Support worker's understanding of the sexual and reproductive health and rights of women with intellectual disability

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Abstract

Women with intellectual disabilities (ID) face significant challenges to their sexual and reproductive health and rights (SRHR). Sexual ableism and gendered assumptions limit their sexual agency and access to education and services. They also contribute to high levels of physical and sexual abuse in this population. Support workers caring for women with ID under in residential disability services play a key role in supporting, or further obstructing, the SRHR of these women. However, there is little research on this topic internationally and almost none in Aotearoa New Zealand. Therefore, the purpose of this research is to explore support workers' understanding of this topic. Framed within a feminist constructionist approach, a reflexive thematic analysis was used to explore patterns in language use: constructions of women with ID's sexuality and needs, the support worker role, and how support workers position themselves and others in their accounts. I considered the wider implications of these constructions for the agency of women with ID and their SRHR. I developed four main themes: (1) "a working relationship like no other"; (2) "powerless and invisible women"; (3) "what if it gets complicated"; and (4) "in the absence of guidance". The findings highlight a tension between managing potential risks to the women in care, while enabling their sexual expression, as discourses of victimisation, human rights, gender, and ableism intersect in various ways. Based on the findings, I suggest opportunities for developing training and policies to help support workers empower women with ID and discuss future directions for research in Aotearoa New Zealand.

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Chapter One: Literature Review

Support workers for people with intellectual disability (ID) play an important role in supporting their sexual and reproductive health and rights (SRHR). Women with ID who live in residential disability services rely on their support workers to provide sexual information, guidance, and opportunity for sexual expression (Charitou et al., 2020). Moreover, support workers' understandings, assumptions, and values often impact the ways care is provided, for example, in administering assessments to determine the support needs for people with ID frequently used by disability services (Rugoho & Maphosa, 2020). Despite the significant impact that support workers have on the lives and choices of women with ID, there is little research that focuses on women with ID's SRHR.

This lack of knowledge forms the rationale for my study which explores the role support workers play in regulating, enabling, and restricting the sexuality of women with ID who reside in residential services in Aotearoa New Zealand. It was motivated by my own experiences of working in the country's disability sector. A key focus of my role was to provide people with ID with greater autonomy and quality of life by developing practice improvement initiatives for support workers to improve the general understanding of the needs of people with ID. Through my conversations with people with ID, support workers, and other roles within the sector, I recognised there was a gap in the support systems for enabling the sexual health of people with ID.

Enabling the sexual health rights of people with ID is not prioritised (Charitou et al., 2020), which I believe is influenced by the constraints within services such as contracts, funding, and risk management. As I continued my post-graduate study in violence and trauma, I focused on the experiences of people with ID and, in doing so, developed a sexual education programme that was able to be individually tailored to meet the needs and current understanding of sexuality.

My study is situated within a feminist constructionist framework, which I describe more fully in chapter two. One of the reasons feminist constructionism is helpful for my research is that it draws attention to the sociocultural and historical contexts that impact how we understand the world and how we behave. To use the religious and gendered discourse of sexual purity as an example, historically, unmarried women who had sex were labelled as impure, defective, or deviant in many cultures. In doing so, societies reinforced beliefs that women can only have sexual relations in "wedlock" and, thus, unlike married men, removed women's autonomy to express their sexuality outside of the marital relationship. Looking through the lens of social constructionism, we are able to highlight and explore the categories we use to make sense of the world are created in and through communication and social practices (Clarke, 2002).

Categories, such as disability, gender, and sexuality, are embedded in and reproduce the assumptions that shape our reality (Bernert & Ogletree, 2013). Historical, political, and cultural contexts are all factors that influence our assumptions. These beliefs serve to restrict and regulate the sexual freedom and agency of women with ID (Dillaway et al., 2019). However, feminist constructionists suggest our social labels can be reconsidered given how our understandings change. If they are not fixed, then we can change them to create a world with greater equality (Clarke, 2002), which is the rationale for the research approach that I have taken.

In this chapter, I discuss the history of women with ID and the recent policy changes that aim to promote a rights-based system. I then explore the discourses of sexual ableism, gender, and race, and the influence this has on the lives of women with ID. Following this, the limited sexual health services, support and opportunities for women with ID are reviewed, leading to a discussion of institutional support for women with ID.

1. Background

As O'Shea and Frawley (2019) assert, "dominant discourses establish the ways in which women with intellectual disabilities are constructed, defining how they can (and cannot) know themselves and be known by others" (p.656). With this in mind, it is essential to consider how women with ID have historically been viewed and treated in relation to their SRHR, as this informs how they are treated currently and how we might intervene. In doing so, it is essential to consider that much of the research about the historical treatment of women with ID comes from a western context. Therefore, the social expectations and assumptions that inform this work may not be consistent with other cultural or indigenous understandings.

Before I discuss the historical treatment and assumptions of disability, I wish to acknowledge the language I have used throughout this research, given the discriminatory language that has been used to construct disability over the years (Walmsley, 2020). I have chosen to use the terminology "women with intellectual disability" to align with the language in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006). Furthermore, such person-first language positions women as women first and places the disability as one of many characteristics of a woman, reducing the stigma and generalisations associated with the disability (Achey, 2020). Aotearoa New Zealand has determined "disabled women" to be the preferred language of choice (Office for Disability Issues, 2020). It suggested that person-first language does not acknowledge that the disability results from disabling social systems external to the individual (Ministry of Social Development, 2019). However, the people with ID I have worked with over the years have favoured the "person with ID"

language. For this reason, and out of respect to the people with ID I have worked with, I will continue to use person-first terminology.

1.1. Historical understandings of the sexuality of women with ID

Throughout history, and across most of the world, women with ID have had their SRHR violated and repressed, removing much of their autonomy and agency in this area (Alexander & Gomez, 2017). However, little is known about the exact extent and severity of the historical sexual abuse of women with ID due to poor documentation of these incidents and the marginalising and silencing of these women (Llewellyn, 2020). Regarding the cause of these abuses, these violations likely stemmed from the abundance of ableist myths and assumptions circulating about the sexuality of women with ID.

In Western contexts, it was (and to a large extent still is) widely believed that women with ID have either deviant or child-like sexual behaviour such that their behaviour and intimate relationships require monitoring by support workers, or that they have a low or no sex drive (Alexander & Gomez, 2017; Smith Rainey, 2011; Young et al., 2012). An example of this is the belief that women with ID are non-sexual, that is, they have no social-sexual behaviours and reactions (Charitou et al., 2020; Cuthbert, 2020). It could be argued that this was a misperception based on broader views of women's sexuality as passive or dormant. On the other hand, it may well be that women with ID did not demonstrate sexual behaviours due to being socialised in highly restrictive ways. Women with ID have been taught not to be sexual, supported to avoid potential sexual relationships, and denied opportunities for sexuality education. Thus, their apparent lack of sexual desires or behaviour is not necessarily a choice, nor a reflection of their wants and needs, but a result of sexual suppression (Liddiard, 2020).

In Aotearoa New Zealand, at the beginning of the last century, women with ID were subject to labels such as 'feebleminded', and were classified as 'mental defectives' under the Mental Defectives Act of 1911. This Act was informed by the eugenics movement that was popular in the country during the first half of the 1900s (Hamilton, 2012). It served to position women with ID as undesirable citizens who posed a threat to national welfare as potential bearers of 'defective' children (Freely, 2016). These women supposedly lacked both sexual self-control and the capacity to control male sexual advances, and were, therefore, seen as vulnerable to sexual exploitation by men. The focus of concerns was on their potential to get pregnant, their unfitness for motherhood, and the potential to produce children with disabilities. As a result, women with ID were institutionalised from a young age and subjected to forced sterilisation (Freely, 2016; Hamilton, 2012; Wanhalla, 2007). At the same time, the discourse of eugenics positioned sex with women with ID as immoral in order to avoid the possibility they would reproduce. Consequently, there was no differentiation between

consensual sex, violent sex, and abuse of women with ID. Thus, placing women with ID at a significantly higher risk of abuse (Whatcott, 2020).

Like Aotearoa New Zealand, several other countries legislated the compulsory and involuntary sterilisation of women with ID in institutions; this became a legal procedure (Greenwood & Wilkinson, 2013). While professionals and families may argue that their intentions were good, the procedure stripped women with ID of their sexual rights and agency (Daly et al., 2019; Gil-Lario et al., 2017). Furthermore, the practice of institutionalisation hid and excluded women with ID from wider society (Smith Rainey, 2011). Doing so fed into the misconceptions, negative attitudes, and exclusion of women with ID (Senne, 2016).

1.2. The contemporary rights-based view of disability

The United Nations' endorsement of the Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006 formally introduced the human rights approach to disability as a new way of conceptualising disability. The Convention highlights the need to recognise that those with disabilities have the right to the maximum achievable standard of health, including sexual and reproductive health, without discrimination based on disability (Addlakha et al., 2017). In line with this shifting understanding of disability, in recent years, there has been the development of policies and legislation recognising that people with disabilities have the same sexual rights and share many of the same needs and concerns as those without disabilities (Addlakha et al., 2017; Gil-Llario et al., 2017; Frawley & Wilson, 2016).

It should not be assumed that the UNCRPD enables equal rights for people with ID in everyday practices. The assumptions still held around disability create complexity for this to occur. For instance, beliefs about the need to protect women with ID remain common in society which, at times, can conflict with the freedom of choice for the woman with ID (Burns, 2019). To use pregnancy prevention as an example, doctors prescribe contraceptives for women with ID for non-contraceptive purposes (Björnsdóttir & Stefánsdóttir, 2020). In doing so, it camouflages the ability for women with ID to choose motherhood through 'normal' safe sex practices, which differs from historical sterilisation processes that breached rights in a more obvious manner (Walmsley, 2020).

New Zealand's Sexual and Reproductive Health Strategy (Ministry of Health, 2001) recognises the sexual health discrimination against both women and people with disability. The policy also aligns with the Māori Health Strategy, and the Pacific Health and Disability Action Plan. By combining these Strategies, the inequities faced by Māori and Pasifika people in Aotearoa New Zealand are included. However, it does not specify issues related to *women* with disabilities.

In addition to policies and legislation, Aotearoa New Zealand has adopted several international agreements to ensure equality and rights for all New Zealanders. Two of these include the Convention for the Elimination of Discrimination Against Women (CEDAW) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Aotearoa New Zealand endorsed the CEDAW in 1985 to fulfil its purpose of ensuring the equality of women within society (New Zealand Human Rights, 2008). It follows three critical principles of affirming women's legal, civil, and political rights, paying attention to their reproductive rights, and addressing social and cultural stereotypes that perpetuate the discrimination of women.

Aotearoa New Zealand did not adopt the CRPD from the United Nations until 2008 (Human Right Commission, 2010). The CRPD came about because disability is invisible in many other human rights guidelines, which typically reference race, religion, politics, social status, and sex (Series, 2019). Its goal is to ensure every individual's human rights are protected and promoted. These rights include freedom of expression, education, and equal access to community services (United Nations, 2006). While the CRPD, as international legislation, does not specify the support and rights for Māori women with ID, it does identify the importance of acknowledging culture (Series, 2019).

Human rights are essential given the abundance of research demonstrating the barriers women with ID face in this area, as discussed throughout. However, initially, the CRPD was considered disruptive by the public, who did not understand the need for change (Series, 2019). Accordingly, Geiringer and Palmer (2007) suggest that the implementation of human rights in Aotearoa New Zealand will improve with greater communication with the public. Without doing so, the public lack insight and understanding of these rights and therefore, may not adhere to policies the government are trying to achieve. Interestingly, if Aotearoa New Zealand policy aligned with te Tiriti o Waitangi principles of partnership, participation, and protection, they would likely have improved outcomes; that is, the rights and responsibilities to ensure equality for all New Zealanders, including social, cultural, economic and health outcomes (Human Rights Commission, 2010).

Despite these commitments from the government, the strategies and policies in place have not prevented the violation of women's SRHR (United Nations Human Rights, 2021). Indeed, the research on the ongoing challenges faced by women with ID, which I discuss in the following section, raises questions about policy implementation and access to rights in their day-to-day lives. Despite the country's adoption of the international agreements and policy discussed above, women with ID in Aotearoa New Zealand continue to experience challenges to their SRHR (Achey, 2020).

While practices that violate human rights, such as institutionalisation and sterilisation described above, occur far less frequently in recent years, segregation and stigmatisation remain a common and current issue for women with ID (Cwirynkalo et al., 2017; Verlenden et al., 2019).

Durvasula and Beange (2001) provide an example of policy discrimination through the exclusion of cervical cancer screening for women with ID. In addition, the belief that women with ID are not sexually active reduces the push for them to seek treatments such as these. Research in Aotearoa New Zealand presents similar outcomes that have found women with ID are underrepresented in breast and cervical screenings compared to the non-disabled population (Mirfin-Veitch et al., 2016). The reasons for this varies from issues with the health systems, others' attitudes towards disability and sexual health, poor understanding of sexual health needs, and the anxieties of women with ID.

2. Intellectual disability, sexuality, and sexual ableism

People with ID are subject to discrimination around their sexuality and sexual relationships. The socio-cultural constructs that commonly inform this discrimination include the beliefs that people with ID do not have sex drives and are therefore not sexual beings, that they are biologically unable to function sexually, and they lack the skills to make necessary and safe judgements about their sexual behaviour (Hamilton, 2008). These common beliefs stem from a discourse of sexual ableism. Sexual ableism is the discrimination faced by people with disability which deny their rights, access, and value to sexual health (Gill, 2015). It encapsulates characteristics such as gender, appearance, race, and social acceptability, and places judgement on their competence, agency, and ability.

When considering the stigma and discrimination that results from sexual ableism, it is important to consider diversity among people with disabilities that may shape their experiences of prejudice in different ways as ableism overlaps with other forms of discrimination such as sexism, classism, and racism. For this reason, the policies and legislation supporting those with disabilities, discussed above, have been critiqued for lack of attention to diversity within the disabled population (Llewellyn, 2020). This criticism is largely about the disregard of children, but the same may be argued for other axes of difference. Furthermore, while using the term 'people' is inclusive, it fails to acknowledge the different experiences of discrimination experienced by people with disabilities, as disability intersects with age, gender, culture and other social categories.

2.1. The interconnection of ableism with sexism, racism, and classism

Experiences related to disability are closely intertwined with gender, culture, and SES, which together feed into the social inequities experienced by women with ID (Dean et al., 2017). Therefore, it is essential to consider the factors of diversity amongst people with disability. The importance of including women with disability in feminist research has been highlighted as a result of recognising the effects of the overlap of inequities related to gender and disability, as well as other social

categories. Therefore, feminist research that involves women with disabilities challenges the ableist ideals and stereotypes that women with ID often face (Bê, 2019).

These ableist stereotypes are important to address in this research, as the sexual needs of women with ID is primarily constructed as involving pregnancy prevention and protection from sexual abuse (Gill, 2015). However, in acknowledging that women with ID are more vulnerable to abuse than men with ID (Hamilton, 2008; Muswera & Kasiram, 2019), the discourses of pleasure and sexual agency are significantly lacking. Presumably, this avoidance is connected to the eugenics discourse that is still prominent throughout disability support systems (Björnsdóttir & Stefánsdóttir, 2020). Consequently, women with ID experience additional sexual health inequalities compared to men, including forced sterilisation, fear of judgement if they openly talk about their sexual needs, and being viewed as eternal children (Björnsdóttir & Stefánsdóttir, 2020; Gill, 2015).

Women with ID are therefore affected not only by ableism, but also by sexism. For example, women often have less access to social resources such as education and employment, compared to their male peers, contributing to a sense of powerlessness (Dean et al., 2017; Kornreich et al., 2003). For the most part, the issues that women with ID experience differ from those of men with ID (Bê, 2019). For example, a study in the USA found women with ID were viewed as less competent than women with other types of disabilities. This view was not reflected in the perception of men with ID (Coleman et al., 2014). Due to a misunderstanding about their competency, women with ID are often excluded from socially valued roles as mothers, colleagues, or friends (Tefera et al., 2018). This competency discourse decreases self-esteem, confidence, and quality of life (Bahner, 2020). Such social participation is important to one's sense of belonging and capability and improves people's standards of living and self-support (Osburn, 2006). Therefore, when discussing the topic of women with ID, it is important to recognise that ableism, and the disability stereotypes it supports, work together with sexist stereotypes (Coleman et al., 2014).

Gender is not the sole reason women with ID are sexually excluded and discriminated against, as racism also shapes their experiences. For women with ID of colour, ideas about their sexuality may be entwined with a racist discourse. For instance, Māori women have been described as 'promiscuous' and may feel whakamā [shame] when utilising sexual health services due to negative past experiences (Cook et al., 2014, Waetford, 2008). In Aotearoa New Zealand, recognising the perspective of Māori women and the impact of colonisation is important in disability research as people with disability also have lived experiences of cultural marginalisation and oppression (Grech & Soldatic, 2015; King, 2019).

Research indicates that classism also plays a role in the marginalisation women with ID face. For example, one study demonstrated that women with higher socioeconomic status (SES) were more accepted sexually, regardless of the perceived attractiveness. In contrast, women with ID who have

poorer SES are further disadvantaged by their perceived sexual attractiveness (Townsend & Levy, 1990). This research was conducted in the United States and would likely produce different results if carried out in Aotearoa New Zealand, due to the different cultural and social norms. Despite the possible cultural differences, the results are concerning, given the consistent findings that, in general, people with ID have poorer SES than those without disability. For women with ID, this may be exacerbated as they are likely to have even less control of their SES, particularly if they are unable to work, and have reduced choice in where they live through residential service providers (Emerson & Hatton, 2007; Graham, 2005; Morris, 1993).

