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Supporting Intellectually Disabled Women's Sexual and Reproductive Health and Rights: A Qualitative Study With Support Workers in Aotearoa New Zealand

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ABSTRACT

This article presents findings from a qualitative study of support worker responses to intellectually disabled women's sex and reproductive health. Drawing on reproductive justice theory, interviews with seven support workers from various disability service providers in New Zealand were analyzed using reflexive thematic analysis. The findings point to the persistence of a sexual risk discourse, which undermines progressive perspectives, including the rights-based approach that is usually advocated for in sexual and reproductive health, and ultimately constrains intellectually disabled women's sexual agency. The value of a reproductive justice framework for countering risk-oriented framings in favor of a social justice perspective that expands the notions of individual rights is discussed. The findings support a growing global evidence base and have implications for national and international policy and practice.

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Across disability groups, intellectually disabled women are most likely to experience opposition to their sexual and reproductive rights (Agaronnik et al., 2020). This opposition is rooted in a long history of regarding marginalized groups as unfit to parent and eugenic policies targeting those with “undesirable” behaviors (McConnell & Phelan, 2022). In the 1920s and 1930s, for example, Aotearoa, New Zealand (where our research was conducted), legally sanctioned gender-segregated incarceration (Wanhalla, 2007) and forced sterilization of “feeble-minded” women as “mental defectives” (Hamilton, 2015, p. 163). Based on expert testimonies, they were deemed “unfit” women whose reproduction, along with “sexual offenders,” threatened “the health of the nation and ... the betterment of the white race” (Wanhalla, 2007, p. 163). In addition to incarceration, and coerced sterilization and contraception, intellectually disabled women have suffered residential segregation, exclusion from sexuality education, restriction of

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intimate relationships, and noninclusion in sexual and reproductive health decision making (Hamilton, 2015; Meier et al., 2019; Mohamed & Shefer, 2015; Wiseman & Ferrie, 2020). Such practices demonstrate how “the relations between reproduction and disability are mediated through women’s bodies, which are often the battlegrounds through which normalcy is negotiated” (Mohamed & Shefer, 2015, p. 2).

In recent years, in line with the rise of disability rights movements, the focus has shifted from segregation and incarceration to protecting intellectually disabled women as an especially vulnerable group (McConnell & Phelan, 2022). The shift is, of course, not without reason because intellectually disabled women encounter sexual harm at a higher rate than their nondisabled counterparts (Wiseman & Ferrie, 2020). However, the protectionist stance often adopted by support institutions has been criticized by feminist and critical disabilities activists. This approach, they highlight, is informed by ableist assumptions about intellect and rationality, which can actually contribute to women’s disablement and increase their susceptibility to exploitation and harm, while at the same time obscuring this (Hollomotz, 2011; Meer & Combrinck, 2015). This argument is founded upon the view that sexual vulnerability is not inherent but arises from particular social contexts (Hollomotz, 2011). Indeed, as McConnell and Phelan (2022) asserted, the sexual and reproductive control of women with intellectual disabilities continues, but covertly. This is attested to by service-user research indicating that support services act as important spaces for sexual and reproductive regulation (Daly et al., 2019; Gill, 2016; Hamilton, 2015; Ignagni et al., 2016).

Consequently, feminist disability studies scholars advocate for sustained consideration of the sociopolitical context and questions of power and agency vis-à-vis intellectually disabled women’s sexuality and reproduction. An essential part of this work is attending to the ways in which power relations are maintained relationally through disability discourses, which are underpinned by (inter alia) gendered ideologies of motherhood and reproduction and particular discourses of embodiment, rationality, and choice (Mohamed & Shefer, 2015). These 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” (O’Shea & Frawley, 2020, p. 656), including those tasked with supporting them.

There is, however, very little feminist or reproductive justice research investigating the power relations shaping intellectually disabled women’s sexual and reproductive lives, including those related to relationships with people in critical roles like support workers (Liddiard, 2018; Morison & Mavuso, 2022). Accordingly, our research focuses on support workers as central and highly influential actors in the sexual and reproductive lives of intellectually disabled women living in residential disability services in Aotearoa.

