors. One participant explained: "But then I was contacting other Korean deaf people and they had no idea what it was all about. So then I went out and I was helping other people who didn't know anything about it as well." This highlights a sense of obligation to help others, who can't access the system because of the disabling factors they face. She continued, "I'm not quite sure on how to be able to help people. I met them last Friday. Then you hear their stories and you just sort of think, it's just not fair." Learning of those who 'have' and those who 'don't have', just because they are not able to access the system, invokes a feeling of injustice in the participant: the fairness of the system and its impact or lack of impact in providing an equity of access is judged. However, this empathy for others, and the feeling of responsibility for perceived injustice, is countered with an evaluative view that it is not a problem that fellow signing deaf people should concern themselves with as another participant states: "Well, you're not responsible to do that", indicating a difference of opinion within the group; a positioning about the issue. The empathetic participant replied: "But not all deaf people are confident to be able to go back and express their feelings and their needs if they're being put down or being controlled." This divergence

indicates a search for an answer to the question of responsibility: who is responsible for this 'lack of equity' situation?

The reality of the complex nature of the lives of signing deaf people, who come from diverse ethnic backgrounds, is shared and the resulting responsibility issue is further explored. "For my husband, he's from another cultural background as well, so he tends to put his tail between his legs. So, all through my marriage, I've tried to encourage him to be independent. However, I realise that the NDIS is very complex and I can't leave him isolated. It's not fair and it's too risky as well." When reflecting on the early stages of the process of obtaining a service package, participants felt free to express the strong negative feelings about the process that they had experienced. Mostly there were feelings of confusion. This confusion could be said to be the result of the uncertainty that they were feeling; not knowing what was happening or what to do. There were strong feelings of frustration that stayed present in their memories, such as the well-rehearsed, 'polished' anecdote (Metcalfe, 2013) that shares a story of where things went wrong. "I can remember last year when I went to have my interview and I brought a copy of everything and I brought the paperwork that I'd sent in to register. The lady says, 'Oh I'm sorry, I'm new'. I said, 'Well, okay then'. Then she's sort of going through and sets the laptop up and says [she] can't find my application. But I sent it three months ago. So she's in a bit of a panic. I said, 'Well I've got a copy here'. But I mean, really, I shouldn't have had a copy, but I'm glad I did have a copy. Then she just said can I then explain it all to her. Then I sort of thought, well, hang on, I would rather that she use the opportunity to read that application. Like, why have I got to explain it? There were a lot of things, I have to say, that was (sic) in that application that I didn't remember, all because she wouldn't take the time to give me the time to read my paperwork, which made me very disappointed. I mean I know she said she's sorry that she didn't receive the paperwork. But, you know, the courtesy of being able to read and have a look and be concerned. Yeah, because of the lack of confidence at the LAC, then it made me feel not confident about how my package was going to go".

Conclusion

In bringing the focus group discussion to an end, a concluding question was asked to allow closure for the group in achieving its purpose, considering that at that stage the rapport within the group was at its peak, and final comments can reveal an essence of

the understanding (Carey & Asbury, 2016). Participants were asked to add anything that they would like to contribute, and the responses were quite divergent; two aspects can be seen: "Just in summary, maybe I would say that maybe 70 per cent it's disappointment, frustration. That would be up until now I'd say it would be 70 per cent. That 30 per cent, we're happy with the funding, we're happy for what it gets and it's a lot of relief. So, yeah, there is that 30 per cent benefit. Better communications happening and the opportunities have improved with the involvement with the community and family, and so there is that good part of it as well. Even now I still feel frustrated because there are so many things that we didn't achieve. Talking about the communication with the NDIA, not getting your responses. You do what's required, then the next person doesn't know. Then they say, well, hang on, I've rung up four times, nobody knows what's going on." One participant responded to this summation with, "God, that's terrible" and then shared a completely different view. "Personally, and my personal experience, I would probably say I'm 95 per cent satisfied. Things have been running from yay, way to go. It's been quite okay, I'd say 95 per cent. I don't think that [for] many people it is the same for them, but for me, I've been lucky." The word 'luck' constantly appears in conversation—regarding the 'lottery chance' of getting a service package and getting what you applied for. Some other participants had the characteristics that enabled them to 'set themselves up'; get their plan, and then extend further to help others in an effort to make sure that no one was 'left behind', especially the more vulnerable people who, paradoxically, need the support the most.

For those participants, it appears that they had a natural 'fit' with the system and an ability to enter and then navigate the system, sometimes with honed strategic mechanisms to 'work the system' and have an experience that results in a feeling of satisfaction. Other participants used their personal skills in persistence and patience to push through and endure such incidents as meetings where the LAC was new (again!), and the plan had been misplaced, or to wait for a response having missed the communication from NDIS only to find that the plan had already been granted and, because time had passed, it was too late to use all the money.

Despite all these challenges, these participants pushed through the system's walls and were able to find out what the NDIS was and how to enter the system. They were able to break through the barriers and rise beyond the feelings of confusion and frustration

that come from not knowing and not understanding. They were able to eventually feel the empowering sense of achievement that comes from gaining an NDIS service package. These people are just four who successfully accessed the NDIS system to obtain an NDIS package. Their experiences and reflections about their experiences provided insights into what the picture may be like for others who have accessed the system, and perhaps for those who have not. This chapter summarised the results of the focus group research exploring signing deaf people's experiences, and their perceptions of their experiences when they reflected on getting their NDIS service package. The chapter explored the results using IPA, which requires the researcher to produce a narrative, an 'analytic write up' that serves to provide an analytic commentary on the 'meaning of the meaning' (Smith et al., 2009) expressed by the participants. The main emergent themes, as noted, were needs, barriers and feelings. These themes were explored with supporting evidence from the data. The chapter concluded by mentioning that the results recount the story of just four people, but the researcher's focused view into their 'lifeworld' is just a 'glimpse' (Larkin et al., 2006). The next chapter will widen the lens and illuminate what this data and its interpretative analysis has brought to light.