3. The sexuality of women with ID

Sexuality is a complex human phenomenon that is contextualised by social, biological, psychological, and cultural factors (Parchomiuk, 2021). It encompasses individual and societal values, beliefs, desires, and behaviours. Acknowledgement of the sexuality of women with ID is predominantly absent. Sexuality policies in residential services are typically non-existent, demonstrating the disregard and marginalisation of the sexual needs of women with ID (Muswera & Kasiram, 2019). The marginalised status and gendered experiences of sexual ableism impact the sexuality of women with ID and several consequences for their sexual and reproductive health. For instance, the denial of opportunities for sexual expression and intimate relationships, adverse sexual and reproductive health outcomes, and limited access to sexual information. I discuss each of these consequences in turn.

3.1. Denial of opportunities for sexual expression and intimate relationships

The marginalisation of women with ID can affect them at an individual level, impacting their sexual confidence and desires, and resulting in feelings of shame (Addlakha et al., 2017). Compared to women without disabilities, women with ID have fewer opportunities for sexual expression and partner selection. The reason for this inequality is their exclusion from traditional feminine ideals held by Western society in which sexual attractiveness is typically based on able-bodied women without disability (Bernert & Ogletree, 2013; Christian et al., 2001; Coleman et al., 2014; Healy et al., 2009). This exclusion is exacerbated by the desexualised, and sexually innocent roles prescribed for them, and the negative evaluations placed on those who identify both as a woman with disability and a sexual being (Charitou et al., 2020; Christian et al., 2001).

The opportunity for women with ID to explore their sexuality and form intimate relationships is associated with poor social opportunities within their communities. That is, the exclusion from employment and leisure activities prevents the ability to develop friendships, in addition to forming

positive feelings about themselves and thus, their sexuality (Bates et al., 2020; Gilmore & Chambers, 2010). One reason for this social exclusion may be due to the belief that sexuality is a behavioural issue rather than socially constructed (Deffew et al., 2021). Therefore, the focus of sexuality is solely on the individual's behaviour and ignores potential social opportunities. Furthermore, in some instances, women with ID are punished for engaging in sexual behaviour, demonstrating the understanding that sexuality is controlled individually (Bates et al., 2020; Ginn, 2021).

For women with ID in residential settings, there are environmental factors which contribute to the denial of sexual expression. For example, support workers regularly observe women with ID in their home, or their restricted access to transport to prevent unwanted sexual interaction or intimate relationships (Ginn, 2021). These examples are not limited to disability services, as women with ID have had similar restrictions enforced by their families (Gilmore & Chambers, 2010). In cases such as these, women with ID are positioned as vulnerable or lacking self-control thus, justify the need to restrict their opportunities (Pariseau-Legault et al., 2019). Moreover, restrictions on their sexual agency can lead women with ID to hide intimate relationships from support networks or avoid such relationships with others due to fear of being caught (Alexander & Gomez, 2017; Senne, 2016). This secrecy may place women with ID at greater risk of harm as they may avoid support when it is needed, and increase feelings of shame within their relationships.

3.2. Poor sexual and reproductive healthcare and outcomes

The sexual and reproductive health needs of women with ID are often overlooked. These women face considerable discrimination that ranges from assumptions about their sexual identity, for example, assuming asexuality, to sterilisation without consent (Cwirynkalo et al., 2017). However, this inequality deepens for women with ID, who experience reduced access to contraception, limited choice in their reproductive health, and higher levels of abuse (Christian et al., 2001; Eastgate, 2008; Young et al., 2012). In addition, gendered power relations means that women with ID are often thought to be unreliable, more so than women without disabilities. This can increase the chances of sexual abuse as since these women are even less to be believed than women without disabilities should they report an incident.

Ultimately, the lack of care, alongside marginalisation and silencing, contributes to poor sexual and reproductive health outcomes (Basile et al., 2016; Gil-Llario et al., 2017; Greenwood & Wilkinson, 2013; Public Health England, 2015; Ramage, 2015). Women with ID experience much poorer health outcomes than women without disabilities (Mohamed & Shefer, 2015), with substantial barriers to their sexual health needs in areas such as reproductive health, unintended pregnancy, sexual victimisation, and lack of access to sexual health services, compared to their non-disabled peers (Gil-Llario et al., 2017; Healy et al., 2009; Verlenden et al., 2019; Wu et al., 2019).

These poor outcomes may be exacerbated for women of racial and ethnic minorities due to institutional and systemic racism, and a lack of culturally safe services (Came & Griffith, 2018). In Aotearoa New Zealand, the SRHR for Māori women with ID may be further impacted by their experiences of ableism and racism (King, 2019). For example, non-indigenous sexual health practitioners may misunderstand Māori women's whakamā [shame] when utilising services due to negative past experiences, seeing it instead as resulting from the tapu nature of sexuality and reproduction (Waetford, 2008). A better understanding of these cultural concepts may improve sexual healthcare and the overall SRHR of Māori women (Le Grice & Braun, 2018). Accordingly, young Māori women have reported a preference for their sexual health to be delivered by Māori professionals (Waetford, 2008).

3.3. Access to sexual information

People with ID have a right to access sexual information yet, the opportunities to engage and learn through sexual education are few and far between (Collier, 2017; Greenwood & Wilkinson, 2013). Sexual education is beneficial for people with ID as it encourages egalitarian sexual relationships and intimacy, sexual identity, and reduces the risks of sexual harm (Murray, 2019). For women with ID, it is an opportunity to develop knowledge about how to assess risk, in addition to understanding female pleasure (McCarthy, 2014).

School is the most accessible place for information for most young people with ID (Schaafsma et al., 2017). In Aotearoa New Zealand, school-based sexual education typically follows a universal approach that can be taught to all students (Rohleder & Flowers, 2018). The concern for people with ID begins here. For example, by not considering the different learning styles of people with ID, they may be excluded from this educational opportunity. This is demonstrated in schools where sexual education for people with disability is removed from the curriculum as teachers do not feel equipped to teach this effectively (Moore et al., 2020; Murray, 2019).

The concern is amplified for women and girls with ID, specifically, as sexual education in schools may rely on the teachers' discretion to do what they believe to be appropriate (Mpondo et al., 2018). With the common beliefs that women with ID are less sexual than men, non-sexual, or in need of protection, there is a heightened possibility of dismissing sexual education entirely for women with ID (Charitou et al., 2020; Christian et al., 2001; de Wit et al., 2022). Indeed, women with ID have reported being refused school-based sexual education, or excluded from these classes (Matin et al., 2021).

There are opportunities for women with ID to access sexual education programmes outside of school, but these are limited. Further, the effectiveness of these community programmes is

questioned due to their poor theoretical underpinnings and the lack of involvement of people with ID throughout the development stages (Sala et al., 2019; Schaafsma et al., 2017). Arguably, the greatest concern with community based sexual education is ease of access. Limited financial support, poor transportation to access services, and restrictions from healthcare services act as a barrier to women with ID attending sexual education (Graham, 2005; Matin et al., 2021).

The existing sexual education for women with ID commonly focuses on risk and avoiding harm (Collier, 2017). This emphasis on risk aligns with the literature which identifies a social stigma about the SRHR and pregnancy for women with ID (Agaronnik et al., 2020; Björnsdóttir & Stefánsdóttir, 2020). It is recognised that facilitators of sexual education programmes are positioned to balance the vulnerability and victimisation of women with ID, with the empowerment of positive sexual health (Sala et al., 2019). However, in developing sexual education around risk, many components of sexual health and rights such as pregnancy, safe sex, masturbation, and sexual diversity are forgotten which, paradoxically, increases vulnerability by removing agency and autonomy (Stoffelen et al., 2017).

Another missing component in sexual education for women with ID is the concept of sexual pleasure. Bypassing this topic stems from the belief that women with ID are non-sexual, or physically unable to experience sexual pleasure (Tepper, 2000). This belief is unsurprising due to the influence of western social norms on sexual education, which largely position disability as a deficit (Le Grice & Braun, 2018). It is also worth highlighting that sexual education is typically embedded in heterosexual assumptions of sexuality and therefore, lacks diversity and inclusive representation in curricula (McGuire & Bayley, 2011). Thus, research that suggests the importance of teaching skills to women with disability about the positive expressions of sexuality, pleasure, and intimacy is generally disregarded (Murray, 2019).

4. Institutional support: Residential living and SRHR

Aotearoa New Zealand, like many countries, has implemented deinstitutionalisation for people with ID as community-based services have opened (McCarthy & Duff, 2019). Deinstitutionalisation is the social and political movement to integrate disability services, among other services, back into the community (Bruijn-Wezeman, 2020). It is a fundamental movement for the rights of people with disability to ensure equality, participation, and higher quality care. Despite this change occurring over the last 40 years, there is minimal research that investigates the impact of deinstitutionalisation on support workers in Aotearoa New Zealand.

As the emphasis on disability service delivery evolved, the scope of the support worker role also changed to enable choice, control, relationships, community connection, and safety of people

with ID (Hamilton, 2008; Windley & Chapman, 2010). Unfortunately, as institutions closed, people with ID moved into community-based homes where smaller institutions were created (Burrell & Trip, 2011). Perhaps understandings of intellectual disability did not progress with the movement, despite the environmental changes to institutions. Thus, it can be assumed that support workers' perceptions of and approaches to intellectual disability also remained the same.

4.1. The support worker role

In Aotearoa New Zealand, community residential services are described as a "home-like setting" in the community with 24 hour paid staff support (Ministry of Health, 2016). The expectations of these paid support workers are briefly outlined by government as someone who helps people with ID with everyday activities and supports their community involvement. The job description for a support worker role for disability services will change slightly between organisations. Generally, they are described as being responsible for supporting people with greater independence, their health and wellbeing, and connecting with the wider community (Careers.govt.nz, 2020). From a sexual health perspective, the role of a support worker is to facilitate relationships while keeping people with ID safe (Bates et al., 2020; Maguire et al., 2018). However, such explanations are an over-simplification of the support worker role.

It is not uncommon for women with ID to depend on others, and those supporting them play a significant role in enabling or restricting their sexual agency and wellbeing (Basile et al., 2016). Moreover, the services and staff who support women with ID contribute to shaping who they are as women (Björnsdóttir & Stefánsdóttir 2020). External factors can increase the dependency women with ID have on support workers. For example, reductions in disability benefits for those in residential care may further reduce socioeconomic status, or inability to access social media unaided may increase dependence on support workers for assistance with sexual needs and opportunities (Abbott, 2020; Moore & Slee, 2019). In this way, the role of 'caring' for a vulnerable person often creates an imbalance of power between a support worker and women with ID (Wolowicz et al., 2021).

It has been suggested that this uneven power dynamic is maintained by the lack of visibility between residential services and the community. This further segregates people with disability as they remain unknown and invisible within their community (Llewellyn, 2020). The power imbalance could see a shift if it is recognised that everybody requires some form of care and support from others, despite their diagnosis or social position. This influence on women with ID is concerning when the literature on modern (and deinstitutionalised) disability services presents themes of inadequate quality of life, health care and poor social opportunity (Bruijn-Wezeman, 2020). Nevertheless, new

generations of support workers are joining the workforce, providing hope that they challenge the existing system.

4.2. The support worker role in assisting SRHR

Good social support is crucial for women with ID to have equal opportunity to realise their full SRHR, and reduce the sexual and reproductive injustices they currently face (Hughes, 2006). Toward this aim, much more knowledge on the experiences of women with ID is required, including research that considers support workers as central figures, and potential gatekeepers, in the sexual and reproductive lives of those they support.

There are minimal studies exploring the support workers understanding of the sexuality of women with ID. Some research focuses on the sexuality of both men and women with ID (de Wit et al., 2022; Gilmore & Chambers, 2010; Leclerc & Morin, 2021; Maguire et al., 2018; Muswera & Kasiram, 2019; Pariseau-Legault et al., 2019). However, generalising sexuality across genders disregards the gender bias that women with ID face, such as their fertility, and sexual activity (Matin et al., 2021). The research that explores the SRHR for women with ID does, however, provide consistent recommendations. That is, disability services, support workers, and more broadly, society, must reduce the social stigma and restrictions that are twisted around women with ID and their sexuality (Björnsdóttir & Stefánsdóttir 2020; Conder et al., 2010; Conder et al., 2015; Fitzgerald & Withers, 2011; Sullivan et al., 2013).

A common finding in the little literature that does exist on this topic is that the attitudes and beliefs of support workers largely affect women with ID's decision-making, access to services, and opportunities for intimacy (Addlakha et al., 2017; Hamilton, 2006; Healy et al., 2009; Ramage, 2015; Wu et al., 2019; Young et al., 2012). What is more, support workers have reported following their own values and beliefs ahead of organisational policy (Christian et al., 2001). This may result, for example, in support workers being more likely to want to protect women with ID from potential harm or risks, than encouraging sexual expression (Hunt, 2019).

Support workers have been found to hold incorrect beliefs about the women they care for. For example, they assume that the more prominent the disability, the less sexual the woman is or that she is unable to have sex (Braathen et al., 2021; Hamilton, 2006). Furthermore, support workers, and families, are shown to hold conservative views and may believe that those with a disability should not have sex (Achey, 2020; Braathen et al., 2021). Some support workers for women with ID have suggested that the risk of discussions about complex topics, such as sexuality, can override any benefits for the person (Wilkenfeld, 2015). Other support workers have reported that women with ID should be sterilised due to their inability to look after a baby (Alexander & Gomez, 2017).

Among these beliefs is the lack of acknowledgement of sexual orientation and gender identity. One UK study found that 67% of people with disability were not asked about their sexuality when professionals reviewed their support needs (Abbott, 2020). The failure to recognise sexuality as a valued need can obstruct opportunities for sexual socialisation and sexual education, as well as the sexual agency of women with ID. The support worker's personal beliefs and values contribute to this obstruction (Bernert & Ogletree, 2013; Christian et al., 2001; Healy et al., 2009).

When support workers and families avoid talking to women with ID about sexual issues, it can create hesitancy towards open communication about sexual health through underlying stigmatisation. As a result, women with ID may feel unable to communicate relationship concerns or question the meaning of consent. Consequently, women with ID's attitude toward sexual health is often a reflection of the attitudes of their support workers and families (Björnsdóttir & Stefánsdóttir, 2020; Healey et al., 2009).

There are numerous reasons for the avoidance of sexual health conversations. For example, support workers may feel embarrassed around the topic, do not see the need for it, or find it unsafe to discuss it within their role for fear of professional repercussions, such as a complaint (Eastgate, 2008; Greenwood & Wilkinson, 2013). Alternatively, people may believe they must try to protect women with ID from issues and upsets related to sexuality and relationships (Public Health England, 2015). As discussed earlier, the emphasis on protecting women with ID is embedded in the long-standing belief that they are sexually naïve (Charitou et al., 2020). These beliefs remain in place despite the positive outcomes of sexual health programmes that develop knowledge, social and behavioural skills adapted to suit the needs of women with ID (Ramage, 2015). Regardless of their reasons and intent, refusing to share knowledge can violate these women's SRHR. Hence, training and supervising support workers in regard to the sexual health of the women they support is essential, and should be a priority of disability services (Charitou et al., 2020). The gap in sexual health training for support workers is particularly noticeable in Aotearoa New Zealand, or at least, a gap in the documentation and literature (Hamilton, 2008).

The family's and support workers' views are not always aligned. These decisions by the family commonly sit on the conservative side of the fence compared to support workers (Cuskelly & Bryde, 2004). For example, a review of research conducted over a 10-year period found that parents generally do not see the necessity of educating their children with ID and fear they would be unsuccessful in their educational outcomes (Tefera et al., 2018). Support workers have reported disagreeing with the opinion of families regarding the importance of supporting the reproductive rights of women with ID (Christian et al., 2001). Parents may oppose their daughter being in a relationship, or become overly controlling of this relationship (Achey, 2020; Cwirynkalo et al., 2017). In instances such as these,

support workers are faced with the challenging dilemma of going against their personal views or against the families' wishes. One of the reasons for this dilemma is that many disability organisations rely on families to consent for decisions related to support needs, including sexual health (Hunt, 2019). However, the consequence of ignoring the voices of the woman with ID in favour of families' wishes breaches women's right of choice and autonomy. Despite this breach of human rights, services and legislation utilise a legal guardianship framework as an appropriate means to protect women with ID.

The role of some support workers includes actively assisting in the SRHR of women with ID. Research into the Swedish policy that promotes support workers assistance in the sexual activity of a woman with disability has initiated a social shift in the acceptance of disability and sex (Bahner, 2020). This practice is known as Personal Assistance Services (PAS) and is becoming more popular in services supporting people with disability (Mona, 2003). The purpose of PAS is to empower choice for sexual expression and opportunity for women with disability who may be otherwise prevented from this. Under this policy, women with disability can request assistance to have their sexual needs fulfilled and provide a preference to who the support person is (Bahner, 2020). While PAS may not be necessary for many women with an intellectual disability due to their ability to perform sexuality independently, it is important to emphasise policies that are being applied to a support worker role to empower SRHR within disability services.

In Aotearoa New Zealand, the role of a support worker does not incorporate PAS, or any other specific sexual health supports into the job description. The poor recognition for SRHR in the role of a support ties into the deinstitutionalisation and history behind the development of the role. Much more research, locally and internationally, is needed about support workers' perspective of the sexual health of women with ID to understand their role in supporting, or obstructing, these women's SRHR.