Exploring support worker accounts offers a way of examining how power is exercised in key institutional relationships and settings vis-à-vis organizational policies, values, and employment contexts. This focus is not to diminish support workers’ concern for service users or the obstacles they encounter when seeking to assist in sexual and reproductive health matters. Rather, our interest is in how support workers grapple with the broader sociocultural meanings and reproductive politics in determinations about

service users' welfare and best interests. Accordingly, using a reproductive justice approach (explained further below), we attend to the discourses drawn on by support workers, how these construct intellectually disabled women, and the implications of these for power relations within residential disability services and the women's sexual agency overall.

We therefore go beyond a simple focus on oppression (e.g., barriers posed by support workers' attitudes) or consideration of the challenges and opportunities for support workers promoting service users' sexual and reproductive health and rights. Such findings are relatively well rehearsed. Instead, we offer more nuanced insights on power and agency, spotlighting those ordinarily in an unmarked/privileged position to illuminate the otherwise invisible role of normativity in shaping and sustaining sexual and reproductive privilege and oppression. The findings of our study are motivated by a commitment to challenging the status quo of sexual health support for intellectually disabled women. They make an important contribution to both reproductive justice and critical disabilities studies literatures. Reproductive justice scholars generally have not focused on disability—tending rather to consider disability alongside other social characteristics (Morison & Mavuso, 2022)—and a feminist or gendered perspective is relatively uncommon in critical disabilities scholarship (Liddiard, 2018).

Intellectually Disabled Women in Supported Living and Support Worker Roles

Community residential support services in Aotearoa, are “home-like” settings located in communities with around-the-clock paid support staff. Support workers play a central role, tasked with assisting service users to attain greater independence, connect with wider communities, and maintain their health and well-being (Ćwirynkało et al., 2017; Deffew et al., 2022). As part of this, support workers must make decisions about the sexual and reproductive health and rights of those in their care, including the provision of information and guidance and allowing opportunities for sexual expression (Charitou et al., 2021; Dillaway et al., 2019; Wiseman & Ferrie, 2020). They are therefore uniquely positioned to either promote or inhibit service users' sexual agency (Petner-Arrey & Copeland, 2015).

However, research with service users suggests that the organization of daily living in residential services is largely oriented to containing, managing, and restricting service users' sexuality (Alexander & Gomez, 2017; Gill, 2016). For example, a service user study in Sweden noted that in place of formal policies restricting women's sexuality, support workers act as “institutional walls” (Löfgren-Mårtenson, 2004, p. 197). Nowhere is sexual control more restrictive than in institutional spaces like residential support services, which ironically are intended to promote empowerment (Shuttleworth et al., 2020). This is especially true for women service users. Residential services' attention to intellectually disabled women's sexuality is often limited to preventing pregnancy or sexual abuse. Consequently, these women's sexual and reproductive lives remain closely monitored and controlled by support workers (Ignagni et al., 2016; O'Shea & Frawley, 2020).

Support workers' protectionist responses to women service users' sexuality and reproduction must be contextualized within the setting in which care occurs. Researchers

often consider support workers' attitudes or perceptions as barriers to intellectually disabled women's sexual and reproductive agency (e.g., Neuman, 2020), especially given service users' reliance on institutional support alongside their relatively less powerful social position. Nevertheless, support workers themselves are also bound up in relations of power. Care relationships are interwoven with dependence, power, and vulnerability. Support work also reflects the gendered, racialized, and classed asymmetries of care work more broadly, most often performed by women, people of color, and migrants (Munévar, 2021). The politics surrounding care—both in the immediate environment and beyond—shapes support worker responses to intellectually disabled women in their care, widely seen as a highly vulnerable group.