CHAPTER SIX: DISCUSSION

Introduction

In this chapter, the results of the research are discussed. An overview of the study will be provided, and the findings given. An amended version of the Levesque et al. model (2013) will be suggested as being a suitable conceptual framework to which providers in health and related health domains can refer to improve their engagement with signing deaf clients. Reflection on the study will be given and recommendations made, including consideration of the limitations and implications of the study.

This study was able to gain a glimpse of the experiences and perceptions of signing deaf clients of the NDIS. Four deaf people who use Auslan as their primary language participated in a focus group to share their understanding of their experience. Through the adoption of IPA, the researcher attempted to get close to the meaning of the experiences of these clients of the NDIS. Analysis shed light on the variety of challenges that faced these people. From the first knowledge of a new government reform to the preparation and planning stage, where meetings were held with LACs, to perhaps a review, renegotiation or renewal of a plan, each person in the group shared their interpreted view of their experience. There was a divergence in the group expressed through the stories of the pathways followed. Some stories contained glimpses of success and achievement while others revealed struggles and disappointment. The data revealed that the needs of these people were realised as challenges to find out information, fill in forms and plans, and justify all the work. Barriers confronted these clients at every turn, from the shallow pool of information in Auslan on the internet to the lack of skills and understanding of the signing deaf person's experience shown by the LACs. Some could cope with the challenges, adapting their strategies to navigate the system with assertiveness and ease and to allow them energy to reach out to those on isolated islands who were more vulnerable: those of other ethnic backgrounds who appeared to be at risk of 'missing the boat'. Then there were the fellow community members who also needed help: those who showed signs of dejection, unable to take the first step, tired of the battle and feeling powerless from the cumulative effects of the pressure to continually fit in with the normalising expectations of the more powerful (Breivik, 2005).

These clients expressed that throughout the process they felt a range of feelings, both positive and negative. In the early days, there was the shared joy and excitement when someone was successful in getting their plan, countered by the disappointment of those who were still negotiating theirs. The lack of knowledge, the 'not knowing' that evoked a sense of confusion. The frustration at not being understood in the planning meetings where the LAC held all the cards. It is here where the nexus of the power was evident. The feeling that this is not working, and it is falling apart, which led to a feeling of being back at the start of the process, powerless again. The negative feelings ran deep and the stories were well polished through use. However, for the skilled, assertive clients, there was an ability to fly solo and self-navigate, feeling justly empowered with their new-found choice and control (Barnes & Mercer, 2006; NDIS, 2017b). While drawn from only four people's accounts and reflections, this data can provide a clear snapshot of the experiences of the rest of this client group, and more importantly, prospective client group members.

Limitations

While the results were positive in providing a clear snapshot of the experiences of this client group, upon reflection the research would have benefitted from including purposeful planning to ensure that the signing deaf people were involved in the research process from the commencement of the design. There is much evidence to support the value of engaging and involving the researched community (Ferndale, 2018; McKee et al., 2012). There was involvement with the Deaf Society, but this was with hearing people in management positions. While necessary and valuable in order to plan the workings of the study, and to provide some 'insider' knowledge, it would have been worthwhile to invite members of the proposed group, or other signing deaf people, to work with the researcher in the planning and, more importantly, the analysis. Instead of me saying to myself, as the researcher, "What is she meaning here?", others who have a signing deaf person's life experience would be able to shed more light on the meanings.

The researcher is aware of her positioning when approaching this study. Having a background as a teacher with children requiring hearing support, and then as workplace trainer with signing deaf people in government departments, there is an attitude and a teacher presence that is difficult to disguise. Notably, in a focus group session, the teacher eye contact and sense of control is very obvious. The impact of such on the

group setting cannot be underplayed or discounted. Cultural awareness is an issue that is ever-present in research. McKee et al. (2012) advise that outsiders enter with their own cultural 'humility'—a necessity for both this study and for the researcher when entering the Deaf community. The positionalities and theoretical framings of the researcher are ever-present and necessarily have an impact (Kusters, De Meulder & O'Brien, 2017).

Implications

The implications for future research are very positive. There is valuable information concerning the importance of mixed methods research within signing deaf groups (Sorde Marti et al., 2014). Participating in shared research projects where the signing deaf members play an active role in the research team can only enrich the process and provide for more valid outcomes. The approach of this researcher to the study is from the view of a person who is interested in equity. It is anticipated that some of the problems surrounding accessibility could be easily removed when a more inclusive and 'can do' attitude exists. This research may establish a starting point for future research in this area of Deaf Studies. Being drawn from a focus group, the results could inform a larger quantitative project which would have a greater impact.

Recommendations

There have been numerous studies concerning equity of access to healthcare for deaf people, most citing the areas of concern as low literacy, lack of health knowledge, the need for access through sign language and the need for better understanding by healthcare staff. The amount of research is testament to the importance of access to health services in our society for all populations. All of these studies concern a need for understanding of the life of a signing deaf person in society, and as a healthcare client (Kuenburg, Fellinger & Fellinger, 2016; McKee & Paasche-Orlow, 2012; Napier & Kidd, 2013; Naseribooriabadi, Sadoughi & Sheikhtaheri, 2017; Steinberg et al., 2002; Steinberg et al., 2006; Barnett et al., 2011; Witko et al., 2017). Recommendations for improved bridging of the divide between providers and users of healthcare systems can include the use of community gatekeepers (McKee et al., 2012) and navigators (Henderson, 2011) to assist at the interface and aid the navigational process.

