"DEAF IS BEST": EXPLORING THE SEXUALITY EXPERIENCES AND

KNOWLEDGE OF DEAF WOMEN IN NEW ZEALAND

BY

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Abstract

This study has two primary purposes. Initially, it explores the accounts of sexuality-related experiences and knowledge of a group of Deaf women in New Zealand. The limited international literature available has primarily focused on Deaf sexuality in terms of deficits and vulnerabilities and no work has been carried out on the topic in New Zealand, so relatively little is known about an influential aspect of Deaf women's lives. The second purpose for this study is to generate recommendations for improving the sexuality information and services available to the women.

This study accomplished the two aims by using an action research framework in which Deaf Aotearoa New Zealand, the national organisation for the Deaf, was a collaborative research partner. The seven women who participated in the study were split into two focus groups, one for NZ European/ Pākeha women and one for Asian and Pacific women. The focus groups were conducted in August 2012 at a Deaf club. Also present during the focus groups were a professional New Zealand Sign Language interpreter, a Deaf woman who served as co-facilitator, and myself.

In the focus groups, the women discussed their experiences and understanding of concepts with regard to intimate relationships, sexual experiences, and sexuality more generally. Their accounts revealed the potential impact their family's cultural background, the ability of those around them to communicate through New Zealand Sign Language, and their personal English literacy levels had on their sexuality knowledge and development. Those who had greater access to information and support reported more positive experiences.

As a result, recommendations are made for improving information accessibility across the lifespan, with a special emphasis on programming and services provided by Deaf Aotearoa. The recommendations conclude with a description of a programme developed alongside Deaf Aotearoa that addresses some of these areas and which will be implemented with regional groups of Deaf women. As a result, the contributions made by the Deaf women who participated in this project are already demonstrating an impact in programme development.

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Chapter 1: Introduction

1.1 Background to study

Sexuality is a multi-faceted, dynamic component of the human experience. It influences our thoughts, shapes our behaviour, affects our interaction with others, and may change over time in response to new information or experiences. Sexuality is much more complex than the physiological drives and anatomical features that are typically used to define it. Instead, it includes gender identity and roles, sexual orientation and attraction, eroticism and pleasure, reproduction, and intimate relationships (Vance, 1998; DeLamater & Hyde, 1998; Baker, 2008; Lamb, 2010; Allen, 2007).

Additionally, sexuality may be expressed in thoughts, desires, beliefs, attitudes, values, behaviours, and practices (Berger & Luckmann, 1966; Jackson & Weeks, 2005). However, considerable variation may attend the expression of those dimensions at the individual or societal level as a result of such contextual factors as socio-political climates or gender. The meaning ascribed to sexuality, or even the labelling of something as "erotic", is a social construction highly influenced by those factors and may continually evolve (Allen, 2007). Research exploring sexuality among non-majority groups is somewhat limited, especially outside the areas of negative experiences or dangers. This is particularly true for individuals who identify as Deaf.

'Deaf' is a term of social and cultural identification for people who experience lifelong deafness (usually from birth or early childhood), prefer to communicate through sign language, and socialise and identify with other Deaf people (Padden, 1980; Ladd, 2003, ch. 5; Dugdale, 2002; McKee, 2001). Many individuals who identify as Deaf develop a strong sense of pride and do not subscribe to the bio-medical model that labels them disabled because of their hearing ability (Bauman *et al.*, 2010). However, the bio-medical view has exerted a strong influence on the type of research that has been conducted with Deaf people.

When Deaf individuals are the topic of sexuality studies, it is usually in terms of deficits, particularly in relation to access to information, which is characteristic of Deaf people's social and educational experiences. For instance, the most well-known studies compare the sexual knowledge of Deaf Gallaudet University students and hearing students at other universities (Joseph *et al.*, 1995; Sawyer *et al.*, 1996; Swartz, 1993). However, little is known about the sexuality knowledge or experiences of Deaf individuals in other areas.

While information is limited about Deaf sexuality in general, it is virtually non-existent for understanding the sexuality needs and experiences of Deaf women. In fact, the majority of the international studies involving Deaf women have focused on their heightened risk for domestic or sexual violence (Sobsey & Doe, 1991; Anderson *et al.*, 2011; Nosek et al., 2001; Kvam, 2004; Merkin & Smith, 1995). There is a complete dearth of information about other aspects of their sexuality, including developmental experiences unique to women, such as menarche, and their perspectives on intimate relationships.

In addition, very little information exists about the 4,000 or so Deaf individuals in New Zealand (McKee, 2001). The limited studies involving Deaf New Zealanders have mainly focused on Deaf education or various aspects of linguistics. No work has *exclusively* concentrated on the knowledge or experiences of Deaf women. Instead, they are often aggregated with Deaf men so that it becomes difficult to evaluate potential variations. The result is that little is known specifically about the experiences of Deaf women in New Zealand.

With the aim of addressing this gap, I met with the national service organisation for the Deaf, Deaf Aotearoa New Zealand (DANZ). The meeting was to explain my interests in exploring the experiences of Deaf women and if they felt a need for this type of research project in the Deaf community. The DANZ services coordinator I met with was supportive of the entire idea, noting the paucity of research with the Deaf community, especially in relation to women. She also stated that DANZ had limited programming for Deaf women and that there was a need to address that as well.

As a result of the limited research and programming, the services coordinator agreed that DANZ would work as a collaborative partner for the research project. During our initial conversations, we discussed the possibility of focusing on violence against women in the Deaf community because of the potential need and my prior work experience. However, because this research project was the first to work exclusively with Deaf women in New Zealand, it was thought that limiting our focus to abuse or violence might not provide a complete picture of their experiences.

Additionally, the scant literature available on Deaf sexuality has focused almost exclusively on the subject in terms of deficits, vulnerabilities, and risk. Relatively little is known about positive sexuality experiences, how Deaf cultural features or practices may influence those experiences, or how those experiences may change over time. Therefore, we decided to broaden the scope of this project and explore multiple areas of sexuality among Deaf women, illustrating the full range of their knowledge and experiences. In doing so, this project is intended to provide a more holistic understanding of the women and the potential opportunities for DANZ to support them through improved programming.

1.2 Aim and scope

The purpose of the research project was to address the gaps in literature on Deaf women's sexuality and DANZ service delivery, in two ways. First, this study documented and explored the accounts of sexuality-related experiences of a group of Deaf women in New Zealand in order to understand their sexuality knowledge and experiences. The exploration included discussions about their early developmental experiences and current experiences to highlight potential variations across the lifespan. Opportunities were provided to disclose positive as well as potentially negative experiences, although care was taken to ensure no one was required to share anything that might make them uncomfortable.

The second aim was to generate recommendations for improving sexuality-related information and services available to the women. As DANZ was a collaborative partner, the primary intent was to develop recommendations for delivery of their information

and services. However, suggestions for ways to enhance the women's access to information and support in other areas were also considered.

The time constraints of a Master's thesis prevented the completion of all stages in an ideal action research cycle. However, the first step of identifying a problem was achieved through the focus groups held in August 2012 and follow up conversations with DANZ. This information comprises the majority of the thesis content. In 2013 and 2014, work also began on the second step and third step of the action research cycle, planning and then carrying out a course of action in response to the findings. These steps are briefly discussed in the final chapter.

1.3 Overview of the study

To achieve the above aims, Chapter 2 provides a review of the relevant theories and background literature for understanding Deaf sexuality. It begins with an introduction of Deaf culture and what it means to be Deaf, to illustrate how the identification and associated experiences influenced the women who participated in this project. Chapter 2 then explores theories of sexuality to understand the role of dominant discourses in constructing sexuality knowledge and experiences. The chapter concludes with a review of sexuality education practices that may have played a role in the women's sexuality development.

Chapter 3 outlines an appropriate research design for this project and explains the action research methodology, then highlights the importance of its use in this project. Chapter 3 describes the collaborative partner, participants, and research methods involved in the action research process, closing with an overview of how the data was interpreted, which is important for understanding the three subsequent chapters.

Chapters 4, 5, and 6 present the key findings that address the first aim of this project. Chapter 4 discusses the women's socialisation experiences to illustrate their understanding of key sexuality concepts. Chapter 5 expands on that information by describing the women's experiences with intimate relationships, beginning with an exploration of their first relationships and ending with descriptions of their current relationships. Throughout the chapter, potential variations in their experiences as a

result of English literacy levels, cultural family backgrounds, and other contextual factors are noted. Chapter 6 then provides insights into the range of sexual experiences they reported, again beginning with their first experiences and continuing to present sexual experiences.

The final chapter in this thesis, Chapter 7, presents recommendations based on the sexuality knowledge and experiences reported by the women. The recommendations begin with improvements to information and services that DANZ provides to Deaf women and girls. Included in these recommendations is an example of one programme that I have developed with DANZ. Two recommendations are then made for improving the accessibility of sexuality education within schools. The chapter then concludes with strengths, limitations, and areas for future research.

Chapter 2: Literature Review

2.1 Introduction

This chapter provides an introduction to the relevant literature for this project. It begins with an explanation of what it means to socially and culturally identify as Deaf, especially in relation to the New Zealand context, so that it may be possible to understand the basis of the women's experiences described in subsequent chapters. It then discusses the social construction of sexuality so that it may be possible to understand how the dominant discourses and practices may have played a role in the women's sexuality development. Finally, it concludes with a review of sex and sexuality education practices internationally and in New Zealand, with particular emphasis on the sexuality education of Deaf students.

2.2 What does it mean to be Deaf?

The dominant bio-medical model of 'deaf' describes someone who was born or became audiologically disabled, handicapped, or impaired (Bauman *et al.*, 2010). The entire frame is one of loss, inability, and being abnormal (Leigh, 2009). In this model, the deaf person is someone who needs assistive therapies and devices to restore as much hearing as possible. This viewpoint is typified by use of the lowercase 'deaf' and stands in contrast to the capitalised 'Deaf', which is based on a socio-cultural model and is a source of pride for Deaf people (Ladd, 2003, ch. 1). The socio-cultural model and term 'Deaf' is used for this thesis.

The following sections describe the importance of Deaf culture, sign language, and socialisation experiences in the lives of Deaf individuals. This information will provide an understanding of the influential role the women's Deaf identity had in their knowledge and experiences that are described in the findings chapters.

2.2.1. Deaf culture and sign language

The concept of a Deaf culture first emerged in the United States in the late 1970s, and stems from the subjective notion of cultural identification and the importance of shared language. Triandis (1972) described subjective culture as the non-tangible features of culture, such as shared sets of categorisations, beliefs, attitudes, norms, role definitions, and group values. Language is the means by which those features are communicated to members and it influences the formation and expression of ideas, feelings, and experiences of both groups and individuals (Boyd, 1988). Therefore, "communication *is* culture. And culture *is* communication" (Hall, 1959, p. 3).

Deaf culture is based on a socio-cultural model of Deafness that views Deaf individuals as whole and complete beings who are simply a reflection of human diversity (Bauman *et al.,* 2010). In this model, Deaf people are not seen as defective or deficient versions of hearing people, but rather they are viewed as competent and capable members of a unique cultural group built around their linguistic minority status (Leigh, 2009; Padden & Humphries, 2005, ch. 1). This view stands in stark contrast to the bio-medical model that has historically pathologised Deaf people as disabled and suffering from an affliction in need of remedy.

The majority of research on Deaf culture originates from North America, and while there are many parallels with Deaf communities in other industrialised countries, numerous differences exist between communities as well, due to differing histories, scale, and cultural context. Carol Padden, one of the leading Deaf researchers in the United States, offered an early definition of Deaf people, Deaf culture, and Deaf communities. She explained:

> A Deaf community is a group of people who live in a particular location, share the common goals of its' members, and in various ways, work towards achieving these goals. A Deaf community may include persons who are not themselves Deaf, but who actively support the goals of the community and work with Deaf people to achieve them…Members of the Deaf culture behave as Deaf people do, use the language of Deaf people, and share the beliefs of Deaf people towards themselves and other people who are not Deaf (Padden, 1980, p. 92-93).

Padden (1980) elaborated further in defining Deaf culture by noting that "the most striking characteristic of the culture of Deaf people are their cultural values. These values shape how Deaf people behave and what they believe in" (p. 95). Some Deaf values are collectivist in nature, including features such as reciprocity, loyalty to the group, close interpersonal relationships, group identity, and group decision-making (Mindess, 2006; ch. 5). However, other values and behaviours are unique to Deaf people. These may include: respect for and use of sign language, sacredness of the hands, oral transmission of cultural values, storytelling or folklore, and participation in the Deaf community (Padden, 1980; Woll & Ladd, 2003).

These cultural values and practices are typically transmitted through Deaf-only activities or in Deaf-only spaces such as Deaf sports, clubs, and schools (Mindess, 2006; Padden & Humphries, 2005, ch. 7; Davis, 2007). These places provide opportunities for socialisation and the development of relationships, either platonic or intimate, in a space where Deaf individuals can fully express themselves and connect with others in an environment free from the marginalisation experienced in the hearing world (Fitz-Gerald & Fitz-Gerals, 1978; Leigh, 2009). As McKee (2001) eloquently notes:

> Deaf territories such as Deaf schools, clubs, and homes are more than just gathering places: they sustain a communal history of links from the past to the present, and ties with Deaf people from other places and countries (p. 35-36).

Therefore, like other cultures, Deaf culture is a social construction centred around language, in this case, the unique sign languages of Deaf people. Deaf communities in most industrialised countries have developed their own sign languages, which may differ considerably among countries, just as spoken languages differ (Mindess, 2006, ch. 3). While some believe that sign languages are nothing more than a gestural version of English or some form of pidgin language, they have been scientifically validated as unique languages with their own complex system for grammar and syntax (Padden & Humphries, 2005, ch. 1; Ladd, 2003, ch. 5). This recognition of sign languages has led many researchers to consider Deaf people a linguistic minority whose first language is sign language, rather than English (Ladd, 2003; ch. 2; Bauman *et al.*, 2010).

2.2.2. Deaf socialisation experiences

While there is considerable variation within and between Deaf communities, many Deaf individuals share common experiences that result from their linguistic abilities and the obstacles imposed by the larger society (Ladd, 2003; ch. 7; Monaghan *et al.*, 2003). These shared histories are integral to Deaf culture and offer a sense of kinship or connection with Deaf individuals from other parts of the world (Woll & Ladd, 2003; Mindess, 2006, ch. 5). These experiences include being born to families that do not sign, challenges with obtaining an education, limited ability to access information from the hearing world, and experiences with isolation and oppression.

Ninety percent of Deaf children are born to hearing parents (Monaghan *et al.*, 2003; Leigh, 2009; Davis, 2007). This immediately introduces communication differences, which become exacerbated when the majority of those parents do not learn sign language (Padden & Humphries, 2005, ch. 1). In fact, one study reported that only 26% of hearing families with Deaf children in the United States had someone other than the Deaf child learn sign language (Gannon, 1998). Often, these parents are advised by audiologists and doctors who subscribe to the bio-medical view of being deaf and encourage assistive devices as well as oral methods of communication to help the child be as hearing as possible (Leigh, 2009; Ladd, 2003; ch. 3; Powers, 2006).

Unfortunately, these attempts may not always meet with success and can result in missed or lost communication, misinformation, frustration, and isolation of the Deaf child (Davis, 2007; Woll & Ladd, 2003). As a result, Deaf children born to hearing families often do not acquire sign language, or any first language, until they reach school (Fitz-Gerald & Fitz-Gerald, 1978; Marschark & Spencer, 2010, ch. 4).

Communication difficulties at home have been shown to result in various academic and learning delays, including in mathematics and reading (Conrad, 1978; Holt, 1993; Powers *et al*., 2000, ch. 3). These delays can continue into the school years as schools with Deaf students in multiple countries have been reported to place low expectations on academic achievement, lack accountability or evaluation of teaching strategies, and fail to educate Deaf students adequately (Powers *et al*., 2000, ch. 3; McKee & Smith, 2003; Marschark & Spencer, 2010, ch. 2). In particular, English literacy development

has proven challenging for Deaf individuals, with the average Deaf person reading at an eight to ten year old level, even as an adult (Davis, 2007).

English literacy barriers have enormous implications in a Deaf person's life. With limited English literacy, Deaf individuals may be unable to read or comprehend books, magazines, newspapers, or even pamphlets, all of which are written at a more advanced level (Bauman *et al.*, 2010; Fitz-Gerald & Fitz-Gerald, 1998; Dudale, 2002). Accessing information on websites, reading captions on a television screen, or even navigating a text message may also prove problematic. In the absence of interpreted materials or programming, the majority of print and visual media remains largely inaccessible to them. As a result, they are unable to glean the explicit and implicit content from some of the most powerful sources of information and socialisation agents (Powers, 1996; Job, 2004; Woll & Ladd, 2003).

In addition to communication and learning obstacles, Deaf people also face social barriers. From the 1800s until the middle of the 19th century, most Deaf children in Europe and the United States were sent to residential schools for the Deaf at a very young age and spent most of the year at such schools. This was also the case in New Zealand. While they were surrounded by other Deaf youth, they could be forbidden from signing during class and often lacked access to Deaf adult role models (Padden & Humphries, 1980; Ladd, 2003, ch. 7).

In the 1970s, education practices shifted to placing a single Deaf child in a hearing school, a process known as mainstreaming. The amount of educational support the child received varied considerably by geographic location and time period, although it was not uncommon to have no access to interpreters or note-takers (Woll & Ladd, 2003). The idea was to expose them to the same curriculum as hearing students and facilitate their integration with the larger hearing society (Marschark & Spencer, 2010, ch. 3; Leigh, 2009). However, mainstreaming has been identified to have a significant social and psychological impact on the Deaf child (Nunes & Moreno, 1997; Dugdale, 2002). At the present time, over 90% of Deaf children in England, the United States, and New Zealand are mainstreamed (McKee & Smith, 2003; Job, 2004; Suter *et al.*, 2009). Mainstream education has continued to result in academic shortcomings for Deaf children and it has the added complication of reduced socialisation opportunities (Holt,

1993; Nunes & Moreno, 1997; Marschark & Spencer, 2010, ch. 2; Powers *et al*., 2000, ch. 3). A Deaf child may be the only Deaf student in the school, or possibly one of a few. Often, there is little staff or student preparation for incorporating a Deaf student, such as sign language classes or training for how to teach Deaf students (Bauman *et al.*, 2010; Gannon, 1998). Additionally, difficulties may exist with the availability and quality of classroom interpreters. As a result, Deaf children may have difficulty engaging with those around them, reducing opportunities for formal and informal socialisation and contributing to feelings of isolation (Ladd, 2003, ch. 7; Davis, 2007).

As adults in society, Deaf individuals are typically positioned as the 'Other' and considered different (Woll & Ladd, 2003). They experience marginalisation because of the small numbers of people who sign and limited opportunities to access interpreted information or media, which renders their "voice" invisible (Padden & Humphries, 2005, ch. 3). This, in turn, can engender feelings of isolation that may be exacerbated by the geographic distances separating one Deaf person from another. They also experience stigma and discrimination because of societal perceptions of them as disabled, which is typically equated with weakness and inability. Perhaps most importantly, they experience systematic oppression because of the sheer number of barriers that are erected, to the point of deprivation, when they try to participate in employment, healthcare, government, and any number of daily activities that hearing people may take for granted (Leigh, 2009; Bauman *et al.*, 2010).

2.2.3. The experiences of Deaf women

Relatively few studies have specifically explored the experiences of Deaf women. However, all have indicated that Deaf women experience more intense marginalisation and oppression as a result of their double minority status (Leigh, 2009; Merkin & Smith, 1995). For instance, they may experience the paternalism associated with being Deaf as well the patriarchal views inflicted upon women in general. In describing societal perceptions of gender in relation to disability, in which they included deaf people, Fine and Asch (1985) elaborate on this problem:

> To be male in [Western] society is to be strong, assertive, and
> independent; to be female is to be weak, passive and dependent, the
> latter conforming to the social stereotypes of the disabled. For both

categories, the disabled woman inherits ascriptions of passivity, and
weakness (p.11).

This has been shown to produce disparities between Deaf men and women. For instance,
Coogan (2005) found that Irish Deaf men have typically assumed leadership roles within
the Deaf community and served as spokespersons or decision-makers for key events.
Irish Deaf women were still involved, but much lower down the ladder, and could often
be found making tea or in the kitchen during community events. Although, she noted
positively that Irish Deaf women reported more close-knit friendships than their male
counterparts.

Differences in employment and education opportunities have also been noted. MacLeod-
Gallinger (1992) reported that American Deaf women who obtained tertiary education
experienced significantly higher underemployment and unemployment in comparison to
Deaf men or hearing peers. Swartz (1993) reported a gender difference in sex knowledge
among American Deaf university students. Meanwhile, Fitz-Gerald and Fitz-Gerald
(1978) noted that young Deaf women in the United States were made to feel more
concerned with their reputation in school and experienced greater guilt in relation to
their behaviours.

However, the area that has received the most attention and also recorded the greatest
disparities is that of domestic and sexual violence against Deaf women. Various
international studies have reported they experience gender-based violence two to three
times as often as hearing women (Sobsey & Doe, 1991; Anderson *et al.*, 2011; Nosek *et
al.*, 2001; Kvam, 2004; Merkin & Smith, 1995). The elevated rates may result from the
barriers that restrict their ability to notify others or access support services. However,
Deaf women involved in intimate relationships with hearing men may also be more
vulnerable because of the power differences existing in those relationships (Anderson, *et
al.*, 2011). The differences in power can stem from hearing privilege, which typically
manifests as the hearing partner is presumed to be more capable, controlling the Deaf
partners' access to information, and generally serving as gate keeper of the relationship
(Sobsey & Doe, 1991; Merkin & Smith, 1995).

2.3 What does it mean to be Deaf in New Zealand?

The New Zealand Deaf community is a diverse reflection of the many groups that live within the boundaries of the country, including NZ European/Pākeha, Māori, Pacific, and other groups. However, the literature in relation to Deaf cultural and sexual minority groups is extremely sparse, with only one study available on Māori Deaf identity development (Smiler, 2004). In addition, while the experiences of Deaf women in New Zealand have been incorporated into other work (McKee, 2001; Dugdale, 2002; Townshend, 2003), they have never been the sole focus of any research until this project.

While no concrete statistics are available on the size of the Deaf community, an estimated range is between 4,320 (McKee, 2001) and approximately 7,700 (Dugdale, 2002) individuals who identify as Deaf. Other statistics that indicate a considerably larger population (Office of Disability Issues [ODI], 2001) may be less accurate as they include all levels of hearing loss or impairment and do not specify use of New Zealand Sign Language (NZSL), which is a defining feature of Deaf culture and community. The following two sections provide a summary of social and educational experiences of Deaf New Zealanders and also describe relevant pieces of legislation that influence those experiences. This information may help contextualise the experiences of the Deaf women who participated in this project.

2.3.1. Social and educational experiences

While Deaf individuals have always resided in New Zealand, they did not begin to form any semblance of a Deaf community until 1880 when the Van Asch residential school for the Deaf opened in Christchurch (Smiler, 2004). This was the first opportunity most Deaf children had to see and interact with others like them. However, the school was highly influenced by the second International Congress on Education of the Deaf held in Milan in 1880 which decreed speech or oral education methods were superior to education with sign language and subsequently banned the use of sign language in schools worldwide (Dugdale, 2002).