These politics are evident in qualitative findings highlighting support workers' experiences of a dilemma (Kahonde, 2023; Neuman, 2020, 2022; Pariseau-Legault et al., 2019). On one hand, they generally endorse intellectually disabled people's sexual rights and wish to support them. On the other, they also feel responsible for keeping them safe and minimizing the potential for harm by restricting service users in various ways (Charitou et al., 2021; Rushbrooke et al., 2014). Overall, findings indicate that ensuring *safety* trumps the intention to promote service users' sexual *agency* (Deffew et al., 2022; Oloidi et al., 2022; Pariseau-Legault et al., 2019).

This tendency toward protectionism can be understood as part of risk-averse institutional cultures that function in service users' interests but also to protect organizations from any adverse repercussions, such as litigation (Petner-Arrey & Copeland, 2015). For instance, support workers in a Canadian study reported being instructed to avoid raising these topics with service users and that their employers only discussed sexual and reproductive matters if a specific incident arose (Pariseau-Legault et al., 2019; Santinele Martino & Perreault-Laird, 2019). Hence, a common theme in the small body of research with support workers is accountability to employers, the guardians and families of service users, and even the wider community (e.g., de Wit et al., 2022; Ginn, 2022; Oloidi et al., 2022; Santinele Martino & Perreault-Laird, 2019). Participants often describe being afraid to act on service users' behalf due to concerns about adverse outcomes and employment-related repercussions. These concerns may be compounded by the frequent lack of clear guidelines or training for disability support employees, alongside the fact that care workers are often women of color and/or migrants who hold less social power and the precarious nature of care work (Charitou et al., 2021; Chrastina & Večeřová, 2020; Rushbrooke et al., 2014). Support workers' uncertainty has been shown to diminish their agency and the duty they feel to uphold service users' rights (Bates et al., 2020; de Wit et al., 2022; Oloidi et al., 2022; Pariseau-Legault et al., 2019; Rushbrooke et al., 2014; Santinele Martino & Perreault-Laird, 2019).

Support Workers as “the New Institutional Walls”

Support workers describe their role as, to a large degree, involving mitigating potential sexual harm through risk assessment (Oloidi et al., 2022) and making judgments about the acceptability of various sexual practices (Ćwirynkało et al., 2017). Without organizational guidance, support workers “depend on their own values and beliefs regarding sexuality and perceived incapability of people with intellectual disabilities” (Kahonde,

2023, p. 141), which are linked to wider societal norms related to gender, sexuality, and reproduction.

Consequently, support workers often only endorse service users' sexual expressions that meet normative expectations of appropriate sexuality and intimate relationships (Wilson et al., 2013). They report limiting service users to sexual practices that they consider appropriate for them, such as masturbation or nonreproductive sex, or allowing only risk-oriented sexuality education (Bates et al., 2020; Leclerc & Morin, 2022; Neuman, 2022; Oloidi et al., 2022; Santinele Martino & Perreault-Laird, 2019).

An important but neglected aspect of these judgments is the gendered understanding of sexuality and reproduction. Service user research indicates that support workers tend to see intellectually disabled women in highly gender stereotypical ways, rarely considering them as sexually competent (Wu et al., 2019). This is echoed in research with support workers—though research from a gendered perspective is distinctly lacking (Wilson & Frawley, 2016). Some studies with support workers suggest differences in views and attitudes toward women and men service users, for example, being more willing to encourage masturbation among men than women (Kahonde, 2023).

The significance of the gender of service users is highlighted in a handful of studies taking a gendered perspective—including studies that consider support workers' responses to female service users (Soniya, 2022), male service users (Wilson et al., 2011, 2013), or both (Gilmore & Chambers, 2010; Wilson & Frawley, 2016; Young et al., 2012). Together, these findings show that women service users are viewed in very gender stereotypical ways: as motivated more by the desire for love or children than sexual desire, for example (Young et al., 2012), and, importantly, as naïve, vulnerable, and in need of protection (Soniya, 2022). However, much more research taking a gendered perspective is needed (Wilson & Frawley, 2016; Wilson et al., 2013), especially concerning the power relations that enable and constrain intellectually disabled women's intimate practices and relations (Mohamed & Shefer, 2015). Our research speaks to this need.