There are health models that assist in providing a conceptual approach to the task of assessing equity of access. One popular conceptual model, the Levesque et al. (2013)

model referred to in the guidance for this study, provides a visual flow chart of the pathway and the place of interface with influencing dimensions. This model has been adapted by one researcher when it was apparent that the patients needed legal status as a precursor to accessing any healthcare (Tschirhart et al., 2016). This researcher also adapted the model because there was deemed to be a need to acknowledge the dynamic nature of the process. One criticism of the original model was that it did not adequately reflect the actual bridging processes that need to occur during the access process. The present adaptation (see Figure 7) highlighted the prospect of working with the same model—for Australian signing deaf patients/clients, to have access through Auslan on the client access side, and then an understanding of signing deaf people's lived experience on the provider side. This proposed, revised conceptual framework for equity of access, could be used by providers to guide their planning, their development, and their delivery of their service to signing deaf people.
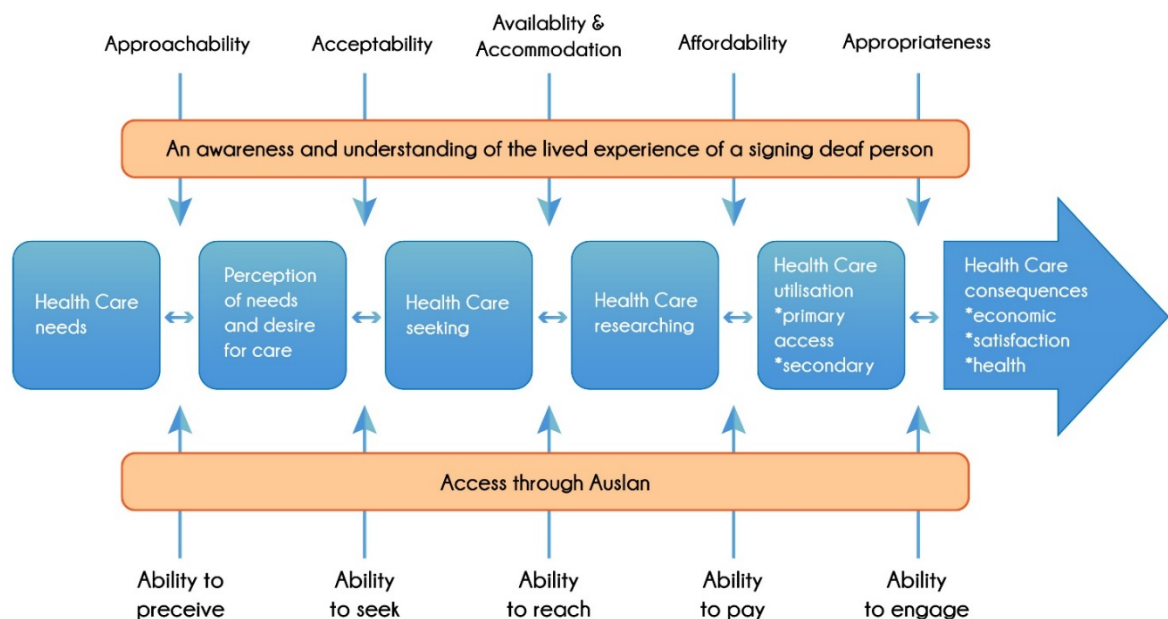

Figure 7: Adapted Levesque et al. (2013) framework for conceptualising healthcare access for signing deaf people

Conclusion

Signing deaf clients seek equity of access through Auslan; however, the process of achieving equitable access from a provider's perspective needs to progress beyond the 'knowing' of the 'characteristics' of a particular population (Levesque et al., 2013). To

engage effectively, the provider needs to have an awareness and an understanding of their client to foster a real sense of working together to ensure real equity of access (Tschirhart et al., 2016). This can be achieved through engagement with signing deaf people to work within the system, to identify the needs and the barriers that exist, and assist in the development of staff awareness and understanding of the signing deaf client. This will facilitate a shared understanding of the lived experience of a signing deaf person: the NDIS's client. From this viewpoint, a shared viewpoint, providers and clients can work together to ensure the achievement of equity of access. The implementation of the NDIS is an opportunity to refine best practice and listen to the experiences of all the new and diverse users of the scheme. After all, as Hilde in Breivik (2005, p. 30) states: "I simply want to have access to the whole society…"

References

Abascal, J., Barbosa, S., Nicolle, C., & Zaphiris, P. (2015). Rethinking Universal Accessibility: a broader approach considering the digital gap. *Universal Access in the Information Society in the Information Society, 15*(2), 179–82. doi:10.1007/s10209-015-0416-1

ABS (Australian Bureau of Statistics) (2017). *Census of Population and Housing*. Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/mf/2024.0

Aday, L., & Andersen, R. (1974). A framework for the study of access to medical care. *Health Services Research, 9*(3), 208–20.

Agudelo-Suárez, A. A., Gil-González, D., Vives-Cases, C., Love John, G., Wimpenny, P., & Ronda-Pérez, E. (2012). A metasynthesis of qualitative studies regarding opinions and perceptions about barriers and determinants of health services' accessibility in economic migrants. *BMC Health Services Research, 12*(1), 461. doi:10.1186/1472-6963-12-461

Alkire, S. (1998). *Operationalizing Amartya Sen's Capability Approach to Human Development: A Framework for Identifying 'Valuable' Capabilities*. D.Phil thesis, University of Oxford.

Alper, M., Ellcessor, E., Ellis, K., & Goggin, G. (2015). *Reimagining the Good Life with Disability: Communication, New Technology, and Humane Connections*. New York NY: Peter Lang.

Altman, B. M. (2001). Disability definitions, models, classification schemes, and applications. In G. L. Albrecht, K. D. Seelman, & M. Bury (Eds.), *Handbook of Disability Studies* (pp. 97–122). Thousand Oaks CA: Sage.

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36*(1), 1–10.

Australian Dept. of Employment, Education & Training. (1991). *Australia's Language: The Australian Language and Literacy Policy, August 1991*. Canberra: Australian Government Publishing Service.

Barnes, C., & Mercer, G. (2006). *Independent Futures: Policies Practices and the Illusion of Inclusion*. Background notes to a verbal presentation to the European Network for Independent Living. www. leeds. ac. uk/disability-studies/archiveuk accessed, 14(07), 2008.

Barnett, M., McKee, M., Smith, S., & Pearson, T. (2011). Deaf sign language users, health inequities, and public health: Opportunity for social sustice. *Preventing Chronic Disease, 8*(2), A45 (epub).

Bat-Chava, Y. (2000). Diversity of deaf identities. *American Annals of the Deaf, 145*(5), 420–28.