Consequently, the "oralist" tradition was strong in New Zealand and Van Asch, along with other residential schools for the Deaf built in the middle of the 20th century, banned the use of sign language (McKee, 2001). This ban remained in place for almost one hundred years until 1979 (Powell & Hyde, 2013). During oralism, the emphasis was on teaching Deaf children to be as hearing as possible, so they were forbidden from using sign language and denied access to Deaf teachers. While some reports of experiences in the schools indicate increased opportunities for informal socialisation and communication with other Deaf children (Dugdale, 2002), many more contain negative experiences such as low education quality and even abuse (Townshend, 1993). McKee (2001) also notes:

> The constraints of the oral teaching method, along with the pathological perception of Deaf people, by and large have failed to deliver an adequate education to previous generations of Deaf in New Zealand. This fact is not only claimed by Deaf people themselves, but also acknowledged by many teachers…As one teacher of the Deaf from the 1950s and 1960s recalls: "We were bound by the chains of oralism...where it should have been part of a total package it was a 'coat of iron'." (p. 25).

In the 1920s and 1930s, Deaf clubs were established in Christchurch, Auckland, and Wellington (Smiler, 2004). These were pivotal developments as they provided Deaf individuals with a space to exchange information, develop sign language skills, take on leadership roles, and enjoy companionship (Dugdale, 2002). However, McKee (2001) noted there were, and remain, gendered differences in Deaf clubs, as evidenced by the overwhelming majority of male Deaf club presidents. The New Zealand Deaf Sports Association was also formed during the 1950s and even hosted the World Games for the Deaf in Christchurch in 1989 (Smiler, 2004).

Very little changed in terms of Deaf education until the 1960s, when the failings of oralism became too apparent to continue to ignore (McKee, 2001). At that time, Deaf units were introduced, where small groups of Deaf children were placed in a classroom inside a hearing school (Dugdale, 2002). In the 1970s, mainstreaming grew in popularity, but oralism was still a powerful practice. In 1979, a shift in education policy created a departure from oralism and the adoption of 'total communication' teaching

methods. Total communication is when English speech is used alongside Signed English, which differs from the sign language used by Deaf people because it follows English word order and grammar structures. While an improvement over oral education methods, total communication still posed challenges for Deaf students (Powell & Hyde, 2013).

The late 1970s and 1980s represented a huge period of growth for Deaf New Zealanders. The New Zealand Association of the Deaf, now known as Deaf Aotearoa New Zealand, was established in 1975 to serve as a "voice" for members of the Deaf community while also educating the larger hearing society (Dugdale, 2001). New Zealand Sign Language was also systematically analysed and validated as a language in 1989 (Powell & Hyde, 2013), which resulted in greater acceptance of the language and pride in using it. Perhaps spurred by this growing awareness, the idea of Deaf as a social and cultural identifier also began to take hold (McKee, 2001).

Not long after, the first and only professional NZSL interpreter training programme opened at Auckland University of Technology in 1992. In addition, the first Deaf teacher for Deaf students was trained in 1992 and the first bilingual-bicultural class (English/NZSL) opened in 1993 at the Kelston Deaf Education Centre in Auckland (Dugdale, 2002). Although, recent studies have indicated 95% of Deaf youth currently attend mainstream classes with a considerable emphasis on oral-aural communication and limited exposure to Deaf adults (Powell & Hyde, 2013). Students in these settings still experience isolation, difficulties acquiring information, limited access to education support staff, and limited access to interpreters (McKee & Smith, 2003; Dugdale, 2002).

2.3.2. Legislation pertinent to Deaf New Zealanders

More recently, there has been a wave of legislation meant to protect the rights of New Zealanders with disabilities, including Deaf people, by increased access to the mainstream society. In 1996, the Ministry of Education released *Special Education 2000* as a framework to support inclusive education for disabled and Deaf children by guaranteeing access to resource teachers, advisors of the Deaf, teacher aid support, and specific funding. However, Powell and Hyde (2013) note that this has not materialised

quickly, citing the elimination of a Deaf mentor and resource programme in the South Island because of insufficient funding.

In 2001, the Office of Disability Issues (ODI) developed the *New Zealand Disability Strategy,* which contained fifteen objectives to break down barriers and promote a more inclusive society for disabled people, including Deaf people. Of particular importance are objectives 6 and 9, which guarantee access to information and support for cultural lifestyles associated with disabled people, including support "in making their own choices about their relationships, sexuality and reproductive potential" (ODI, 2001, p. 9.1). Objective 14 specifically focuses on improving the quality of life for disabled women so they can "live independent and secure lives" (ODI, 2001, 14.3). Objective 14 also ensures "health and reproduction-related treatment of disabled women [is] the same as for non-disabled women" (ODI, 2001, p. 14.4).

The government implemented the New Zealand Sign Language Act in 2006, which recognised NZSL as the third official language of the country. A ground-breaking piece of legislation, it aimed to promote the use of NZSL through four main initiatives. The last initiative set out guiding principles for "NZSL [to] be used in the promotion of…information to the public" (ODI, 2006, p. 9.1.b.) and that "government services and information should be made accessible to the Deaf community through the use of appropriate means (including the use of NZSL)" (ODI, 2006, p. 9.1.c.).

Regrettably, there has been a lack of progress since the New Zealand Sign Language Act was passed. In fact, the first review of the legislation in 2011 noted "a lack of active implementation by government departments in both making information accessible and provision of NZSL interpretation" (ODI, 2006, p. 58). A separate report, called The New Zealand Sign Language Inquiry, also found gross inadequacies in terms of interpreter availability, access to captioned programming, support services within school, and NZSL training for hearing parents of Deaf children (Human Rights Commission, 2013).

The final piece of legislation is the United Nations Convention on the Rights of Persons with Disabilities which was ratified by the New Zealand government in 2008. The ratification was meant to show a deep commitment to the rights of disabled people,

including Deaf individuals, by holding the country accountable to an international body. It contains a detailed list of articles designed to protect fundamental human rights to concepts and services such as information, communication, respect, freedom, safety, justice, and equality.

The most pertinent sections of the Convention are Articles 6, 9, 21, 24, and 25. Article 6 states, among other things, that "state parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women" (United Nations [UN], 2008, 6.2). By ratifying the convention, the New Zealand government has agreed to do everything possible to ensure that women with disabilities, including Deaf women, are able to reach their full potential.

Articles 9 and 21 discuss the importance of promoting access to information to ensure that individuals with disabilities have equal opportunities for inclusion and participation in society. Article 21 specifically prioritises "facilitating the use of sign languages" (UN, 2008, 21.b). Article 24 specifically recognises the right of Deaf people to receive education from teachers fluent in sign language, at all stages of schools and including lifelong education. Article 25 also explicitly states that individuals with disabilities should have the "same range, quality and standard of free or affordable health care and programmes…including in the area of sexual and reproductive health" (UN, 2008, 25.a). Taken together, these two Articles should provide for lifelong learning opportunities for Deaf individuals, especially in relation to sexuality.

2.4 Sexuality theories

Sexuality can be one of the most influential aspects of our lives, but also one of the most challenging to define. As it encompasses so many thoughts, feelings, behaviours, and attitudes, it can be difficult to articulate or categorise. However, sexuality is more than mere anatomical features or physiological drives. Sexuality, instead, includes gender identity and roles, sexual orientation and attraction, eroticism and pleasure, reproduction, intimate relationships, and a range of associated desires, values, and practices (Vance, 1998; DeLamater & Hyde, 1998; Baker, 2008; Lamb, 2010; Allen, 2007).

Language, which is influenced by socio-political climates and time periods, is pivotal in the identification and development of every aspect of sexuality (Berger & Luckmann, 1966; Fine, 1988; Halloway; 1996; Jackson & Weeks, 2005). With that in mind, social construction theory offers a framework for understanding sexuality and how it can shape our experiences. The following two sections detail a social construction perspective of sexuality, especially in relation to women from Western cultures.

2.4.1. Social construction of sexuality

Historically, one of the predominant sexuality theories in Western traditions has been essentialism, which asserts that certain acts, behaviours, and identities are natural, inevitable, universal, and biologically determined (Jackson & Weeks, 2005). This theoretical framework has been propagated by psychoanalysts, sociobiologists, and sexologists since the late 19th century, but fails to account for historical and socio-cultural factors (Vance, 1998). As a result, more recent theories have rejected the biological reductionist way of thinking in favour of a constructionist approach towards understanding sexuality.

The constructionist paradigm posits that "reality is socially constructed" (Berger & Luckmann, 1966, p.1). Drawing heavily from symbolic interactionism, it states that individuals experience the world as an objective reality and language provides the basis on which they make sense of it. The realities of everyday life are shared through language and those experiences or knowledge may become institutionalised at the societal level or within subgroups (DeLamater & Hyde, 1998). This process happens through lifelong socialisation experiences, which Berger and Luckmann (1966) considered successful when a "high degree of symmetry between objective and subjective reality" (p.163) was present.

DeLamater and Hyde (1998) apply social constructionist theory to sexuality by stating that, although there are certain biological features, "sexuality is created by culture, by the defining of certain behaviours and some relationships as 'sexual' and the learning of these definitions or scripts by members of a society" (p. 14). For example, while concepts such as attraction, sexual orientation, and gender are universal experiences,

individual understanding of all three concepts varies considerably according to societal norms, political climate, and historical period.

DeLamater and Hyde (1998) note that each society has discourses about sexuality, a way of thinking and talking about the broad array of behaviours. The discourses offer ways of understanding sexuality and are influenced by education, law, medicine, and religion (Allen, 2007). They are also inextricably linked to power, rendering some more 'truthful' or persuasive than others (Allen, 2005).

Despite often being referred to as social constructionism, implying a unified approach, multiple perspectives attend a social constructionist view of sexuality. Vance (1998) notes that all social constructionist perspectives will at least:

> Adopt the view that physically identical sexual acts may have varying
> social significance and subjective meaning depending on how they are
> defined and understood in different cultures and historical periods (p.
> 163).

Jackson and Weeks (2005) elaborate further by noting that a modernist perspective of social constructionism emphasises identity politics, power as oppressive, and the structural limits imposed by larger forms of power. In fact, this approach places considerable emphasis on the material and economic nature of sexualities, which can be heavily influenced by capitalism, as evidenced by groups in Papa New Guinea and India which have experienced radical re-definitions of relationships, sexual categories, and identities as a result of transition to capitalism (Connell, 2002, ch. 5). This is the perspective adopted in this thesis.

2.4.2. Social construction of women's sexuality in Western cultures

Social constructionist theorising about women's sexuality is focused on the ways that sexuality is constructed and represented in society. In Western societies, patriarchal discourses and practices can serve to regulate women's sexuality (Fine, 1988; Vane, 1998). These can be heavily influenced by religious beliefs about women, who are figuratively positioned beneath and secondary to men in Judeo-Christian texts (Carabine, 1992; Ussher, 1994). Often, what is considered immoral or unethical

according to these beliefs becomes illegal (Lamb, 2010), such as the criminalisation of abortion in New Zealand. Media representations can then further reinforce these messages by normalising the differences in status and power (Baker, 2008, ch. 4).

Several scholars have noted an absence of desire and pleasure in this representation of women's sexuality (Jackson & Weatherall, 2010; Halloway, 1996; Allen, 2004a). Without the ability to take ownership of these two things, women are stripped of the ability to negotiate and define aspects of their sexuality and denied their sexual subjectivity or agency (Lamb, 2010). Writing about young women in New Zealand, Louisa Allen (2007) drew connections between desire, pleasure, and overall well-being by stating that "silence about female pleasure may fail to convey a sense of personal empowerment and pleasurable entitlement" (p. 252). This, in turn, can render women helpless and at risk of victimisation or danger (Jackson & Weatherall, 2010).

As a result of this social construction and representation, women's sexuality is positioned as the "Other" in relation to men, both symbolically and in everyday practice (Holloway, 1996). In fact, some of the most influential sexuality research conducted by Kinsey in 1949 and Masters and Johnson in 1966 discussed women's sexual responses as support for men's experiences or were judged inferior in comparison (Jackson & Weeks, 2005).

Women are also positioned as the object of male sexual drives, considered passive recipients of their attention or advances (Fine 1988; Vance, 1998). In line with this view, great importance is placed on their physical attractiveness and perceived sexual availability (Holloway, 1996). However, they are often subjected to a virgin/whore double standard where only heterosexual monogamy, marriage, and motherhood are considered "good" by society (Carabine, 1992; Ussher, 1994). When women deviate from those ideals, they may experience social sanctions, such as stigma or, at the extreme end, even violence or abuse (Lamb, 2010; Baker, 2008, ch. 4).

2.4.3. Social construction of Deaf women's sexuality

While no study on the topic could be located, the social construction of Deaf women's sexuality may be influenced by two things. As previously mentioned, their double minority status may expose them to more rigidly defined gender roles, discrimination, and marginalisation. If they do experience these things, it would be a powerful influence in shaping their understanding of almost every aspect of sexuality from gender identity to intimate relationships. In addition, their experiences associated with being Deaf may affect their sexuality socialisation experiences.

For instance, the inability of parents to communicate with their Deaf daughter may be problematic given the influential status of parents as primary socialisation agents, especially in relation to sensitive or value-laden topics such as sexuality (DeLamater & Hyde, 1998; Maccoby, 1992). According to social constructionism, it means the numerous formal and informal methods parents typically use to convey understanding and meaning regarding sexuality are limited, or even prevented all together. In addition, Job (2004) notes that even when hearing parents do find a *way* to communicate with their Deaf children, they are often unsure *what* to communicate. This may be out of fear or uncertainty about exposing their "disabled" children to any and all aspects of sexuality, misguided attempts to protect them, or unconscious beliefs that Deaf children are asexual (Gannon, 1998). This can ultimately create an atmosphere of taboo and inhibition where Deaf girls may feel discouraged or unable to explore their sexuality.

In addition, opportunities for informal sexuality socialisation through media and entertainment sources may be limited. As an example, youth magazines, advice columns, and to a lesser extent, websites, have all been identified as significant sources of informal information regarding sexuality for young adults in New Zealand (Jackson, 2005). If Deaf women experience difficulties with English literacy, it may render the sexuality information within these materials inaccessible. Another study conducted in the United States found 94% of hearing youth reported turning to television or film for ideas of romantic love and sexual knowledge (Ward, 2003). However, as only 23% of television programming in New Zealand is available with captions, Deaf women may only have access to the visual images on the screen and may miss what is said between-the-lines. As a result, the intended message may get misconstrued, especially in relation to something as highly nuanced as sexuality (Roberts, 2006).

Peers have been identified as another source for sexuality socialisation because of their ability to provide information regarding gender-specific roles and expectations as well as opportunities for modelling or comparing behaviours (Treboux & Busch-Rossnagel, 1990). The pivotal role of peers in sexuality socialisation has been identified as even more important for Deaf people, in part because of the difficulties accessing information elsewhere (Fitz-Gerald & Fitz-Gerald, 1978; Swarz, 1993; Joseph *et al.*, 1995 Roberts, 2006). However, if Deaf women are in mainstream settings and unable to meaningfully engage with other hearing students, they may not have access to a range of formal and informal exchanges which provide that type of information.

If Deaf women are routinely unable to access this type of information, it could affect their knowledge of key sexuality concepts or their ability to have positive sexuality experiences. It may also impede their ability to form complete, balanced social and sexual selves (Job, 2004). This, in turn, may affect their ability to engage in a broad range of areas, and, potentially, even their ability to "do" sexuality.

2.5 Sexuality education

The dominant sexuality discourses have always played an influential role in the type of sex or sexuality education in a particular time or place. In the beginning of the 20th century, conservative discourses, which were based on essentialist ideas about sexuality and were guided by moral as well as medical authorities, determined sexuality practices in many places (Pilcher, 2005). When more liberal discourses emerged in the 1960s, sexuality education broadened to include biological processes and reproduction. By the end of the 20th century, sexuality education in some areas attempted to provide more holistic information about relationships and identities, although risk minimisation discourses still permeated the content (Weaver *et al.*, 2005; Allen, 2007).

The following sections begin with a description of sexuality education practices worldwide and then focus specifically on what is happening in New Zealand. Subsequently, a review of sexuality education for Deaf students is provided. This information is shared to provide insight into the influence of sexuality education experiences on subsequent sexuality-related experiences and knowledge.

2.5.1. International sexuality education practices

Sex education in England began during the start of the 20th century, but it was limited to health and hygiene for the first fifty years (Pilcher, 2005). In the 1980s, it was heavily influenced by conservative morality discourses that considered students non-sexual and in need of protection from information, themselves, and their hormones or desires (Fine, 1988). Therefore, the curriculum utilised a risk-based approach that encouraged "stable married and family life" and discouraged anything else (Pilcher, 2005). In 2000, the curriculum was broadened to provide a more comprehensive "sex and relationship education," but only biological topics are compulsory components from age 11 onwards.

In Australia, the 1980s AIDS crisis resulted in expanded sex education content, but it wasn't until the early 2000s that several Australian states implemented state-wide sexuality education curricula that covered a range of sexuality topics, including consent, healthy relationships, puberty and reproduction (Harrison, 2000). However, they were still influenced by a risk minimisation discourse rooted in the notion that sexuality was "dangerous" or "problematic", with negative sexual consequences that needed to be managed or avoided through information dissemination (Weaver *et al*., 2005). More recently, a shift has occurred and a national curriculum is in development that is strengths-based and aims to teach students about managing interpersonal relationships, sexual and gender identities, bullying and harassment, and diversity (Australian Curriculum, Assessment, and Reporting Authority, 2012).

Historically, in the United States, the morality and victimisation discourses in most states, which were particularly targeted at young women, have resulted in sex education practices that primarily teach abstinence (Weaver *et al*., 2005; Fine, 1988). However, in 2012, the National Sexuality Education Standards were introduced as a guide for what should be considered the minimum core content for sexuality education from Kindergarten to 12th grade (5 or 6 years of age to 17 or 18 years of age). The standards include seven topics primarily focused on puberty and biological functions (Future of Sex Education Initiative, 2012). They also still utilise a risk minimisation discourse that focuses on preventing negative sexual consequences, such as transmitted infections or unintended pregnancy.

2.5.2. Sexuality education in New Zealand

Early requests for sex education in New Zealand can be traced back to the 1920s, but conservative morality discourses prevented anything from making its way into the curriculum until much later (Jackson & Weatherall, 2010). At the legislative level, the Police Offenses Amendment Act of 1954 prevented children under the age of 16 from learning about contraceptives and also prohibited other sex education topics. In 1977, the Contraception, Sterilisation and Abortion Act criminalised instruction by anyone except a teacher who had school permission. Jackson and Weatherall (2010) note that this legislation was reflective of "discourses of violence (informing as terrorising)" (p. 49) that equated teaching sex education with encouraging it and discourses of victimisation.

In the 1980s, the election of a more liberal government and growing public health concerns regarding sexually transmitted infections contributed to changes that finally permitted basic sex education (Elliot, 1998). The Education Amendment Act in 1985 allowed some sex education topics, but approval was necessary from parents, the school, and the school committee before implementation and parents could remove children from any component. Then, in 1990, section 3 of the Contraceptive, Sterilisation, and Abortion act was removed, which allowed for contraceptive information to be provided to those under the age of 16 (Clark, 2001). However, Jackson and Weatherall (2010) note that sex education was still ad-hoc well into the 1990s.

A shift towards a more holistic type of education resulted in the development of the national Health and Physical Education Curriculum in 1999. It aimed to provide comprehensive sexuality education that moved beyond simple biology and addressed:

> The concept of total well-being, health promotion, and a socioecological perspective. Included [in this is] sexual development, sexual and reproductive health, personal and interpersonal skills, relationships, and social and cultural influences (Clark, 2001, p. 28).

The Health and Physical Education Curriculum enabled sexuality education at both the primary and secondary school levels. It made sexuality education compulsory until Year 10 (13 or 14 years of age), with schools able to discretionally offer additional classes that students may choose to take. The curriculum also encouraged the involvement of Māori and Pacific people in the development of sexuality education classroom materials when relevant to remain inclusive and culturally appropriate (Ministry of Education, 1999). However, sexuality education is the only part of the education curriculum that requires consultation with and approval from a school's community every two years, including parents and community members (Elliot, 1998).

In theory, the curriculum recognises that sexual well-being of students is more than the absence of disease. In practice, however, sexuality education still clings to a risk minimisation focus on preventing disease, pregnancy, and abortion (Allen, 2005; Jackson & Weatherall, 2010). In line with this view, students are considered childlike and in need of adult intervention, which denies their sexual agency (King, 2011). Students are also sent contradictory messages, such as being told to practice safer sex, but then denied access to condoms in school or instructed in condom use (Allen, 2007; King, 2011).

As a result, a repeated critique made by students in New Zealand is that sexuality education content is not relevant to their needs, is perceived as overly scientific or boring, and contains too little information too late (Elliot, 1998; Allen, 2007). For instance, Allen (2004a) found in a nationwide study of 1000 New Zealand secondary school students that they wanted to hear less about "pipes and plumbing" and more about emotions, identities, and communication in relation to sexuality.

Furthermore, current sexuality education practices do not contain a discourse of desire or erotics (Jackson & Weatherall, 2010; Allen, 2007). The absence of this limits student access to information, removes any aspect of the sensual or sexual, and prevents discussion about positive sexuality experiences. This has particular ramifications for young women, who are perceived as having less pleasure or sexual desire than young men and who are also interpreted as being disproportionally responsible for negative sexual consequences (Jackson & Weatherall, 2010). In addition, Allen (2004a) cautions that:

If there is no acknowledgement that young women's bodies can have strong pleasurable physiological responses during sexual activity and that these are "normal" and positive outcomes, then the possibility of this being their experience may be reduced (p. 156).

2.5.3. Deaf students and sexuality education

Prior to this study, no work has explored the sexuality education experiences of Deaf New Zealanders. International research about the sexuality education of Deaf students has been sparse as well, with most of it conducted in the United States and only an extremely limited offering of work from England, Canada, or elsewhere. The limited research has also predominantly focused on white, heterosexual, middle class college students (Gannon, 1998). In addition, some of the most well-known studies in relation to the sexuality education of Deaf students were conducted decades ago, only examined programming in Deaf residential schools, or only asked for hearing teacher self-reports of sexuality education practices (Grossman, 1970; Fitz-Gerald & Fitz-Gerald, 1978; Luckner & Gonzales, 1993; Getch *et al.,* 1998).

As a result, very little is known about the current experiences of Deaf students in relation to sexuality education, especially in mainstream settings where the majority of Deaf students are now located. There is also a dearth of information about Deaf student perceptions of effectiveness or other evaluative measures for sexuality education. However, all work done to date has indicated a risk minimisation focus with severe inadequacies that have persisted for almost four decades (Fitz-Gerald & Fitz-Gerald, 1978; Gannon, 1998; Fitz-Gerald & Fitz-Gerald, 1998; Getch *et al*., 2001; Roberts, 2006; Suter *et al.*, 2009).

For instance, a handful of studies have compared the knowledge levels of Deaf and hearing American university students. It should be noted that the university studies included Gallaudet university students, who are often considered to be at the higher end of educational outcomes for Deaf students, but still reported considerable differences. For instance, one of the earliest studies by Grossman (1970) found Deaf university students had less sexual knowledge, held more myths, practiced more risky sexual behaviours, and reported being more sexually active than hearing students at another

university. Deaf university students have also been show less likely to get tested for sexually transmitted diseases or change their sexual behaviour to decrease risk (Bat-Chava *et al*., 2005;Woodroffe *et al.*, 1998).

Swartz (1993) found that when administered the Sex Knowledge Inventory to students at three different universities, the Deaf university students lagged behind their hearing counterparts in "nearly every aspect of sex knowledge examined" (p. 129). He identified anatomy and physiology as the areas where Deaf students demonstrated the least amount of knowledge. This has important implications, as Fitz-Gerald and Fitz-Gerald (1980) note:

> Understanding such abstract concepts as maleness, femaleness,
> parenting, relationships and reproduction becomes secondary when one
> has to struggle with the basic labelling of one's body parts (p. 179).