Methodology

We use a sexual reproductive justice lens, a relatively novel feminist theory, to center power in our analysis (Ross & Solinger, 2017) and explore “crisscrossing power dynamics that proceed along multiple interconnected axes of difference” (Morison, 2023, p. 176). Accordingly, we understand people's ability to exercise their sexual and reproductive rights as facilitated or impeded by systems of difference and inequality—ableism, sexism, racism, and so on. These systems are interconnected and comprise a web or matrix of power relations (Collins, 1991), exercised through structural and systemic dynamics (e.g., exclusion from sexual education, health care, and resources), social relations (e.g., discrimination, sexual exploitation), and sociocultural discourses and practices (e.g., representation of disabled women as asexual or lacking desire, denying opportunities for sexual expression) (Chiweshe et al., 2017). Following a post-structural feminist approach to sexual reproductive justice, our analysis “focuses on how language constructs identities and reproduces power structures” (Morison, 2023, p. 184) and expands the focus on intersectional structural power, to consider the micropolitical dimension (Morison, 2023).

Table 1. Participant demographic characteristics.

	Hana	Molly	Kylie	Lilian	Luna	Piper	Madison
Age group	20–30	30–40	30–40	30–40	20–30	50–60	40–50
Ethnicity and nationality	New Zealander (Pākehā)	South American	South American	Pākehā	Eastern European	New Zealander (Māori-Pākehā)	East Asian
Service type	Residential (general)	Supported living	Residential (youth)	Residential (offenders)	Residential (general)	Residential (general)	Residential (general)
Years of experience	3–5	3–5	3–5	3–5	<2	<2	15–20
Qualification/other experience	Psychology; healthy relationships facilitator	Psychology	Psychology	Early childhood education	Psychology	Early childhood education	Health care management

Note. All names are pseudonyms.

Participants and Procedure

To take part, potential participants had to have experience working as a support worker for intellectually disabled women and be employed in a disability service in Aotearoa. Recruitment was conducted, after obtaining ethics clearance by Olivia, a White Pākehā (non-Indigenous New Zealanders of European Settler descent) woman. Olivia is not disabled but has several years of experience working in the disability sector. Seven women with a range of experience as support workers from five disability service providers across the country volunteered. The group's composition (see [Table 1](#)) broadly reflects the country's support workforce composition, barring educational background (Ravenswood et al., 2021).

Olivia conducted virtual semistructured interviews via online video conferencing due to COVID-19 travel restrictions. This method enabled us to include participants across the country, adding diverse experiences and enhancing research equity (Oates et al., 2022). The interview guide was flexible and open ended to allow Olivia to follow the conversational directions taken by participants as appropriate. Participants were asked about their understanding of sexual health, their role as support workers, what it means to them, how their role relates to sexual health, and their experiences of accessibility and availability of sexual health support for intellectually disabled women. They were each given a gift voucher to thank them for their time.

Data Analysis

We followed Braun and Clarke's (2021, 2023) approach to reflexive thematic analysis, alongside their checklist to ensure the rigor and quality of the analytical process. We took a critical, deductive approach to analysis, using poststructural feminist theory as our interpretative lens. From this perspective, our interest was in the latent meaning of the text; that is, the underlying assumptions, worldviews, or frameworks of meaning, which we refer to as *discourses*. Discourse can be defined as discrete sets “of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events” (Burr, 2015, pp. 74–75). Accordingly,

we focused on identifying patterns of language usage across the data set based on recurring words, phrases, imagery, metaphors, and so forth that demarcate a distinct viewpoint or understanding of a phenomenon.