Bat-Chava, Y., Martin, D., & Kosciw, J. G. (2005). Barriers to HIV/AIDS knowledge and prevention among deaf and hard of hearing people. *AIDS Care, 17*(5), 623–34. doi:10.1080/09540120412331291751

Bauman, H-D. L. (2008). Introduction. In H-Dirksen L. Bauman (Ed.), *Open Your Eyes : Deaf Studies Talking*. Minneapolis MN: University of Minnesota Press.

Bauman, H-D. L. & Murray, J. (2009). Reframing: From hearing loss to deaf gain. *Deaf Studies Digital Journal, 1*(1), 1–10.

Bauman, H-D. L. & Murray, J. (Eds) (2014). *Deaf Gain: Raising the Stakes for Human Diversity*. Minneapolis MN: University Of Minnesota Press.

Baylies, C. (2002). Disability and the notion of human development: Questions of rights and capabilities. *Disability & Society, 17*(7), 725–39. doi:10.1080/0968759022000039037

Baynton, D. (2008). Beyond culture: Deaf studies and the deaf body. In H-Dirksen L. Bauman (Ed.), *Open Your Eyes: Deaf Studies Talking* (pp. 293–313). Minneapolis MN: University of Minnesota Press.

Biggerstaff, D., & Thompson, A. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology, 5*(3), 214–24.

Breivik, J. (2005). *Deaf Identities in the Making*. Washinton DC: Gallaudet University Press.

Breivik, J. (2009). New perspectives in disability research? *Scandinavian Journal of Disability Research, 11*(2), 65–66. doi:10.1080/15017410902830447

Burchardt, T. (2004). Capabilities and disability: The capabilities framework and the social model of disability. *Disability & Society, 19*(7), 735–51. doi:10.1080/0968759042000284213

Carey, M. A., & Asbury, J. E. (2016). *Focus Group Research*. London: Routledge.

Carpiano, R., & Daley, D. (2006). A guide and glossary on post-positivist theory building for population health. *Journal of Epidemiology and Community Health, 60*(7), 564–70. doi:10.1136/jech.2004.031534

Carty, B. (2006). Comments on "W(h)ither the Deaf Community?". *Sign Language Studies, 6*(2), 181–89.

Charlton, J. (1998). *Nothing about Us Without Us: Disability, Oppression and Empowerment*. Berkeley CA: University of California Press.

Clark, M., Hauser, P., Miller, P., Kargin, T., Rathmann, C., Guldenoglu, B. . . . Israel, E. (2016). The importance of early sign language acquisition for deaf readers. *Reading & Writing Quarterly, 32*(2), 127–51. doi:10.1080/10573569.2013.878123

Council of Australian Governments (COAG). (2017). *NDIS Quarterly Report 2016-17, Q4.* Retrieved from https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports

Comino, E., Davies, G., Krastev, Y., Haas, M., Christl, B., Furler, J. . . . Harris, M. (2012). A systematic review of interventions to enhance access to best practice primary health care for chronic disease management, prevention and episodic care. *BMC Health Services Research, 12*(1), 415. doi:10.1186/1472-6963-12-415

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum, 1*(8), 139–67.

Creswell, J. (2007). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 2nd edn, Thousand Oaks CA: Sage Publications.

Creswell, J., & Plano Clark, V. (2007). *Designing and Conducting Mixed Methods Research*. Thousand Oaks CA: Sage Publications.

Cth (Commonwealth of Australia). (1973) *Health Insurance Act 1973*. Retrieved from https://www.legislation.gov.au/Series/C2004A00101

Cth (Commonwealth of Australia). (1992). *Disability Discrimination Act 1992*. Retrieved from https://www.legislation.gov.au/Series/C2004A04426

Cth (Commonwealth of Australia). (2012). *National Disability Strategy*. Canberra: Australian Government. Retrieved from https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-disability-strategy-2010-2020

Cth (Commonwealth of Australia). (2013). *National Disability Insurance Scheme Act 2013*. Retrieved from https://www.legislation.gov.au/Details/C2013A00020

Damasio, A. (2000). *The Feeling of What Happens: Body, Emotion and the Making of Consciousness*. London: Vintage.

Damasio, A. (2001). Fundamental feelings. *Nature, 413*(6858), 781. doi:10.1038/35101669

Daoust, D. (2017). Language planning and language reform. In F. Coulmas (Ed.), *The Handbook of Sociolinguistics*. Oxford: Blackwell.

Davis, L. (2007/). Deafness and the riddle of identity. *The Chronicle of Higher Education, 53*(19), B5–B8.

Davis, L. (2013). *The Disability Studies Reader*. London: Routledge

De Meulder, M. (2015). The legal recognition of sign languages. *Sign Language Studies, 15*(4), 498–506.

Deaf Australia. (2015). *Strategic Plan 2015–2020*. Retrieved from https://deafaustralia.org.au/about-2/strategic-plan/

Deaf Australia (2018a). Personal communication, 22/04/2018—CEO's response regarding Deaf Australia's view regarding the placement of Auslan within CALD groups in Australia.

Deaf Australia. (2018b). *What We Do*. Retrieved from https://deafsociety.org.au/about

D'Mello, S., Lehman, B., Pekrun, R., & Graesser, A. (2014). Confusion can be beneficial for learning. *Learning and Instruction, 29*, 153–70.

Degener, T. (2016a). Disability in a human rights context. *Laws, 5*(3), 35. doi:10.3390/laws5030035

Degener, T. (2016b). A human rights model of disability. In P. Blanck & E. Flynn (Eds.), *The Routledge Handbook of Disability Law and Human Rights* (pp. 31–49). London: Routledge.

Department of Families, Housing, Community Services and Indigenous Affairs (2005). *National Auslan Interpreter Booking and Payment Service Program (NABS)*. Retrieved from https://www.dss.gov.au/sites/default/files/documents/02_2013/comm_s_part_c_nabs_program_guidelines_0.pdf.