Similarly, Joseph, Sawyer, and Desmond (1995) reported that "students do not have sufficient knowledge about sexual health issues to make well-informed choices about sexual health behaviour" (p.343) and subsequently practiced high risk sexual behaviours. The results of those studies do not reflect positively on the effectiveness of primary or secondary school sexuality education for Deaf students in the United States. Some of the starkest disparities may be seen in relation to HIV/AIDS knowledge as the bulk of sexuality education research in relation to Deaf people that was conducted in the 1990s and early 2000s focused on the topic. As an example, Bares (1992) found that American Deaf youth in her study lagged eight years behind hearing youth in HIV/AIDS knowledge. Luckner and Gonzales (1993) also found that Deaf respondents could not answer many questions regarding transmission and prevention of the virus:

> 70% of respondents…did not realise that HIV and AIDS cannot
> be contracted by giving blood…43%...were unaware that all gay
> people do not have AIDS… [and] 62%...thought that married
> people [could not] get AIDS (p. 341).

In addition, Baker-Duncan, Dancer, Gentry, Highly, and Gibson (1997) found that adolescents at a Deaf residential school in the United States had extremely limited knowledge about most aspects in relation to HIV/AIDS, and that it did not improve with grade level. Heuttel and Rothstein (2001) also found that only 41% of Deaf university

students in the United States correctly answered a majority of their survey questions about HIV/AIDS, as compared to 91% of hearing students.

The results of these studies identified numerous contributing factors to the state of sexuality education and knowledge acquisition for Deaf students. One potential issue is the lack of special sexuality education training for teachers of Deaf students, resulting in educators who are uncertain how to effectively communicate basic sexual knowledge as well as more comprehensive sexuality topics, such as self-esteem, communication, and sexual agency (Fitz-Gerald & Fitz-Gerald, 1998; Swartz, 1993; Roberts, 2006; Suter *et al.*, 2009). Absence of this education can leave teachers feeling "uncomfortable in the role of sexuality educator" (Getch *et al.*, 2002, p. 402). However, as several of those studies included Deaf residential school staff, the problem may be even more pronounced with teachers in mainstream schools.

Potentially compounding the problem may be the absence of sexuality education training for interpreters working with Deaf students in mainstream settings. Gannon (1998) found that interpreter misinformation, values, or embarrassment may influence interpretation of sensitive topics. Swartz (1993) also found that limited knowledge of sexuality or sexual behaviour signs as well as overreliance on fingerspelling to convey information may further complicate matters. Additional difficulties with interpreting English idiomatic expressions such as "messing around" or "getting it on," which have no direct translation in sign language, may further impede negotiation of these topics (Job, 2004; Roberts, 2006).

However, the greatest hindrance may be posed by the limited availability of sexuality education materials specifically designed with Deaf linguistic and developmental needs in mind. As a result, teachers rely on materials meant for hearing students, which can contain complicated language written at an advanced level with an assumption of English literacy skills and basic knowledge that may not be present among Deaf students (Suter *et al.*, 2009; Heuttel & Rothstein, 2001; Joseph *et al.*, 1995). For example, abstract concepts such as "affection" and "romance" may quickly get picked up by hearing children through repeated incidental exposure to the words through conversations, television, and radio (Gannon, 1998; Roberts, 2006). Deaf children do

not have incidental exposure to this repetition that eventually leads to word comprehension and concept clarity (Swartz, 1993; Job, 2004; Powers, 1996).

Consequently, Fitz-Gerald and Fitz-Gerald (1978) note that potentially simple phrases in English are, in actuality, incredibly loaded and can pose problems for the average Deaf reader:

> "Boys become men" entails the necessity of determining that the three word concepts are understood, that the plural is understood, and that the Deaf person has a visual image of the meaning of the written concept. Concepts like "maturing," "menstruation," and "pregnancy" must be reduced to simple terms (p. 65).

Unfortunately, the same calls for improvements to sexuality education for Deaf students that began in the 1970s (Grossman, 1970; Fitz-Gerald & Fitz-Gerald, 1978) are still being made today. These include generating information and materials in sign language and specifically for a Deaf audience (Fitz-Gerald & Fitz-Gerald, 1998; Suter *et al.*, 2009; Gannon, 1998). Another need is a greater utilisation of highly visual and interactive materials such as pictures films, photographs, role-play, and experiential situations to enhance concept development and understanding about sexuality (Fitz-Gerald & Fitz-Gerald, 1980; Swartz, 1993; Baker-Duncan *et al.*, 1997; Job, 2004). Sexuality education could be further improved by incorporating Deaf cultural features such as using Deaf mentors (Getch *et al.*, 2001; Gannon, 1998) and peer education (Joseph et al., 1995; Heuttel & Rothstein, 2001; Roberts, 2006). Finally, adequate teacher, interpreter, and parent training has also been identified as essential for improving knowledge acquisition (Swartz, 1993; Garbiel & Getch, 2001; Suter *et al.*, 2009; Job, 2004).

2.6 Conclusion

This chapter has provided an in-depth literature review of three influential areas in the lives of the women who participated in this project. Background information about the culture, language, and socialisation experiences of Deaf people was reviewed to offer an understanding of what it means to be Deaf in industrialised societies, in New Zealand, and as Deaf women. Then, social constructionist theories of sexuality were discussed as

a framework for examining the experiences of the Deaf women who participated in this study. Finally, literature on sex and sexuality education practices globally, in New Zealand, and with Deaf students was examined to provide context for the role that participants' educational experiences may have played in their sexuality knowledge and development.

The next chapter will detail the research design that guided this project, including the action research methodology, research methods, procedure, and steps in analysis. This is necessary to understand how the women's accounts of their sexuality-related experiences were gathered and interpreted for this project.

Chapter 3: Research Design

3.1 Introduction

As outlined in the introduction chapter, the primary purpose of this thesis was to investigate the sexuality-related knowledge and experiences of a group of Deaf women in New Zealand. This chapter provides information about the research design in order to explain how that was achieved. First, details are provided about the action research model which served as the overall approach for this project. Then the research methods are described, including information about the collaborative partner, participants, and procedure. Finally, the chapter closes with an explanation of the data analysis techniques used for this project and the importance of a feedback loop with participants.

3.2 Methodology

Action research methodology guided the research project. This section provides information about action research, how it can be used as a research model, and why it was selected for this research project.

3.2.1. Action research

Kurt Lewin (1946), considered by many to be the pioneer of action research, offered an early definition of the approach as "comparative research on the conditions and effects of various forms of social action and research leading to social action" (p. 202-203). Therefore, action research is meant to improve "real-life" practical problems through the production of new knowledge and social system change (Rapoport, 1970). As a methodological approach, action research is intended to integrate theory and practice in a way that addresses critical social issues and injustices.

Action research is also meant to address several shortcomings that may be found within some positivist scientific approaches. For instance, action research "challenges the positivistic view of knowledge which holds that in order to be credible, research must remain objective and value-free" (Brydon-Miller *et al.*, 2003, p. 11). As mentioned in

the literature review, knowledge is a socially constructed phenomenon that is influenced by the culture and climate surrounding an individual, so it can be quite challenging, if not impossible, to disentangle oneself from values, histories, or other situational contexts. Therefore, rather than consider those features as bias, Wadsworth (1998) states that action research views them as essential steps toward engaged understanding.

To promote a more democratic process of knowledge creation, action research also rejects the positivistic tendency to treat research participants as "objects of inquiry, even though they are subjects or initiators of action in their own right" (Susman & Evered, 1978, p. 586). Action researchers, therefore, recognise that participants are capable of self-reflection, and respect their ability to understand and address the issues confronting them (Brydon-Miller *et al.*, 2003). Action researchers give participants a more equal role as active research collaborators, continually engaging them in a communication feedback loop and incorporating their ideas throughout the entire research process.

Lastly, and perhaps most importantly for the research, whereas those using positivistic approaches seek to remain objective and detached, action research allows for a sensitive and empathetic approach in which people are deeply committed to the empowerment of those involved and seek to shine a light on the potential sources for social injustice. Action research, then, offers opportunities to participants for self-reflection and self-help (Wadsworth, 1998), by providing them a voice and the tools to improve their own situation. Thus, ideally action research facilitates "the flourishing of individual persons and their communities" (Brydon-Miller *et al.*, 2003, p. 11).

3.2.2. The action research model

Action research involves five key steps: Diagnosing, planning, taking action, evaluating, and reflecting (*see Figure 1*). The diagnosis stage involves the collection of data and identification of a social problem or issue, which can be a lengthy and reflective process (Susman & Evered, 1978). Once a problem has been identified, the next steps are to collaborate with research participants in the development of a course of action and to implement it.

The final two stages of action research require an evaluation of the effectiveness of the course of action as well as future recommendations for improvements. Interwoven between each step is a feedback stage where research collaborators come together to discuss current developments and future directions (Susman & Evered, 1978). Therefore, action research is considered cyclical in nature and is heavily influenced by the feedback loop between researcher and collaborators.

Figure 1.The Action Research Model

3.2.3. Action research for this project

Action research was selected for this project to avoid the typical pitfalls of research concerning Deaf individuals. Historically, Deaf individuals have been positioned as the passive recipients or subjects of research at the hands of hearing academics; it is something done "to" or "on" them (Ladd, 2003, ch. 6). In this type of research production, Deaf individuals have limited ability to decide what or how research is carried out as well as how their participation (or data) is represented. As a result, even

though they are the core of the research, they have little control over any aspect of it.

Therefore, use of a transformative approach such as action research was meant to offer the participating women an opportunity to set the agenda as active contributors to the overall research project. Through the feedback loop, action research allowed the women to provide input into how their accounts were represented and subsequent treatment of the accounts. Action research also presents the women as experts in their own experiences as Deaf women and as equal participants throughout the process. Finally, action research was considered the best approach for demonstrating a commitment to the women and the Deaf community beyond the timeframe of this project.

3.3 Research methods

The qualitative research methods for this project were shaped by the action research approach. This section provides information about the research aims and the collaborative partner who was involved in every aspect of the research. It also describes the women who participated in this project, how they were recruited, and the ethical steps that were taken to preserve their confidentiality. Details are then provided about the research procedure that involved hosting an information session and facilitating two focus groups.

3.3.1. Research interests and aims

In qualitative research, the researcher is an instrument in the processes of data collection and interpretation (Temple & Young, 2004), and it is therefore important to make explicit my own motivations and experience in relation to this project. I am originally from Dallas, Texas, USA and am hearing. I became aware of sign language and Deaf culture when I started secondary school in 1998. The school I attended was experimenting with a new foreign language class that year, American Sign Language, and I signed up out of curiosity. I enjoyed that first class so much that I took it every year of my high school career and even had an internship as a teacher's assistant at a local intermediate school that housed a Deaf unit.

When I began university, I decided to build on the experience and secured another internship at a Deaf services agency called the Deaf Action Center. I worked there off-and-on over a two year period in a variety of roles, including counselling assistant. During my time in the counselling department, I was surprised by the sheer number of Deaf women who reported limited access to information or support, experiences of abusive or unhealthy relationships, difficulties interacting with their families or partners, and countless other daily obstacles. It was a powerful experience that cemented my interest in working with women, especially Deaf women.

My first job out of university was at a rape crisis centre, The Turning Point, located in Plano, Texas. I was employed as a community education coordinator, but also regularly met survivors who reported to a hospital after experiencing sexual violence. In both activities, I encountered Deaf girls and women who experienced sexual violence. Again, I was surprised by how little information or support they received as well as the amount of obstacles they faced.

The collective experience of working at the Deaf Action Center and The Turning Point fuelled my desire to explore the experiences of Deaf women in other communities. I was curious if Deaf women in other communities had similar or different experiences. I also wanted to explore what contributed to those experiences in order to generate ideas for potential improvements. These interests ultimately led to my relocation to New Zealand as a postgraduate student, connection with the Deaf community, and the development of the research aims for this project.

As described in the introduction chapter, there were two research aims for the research project. They are summarised in Figure 2 on the next page.

Figure 2. Two Research Aims

> **Research Aim 1**
> - Explore the sexuality accounts of a group of Deaf women in New Zealand in order to understand their sexuality-related knowledge and experiences.

> **Research Aim 2**
> - Generate recommendations for improving sexuality-related information and services available to the women.
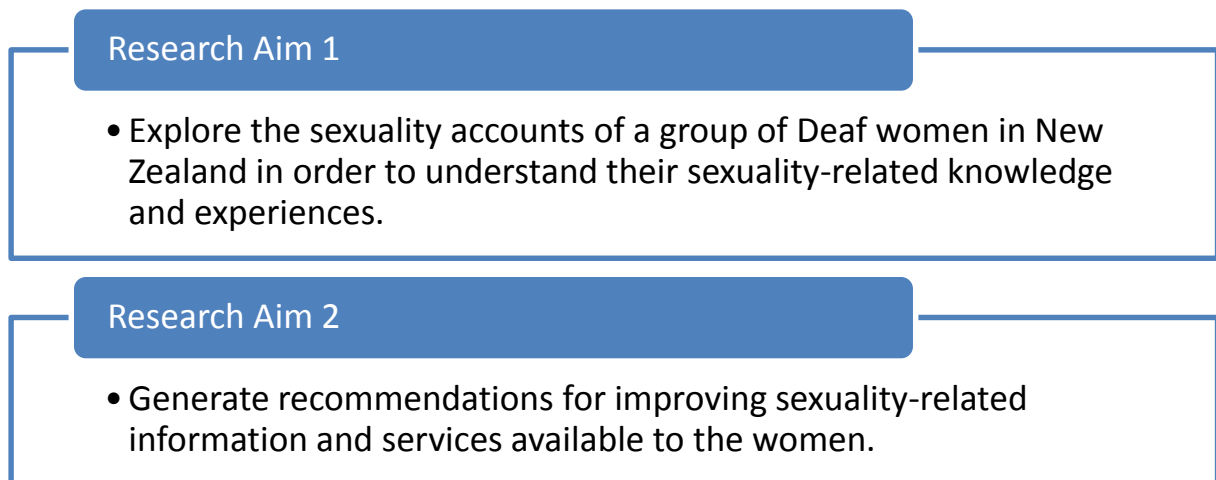
3.3.2. Collaborative research partner

The collaborative partner for this project was a branch of Deaf Aotearoa New Zealand (DANZ). In order to preserve the privacy of research participants in a small community, the location of the branch is not named in this thesis. DANZ is the national organisation for the Deaf and has been in operation since 1975 (Dugdale, 2001). With fourteen branches across both islands, DANZ provides employment consultancy services, community outreach for the hearing public, service coordination for Deaf clients, and a variety of community needs. The primary aim of DANZ is to provide a means for national level advocacy and service delivery, to "ensure that Deaf people have full access to the same services and information as all New Zealanders" (Dugdale, 2001, p. 269). At the national level, DANZ provided services to over 4,000 Deaf individuals a year. Clientele demographics for the branch involved in this project are as varied as the community itself, but the Services Coordinator for the branch stated that they provide services to an equal number of men and women, and the majority of clients are between the ages of 20 and 50.

The Services Coordinator for the DANZ branch involved in this project was the primary contact for this collaboration. She has been an enthusiastic supporter from the beginning and was instrumental with logistical arrangements. She also facilitated contact with the

CEO of DANZ, who offered encouragement for the research project. While she will be referred to throughout this thesis, the pseudonym Moana will be used to protect her identity as well as the anonymity of the women involved in this project.

Moana was vitally important to every aspect of this project. We began regularly meeting in May 2011 and conversations with her helped me to understand the New Zealand Deaf community and the type of research that would be appropriate. With her assistance, the decision was to focus on the sexuality theme in order to highlight areas of Deaf identity and experiences that may be inadequately supported through DANZ services. She also helped identify potential interview questions and focus group topics that would elicit the richest data. Based on the recommendation of Krueger & Casey (2000), Moana even served as a practice participant so I could test the clarity and effectiveness of the questions and topics. She was also responsible for the recruitment of several women who may not have otherwise participated.

3.3.3. Project participants

Seven women participated in the research project and were given pseudonyms to ensure their anonymity. The table on the next page (*Table 1*) provides a summary of their background information and relationship status. The table on the following page (*Table 2*) describes their employment and education background.

Table 1. Participant Information and Relationship Status

Name	Age	Ethnicity	Marital Status	Children
Jessica	47	NZ European/ Pākeha*	Married	Yes: 2
Leilani	32	Pacific Island	In a relationship, living together	No
Emily	32	NZ European/ Pākeha	Married	Yes: 1
Lara	27	NZ European/ Pākeha	In a relationship, living together	No
Amy	25	NZ European/ Pākeha	In a relationship, not living together	No
Sereana	23	Pacific Island	Single	No
Kyla	20	Southeast Asian	Single	No

*NZ European and Pākeha are alternate names for the same ethnicity.

Table 2. Participant Education and Employment Status

Name	Employment Status	Highest Education Level	Type of Schooling
Jessica	Homemaker, looking for work	Certificate Programme (finish)	1.5 years at a school for the Deaf, 2 years in a Deaf unit, 8.5 years in mainstreaming
Leilani	Looking for work	Secondary school	6 years in a Deaf unit, 2 years at a school for the Deaf, 4 years in mainstreaming
Emily	Employed full-time, but on maternity leave	University degree	12 years in mainstreaming
Lara	Student	Certificate Programme (some)	6 years in a Deaf unit, 6 years in mainstreaming
Amy	Employed full-time	Certificate Programme (finish)	3.5 years in a Deaf unit, 8.5 years mainstreaming
Sereana	Looking for work	Secondary school	12 years in mainstreaming
Kyla	Employed part-time, student	Certificate programme (some)	2 years at a school for the Deaf

All seven women had several features in common. First, they were pre-lingually deaf (i.e., had been deaf since birth or infancy) and utilised New Zealand Sign Language (NZSL) as their primary method of communication. Previous research has shown that Deaf individuals who primarily communicate through sign language may not have access to the same formal and informal channels of information, which may affect their sexuality experiences (Fitz-Gerald & Fitz-Gerald, 1998; Gannon, 1998; Heuttel & Rothstein, 2001). Therefore, this was considered important to highlight the potential

influence of language and English literacy on the women's information acquisition and sexuality development.

Second, the women self-identified as culturally Deaf, regularly socialised with other Deaf individuals, and participated in Deaf community events. Most of the women had intimate partners who self-identified as Deaf as well. Including only women who identified as Deaf was necessary to understand their socialisation experiences within the Deaf community, including what role Deaf culture may have played.

In addition, the women descended from hearing parents. This was significant because the majority of Deaf children are born to hearing parents who do not use sign language, which has been shown potentially to affect the development of Deaf children because of limited communication and information exchange (Powers *et al.*, 2000, ch. 4; Padden & Humphries, 2005, ch. 1; Ladd, 2003, ch. 5). I sought to explore whether these women might have had similar experiences in their hearing families and how that may have shaped their sexuality knowledge and experiences.

Finally, the women also identified as heterosexual. The choice was made to only include heterosexual women for two reasons. Primarily, it was to make sure all participants felt safe and comfortable enough to share their sexuality experiences. Previous research among gay members of Deaf communities in the United States has shown elevated levels of homophobia (Roberts, 2006) and anecdotal evidence from my Deaf cultural informants suggested that it may also be common in New Zealand Deaf communities as well. It was also thought that lesbian Deaf women may have varying experiences that could not adequately be addressed within the constraints of this project. Therefore, including only heterosexual women was an attempt to avoid confounding or misrepresenting the experiences of Deaf lesbians as a sexual minority within the Deaf community.

3.3.4. Participant recruitment

The women were recruited using multiple methods. First, the community relations officer at the DANZ branch involved in this project sent two email notifications about the research to the branch member database. These notifications contained a video

briefly describing the research in NZSL and also featured a text summary of this project. The community relations officer also posted the same information on the Facebook page for the DANZ branch. In addition to the emails and Facebook posts, flyers that advertised the study were posted both in the DANZ office and the local Deaf club. Care was taken to design the flyers for a Deaf audience, which meant minimal text and supporting NZSL imagery. A copy of the flyer may be found in Appendix A. These two methods resulted in eight replies from interested women.

Moana conducted face-to-face recruiting with women who received support services from her. She was chosen to assist with recruitment because of her role and established networks within the Deaf community. She was very helpful with recruitment because she was able to reach a broader range of Deaf women in terms of geographic location, socioeconomic status, and cultural background. The women she spoke with did not frequent the DANZ branch and typically had limited access to email or other resources. Therefore, her contacts ensured that a diverse range of women participated in the research. This method resulted in five replies from interested women.

Women who were interested in participating received follow up action in one of two ways. I sent emails to the eight women who responded to the email, Facebook, and flyer notifications. In those messages, I reviewed the overall aims of the study as well as the topics that would be discussed to ensure they were comfortable with this project. I also emphasised the voluntary nature of participation, their option to withdraw at any time, and that none would be under obligation to divulge any information they did not want to share. Of the eight who initially replied, six were comfortable with participating in this project.

Moana's face-to-face recruiting made it easy for her to follow up with the five women who were interested. She provided the same information to them that was contained in my emails to the other women. However, she did so in person during service appointments with them and helped to arrange for transportation and childcare for those who needed it. Again, she was instrumental in making sure every woman who wanted to participate could do so. All five of the women who originally expressed interest wanted to continue in this project.

3.3.5. Participant ethics and confidentiality

Given the complex and sensitive nature of the research project, great care was taken during the planning stage to ensure the comfort and confidentiality of the participants. For example, an ethics application for this project was submitted to the Victoria University Human Ethics Committee and approved in December 2011. A copy of the ethics application may be seen in Appendix B. In addition, considerable effort was spent making sure the project information sheets and confidentiality agreements were fully accessible for Deaf women.

When drafting the project information sheet, simple English was utilised to minimise difficulty when reading. The draft was then shared with a staff member of the Deaf Studies Research Unit at Victoria University of Wellington who helped convert the English text to NZSL-friendly format. Then, images of corresponding signs were placed next to the subject headers of the information sheet to help guide the reader. The same Deaf Studies Research Unit staff member helped ensure that images were placed in correct NZSL format. A copy of the information sheet may be seen in Appendix C. To further aid comprehension, the information sheet was also reviewed in person during the information session, which will be discussed more thoroughly in the next section.

Confidentiality agreements were also created to protect the anonymity of everyone who participated in this project. The agreements were written in simple English language and featured images of supporting signs. The same Deaf Studies Research Unit staff member helped ensure that both the English language and imagery were as close to NZSL sentence structure and format as possible. A copy of the confidentiality agreement may be seen in Appendix D. The confidentiality agreements were reviewed in person during the information sessions and the women were given an opportunity to ask questions and provide feedback on the content. They were reviewed again before the start of each focus group before participants were asked to sign. By the end of this project, all the project participants, both focus group facilitators, the professional interpreter, and I signed the agreements.

In order to provide on-going support to the women after the project was concluded, information packets with community resources were assembled for each participant.

The packets consisted of a folder that had three envelopes inside. Each envelope was labelled either physical health, sexual health, or relationship health. Images of corresponding signs were included under the labels. Each envelope contained a variety of health and safety pamphlets from agencies such as Breastscreen Aotearoa, Family Planning, the local rape crisis centre, Women's Refuge, Relationships Aotearoa, and Ministry of Health.

The packets also contained an Excel spread sheet that listed emergency services on one side and health services on the other side. The list featured the agency name, location, phone number, and contact person. In terms of accessibility, phone numbers can be challenging for Deaf people, so a contact person was included to help the Deaf women know exactly who to ask for when accessing the service in person. In order to find the contact person, I called each agency to explain the purpose of the resource and asked for a person who felt comfortable assisting the women if they wanted to access the service. I also made sure the contact person knew how to book a professional interpreter through I-Sign, the national booking agency for NZSL interpreters.

Another attempt at providing on-going support to the women included contacting a crisis counsellor. Personal experience with group facilitation had shown that discussing sensitive topics has the potential to elicit strong emotional reactions, especially if someone discloses personal experiences with violence or abuse. Personal experience has also shown that Deaf individuals value personal introductions and the ability to meet face-to face. Therefore, a crisis counsellor was asked to attend the end of the information session and focus groups in case anyone wanted follow up support. Unfortunately, the counsellor was unavailable when the dates for both were re-scheduled, so I offered to personally go with anyone who wanted to visit the counsellor at a later date.