5. Research questions

My research begins to address the gap in knowledge about women with ID's sexual health and rights of by investigating how support workers in Aotearoa New Zealand understand their role in helping to promote sexual agency and rights for those in their care. The following three questions guided the research:

1) How do support workers construct the sexuality and sexual needs of women with ID? What common gender discourses and subject positions do they draw on?
2) How do support workers account for their role in supporting sexual health for women with ID? How do they commonly position themselves and others?
3) What are the wider implications of these common constructions for women with ID, particularly with respect to their agency in SRHR?

6. Conclusion

The historical, political, and social barriers toward sexual health that women with ID are presented with throughout their lives are consistent throughout the research. That is, their rights are violated, their role as women ignored, and many other forms of discrimination, including prevention of intimate relationships (Cwirynkalo et al., 2017). While there is policy and legislation to prevent this from occurring, the little research that exists demonstrates the poor implementation of these policies.

Research is sparse on the support workers' role in supporting the SRHR for women with ID, especially in the cultural landscape of Aotearoa New Zealand. This is despite the significant influence they have on the lives and choices of women with ID. The research does suggest, however, that support workers have a complex role of balancing the organisational policy, families' wishes, and their own personal beliefs about the sexual health and rights of women with ID. This is part of a wider lack of societal knowledge about the sexual health of women with ID more broadly.

The lack of knowledge raises concerns for addressing the inequities and harm that women with ID experience. Hence, there is a need for further exploration in this field and position women with ID first and foremost as women, ensuring their disability diagnosis does not define them. The objective of this qualitative study is to gain in-depth insight into support workers' understanding of the sexual health and rights of women with ID, and their role in providing support in this area.

Chapter Two: Methodology

1. Theoretical Framework

The theoretical approach I have used in this research is feminist social constructionism. I chose to use this theory rather than disability theories to ensure that women with ID are positioned first and foremost as women. As Burns (2019) argues, a disability centric view means that disability is most commonly foregrounded as the primary identity, and only after this might their gender be considered and, as a consequence, "health issues associated with gender may either not receive the attention needed (health screening; menstruation; reproduction; menopause) or may receive discriminatory attention (contraceptive methods; perinatal care)" (p.591). To avoid a disability centric view, I have used feminist constructionism to ensure women with ID are not defined by their disability, which is typically diagnosed through a deficit-based lens, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM-V). The feminist constructionist lens aims to repair these disadvantages by addressing inclusivity, equal rights, and equitable justice (Preissle & Han, 2014).

Interestingly, feminist disability theory advocates for greater support, and accessibility to take advantage of equal rights (Achey, 2020). It includes a focus on the control over one's own body and focuses on what it is like living with a disability (Achey, 2020). Despite the core principles of this theory being of great importance, it views disability itself as a problem. That is, understanding disability to be something someone must live with. For research promoting the rights of women with ID, it is important to acknowledge language as a pre-condition for thought (Burr, 2015). Hence, feminist constructionism is used in this research to explore the conversations that construct disability and challenge the mainstream deficit understanding of disability.

Sleeter (2010) suggested that using one theory alone to explore disability does not accomplish the complexities of the phenomena of disability. Feminist theory provides a moral and ethical framework by listening and validating women's voice and values (Kitzinger, 2011; Morris, 1993; Preissle & Han, 2014). However, feminist theory does not provide the tools to understand the subjective reality of people without the layer of social constructionism to enable a critical understanding of experience (Coyle, 2011; Hesse-Bibber & Piatelli, 2014). Therefore, a framework of feminist constructionism forms an amalgamation of historical, political, social, and economic factors that influence a person's subjective experience (Kitzinger, 2011; Morris, 1993).

2. Feminist Constructionism

Feminist constructionism draws on the notion that our knowledge is value laden and formed through the social process of language (Clarke, 2002; Stoppard, 2000). In doing so, society create discourses, such as

gender, sexuality, and disability. These discourses are embedded in historical and cultural context and coalesce to shape a shared understanding. Rohleder and Swartz (2009) highlight the language used to describe the sexuality of people with ID, such as child-like, non-sexual, having poor self-control, and a 'menace to society'. Further, discourses grant social advantage for some, and disadvantage others. For example, a eugenics discourse was drawn on in Aotearoa New Zealand government policy to justify incarceration of the 'feeble-minded' in segregated institutions (Wanhalla, 2007).

Societal expectations on health and intelligence view those outside of the neurotypical population to be disabled (Emerson et al., 2012). As a result, disability is often theorised within a deficit framework. That is, many disability theories focus on people's deficiencies, limitations, or problems. This emphasis on deficit reinforces the view that people with disability have poorer opportunities and chances in their lives (Dinishak, 2016). However, the models and theories alone are not deficit-based. The language used in these theories encourage the ongoing deficit focus. For example, the word 'lack' is prominent across research in people with disability (Dinishak, 2016). This suggests that people with disability do not meet the criteria of "normal". The construction of normality in itself is variable and changes between cultures and context, and according to various axes of difference, notable age, race, ethnicity, and gender.

Feminist constructionism shines a light on gendered power relations and the way gender intersects with other social categories such as disability (Foss, 2010). The experiences of disempowerment for both women and people with ID more broadly are intertwined (Morris, 1993). However, the combined cultural devaluation of women and persons with disabilities results in unique gendered experiences such as overprotection, reduced social expectations, denial of sexuality in women with disabilities, the perception of women with disabilities as sexually deviant, or inadequate sexuality education (Mohamed & Shefer, 2015). These discourses that restrict the sexual health rights of women with ID creates a tension around a human rights discourse (Rohleder & Swartz, 2009). The intersection of gender and intellectual disability is evident in the historical practice of coercive sterilisation of 'mentally defective' women in Aotearoa New Zealand, sanctioned by the Mental Defectives Act, discussed in the previous chapter (Wanhalla, 2007). Sterilisation, in addition to segregated education and institutionalisation, were thought to be justified supports and practices for women with ID in particular (Wołowicz et al., 2021). The gendered discourses that underpinned these practices continue to influence the discrimination of women with ID in the present day. For instance, amplifying existing gendered understandings of sexuality, women with ID are viewed as sexually innocent compared to their male peers, who are viewed as sexually motivated (Wilson & Frawley, 2016). Furthermore, women with ID experience less control and autonomy around their fertility compared to men with ID (Matin et al., 2021).

Yet, as the historical examples I have presented indicate, discourses are not fixed, and will change over time, hence the importance of language (Diorio, 1989; Foss, 2010). This is also evident in the more

recent rise of diversity discourses, such as that of gender diversity. As a result, there has been changing language around gender from a binary construction (woman/man) to a more fluid construction (gender on a continuum) (Wiggington, 2017). Other issues related to gender power dynamics are also changeable. Accordingly, the feminist construction lens aims to draw attention to gendered power relations so that they can be addressed (Preissle & Han, 2014).

3. Reflexivity

The need for researcher reflexivity comes from the acknowledgement that my subjectivity, as the researcher, affects the data through the process of interviewing, analysis and generating themes. Thus, to produce ethical research, it was essential that I recognised my role as the researcher (Braun & Clarke, 2020b; Frewin, 1997). I have worked in the disability sector for eight years, providing behaviour support for children, youth, and adults with intellectual disability. During this time, it became apparent that many of the issues and concerns for people with ID related to poor social opportunities such as jobs, housing and relationships. My interest in sexual health and rights grew after observing the separation of supports between the social, physical and emotional connection involved in different types of relationships. The women with ID I worked with were craving an emotional connection yet, did not have the opportunity to experience this. After further study in violence and trauma, I started work in the family harm and sexual harm sector, supporting adults (predominantly women), and children who are victims of abuse.

In this paper, my focus was on the support workers understanding around sexual health and rights for the women they are supporting. I was careful in the way I reflected on the participant's responses to ensure my personal assumptions and experiences in the disability sector was not the dominant one. As a woman, I had insight into the expectations that are placed on women and recognised that this may be present in my analysis.

Maintaining reflexivity through the research process, from inception to write up, is an important skill that ensured I was aware of my thoughts, feelings, values, and beliefs, in addition to the political and social factors intertwined within the participant's narratives (Bolton, 2009; Hesse-Bibber & Piatelli, 2014). It was unavoidable to remove or separate my understandings and experiences when interviewing participant's and analysing data (Foss, 2010). As a result, Stoppard (2000) raises a potential risk that the participant's voices fade, and their stories ignored. However, in recognising and accounting for my subjective positioning, I was also able to identify my limitations (Womersley et al., 2011).

Reflexivity is commonly accepted as a process for responsible qualitative research as it enables clear and effective interpretation of data (Mohammadzadeh, 2021). Reflexivity has been described in many ways throughout the literature however, I connected most with Finlay's (2017) explanation that

reflexivity is a compass guiding the researcher through their analysis. This metaphor demonstrates how reflexive skills are embedded throughout the research process (Attia & Edge, 2017). To assist with this, I followed a reflexive framework by Duffy and colleagues (2021), who present five key themes. The first theme is social and relational context of knowledge. Using this theme, I considered how my professional training in the field of disability influenced my views in this research and challenged my thinking through reading a multitude of literature on the topic. The second theme is representation and voice. I applied this theme through the way in which I represented the participants voice within my analysis, while paying attention to how women with ID are presented in literature. Thus, it was important for me to carefully consider language that was both respectful to participants, and empowering for women with ID.

I also closely examined how my background, privilege and culture shape my understanding of the world through the third theme of embodiment and positionality. Within the next theme of awareness of politico-ideological character, I considered the political stance I took in my research to challenge the status quo of the sexual health supports for women with ID. Finally, the theme of unconscious/emotional entanglement raised my awareness to the situations that triggered my emotional responses throughout the research. For example, experiences and stories shared by participant, or findings in the existing literature.

Aside from questioning my knowledge and where my knowledge has come from, practical ways I engaged in reflexivity included note taking and diary entries following the interviews (McGhee et al., 2007). I also kept notes on my phone to capture my thinking while I was at work, or out for a walk. These reflexive strategies were particularly beneficial for my reflexive thinking as I regularly referred to these notes while creating themes, and later when writing my analysis (Attia & Edge, 2017).

4. Methods

4.1. Participants and Recruitment

To take part in this research, potential participants had to meet the following requirements, namely: (1) be employed as a support worker in a disability service in Aotearoa New Zealand, (2) have experience working as a support worker with women with ID, (3) be over the age of 18 years old. According to the thematic analysis guidelines by Braun and Clarke (2013), the recommended number of participants for a small project, such as this one, is six to 10. In following this, seven participants were recruited. To avoid a conflict of interest between support workers and their employees, I recruited from various disability service providers across Aotearoa New Zealand. These providers were built upon various values and support models including Kaupapa Māori, religious, specialist, and mainstream services.

After seeking permission from disability services, I advertised to potential participants via email. The email was sent to a service manager who kindly forwarded information about the research to their support worker employees (see information sheet in Appendix 1). Advertisement for the research was also shared through relevant Aotearoa New Zealand student Facebook groups. Participation was voluntary; participants were given the opportunity to express their interest prior to completing a consent form (see consent form in Appendix 2). I ensured participants were fully informed, and understood their rights, the benefits, and any implications related to the research prior to gaining consent (Willig, 2013). These rights were explained again at the beginning of the interviews to give the participants further opportunity to ask questions before the interview commenced. Participants were reminded they were able to ask questions at any point throughout the research. (See ethics section further below).

During this brief discussion, I highlighted the limits to confidentiality. For example, if a participant were to describe an event that occurred at work, while their personal information will remain unidentifiable, their colleagues may recognise key information about the event. Every effort was made to hide these details where possible. The use of multiple service providers reduced the likelihood of participants being identified. Understandably this may have affected the data shared with the researcher (Willig, 2013). Nevertheless, I felt the participants spoke openly about their experiences throughout their interviews.

4.2. Participant Demographics

Participant's experience as support workers varied from one to 20 years. They were women of various ages, education levels, and cultures. The diversity of participants appears to be a true representative of support workers in Aotearoa New Zealand (Kiata et al., 2005). However, it should be noted that over half of the participants had a degree in psychology which does not necessarily accurately reflect the diversity of educational backgrounds for support workers. These demographic characteristics are summarised in Table 1 below.

Table 1

Participant demographics

Pseudonym	***Ethnicity/culture***	***Experience***	***Additional work or education experience***
Hana	NZ European	3-5 years	Psychology & healthy relationship programme facilitator
Molly	Brazilian	3-5 years	Psychology
Kylie	Chilean	3-5 years	Psychology
Lilian	NZ European	3-5 years	Early childhood education
Luna	Macedonian	1-2 years	Psychology
Piper	Māori NZ European	1-2 years	Early childhood education
Madison	Japanese	15-20 years	Healthcare management

In recruiting participants from various cultures and ethnicities, many of the participants spoke English as their second language. While all the participants spoke excellent English, I recognised that this may influence the analysis of the interviews. Therefore, where appropriate, I repeated back my understanding of the discussions in my own words to confirm I had understood correctly.

4.3. Interview procedure

I conducted virtual semi-structured interviews using the online video conferencing service, Zoom (see interview guide in Appendix 3). This enabled access to participants from across Aotearoa New Zealand which would not have been possible though face-to-face interviews thus, improved the research equity (Oates et al., 2022). It further safeguarded participants, and myself, from the health risks associated with the COVID-19 pandemic, and prevented delays in the research due to potential lockdowns.

The current pandemic has normalised the use of online communication and working (or researching) from home as it became a necessity for many people. Interestingly, virtual interviews are not new to the research scene as they allow participants to feel safe, and provide convenience and ease (Sah et al., 2020). Furthermore, according to Santana et al., (2021), there are no significant differences in data collected through virtual interviews, compared to in-person interviews. Some of the advantages of online interviewing include improved participant engagement, and increased idea sharing (Marhefka et al., 2020; Oates et al., 2022). Despite these benefits, I recognised that there were also some disadvantages to conducting online interviews. Aside from the occasional interruption by my dogs, there were potential challenges around developing trust with participants online (Santana et al., 2021). For this reason, I scheduled the interviews with additional time for building rapport.

Research questions were flexible and open-ended due to the need for interviews to adapt to the direction of the participant, when appropriate. For instance, when a participant was hesitant to answer a question, I provided a vignette, or hypothetical scenario for the participant to talk through instead (Clarke et al., 2017). Additionally, open-ended questions ensured the participant responded in their own words when sharing what was important to them (Braun et al., 2017). Therefore, only a small number of questions were developed that aimed to draw from the participants understanding and experience in particular topics. These topics included understanding the support worker role, understanding sexuality, barriers to current supports for the sexual health needs of women with ID, sexual education, sexual health rights, contraception, and pregnancy and parenting (Addlakha et al., 2017; Charitou et al., 2020; Christian et al., 2001; Cwirynkalo et al., 2017; Gil-Llario et al., 2017; Wu et al., 2019; Verlenden et al., 2019).

Having worked in the disability sector for several years, I was able to empathise, acknowledge, and validate the experiences of support workers with greater sincerity. It enabled me to ask follow-up questions that dive deeper into the understanding of the support workers' role due to my knowledge of

their role and responsibilities within disability providers. However, I also endeavoured to be mindful of my own assumptions about their experiences shared with me, and avoided directing the interview towards a particular route because of these assumptions through supervision sessions. Throughout the research, I was conscious of my role within a disability service and aimed to avoid addressing practices that I would otherwise respond to. For example, practices that I believe breached the rights of women with ID, or organisational policy. However, when the interviews were arranged, I was no longer working in the disability sector therefore, this conflict had lessened.

4.4. Data Analysis

Once the interviews were transcribed, the procedure for analysis commenced. The analysis followed Braun & Clarke's (2006) six-phase process for reflexive thematic analysis (RTA). In using this process, it provided theoretical flexibility that emphasised on my reflexive positioning as the researcher to produce high quality qualitative research (Baker, 2006; Hesse-Bibber & Piatelli, 2014). The purpose of the six phases is to guide the researcher, rather than create a strict procedure (Braun & Clarke, 2020b).

In the first step, familiarisation, I reviewed each individual interview transcript thoroughly. Items of interest were noted through an analytical lens and documented in a research diary. Then, I progressed to the systematic data coding in step two. Within this step I identified both semantic and latent codes from the data. These two steps occurred individually for each interview transcript. Following this, in step three, I collated the codes from all interviews to create meaningful initial themes from the data. These themes reflected patterns within the data that is central to the sexual health and rights of women with ID.

In step four and five, I reviewed, refined, and named the themes. This step required regularly referring to the transcripts and audio recordings of participants. Finally, for step six, I wrote the research. Throughout the research writing, I remained reflexive and analytical of the data and the themes to ensure awareness of my personal assumptions around participants comments. It was also important for the examples chosen and discussed to relate to the literature and the research question.

RTA coding does not attempt to find evidence for pre-conceptualised themes (Braun & Clarke, 2020b). Therefore, when working through steps two to five, I followed an open framework that allowed the inductive generation of themes to present as an outcome of the research, and guided by the theoretical frame (Alhojailan, 2012). Upon writing the research, the themes I generated were presented using direct quotes from the interviews. In doing so, it allows for the reader's own interpretation of findings (Gower et al., 2019).