Dowse, L., Wiese, M., Dew, A., Smith, L., Collings, S., & Didi, A. (2016). More, better, or different? : NDIS workforce planning for people with intellectual disability and complex support needs. *Journal of Intellectual and Developmental Disability*, 41(1), 81–84. doi:10.3109/13668250.2015.1125868

Duff, P. (2003). Some guidelines for conducting quantitative and qualitative research in TESOL. *TESOL Quarterly, 37*(1), 157–78. doi:10.2307/3588471

Dunn, J., & Creek, S. J. (2015). Identity dilemmas: Toward a more situated understanding. *Symbolic Interaction, 38*(2), 261–84. doi:10.1002/symb.146

Easton, C. (2012). Revisiting the law on website accessibility in the light of the UK's equality Act 2010 and the United Nations Convention on the Rights of Persons with Disabilities. *International Journal of Law and Information Technology, 20*(1), 194–97.

Ekman, P. (1992). An argument for basic emotions. *Cognition & Emotion, 6*(3-4), 169–200. doi:10.1080/02699939208411068

Ellis, K., Goggin, G., & Kent, M. (2015). FCJ-188 Disability's digital frictions: Activism, technology, and politics. *The Fibreculture Journal, 26*, 7–30. http://twentysix.fibreculturejournal.org/fcj-188-disabilitys-digital-frictions-activism-technology-and-politics/

Erikson, E. H. (1968). *Identity, Youth and Crisis*. New York NY: W. W. Norton.

Erting, C. (Ed.) (1994). *The Deaf Way: Perspectives From the International Conference on Deaf Culture*. Washington DC: Gallaudet University Press.

Fernandes, J., & Myers, S. (2010). Inclusive deaf studies: Barriers and pathways. *Journal of Deaf Studies and Deaf Education, 15*(1), 17. doi:10.1093/deafed/enp018

Ferndale, D. (2018). "Nothing about us without us": Navigating engagement as hearing researcher in the Deaf community. *Qualitative Research in Psychology, 15*(4), 1–19.

Finkelstein, V. (1975). Union of the physically impaired against segregation: Comments on the discussion held between the Union and the Disability Allaince, November, 1975. In Union of the Physically Impaired Against Segregation, *Fundamental Principles of Disability*. Retrieved from https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-UPIAS-Principles-2.pdf

Finkelstein, V. (1981). Disability and the helper/helped relationship: An historical view. In Brechin, A., Liddiard, P. and Swain, J. (Eds), *Handicap in a Social World* (pp. 58–65). London: Hodder and Stoughton.

Fiscella, K., & Shin, P. (2005). The inverse care law: implications for healthcare of vulnerable populations. *The Journal of Ambulatory Care Management, 28*(4), 304–12.

Fitzgerald, T. K. (1993). *Metaphors of Identity: A Culture–Communication Dialogue*. New York NY: SUNY Press.

Freeman, M., & Given, L. (2008). *The Sage Encyclopedia of Qualitative Research Methods*. London: Sage Publications.

Glickman, N. (1993). *Deaf identity Development: Construction and Validation of a Theoretical Framework.* PhD thesis, University of Massachusetts. Retrieved from https://scholarworks.umass.edu/cgi/viewcontent.cgi?article=2202&context=dissertations_1

Goggin, G., & Newell, C. (2007). The business of digital disability. *The Information Society, 23*(3), 159–68. doi:10.1080/01972240701323572

Grosjean, F. (1996). Living with two languages and two cultures. In Ila Parasnis (Ed.), *Cultural and Language Diversity and the Deaf Experience* (pp. 20–37). New York NY: Cambridge University Press.

Grotevant, H. (1992). Assigned and chosen identity components: A process perspective on their integration. In G. R. Adams, T. P. Gulotta & R. Montemayor (Eds.), *Advances in

Adolescent Development, Vol. 4. Adolescent Identity Formation (pp. 73–90). Newbury Park CA: Sage. Retrieved from https://www.researchgate.net/publication/232439404_Assigned_and_chosen_identity_components_A_process_perspective_on_their_integration

Hauser, P., McKee, M., Steider, A., & Thew, D. (2010). Deaf epistemology: Deafhood and deafness. *American Annals of the Deaf, 154*(5), 486–92. doi:10.1353/aad.0.0120

Heidegger, M. (1962/1927). *Being and Time*. Oxford: Blackwell.

Helsper, E. J. (2012). A corresponding fields model for the links between social and digital exclusion. *Communication Theory, 22*(4), 403–26. doi:10.1111/j.1468-2885.2012.01416.x

Helsper, E., & Reisdorf, B. (2017) The emergence of a "digital underclass" in Great Britain and Sweden: Changing reasons for digital exclusion. *New Media & Society, 19*(8), 1253–70..

Henderson, S. (2011) 'Community Navigators': Making a difference by promoting health in culturally and linguistically diverse (CALD) communities in Logan, Queensland. *Australian Journal of Primary Health, 17*(4), 347–54.

Hintermair, M. (2008). Self-esteem and satisfaction with life of deaf and hard-of-hearing people: A resource-oriented approach to identity work. *Journal of Deaf Studies and Deaf Education, 13*(1), 124–46.

Humphries, T. (2008). Talking culture and culture talking. In H-D. L. Bauman (Ed.), *Open Your Eyes: Deaf Studies Talking* (pp. 35–41). Minneapolis MN: University of Minnesota Press.

Humphries, T. (2014). Our time: The legacy of the twentieth century. *Sign Language Studies, 15*(1), 57–73.

Humphries, T., Kushalnagar, R., Mathur, G., Napoli, D., Padden, C., Rathmann, C., & Smith, S. (2013). The right to language. *The Journal of Law, Medicine & Ethics, 41*(4), 872–84.

Husserl, E. (1927). Phenomenology: Psychological and transcendental phenomenology and the confrontation with Heidegger (1927-1931). *Encyclopaedia Britannica*. Dordrecht: Kluwer Academic Publishers.

Johnson, B., & Christensen, L. (2017). *Educational Research: Quantitative, Qualitative, and Mixed Approaches*. 6th edn, Thousand Oaks CA: Sage Publications.