3.3.6. Participant information session

The eleven women who were interested in participating were invited to an informal information session at the local Deaf club where they could get to know more about me and this project. The information was originally scheduled for the 19th of July, but was ultimately postponed until the 23rd of July 2012. In order to facilitate the attendance of

four women, Moana provided transport to the venue, and I agreed to take them home after the session concluded. As a result, ten women were able to attend the information session in addition to Moana, a professional NZSL interpreter, and myself.

To prepare for the information session, I contacted local businesses for food and beverage donations. The goal of providing refreshments was to create a casual, friendly atmosphere where sensitive topics could be discussed informally over shared food. A local wine store graciously donated two bottles of wine and a local bakery donated three boxes of gourmet pastries.

According to field notes from the information session, the information session started seventy minutes late because of delays such as extended socialising between the women. This is not uncommon with Deaf events because Deaf individuals may have long periods of time between seeing each other, which means there may be a significant amount of personal news to catch up on (Ladd, 2003, ch. 1; Padden & Humphries, 2005, ch. 7). In fact, one of the women suggested to me after the event that I should have told everybody to arrive by 3:30pm if I wanted to start at 4:00pm.

Once all were gathered, I introduced myself to the group in NZSL. There was no video or audio recording equipment so the women felt comfortable and relaxed. In my introduction, I shared personal details about my background and upbringing, including my involvement with the Deaf community in Texas. The purpose in sharing this information was to let the women know that I had experience addressing sensitive topics with women and working with Deaf individuals. It was an attempt to help them feel at ease and build trust.

After my personal introduction, I reverted to spoken English and asked the interpreter to take over for the more complicated information. Before we continued, the interpreter asked if it was okay to introduce herself to two participants she didn't recognise. She explained, "This feels like a very personal and intimate event and I would feel rude if I didn't introduce myself." Although it was clear that the interpreter was participating only in the role of an interpreter, her personal introduction was important to establish rapport with the group, and set the tone for a conversation among friends rather than a formal research meeting.

With the assistance of the interpreter, we reviewed the information sheet I prepared about this project. We slowly reviewed the entire sheet and I repeatedly stressed the importance of protecting their privacy and their trust. We stopped after every item to address questions and considerable time was spent breaking down abstract concepts, such as "research" and "confidentiality", which may have been difficult to understand.

After the information sheet, we reviewed the consent form, and the women, interpreter, and focus group facilitators all signed. The purpose in reviewing the document item by item was to make sure they completely understood every aspect of this project rather than assuming they could understand the printed English text. Ladd (2003, ch. 6) has noted ethical concerns when Deaf participants are asked to sign consent forms without this level of explanation provided in their preferred sign language.

Field notes from the event indicated that while originally nervous about how the information session would be received, I began to feel a great sense of rapport with the women as the evening continued and their excitement grew for this project. It felt like we were actively creating a women-only space for support, socialising, and learning from each other. Several of them expressed a longing for this type of activity. For instance, Jessica commented at the end of the session, "It's about time someone wanted to hear about us." Her remarks caught my attention and appeared to simultaneously be a positive expression of support for this project and a description of the invisibility Deaf women sometimes feel.

3.3.7. Procedure

The first procedural step in the action research process was the identification of a problem. This step was originally supposed to comprise two focus groups followed by four individual interviews, but a delay in carrying out the research project resulted in completion of only the two focus groups. Face-to-face data collection methods were chosen over written surveys because Deaf women struggle with understanding written English, especially when it deals with the "idioms, expressions, and innuendos surrounding sex and sexuality, as well as…abstract terms such as 'menstruation' or

'maturing'" (Job, 2004, p. 266). Focus groups also allowed for the practice of Deaf storytelling or narration, which is an important discourse style for Deaf people (Ladd, 2003, ch. 1). Therefore, qualitative methods were the linguistically and culturally appropriate methods for data collection.

The two focus groups were conducted to explore personal knowledge and experiences in relation to sexuality. Focus groups were chosen because they allow for an understanding of how participants spontaneously structure an issue, they assume that meaning-making is a shared activity, and they create an opportunity to learn the process through which meanings are constructed and negotiated between the participants (Temple & Young, 2004). An added benefit of focus groups was that they allow those who feel uncomfortable in one-on-one interviews to share their experiences.

The intended plan was to separate the focus groups by age, with an older group and a younger group, in order to highlight potential generational differences in sexuality knowledge and experiences among the women. However, the women seemed to naturally separate into two groups based on friendship and similar cultural background during the information session. Therefore, it was decided to split the focus groups according to those two features in order to facilitate discussion within the groups and also allow for comparisons between the groups based on potential cultural influences. Jessica, Amy, Emily, and Lara comprised the NZ European/Pākeha group, while Leilani, Kyla, and Sereana were in the Asian and Pacific group. The clustering of women into an Asian and Pacific group was not to indicate that all Asian and Pacific cultures are the same. It was due to the small sample size of this project.

The NZ European/Pākeha focus group was scheduled for 8 August 2012, while the Asian and Pacific focus group was scheduled for 17 August 2012. Both took place at the local Deaf club and each lasted for 2.5 hours. To prepare for each focus group, food was donated by the same local bakery in a continued attempt to help the women feel relaxed while participating. The chairs were arranged in a semi-circle so that everyone could clearly see one another and what they were signing. A whiteboard was placed at one end for writing the outline for the focus group as well as collecting their answers to the wrap-up questions at the end.

The focus groups were conducted in NZSL so the women could easily express themselves and communicate with each other. The same professional NZSL interpreter from the information session was present to interpret what the women said into spoken English. A video camera was used to capture the group discussions, while an audio recorder was used as a backup for what the interpreter said.

Each focus group was led by me and a Deaf woman from a similar background as the women. The rationale for having a Deaf co-facilitator was to help the women feel more comfortable discussing sensitive topics with someone from a similar background. Having a cultural insider present during data collection is also considered good practice when attempting action research as an outsider (Brydon-Miller *et al*., 2003).

Moana served as the co-facilitator for the women in the Asian and Pacific group. There was initial concern about potential complications caused by her job as a Services Coordinator for DANZ, but she had close relationships with the women and they all privately indicated they were comfortable with her guiding the group discussion. A Deaf woman who will be referred to by the pseudonym, Rebecca, was asked to co-facilitate the NZ European/Pākeha group because she was a similar age and background, and was also close friends with several of them. This turned out to be an asset because she was able to guide the discussion in much greater detail.

With the assistance of the interpreter, I began each focus group with an explanation of the outline for the focus group, a review of the consent form for the women participants, and a review of the confidentiality agreements for the interpreter and co-facilitator. There was an opportunity to ask questions before everyone was asked to sign their respective documents. We then reviewed the participant demographic sheets in NZSL and all participants were asked to complete a sheet. Finally, participants were allowed to select either a grocery voucher or a Warehouse voucher in return for their participation.

The focus groups then continued with a review of the entire contents of the information packet. I led this portion, with the assistance of the interpreter. After the information packets were reviewed, Moana and Rebecca took over as co-facilitators for their respective groups. While they facilitated, my role was supportive and meant to clarify

confusing statements, ask follow-up questions, and take detailed notes during the group discussions.

To encourage storytelling and the development of narratives, the co-facilitators conducted the remainder of the focus groups in a responsive, conversational style meant to blur the boundary between speakers and listeners (Fraser, 2004). Rather than relying on a rigid question-based structure, they engaged with the women in informal and friendly ways, did not restrict the women's comments, did not rush them, and allowed the women to translate their experiences into stories (Fraser, 2004).

To support the co-facilitators in their roles, I prepared a topic guide centred on two themes and each theme had several suggested questions the co-facilitators could pose to the group. A copy of the document may be seen in Appendix E. However, Moana and Rebecca had considerable flexibility in order to encourage narrative development. I also developed a facilitator tip sheet of group discussion goals and encouraging participant responses.

The focus group discussions closed with a quick round of wrap-up questions and heartfelt thanks for everyone who was involved. Field notes from the NZ European/Pākeha group show that no one wanted to leave when their group ended. In fact, several asked if they could keep going and Rebecca even suggested a regular women's chat. The day after each focus group, debriefing sheets were sent to the co-facilitators to get their feedback on the process. Rebecca returned hers, while Moana was unable to because of her workload after the focus group.

3.4 Analysis

Data from the focus groups was transcribed using two methods. First, I reviewed the video recordings and transcribed what the interpreter said. If the video did not adequately capture a word or sign, I checked the audio recording, which typically helped. As I am also conversant in NZSL and had the advantage of repeatedly playing the video in slow motion, I was able to detect occasional words or signs missed by the interpreter or recording devices. The process was very time-consuming because I was

attempting to transcribe spoken English which itself was a recorded interpretation of discussion originally in NZSL.

Ethical concerns have previously been raised about using interpreted information as direct quotes from Deaf research participants. The problem stems from potential misrepresentation of participants' "voice" because of the linguistic differences between spoken English and sign language as well as the constraints placed on interpreters who deliver on-the-spot interpretations for multiple people at once (Ladd, 2003, ch. 6). Therefore, a second step in the transcription process was to show the transcribed information to a second professional interpreter who was able to compare it with the video recordings and confirm the accuracy. This second interpreter also signed a confidentiality agreement. This was an attempt to reduce the chance of misrepresenting the women's accounts by getting as precise an English interpretation as possible.

Once the transcriptions were complete, constant comparative analysis was used to interpret the data. Constant comparative analysis was originally developed by Glaser and Strauss (1967) as a method for producing data-driven theories, or, grounded theories. It is an inductive approach that involves simultaneously coding the data and systematically analysing it through repeated review. Data is originally coded into as many categories as possible, then the categories are integrated through continual analysis, and a theory is ultimately delimited and developed (Glaser, 1965). Constant comparative analysis was considered an ideal fit as an analytical tool because of the exploratory nature of the research project and the action research methodology that guided it.

In line with the constant comparative analysis method, the first step in sorting through the data was to develop codes for the transcripts from both focus groups. The codes were not pre-determined. Instead, they were developed from an inductive approach based on certain themes, or categories, which emerged through repeated readings of the data (Corbin & Strauss, 1990). Codes were assigned to sentences, or entire paragraphs, that aligned with any of the categories and written on hard copies of the transcripts. New codes were added as new categories emerged. See Table 3 on the next page for a list of codes that were used.

Table 3. Coding Categories Used in Analysis

Code	Definition	Abbreviation
Positive sexual experiences	Any reference or indication the participant reported a positive experience during previous or current sexual activities	PSE
Negative sexual experiences	Any reference the participant reported a potentially negative experience during previous or current sexual activities	NSE
Positive relationship experiences	Any reference the participant reported a positive experience during previous or current intimate relationships	PRE
Negative relationship experiences	Any reference the participant reported a potentially negative experience during previous or current intimate relationships	NRE
Positive experiences in development	Any reference the participant reported a positive experience during previous or current intimate relationships	PED
Negative experiences in development	Any reference the participant reported a potentially negative experience during previous or current intimate relationships	NED
Influence of English literacy	Any reference the experience or knowledge of the participant was potentially influenced by her English literacy skills	IEL
Influence of cultural background	Any reference the experience or knowledge of the participant was potentially influenced by her family's cultural background	ICB
Information from peers	Any reference or indication the participant learned about any aspect of sexuality from her peers	IP
Information from family	Any reference or indication the participant learned about any aspect of sexuality from her family	IF
Information from media sources	Any reference or indication the participant learned about any aspect of sexuality from media or other sources	IM

Once all the relevant pieces of data were coded into categories, Word documents were created for each of the categories. There were separate Word documents for each focus group so that comparisons of categories could easily be made between and within the groups. For example, two Word documents were created for the "PSE" code: "Focus Group 1 (PSE)" and "Focus Group 2 (PSE)." Excerpts from the transcripts or field notes that related to each category were then placed in the corresponding Word document. In addition to the excerpt, the line from the original transcript, and the attributed participant were also included. This facilitated comparison of the excerpt with the overall transcript to understand other contextual details that may have been important.

To ensure accurate analysis of the data, the transcripts were systematically re-read and repeated coding was done until no new information emerged from the data. Coded excerpts were compared with other similar excerpts within the same group as well as with the other focus group to confirm coding consistency and accuracy (Corbin & Strauss, 1990).

When the coding process was complete, categories were clustered into four themes based on the focus group question guide and research aims of this project. The four themes were: The women's experiences with intimate relationships, their sexual experiences, how they learned about sexuality, and their recommendations for sexuality information or services for Deaf people.

Clustering the categories involved electronically merging the Word documents for all the categories related to a particular theme. All four newly combined Word documents for each theme still separated the focus groups so that comparisons could easily be made within a particular theme. The contents of the four themes were then reviewed again and compared with the complete transcripts to ensure all pertinent data was included. The key findings for each theme are presented in the remaining chapters.

3.5 Feedback loop

After the data was analysed, I met with Moana to review some of the initial findings and discuss potential courses of action that could be achieved in the second step of the action research cycle.

In our conversation, we identified several potential ways to translate research outcomes into tangible benefits for the community. Her suggestions included convening a one-off women's camp for all women in the region, a women's support group that met throughout the year, and a summary document that could be used to petition the government for increased funding for education or support services.

As a result of time limitations and conflicting schedules, I did not have an opportunity to organise a similar meeting with the women who participated. However, a meeting has been scheduled after the thesis is completed to share the results, get their feedback, and also get their opinion on potential courses of action. Two sets of workshops have already been piloted since completion of the thesis, involving two different communities of women. Details about this are provided in the recommendations chapter.

3.6 Conclusion

In this chapter, details of the research design for this project were reviewed, beginning with the action research model that served as an over-arching methodological framework. All aspects of the research methods were subsequently described, including the collaborative research partner, participants, and procedure. The analysis techniques and the feedback loop used with this project completed this chapter. This information was meant to highlight the framework and process that guided this research so that it may be possible to understand how the women's reports were gathered and interpreted The following chapter represents the first of three findings chapters that have developed from the analysis and interpretation process. It provides a review of the women's experiences with sexuality-related knowledge and socialisation, which will shape their experiences described in subsequent chapters.

Chapter 4: Developing an Understanding of Sexuality Concepts

4.1 Introduction

The purpose of this chapter is to provide analysis on how the women understood sexuality concepts. This is achieved by presenting the data on development and socialisation experiences the women shared. They were given relative freedom to choose how they wanted to introduce topics listed in the focus group guide. This chapter begins with an analysis of discussion of discussion on the first sexuality-related developmental experience the women chose to discuss, puberty. The women's accounts of their conversations with family are then provided to illustrate sexuality socialisation experiences within the home. This is followed by a description of the importance of magazines, as a form of sexual socialisation for the Deaf women with advanced English literacy.

The women's sexuality and socialisation experiences within school are discussed next to highlight both the formal and informal types of information that were available to them. It is shown how these experiences play a significant role in sexuality-related knowledge for both adolescents and adults. The chapter closes with analysis of discussions from a review of a Ministry of Health pamphlet, carried out by the women in the focus groups. The women found the pamphlet to be inadequate in conveying sexual health information appropriately for Deaf, and the exercise showed differences in sexual health knowledge between the two groups because of literacy levels.

To clarify the concepts discussed in this chapter, the term "intimate relationships" is used to explain how the women came to understand close, loving, intimate relationships with partners (Jamieson, 1991, ch. 1). "Sex" refers to all forms of sexual behaviour and sexual contact, from kissing and fondling to sexual intercourse (Jackson, 2005). In addition, "sexual health" includes health topics related to sexual activities or reproductive organs, such as cervical smears, contraception, and AIDS. While the

women did not explicitly share their definitions of these concepts, their understanding was implied through their accounts.

4.2 The influence of language proficiency

A noteworthy point from the women's discussions was the critical role of language proficiency in shaping their experiences. As previously mentioned, a social constructionist perspective views sexuality as a cultural construct that only has meaning because of the discourse surrounding it (DeLamater & Hyde, 1998; Jackson & Weeks, 2005; Fine, 1988). Therefore, language is necessary to understand and make sense of all the nuanced complexities associated with sexuality. Through the discussions, it became evident the women may have experienced challenges with this process.

The initial difficulty may be attributed to the fact that Deaf children of hearing parents typically do not acquire a first language until they reach school (Fitz-Gerald & Fitz-Gerald, 1978; Marschark & Spencer, 2010, ch. 4; Ladd, 2003, ch. 3). However, additional difficulties occur with sign language itself, as it often does not feature a conventional sexuality vocabulary, nor does it contain many signs for sexuality terminology or concepts (Fitz-Gerald & Fitz-Gerald, 1998).

This is especially true for New Zealand, which has a young, still-developing sign language that varies widely because of geographic and cultural influences. In fact, no direct translation of the word "sexuality" exists in New Zealand Sign Language (NZSL). Instead, Deaf individuals often sign "sex" to indicate "sexuality", even though they are theoretically different concepts. In the group discussions, the women debated signs for "puberty", menstrual "period," "oral sex", "groping," and "AIDS". All of these are profoundly important concepts to sexuality, and all are associated with a myriad of information, values, and behaviours. Tin the sections that follow, I show how the limited vocabulary available to the women influenced both how the women understood sexuality concepts as well as how they described them.

4.3 "Mum I'm bleeding": Experiences with menarche

Some of the first sexuality-related conversations the women reported involved the topic of puberty. Menstruation was a particularly salient topic when discussing puberty, suggesting its pivotal role in the lives of the women. After all, menstruation has been identified as a crucial juncture between childhood and adult womanhood, a time representing growth and fertility as well as the beginning of a woman's sexual and reproductive life (Lee & Sasser-Cohen, 1996). The beginning of menstruation, or menarche, may also be a vivid and powerful experience for women, helping to shape their identities and becoming crystallised in their memories (Uskul, 2004). Individual experiences with menarche and menstruation vary according to a variety of personal and socio-cultural factors. The women's accounts described in the next two sections offer insight into how those variations may occur.

4.3.1. Women in the NZ European/Pākeha group

The women in the NZ European/Pākeha group willingly shared at length their pubescent experiences. Their obvious ease in dealing with this topic may reflect an understanding in Western cultures that sexuality is a socially acceptable topic to discuss in public (Lee, 1990; Meneses *et al*., 2006; Uskul, 2004). Consequently, they may have felt less inhibited while engaging in such conversations, since all four of these women described their experiences with menarche in considerable detail, remembering times, locations, and accompanying emotions.

Jessica and Amy reported relatively positive experiences with menarche. When Jessica achieved menarche, she calmly thought to herself at the time, "'It's ok, this is what mum's gone through. I'm growing up a little bit more. It's ok.'" In addition to feeling confident, Amy also felt excited when her first period came:

> I bent down, and stood straight up, and went into the toilet. Like, I knew
> what to do. I changed my pants and wore black after that and said,
> "Mum, I'm bleeding." Mum's like, "What do you mean you're
> bleeding?" And I said, "Ummm…". "Oh, you've got your period. Yay!"
> We both jumped up and down. She told my grandma, my auntie. It was
> humiliating, but I was so excited.

The experiences of these two women may be related to their prior information about what to expect. Chrisler & Zittel (1998) found this can decrease negative experiences with menarche, including some of the social stigma and shame that can occasionally accompany the event. Evidence for this was seen when Emily and Lara both remembered being very confused about menstruation initially, but expressed relief after acquiring more information.

When Emily's primary school friends attempted to educate her about pads and periods, she was hesitant to trust them, and asked her mum for more information. According to Emily, "I didn't believe them. It was like they were making this story up! Like I had no idea that people could have this experience." However, Emily's mother provided information and she reported finally understanding the process. Lara was similarly confused until she talked with her mother when she got her first period. As she recalled:

> I was upstairs, in the toilet, and I saw blood and I just screamed. I said, "Mum!!" Mum came up the stairs and she was like, "What?" And she went, "Oh! Oh!," and she pointed. And I went, "What?! What's that face for? What?!" And she went, "Uh.." And she went downstairs, took a few minutes, and I was waiting, and she came back, and she goes, "You've got your period." And I said, "What's that?!" You know, I didn't know what to do. Mum helped me and she gave me a book and I read it.

Lara's age at menarche, 9 years old, may have been partially responsible for her confusion. Lara's mother, whose response was to provide a book specifically about menstruation, might have intended to provide that information at a later date. It is interesting to note that three of the women in the group reported immediately going to their mothers for information or support. This experience of seeking assistance from a maternal caregiver appears to be the typical reaction for adolescent girls who achieve menarche in Western cultures and countries (Chrisler & Zittel, 1998). It also supports the importance of the mother-daughter relationship in the sexuality socialisation process (Fox, 1980).

4.3.2. Women in the Asian and Pacific group

The women in the Asian and Pacific group did not share many details about how or where they learned about menstruation, nor did they offer accounts about their menarche. Sereana was the only one who offered some insight into her experiences. As she explained, she did not have many in-depth conversations with her family about the topic:

> Sereana: I would [talk] with my mother. We didn't go into a lot of detail about…periods…a little bit of information. And a little bit of information about breast growing.
>
> Sunshine: But just a little?
>
> Sereana: No details. Yeah.

The limited information Sereana received resulted in serious confusion about menstruation and puberty that was not clarified until she achieved menarche at 12 or 13 years of age. When she did eventually get her period, Sereana recalled:

> [My mum] was like, 'It's your period,' and she gave me a pad. I was like, 'Okay.' Then, as I went along, I found out from school what this was all about.

Sereana's experiences may ring true of other sexuality socialisation experiences in Asian and Pacific cultures. Research with Asian American parent-child communication has indicated the children may receive very limited sexuality information, often paired with restrictive sexual messages (Kim & Ward, 2007; Meneses *et al*., 2006). Tupuola (2000) also noted that young Samoan women are socialised to honour the family and refrain from open discussion of sexuality topics. Therefore, her family's attitudes may have further restricted communication already limited because of the communication barrier that can exist between hearing parents and Deaf children (Job, 2004; Joseph *et al.,* 1995).

4.4 Family and sexual socialisation experiences

As mentioned in the literature review, parents have been identified as primary sources for sexuality information and socialisation (Maccoby, 1992; DeLamater & Hyde, 1998).

However, in keeping with other research into Deaf sexuality socialisation within the family (Job, 2004; Gannon, 1998; Roberts, 2006), several of the women's reports indicate that may not have happened for them. For instance, only one of the women reported turning to her father for information, which supports the notion that daughters prefer sexuality socialisation from their mothers (Fox, 1980). However, the amount of information they received from their mothers varied as a result of topic and the family's cultural background. The next two sections describe the variations reported by the women in the NZ European/Pākeha group and then the Asian and Pacific group.

4.4.1. Women in the NZ European/Pākeha group

Of the women in the NZ European/Pākeha group, Emily was the only woman who reported feeling sufficiently close to her family to ask them about a comprehensive range of sexuality-related information. As she explained:

> Family would give me information about sex, like keeping myself safe,
> um, if there was a problem with periods and cramping, or even
> relationships.

When asked why she turned to them for information, she said, "I felt quite vulnerable, um, and was more trusting of my family." Her experiences appear to differ from some of the other women's, but Emily has a particularly tight-knit family who communicate with her through NZSL. This appears to have provided her with a much higher level of support and access to information than the other women experienced.

Lara reported she did not feel able to discuss intimate relationships with her mum, but she did state: "I read [a book about sex] and I asked a lot of questions of my mum." Therefore, she may have had access to some clarifying information, but her experiences reported in later chapters indicate it may not have been in-depth.

Amy explained that she received minimal early information about "growing boobs, but [she] didn't ask [her] mum lots of questions." She also rejected the idea of turning to her mother for information about sex:

> I would *never* ask about that. I didn't ask my mum about sexual topics
> or anything to do with sex.