Themes could not be generated in isolation to my interpretation therefore, RTA created a platform for me to make sense of the data by generating themes across the dataset (Braun & Clarke,

2020a). In doing so, the codes evolved with my understanding of the data (Braun & Clarke, 2020a). In this research, I held underlying assumptions about the inequalities experienced by women with disability. Using a feminist social constructionism framework, RTA allowed for an understanding of participant's experiences, in addition to understanding what has social constructs and assumptions have shaped these experiences. Therefore, RTA is an appropriate method to analyse the values, beliefs, and experiences of support workers with regards to the sexual health and rights of women with ID.

4.5. Quality assurance and evaluation criteria

I considered four key factors that ensure credible qualitative research. These were; sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance (Coyle, 2011; Yardley, 2000). In practicing reflexively throughout the process, I was mindful of the influence that questions, responses, and interpretations of the information had in this research. By taking this approach, it aligned with the feminism social construction principles whereby perspectives are thought to be embedded in personal and cultural bias (Hesse-Bibber & Piatelli, 2014). Furthermore, it acknowledged that data cannot conclude a full subject account of the participants experience due to interpretation of the interview, and the framework used to code the transcripts (Coyle, 2011).

5. Ethical Considerations

5.1. Participant protection

This research project gained ethics approval from Massey University Code of Ethical Conduct for Research, in addition to the approval of the disability service providers who supported with recruiting participants. Research followed an ethical approach by aligning itself with multiple legislations and standards in Aotearoa New Zealand. Namely, the Code of Health and Disability Services Consumers Rights, and United Nations Convention on the Rights of Persons with Disabilities. The latter legislation is an international human rights standard signed by Aotearoa New Zealand in 2008 (Office for Disability Issues, 2016). In line with these codes of conduct, all participants were fully informed of the benefits and risks of the research. Any unforeseen risks would have been communicated with the participants should this have occurred.

5.2. Benefits and potential risks for participants

One of the main benefits of this research is the potential policy changes for supporting the sexual health of women with ID. More so, there is an opportunity to develop of training for support workers

and, inform the field of disability. Participants had an opportunity to share their personal experiences, playing an active role in Aotearoa New Zealand disability research. Lastly, this research highlights areas of future research that may positively influence the sexual health attitudes, beliefs and understanding around women with ID. The research findings were shared with all participants.

While this project was generally considered to be low risk, there were several identified risks involved. Firstly, while it was not anticipated, it was possible that there may have been emotional consequences for participants discussing upsetting topics that triggered memories of past traumatic events related to sexual health, for example, sexual abuse. To ensure each participant's emotional safety, I offered additional time to debrief after each interview to gauge how the participant had experienced the interview. I provided each participant with support services information on the information sheet should they have required this. In addition, participants were aware of their right to stop the interview or withdraw their participation at any time. During the interview, I monitored the participant's reaction for potential distress. While there were no signs that participants were distressed during the interviews, I had planned to pause, stop, or draw the interview to an end should this had occurred.

A second risk related to the confidentiality of participants. Confidentiality was prioritised throughout the research by using an alias and removing all private and personal information from the data. Furthermore, interviews were recorded in a private space without disruption from others, and the protection of this data stored safely and securely on a drive. However, sharing information about an experience that occurred in their place of work, may have identified the person to their employer or colleagues. This risk was reduced by having participants from multiple organisations thus, decreasing the likelihood of identifying the participant.

While not necessarily considered a risk, it was possible that participants experienced fatigue where they were sat in front of a computer for long hours (Santana et al., 2021). The online interviews may have exacerbated their fatigue, influencing the quality information shared. For this reason, participants were able to choose a time and date for the interview that best suited them.

5.4. Privacy of participants

Data were stored on a private share-drive accessible only to my supervisor and myself. Digital recording files were saved temporarily using the interview date as a file name, and then deleted once transcribed. Transcriptions were anonymised immediately and saved as a secured computer file on the private share-drive, using the participant's pseudonym as a file name. Hard copies of transcripts did not contain any identifying materials and were destroyed immediately after use. Only myself and my supervisor have access to consent forms, audio files, and transcripts. Paper consent forms were scanned, and the

originals destroyed. PDF files were saved on a private share-drive, in a secured version, using the interview number as the file name so that it cannot be linked to a specific transcript. Data has been stored digitally and securely by my supervisor for a period of five years and will then be securely destroyed/deleted.

6. Cultural considerations and safety

My project took a mainstream research approach to women with ID, and may not have direct relevance to the cultural supports involved in sexual health for Māori women with ID. I endeavoured to ensure Māori had an equal chance to non-Māori to participate in this project (Hudson et al., 2010). Although there was little Māori uptake for participating in the research process or outcomes, I aimed to protect the rights and interests of Māori following the guidelines provided by Hudson et al. (2010) in *Te Ara Tika*, as detailed below. This framework is also interlinked with the three principles of te Tiriti O Waitangi; partnership, participation, and protection.

6.1. Whakapapa (relationships)

Whakapapa relates to why relationships have been built, the quality of these relationships, and how they develop over time (Hudson et al., 2010). Prior to recruiting participants, I consulted with a Māori cultural advisor from a disability service provider. The hui with the advisor provided support for writing the participant recruitment advertisement in a way that aligns with Tikanga Māori. We also discussed how best to ensure equal opportunity for Māori participants to take part in the research, in addition to advice on Tikanga Māori procedures throughout the research. This consultation process ensured that there had been critique of the research and the benefit to Māori. It was through this kōrero that the concepts of tapu and noa were discussed from a sexual health context. For instance, the cultural advisor shared knowledge that sexual health is often tapu for males to discuss with females. This made it challenging to recruit Māori male participants. This advice was taken on board and acknowledged throughout the research.

6.2. Tika (research design and procedures)

Tika is foundational to understanding the right thing to do within research. The rights and interests of Māori were protected in the research processes. For instance, the method of recruitment, process of the interview, and protection of participants confidentiality throughout the research. The purpose of the research was reviewed by the Māori cultural advisor to ensure its relevance to Māori women with

ID. Only some participants shared the ethnicity of the women with ID they supported. In these instances, it may contribute to the application for future research that can bring about positive change for Māori communities.

6.3. Manaakitanga (cultural and social responsibility)

Manaakitanga highlights my responsibility to care and protect. With a focus to uphold the mana and dignity of participants, I ensured participants were treated with dignity and respect. Through my reflexive practice, I remained culturally sensitive, and safeguarded the privacy and confidentiality of participants.

6.4. Mana (justice and equity)

Mana encompasses the power and authority held by a person. In the context of this research, mana ensured a quality relationship between the participants and myself. This partnership was one of trust, fairness, and transparency. I aimed to maintain the spiritual integrity of participants by ensuring they were appropriately informed of their rights, roles, responsibilities of the research during the consent process, prior to interviewing. The benefits, and risks of the research were also discussed with participants at this time. Following the interview, participants were gifted kohā for their participation and sharing of knowledge.

Chapter Three: Analysis and discussion

Throughout the interviews, the support workers discussed their role around the sexual health of women with ID. The participant's understanding of sexuality was the foundation on which they framed their role to support and respond to the sexual health needs of women with ID. In making sense of their role, participants navigated their way through discourses of gender, sexuality, and disability. These discourses are intertwined with culture, personal experience, and organisational policies and practice (Maguire et al., 2018). For example, one participant explained her role is "to look after and support disabled people" (Piper) which suggests a disability is a vulnerability that requires the protection of others.

I created four main themes from the data, with four sub-themes, named in Table 2 below. Each theme interlinks the complex struggles of being a woman with ID, and the social prejudice, lack of power, and seeking empowerment through a lens of vulnerable women. The participants drew from their own culture, religious beliefs, and personal experiences to produce rich discussions about the women with ID they support. These differing experiences and views across the participants allowed me to develop themes that promote the sexual health and rights of women with ID, while highlighting the existing factors that create complexity in the disability sector more broadly.

Table 2

Themes and sub-themes

Theme	Sub-theme
1. A working relationship like no other	
2. Powerless and invisible women	a. Women with ID as potential abuse victims b. Women with ID as victims of societal prejudice
3. What if it gets complicated?	
4. In the absence of guidance - "I just need a little bit of guidance"	a. Making a best guess b. Family knows best

It is important to note that these accounts are shaped by the fact that participants all had a special interest in this topic and volunteered to discuss a subject that others might find challenging, embarrassing, or shameful. It is likely that many people who read about this research in sexual health and disability chose to ignore the advertisement due to their personal beliefs that they do not wish to share or discuss. Having trained support workers in the sexual health and rights of people with ID, and holding many discussions on this subject, I was prepared for there to be many support workers who would choose to avoid this research. Indeed, participants spoke about their experiences with

colleagues who are uncomfortable with discussions about the sexual health of the people they support. Instead, the call would more likely attract those who feel more strongly about the subject in one way or another.

Theme 1: A working relationship like no other

This theme speaks to the interpersonal bond between support workers and the women they support based on participants' understanding of the *support* component of their role. The picture of being a paid support worker that emerges from participants' accounts is of working relationship is like no other. The working relationship between support workers and women with an ID that is constructed is one of complexity, comprising professional boundaries and power relations alongside connection and involvement in each other's lives. Overall, participants depicted the relationship with the women they support in a positive light as involving meaningful connection and mutual benefit. The extracts below show how participants constructed a unique working relationship with the women they support.

> **Extract 1, Lilian (3-5 years as a support worker):**
> So, I've worked with [a woman with ID] for last four years, um, and [the manager] taken me off her team, just within the last week because they want us to see, they want us to be on one team or another, so I had to be with youth. And I'm really gutted about it because we've got a really good relationship, and you know, she's really sweet and kind and vice versa. So yeah, I feel I will miss not working with [her].
>
> **Extract 2, Molly (3-5 years as a support worker):**
> I like the job, and I like [Josie] So, I don't know, I think [it] is because I worked here for different people too. And it's good when you have a good connection with the person and all can work together and can improve how the things can work, and how the things can be for the person.

Despite speaking about the relationship in the context of paid employment ("the job", an "opportunity", "worked with"), in these extracts the language of mutuality ("good connection", "work together") suggests a mutual care and reciprocity in the relationship with the women they support. The extracts convey the participants' care and affection for the women in their care. For instance, in extract 1, Lilian shares her disappointment after moving to support another service and the description of being "really gutted" suggests the organisation change triggered strong feelings for the participant and implies a relationship beyond an ordinary professional working relationship. In extract 2, Molly constructs the relationship as mutual or reciprocal as she recounts how she has enjoyed the

opportunity to learn and grow from working with the women she has supported and speaks of "working together" with her.

These extracts illustrate how the working relationship was consistently described through language rooted in care and respect towards women with ID. Participants communicated wanting to develop open and trusting rapport and described feelings of genuine care for the women they support. Similarly, Bourke (2021) suggested support workers are attuned to the needs of the women they support, in addition to a relationship embedded in respect, and trust. Further to this, in extract 2, Molly constructs "a good connection" and a relationship of mutuality as necessary to improve outcomes for women with ID. Like Molly, other participants also highlighted the quality of the relationship as integral to the success of their work and described seeing women with ID evolve as increasing job satisfaction.

These findings resonate with existing literature in which positive relationships is associated with quality of outcomes for people with ID (Haines & Brown, 2017). In one study that interviewed Australian support workers and young people with ID, quality relationships were suggested to influence self-identity of young people with ID, in addition to helping them with their emotional distress (Robinson et al., 2020). Similar findings in a USA study suggested that the care between support workers and the people with ID they supported contributed to autonomy (Petner-Arrey & Copeland, 2014). This genuine care was demonstrated through communication and advocacy for the people they supported.

In this vein, almost all the support workers were positioned as influential role models and advocates of sexual health to "make a big difference in [women's] lives" (Luna) and "introduce a lot of things to [women with ID]" (Madison). Unfortunately, advocacy is not well defined due to the constraints and limitations on the role itself (Brolan et al., 2012). For example, when participants attempted to advocate for the women they supported, "a lot of the time, it was shut down by management" (Hana). This uncertainty of role within an advocacy context implies there are multi-layered power imbalances between a woman with ID and her support worker, and between the support worker and their manager. The power imbalances of this relationship are discussed in more detail in the next theme "Powerless and invisible women".

In research in the UK, support workers perceived their role to be both facilitative and caring for people with ID (Windley & Chapman, 2010). Thus, the need to teach and advocate is closely associated with the ideas of mutuality and connection between support workers and the people they support. In the following extract Kylie shares an understanding of her role as one of modelling appropriate male-female social interactions for people with ID.

Extract 3, Kylie (3-5 years as a support worker):

My main role is mentoring the youth and try to develop some skills in them to make them ready when they become 18 [and leave the service]. Most of them, they come from a really broken families with a lot of traumas around attachment or sexuality, or other kind of negligence. (. . .) I think, I don't know, but because thinking this, in the staff we've got males and females on shift all the time. So [the women with ID] also are able to see how some normal interactions between males and females are. We can be respectful, we can be playful, but always in a respectful way, and show that they can be respected.

The connotation of "mentor" is embedded in working alongside people to teach and guide them. This holds significant importance as sexuality is co-constructed within a social environment (Maguire et al., 2018). In highlighting a need for young women who have experienced trauma to normalise respectful female-male interactions, Kylie positions herself as a gender role model who is preparing women with ID to better understand acceptable ("normal") and appropriate ("respectful") gendered adulthood, and specifically, heterosexual relations, drawing on a heteronormative discourse. The gender role model position in is supported by the powerful child development discourse in which children and young people need gender role models to set an example of how to interact with the opposite sex and behaviours deemed correct as a presumed heterosexual woman/man. There is an assumption that male and female genders are different, and these differences must be considered in a child's development (Folgerø, 2008).

Support workers mostly depicted the working relationship with the women they support as challenging the discriminating discourse of sexual ableism that combines problematic assumptions about gender, disability, and sexuality. Robinson and colleagues (2020) highlight that this relationship is essential for improving social connectedness, and reducing the social stigma that is experienced by people with ID. This was evident in a discourse of advocacy as shown in Hana's response to a sexual relationship between two housemates with ID:

Extract 4, Hana (3-5 years as a support worker):

So, when [the two housemates had sex], um, there was myself and one other staff member who said, alright, we need to have some basic education around what consent is. We need to have a chat to them to make sure that they understand that. And my belief is that both of them are able to consent, um, that they're both able to understand what some of the consequences of sex [are] and are both able to understand what an enthusiastic "yes" looks like. And they're both able to say "Actually, I don't want to do this," and No, I don't like that" or whatever. So, I think they can consent. So, we were talking about, you know, talking to

> them about it, getting them sexual health checks as being responsible adults who were involved in sexual activity and getting her on contraception.

In this quote, Hana takes up the role of educator as she focuses on the information that she needs to "make sure" is understood by the people with ID involved. She also, however, positions the two people with ID in question as able to manage any risks associated with sex ("consequences", "responsible") and capable of consensual sex, based on her knowledge from their working relationship. Hana's account challenges the discourse of sexual ableism, in which women with ID are positioned as eternal children. This view that women with ID are child-like is based on the social expectations that chronological age must align with intellectual age (Muswera & Kasiram, 2019). Instead, the housemates are positioned instead as "responsible adults" who are consensually engaging in sex. This places them on equal footing to those without disability through the language of responsible sexuality.

The positioning of a support worker as an advocate can be seen as contradicting their later positioning as rescuers of women with ID. However, it is important to recognise that the relationship between support workers and people with disabilities is complex and embedded in sensitive power relations whereby support workers are confronted with a choice to advocate for the sexual rights of people with disability, or act on their duty of care to prevent abuse (Fisher et al., 2018). While the latter may sit in the category of advocating for rights, it may also, at times, restrict rights. I discuss this in more detail below in the theme "What if it gets complicated".

Of course, the question of power relations remained difficult, as illustrated by extract 3, in which the support worker positioned herself as providing guidance for the development of appropriate future (hetero)sexual or romantic social experiences, opportunities, and relationships. Research shows how the working relationship is embedded in power relations that sit between support workers and women with ID (Robinson et al., 2020). As a result, support workers can support greater opportunities and experiences around sexuality for women with ID (Maguire et al., 2018). Despite these findings, participants contested the power relations, with one participant who disputed the power relations between herself and the women she supported stating they were "kind of [the] same balance" (Madison).

Another tricky issue with this close working relationship was the personal/professional divide. The relationship is described as one of closeness, and even intimacy, as they are with the women they support for "a big bulk of the time" (Hana) and present for day-to-day issues that occur. Some participants constructed their close bond whereby they learned to observe and read the body language, feelings and needs of the women they supported. For example, in the following quotes:

Extract 5, Kylie (3-5 years as a support worker):

Every time they, I don't know, they have some experience in the day and they come to you because you are the person who is there every day. So, you can be cooking, and they can say, "Oh, you know, this is happening. One boy kiss[ed] me today, and I didn't want to be kissed by this boy."

Extract 6, Molly (3-5 years as a support worker):

I think she talks, because we are together for a long time, she talked to me about everything, um, and sometimes, for example, she had a boyfriend, I think beginning of 2019, and they have lots of sex and the family doesn't know. (. . .) She talked with [other] people like he was really romantic, but [he] was not. With me, she talks about "he likes to have sex all the time, and doesn't want to watch a movie first" or something.

In extract 5, Kylie positions herself as the first point of contact, "the one person" continually present for the woman with ID, who can be trusted as a confidante ("they come to you"). Similarly, Molly expresses the openness and honesty about sexuality in their relationship ("she talked to me about everything") that may not necessarily be reflected in their other social relationship.