Johnston, T., & Schembri, A. (2007). *Australian Sign Language (Auslan): An Introduction to Sign Language Linguistics*. Cambridge: Cambridge University Press.

Joseph, J. M. (1993). Peer education and the deaf community. *Journal of American College Health, 41*(6), 264–66. doi:10.1080/07448481.1993.9936339

Kitzinger, J. (1994). The methodology of Focus Groups: the importance of interaction between research participants. *Sociology of Health & Illness, 16*(1), 103–21. doi:10.1111/1467-9566.ep11347023

Komaric, N., Bedford, S., & van Driel, M. L. (2012). Two sides of the coin: Patient and provider perceptions of health care delivery to patients from culturally and linguistically diverse backgrounds. *BMC Health Services Research, 12*(1), 322.

Krueger, R. A. (1994). *Focus Groups: A Practical Guide for Applied Research*. Thousand Oaks CA: Sage Publications.

Kuenburg, A., Fellinger, P., & Fellinger, J. (2016). Health care access among deaf people. *The Journal of Deaf Studies and Deaf Education, 21*(1), 1–10. doi:10.1093/deafed/env042

Kusters, A., De Meulder, M., & O'Brien, D. (Eds) (2017). *Innovations in Deaf Studies: The Role of Deaf Scholars*. New York NY: Oxford University Press.

Ladd, P. (2003). *Understanding Deaf Culture: In Search of Deafhood*. Clevedon: Multilingual Matters.

Lane, H. (1995). Constructions of Deafness. *Disability & Society, 10*(2), 171–90. doi:10.1080/09687599550023633

Lane, H. (2005). Ethnicity, ethics, and the deaf-world. *The Journal of Deaf Studies and Deaf Education, 10*(3), 291–310. doi:10.1093/deafed/eni030

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102–20. doi:10.1191/1478088706qp062oa

Leigh, I. W. (2009). *A Lens on Deaf Identities*. New York NY: Oxford University Press.

Levesque, J., Harris, M., & Russell. (2013). Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health, 12*(1), 18. doi:10.1186/1475-9276-12-18

Liamputtong, P. (2010a). Cross-cultural research and qualitative inquiry. *Turkish Online Journal of Qualitative Inquiry, 1*(1), 16–29.

Liamputtong, P. (2010b). The science of words and the science of numbers: Research methods as foundations for evidence-based practice in health. In P. Liamputtong (Ed.), *Research Methods in Health: Foundations for Evidence-Based Practice* (pp. 3–26). South Melbourne: Oxford University Press.

Liamputtong, P. (Ed.) (2011). *Focus Group Methodology: Principles and Practices*. Thousand Oaks CA: Sage Publications.

Lo Bianco, J. (1987). *National Policy on Languages*. Canberra: Australian Government Publishing Service.

Lytton, M. (2013). Health literacy: an opinionated perspective. *American Journal of Preventive Medicine, 45*(6), e35–e40.

Marschark, M., Sapere, P., Convertino, C., & Seewagen, R. (2005). Access to postsecondary education through sign language interpreting. *Journal of Deaf Studies and Deaf Education, 10*(1), 38–50.

Mauss, I. B., & Robinson, M. D. (2009). Measures of emotion: A review. *Cognition & Emotion, 23*(2), 209-237. doi:10.1080/02699930802204677

Maxwell, D., & Zea, M. (1998). *The Deaf Acculturation Scale (DAS): Development, Reliability, and Validity.* Paper presented at the 106th Annual convention of the American Psychological Association, San Francisco CA.

Maxwell-McCaw, D. L., Leigh, I. W., & Marcus, A. (2000). Social Identity in Deaf Culture: A Comparison of Ideologies. *JADARA, 33*(3), 14–28.

Mayer, C. (2007). What really matters in the early literacy development of deaf children. *Journal of Deaf Studies and Deaf Education, 12*(4), 411–31. doi:10.1093/deafed/enm020

Mayer, C. A., & Trezek, B. J. (2014). Is reading different for deaf individuals?: Reexamining the role of phonology. *American Annals of the Deaf, 159*(4), 359–71.

McIlroy, G., & Storbeck, C. (2011). Development of deaf identity: An ethnographic study. *The Journal of Deaf Studies and Education, 16*(4), 494–511. doi:10.1093/deafed/enr017

McKee, M., & Paasche-Orlow, M. (2012). Health literacy and the disenfranchised: The importance of collaboration between limited English proficiency and health literacy researchers. *Journal of Health Communication, 17,* 7-12. doi:10.1080/10810730.2012.712627

McKee, M., Thew, D., Starr, M., Kushalnagar, P., Reid, J. T., Graybill, P. . . . Pearson, T. (2012). Engaging the Deaf American sign language community: Lessons from a community-based participatory research center. *Progress in Community Health Partnerships, 6*(3), 321–29. doi:10.1353/cpr.2012.0037

McKee, R. (2006). The Eyes Have It! Our third official language: New Zealand Sign Language. *Journal of New Zealand Studies, 4/5*, 129–48.

McKee, R. (2011). Action pending: Four years on from the New Zealand Sign Language Act 2006. *Victoria University of Wellington Law Review, 42*(2), 277.

Memon, A., Taylor, K., Mohebati, L., Sundin, J., Cooper, M., Scanlon, T., & de Visser, R. (2016). Perceived barriers to accessing mental health services among black and minority ethnic communities: a qualitative study in southeast England. *BMJ Open, 6*, e012337. doi: 10.1136/bmjopen-2016-012337

Metcalfe, A. (2013). Who Am I Interviewing? *International Journal of Social Science Studies, 1*(2), 44–54. doi:10.11114/ijsss.v1i2.123

Mitra, S. (2006). The capability approach and disability. *Journal of Disability Policy Studies, 16*(4), 236–47.

Napier, & Kidd, M. R. (2013). English literacy as a barrier to health care information for deaf people who use Auslan. *Australian Family Physician, 42*(12), 896–99.

Naseribooriabadi, T., Sadoughi, F., & Sheikhtaheri, A. (2017). Barriers and facilitators of health literacy among D/deaf Individuals: A review article. *Iranian Journal of Public Health, 46*(11), 1465–74.