In addition, she indicated that intimate topics were challenging to broach as well:

> Not family, no way. I didn't feel inspired to talk to them about
> relationships in any detail. No. No way.

Jessica reported similar limited communication with her mother, which she attributed to her own description of her mother as "very conservative." In fact, Jessica's mother waited until Jessica's wedding, when Jessica was in her twenties, to offer information, which was not only late, but also incomplete:

> One or two nights before I got married, my mum told me about sex.
>
> …
>
> And I thought, "Mum, not now," but I didn't say anything, I just kept ironing. I was ironing at the time. I was like nodding and smiling at her and she just kept yapping at me and I felt really un-empowered to say, "Wait, I'm not ready" or "I already know about this stuff". I felt like I had no power.
>
> …
>
> Rebecca: So your mother, what did she say? Did she talk about safe sex or how to do it?
>
> Jessica: She explained, um, what it is like when a man has an erection. He can't walk properly. That's what she said.
>
> Rebecca: That's all she said?!
>
> Jessica: It was a *very* brief bit of information.

The women in the NZ European/Pākeha group attributed the limited information they received from their parents to a need for self-sufficiency. Jessica and Amy self-identified as "quite independent" and their independent streak often resulted in proactive investigation. Similarly, Lara recalled, "I just did things on my own. I just experimented." Emily also reported, "I would look into it myself."

It is interesting that these women mentioned a yearning for independence. As previously indicated, independence is often important to Deaf individuals because it has historically been denied to them as a result of the pervasive and persistent view that they are defective and dependent (Leigh, 2009; Ladd, 2003, ch. 3). These women may have

potentially experienced this within their family, perhaps even more intensely because of their status as Deaf women (Fine & Asch, 1985; Merkin & Smith, 1995).

However the ability to communicate within the family may have also been an influential factor. Since Emily was the only one who reported that her family used NZSL, family members of the other women may have relied on oral or written communication. This may have presented challenges acquiring formal and informal information from them. As Jessica noted:

> I think Deaf people can't really learn a whole lot from their [hearing] parents, from incidental information, by hearing it, about how their parents communicate. Because you can't hear it and how do they talk, what do they say to each other. We don't hear that.

4.4.2. Women in the Asian and Pacific group

In general, the women in the Asian and Pacific group noted their parents were strict and rarely shared sexuality-related information. For example, Leilani recalled a brief conversation with her mother:

> My mum and dad were very strict. You know, there were rules and they said, "You need to go to school. You're not to have sex."

Sereana stated she even felt uncomfortable asking her parents sexual health questions because they would think she was trying to have sex. As she explained:

> I felt embarrassed [asking] my family, uncomfortable…Like, I might look at something, you know the [cervical] smears, the smears that they do…I would never ask-if I showed a smear pamphlet to my folks, like what [Sunshine has] given me today, they would question me about it. They'd say, "What do you want to know about that for?"

Two of the women also recalled being given specific warnings, obviously meant to prohibit sexual activities. Leilani stated:

> My mum said, "Don't have sex. Don't get pregnant or you'll be in big trouble and you'll need to stay home. If you get pregnant, you'll need to stay home". So, I thought, "Okay, I don't want to do that."

Potentially as a result of similar conversations, Leilani noted that she often stayed at home, "I'd be with my family and then I'd be at school." Kyla also reported her parents expressed concern for her behaviour, but included description of possible punishments for sexual exploration:

> My mum and dad said, "If you have sex and get pregnant or something, you'll get in serious trouble and get kicked out of home. And you'll have to go with the boy and you won't be able to come here and visit us anymore.

The views expressed by the women's families may be a commonly held among some Asian cultures or Pacific cultures that are guided by strict Christian theology (Tupola, 2000; Kim & Ward, 2007; Kim, 2009). However, the women's Deaf status may have exacerbated those beliefs and practices. All three referenced the intertwined relationship created as Deaf women from culturally diverse backgrounds. For instance, Kyla noted:

> Being Deaf, I felt different to hearing people. [My parents] just said, 'You'll get in trouble, serious trouble.' I had to obey them…It was hard because I was the only one that was Deaf in the family. They were worried about me.

Leilani provided further elaboration about the potential difficulties navigating between Deaf and Pacific cultures:

> It's different for me because I feel like I'm Deaf and [of Pacific Island heritage]. Like I wanted to do my own thing, but [my parents] were really tough, they were different. So I couldn't do what I wanted to do, I had to follow my family's rules, you know? It was like me or my family. You know, I wanted to go off and be with a Deaf person and sign.

Sereana described a similar situation related to her socialisations experiences within the family:

> I was the only [Deaf child] and my parents were very protective of me. They wanted me to be at home. They didn't want me to go out. They

were worried about me being raped, so they wanted me to stay home a
lot.

Therefore, if the literature is correct, it may be that the parents' attitudes were rooted in religiously influenced cultural beliefs about appropriate behaviour for children, especially girls. The data indicates that this is magnified by parents' perceptions of Deaf as a debilitation. If they subscribed to the medical model of Deaf as incapable and dysfunctional (Leigh, 2009), they may have felt an even greater need to protect their Deaf daughter through the restriction of information and behaviour.

4.5 Other sexuality socialisation experiences

The women in the NZ European/Pākeha group also reported finding sexuality-related information in literary sources. Amy and Emily expressed a preference for the teen magazines, *Dolly* and *Girlfriend*. Emily mentioned it was because "they always have visual information, which helps." In addition to plenty of imagery, magazine articles also tend to be shorter and written in catchy, everyday language that may have been easier for the women to understand.

Moving beyond the stylistic elements of magazines, Amy commented that "there is confidence in magazines because no one knows you're reading it and you can hide it very easily." This is interesting because she also reported she felt confident in talking about sex and sexuality in other conversations, but she still makes it clear that hiding sexuality is a "normal" course of action.

Teen magazines have been shown to encourage sexuality as an expression of independence and womanhood, something that may been highly attractive to adolescent Deaf girls (Jackson, 2005). Jackson also noted that the appeal may also consist in their ability to provide insight into "doing" sexuality, such as how to engage in certain sexual behaviours or what exactly constitutes femininity and heterosexuality. Emily's recollections suggest this was true in her experience:

> [School taught] how babies are made, but not *how* to do it, like sex.
> Mostly it was stuff from magazines that I learned about sex.

Books were another option preferred by Lara, who read a book about how babies are made, and Jessica, who read *The Clan of the Cave Bear*. Jessica's book was slightly unconventional, as that book was a novel, rather than a sexual education book, but according to her, "[I was] quite inspired by those books. So, that's how I learned about sex."

It is important to note that these women appeared to possess a higher level of literacy than the average Deaf person (Davis, 2007). So, while they were able to obtain information from magazines and books, these sources may be inaccessible to other Deaf women, including several involved in this project who reported struggling with English literacy.

4.6 Sexuality socialisation and education in school

When it came to their experiences with learning about sexuality within school settings, the women's reports varied. However, their experiences may allude to continued difficulties with access to interpreters and appropriate materials that have been identified in previous studies with Deaf students (Fitz-Gerald, 1998; McKee, 2008). In addition, the few formal sexuality education topics they mention indicate that a risk minimisation discourse remains influential in New Zealand schools (Allen, 2007; King, 2011). The next three sections describe their experiences with formal sexuality education and informal sexuality socialisation through peers or teachers.

4.6.1. Formal sexuality education experiences

Amy and Emily were the only ones to report positive experiences in relation to the formal sexuality education they received in school. In fact, Amy proclaimed:

> I learned a lot of [information] from health class, actually. They used
> visual things to talk about STI's. They showed us real pictures…which
> had a huge impact.

Emily also felt she learned a lot about the reproductive system and found that very beneficial. Their positive experiences may be a reflection of the calibre of teaching, interpreting, or materials available at their respective schools. It may also be an

indication of their English literacy levels, which may have pre-disposed them to engage with the material in a more meaningful way.

However, the topics they mentioned indicate that they were primarily exposed to basic sex education that is focused on preventing sexually transmitted infections or pregnancies rather than recognising the sexual agency of students and supporting their empowered sexuality development (Jackson & Weatherall, 2010; Allen, 2004a).

Leilani and Sereana did not comment on the type of information they received from school, implying this source did not have a significant impact, or was not memorable.

The remaining three women indicated negative experiences while learning about sexuality in school. For instance, Jessica struggled with simply understanding her teacher during a one-off sex education class:

> Jessica: I remember one time, the guy was writing on the board and he
> put an "X", which meant one kiss. Next to it, he put a bunch of lines
> diverging from each other. Then he put heaps and heaps of crosses. And
> he kept putting all these crosses and then he went, "Bang!," at the end
> of these diverging lines. And I thought, "Ok, I get the message that
> kissing's no good." But I didn't know what it meant or what he was
> talking about. There was no interpreter, no microphones…and I
> thought, "Right, kisses are bad."
> Rebecca: So you were looking at them and got the message that kissing
> was bad?
> Jessica: Well, it could lead to trouble. That was the message that I got.
> Kisses lead you to trouble or lead you down the wrong path.

Given her age, Jessica's experiences initially may not be considered that unusual for Deaf youth in New Zealand. At the time of her schooling, sign language was still banned in school and access to interpreters or educational support staff was also unavailable (Dugdale, 2002; Powell & Hyde, 2013).

However, a more recent negative experience with sexual education reported by Lara may indicate that little has changed about the accessibility of sexuality education in schools:

> I feel like I've missed out on a lot of information. I feel like my education wasn't that great. Sex, puberty, relationships…from my experience, being mainstreamed most of my life, I feel like I've missed out on all of that kind of information. I wasn't even educated properly.

In addition, accounts shared by Kyla highlight the importance of having sexuality education materials that are both Deaf-friendly and culturally appropriate:

> I learned about sexual health stuff [in school], but I didn't really understand all of it because I didn't really use the same [English] language fluently …. They talked about sex at school, and I was embarrassed about that. I was sort of looking around the classroom, and they were so openly talking about things, a group of girls and a group of boys, and I just wanted to go run away and hide. But, after a while, I got used to them talking about it and I thought, "It's okay. Be calm." But, it was a little bit- I thought, "What is this white way of doing things?" I'm from [the Pacific region]. That's a private conversation! And so it was really hard for me to take that open discussion about it.

Despit the women all reporting different experiences with sexuality education in schools, I found the majority of them either had nothing to say about the quality of education they received or reported negative experiences. These women all attended New Zealand schools and were supposed to have been exposed to sexuality education material, depending on their age. Yet, they left school with very limited understanding of key sexuality concepts. For example, at one point in the discussion, Kyla had a side conversation with Sereana in which she asked several questions about female anatomy, including, "Why do you bleed when you break your virginity?"

4.6.2. Informal sexuality socialisation experiences

When it came to other sexual socialisation sources, most of the women did not feel comfortable about connecting with friends about sexuality-related topics. This was

surprising given the literature previously mentioned that identified peers as important sexuality socialisation sources among adolescents (Tresboux & Busch-Rossnagel, 1990), especially among Deaf teenagers (Gannon, 1998; Gabriel & Getch, 2001; Heuttel & Rothstein, 2001; Job, 2004).

However, only two of the women recalled discussions with their friends about the subject, and then only in limited detail. Amy explained:

> A lot of my friends were a bit older than me, so I could ask them questions… but there wasn't any one particular person that I trusted a whole lot.

Similarly, Sereana remembered, "My friends had already done these things and had sex… [so] I'd always ask them questions." Although, when asked specifics, she stated it was usually for definitions of words in magazines or books, such as "what a virgin was, sex, [or] what gay meant." Therefore, even though these women described conversations with friends, they may have mirrored the brief, cursory type of Deaf - hearing informational exchanges often documented in the literature (Gabriel & Getch, 2001; Roberts, 2006).

The women's inability to discuss sexuality information with friends may be partially a result of being mainstreamed for large portions of their education. These settings have been shown to result in smaller networks of friends and also more limited communication with them (McKee & Smith, 2003; Dugdale, 2002; Nunes & Moreno, 1997). Lara provided support for this possibility:

> Friends? We didn't talk in any detail…They were all hearing and I was the only Deaf person and I sort of felt like the outsider…I just kept it all to myself and experimented on my own.

In addition, Jessica recalled, "I didn't have anyone to ask or any Deaf friends in that [mainstream] environment." When asked how that felt, she simply replied, "lonely." The effects of mainstreaming have yet to be empirically explored in New Zealand (McKee, 2008), but the women's experiences of missing valuable sexuality socialisation opportunities suggests that the mainstream model may require some improvement to foster better social networks for the students.

4.6.3. Potential teacher sexuality socialisation

The women in the Asian and Pacific group claimed they only really felt comfortable discussing the topic with a teacher. Trust was reported as an underlying reason for going to the teachers. For instance, Sereana stated, "I didn't really trust anyone to talk to…I only trusted the teacher, really." Similarly, Kyla noted:

> I would trust the teacher to talk to him and ask about sex…I didn't rely on my friends. It was the teacher I trusted more. And I didn't really trust my parents much.

The trust could stem from the teachers serving as authority figures responsible for sharing information with the students. Therefore, consulting the teacher one-on-one may have been a way for the women to gain information in private, which may have been more culturally-appropriate and comfortable than open discussion of sexuality (Okazaki, 2002 ; Kim, 2009; Tupuola, 2000).

4.7 Ministry of Health pamphlet review

Towards the end of the discussion, the women were asked to review a Ministry of Health pamphlet. The aim of the activity was to understand how their English literacy levels may have affected their sexuality-related socialisation experiences and knowledge. The pamphlet reviewed was entitled, "Preventing HIV infection" (Ministry of Health, 2005). It was selected because it was geared towards a younger audience, contained less medical jargon, and slightly more images, which was I felt would be easier for the women to digest. It was also selected because HIV / AIDS is one of the most researched and discussed topics in Deaf sexuality, enabling comparisons of the women's experiences with other research that has been carried out (Swartz, 1993; Fitz-Gerald & Fitz-Gerald, 1998; Woodroffe *et al.*, 1998).

The next two sections describe their reactions and experiences during the review of the material, their suggestions for improvement, and the potential implications of their experiences.

4.7.1. The review exercise

The women were given three minutes to review the pamphlet and identify any sentences, sections, or ideas they understood. Of the women, Emily, Amy, and Jessica were able to describe portions of the pamphlet. Interestingly, Emily was the only one who went into great detail and seemed to enjoy the process. As she explained, "I like a lot of information to look at. Um, the more the better." However, Emily can read and write at an exceptionally advanced level, which may explain why she found the task relatively easy.

Amy and Jessica noted they could understand most of the pamphlet, but they felt strongly that others would experience more difficulty and consequently spent most of their time identifying problem areas. For instance, Amy found the language particularly cumbersome for Deaf readers:

> If I translated it or was thinking of another Deaf person who didn't have as good English as me, they wouldn't understand what "menstrual blood" would mean…and then it talks about "vaginal secretion," and they may not know what that means, and "moisture"…and "arousal"…and "breast milk" and "semen."

Amy's observations are concerning for several reasons. First, Amy lives and works in the Deaf community, has daily interactions with a wide range of Deaf individuals, and would consequently have good insight into the abilities of a range of some Deaf New Zealanders. Also noteworthy is that Amy identified almost every single major word in the section she reviewed. As that section contained some of the most important concepts related to HIV transmission among women, it is particularly worrisome that she considered it incomprehensible for others.

However, the most concerning aspect about Amy's prediction was that it played out during the focus group. The four remaining women all found the pamphlet extremely challenging and could not get through it. The following excerpts illustrate some of their experiences with it:

> Sunshine: Um, were there other things that you understood in the pamphlet? Anything else? You can just point to it.

…

<Sereana spends an additional seventeen seconds reviewing the pamphlet>

Sereana: Um, only, like I understood this bit and this bit and this bit

<Points to topic headlines, such as "HIV and AIDS" and "Women and Pregnancy">, but then none of the detail.

Sunshine: So you understood the titles in red?

Sereana: Yeah.

Sunshine: But not the description?

Sereana: Yes, exactly.

While Sereana was able to identify key phrases and the flow of the pamphlet, the other women struggled more. For instance, Leilani summarised her experience with the exercise by stating, "I don't understand it, reading this without any images." Similarly, Kyla was only able to pinpoint single words without being able to connect them to each other or the overall topic of the pamphlet:

Sunshine: Is there anything that you understood? Any words? Ideas? Sentences?

Kyla: No. Well, a little bit, some stuff.

Sunshine: Oh, give me an example of a little bit.

<Kyla looks over pamphlet>

Kyla: Skin piercings?

Sunshine: Oh, skin piercings? So what about skin piercings?

Kyla: Ear piercings, nose piercings, belly button piercings, but that's it.

…..

Sunshine: So you get that it's about skin piercings, nose piercings, but does it kind of make sense? Does it connect to anything else? Or does it seem like it explains how it somehow relates to HIV?

Kyla: No. I don't know.

Only single words or phrases found in the titles of each information section were decipherable for these four women. The information was not presented in ways that enables the women to gain enough information to elaborate on anything related to protection, transmission, or detection of HIV. Additionally, they spent more time

explaining what they could not understand rather than what they could. For instance, Leilani had trouble with some of the "hard words in there, like 'transfusion.' I don't know what that is."

Even if they were able to somewhat work through parts of the material, it was a much more repetitive, drawn out process, as Lara explained:

> Um, for me, I'm not a big reader, so I find it easier not to read things a whole lot. Like I prefer pictures, um, images, graphs, or graphics that link to the words, um, so that I can understand. But for this, for me, I would read it at night if I was in bed, where I've got a longer period of time, so that I could read it over and over and over again to understand it.

Pamphlets are designed to be concise, easy to read pieces of information that can be easily distributed and absorbed by a wide audience. The fact that Lara wanted to use the pamphlet as night-time reading in order to revisit the material multiple times highlights the intense concentration required for her to obtain the information. However, while she may have eventually been able to understand the material, the other three women were much less likely to, given their extreme difficulty with the pamphlet format. In fact, all the women, including those who fared slightly better at reading the pamphlet, felt the presentation of this material was not Deaf-friendly.

4.7.2. "What's HIV?"

The result of this exercise is cause for concern because several of the women could not understand the information contained within the pamphlet. The women who could understand the material still identified numerous ways the content and formatting were inappropriate for most Deaf people. Given the topic and aim of the pamphlet, its inaccessibility signals a problem, especially considering the socially-induced increased vulnerability that Deaf people may experience because of limited knowledge (Luckner & Gonzales, 1993; Swartz, 1993; Bat-Chava *et al.*, 2005; Woodroffe *et al.*, 1998). Evidence of this limited knowledge emerged when Kyla was originally handed the pamphlet and asked, "What is HIV?" This prompted a brief discussion about the relationship between HIV and AIDS. After the explanation, Sereana posed a follow up

question: "HIV, is it blood or gay people as well?" Another informational discussion followed and at the end, Sereana remarked:

> Breast milk? Really? Ah. I really thought it was just those things, blood and gay people.

The surprise of both women as they learned about HIV transmission suggests a number of knowledge gaps about HIV/AIDS. It also demonstrates that even after three decades of HIV/AIDS prevention education and services in New Zealand, information is still not reaching the Deaf community. Even more troubling is the evident lack of awareness around the need for this type of programming, as evidenced by the Ministry of Health pamphlet and the New Zealand AIDS Foundation prevention plan that only focuses on men and New Zealand-based African communities (New Zealand AIDS Foundation, 2010).

4.8 Conclusion

This chapter discussed the sexuality-related knowledge and socialisation experiences reported by the women. It began with a review of their pubescent experiences and associated conversations before continuing on to describe their socialisation experiences within the family and school. Within the family context, Emily was the only one who reported she obtained a sufficient amount of sexuality socialisation from her parents. The other women reported acquiring very little information, and the women in the Asian and Pacific group reported their parents only sent prohibitive messages.

The women then discussed issues with socialisation at school. The most pressing issues were the limited availability of information in NZSL, either through the interpreter or peers, and inadequate materials. The inaccessible nature of these two things would have greatly reduced their access to formal and incidental sexuality socialisation. The Ministry of Health pamphlet that was reviewed was also found to be inaccessible. Therefore, the key finding from this chapter is that the women agreed that information from these sources was inadequate.

The women's experiences described in this chapter shaped their understanding of key sexuality concepts and suggest that this influenced the experiences of sex and sexuality

themselves. The next chapter will elaborate on their experiences with intimate relationships.

Chapter 5: Intimate Relationship Experiences

5.1 Introduction

This chapter focuses on the women's descriptions of their intimate relationships. It begins with an introduction to their earliest experiences with intimate relationships. The women's stories illustrate how a partner's hearing status can affect the quality and duration of the relationships. Then, attention is turned to the women's more recent and current intimate relationships, with both positive and negative experiences described. It then closes with a brief discussion of the potential influence of language and the cultural background of the women's families on their experiences on their abilities to carry out intimate relationships.

While the women did not explicitly share their personal definitions of intimate relationships, their understanding was implied through the descriptions of their partners and experiences. They discussed relationship features such as disclosure, trust, companionship, and acceptance, all of which have been identified as indicators of intimacy elsewhere (Jamieson, 1991; ch. 2). Jamieson also noted the importance of intimacy as "the centre of meaningful personal life in contemporary societies…[intimacy] is often a very specific sort of knowing, loving, and 'being close' to another person" (p. 1). It is therefore unsurprising that intimate relationships were a central theme in the focus groups and were discussed at length.

It should be noted that communication about this topic may have been ambiguous at times because of the limited amount of sexuality-related signs. At the beginning of the focus groups, the interpreter asked to use the sign "boyfriend" because the sign for "relationship" was vague and open-ended. Upon reflection, these two terms have entirely different connotations and may have influenced the type of information they shared. However, it did not affect the conversation too much, as evident in the quotes in the following sections.

5.2 Early intimate relationships

When the women were originally asked to share their first experiences with relationships, several began to offer primary school memories of handholding and note passing. However, details soon emerged of their first intimate relationships during adolescence and young adulthood. These experiences were influential in their subsequent intimate relationships, sexual experiences, and sexuality development. The following two sections describe how the relationships began and what factors contributed to their demise.

5.2.1. How the first intimate relationships began

Perhaps not surprising, the women gave a range of ages for experiencing their first intimate relationships. Leilani was the youngest of all of the women, reporting that she began one at 14. Although, she was quick to note that she considered this "too young." Emily and Jessica both began theirs later when they were in their twenties. The remaining four women claimed to start their first relationship when they were teenagers, between the ages of 15 and 17. Research indicates this is typical for their age group in New Zealand and elsewhere (Allen, 2004a; Furman & Shaffer, 2003; Regan *et al.*, 2004).

The details of how these first relationships began are equally varied, reflecting a range of modern and more stereotypically traditional methods. For instance, Amy stated that she met her first intimate partner through online chatting. Sereana and Lara, on the other hand, alluded to relationships that started in school. Lara's began with a simple declaration of, "I like you", to which she replied, "Oh, ok," whereas Sereana's started with a more formal request, "Do you want to go out?"

Kyla and Leilani did not specifically mention how they met their first intimate partners. The two women who began their first intimate relationship in their twenties, Emily and Jessica, are both still happily married to their partners. Emily said she was set up with

her now husband during university because her friends thought, "we would be a good fit for each other." Jessica reported she finally got together with her now husband after seeing him at multiple Deaf events while growing up.

5.2.2. The role of information and communication

The women who had their first intimate relationships in their teenage years reported that the relationships did not last long, ranging from a few days to a few months at the most. Interestingly, all the women reported that it was their decision to end the relationships. Several reasons were offered for the demise, although confusion was a common theme. As an example, Sereana explained that she "wasn't used to relationships" and "didn't really understand what it was." Similarly, Lara remembered that she wasn't aware of "the process of what to do, what's right, [and] what's wrong" in a relationship. Statements of confusion regarding their roles and expectations in these first intimate relationships were made by all of the women.