While most participants spoke positively about the importance of the working relationship this also raised tensions, as shown in other research on support work (Shakespeare et al., 2017). Some participants spoke about a conflict between needing to develop a good relationship between the support worker and women with ID for effective care but, at the same time needing to set boundaries against relationships becoming 'too personal' due to professional, organisational, and personal requirements. Although, participants were not all aligned in this boundaried positioning. One participant talked about treating the women with ID as if they were her own children.

For one of the participants, assumptions were drawn that these blurred lines between a working relationship and personal relationship with the women with ID may influence the comfort in having sexual health discussions and the practical implications for support. For example, she questioned "how closely do we need to be monitoring them?" as she explained the "controversy" of this "grey area" (Luna).

More than half of the support workers' accounts imply a discrepancy between the boundaries of their role and responsibilities, and advising around sexual health, either directly from them, or observed in their colleagues. A similar study in the UK suggested the emotional and psychological sexual health needs of people with ID were also perceived by support workers as outside of their professional duties (Maguire et al., 2018). Ethical implications around conversations about sexual

health are considered as support workers position themselves as professionals, rather than friends of the women they support. For instance, participants explained that many women with ID would agree with the opinion of the support worker to "try to please [the support worker] a lot" (Kylie).

Theme 2: Powerless and invisible women

The theme powerless and invisible women centres on the denial of agency of women with ID. This theme is crucial as it is a reminder that women with ID are at the centre of this research. This theme encapsulates a set of unspoken rules that exist for women with ID which largely revolve around the protection from sexual abuse, and pregnancy prevention (Gill, 2015). This theme points to the absence of choice and to disempowerment in the lives of women with ID, particularly in relation to their sexual health and rights. The participants, talk largely support the ableist, deficit discourse of disability in which sexual health is rendered non-existent or a problem (Cwirynkalo et al., 2017).

Accordingly, the association between women with ID and vulnerability to abuse underpins talk in this theme (Nosek et al., 2001). Piper explains in the extract below:

> **Extract 7, Piper (1-2 years as a support worker):**
> Yeah, because [women with ID are] so vulnerable. They haven't got a voice for themselves, um, and having a stranger look at them or them feeling unsafe to…yeah, I could never see [the women with ID] being able to walk down the road by themselves without something maybe happening.

Emphasising the vulnerability of women with ID ("so vulnerable"), alongside an assumed inability to self-advocate ("haven't got a voice"), Piper suggests that the safety of the women she supports can be jeopardised if they were to be approached by a stranger or left alone in the community. In these instances, she indicates the possibility of abuse ("something happening"). This construction of women with ID as vulnerable to abuse is common in society (Pownall et al., 2017). For example, findings from a UK study suggested women with ID are viewed as vulnerable and in need of protection, unlike men with ID (Young et al., 2012). Bernert and Ogletree (2013) highlight that these social assumptions about the sexuality of women with ID are further complicated by traditional constructions of femininity in which women are passive and vulnerable to being taken advantage of by men.

It is important to note that I am not denying that women with ID are susceptible to sexual abuse. Rather, I wish to show how this dominant concern is rooted in sexual ableism that denies the sexual agency of individuals due to their perceived competency, and assumptions about what is or is not appropriate (Gill, 2015). Accordingly, the victim discourse was dominant throughout the

interviews, positioning women with ID as powerless and vulnerable and dependent on support workers to keep them safe or provide help. This discourse ultimately denies women with ID agency and reinforces a power imbalance between support workers and women with ID, as I discuss below. The victim discourse was drawn on in two key narratives in support workers' accounts, namely: (a) women with ID as potential victims of abuse and (b) women with ID as victims of societal prejudice. As I show, both narratives reinforce inequality related to disability, as those without disability are consistently positioned as holding greater power than women with ID.

Sub-Theme 2a: Women with ID as potential victims of abuse

Most often, women with ID are positioned in the data primarily as victims who are entangled in their vulnerability, rather than as sexually agentic and thriving in healthy sexual relationships. Many of the examples shared by participants were not dissimilar to experiences of women I have supported while working in the disability sector. The discourse of women with ID as victims resonates with international research findings that suggests risk is a core factor of sexuality due to the potential abuse and exploitation (Charitou et al., 2020). Having an intellectual disability increases this risk of sexual abuse compared to those without disability and compared to people with other disabilities (Rohleder & Swartz, 2009). The positioning of women with ID as vulnerable is due to their susceptibility to sexual abuse is linked to their limited understanding of sex and consent, their hesitation to refuse those in more powerful positions, and the likelihood of following the actions of others.

When discussing women with ID's sexual health, they were described in child-like ways, for example "*technically* they are adults" (Luna), "make sure there is a *woman* [support workers] on site for our *girls* [women with ID]" (Piper), and "if they are not controlled at all, they could get quite wrong information from the internet" (Madison). These statements concur with research highlighting women with ID are unable to escape an eternal child discourse (O'Shea & Frawley, 2019). This construction of women with ID as forever-children supports the construction of women as victims in need of protection and denies women with ID's sexuality by positioning them as non-sexual, and therefore not in need of sexual health information and support. This positioning is mirrored in research showing that the sexuality of people with disability is commonly viewed as socially unacceptable (Tepper, 2000).

The infantilisation of women with ID is commonly discussed throughout the literature with instances acknowledgement of women with ID as sexual agents as rare (Gill, 2015; Mohamed & Shefer, 2015). This perception of women with ID as child-like opposes a common experience of women without disability who are viewed and treated as sexual objects (Kellie et al., 2019). Based in this view of women with ID as child-like, there was also the common suggestion that women with ID may not

have sexual needs and that sexuality is “not really something that [women with ID] have asked about” (Luna). Participants cited this as a reason for why they had not provided and sexual health support, for example that they “don’t instigate dating or take [women with ID] to Family Planning” (Lilian). The perceived sexual innocence of women with ID may be an outcome of the lack of sex education or sexual experience and it is possible that support workers recognise their naiveté and associate this with heightened vulnerability.

In this way, women with ID are denied as sexual beings. Instead, they are connected almost solely with vulnerability associated with their disability, as reflected in the victim discourse. This discourse, as I discuss further below, is closely entwined with a risk discourse that envisages women with ID as vulnerable to dangers associated with them as potential victims who might be taken advantage of or coerced by men. Participants therefore observed that the encouragement of non-sexual relationships was common.

The lack of acknowledgement of the sexuality of women with ID was commonly seen as practical and protective. For example, participants shared that their role was task-based such as supporting women with ID in the community, making meals, bathing them, attending GP appointments and the like. Sexual health was not considered as part of this as this could lead to sexually inappropriate behaviours, such as “using photos of staff members to masturbate” (Luna). Risk and danger were thus foremost in discussion. For example, discussing the lack of formal support in place to support the sexuality of women with ID, both Lilian and Luna focus on unsafe sexual behaviour:

Extract 8, Lilian (3-5 years as a support worker):

I'm not used to that process when those [sexual health] plans and all those documents are drawn up […] apart from any biological issues or anything along those lines will be addressed but nothing in terms of sexual health. And I guess was most, some of the [people with ID] that we have had up in the unit, they are going through like the [sexual harm prevention] programme, or have got charges for rape or abuse and stuff along those lines.

Extract 9, Luna (1-2 years as a support worker):

I think [beliefs around sexual health] comes from fear of the unknown of, you know, if, like, if we let [women with ID] have sex or if we let her masturbate like what's gonna happen? Is she gonna hurt herself? And does she know how to do it properly? Is she going to end up falling pregnant? I think it's all of those risks that naturally come with somebody with ID having sex or masturbating or oral sex or whatever it might be. I think it's that fear, I guess, that anxiety of like we don't want anything to happen to this person.

In extract 8, Lilian positions herself as unfamiliar with the process of developing formal support plans and describes sexual health as excluded from these plans compared to other aspects of health, such as physical health ("biological issues"). Her role is depicted as offering support to people with ID who have unsafe sexual behaviours ("rape or abuse") to attend sexual health programmes, echoing findings from Canadian research in which participants were found to highlight the importance of resolving inappropriate sexual behaviour for people with ID (Saxe & Flanagan, 2016). Lilian's quote illustrates the invisibility of sexual health as an issue for women with ID as the construction of women with ID as sexual beings has largely been rejected by society and within disability services due to the perceived need to protect women with ID from possible harm (Winges-Yanez, 2013).

Similarly, in extract 9, Luna highlights concerns about potential "risks" as central to (non)responses to women with ID's sexuality, notably harm and unintended pregnancy. These are constructed as inherent and inevitable, as she claims that risks "naturally come with" sexuality in the context of ID. She therefore highlights "fear" and "anxiety" as underlying responses to the sexuality of women with ID, consistent with other research findings, for example in which support workers raised concerns around the vulnerability of women with ID in relationships, suggesting they may become pregnant (de Wit et al., 2022).

The victim position was the most dominant, but there were some challenges to it. Kylie challenged the dominant protectionist approach she encounters in her work and instead spoke of empowering women with ID and informing them how "you can protect yourself" (Kylie). Nonetheless, the potential for harm and need for protection is still assumed. The dominant victim positioning, discussed above, suggests that women with ID cannot have deep and meaningful sexual relationships because they are not able to manage potential risk. The emphasis on the vulnerability of women with ID meant that some participants reported being reluctant to deal with these women's sexual relationships, displays of physical affection, and even menstruation. These sexual health issues were "too hard" or merely "swept under the carpet" (Luna). This data therefore reflects the wider reluctance of support workers to engage in this area and contributes to the construction of sexual health for women with ID as taboo reported by Matin et al. (2021). However, framing women with ID as victims reinforces stigma and further isolates women with ID which, in turn, reduces social protective factors against abuse (Meer & Combrinck, 2015).

Sub-Theme 2b: Women with ID as victims of societal prejudice

Some participants recognised the disempowering judgements that women with ID experience, positioning women with ID as victims of societal prejudice. Madison, for example, maintained that the

sexuality of women with ID is “a really had area to talk [about], because some people might be feeling people with intellectual disability shouldn't have any sexual interaction with a male. So, it's quite hard to talk [about] topic wise, it's [a] really hard one because people have kind of [a] narrow mind”. She therefore attributes social stigma associated with sexually active women with ID to prejudice and difficulties being open-minded (“narrow mind”, “hard to talk”) about sexuality. This social stigma is consistent with current research in which women with ID are shown to be widely perceived as sexually innocent and, accordingly, heavily judged for any sexualised behaviours (Young et al., 2012). A heteronormative discourse is once again present as Madison relates a woman with ID’s “sexual interaction” specifically in relation to a “male”. It is common for sexuality of people with ID to focus on heterosexuality, with little research exploring the stigma and prejudice for women with ID in the rainbow communities (Parchomiuk, 2021).

In discussing societal prejudice, several participants also highlighted how women with ID were often positioned negatively in comparison to male peers. In contrast to women with ID, men with ID who were described as being seen as “superior,” “dominant,” “stronger,” (Madison), “leader[s]” (Kylie) and “more [sexually] expressive” (Luna). This language is in line with gendered expectations that centre around the uncontrollable male sex drive and men’s biological need for sex (Du Plessis, 2015). For example, Hana recounted how other support workers warned her about one woman with ID “they literally said, you know, ‘watch out, be really careful’” and explained that such negative judgements of the sexuality of women with ID is “not conscious all the time, but it’s that misogyny and the patriarchy […] I don’t think it was necessarily a conscious thing by people, but it is ingrained into our society”.

At the same time as being depicted as being *at risk,* those women with ID who expressed desire or acted in sexual ways were deemed *a risk* (“watch out”, “be really careful”). Hana suggests these ideas surrounding risk are rooted with gendered assumptions (“misogyny”, “patriarchy”) throughout society (“ingrained”). This gendered positioning of women is congruent with research around the sexual double standard in western society whereby men and women are judged differently for the same behaviours (Sagebin Bordini & Sperb; 2012; Endendijk et al., 2019; Gomez Berrocal et al., 2019). However, women with ID have less sexual freedom than women without ID due to the perception of risk (Gilmore & Chambers, 2010). Thus, highlights the social prejudice experiences by women with ID.

In contrast, some women with ID were also constructed as sexual subjects with sexual rights, including the right of sexual pleasure. In the following extracts, both participants demonstrate examples of the rights discourse:

Extract 10, Madison (15-20 years as a support worker):

But I asked her, 'Do you think if you don't want to do [sex] you can say no?' She said, ah, she wasn't sure. And she wasn't sure if she should say no or yes, or no, if she doesn't want to do it. So, we just taught her, if you don't want to do it, you just need to do 'no, I don't want to do it'. You have a right to say no.

Extract 11, Lilian (3-5 years as a support worker):

Well, I guess at the end of the day, it's all about informed choices is it not? And, you know, if [support workers are] not giving these people all that, you know, all the information they need because they're not in a position to be able to do that. We're not, we're doing them a bit of a [dis]service really, aren't we?

In extract 10, Madison shares her experience around discussing consent to a woman with ID in a relationship. She places importance in educating and supporting the woman to understand her rights ("asked her", "taught her") to allow her to decide if she wants to engage in sex or not. In doing so, Madison makes the assumption that women with ID have sexual desire and needs. However, in framing the initial question against sex ("don't want", "say no"), the motivation for this conversation may be to avoid risk. The discourse of consent was raised by several participants as a starting point to providing education for women with ID suggesting consent is "simple stuff" (Hana, extract 9). Similarly, support workers in Canada proposed consent was an important skill to teach people with ID (Saxe & Flanagan, 2016).

In extract 11, Lilian explains her understanding around her role in supporting women with ID with their sexual health needs. She positions women with ID as having a legitimate "need" for information, and the right to have this ("informed choices") and places high importance on this ("it's all about"). In Lilian's account, the practice of information sharing is not necessarily occurring which challenges her perception of the service support workers should provide ("not giving", "doing them a disservice"). Similarly, Vehmas (2019) implies limiting or avoiding supports for sexual health presents a conflict with the rights of people with ID. In both extracts, the language used around 'rights,' and 'wants' provide women with ID with a 'need' to have a choice, thus construct the empowerment and simplicity around consent.

Following on from the recognition of women with ID as sexual subjects, support workers positioned themselves as responders of sexual health, pointing to an underlying assumption that women with ID would initiate these discussions. For example, one participant explained "you need to be ready for [sexual health] questions" (Kylie). This assumption connects with the gendered roles of

sexual health that hold women accountable for their own, and their male partner's sexual health and pleasure (Rohleder & Flowers, 2018). The search for information also occurred through the internet, pornography, TV, and film, as Hana's example highlights:

> **Extract 12, Hana (3-5 years as a support worker):**
> And so, she explained that she had sex and absolutely broke my heart because she said that they'd figured out how to do it by watching animals on *Animal Planet*. Um, and I just thought that isn't it so sad that that's how they had to learn, because they couldn't have a conversation about "how can we do this?". And it's, I don't like to think about it too much, but I do worry about how that experience was for both of them. Because the both of them, that was their first experience, you're watching animals on *Animal Planet*, you know, the animal just kind of jumps on goes for it and that's that. And I'm just thinking, like, it probably wasn't the most pleasure and enjoyable first sexual experience for them.

Hana describes extreme upset ("broke my heart", "so sad") about the way in which this woman with ID is exposed to sex through an animal television programme. She implies this way of learning about sex was a necessity ("had to", "figured it out") due to the lack of discussion around sexual health ("couldn't have a conversation"). In retrospect, she suggests a straightforward question ("how can we do this?") to teach this couple about sex. Additionally, Hana acknowledges that 'pleasure' and 'enjoyment' should be part of the sexual experience for women with ID which, in society, is often disregarded as unimportant (Alexander & Gomez, 2017).

While the Internet can be a valuable source of information, inadequate media literacy decreases one's ability to sieve out unsafe and harmful information (Byron et al, 2020). In extract 12, Hana shares an example of the potential risk of copying images in the media ("jumps on and goes for it"). Further, sex in the media, is associated with discourses around gender, race, sexuality, power, and consent, all of which are intertwined with social expectations (Byron et al., 2020; Goldstein, 2019; Weingarten, 1991).

Although some participants argue that organisation and social structures to empower the voice and value of the sexual needs of women with ID do not exist, they still position women with ID as victims, even as they draw attention to problematic assumptions and stereotypes of women with ID and highlight social barriers the women face in sexual health. Participants make sense of social inequality that they described as a result of the women's limited education and knowledge in sexual health and position women with ID as being without the tools to succeed and, importantly, positioned support workers as able to help with this. As the following extracts show, support workers were

positioned as occupying a role that informs and empowers choice for women with ID in a way that women with ID are disadvantaged:

> **Extract 13, Lilian (3-5 years as a support worker):**
> I think [women with ID] have got a voice that needs to be listened to, and I don't think we ask them to. I think we undervalue and undermine them. They may have an intellectual disability of some sort, shape or form, [but they're] still smart people at the end of the day. And they still have rights, and they still have responsibilities. And if we're not giving them all the facts, and giving them the knowledge, I think knowledge is such a powerful thing, giving them the knowledge and understanding then maybe [support workers] can, yeah, maybe [support workers] can help them better to be more well-rounded individuals.

> **Extract 14, Molly (3-5 years as a support worker):**
> She was totally capable, and when I go with her, whatever the place be, they talk with me and not talk with her. Or other times I need to say 'no, ask her', you know, because she can answer. [It] is her decision, I can help, but it's not my decision.

In extract 13, Lilian reflects on the importance of knowledge and education for women with ID ("powerful"), positioning women with ID as unfairly dismissed and undervalued by other support workers and wider society. Lilian suggests that withholding information from women with ID is a violation of their rights and argues that these women should be *given* the information ("facts" and "knowledge") to be empowered to make a choice about their sexual lives. This positions support workers as able to "help" women with ID.