National Archives of Australia. (2015). *Digital Continuity 2020 Policy*. Retrieved from http://www.naa.gov.au/information-management/digital-transition-and-digital-continuity/digital-continuity-2020/index.aspx

NDIA. (2017a). *The NDIA.* Retrieved from https://www.ndis.gov.au/about-us/access-information/information-publication-scheme-agency-pl.html

NDIA. (2017b). *Participants' Reasonable and Necessary Supports*. Retrieved from https://www.ndis.gov.au/participants/reasonable-and-necessary-supports

NDIA. (2018). *Improving the NDIS Participant and Provider Experience*. Retrieved from https://www.ndis.gov.au/medias/documents/pathway-review-report/Report-NDIS-Pathway-Review.pdf

NDIS. (2017a). *NDIS Glossary*. Retrieved from https://www.ndis.gov.au/glossary

NDIS. (2017b). *NDIS – About Us*. Retrieved from https://www.ndis.gov.au/about-us/what-ndis.html

NDIS. (2018). *NDIS – About Us*. Retrieved from https://www.ndis.gov.au/about-us/what-ndis.html

Ngulube, P., Mathipa, E., & Gumbo, M. (2015). Theoretical and conceptual frameworks in the social and management sciences. In E. R. Mathipa and M. T. Gumbo (Eds),

Addressing Research Challenges: Making Headway for Developing Researchers, (pp. 43–66). Vorna Valley: Mosala-Masedi Publishers.

Nikolaraizi, M., & Hadjikakou, K. (2006). The role of educational experiences in the development of deaf identity. *Journal of Deaf Studies and Deaf Education, 11*(4), 477–92.

Nussbaum, M., & Sen, A. (Eds) (1993). *The Quality of Life*. New York NY: Oxford University Press.

Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine, 67*(12), 2072–78. doi:10.1016/j.socscimed.2008.09.050

Oliver, M. (1986). Social policy and disability: Some theoretical issues. *Disability, Handicap & Society, 1*(1), 5–17. doi:10.1080/02674648666780021

Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society, 28*(7), 1024–26. doi:10.1080/09687599.2013.818773

Oliveri, S., & Pravettoni, G. (2017). Capturing how individuals perceive genetic risk information: A phenomenological perspective. *Journal of Risk Research, 21*(2), 259–67. doi:10.1080/13669877.2017.1281333

Overs, B. J., Woolfenden, S., Williams, K., Jalaludin, B., Axelsson, E. L., Dissanayake, C. … the "Watch Me Grow" Study Group. (2017). Predictors of developmental surveillance completion at six months of age in south western Sydney. *Child, 43*(2), 307–15. http://doi.org/10.1111/cch.12425

Padden, C. (1989). The deaf community and the culture of deaf people. In S. Wilcox (Ed.), *American Deaf Culture: An Anthology*: Burtonsville MD: Linstock Press.

Padden, C. (1996). From the cultural to the bicultural: The modern deaf community. In I. Parasnis (Ed.), *Cultural and Language Diversity and the Deaf Experience* (pp. 79–118). New York NY: Cambridge University Press

Padden, C., & Humphries, T. (1989). Deaf in America: Voices from a culture. *Ear and Hearing, 10*(2), 139. doi:10.1097/00003446-198904000-00022

Panksepp, J. (1998). *Affective Neuroscience: The Foundations of Human and Animal Emotions*. New York NY: Oxford University Press.

Peek, L., & Fothergill, A. (2009). Using focus groups: Lessons from studying daycare centers, 9/11, and Hurricane Katrina. *Qualitative Research, 9*(1), 31–59. doi:10.1177/1468794108098029

Pham, L. (2018). Course Notes: NVivo Pro 11 for PC User Guide. Graduate Research School. University of Technology Sydney.

Pietkiewicz, I., & Smith, J. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal, 20*(1), 7–14. doi:DOI10.14691/CPPJ.20.1.7

Piller, I. (2014). Linguistic diversity and social inclusion in Australia. *Australian Review of Applied Linguistics, 37*(3), 190–97.

Pollard, R., & Barnett, S. (2009). Health-related vocabulary knowledge among deaf adults. *Rehabilitation Psychology, 54*(2), 182–85. doi:10.1037/a0015771

Powell-Williams, M. (2017). Life in the Neither World: Identity work as relational negotiation of authenticity and stigma management for biculturally deaf individuals living between worlds. *Deviant Behavior, 39*(2), 243–56. doi:10.1080/01639625.2016.1266890

Power, D., & Leigh, G. (2000). Principles and practices of literacy development for deaf learners: A historical overview. *Journal of Deaf Studies and Deaf Education, 5*(1), 3–8. doi:10.1093/deafed/5.1.3

Productivity Commission. (2011). *Disability Care and Support*. Report No. 54. Canberra: Productivity Comission. Retrieved from https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-overview-booklet.pdf.

Quinn, G., Degener, T., Bruce, A., Burke, C., Castellino, J., Kenna, P. . . . Quinlivan, S. (2002). Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability. HR/PUB/02/1, United Nations.

Reagan, T. G. (2010). *Language Policy and Planning for Sign Languages*: Washington DC: Gallaudet University Press.

Richard, L., Furler, J., Densley, K., Haggerty, J., Russell, G., Levesque, J., & Gunn, J. (2016). Equity of access to primary healthcare for vulnerable populations: The IMPACT international online survey of innovations. *International Journal for Equity in Health, 15*(64). doi:10.1186/s12939-016-0351-7

Schiffman, H. F. (1996). *Linguistic Culture and Language Policy*. New York NY: Routledge

Sen, A. K. (1992). *Inequality Reexamined*. Cambridge MA: Harvard University Press.

Shakespeare, T. (1993). Disabled people's self-organisation: A new social movement? *Disability, Handicap & Society, 8*(3), 249–64. doi:10.1080/02674649366780261

Sheppard, K. (2014). Deaf adults and health care: Giving voice to their stories. *Journal of the American Association of Nurse Practitioners, 26*(9), 504–10. doi:10.1002/2327-6924.12087

Smith, A. (1986). *The Ethnic Origins of Nations*. New York NY: Blackwell.