To some extent, research has shown that hearing women may experience limited knowledge regarding early intimate relationships (Jackson, 2006; Regan *et al.*, 2004). However, the women in this project intensely expressed feelings of confusion throughout the focus group discussions. It was also coupled with a wistful longing for more information from various sources. For example, Lara yearned for:

> Discussions with my friends…my mum or *someone, something*…to understand what a relationship really meant. The term "relationship", it meant nothing to me.

In addition to a lack of information about what constituted a relationship, communication struggles with partners were also identified as a significant reason for terminating the romances. The women indicated that communication breakdown happened because, for most of the women, their first intimate relationships were with hearing men who did not communicate through New Zealand Sign Language (NZSL). This ultimately led to a reliance on written communication, as Sereana explained:

> We'd be friends and then after a while, suddenly you would go out, and with a hearing person, you would text or email. It would be hard when

you actually physically got together. You'd have to write each other.

Communicating only through pen and paper would have been challenging enough by itself, but the problem may have been made even more difficult if the women had limited literacy. Amy further described the difficulties associated with written communication:

> We didn't know what to do. We wrote notes to each other, and it was just different and uncomfortable, and I thought, "Oh no, I'm leaving this. No. Never again".

Kyla expressed similar frustration with attempts to communicate with her first intimate partner who was hearing and did not use NZSL, although he knew the manual alphabet:

> It was hard to communicate. We'd text and I taught him a bit of signing, but in the end, we just started fingerspelling with each other…it was hard…so, we split up because it was hard to communicate and I wasn't comfortable. Like, I said to him, "I need to be with someone who is Deaf because it's easier to communicate."

The transition to notes or emails from the richness of NZSL (with its complex use of facial expressions, spatial arrangements, and body language) was both unfulfilling and impractical. Text messages, which often contain acronyms and abbreviations, would have made communication even more difficult. This combination of challenges would have significantly reduced the quality of the exchanges.

The women's accounts of the difficulties in communicating with hearing partners that don't use NZSL support the literature that proposes that the fundamental quality of sign language and speaking language is different (Padden & Humphries, 2005, ch. 1; Gannon, 1998). As noted earlier, even the word "relationship" has different connotations between the two. Therefore, the conversations may have been restricted in terms of breadth and frequency.

Given the necessity of communication in health relationships, the women's problems in communicating with hearing partners who do not use NZSL is significant.

Communication has been strongly linked to nurturance and overall relationship quality (Jamieson, 1991, ch. 6; Collins, *et al.,* 2009). The presence of positive, meaningful communication has also been noted to create more intimate relationships, which are associated with more positive psychosocial outcomes and increased happiness within the relationship (Freeney, 1994; Collins, *et al*., 2009). More positive experiences with early intimate relationships has been linked with more positive subsequent relationships as well (Collins, 2003). The absence of close, intimate communication, on the other hand, can lead to greater feelings of dissatisfaction, which was evident in the women's remarks noted above.

Also noteworthy is that, throughout discussions, it became clear these men appeared uninterested in learning NZSL. As noted in the literature review, sign language is a key cultural feature of the Deaf community (Padden & Humphries, 2005, ch. 5; Woll & Ladd, 2003). Therefore, to refrain from using it or participate in other Deaf activities, in essence, meant ignoring a large part of the women's cultural and personal identity. It would have also resulted in an automatic disconnect, the creation and separation of two distinct worlds: Hearing and Deaf. The subtle implication by the separation is that hearing ways are "better" than those of the Deaf, which would not have been a pleasant feeling for the women. Evidence for this was seen in Kyla's remarks "it was hard to communicate and I wasn't comfortable."

5.3 "Deaf is best.": Current intimate relationships

For several of the women, the conversation took on a different tone when the discussions about intimate relationships shifted to current experiences. Leilani, Jessica, Amy, and Lara were all involved in long-term intimate relationships with Deaf partners. In each instance, the women discussed their relationships with Deaf partners, or hearing partners who communicated through NZSL, in more positive and meaningful terms. The next two sections discuss their thoughts as to how and why their relationships with Deaf partners have been more satisfying.

5.3.1. How the current intimate relationships began

Amy and Lara met their Deaf partners shortly after ending intimate relationships with hearing men. Amy appeared exasperated with her experiences in relationships with these men. In describing the end of her second relationship with a hearing man, she summarised the experience by saying:

> Oh no, [that was] no good, but that's what hearing people are like.

Having had similar experiences, Amy and Lara recalled feeling a desire for change and a yearning for something different. Lara elaborated on her thought process thus:

> I thought 'Right, Deaf guy next, see if it works, and if it fails, I'll go
> back to hearing people.'

Therefore, her next partner was a Deaf man she met through Deaf club activities. They have been together for almost two years and she says "it works." Amy also met her current Deaf partner through Deaf activities. They have been together for two and a half years and have recently become engaged. However, she noted it was challenging in the beginning:

> He grew up in another [country and sign] language…When I first met
> him, like when we emailed each other, his English was really different.
> It was hard for me to understand what he was trying to say…I learned
> [his language] because I wanted to understand him better…he also
> learned New Zealand Sign Language. We sign to each other. New
> Zealand Sign Language.

Jessica's Deaf partner, however, was her first and only intimate relationship. She indicated that she went on dinner dates with other men before her husband, but it never turned into anything serious. She fondly noted: "My first time kissing was with [my husband]. I never kissed anyone before." She reported she has been happily married to her husband for over twenty years and described their relationship as "very close." Although, she explained it wasn't easy in the beginning:

> Rebecca: With your age group, can there have been many Deaf people
> that were together and getting married?

Jessica: No, not many. You know, it's not very easy in New Zealand. No, not many people. He thought he should marry a hearing person and then I convinced him that Deaf is best.

Given the time period of their marriage in the late 1980s, the idea that Jessica's partner had to marry a hearing person may indicate how influential the bio-medical model of deaf was at that time in New Zealand (Dugdale, 2002). Socialisation experiences may have originally taught him that he needed a hearing person to survive and the limited access to other role models that Jessica stated may have reinforced the idea. These three women began their intimate relationships in more traditional Deaf-only spaces and activities, which is a common experience within the Deaf community (McKee, 2001). Leilani, on the other hand, met her Deaf partner in a less traditional manner, at least in terms of the Deaf community. According to her, it was a surprise when he asked her out:

He was my flatmate. We were flatmates for quite a while. And, you know, on my birthday, it was a surprise. He asked me out on my birthday and it was a surprise. Yeah, it's been two years and two months.

Even though they have been together for over two years, her parents have not met her partner, because, according to her, "he was Deaf and they're hearing. It's a cultural thing." She further explained:

[My parents] were just like, "No, we don't want you to have a Deaf boyfriend. It would be better to have a hearing boyfriend so he can help you with everything." I was like, "No way!" I want a Deaf boyfriend so I can communicate with him and talk with him. If I have a hearing boyfriend, how will I know what he's doing? What he's saying behind my back?

The insistence of Leilani's parents that she date a hearing man again highlights the fear that can stem from a bio-medical view of deaf as perpetually in need of assistance or unable to navigate the world on their own (Bauman *et al.*, 2010; Job, 2004). However, it also shows how that paternalism can be exacerbated for Deaf girls and women, who are socialised through numerous avenues that they *need* to partner with a hearing man

because they are both female and Deaf, and therefore twice as incapable (Fine & Asch, 1985; Sobsey & Doe, 1991). However, even without her parents' acceptance, Leilani has continued to enjoy her relationship with her Deaf partner.

The activities these four women enjoyed with their partners varied considerably, as one may expect given the uniqueness of individual lives and experiences. Amy appreciated the more intimate activities, such as "being with him. Just cuddling, holding." Lara and Leilani, however, enjoyed the more social aspect of being able to go out and do things with their partners, such as visiting friends, shopping, or outdoor activities. Meanwhile, Jessica relished the camaraderie found in being "good mates." As she explained:

> Jessica: We've been together for so long and I still really appreciate
> being together…I love to see him teasing me. He makes me laugh. So,
> yeah, we're good mates. We appreciate each other. It's like when you
> see lovebirds, sort of sitting next to each other, pecking each other.
> We're like that. And they ignore everything around them. That's what
> we're like.
> Emily: Awww, that's amazing!
> Jessica: Yeah, we're still like that. I don't know how it happens or why
> it's like that. He says, "Stop kicking a gift horse in the mouth." Like, I'll
> say, "How are we still in love?" And he'll say, "Stop. Just enjoy it and
> appreciate our time together."

> The level of companionship and contentment reflected in Jessica's remarks
> indicate a committed and trusting relationship with a high degree of intimacy
> (Jamieson, 1991, ch. 2;Collins, *et al.,* 2009; Freeney, 1994).

5.3.2. The role of communication

The common experience among all four women appeared to be that their relationships were enhanced by a shared Deaf status with their partners who used NZSL, which opened up a whole new world of improved communication. As Lara explained:

> It's completely different. Like the experience being with hearing people
> compared to [my Deaf partner]. Communication is much easier. We
> sign to each other. We don't miss anything. Yeah, I don't miss anything.

However, it wasn't simply that the women were able to express themselves more fully, but also that they also could better understand their partners. Jessica described the joy she found in being able to understand each other:

Rebecca: What do you enjoy the most in your current relationship?

> Jessica: Communication. Having a Deaf partner and enjoying the communication because you can always understand each other. Like I've always said to [my partner] that I appreciate that he's Deaf and that we understand each other. It makes life so much easier and I appreciate that. Dating a hearing person, I know from my family, just growing up with them, I would miss out on a whole lot of information rather than with a Deaf person.

For all four of the women, this was the first time they experienced such full and open communication with an intimate partner. Given that Deaf women can experience daily communication barriers, and the critical role of communication in relationships (Jamieson, 1991), it is understandable that the experiences of being in intimate relationships with other Deaf were described as profound.

Amy and Leilani also mentioned an appreciation for not having to worry about what they were missing both face-to-face and in conversations with others, perhaps alluding to the amount of emotional energy spent on guessing and wondering while in relationships with hearing partners.

There is also indication that the newfound ease and openness of communication improved conflict resolution, perhaps enhancing the quality of the relationship. For instance, Jessica mentioned that even though she and her partner occasionally argue about money, they typically come to an understanding:

> Jessica: Most of the time we argue, we're not agreeing on money. We both have different ideas about that. But we've survived so far. We're Okay.

> Rebecca: So arguments would be the most difficult thing about your relationship?

Jessica: Yes, I think so…I think the difficult thing to decide is about the education for your children, you know, that's money issues. But, we've tried to come together and meet halfway on things and proceed.

Lara reported similar conversations resolving disagreements about money with her Deaf partner:

We both argue mostly about money. I like to save because I want to save for travel, a house, children, you know, whatever. But, he likes to spend. So, that's a constant argument. We have really different views on it and it just conflicts sometimes. But, the next day, we're always like, 'Okay, I get your point', and he'll say, 'Okay, I get your point' And then we agree on something.

The ability to come together in mutual understanding as described by Jessica and Lara is more feasible when the two individuals share the same language. Now, Jessica and Lara have the ability to reach an amicable middle ground in their preferred language. As noted earlier, communicating via written text was confusing and infuriating. Not only would any negative emotions resulting from the argument itself impede conflict resolution, but also the frustration arising from miscommunication might further compound the problem.

5.4 Negative experiences with Deaf partners

The accounts shared by Sereana and Kyla contained different experiences with their intimate relationships. Both Sereana and Kyla reported their early intimate relationships were with Deaf partners, but they ended them because of their partner's negative behaviour such as lying and cheating. Both women expressed frustration at the betrayal and broken trust caused by those partners. As Kyla explained:

I was 16, I was with someone. I didn't really know what a relationship was, you know? I was just sort of playing around and I guess it was good learning. We held hands and I would copy what other people did in relationships, but I dumped him. He was lying. He was upset and cried, but I was like, "No, go away" I wanted to make sure I could trust

somebody and he was lying. There was just something not quite right up there.

Sereana reported a similar experience with her first partner who was Deaf:

> When we met, he was really nice to me. And I thought he was nice, but inside, he wasn't so nice. Like, he was shit and he lied. It was like he duped me into believing he was a good person.

After their relationships ended, Kyla seemed content to focus on her academic work, stating, "I don't want to think about a relationship anymore, I just want to study." Sereana, however, was left "heartbroken" by her relationship and "really grieved" over it, prompting her to choose to remain single ever since. Their differing outlooks may be partially explained by the age difference of the two women, as Sereana was a few years older when her relationship ended. However, the level of commitment in the relationship may also have been a factor. Kyla was only with her partner for a few weeks while Sereana's lasted for an entire year.

5.5 Positive experience with a hearing partner

Emily's experience with intimate relationships is different from the other women because her first partner was hearing and they have been married for over ten years. What is unique about their relationship is her partner's attitude toward being Deaf because according to Emily:

> He wanted to know more about me as Emily, not as a Deaf person.
> Being Deaf was a bonus. It was a special thing that added to me.

Her partner not only accepted Emily as she was, he embraced her uniqueness, and even celebrated it. His interest in Emily as a person also prompted him to become fluent in NZSL, allowing for even better communication. In fact, Emily noted that he asks her to "turn [her] voice off because he finds it easier to understand [her]." Emily described his learning process and the impact it had on her:

> [My partner] didn't have any sign language experience before he met me, but he was really keen and had a huge motivation to learn it. What he did was get the New Zealand Sign Language Dictionary book and

found specific words. Like when he first met me, he was at the library and he tried to sign to me, and he tried to say that he was interested to go out with me and he wanted to know more. I was like, "Whoa!" I never expected him to do that. Our classmates set us up. They knew that we would be a good fit for each other. So for about two or three weeks, we wrote a lot to each other and talked about our life experiences and I taught him some sign language. He picked it up quite quickly. And we would often go out and do things together. He made time for communicating with me. He wouldn't rush. It was quite easy to communicate with him, really.

Consequently, even though Emily's partner may be hearing, she gets to enjoy complete communication with him in her preferred language. In fact, Emily explained, "Communication [is] a really big part of our relationship and made it stronger. And it [is] a more solid relationship because of that."

While Emily's experience does not seem typical of hearing men who become involved with Deaf women (Merkin & Smith, 1995), it does mean she experiences the benefits that Deaf women are sometimes only able to find in Deaf partners, such as communication and understanding. His dedication to learn her language and attend Deaf community events also demonstrates his respect and validation of her social and cultural Deaf identity. This may have influenced her ability to experience a complete and balanced sexual self (Job, 2004) and played a role in the positive sexuality experiences featured in her accounts.

5.6 Conclusion

This chapter shared detailed accounts of the women's experiences with intimate relationships. Some of the women's first experiences with hearing partners were discussed in order to offer a comparison point with their current experiences with Deaf partners, which were considered more positive. Then, a description of negative experiences with Deaf partners was shared, suggesting that Deaf may not always be best for everyone. Emily's positive experiences with her hearing partner were addressed next, highlighting the impact a hearing partner's level of support for a Deaf partner's

cultural identity and NZSL usage can have on a relationship. Throughout all of the accounts, the influence of English literacy and the cultural background of the women's families became apparent.

The reports of their experiences with intimate relationships are important in comprehending their overall sexuality understanding and development. They also contextualise aspects of the sexual experiences described in the next chapter.

Chapter 6: Sexual Experiences

6.1 Introduction

As previously mentioned, sexual experiences can include a range of non-coital behaviours, such as kissing and fondling, as well as intercourse (Jackson, 2005). These behaviours are typically accompanied by numerous emotions and thoughts, and can be highly influenced by socio-cultural factors (Carpenter, 2005, ch. 2; Regan *et al.*, 2004; Impett & Tolman, 2006). Jamieson (1991) also notes that sex, love, and intimacy may be "analytically separate, but in social practices they are often linked, as the phrase 'making love' illustrates" (p. 106). Therefore, this chapter explores the women's sexual experiences in order to demonstrate how those experiences have been interwoven with their intimate relationships and overall sexuality development.

This chapter begins with a review of their first sexual experiences, noting potential contributing factors in either positive or regretful accounts. Then, the more recent or current experiences of the women are discussed, beginning with reports from the women in the Asian and Pacific group and continuing to the experiences of the women in the NZ European/Pākeha group. The chapter then concludes with two examples of how the women's sexual experiences may have been unique or similar to the experiences of hearing women.

6.2 First sexual experiences

The first sexual encounter a person has can be a pivotal experience, both for the individual and their relationship with the other person involved. If the first experience is positive, it may improve a person's sexual self- concept, development of safer sexual practices, and pave the way for additional positive experiences in future (Carpenter, 2005, ch. 2; Impett & Tolman, 2006). It can also lead to increased feelings of closeness and a greater development of intimacy within a relationship (Theiss & Solomon, 2007; Jamieson, 1991; ch. 5).

The next two sections describe the women's accounts of their first sexual experiences, beginning with positive experiences and contributing factors, and then followed by first experiences characterised by regret.

6.2.1. Positive sexual experiences

The accounts shared by the women about their first sexual experiences highlighted the contextual variety in which they can occur as well as the range of reactions that may accompany the experience. Amy, Emily, and Jessica remembered their first sexual encounter as an enjoyable experience. As an example, Amy recalled:

> It was both of our first time. So, my first sexual experience was good. We talked it through. We made sure we were all ready. There was no pressure or anything like that from each other. When we were both ready and both comfortable and both felt ok, we just sort of went with it.

Amy's account indicated a level of relaxation and comfort that resulted from prior preparation. Her experiences mirrored the accounts shared by Emily and Jessica. In fact, Emily's description of her first sexual encounter sounded almost identical. As she explained:

> My first experience was [with my husband]. Like, I was a virgin and he was a virgin. There was no rush. We talked beforehand…We did it when we felt ready. We were both a little bit nervous before then, but I think it went ok. We took our time. There was no horrible experience because we took our time.

In fact, all three women remembered feeling comfortable and ready to engage in sexual activities. This has been reported in other studies, such as Impett and Tolman (2006), who found statements of readiness were the top sexual motivator for young women. A recent Australian study about the sexual experiences of adolescent women (Skinner *et al*., 2008) also found feelings of comfort and readiness imply an element of control and preparation, which may explain their connection to positive experiences.

Noteworthy about these women's experiences is the timing of their first sexual experience: Emily was in her early twenties, while Amy and Jessica were in their late teenage years. Studies conducted in New Zealand with hearing participants have noted most female respondents had engaged in intercourse by sixteen to eighteen years of age (Davis & Lay-Yee, 1999; Dickson *et al.*, 1998). Therefore, the sexual debut for these three women could be considered typical, or slightly delayed.

The timing of a person's first sexual experience can be important, as early sexual debuts have been linked to increased risky behaviours, such as inconsistent utilisation of contraceptive methods, and negative emotions, such as regret (Davis & Lay-Yee, 1999; Skinner *et al.*, 2008; Carpenter, 2005, ch. 2; Rissel *et al.*, 2007). As a result, the timing of their first sexual experiences helps to explain their levels of readiness and preparation.

The presence of open communication between the women and their partners may have further improved the experience. In particular, all three women mentioned having discussions with their partners about sexual activities before anything took place. Studies have found these early conversations that occur before sex are important because they increase the likelihood of personal boundaries being established and respected (Impett & Tolman, 2006; Jackson *et al.,* 2000; Allen, 2005).

For Emily and Jessica, the fact that both of their partners could communicate through New Zealand Sign Language (NZSL) would have provided additional communication benefits. This is important considering the role of sexual communication in the identification of all the nuanced behaviour and feelings associated with sex, such as needs, desires, and boundaries (Freeney, 1994; Theiss & Solomon, 2007). Therefore, while the exact details of their conversations were not explored, it appears likely the women were able to communicate more freely with their partners and consequently experienced more positive sexual activities with them.

It is also possible that the level of commitment to their partners may have positively influenced the women's experiences. For example, both Emily and Jessica mentioned the first time they engaged in sexual activities was with their husbands who were virgins as well. In fact, Jessica stated, "My first sexual experience was when I got

married and nothing before that." Therefore, their relationships may have possessed a greater degree of intimacy, trust, and support that engendered a more positive sexual experience (Jamies, 1991, ch. 5; Freeney, 1994).

6.2.2. Regretful sexual experiences

Given the complexity of sexual experiences, it may not be too surprising that sexual experiences are not always positive. First sexual encounters are particularly vulnerable to negative experiences, as communication and intimacy may not be firmly established between partners. In fact, almost two-thirds of participants in an Australian study remembered their first sexual experience as less enjoyable than subsequent encounters (Rissel *et al*., 2007).

Lara, Sereana, and Leilani also reported their first sexual experiences in negative tones. An example is Lara's recollection of her first sexual experience:

> Lara: My first sexual experience was more of a one-off thing. Because all of my friends had done it and I hadn't, and I thought, "Well, I'm the only one now and I really want to do this thing." So, I texted a friend of mine and said, "Do you want to do it?" And he said, "Fine." So I went over and we did it. Looking back, I wish I had done it with someone who was special, but I didn't.
> Rebecca: So how was it? Was it enjoyable?
> Lara: No.

Lara's description indicates that her first encounter could be considered casual sex, referred to in New Zealand as a "one night stand." Grello, Welsh, and Harper (2005) explain that adolescents who engage in casual sex with "a friend" or someone they "just met," which is often a function of the amount of time an adolescent is sexually active (i.e., those who begin having intercourse at a younger age are more likely to have casual partners). Individuals who engage in casual sex for their first sexual encounter may view virginity as "a stigma, something to be shed as quickly as possible" (Carpenter, 2005, ch. 2). This may help to explain the urgency and lack of intimacy expressed in Lara's remarks.

Sereana also did not recall enjoying her first sexual experience, which she experienced at the age of sixteen. However, alcohol played a significant role in that encounter, as she explained:

> Sereana: I had been drinking. I got drunk. And, you know, I liked this person and things carried on…We went home with each other, and then he said, "Do you want to sleep there?" And so I laid there…And then we sort of had sex. And we did it, and finished, and I thought, "Ah, ok."
>
> …
>
> Sunshine: Was that an enjoyable experience or was it just something to just have sex to say you've done it?
>
> Sereana: Yeah…like I had done it. Before that, I wasn't keen. People would ask me and I was like, "No, I'm waiting until I get married." And then that happened and I was like, "Oh." Yeah…
>
> Sunshine: And you said you had been drinking. Were you drunk? Or had you just maybe had a beer or two?
>
> Sereana: I was pretty drunk. I was still able to sign. But, it was at my friends' house, and now I realise I wouldn't do that again. Like, maybe my friends should have looked after me…They weren't very good in that way. They didn't look after us and get us to sleep in a separate place and make sure we were safe.

While Sereana did not seem to discuss her experience in overtly negative tones, there may be cause for concern. For instance, Sereana indicated she originally wanted to wait until marriage for sexual activities and expressed remorse because her friends did not watch out for her that evening. These sentiments convey a feeling of regret and suggest the activities may have been unwanted. Furthermore, Sereana indicated she was intoxicated at the time of the encounter, which is concerning because the New Zealand penal code states a person is legally unable to consent to sexual activities if intoxicated.

However, Sereana was not alone in recounting a first sexual experience that may have been problematic. Leilani's description of her sexual debut also contained themes of uncertainty and discomfort:

I was young, 15 or 16, and I met this person. I was a bit nervous. He was a hearing guy, but we were talking, and I was on a holiday…and he said, "Have you had sex before?" And I said, "No." He was like, "Okay, do you want to try it?" I wasn't sure. I was a bit scared. And I was like, "No." He was like, "Come on, you should try it." And I was like, "Yeah, okay." And that was the first time. But, there wasn't a condom used…They don't have them [on the island]. So, that was the first time and I was scared…He was like, "You alright?" And I was like, "Ah, no, it's sore. It's painful. It feels funny."