Similarly, in extract 14, Molly gives an example of how the powerlessness of the woman she supports develops into invisibility when she is in the community with her due to the responses of people in the community ("not talk with her"). As in extract 14, the support worker is positioned as a rescuer who advocates for women with ID. However, in doing so, it further implies women with ID are victims. This positioning feeds off the wider social ideology of the powerlessness of women with ID and can reduce their identity as a woman with legitimate sexual needs.

In both narratives I discussed, the emphasis on the vulnerability and powerlessness of women with ID reinforce a victim position that is commonly associated with disability. Ironically, even though some participants sought to challenge the marginalisation of women with ID, the victim position makes it difficult to step away from their powerlessness and invisibility. Positioning women with ID as victims potentially limits the possibility of their meaningful or authentic inclusion in decisions about

their own sexuality. Therefore, women with ID are positioned as victims in need of either a man or a support worker to protect and defend them from harm from others, sexual or otherwise.

In constructing women with ID as vulnerable victims, and thus avoiding sexual health education, women with ID are unintentionally exposed to greater risk and reduced pleasure. That is, the pleasure of women with ID is rendered meaningless (Addlakha et al., 2017). Ultimately, the rights and voices of women with ID are undermined by the combined discourses of traditional gender and disability as they work to position them as passive victims. Research suggests that such negative constructions of gender and disability are linked to the risk of sexual violence and abuse for women with ID (Meer & Combrink 2015). Gustafson and Brunger (2014) discuss the need to form a new understanding of the relationship between vulnerability and empowerment for women with disability. From a strength-based perspective, 'vulnerability' could be reconstructed as 'diversity' offering a better position to confront the oppression of women with ID.

Theme 3: What if it gets complicated?

The way sexual health is constructed through the lens of fear and risk to support workers, and the women with ID, presents the complications discussed in this theme, "what if it gets complicated?". This question is layered with the practicalities of safeguarding women with ID, while feeling constrained by fears of risks or negative consequences. This theme is rooted in the discourse of sexual ableism and the construction of the sexuality of women with ID as risky and needing to be supervised and controlled (Gill, 2015). Furthermore, it relates to the common view of educating and informing women with ID as dangerous because it may encourage sexual engagement (Rohleder & Swartz, 2009).

Given the high rates of sexual abuse of women with ID, it is not surprisingly that support workers might take an overly cautious approach around sexual health (Basile et al., 2016). Indeed, participants depicted sexuality being a "really big subject" (Molly), and a "hard" topic (Madison) to discuss. Without training and policies, support workers lack clarity in their role of supporting sexual health and may be hesitant to act or fearful of taking ownership of decisions around sexuality because of the significant potential consequences of these decisions (Charitou et al., 2020). Once again, the sexuality of women with ID is associated with their vulnerability and risk. Luna discusses the tension between the positions of rights versus protection:

> **Extract 15, Luna (1-2 years as a support worker):**
> I think in terms of ethical boundaries, there's a lot of, you know, controversial things around how involved [support workers] should be if we are going to teach [women with ID] about this

> sort of concept like sexual health and rights (. . .) It's like, how involved should we really be, you know? Like, where's that kind of line? Because at the end of the day they still need to make their own decisions, and people with ID are very vulnerable when it comes to decision making about anything, let alone, you know, sexual health and rights.

Here, Luna constructs the sexuality of women with ID as "controversial" of the support worker role as a balance of expectations from the organisation, sociocultural factors, her personal beliefs, and from the woman she supports. In framing women with ID as vulnerable, she implies a need for support worker input, however, is left questioning the extent of "how involved" support workers should be. Luna suggests sexual health is more complex and difficult compared to other decisions in her role and questions her capacity to do so ("let alone", "where's that line?"). Luna's extract illustrated an ethical dilemma that participants frequently alluded to, the dilemma between recognising the rights and empowerment of women with ID and their vulnerability and possible need for protection. Considering such uncertainty, participants often described avoiding conversations about sexual health. Such responses are exacerbated by the discourse of risk, mentioned earlier. However, in focusing on the risks related to sexual health, women with ID are positioned as possibly incapable of decision-making, as in this extract. Support workers in other research have suggested that the risk of harm overrides the self-determination of women with ID (Bigby et al., 2017).

While *all* women's sexuality is embedded with notions of risk, such as sexual violence, for women with disability these risks are closer to the surface of discussions, possibly due to the higher prevalence of sexual harm in this population of women (Moore et al., 2020). Research frequently uses data to compare disability with non-disability, highlighting a larger risk for people with disability, which feeds into the discourse of women with ID as victims, encouraging support workers to take a cautious approach to sexual health. Throughout the interviews participants commonly spoke of the avoidance of sexual health support from support workers, families, and disability organisations because of perceived risks. Hana described "restrictions" on women with ID's sexuality as "purely due to like, a policy, risk management sort of thing". Such constraints are rooted in a conservative risk discourse that contains the sexual expression of women with ID, and will not accept the autonomy, empowerment, and opportunity for positive sexual experiences (McGuire & Bayley, 2011).

Support workers described juggling myriad factors that constructed the risks associated with sexual health as 'tricky'. For example, job obligations, management input, and duty of care to keep women with ID safe. The language used by other participants suggested the risks were inevitable by indicating "bad things happen all the time" (Hana). Thus, the assumptions around risk appear to be related to the positioning of women with ID as unable to cope with negative experiences, or safely

engage in sexual relationships. Luna highlights her thoughts around the sexual health of women with ID:

> **Extract 16, Luna (1-2 years as a support worker):**
>
> I think, in terms of, you know, legally, in terms of [the] liability of the company, it makes a lot more sense for families to be involved, to be informed, to always be kept in the loop because if something were to happen, and it was something that we did at our discretion, and the parents had no idea about it, they weren't informed or they, they weren't involved, um, I think that there's a lot more risk there. I'm thinking specifically of falling pregnant, being sexually abused, you know? People with ID don't, wouldn't necessarily (.) again, I'm generalising, some might, but most of them probably wouldn't be able to understand what a sexual assault even looks like or what harassment looks like or feels like.

This extract illuminates the complex risk-assessment process that occurs for this support worker. Luna considers the legalities ("legally", "liability") of the potential negative consequences of women with ID engaging in sexual relationship ("if something were to happen"). In doing so, she positions herself at risk should there be negative consequences, and instead, suggests it "makes a lot of sense" to involve the family to reduce this risk. The uneasiness for support workers to hold this risk has been found in similar research where support workers reported needing to seek advice and permission to support sexual health of people with ID (Maguire et al., 2018). Though she admits there might be exceptions, Luna positions women with ID as vulnerable, as she highlights their susceptibility to the negative consequences of sex ("falling pregnant", "sexually abused", "assault", "harassment") due to their incapacity to understand sexual experiences. Thus, the need for prevention of risk is justified, supported by the victim discourse.

This construction of vulnerability was common across the data, as support workers described shying away from sexual health conversations and focused heavily on risk. This was not verbally communicated, but also the information that was deliberately left out of conversation. For example, Piper reported that a woman with ID was told her boyfriend is "just your friend". Molly recounted that another women was informed that her "dream" to have children was "a bit complicated". They also reported women being told that contraception would makes things "simple" (Molly), and relationships are "totally fine" (Hana) if women with ID have no interest in sex. These examples highlight the common avoidance of sexual, which research indicates has resulted in women with ID viewing their sexuality as negative (Healey et al., 2009).

The avoidance of sexuality conflicts with the human rights discourse, discussed earlier, highlighting the complexity of this topic for support workers. They are tasked with determining acceptable versus unacceptable risk, and draw on their socio-cultural background, personal experience, and context of the situation to do so (Mohammed, 2007). For example, the two accounts below show how practices and desires of women with ID are evaluated on the basis of risk to women with disability.

Extract 17, Piper (1-2 years as a support worker):

We got worried with her one part there. Um, there was a young chap that was older than her, old enough to be her father. He was like 60 or something and she was 25 but [their] mentalities was very similar. But we just, it just made me feel uncomfortable knowing that, this old person wants to go with [her]. So I felt really, and still now, I still feel uncomfortable about it.

Extract 18, Lilian (3-5 years as a support worker):

But she has always said that she wanted to go the strippers and I'm like, "Oh, let's take [her] to the strippers" because that's something that's she would absolutely rock her world. And I'm like, why not? What's the, where's the harm in that? It's like her behaviour team have a bitch about it. But I just don't see… If that's something that she wants to do as a grown 50-year-old woman, let her do it.

Piper's account in extract 17 suggests a concern about a relationship ("uncomfortable", "worried") between a woman with ID and her male partner due to a large age gap. This relationship is suggested to be inappropriate based on gendered assumptions that older men will take advantage of younger women (Collisson & De Leon, 2018). This results in the positioning the woman with ID as in need of protection. No concern is expressed for the male with ID. There is an implication that the couple might otherwise be well suited ("mentalities was very similar") if it were not for the age difference, but the potential risk for the woman with ID rules out support of the relationship. This illustrates the intersection of the victim and risk discourses, which was present throughout participants' accounts. Similar to Piper's account of an inappropriate relationship, several participants explained that policy would only allow female workers to work with women with ID. Some suggested that people with ID were strategically placed in residential homes to safeguard and reduce potential harm.

In a similar vein, in extract 18, Lilian's account highlights how women with ID require approval to make decisions, even when a support worker if sympathetic to the request ("let her do it"). Lilian's

account shows that there is a risk of controlling people with ID or making decisions on their behalf that do not meet their needs (Dean et al.,2017; Muswera & Kasiram, 2019). Her account shows how the request was construed as a problem, and thus inappropriate, causing the behaviour team to complain about. She challenges this construction, positioning the woman with ID as a "grown 50-year-old woman"who shouldn't require permission, and suggesting that her wish is an acceptable way to meet her sexual needs due to the lack of potential "harm". This implies some sort of risk assessment of particular requests. Indeed, participants said that organisations would "encourage" (Luna) and be "really good" (Hana) about supporting masturbation, suggesting that notions of risk are as central to gatekeeping of perceived acceptable and unacceptable sexual activity, also often related to support workers' personal beliefs (Gill, 2015). These examples both highlight how decision-making related to the sexuality of people with ID was commonly constructed as a balance between enabling rights, and preventing potential harm (Wickstrom et al., 2020).

Fear about potential risks or negative outcomes was commonly described as dictating organisational practice. Throughout Hana's interview, for example, she described managers and support workers as "too scared" of potential negative consequences of sexual health to empower women with ID in their sexuality. In the following extract, she explains how such risk aversion placed her in a complicated position:

> **Extract 19, Hana (3-5 years as a support worker):**
>
> [Managers] were always saying we work with vulnerable people, and we need to advocate for them. But the second that I would advocate for someone, it was always shut down. […] It felt like an uphill push all the time and you go back to work the next day and things aren't changing. And it just, yeah, I really, really struggled with that so, that was really hard. […] You know, like, [teaching consent] is really simple stuff. So, assuming that they wouldn't understand that just was like, "That's so shit". [Women with ID] can understand [consent]. […] It just absolutely blows my mind that on one hand, [managers] can be like, you know, [people with ID] deserve to be in employment, and they deserve to have regular lives, but then it's like, "Oh, but not sex" that's just not included.

Here, Hana expressed frustration and disappointment ("really hard", "so shit", "blows my mind") with a double standard around the "need" to empower women with ID that does not extend to their sexuality. Hana describes her attempts to support women's sexuality, such as teaching consent, as thwarted and an "uphill battle". This aligns with recent Australian findings that staff from disability services acknowledged that people with ID could be autonomous and independent, yet the disability

service systems did not allow for this (Fraser-Barbour, 2018). This resistance is attributed to assumptions about the capacity for women with ID to understand "simple" sexual health education.

Likewise, Molly advocated for the normalisation of sexual health of women with ID, stating about the woman she supports: "She is [a] disabled person, [this] is not a problem to have a good sexual life, and because she is an adult woman, and is not different for anybody just because her condition." This statement communicates advocacy for equality as Molly positions the woman with ID equal to other women ("an adult woman", "not different"), despite diagnosis, with equal rights to sexual enjoyment. Interestingly, an Australian study found support workers understood advocacy as a means to protect the rights and values of people with ID (Brolan et al., 2012). However, the equal rights of women with and without disability does not always materialise in practice when sexuality becomes a problem and restrictions are put in place by organisations (Cwirynkalo et al., 2017). Hana commented on this as follows:

> **Extract 20, Hana (3-5 years as a support worker):**
>
> I haven't worked in management, but my perception was that with the sexual health stuff management was so terrified of anything going slightly wrong, that rather than letting human beings be human beings, they [were] like, "We're just going to put all these restrictions in place and we're going to police things". So, basically, we're making sure that nothing could potentially go wrong or whatever.

Here, Hana describes having little control in her role to support women with ID with their sexual health due to the hierarchy of decision making sitting with "management". She identifies the justification for strict monitoring of sexual health is related to fear of harm or possible harm ("terrified", "slightly wrong", "potentially go wrong"). Hana challenges the denial of women with ID's sexuality as dehumanising and instead construes sexuality as a normal human experience for all people ("human beings be human beings"). These discourses of sexuality and intellectual disability often encompass the restrictions of people with ID, overprotection, and neglect of their sexual needs (Parchomiuk, 2021).

These examples highlight the difficulties that support workers experience in a context in which the sexuality of women with ID is either construed as non-existent or as problematic and needing to be heavily regulated. However, without sexual health policies, support workers must rely on the personal views, values, and experiences around sexual health and disability to make decisions (Christian et al., 2001). In doing so, support workers are "driven by fear" (Hana) as they construct sexual health around the concept of risk and are left questioning what to do if it gets complicated. For instance, in the following extract Luna discusses her knowledge on the sexual health policies within her organisation.

Extract 21, Luna (1-2 years as a support worker):

I think there's probably a policy where if something were to happen, then this is how we would go about it. But there's no, it's not something that is like practiced or applied in our monthly meetings, or in our way that we work with [women with ID]. So, I'm sure there is a policy on it but, yeah, it's probably more of a responsive, like, "how do we respond if something were to happen?" as opposed to "how we talk about this".

Luna is not certain of a specific policy related to sexual health but assumes a policy that exists would be risk averse and reactive rather than proactive ("if something were to happen", "responsive"). She implies that support for sexual health is not a priority in the organisation, which research suggests can lead support workers to question their ability to make decisions around risk and feel it is out of their scope of practice (Roberts et al., 2012). I pick up on this in the following theme.

Theme 4: In the absence of guidance - "I just need a little bit of guidance"

This theme is founded on participants' reports of minimal sexual health training and education for support workers and for women with ID. In absence of training and policies, support workers relied on their personal knowledge and judgement to support women with ID with their sexual health, or alternatively, relied on the women's family members. Understanding the guidance required for support workers is important given the literature suggests that women with ID often rely on their support workers to support their sexuality (Bernert, 2011). With this in mind, this theme is split into two sub-themes: (a) making a best guess, and (b) family know best.

It was common for support workers to present themselves as helpless to empower women with ID around sexual health. For instance, they reported that some colleagues didn't feel "totally comfortable" (Kylie) responding to sexual health issues for women with ID or were not confident to "just come out [and] start a conversation" about sexual health (Piper). Furthermore, the conflicting messaging implicitly added to the support workers' construction of the unclear boundaries of their role, consistent with research that implies the ambiguity of the role us due to a lack of organisational training and policy (Leclerc & Morin, 2021; Maguire et al., 2018).

The support workers said that they look to their organisations for guidance on the expectations for their role and commonly positioned themselves as unsupported in relation to dealing with sexual issues. Training was commonly depicted as lacking. Piper labelled training like first aid as 'your normal courses', implying that sexual health training is unusual. Below, Madison describes her experience with professional training in her current workplace:

Extract 22, Madison (15-20 years as a support worker):

I haven't seen any, or I don't know, we haven't got a lot of information, like workshops or training about sexual [issues] from my company. I haven't had any probably. So, it's quite behind I think. So we are not really supported. I'm feeling that much. More like 'Oh you have to think by yourself,' 'depends on the situation', or 'you have to work with your team member.' Not like, support by specialists. I think we do need a little bit more support from the company.

Here, Madison maintains that the lack of sexual health training does not meet her expectations of support from the organisation, which she describes as "quite behind". As a result, she positions herself as expected to be self-supporting in her role. Constructing sexual health support as a "specialist" role, suggests that this is not a commonplace aspect of the job and that support workers are not equipped in this area. Indeed, Cwirynkalo and colleagues (2017) emphasise that the system constraints in the disability sector play a part in support worker competency around sexual health.

It is important to recognise that sexual health policies and training possibly do exist for support workers in disability organisations in Aotearoa New Zealand. One participant made reference to a sexual health standard operating procedure, while others were uncertain of the policies that existed ("probably a policy" (Luna)), and referred to policies hypothetically ("if there was an organisational policy…" (Hana)). The reliance on the organisation to provide guidance for support workers relates to the workplace discourse that builds on hierarchy structure, organisation values, knowledge, and culture as implications of practice (Gunnarsson, 2009).

Sub-Theme 4a: Making a best guess

This sub-theme relates to the ways that support workers described drawing on their own sociocultural background (e.g., their culture, and religion) and experiences to make decisions related to the sexuality of women with ID. Without the structure and guidance in the disability sector, support workers are positioned as making a best guess based on their own views and experiences. One risk of minimal guidance is the inability for support workers to address sexual health issues if they are unaware of its importance (Saxe & Flanagan, 2016). For instance, in the following extract, in lieu of organisational guidance, Kylie explains her experience of providing advice to her colleagues around their role in supporting the sexual health, and more specifically, the 'sexual diversity', of women with ID. She positions herself as progressive in relation to conservative co-workers.