Smith, J. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health, 11*(2), 261–71. doi:10.1080/08870449608400256

Smith, J. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*(1), 39–54. doi:10.1191/1478088704qp004oa

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.

Smith-Merry, J., Hancock, N., Gilroy, J., Llewellyn, G. & Yen, I. (2018). *Mind the Gap: The Nationl Disability Insurance Scheme and Pyschosocial Disability. Final Report: Stakeholder Identified Gaps and Solutions*. Sydney: Sydney Policy Lab, The University of Sydney.

Söder, M. (2009). Tensions, perspectives and themes in disability studies. *Scandinavian Journal of Disability Research, 11*(2), 67–81. doi:http://doi.org/10.1080/15017410902830496

Sorde Marti, T., Mertens, D. M., Wilson, A. T., & Winiarczyk, R. E. (2014). Mixed methods research strategies with deaf people. *Journal of Mixed Methods Research, 8*(3), 266–77. doi:10.1177/1558689814527943

Sourbati, M. (2012). Disabling communications? A capabilities perspective on media access, social inclusion and communication policy. *Media, Culture & Society, 34*(5), 571–87. doi:10.1177/0163443712442702

Spinelli, E. (2005). *The Interpreted World: An Introduction to Phenomenological Psychology*. 2nd edn, London: Sage.

Stein, M. A. (2007). Disability human rights. *California Law Review, 95*(1), 75–121. doi:10.15779/Z38XQ4Z

Steinberg, A., Wiggins, E., Barmada, C., & Sullivan, V. (2002). Deaf women: Experiences and perceptions of healthcare system access. *Journal of Women's Health, 11*(8), 729.

Steinberg, A. G., Barnett, S., Meador, H. E., Wiggins, E. A., & Zazove, P. (2006). Health care system accessibility. *Journal of General Internal Medicine, 21*(3), 260–66. doi:10.1111/j.1525-1497.2006.00340.x

Stokoe, W. (1960). *Sign Language Structure: An Outline of the Visual Communication Systems of the American Deaf*. Studies in Linguistics Occation Paper No. 8. Buffalo NY: University of Buffalo.

Stokoe, W. (2005). Sign language structure: An outline of the visual communication systems of the American deaf. *Journal of Deaf Studies and Deaf Education, 10*(1), 3–37.

Thayer-Bacon, B. J. (1997). The nurturing of a relational epistemology. *Educational Theory, 47*(2), 239–60. doi:10.1111/j.1741-5446.1997.00239.x

Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society, 19*(6), 569–83. doi:10.1080/0968759042000252506

Tomlinson, M., Swartz, L., Officer, A., Chan, K. Y., Rudan, I., & Saxena, S. (2009). Research priorities for health of people with disabilities: An expert opinion exercise. *The Lancet, 374*(9704), 1857–62.

Trovato, S. (2013). A stronger reason for the right to sign languages. *Sign Language Studies, 13*(3), 401–22.

Tschirhart, N., Nosten, F., & Foster, A. (2016). Access to free or low-cost tuberculosis treatment for migrants and refugees along the Thailand-Myanmar border in Tak province, Thailand. *International Journal for Equity in Health, 15*(1), 100. doi:10.1186/s12939-016-0391-z

Turner, G. (1994). How is Deaf Culture?: Another perspective on a fundamental concept. *Sign Language Studies, 1083*(1), 103–26. doi:10.1353/sls.1994.0022

Ubido, J., Huntington, J., & Warburton, D. (2002). Inequalities in access to healthcare faced by women who are deaf. *Health & Social Care in the Community, 10*(4), 247–53. doi:10.1046/j.1365-2524.2002.00365.x

UNCRPD. (2006). *United Nations Convention on the Rights of Persons with Disabilities*. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Waterman, A. S. (1992). Identity as an aspect of optimal psychological functioning. In G. R. Adams, T. P. Gullotta, & R. Montemayor (Eds.), *Advances in Adolescent Development, Vol. 4. Adolescent Identity Formation* (pp. 50–72). Thousand Oaks CA: Sage Publications.

WCAG. (2005). *Web Content Accessibility Guidelines (WCAG)*. Retrieved from https://www.w3.org/WAI/standards-guidelines/wcag/

Wechkunanukul, K., Grantham, H., & Clark, R. (2016). Presenting characteristics and processing times for culturally and linguistically diverse (CALD) patients with chest pain in an emergency department: Time, ethnicity and delay (TED) Study II. *International Journal of Cardiology,* 220, 901–8. doi: 10.1016/j.ijcard.2016.06.244

Willig, C. (2013). *Introducing Qualitative Research in Psychology*: London: McGraw-Hill Education.

Witko, J., Boyles, P., Smiler, K., & McKee, R. (2017). Deaf New Zealand Sign Language users' access to healthcare. *The New Zealand Medical Journal, 130*(1466), 53.

Woodward, J., & Horejes, T. P. (2016). deaf/Deaf: Origins and usage. In Genie Gertz and Patrick Boudreault (Eds), *The SAGE Deaf Studies Encyclopedia* (pp. 284–87).Thousand Oaks CA: Sage Publications. Retrieved from http://sk.sagepub.com/reference/the-sage-deaf-studies-encyclopedia. doi:10.4135/9781483346489

Woodward, K. (1997). Concepts of identity and difference. In K. Woodward (Ed.), *Identity and Difference* (pp. pp 7–50). Thousand Oaks CA: Sage Publications.

World Bank Group. (2016). *World Development Report 2016*. Retrieved from http://www.worldbank.org/en/publication/wdr2016

World Health Organization. (2001). *International Classification of Functioning, Disability and Health.* Retrieved from http://www.who.int/classifications/icf/en/

World Health Organization. (2013). *Health Literacy: The Solid Facts*. Retrieved from http://www.euro.who.int/en/publications/abstracts/health-literacy.-the-solid-facts