In addition, Leilani went on to state that the man was in his early twenties, a hearing friend of her cousin's, and had been drinking. When considering the age difference between Leilani and the man, as well as his hearing status and relationship with her cousin, it appears the sexual encounter contained a significant power difference (Anderson *et al*., 2011; Merkin & Smith, 1995).

Power differences such as these can create situations in which an individual does not have ability to freely choose what to do, a concept known as consent (Jackson *et al.,* 2000). When coercive tactics are used, such as repeatedly asking someone to engage in sexual activities, it further reduces a person's ability to consent. In addition, the minimum age for consent in New Zealand is 16, so if Leilani was only 15 years old at the time, it may have complicated matters further.

Jackson, Cram, and Seymour (2000) found in a study of secondary school students in New Zealand, that sexual coercion can result in feelings of anger, anxiety, feeling "dirty," or feeling "duped." Other studies have also indicated that when first sexual experiences are regretful or unwanted, they may be linked to future risky sexual behaviours, such as multiple partners or unprotected sexual activities (Impett & Tolmna, 2006; Davis & Lay-Yee, 1999). Therefore, the first sexual experiences of these women may have affected their understandings of sexual feelings and desire, or sexual self-concept. It may have also played a role in their development of sexual agency by implicitly, or even explicitly, sending messages about their passive or submissive role during sexual encounters. As demonstrated in the next section, this may have influenced

their understanding of sex, especially its relation to intimacy or love (Jamieson, 1991, ch. 6).

6.3 Current sexual experiences of the women in the Asian and Pacific group

As the women changed over the years, so did their sexual encounters. This section discusses the more recent or current sexual experiences of the women in the Asian and Pacific group. However, they shared relatively little information about those experiences. This may be a further reflection of their discomfort with open discussion of sensitive sexuality topics as a result of their family's cultural background (Ozazaki, 2002; Kim, 2009; Kim & Ward, 2007; Tupuola, 2000).

When the women did disclose details about their experiences, it was often only brief situational descriptions of how sex typically occurs. For Leilani and Sereana, alcohol appeared to play a role in their sexual experiences. As Leilani explained how sex typically happened with her current partner, "When he drinks, he gets really drunk and gets turned on." Similarly, Sereana described how sex occurred in her life:

> We would meet at a party, then there'd be drinking, and then he would come up close, like a dog sort of following me. And then we'd go home and then there'd be, you know, sex, and you'd enjoy it sometimes. But, when we normally went out, it wouldn't happen.

In essence, if there was no social atmosphere or alcohol, sex did not typically happen for Sereana, and Leilani's comments also indicate a relationship between alcohol and frequency of sex. In the New Zealand context, Hutton and Wright (2014) have noted that Māori and Pacific young women consume alcohol more often and in larger quantities than non- Māori or non-Pacific young women for a variety of social reasons. Therefore, this may not be atypical considering their ethnicity. However, alcohol has also been linked to a variety of negative sexual experiences, including unsafe sex practices and sexual assault, and can often be used to mask negative feelings (Rissel *et al*., 2007; Davis & Lay-Yee, 1999).

In the case of these women, alcohol may have been used to cover feelings of disinterest or discomfort about engaging in sex. For instance, when Sereana was asked if sex was a big part of her relationships, she very simply replied, "Not really, no." She explained that it was because sometimes, "You don't feel like it. You don't want to show your vagina to them. Like, you get embarrassed." However, Sereana resigned herself to the fact that sex was something "you get used to" in order to please a partner. Her statements do not reflect an active sense of sexual agency or confidence with her body, especially when exposed and made vulnerable to someone else.

While Leilani did not discuss her body, she did indicate that she did not ascribe importance to sex in her relationship. In fact, she initially stated, "I don't really want sex." However, Leilani then clarified her position by explaining:

> Well, I like sex, but you know, it's boring. I've got stuff to do. Got to clean up. He wants sex all the time…It's like, "Enough.…Calm down with that sex thing. Look for a job."

The discomfort and ambivalence evident in the statements made by Sereana and Leilani comes from a variety of sources. The apprehension may result from their first sexual experiences, which, as previously mentioned, can have a profound influence on a person's sexual understanding as well as their subsequent sexual encounters (Carpenter, 2005, ch. 2; Impett & Tolman, 2006; Jamieson, 1991, ch. 5).

However, their comments may also reflect their limited exposure to sexuality information, discussed in Chapter 4, which may have contributed to a limited understanding of sex and sexual agency. Research has shown that as women become more familiar with their own body parts and sexual responses, and are exposed to a discourse of erotics that recognises their sexual agency, they may experience less embarrassment, feel more sexually empowered, and experience more sexual pleasure (Jackson & Weatherall, 2010; Halloway, 1996; Allen, 2004a).

In addition, these women's accounts may show their sexuality socialisation experiences within the family as a result of their family's religiously-influenced cultural background. As mentioned in the literature review, some Christian theological beliefs typically condone sexual experiences only within the confines of marriage and for procreative

purposes (Carabine, 1992; Ussher, 1994; Lamb, 2010). Excerpts shared in Chapter 4 indicate that those were the messages they received about sexual experiences. Therefore, the women either may not have felt comfortable engaging in sexual activities for pleasure or they simply may not have felt comfortable discussing those experiences.

In addition, the moral conservative discourses around sexuality also typically position women as subservient to men or as passive recipients of their attention and desires (Fine 1988; Vance, 1998). This may be even more accurate for Deaf women, who are often socialised to be submissive, and thus may feel dependent on a hearing man (Job, 2004; Sobsey & Doe, 1991). As a result, the women may have been socialised to believe that they need to please others, especially men. This concept might help to explain Sereana's statement about sex as something she had to "get used to."

6.4 Current sexual experiences of the women in the NZ European/Pākeha Group

A noticeable difference was evident in the information shared by the women in the NZ European/Pākeha group, in relation to their more recent or current sexual experiences, both in terms of quantity and depth. The next two sections provide their accounts about both the positive and negative aspects of their sexual experiences.

6.4.1. Positive sexual experiences

Overall, the women viewed their recent sexual experiences with intimate partners as positive, often revealing gains for themselves and their partners. For instance, Jessica discussed the playful, open nature of sexual activities with her husband of over two decades:

> We're more relaxed [now]. We know how to please each other. We find out more and more what we like best and we try different positions. We're never happy staying with one particular position, we've discovered….We enjoy it and we do it when we want, when we're ready. You know, and I think, "Yeah, yeah, I'm going to do things randomly now and surprise him and hop on him." You know, and we have cuddles and it's really good.

Accounts similar to Jessica's remarks have been found in other academic work as well. For instance, Fenney (1994) found married couples reported more positive sexual experiences, typically a result of the increased disclosure and feelings of trust.

Amy also indicated emotional benefits from positive sexual experiences with her fiancé. At one point in the discussion, she commented on how she enjoyed "developing more of a bond with each other. Enjoying and satisfying each other." This type of mutual pleasure has been shown to contribute to stronger feelings of intimacy and relationship satisfaction (Jamieson, 1991).

Emily also commented about the increased intimacy she found in sexual activities with her husband:

> I enjoy the closeness. I know there are a lot of love languages
> that make you feel close, but for me, sex doesn't happen always.
> You know, just at special times, when we're really, really in the
> mood. Yeah, and that's a special part of the relationship.

Emily's description of the benefits and importance derived from her sexual experiences reflect her understanding that sex is a gift to share with the right person and in the right circumstances. This is not uncommon of individuals from Western backgrounds, especially women who are socialised to protect their virginity (Ussher, 1994; Fine, 1988). In New Zealand, Allen (2004b) found a gendered difference in the meaning ascribed to sexual experiences among young people and she noted this can be traced back to Christian doctrine aimed at preventing promiscuous sexual behaviour, particularly among women.

6.4.2. Negative sexual experiences

When it came to discussing negatives in their sexual experiences, the women did not have much to share and the remarks seemed to fall into two categories: Difficulties with pain during intercourse and difficulties with timing. In terms of discomfort associated with sexual activities, Lara found that penetration itself could be painful because of the large size of her partner's penis. As she explained:

> Lara: One thing I don't enjoy is: You know some men are easy to get
> in and some just can't get in? That's what I don't enjoy. Because,
> sometimes it takes a longer time to expand so they can come in. I like
> to go with the flow and sometimes-
> Rebecca: Do you mean men with big penises?
> Lara: Yeah. Even now, it's really hard because we're in a relationship.
> It's really hard for him to do it and I'm just imagining when we have
> children. I'm not sure how that's going to work.

Upon hearing this, Emily offered, "You need more foreplay before you can have successful sex." Lara, however, rebuffed the suggestion, stating, "We have a lot of foreplay!" However, pain during intercourse has been reported in studies with other women, potentially a result of hormone levels or physiological stressors (Rosen *et al.*, 1993; Impett & Tolmna, 2006). While the root cause for the pain varies with each case, sex therapists have found that extended sessions of foreplay can sometimes be an effective treatment (Rosen *et al*, 1993). Therefore, Lara may actually benefit from increased foreplay and perhaps additional lubrication.

Similarly, Emily also recalled sex occasionally being painful. In her words, "Sometimes it can hurt. Sometimes, things aren't quite right and afterwards you feel a little bit sore." While it is difficult to know the aetiology of Emily's symptoms, it may be similar to those reported by Lara. Difficulties with successful penetration are an often ignored part of female sexuality because women are typically socialised to feel responsible for any difficulties with sexual experiences, which is often part of a wider social discourse that views women as carers and nurturers, responsible for the maintenance of multiple relationship features (Vance, 1998; Fine, 1988; Impett & Tolman, 2006).

Therefore, it was surprising to hear Emily's response to the occasional difficulties she and her partner had with sex: "It's not always perfect every time, right?" Rather than feeling remorse or self- blame, it appears she had increased awareness of the physiological changes associated with sexual intercourse, and how they may not always perform at optimal level, regardless of personal desire.

In addition to difficulties with sexual intercourse, two of the women noted challenges associated with the timing of sexual activities. For instance, Jessica commented that, sometimes, "He wants it and I don't want it, and it's like, 'Ugh!'" Emily elaborated on the issue even further:

> It can be frustrating, and if you're frustrated, it's not going to work. It just undermines it and the experience. And, it's hard to find the right time and be in the right mood for it.

It is worth noting that both of these women are mothers, and it may be challenging to find time for sexual activities around domestic responsibilities or paid employment. The result may be that married couples with children, especially young children, find making time for sexual activities a difficult part of parenthood.

The silver lining to difficulties with timing as a result of children is that it may improve as the children grow older. Jessica provided support for this possibility:

> When the children were growing up, it was more difficult and more difficult to find the time for sex…Once they were out, we would do it [more frequently]. We had to be really careful while they were growing up, thinking they could hear, but they never mentioned anything to us. I was sort of surprised about that.

6.5 No previous sexual experience

Kyla, one of the women in the Asian and Pacific group, disclosed she had yet to engage in sex. As she explained, "I've never had sex with a boy." However, she did admit at a later point that she "fooled around" with a boy and kissed him, so her previous statement apparently referred to intercourse. Therefore, her statements indicate her conceptualisation of sex was purely related to coital behaviours. Subsequent remarks also illustrated the meaning and values she ascribed to sex. For instance, when asked if she was waiting to have sex until she was married, Kyla replied:

> Yes! First, get married, and then, sex and children…First, I want to work, get married, and then I'll wait to make sure everything is okay. We'll need to get a house and other things. Then, babies.
>
> …

> Sunshine: So, you haven't really thought too much about sex with your future husband?
>
> …
>
> Yeah, later. I don't need to think about sex, and what that is, right now. I'll just wait. I'll put it to the side while I study.

Noteworthy about Kyla's remarks is the absence of a discourse about pleasure, desire, or erotics (Jackson & Weatherall, 2010; Allen, 2007). This may be a reflection of the limited amount of formal sexuality information Kyla received. For instance, Job (2004) noted that without access to signed sexuality information delivered at an appropriate level, Deaf people can only understand the literal, physical aspects of sexuality. Therefore, the more nuanced aspects of sexual experiences, such as sexual agency and empowerment, may have never been conveyed to her.

In addition, her statements appear similar to the reports from the other women in the Asian and Pacific group that may have indicated an understanding of sex as a procreative function. This may also have been a result of socialisation experiences that were influenced by her family's cultural background and religious faith. As she noted her mother was Catholic, Kyla may have been exposed to religious doctrine that espouses a virgin/whore dichotomy for women's sexuality and often links women's identity or sense of worth to their virgin status, until married, after which the emphasis switches to motherhood (Carpenter, 2005, ch. 2; Ussher, 1994). As a result, the understanding of sex as purely for pleasure or something she should engage in outside of wedlock may have been a foreign concept to her.

6.6 "Lights on!"

When asked about the joys they experienced with sexual activities, an unexpected revelation surfaced about the importance of lighting in the NZ European/Pākeha group. Lara enthusiastically stated that she enjoyed sex with "the lights on!" Lara explained her rationale for the lights to remain on: "So you can see each other. I like to be able to see!" All three of the other women agreed with her as well, which offers a glimpse into a unique aspect of Deaf sexual experiences.

For instance, Deaf cultural values prioritise clear and unobstructed lines of sign to detect visual cues (Mindess, 2006, ch. 5). In addition, the women needed the lights on so they could communicate with their partners in NZSL. As Jessica explained: "both of us like the lights on so we can communicate with each other." This is important given the crucial role that communication plays in the identification of interest or boundaries during sexual activities (Allen, 2004a; Jackson, 2005; Collins, 2003). Consequently, the women and their partners may have been able to communicate more effectively with the lights on, which in turn contributed to more pleasurable sex.

6.7 "I was the queen of love bites."

Perhaps the most jovial portion of the discussion emerged when the women in the NZ European/Pākeha group shared experiences with kissing and "love bites." A "love bite" resembles a bruise and is the mark that can sometimes be left on the neck or shoulder after a partner has suckled the area. Three of the four women in the NZ European/Pākeha group discussed their history with "love bites" and speculated about their purpose. Jessica began the discussion when she explained that she relished, "You know, just to kiss [my husband] all over, bite him…I bite him. He gets a bit of a fright." After this, the women laughed and began to share their experiences in more detail.

For instance, Emily stated, "In the beginning of our relationship, there were a lot of love bites going on. I used to have love bites all over me." She also noted that she "used to cover them with scarves," indicating her desire to keep the marks hidden from others. Also commenting on the frequency of her "love bites," Lara boldly claimed:

> Lara: I was the queen of love bites.
> Sunshine: Wait, the queen of what?
> Lara: Of love bites. Because I used to get them all the time and heaps of
> my friends would say, "I remember you, you used to go to parties with
> big hickeys all over your neck." And I'd be like, "Yep, yep, that's true."

Without prompting, the women then continued to ponder the need for "love bites" and offered personal theories. For instance, Emily felt that it was because of the newness of the relationship and "you're excited about being with each other." Amy, on the other hand, considered it an indication of ownership. As she reasoned:

> Yeah, because it's a new thing and you want to make your mark that
> says he's yours and other people run along. Like a territorial mark: "Go
> away." That's what it feels like.

While light-hearted in nature, and completely spontaneous, this portion of the discussion provides valuable insight into some of the positive features of female sexual experiences. This is important considering the dearth of information available on positive aspects of women's sexuality (Impett & Tolman, 2006).

6.8 Conclusion

This chapter presented selected key findings about the women's sexual experiences. In describing their first sexual experiences, positive experiences were attributable to the age of sexual debut, prior communication and preparation, and levels of intimacy they shared with their partners. By contrast, accounts that were potentially negative in tone were the result of casual sex or the presence of alcohol and power differences. When the women shared their current sexual experiences, descriptions of ambivalence or displeasure with sex were a result of sexuality socialisation experiences and the quality of the first sexual experience. Current sexual experiences that were reported in positive terms were a reflection of increased communication and intimacy shared with partners. Kyla's decision to wait to engage in intercourse until marriage reflects her sexuality socialisation experiences, particularly within a Christian upbringing. This chapter then concluded with two examples of positive sexual experiences that were shared by the women in the NZ European/Pākeha group.

Throughout this chapter, the women's sexuality socialisation experiences, and experiences with intimate relationships, demonstrated an influence on every aspect of their sexual self-concept, sexual agency, and overall sexual experience. Their accounts also illustrated the complex way these experiences are interlaced and contribute to the women's ability to understand, or "do" sexuality. Similar themes emerged from the previous chapters about the importance of accessing information in order to support positive experiences and, together, all will serve as the basis for the recommendations provided in the next chapter.

Chapter 7: Recommendations

7.1 Introduction

Following the action research model, this chapter collates the women's accounts to identify areas in need of improvement and recommend courses of action. As one of the primary aims of this study was to develop specific recommendations for improvements to the information and services provided by Deaf Aotearoa New Zealand (DANZ), they comprise the bulk of this chapter.

The first two recommendations involve improvements to the accessibility of information for adult Deaf women through the development of community education programmes and sexuality information resources. Included in this set of recommendations is a description of one type of programme that I have since developed with DANZ and have twice implemented. To support sufficient opportunities for meaning-making while young, two recommendations are made for educational programmes for Deaf girls or adolescents as well as the provision of Deaf mentors for hearing families.

Two subsequent recommendations are included for improving formal sexuality education within schools through access to interpreters and sexuality education training for them and classroom teachers. This chapter then concludes with implications for future work in this area.

7.2 Recommendations for DANZ adult programming

The findings chapters provided detailed analysis of the women's sexuality-related knowledge and experiences. Chapter 4 established the importance of sufficient opportunities to develop understanding of key sexuality concepts because of the role they play in subsequent sexuality experiences. Women in the Asian and Pacific group had less access to sexuality-related information with the family, in school, and among peers. As a result, they demonstrated limited understanding of key sexuality concepts, such as sexual agency, personal rights, pleasure and desire, sexual and reproductive

health, and HIV/AIDS. This information was critical in supporting their subsequent sexuality experiences. Leilani and Sereana both discussed sexual experiences in regretful terms, while Kyla and Sereana disclosed intimate relationships that ended badly.

In comparison, Emily had the greatest access to a comprehensive range of sexuality-related information through formal and informal sexuality socialisation sources. As a result, she reported the most positive experiences, whether menarche or intimate relationships, and also demonstrated a broad sexuality knowledgebase.

Lara, Amy, and Jessica reported reduced sexuality socialisation opportunities through family or school, but all three indicated an ability to develop understanding from literary sources and Deaf intimate partners. As their knowledge grew, and they had greater exposure to others who used NZSL, like intimate partners, their experiences were reported in more positive tones.

Therefore, ensuring sufficient opportunities to develop an understanding of sexuality-related concepts is one of the most important needs, often paving the way for positive sexuality experiences. As DANZ is the consumer and service organisation for the Deaf community, it is in a unique position to address this need through improvements in two areas: the development of adult education programmes and sexuality information resources.

7.2.1. Community education programmes for Deaf women

The creation of a workshop series or a women's camp is an ideal opportunity to provide information in a group setting for those who are comfortable with open discussion of sexuality topics. This format would support Deaf cultural practices of peer education by enabling Deaf women to discuss their thoughts with others and collectively develop an understanding of sexuality-related topics (Joseph *et al.*, 2005; Roberts, 2006). Amy, Lara, Emily, and Jessica considered this a valuable contribution to the information available to the community. As Amy explained:

> You could have courses a multiple number of nights, or gatherings
> where people could learn various things in a certain amount of time and

not just a one-off, go home, see you later, but an on-going series with
activities and connections. I think that would be helpful.

However, Sereana and Leilani did not feel that would be an appropriate channel,
reflecting their discomfort with public disclosure of sensitive topics such as sexuality.
Sereana elaborated:

If we're talking about having a women's camp that would talk
about things like we are right now, it would feel a little bit out of
place. We wouldn't be able to share personally in the women's
camp.

This variability suggests that community education programming should be provided in
different formats to support the diverse needs of the Deaf community. In terms of the
concern raised by Sereana, an alternative would be the availability of education in small
group settings that would afford more privacy. Leilani, Emily, and Jessica also
mentioned the importance of having this information provided by a Deaf person. This
has previously been identified as an important component for effective sexuality-related
education with Deaf people (Gannon, 1998; Getch *et al.*, 2001).

While the education should address some of the crucial health and safety issues
identified in this project, such as HIV/AIDS and biological processes, it should also
provide an opportunity for Deaf women to explore positive aspects of sexuality, an
exercise that facilitates experiencing their complete, balanced sexual selves (Job, 2004).
Therefore, community education programming should include the sensual aspects of
sexuality-related information, such as desire, agency, pleasure, and communication
(Jackson & Weatherall, 2010; Swartz, 1993; Gannon, 1998). In addition, Emily noted
the need for specific information about certain life stages, such as motherhood:

There's a lot of information out there about pregnancy, being a mum,
looking after baby, and how to look after yourself, because your body
changes a whole lot, and it's quite significant. We need access to that.

Thus, it is important that such education is sufficiently comprehensive to
support sexuality development and experiences across the lifespan. Since the
Ministry of Education provides funding for this type of education through the

Tertiary Education Commission, it is feasible to request financial support for programme development.

7.2.2. One programme developed with DANZ

After the data was gathered and interpreted, I met with Moana at the DANZ branch, who had been involved as collaborative research partner. We reviewed the findings and discussed possibilities for converting these insights into benefits for the community. She supported development of a series of women's workshops and subsequently introduced me to the DANZ staff member responsible for coordinating community education , who ultimately approved the idea. Beginning in the middle of 2013 and continuing until early 2014, I met with the DANZ staff member several times to discuss programme content, length, and format. Amy was also present during those meetings because of her work in the Deaf community and involvement in this project.

The outcome of those meetings was a series of six workshops specifically tailored to the needs of Deaf women. Topics for the workshops were: consensual versus non-consensual sexual experiences, sexual and reproductive health, healthy versus unhealthy intimate relationships, sexuality and queer experiences, physical health, and communication. Also included was an emphasis on the physical aspects of sexuality, such as biological processes, motivated by the findings of this study, but when possible, information was provided about the sensual aspects of sexuality-related experiences, such as how healthy intimate relationships can feel and the potential for personal agency within them.

A summary sheet was developed that introduced me, personally, as well as listing the workshop topics and content. This sheet was sent to community relations staff at regional DANZ branches and they were given freedom to choose to make the workshops available, but implementation is still ongoing because of limited funding and difficulties with scheduling. As a result, I have only facilitated two workshops to date, and both workshops were delivered to the same group of Deaf women. Four additional workshops are scheduled for implementation in two additional areas by the beginning of 2015.

While the workshop participants were not an official part of this research project, their comments shared within the workshops provide additional support for the findings in this study which indicate limited sexuality-related knowledge among some Deaf women. For instance, one workshop participant was in her mid-40s and developing, for the first time, an understanding of the laws around when a person can and cannot consent to sexual activities. Another woman in her late 30s was excited to learn conflict resolution techniques within intimate relationships. Therefore, programming has been developed that has been influenced by the accounts shared by the women in this project and is already supporting the development of sexuality-related knowledge and positive experiences of other Deaf women.

Although promising, this programme is only a stepping stone. Ideally, this type of programming should be implemented by a Deaf woman, which would remove the obstacle imposed by my reliance on a professional New Zealand Sign Language (NZSL) interpreter while facilitating workshops. It would also ensure that Deaf women are able to reflect on the information and build meaning with others like them, which would engender a richer understanding of sexuality-related information. Furthermore, this type of programming should be delivered within a multicultural framework that takes into account the diversity of Deaf women in New Zealand. To this end, it would be beneficial to have a co-facilitator from a similar religious or ethnic background as programme participants so the co-facilitator could ensure that the information is presented in a culturally-sensitive manner.