Extract 23, Kylie (3-5 years as a support worker):

So it was very hard to validate myself or try to tell them what I am saying is not rubbish, is how [I] used to work, and what can [be] complicated. Because it's a lot of moral concepts around, and I've got very religious, religious [support workers] as well in the house. So for them, some kinds of things are more appropriate or inappropriate. For example, sexual diversity: when we talk about, um, gays or something, they get very uncomfortable because they've got their own way to think about.

In this extract, Kylie constructs sexual health as a 'complicated' a moral-laden issue, and the absence of guidelines implicitly puts her at odds with "religious" co-workers who have their "own views" about what is sexually "appropriate". Kylie gaining colleagues' buy-in to support people with ID with their sexual health as difficult ("very hard to validate"). Her description of this support as "not rubbish" suggests not only that she sees it as warranted, but also alludes to opposition she has faced from those who have different, more conservative views. She depicts colleague as "uncomfortable" and attributes their discomfort to personal and religious beliefs around sexuality ("religious people", "own way to think about it"). Indeed, international research indicates that ideas about morality, in addition to individual capacity and capability, play a role in support workers' assessments of the appropriateness of sexual activity (Gill, 2015).

Cultural understandings were also cited as playing a role in how issues of sexuality are approached. Indeed, research in the UK suggests the culture of support workers influenced on the development of relationships for the people with ID they support (Bates et al., 2020). For example, Piper drew attention to her own culture and how it weighs on discussions around sexual abuse.

Extract 24, Piper (1-2 years as a support worker):

I am half Māori so, in our culture, it [sex] was not talked about. And [sexual abuse] did happen (. . .) They have community groups, or they have marae meetings with just women, and they start to talk about it. You know, and then introducing our young people into the marae and then talking to them about it (. . .) they can talk openly about it, um, and not feel ashamed and know that it's OK and we stop these people from hurting us.

In this example, "culture" features as both a reason for the avoidance of discussions about sexual health ("not talked about"), and especially sexual harm, as well as a potential avenue for addressing taboo and harm by bringing together cultural customs to encourage discussion that connects women in a safe space ("community groups", "marae meetings", "introducing"). The latter echoes Le Grice

and Braun's (2018) observations of how mātauranga Māori about sexual health occurs in the conversations within a marae. Referring to "our young people", Piper takes a up a protective position, similar to the maternal position she adopted when discussing her the woman she supports, and construes openness about sexuality as necessary for tackling harm and shame ("talk openly", "not feel ashamed", "it's OK").

Support workers have been found to hold more positive understandings of sexual health in recent years, but there remains discomfort supporting women with ID with their sexuality (Leclerc & Morin, 2021). Resonating with the findings above, international research highlights the complexity and centrality of social and cultural norms in support workers' understandings of sexuality and their practices with women with ID (Rohleder & Flowers, 2018). Providing space to enable support workers to understand their social and cultural views around sexual health is believed to be essential in reducing the victimisation and vulnerability of women with ID (McCarthy, 2014). In this vein, Saxe and Flanagan (2016) propose that sexual health training for support workers will prevent the reliance on their personal experiences and cultural beliefs and improve their confidence accordingly. Sexual education can encompass the social and cultural components of sexuality to prevent sexual violence (Valentiner, 2021).

Participants themselves commonly referred to the need for support workers to be educated and equipped to deal with sexual and reproductive issues. Talk of the lack of formalised training and education for support workers commonly positioned them as responsible for making judgements about the role they should play in the sexual and reproductive health of women with ID. However, as Luna's comments on formalised education illustrate this was commonly understood as only *part* of the solution.

> **Extract 25, Luna (1-2 years as a support worker):**
> I think [formal education is] needed, but, then it's like, where do you go from there? Like, once you educate, whether it's the client or the staff, on, 'OK this is what we're going to do', how do you then apply it? I think that's the hard part. But, I think even educating people about it, is still very helpful.

The language used by Luna indicates that she believes sex education is necessary and beneficial for women with ID, and support workers ("needed", "very helpful"). However, she highlights the potential difficulty ("hard part") in 'applying' the learnings from these trainings. By questioning what potential changes might occur through trainings ("where do you go from there?"), Luna remains uncertain about supporting sexual health. This example shows how participants frequently positioned support

workers, themselves included, as ill-equipped to deal with sexual and reproductive issues. Luna's account suggests that education is "helpful" but alone not enough and that support with implementing knowledge is needed. This view was echoed by other, for instance, one participant described the lack of organisational support as the "nature of the beast" (Lilian), suggesting this was something she did not see as a possible change.

Sub-Theme 4b: Family knows best

Family knows best is the second sub-theme under the main theme "In the absence of guidance – 'I just need a little bit of guidance'". Following from the sub-theme above, when lacking formal guidance support workers commonly described turning to the family of the women with ID to make decisions for her, and feeling unable to make decisions about sexuality themselves. For example, one participant shared she "would support them [for sexual health screenings] if parents weren't able to take them" (Piper), clearly positions herself as referring to the family. In the context of this research, family refers to any relation of a women with ID such as parents, grandparents, and siblings.

From the initial stages of analysis, it was clear that family was significant in sexual health discussions, due to the frequent references to family and family-like relationships. Participants described the family and parents of women with ID especially as highly significant, with Hana stating for example that "parents are a massive factor", supporting international findings indicating that families hold a significant role in the decision-making around the sexuality of women with ID (Charitou et al., 2020). In part this has to do with the family's legal status as guardian, but it also aligns with and reinforces the wider infantilisation of women with ID (Mohammed & Shefer, 2015). This construction can be seen as justifying support workers reports of relying primarily on the guidance and advice of families and letting them direct decision-making. Accordingly, the participants discussed the influential role of family in paternalistic terms, suggesting that parents know what is best for their child. Molly, for example, explained a particular woman's use of Long-Acting Reversible Contraception as follows.

> **Extract 25, Molly (3-5 years as a support worker):**
> It [Long-acting Reversible Contraception] was a family decision with her, a long time ago. For two reasons, just, well, because the [pregnancy prevention], and because she doesn't have to have the period. And so, it's just one thing that she does[n't] need to think about. So, the family, with her, they decide to put to the [IUD, Intrauterine device]. I don't know, life is simple because she has the *Mirena* [IUD]. She is really fine with this and doesn't have any problem.

> She, sometimes she's worried about "I have this *Mirena* in for a long time, I maybe need to check if it's OK or not." But when we went to the doctor, she ask[s] all the time and is OK.

In this extract, the woman with ID's contraceptive use is constructed as "a family decision" made in collaboration with the daughter ("with her"). In Molly's account of this situation, the family constructed safe sexual experiences that are responsive to the sexual health needs of this woman with ID, such as pregnancy and periods. Following the family's decision, Molly appears to position herself as responsible for maintaining good sexual health for women with ID ("went to doctor"). Furthermore, the woman with ID has control over her sexual health as she shares her concerns ("worried") which trigger this doctors visit. However, this positioning of autonomy and control conflicts with the suggestion that these decisions were made so "she doesn't need to think about it" thus, indicates autonomous decision-making for women with ID is a burden.

Positioning families as the default decision-makers in relation to sexual health and positioning of women as de facto children is supported by, and reinforces, the victim discourse that positions women with ID as incapable, vulnerable and, consequently, in need of protection. Furthermore, it ultimately gives the family greater authority to choose situations related to contraception, sexual health education, and motherhood. Kylie discussed the consequences of a lack of parental guidance for one woman with ID:

> **Extract 26, Kylie (3-5 years as a support worker):**
> One of [the women with ID] believed that she got some kind of sexual abuse by her brother, older brother, who [has] also got high disability. That make[s] sense why, if she was reacting in that way, but it's also a lack of knowledge from part of the parents and a lack of communication and, um, information to the child as well.

Here, Kylie suggests that this family has failed to safeguard this woman with ID from sexual harm ("sexual abuse") by not providing her with necessary "knowledge", "communication", and "information" about sexual health. As such the responsibility of supporting sexual health is rendered the family's role and, correspondingly, they are also deemed responsible for any negative outcomes. This is not to say that families of women with ID were only depicted negatively. They were also depicted as a source of positive support for the sexual health of women with ID. For example, Hana talked about a family who had paid for the wedding and first home of their son and daughter-in-law.

Nevertheless, families were positioned as gatekeepers and the participants commonly highlighted the importance of building a positive relationship with the family. Luna said, for example,

“I still have quite an active role as a support worker, in getting to know the family as well as the client”. Molly positioned one family that she worked with to be the primary influence and decision-makers for sexual health:

In many circumstances, family of women with ID will advocate for the safety and protection of their family member in favour of facilitating the exploration of sexuality and sexual rights (Kahonde et al., 2018). Due to the different values between support workers and families, it is common for there to be conflicts in how to support sexual health (Cuskelly & Bryde, 2004). Although interestingly, the participants mostly positioned themselves as supportive of the families’ decisions around sexual health. There were exceptions to this in some circumstances, for example:

Extract 27, Madison (15-20 years as a support worker):

I think she was brought up by her grandparents and they are so Catholic, and they are thinking also until you get married you should be a virgin. So you shouldn't have any sexual interaction with men, so you shouldn't do that. So she was brought up like that, and then suddenly, ah not suddenly, but she had a boyfriend, and then they, they decided to live together. And the boy, he is active, is active for sexual act. We were so concerned about how… ‘cause she never ever had nothing happened in her life and then suddenly she will be living with a man with a lot of experience.

Extract 28, Piper (1-2 years as a support worker):

I haven’t heard none of the parents even speak of [sexual health]. […] I don’t know whether they’ve accepted that their child has become a young adult. Yeah, I don’t know, I don’t know why they don’t or haven’t spoken of it.

In extract 27, Madison suggests the woman’s religious values around sex were learned from her family and implies that these values place her in a vulnerable position due to her sexual inexperience, leading to support workers being “so concerned”. In extract 28, Piper suggests that none of the parents she has worked with have spoken about sexual health. Ignoring the sexuality of people with ID is commonly deemed a safe way to address concerns related to sexual health (Vehmas, 2019) and Piper attributes this avoidance to the failure to see the person with ID as an adult, drawing on the construction of women with ID as forever-children (Tepper, 2000). While Piper claims not to know reason parents were hesitant to discuss sexual health, it is recognised in literature that families may be fearful of the abuse, exploitation, and harm that could occur for women with ID (Brown and McCann, 2019).

Families' denial of the sexuality of women with ID is a barrier for disability organisations (Alexander & Gomez, 2017). For example, one participant shared an account of parents threatening to "remove" their child from the service if the sexual relationship with a housemate was not stopped (Hana). In such instances, support workers hold professional liability if a family were to make a complaint against them (Bigby et al., 2017). Furthermore, Healy and colleagues (2009) discuss that there are possible legal complications for services that promote the sexual health of women with ID. Support workers are thus tasked with balancing protection of themselves and enabling the sexual and reproductive rights of the women they support. This may amplify the sense of fear around sexual health raised by participants across the data as suggested in Luna's appraisal of the families' positioning around sexual health for women with ID:

Extract 29, Luna (1-2 years as a support worker):

As a support worker I think your role is always going to be overruled, or compounded by their family members. Because a lot of them, as much as they are adults, a lot of their parents are still very involved because they care and because they, you know, they still care for them and some of them will go home on the weekends and, you know. So they're still very much like involved in their lives and their opinion, or their core beliefs on sexual health and needs.

Luna positions herself as holding less power than the family in the decision-making around sexual health, with the potential to be "overruled" by a family. She attributes this power imbalance to the family's ongoing involvement and influence on woman's "core beliefs" despite their adult status. In Luna's account, the family's involvement intertwined with the positioning of women with ID as a defacto child ("as much as they are adults") whose parents "still care" for them and receive regular visits. This aligns with evidence showing that people with ID often rely on their family for receiving information about sexuality (Leclerc & Morin, 2021). Yet, families' strong values about sexuality of people with ID can contribute to women's sexual needs not being met (Greenwood & Wilkinson, 2013).

Family involvement in sexual health differed across the participant's accounts suggesting differing support in this area. The participant's accounts and examples shared in this sub-theme are correspond with international research findings showing that families are unsure about how to manage the sexual health of people with ID, as they too balance the role of protector of harm, and supporter of sexual rights (Hamilton, 2012; Kahonde et al., 2018).

Chapter Four: Concluding Discussion

The topic of SRHR for women with ID is largely underreached, especially in Aotearoa New Zealand. This gap in the literature speaks to the country's lack of policies about sexual health for women with ID more broadly. Research shows that support workers play a significant role in the sexual education and experiences of women with ID (Maguire et al., 2018), hence the importance of gaining in-depth insight into the account of support workers employed in Aotearoa New Zealand. Therefore, the purpose of my study was to address the lack of knowledge about women with ID's SRHR in Aotearoa New Zealand. I have investigated how support workers, as key support agents, understand their role in helping to promote sexual agency and rights for those in their care. The research was guided by three sets of research questions. First, how do support workers construct the sexuality and sexual needs of women with ID? What common gender discourses and subject positions do they draw on? Second, how do support workers account for their role in supporting sexual health for women with ID? How do they commonly position themselves and others? Third, what are the wider implications of these common constructions for women with ID, particularly with respect to their agency in SRHR?

My research is one of the few studies on the topic in Aotearoa New Zealand, and internationally, and will help raise awareness of the sexual inequities, injustice, and disempowerment experienced by women with ID. It is important to remind readers that the themes I generated and discussed are tied to the participants' subjective experiences. My participants reported on their experiences of women with ID having no opportunity to engage in positive sexual relationships and highlighted situations where women with ID faced discrimination and disempowerment. These findings reflect the everyday discourse of sexual ableism that prevents equal rights for women with ID (Addlakha et al., 2017; Dinishak, 2016; Fitzgerald & Withers, 2011; McGuire & Bayley, 2011). In addition, the themes were developed through my personal socio-cultural perspective as the researcher. In acknowledgement of this, I recognise my background as a privileged, educated woman without a disability, who has been predominantly fortunate to have opportunities for sexual education and sexual expression and exploration, unlike many women with ID. My passion for social justice, and the need for greater sexual and reproductive freedom and justice for women with ID has fuelled much of my work and the development of this research project. My determination to make change in this field of work, has only become stronger as I have immersed myself in the existing. I attempted to bring critical awareness of my agenda through a reflexive approach to research analysis that enabled the freedom to generate themes through my sense-making of the data (Braun & Clarke, 2020b; D'Souza et al., 2020). Thus, my personal agenda to normalise and empower sexual health for women with ID will shape the findings.

Ultimately, discourses that position women with ID as 'at risk' and in need of protection, which I recap below, highlight why the SRHR of women with ID is a social justice issue that requires change at an individual, structural, and social level. Critical health psychology, the broad subfield within which my research sits, seeks to examine and reshape structures that are harmful to individual's health and wellbeing, ensure people's voices are heard, and emphasise the importance of social change (Lyons & Chamberlain, 2006). I conclude this research, therefore, by highlighting the broader, social, cultural, and political queries demonstrated by this work, and propose interventions for change. In this final chapter, I bring together an overview of the findings of this research project, and how they contribute to the existing literature.

1. Research overview

I interviewed seven support workers from across Aotearoa New Zealand about their understandings of the SRHR of women with ID and their roles in supporting this. Their accounts highlighted the complexities of balancing the risks associated with sexual health and enabling women with ID through victimhood, human rights, gender, and risk discourses. These discourses interweaved with an ableist discourse that sees disability as a deficit that sits outside the social ideal of an 'able' person (Ignagni et al., 2016).

I have shown that the dominant discourse throughout the data was the victim discourse. This discourse denies agency to women with ID, as manifested in an absence of choice and disempowerment in relation to sexuality. Support workers' concerns about "risk" centre on protecting women with ID from sexual abuse and unintended pregnancy. These women's assumed vulnerability meant that they were construed as not able to be trusted to make autonomous decisions about their sexual health. This perception of vulnerability and potential victimisation, as I showed, is rooted in a conservative understanding of gender and disability that render women with ID especially at risk so that it is seen as dangerous and undesirable for them to have sexual experiences (McGuire & Bayley, 2011). Reinforcing this construction, and in alignment with existing research, women with ID were viewed as eternal children by their families, other support workers, and society and therefore sexually naïve and incapable of making wise decisions or looking after themselves (Björnsdóttir & Stefánsdóttir, 2020; Gill, 2015; O'Shea & Frawley, 2019). These constructions are part of the history of institutionalisation that plays an ongoing role in the avoidance of women with ID's sexuality (Gil-Llario et al., 2017).

The findings suggest that dominant victim discourse supports power imbalances between women with ID and support workers in as it draws on and supports the ableist, deficit discourse of disability in which sexual health is rendered non-existent or a problem (Cwirynkalo et al., 2017). The

participants' accounts point to multi-layered power imbalances between women with ID and support workers. As I showed, the women are depicted as relying on their support workers to a large degree and support workers are common positioned as influential gender role models, advocates of the needs and rights, and, frequently, the protectors of those they care for. Participants constructed the working relationship with the women they support as a close and intimate one, characterised by care and affection. This rapport and trust between the support worker and women with ID resulted in participants positioning themselves as advocates and a voice of women with ID. The need to advocate emerged through different situations. Some support workers described challenging the system and taking risks to empower relationships, while others or avoiding risk entirely. Some participants expressed frustration with restrictions placed on women with ID, positioning themselves as professionals and employees conflicted by a complicated relationship of personal and professional boundaries. Regardless of their approach (supportive or restrictive), support workers hold much influence and control in sexual decision-making and practices of those they care for. This uneven positioning between support workers and women with ID aligns with international research showing how the working relationship is embedded in power, as are the the professional/private boundaries (Robinson et al., 2020; Wolowicz et al., 2021). Despite this, participants themselves did not recognise power relationships, assuming that their working relationship was collaborative with the women they support. However, because women with ID rely on support workers to access resources such as health care and negotiating issues thus, the relationship cannot be free from power relations (Matin et al., 2021; Robinson et al., 2020).