7.2.3. Develop sexuality information resources

The findings of this study also indicate that sexual health information contained in pamphlets, such as the Ministry of Health pamphlet reviewed, may be inaccessible to Deaf individuals with limited English literacy because of the complex wording and professional jargon involved (Suter *et al*., 2009; Heuttel & Rothstein, 2001; Joseph *et al*., 1995). As Sereana explained, "Some Deaf people are okay with reading. Not all of us." Therefore, DANZ should advocate for collaborative projects with the Ministry of Health to ensure that Deaf women have access to the sexuality information that is their protected right through several pieces of national and international legislation (United Nations [UN], 2008; Office of Disability Issues [ODI], 2001; ODI, 2006).

Ideally, this would mean the generation of visual materials in NZSL, created especially for a Deaf audience. As Jessica explained, "I'm a visual person and I like visual information in New Zealand Sign Language." In addition to linguistic needs, it will be important to design materials with the developmental needs of Deaf women in mind to ensure that information is conveyed at an appropriate knowledge level without assuming a basic understanding that may not exist (Fitz-Gerald & Fitz-Gerald, 1978; Joseph *et al*., 1995; Heuttel & Rothstein, 2001; Suter *et al.*, 2009). This is where the expertise that DANZ has may be truly beneficial.

Noteworthy is that all women in this study identified DVDs, as opposed to online videos, as the preferred format for sexuality information resources. As Leilani explained:

> It would be good to see [information] on a DVD with someone signing it, but not give access to the parents because of their culture. [It should be viewable] in private. I don't understand, reading [things] without images. But on a DVD, with someone signing it and showing us what the words mean, yeah, that would make it easier.

Therefore, a DVD would enable women to access their preferred information, and on their own terms. Amy expressed a similar desire for DVDs because of the privacy afford and obvious potential to revisit the material. She noted:

> A lot of Deaf people are very, really value being independent. So, a DVD [instead], you could take that home and watch it in your own time and privacy, even several times. But, you wouldn't want to be looking at a website in a public place. So, a DVD, you could probably watch it in a little bit more privacy.

This information could be made available through resource libraries at regional DANZ branches. However, as some Deaf women may live in remote areas or may feel uncomfortable hiring a DVD, it would still be beneficial to make this information available online as well. This is particularly crucial because HealthEd, a health information website co-managed by the Ministry of Health and Health Promotion

Agency, currently provides no information in NZSL.

The lack of online information is problematic because Article 6, 9, 21, and 25 of the United Nations Convention on the Rights of Persons with Disabilities protect the rights of Deaf women to information in sign language, while 25 specifically protects the right to equal access to health care programmes (UN, 2008). In addition, the New Zealand Sign Language contains guiding principles for the government's provision of information in NZSL (ODI, 2006).

Since development of these materials may be time intensive and costly, DANZ should also create a guide for improving accessibility of printed materials that can be shared with the Ministry of Health in the meantime. The guide should contain straightforward recommendations for the type of language appropriate in sexuality information resources, and should also stress the importance of avoiding the use of verbally-loaded text that contains idiomatic expressions or are written at an advanced level (Bat-Chava *et al*., 2005; Suter *et al*., 2009 Baker-Duncan *et al.*, 1997; Roberts, 2006; Fitz-Gerald & Fitz-Gerald, 1998). It should also emphasise the importance of sufficient visual imagery and present information in smaller, condensed formats, such as cards or posters (Getch *et al.*, 2001; Gannon, 1998; Job, 2004).

Using the Ministry of Health pamphlet as an example, several women in this project noted the importance of such adjustments. For instance, Lara commented that "plainer English…basic English" would have helped make the pamphlet more accessible, while Jessica noted that "having the text matching the images" would have helped connect important concepts. Sereana and Leilani also supported this recommendation:

> Sunshine: Do you think anything else could help…make [printed material] more accessible to Deaf people?
>
> Sereana: Um, pictures and you know, arrows, graphics that connect to different things, like labelling.
>
> Leilani: Like a picture of a tree with a line to the word. Like a family tree. Or a flow chart. I like that.
>
> Sereana: Yeah, labels with words that point to various things on an image, like a diagram.

While this guide would be helpful for improving the accessibility for some Deaf women, it may still pose a problem for those with limited English literacy and should consequently be considered supplementary to the development of materials in NZSL. In addition, while the recommendations for the development of sexuality information resources were discussed in terms of collaboration opportunities with the Ministry of Health as a result of the focus of this research, the recommendations can (and should) be applied to development of other resources as well. For instance, the guide could be available on the DANZ website for other organisations to access.

7.3 Recommendations for DANZ youth programming

Research from the United States has shown that sexuality education with Deaf children should begin as early as possible to avoid the potential negative outcomes that result from misinformation or an absence of information, such as risky sexual practices and vulnerability to abuse (Baker-Duncan *et al*., 1997; Joseph *et al*., 1995; Swartz, 1993). The women's accounts also demonstrated the significant difference it can make on sexuality knowledge development and even the quality of sexuality-related experiences, such as intimate relationships and sexual activities.

For instance, Emily was the only woman who reported sufficient opportunities for formal and informal socialisation opportunities while young, and subsequently demonstrated a detailed understanding of sexual and reproductive health, personal agency, sexual self-concepts, and the role of communication in the negotiation of desire, boundaries and pleasure. As a result, her descriptions of her first and current intimate partner and sexual experiences indicated a high level of intimacy, closeness, and support.

The positive progression of accounts shared by Lara, Amy, and Jessica indicate they eventually established similar meaning around those topics, but it was delayed and occasionally resulted in frustration. As an example, Lara lamented not having:

> Discussions with my friends…my mum or someone, something…to understand what a relationship really meant.

This limited access to information resulted in the three women learning by doing, which did not always result in positive experiences. For instance, Lara and Amy indicated their first intimate relationships were with hearing men, which they did not find enjoyable because of limited communication and limited knowledge about what intimate relationships entail. However, they did develop a broad sexuality-related knowledge as a result of informal socialisation opportunities with literary sources, peers, or personal experiences. Their reports indicated that their experiences improved most when they became involved with their current intimate partners who were Deaf. From a social constructionist perspective, this would have introduced unparalleled opportunities for shared communication and meaning-making with their partners, a situation which supports sexuality knowledge development and experiences.

In comparison, the women from the Asian and Pacific group appeared to have the least access to formal or incidental sexuality-related information while young. From the women's comments, it seemed their status as Deaf women exacerbated religiously-influenced cultural beliefs held by their family. For instance, Leilani shared at one point:

> It's different for me because I feel like I'm Deaf and [of Pacific
> heritage]. Like I wanted to do my own thing, but they were really tough,
> my parents. They were different.

In fact, all the women described early socialisation experiences with their family using the terms, "tough," "difficult," or "hard" because of the strict messages that did not provide adequate opportunities to understand or experience aspects of sexuality. As an example, Leilani and Kyla were provided prohibitive messages about sexual activities, such as when Leilani's family said: "Don't have sex. Don't get pregnant or you'll get in serious trouble." Therefore, both came to understand sexual experiences as only serving procreative purposes.

As a result of those experiences, and limited English literacy, the women in the Asian and Pacific group reported delays in conceptualisation of sexuality-related topics. For instance, Sereana indicated she did not develop full understanding of puberty, including breast development and periods, until she experienced menarche at 12 or 13 years of age. The women in the Asian and Pacific group also demonstrated limited understanding of personal agency, especially with negotiation of boundaries or desire, which partially

influenced the experiences of regret all three reported with intimate relationships or sexual activities.

7.3.1. Education programme for Deaf youth

Since the women's accounts illustrate the positive effect of early access to sexuality-related information which can impact subsequent experiences and sexuality development, DANZ should incorporate sexuality-related information into the educational programming that they provide to Magnet, their youth arm. This programming should be implemented in the form of workshops, or small group discussions, at the regional camps hosted throughout the year by Magnet in order to remain logistically feasible, given the geographic distance separating many Deaf youth.

When creating the programming, care should be taken to develop it in a culturally sensitive manner. Accounts shared by the women in the Asian and Pacific group indicated they appeared uncomfortable with open discussion of sexual experiences and sexuality in general. They also valued respect for the family, including their religiously-influenced beliefs, and privacy. Thus, the educational programming should reflect those needs, and ideally, should be presented by someone from a similar religious or ethnic background.

In addition, programming should support the development of sexuality-related knowledge, preferably through interactive sexuality-related information that provides opportunities to role play and compare behaviour with others (Suter *et al.*, 2009; Swartz, 1993; Joseph *et al*., 1995; Fitz-Gerald & Fitz-Gerald, 1978). Peer education from other Deaf youth, and access to adult Deaf role models, should also become an integral component because of the opportunities provided by incidental learning (Heuttel & Rothstein, 2001; Roberts, 2006).

These workshops should provide straightforward information about a range of sexuality-related topics that will allow Deaf girls and adolescents to develop an understanding of key concepts in an environment free from embarrassment or feelings of shame (Job, 2004). Topics identified in this project as important for inclusion are: personal agency in sexual experiences or intimate relationships, the role of

communication and intimacy within relationships, the potential implications of sexual experiences that involve alcohol, the negotiation of desire or boundaries, and sexual as well as reproductive health. Providing this programming will enable Deaf girls and adolescents to develop a comprehensive sexuality knowledge base, which will empower them to make fully informed decisions and will support their negotiation of the nuanced aspects of sexuality.

7.3.2. Support for hearing families with Deaf children

DANZ should also provide education programmes for hearing families to support them in the sexuality socialisation of their Deaf children. The education could provide information about sexuality signs and tools for comfortably, as well as effectively, communicating sexuality information to Deaf children (Gabriel & Getch, 2001; Job, 2004). The programming could also include tips for beginning conversations, understanding the needs Deaf children have in accessing sexuality information, and how to support opportunities for formal and incidental knowledge development (Fitz-Gerald & Fitz-Gerald, 1998; Roberts, 2006). Parents should also be encouraged to work closely with sexuality education programming in schools to supplement or reinforce the information at home (Getch *et al.*, 2001; Suter *et al.*, 2009).

As with the educational programming for youth, it would be beneficial to develop this in collaboration with a range of ethnic and religious organisations to ensure that accurate information is shared in a culturally appropriate manner. It would also be beneficial to have the programming delivered by Deaf adults who could serve as mentors to both the hearing parents and the Deaf child. As Emily noted:

> It would be good if you could have mentors, Deaf people, visiting schools or families, talking about relationships and health. Deaf people talking to other Deaf people, learning more and [creating] a better understanding.

The mentors could provide sexuality information to parents so they could support the early, positive sexuality socialisation of the child. The adult Deaf mentors could also support Deaf youth by serving as adult role models, which has been identified as an important function in sexuality development in Deaf children (Getch *et al*., 2001; Job,

2004; Suter *et al*., 2009). As Gannon (1998) explains:

> Individuals who are Deaf can...personalise sexuality issues. In HIV
> education, this can reduce the "it can't happen to me" attitude. In other
> aspects of sexuality [development], such as self-esteem, mentors
> provide a face with a subject matter and a success story. It is a way to
> promote positive sexual behaviour and attitudes through modelling,
> instead of just through lecturing (p. 291).

The development of an education programme involving adult Deaf mentors could be
done collaboratively with the two Deaf residential schools, Van Asch and Kelston Deaf
Education Centres, both of which have previously run Deaf mentor programmes that
were highly regarded by hearing parents and the Deaf community (Powell & Hyde,
2013; Human Rights Commission, 2013; McKee & Smith, 2003). It could also
incorporate the Ministry of Education, which has allocated additional funds for
education programmes for hearing families with Deaf children as a result of
recommendations made in the *The New Zealand Sign Language Inquiry* (Human Rights
Commission, 2013).

7.4 Recommendations for sexuality education in schools

While outside the range of services provided by DANZ, the sexuality education
experiences within school that were reported by several of the women necessitate
recommendations for sexuality education in New Zealand schools. The Health and
Physical Education Curriculum provides a framework for delivering comprehensive
information about sexual and reproductive health, personal and interpersonal skills, and
even information about gender or sexual identities (Ministry of Education, 1999). On
the other hand, the remarks shared by Emily and Amy about pictures of sexually
transmitted infections and reproductive stages provide support for findings in other
studies that practical implementation of the curriculum still results in an emphasis on
risk minimisation and disease prevention (King, 2011; Allen, 2007; Jackson &
Weatherall, 2010).

Nevertheless, the accounts shared by the remaining women indicate that even basic sex

education is inaccessible to some Deaf women. Lara, Jessica, and Kyla all specifically stated they did not have sufficient opportunities to develop an understanding of key sexuality concepts. Lara provided a poignant summary:

> Sex, puberty, relationships...being mainstreamed most of my life, I feel like I've missed out on all of that kind of information. I wasn't even educated properly.

The ineffectiveness of formal sexuality education was also implied through the limited sexuality knowledge demonstrated by some of the women during the Ministry of Health pamphlet review. Sereana thought HIV/AIDS was something "gay people" got, Leilani did not have a concept of the word "transfusion," while Kyla asked a simplistic, yet concerning question, "What is HIV?," which was followed later by an inquiry about the effect of first intercourse on a woman's hymen. As each of these women attended secondary school after implementation of the curriculum, their comments illustrate a failure to support some Deaf students in building meaning about one of the most frequently discussed sexuality topics in sexuality education.

As these women were not given adequate opportunities to develop an understanding about sexually transmitted infections or anatomical features, it is not surprising that they demonstrated limited understanding of more nuanced sexuality topics, such as personal agency within intimate relationships or sexual self-concept. Without such information, they were vulnerable to regrettable sexual experiences and were not able to actualise fully more positive sexuality-related experiences, as expressed in Sereana's remarks about having sex to please partners and her decision to remain single.

While Lara and Jessica indicated a similar absence of personal agency and sexual self-concept in their formal sexuality education, they were able to develop an understanding of this information through the literary sources they accessed. This, in turn, may have contributed to their broader sexuality knowledgebase and sexual embodiment.

One of the most basic problems identified by Jessica, Lara, and Kyla was the inability to understand the educator because of limited or no interpreter availability in mainstream education settings. There is an educational as well as a legislative imperative to provide

this service as it is the only way to support the effective education of Deaf students and protect their right to information in their primary language (Office of Disability Issues[ODI], 2001; ODI, 2006;United Nations [UN], 2008). Previous calls have been made for this in several New Zealand studies or reports (Mckee & Smith, 2003; Powell & Hyde, 2013; Human Rights Commission, 2013).

In addition, it is important that interpreters, and the educators who they are interpreting, are skilled in supporting sexuality knowledge development. Therefore, specialised training should be offered to provide hearing interpreters and educators of Deaf students in mainstream settings with basic sexuality information, ethical and cultural considerations, sexuality vocabulary, and the cognitive needs of Deaf students in building meaning around these topics.

To accomplish this, the training should emphasise the importance of breaking down abstract concepts, such as "affection" or "romance," providing repeat exposure to ideas to support development of concept clarity, and providing experiential and tactile learning opportunities, such as role-play activities and imaginative games, to enhance the development of sexuality-related knowledge (Getch *et al.*, 2001; Fitz-Gerald & Fitz-Gerald, 1998; Suter *et al.*, 2009). It should also feature a discourse of desire and provide information about how to support student understanding of pleasure, personal agency, sexual self-concept, desire, intimacy, and communication (Jackson & Weatherall, 2010; Allen, 2004; Swartz, 1993).

These two types of training should be supported by the Ministry of Education as they developed the The Health and Physical Education Curriculum and the *Special Education 2000* framework that guarantees an inclusive education through the provision of education supports for teachers and students.

7.5 Conclusion

This study demonstrated several strengths as a research project. It added to the limited body of literature about Deaf experiences in New Zealand, including ethnically diverse Deaf New Zealanders. It did this in a manner that was supportive of their needs by incorporating New Zealand Sign Language and Deaf cultural features, such as group

information sharing. Although, the most significant contribution was that it was the first of its kind to explore a comprehensive range of sexuality-related information and experiences of Deaf women, highlighting strengths as well as vulnerabilities.

This study accomplished these things by recruiting Deaf women through a variety of Deaf-friendly formats, such as videos in NZSL and face-to-face recruitment. Women who were initially interested in participating were invited to an information session where detailed about the project were provided through NZSL interpreted information that was created for a Deaf audience. The seven women who agreed to participate were split into two groups, based on pre-existing friendships, in order to facilitate narrative development. The groups were then invited to separate focus groups where a Deaf woman co-facilitated the discussions.

The findings from the women's accounts during those focus groups provided rich, descriptive data about how they built meaning around sexuality concepts and how that knowledge influenced subsequent experiences. The women with greater access to sexuality-related information from family, peer, and literary sources demonstrated the most comprehensive knowledge. They also reported their experiences with intimate partners and sexual activities more positively. Access to others who could communicate in NZSL, either within the family or within the intimate relationship, was also influential in supporting positive sexuality development.

Therefore, recommendations were made for the information and services provided by Deaf Aotearoa New Zealand to support positive sexuality knowledge development and experiences. The recommendations included:

1. Develop community education programming for Deaf women.
2. Develop sexuality-related information resources.
3. Develop educational programmes for Deaf girls or adolescents.
4. Provide educational programmes for hearing families to support the sexuality development of their Deaf child.

Two additional recommendations were made to improve the formal sexuality education available to Deaf students by increasing interpreter availability and equipping classroom

teachers, as well as interpreters, with the tools necessary to support sexuality knowledge development with Deaf students. While outside the specific range of DANZ programming, they were considered essential.

There were limitations with this study. The small sample size limited the amount of information that could be included in this project. The reliance on a professional NZSL interpreter may have affected the quality of the discussions in some way. In addition, the need for privacy when discussing sexuality, expressed by the women in the Asian and Pacific group, may have been better supported in one-on-one interviews.

Future work in this area could explore the experiences of a broader range of Deaf women, including Māori , lesbian or queer, or those living in remote areas, to understand what variations may occur and how to adjust the DANZ programming to reflect that diversity. It may also be worthwhile to examine the current sexuality education programming available to Deaf student to determine if there is a need to develop new materials that are tailored to specifically support the sexuality development of Deaf students in an accessible manner. Furthermore, the findings from this study, and subsequent studies, could be used in requests for increased support in the implementation of national and international pieces of legislation that should protect the rights of Deaf women to sexuality-related information and services.

Appendix A

Appendix B

MEMORANDUM

Phone	0-4-463 5676
Fax	0-4-463 5209
Email	Allison.kirkman@vuw.ac.nz

|	
TO	Sunshine Prior
COPY TO	Allison Kirkman Rachel McKee
FROM	Dr Kathy Nelson, Acting Convener, Human Ethics Committee
DATE	6 July 2012
PAGES	1
SUBJECT	**Ethics Approval: 19010 Sexuality Narratives Among New Zealand Deaf Women: An Action Research Approach**

Thank you for your request to amend your ethics approval. This has now been considered and the request granted.

Your application has approval until 1 March 2013. If your data collection is not completed by this date you should apply to the Human Ethics Committee for an extension to this approval.

Best wishes with your research.

Kathy Nelson
Human Ethics Committee

Appendix C
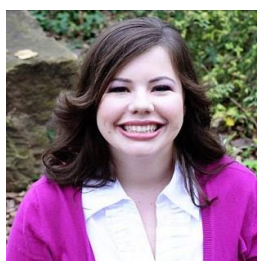
Sunshine Prior
Masters Student in Social Policy
Victoria University of Wellington

Research aims

1. I am a hearing research student at Victoria University. I want to research about Deaf women's experiences and views about:
   - o Relationships
   - o Sex
   - o Growing up
2. This study has ethics approval.

Why am I interested in researching Deaf women?

1. I am from USA, and I used to work with Deaf women in Texas.

2. I helped them with learning how to read, leave school, getting jobs, and counseling.

3. I was a counselling assistant. I talked with the women about their bodies, dating relationships, and get better after rape or abuse.

4. Now, I want to talk with Deaf women about these topics.

What does it mean if you want to be involved in the research?

1. I will ask you questions about your experiences.

2. You can choose to answer questions in a focus (discussion) group or on your own (interview).

3. Anything we talk about will be confidential.

4. All sessions will be videotaped, audiotaped, and transcribed (written down).

5. There will be a Sign Language interpreter for all interviews and focus groups.

6. Sunshine Prior will do the interviews (one-on-one).

7. Sunshine Prior and a co-facilitator will do the focus (discussion) groups.

8. Interviews will be 1 hour. Focus (discussion) groups will be about 2 hours.

9. If you want to stop (not include your comments in the research), you can tell me up to four weeks after your interview.

10. You cannot stop (not include your comments in the research) if you participate in the focus group.

Feedback opportunities

1. After I have collected information from group discussions and interviews, I will invite everyone to a meeting. I will explain to you what I found out from everyone (no names).

2. You can add comments and feedback to make sure my research information is correct and true. You can also offer suggestions for what I should do next.

3. When I have finished writing the research, I will again invite everyone to a meeting to review the final results. If you cannot attend the meeting, I can send you a final report by email or post.

Privacy and confidential

1. I will keep the information for two years (consent forms, transcripts, and your comments).

2. Only my supervisor and I will see the original videotapes and transcripts.

3. I will not use your names in anything I write.

4. I will use quotes from the focus groups and interviews in my research. Again, I will not use your names.

5. I may share what I found out from my research in articles, books, or at a conference.

Questions? Email.

Thank you.

Appendix D

TE WHARE WĀNANGA O TE ŪPOKO O TE IKA A MĀUI

VICTORIA
UNIVERSITY OF WELLINGTON

Confidentiality Agreement

I have read the information about this research and understand it deals with sensitive issues surrounding sexuality.

I agree to protect the confidentiality of the research participants and will not disclose any information obtained during the interviews or focus groups with any outside parties.

Name: _____

Signature: _____

Date: _____

Appendix E

Focus Group Rough Draft

➢ Welcome and introductions
1. Complete demographic forms and sign consent sheet.
2. Overview of focus group structure (i.e. We will begin with early experiences and move to more recent ones).

➢ Explanation of information packs
1. Explain three categories of information.
2. Review contents in each category.
3. Ask women to review one brochure.
   ▪ Then ask them to point to the portions they understood.
   ▪ Ask them to explain those portions.

➢ First theme: Where and how women got information when they were younger.

1. When you were a teenager, who were the people you trusted the most?
   ▪ Example: Parents, other family members, friends, school staff, etc.

2. What kinds of information or support did you go to them for?
   ▪ Example: Help with school work, life issues, friend troubles, general questions, etc.

3. Did anyone ever talk with you about the changes associated with puberty?
   ▪ Example: Growth spurts, hormone changes, menstruation, acne, etc.
   ▪ Follow up question: What kinds of things did they say?

4. Who did you talk to when you wanted to know about dating relationships?
   ▪ Follow up questions: What kinds of things did they say?

5. Where did you go for information about sex or sexual activities?
   ▪ Example: How to do things, when to do things, birth control, what was good/bad, etc.
   ▪ Follow up questions: What kinds of things did they say?

- Second Theme: Positive and negative sexuality experiences.

    1. Okay, now think back to your own first dating experience. What was that like?
        - Example: Fun and flirty, awkward, too fast, too slow, loving, mean, etc.

    2. What are some of the joys or rewarding experiences you've had with dating relationships?
        - Example: Someone to talk with, do things with, love, laugh with, someone to care for and be cared for, etc.

    3. What are some of the struggles you've had with them?
        - Example: Disagreements, fights, cheating, abuse, etc.

    4. Okay, what about your own first sexual experience. What was that like?
        - Example: Enjoyable, awkward, caring, uncaring, too fast, too slow, etc.

    5. What are some of the joys or pleasures you've experienced with sex?
        - Example: Feels good, intimacy, closeness, feels good, etc.

    6. What are some of the less enjoyable things you've experienced with sex?
        - Example: Confusing, painful, awkward, no communication, etc.

- Wrap up questions
    1. What information do you think Deaf women would find beneficial about some of the things discussed today, such as changes associated with getting older, relationships, or sex?

    2. If you had to rank them, what would you consider the most important information to share with Deaf women?

    3. What do you think is the best way to share that information?
        - Follow up question: How do we get Deaf women interested in that?

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