At times, support workers' accounts suggested being caught between obligations to the women with ID, their families, and their employers. Indeed, support workers are ultimately answerable to their managers, as well as the families and legal guardians of women with ID, and there are further power relations for support worker to navigate. Organisational regulations that expect support worker's to manage risk reinforce the victim position of women WID and power imbalance between them and support workers. The decision-making hierarchy that participants described in disability services also limits support workers' full support of SRHR, because of the associated risks (Maguire et al., 2018). Participants reported feeling ill-equipped to help women with ID with their sexual and reproductive health due to inconsistent expectations of their role, limited education and training, and sometimes their own values. The findings, with some exceptions, echo international findings that the risk of harm often overrides the self-determination of women with ID when making decisions about their SRHR (Bigby et al., 2017).

2. Research reflections

The area of SRHR was a personal interest of mine due to my many conversations with support workers through my role in disability services. I felt it was important to formally research the discussions I have had with support workers over the years, while being mindful not to allow these previous discussions to influence my analysis of this research. Despite my previous experience and assumptions about sexual health and disability, the process of writing a literature review and completing the analysis helped to create a platform for furthering my knowledge.

The objective of this research was to explore the support workers' understanding of the SRHR of women with ID. This was achieved through interviewing support workers on issues such as sexuality, contraception, sexual rights, and sexual education. The significance of researching support workers specifically relates to the strong influence they have on the lives, and opinions, of women with ID (Petner-Arrey & Copeland, 2014). Respectfully, support workers are a resource for women with ID to develop independence and become agentic sexual beings.

The present research provides rich and meaningful data that answered my research questions. However, the findings must be contextualised in light of the fact that participation was entirely voluntary. As a result, those who volunteered had a special interest in the topic on sexual health and rights of women with ID. While this interest came from different situations, for example, personal experiences or workplace experiences, it eliminated the opportunity to discuss the topic with those who may hold different views or who did not feel comfortable or safe discussing sexual health.

Another important consideration is the make-up of the participant group. While there is some diversity in terms of the participants' age, culture, gender, and experience, a male support worker narrative is missing. This can be explained as related to existing policies that restrict men from working directly with women with ID. It would have been an interesting point to explore in the interviews to gain insight into similar and differing views from a male perspective. This is a possible avenue for future research. Research about supporting men with ID is also lacking and would be a welcome topic for further research.

On reflection, I note that the gender of participants was assumed as women, and not specifically queried. Additionally, the sexual identity of participants was not disclosed as part of this research. Participant's personal sexual identity and their experiences related to this would have been beneficial for better understanding their position and construct around sexual health. These gaps in the participant information are largely the result of my inexperience as a researcher.

Each participant's account of their experiences and values were different yet, they were all affected by the SRHR of women with ID in one way or another. While qualitative research such as this cannot be generalised, the similar examples shared between participants across various organisations indicates that comparable findings may be explored through further local research (Baker, 2006). The

literature review, and research findings discussed throughout this research emphasise the complexity of interwoven social and cultural layers that determine the SRHR of women with ID. It is essential to consider these common discourses and constructions that at times restrict these rights for women with ID in future research.

2.1. Implication of findings

The research findings illuminate the need to challenge the status quo for women with ID. The barriers to equal SRHR for women with ID are unacceptable, and the findings of my study suggest that change is needed. However, this change is outside of the control of both women with ID and their support workers (Petner-Arrey & Copeland, 2014). I therefore make three recommendations to address the issue. It should be noted, there are many strengths within the current systems that can be built upon. For example, the influential relationship between support worker and women with ID. Furthermore, support worker's good intentions and desire to do what is best for women with ID can be leveraged to bring about positive change.

Recommendation 1: The first recommendation is a review of Aotearoa New Zealand's social policy, systems, and structures to improve the support for sexual education for women with ID. These systems include government, schools, health and disability organisations, and other services (Stoffelen et al., 2017). Promoting the SRHR and encouraging sexual agency of women with ID cannot come from social policy alone however, policy can enable the knowledge and education in SRHR to start to address discrimination and stigma (Daly et al., 2019). For instance, embedding disability-inclusive conversation into mainstream sexual education can change the perceived vulnerability of women with ID to a discourse of empowered women with ID (Bernert & Ogletree, 2013). An important par of this is cultural safety. There must be a consideration for Māori women with ID, as international legislation does not specify support for indigenous people (Series, 2019). The literature describes this as gatekeeping and suggests prejudice, professional obligations, and uncertainty of the legal implications are all factors which prevent SRHR in disability services (Alexander & Gomez, 2017). Thus, the policies and systems that are put in place must take this cultural consideration into account.

Recommendation 2: Secondly, support workers have good intentions to help those in their care, but require guidance and training to support the SRHR of women with ID in a way that both responds to potential vulnerabilities and enables opportunities for agency and positive SRHR. Therefore, at a service level, disability organisations can revise the support worker job descriptions to integrate a focus on supporting relationships for women with ID, in addition to their day-to-day tasks. This will allow for changes to the positioning of women with ID and their sexual health by utilising the highly valued relationship between support workers and women with ID to promote inclusion,

participation, and autonomy (Robinson et al., 2020). At a community level, advocating for and promoting sexual health within communities or creating an open platform for discussion about SRHR may build confidence in this specific area of a support worker's role.

Recommendation 3: Finally, there is certainly a need for further research to understand the role and responsibility of disability service managers to ensure greater practices for SRHR (Lines et al., 2020; Maguire et al., 2018). Without further research, social and structural systems may see little change. Qualitative research is required to understand the populations marginalised by society (Wilkenfeld, 2015). With this in mind, first and foremost, women with ID must be involved in the research that promote their rights.

For the bicultural country of Aotearoa New Zealand, it is important to include the voices of Māori women with disability in future research. By including the Tikanga Māori principles that promote inclusion within education and policy, culturally safe SRHR practices can be developed (Bevan-Brown, 2013). To ensure these practices and programmes are embedded within service supports, research should gain an understanding of those who are influential in the lives of women with ID, such as family members or organisations.

3. Participant ideas to improve sexual health supports for women with ID

Throughout the interviews, participants suggested steps that can be taken to empower women with ID with their sexual health and rights. As identified in the literature review, there is a need for more knowledge from a support worker's perspective in addressing the SRHR for women with ID (Hughes, 2006). Therefore, there is significant relevance in the participant's ideas as they are working directly with women with ID, and observing their frustrations and discrimination in the battle to achieving equal rights for their sexual health.

I found myself relating to my own experiences in the disability sector where many support workers shared solutions to existing issues. However, these ideas were not always communicated to those who are able to implement them. Therefore, I felt it important to utilise the platform of this research to ensure participant's ideas to empower the SRHR for women with ID are heard. Interestingly, the points below were generally aligned across all participants, despite their different cultures, experience, and understandings of the issues.

- For support workers to be supported by their organisation to talk about sexual health and rights more frequently, and not to "hide behind closed doors" (Piper).
- For organisations to upskill their support worker staff by providing education for support workers around supporting sexual health and rights for women with disability and promote healthy relationships.

- For women with ID to be given the opportunity to have an appropriate educational programme around their sexual health and rights. Preferably, a programme that support workers can be trained to implement, and with a trauma-informed lens.
- For organisations to have access to specialist support for staff in addition to the health and behaviour lenses that they currently have access to.
- For organisations to review their policies that prevent potential harm and increased vulnerability to the women they support.

These points raised by the participants are consistent with existing research that highlight a need for more resource, a review of policy, and sexual education for women with ID and support workers with a rights based and trauma-informed lens that take into account the high levels of abuse and discrimination experienced by women with ID (Charitou et al., 2020; Eastgate et al., 2012; Leclerc & Morin, 2021; Maguire et al., 2018; McCarthy, 2014; Murray, 2019).

4. Conclusion

It is widely acknowledged that the SRHR for people with disability, in particular, women with ID, require focus on the inequities, and ideological and social structures that currently prevent opportunity and access to services (Addlakha et al., 2017). This research only starts to explore the social constructions that enable and challenge the discrimination of women with ID regarding their SRHR. Through the support worker's lens, the research provides insight into how things are, and how things could be for women with ID in assisted living services. The findings demonstrate how women with ID are largely disempowered in their sexual and reproductive lives. However, support workers currently lack the guidance and training to consistently promote and empower sexual agency. Thus, highlights the urgent need to bridge the gap, and remove the stigma that exists for women with ID and their SRHR.

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Appendix 1: Information Sheet

Support Workers' Understandings of the Sexual Health and Rights of Women with Intellectual Disability in Aotearoa New Zealand: A reflexive thematic analysis

Information Sheet

My name is Olivia Bloom and I am currently studying Health Psychology at Massey University. I am conducting a research project that explores the support workers' understanding on the sexual health and rights of women with intellectual disabilities. The project may cover topics such as sexual education, sexual abuse, contraception, pregnancy, parenting, and sexuality.

I will be interviewing people who:

1) are employed as a support worker in a residential service setting,
2) have experience working as a support worker with women with ID,
3) are over the age of 18.

Participants may be of various ages, cultures, and level of experience as a support worker.
If you fit these criteria, I would like to invite you to participate in this research.

Participants will be invited, via email, through a variety of disability care providers in Aotearoa, New Zealand. Participation is completely voluntary.

Project Procedures

Participation involves a 1:1 interview, held online (e.g. Zoom or Teams) conducted by myself. This interview will be scheduled at a time that suits you, and will be around 1 to 1.5 hours.

With your consent, interviews will be recorded and analysed to create themes of understanding.

Risks

There are a number of potential risks involved in the research.

- *Participants may experience emotional upset when discussing topics related to sexual health – participants will be offered a debrief interview.*
- *Confidentiality will be prioritised throughout the research by using an alias, and removing all private and personal information from the data. However, sharing information about an experience that occurred at the participants place of work may identify them to the organisation or their colleagues. This risk is reduced by participants being invited from multiple organisations.*
- *Participants may experience technology fatigue during online interviews.*
- *Any unforeseen risks will be communicated with the participants.*

Benefits

- *This research has the potential to influence policy changes for supporting women's sexual health.*
- *There is an opportunity to develop training for support staff, and inform the field of disability.*
- *This research will highlight gaps for future research.*
- *This research may positively influence the sexual health attitudes and beliefs around women with ID.*
- *Participants will have an opportunity to share their personal experiences, playing an active role in New Zealand disability research.*
- *Participants will receive $25 for participating.*

Data Management
Interviews will be recorded using the video recording function on Zoom or Microsoft Teams, and stored on a private shared drive. This drive is only accessible to the researcher and their supervisor. Recordings will be deleted once transcribed. All transcripts will be anonymised immediately. Only the researcher and their supervisor will have access to consent forms, audio files, and transcripts. The interview data will be stored digitally and securely by the supervisor for 5 years before getting destroyed/deleted.

Participant's Rights
You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- *decline to answer any particular question;*
- *ask for the recorder to be turned off at any time during the interview.*
- *withdraw from the study, without reason, at any point up to one month after your interview.*
- *ask any questions about the study at any time during participation;*
- *provide information on the understanding that your name will not be used unless you give permission to the researcher;*
- *be given access to a summary of the project findings when it is concluded.*

Further Support for Participants
Are You OK – 0800 456 450 family violence helpline.
Shine – 0508 744 633 confidential domestic abuse helpline
Skylight – 0800 299 100 for support through trauma, loss and grief
OUTLine NZ – 0800 688 5463 (OUTLINE) Rainbow mental health support
Need to talk – 1737 free call or text any time for support from a trained counsellor

Thank you for your consideration to take part in my research. If you have any queries, please do not hesitate to get in touch.

Olivia Bloom
Oliviasjeffers@gmail.com

MUHEC APPLICATIONS

Committee Approval Statement

> This project has been evaluated by peer review and judged to be low risk. Consequently it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Professor Craig Johnson, Director (Research Ethics), email humanethics@massey.ac.nz.

Appendix 2: Consent Form

Support Workers' Understandings of the Sexual Health and Rights of Women with Intellectual Disability in Aotearoa New Zealand: A reflexive thematic analysis

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I **agree** / **do not agree** to the interview being sound recorded.

I **agree** / **do not agree** to the interview being image recorded.

I **want** / **do not want** to have my recordings returned to me.

I **want** / **do not want** to have data placed in an official archive.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: ..... **Date:** .....

Full Name - printed .....

Appendix 3: Interview Guide

Ground rules

The rules for the interview as advised by Sandfordt & Morison (2013):

1) Model comfort in talking about sexuality with the participant
2) Avoid passing judgement
3) Build and maintain rapport
4) Defuse and disarm participant's reactions (for example, their discomfort)
5) Engage in accurate tracking and accurate probing

Interview opening script

"Hello, I am Olivia. I am currently studying my Masters in Health Psychology at Massey University, with the goal to become a registered psychologist. I have worked as a support worker, and behaviour specialist in a couple of residential disability organisations. I now work in a family violence organisation.

This project focuses on support workers understandings of the sexual health rights for women with ID. I want to thank you for your participation in this project. Please remember you have the right to:

- *decline to answer any particular question;*
- *ask for the recorder to be turned off at any time during the interview.*
- *withdraw from the study, without reason, at any point up to one month after your interview.*
- *ask any questions about the study at any time during participation;*
- *Your name will not be used unless you give permission to the researcher;*
- *be given access to a summary of the project findings when it is concluded.*

Have you got any questions or anything you would like to ask me?
It would be great to hear a little bit about yourself…."

Opening questions To build rapport between researcher and participant	Tell me a bit about your background; Where did you grow up? Tell me about your job • When did you start working as a support worker? • What interested you about the job? • How long have you worked for Spectrum? Tell me about your previous roles.
Support worker related questions	**Could you tell me about how you understand your role, in general, as a support worker?** ▪ What does it mean to you to be a support worker? ▪ What expectations are there for how you support people within your role? ▪ What is something you like about your role? ▪ What is something you dislike about your role? ▪ Tell me the sorts of things you deal with in your role.
I am interested in the role support workers play in relation to the sexuality of the women they support. I just want to be sure we're on the same page before we go on. - What does the word sexuality mean, or include? - How does this relate to the women you support, and your role in supporting them? From my perspective, this topic includes issues related to relationships, safer sex practices, contraception, pregnancy and birth, and sexual orientation.	

<table>
<tr><td colspan="2">

- Is there anything that you think should be included or removed from that list? [Discuss, probe]

I'm aware that these topics are quite personal and sometimes controversial, so if there is anything you would rather not discuss just let me know, and we can move on to something else.

</td></tr>
<tr><td>Sexual health related questions</td><td>Can you tell me a bit about what you think a support worker's role is in relation to a female person's sexual health or needs?
How is sexuality and sexual relationships handled in your workplace?
What expectations are there for how you in terms of supporting people with their sexual health or needs?
▪ Probe: What are your thoughts or feelings about these expectations?
What supports currently exist for women with ID regarding their sexuality? Barriers/challenges?

What do you think 'sexuality' means for the women you support?
- Probe: What rights do women with ID have in this area? /what is missing?
How have they found out about sex and related topics?
- Probe: Tell me about the sexual education available to women with ID
- What conversations are held about sexuality between support workers and the women you support?
- What conversations are held about parenting and pregnancy between CSW and women you support?

Tell me how you think culture and sexuality interact with each other?</td></tr>
<tr><td>Case scenario</td><td>I'm interested in your thoughts on a particular case scenario: a 50-year-old woman in residential care whose family does not want her to learn about sex. She has a long-term boyfriend and wants to have a baby despite being post-menopausal and unable to have children. She has to be supervised by staff when with her boyfriend. Due to her sexual behaviour towards men, she has been suspended from her day programme.
▪ How would you approach this?
▪ How much input do you believe family should be involved with situations like this?
○ How sexually appropriate and inappropriate behaviour is defined and managed among women with ID in workplace (and do you agree?)
▪ How women with ID express sexuality.
▪ motivations of women with ID for intimate/sexual relationships; to marry and have children.
▪ use of contraception by women with ID. (What has been your experience in supporting people with contraception?)

Tell me about a particular case or situation that has stood out to you (positive or negative).</td></tr>
<tr><td>More challenging questions</td><td>Areas to probe/follow up on:
• Training and info for support workers in your place of work?
• Challenges</td></tr>
</table>

	• What factors might influence discussions about sexual health and sexuality? • Sexual risk (abuse, exploitation) – greater than for non-disabled women? Men with ID?

Interview closing script

"Thank you so much for meeting and sharing your experiences with me today. From here, I will write up our interview into a transcript and begin to look for themes of information across all of the interviews. These themes will be included in the 'findings' section of the thesis, and submitted to Massey University.
I may need to get in touch with you again to make sure I have all the information, or to clarify my understanding of what you have shared with me. Would this be ok?
Please don't hesitate to get in touch with me if you have any concerns or questions.
Thank you again."