In practice, this involved iteratively following the six phases provided by Braun and Clarke (2023). After gaining familiarity with the data set through listening to the recorded transcripts, manually transcribing, and repeated rereading, Olivia conducted the preliminary analysis: reading the data through the analytical lens and in relation to the research questions and noting items of interest. She then discussed this with Tracy—also a nondisabled, White Pākehā woman—and we refined the codes together. Next, Olivia conducted systematic data coding as the basis for theme development. This involved identifying and grouping portions of text based on recurrent patterns related to the research questions. Olivia then completed the coding and generated a series of initial themes. We discussed and refined the themes to ensure that each was discreet and had a central organizing concept (Braun & Clarke, 2021) and generated names to capture the unique aspect of each theme and discussed how they relate.

This iterative and dialogic process of reviewing and refining continued throughout writing up the analysis as we gained deeper insights into the data and connected these to existing research findings. As part of the interpretative process, we continually reflected on how the data are shaped by the questions asked of participants, the interactional dynamics of the interview, and the broader discursive context in which they occur (Braun & Clarke, 2021).

Analysis and Discussion

Our participants were committed to the well-being of the women in their care. They foregrounded care and respect for service users as integral to their work and described a close, connected, and reciprocal relationship as the foundation for their support work, resonating with research in other parts of the world (e.g., Petner-Arrey & Copeland, 2015). Also echoing international findings, the participants overtly or implicitly expressed support for the sexual rights of service users (Rushbrooke et al., 2014). However, as we show in this analysis, this support was often undermined by a discourse of sexual risk, which constructs sexuality in the context of intellectual disability as uncertain and risky. This long-standing construction is firmly entrenched in the largely risk-averse disability care sector (Daly et al., 2019; Shuttleworth et al., 2020).

We highlight how a sexual risk discourse operates in participants' talk and to what effect. That is, whether it serves or resists the status quo and mitigates or contributes to intellectually disabled women's risk of sexual harm. The analysis shows how participants construct the support worker role concerning supporting service users' sexuality and reproductive health, drawing on sexual risk discourse—along with developmental, gender, and rights discourses. We present three themes representing distinct patterns of talk, namely: (a) "They're just so vulnerable"—restricting sexuality, (b) "We had better just leave it at that"—avoiding sexuality, and (c) "We have to correct them to make it the safest"—directing sexuality. We discuss each of these themes using anonymized extracts to illustrate analytical points.

“They’re Just So Vulnerable”—Restricting Sexuality

Participants often echoed the protectionist sentiments typical of institutions chiefly concerned with preventing sexual harm and pregnancy (Gill, 2016). One of the primary explanations for restricting opportunities for service users’ sexual expression was that such actions are a protective measure rooted in the typical “ableist justification that disabled people are too vulnerable and/or at risk to negotiate the sexual realm” (Daly et al., 2019, p. 239). Intellectually disabled women were frequently depicted as “high risk” (Piper) and “more vulnerable” (Madison) to sexual risk and harm than their male counterparts, echoing international findings (Soniya, 2022; Young et al., 2012). This common positioning is supported by mutually reinforcing sexual risk, developmentalist, and gender discourses.

The extracts below illustrate how these discourses work together to emphasize women’s incapacity to understand sexual information or decipher in/appropriate or un/safe behavior or practices, leaving them vulnerable to harm.

Extract 1

Madison: They could misunderstand, because we don’t know how much they can understand, and they could be influenced by information from the Internet. Even, say, with vaccination, if we click some site and get the wrong information, we will be believing that information. So that could happen to them if they don’t understand. Their competence is quite low. They could believe particular parts of the information. So that’s quite toxic probably. They might think, “Oh we have to do sex if men ask” or it could be quite violent. [...] If no one controls what they can watch, “until this area you can watch, but if you exceed beyond this area. ...” If they are not controlled at all, they could get quite wrong information from the Internet.

Extract 2

Kylie: One of the girls ... she was raped by a group of males when she was very young, like 14, and after that she was a victim of prostitution. [...] So, she was very hypersexualized, and she doesn’t [...] feel the difference between actually someone who really cares about you or not. So, she’s very vulnerable to someone saying, “I love you. You are very pretty, come to my car,” or whatever, you know? She’s very—she was very vulnerable about this. [...] So, this is one of the examples about trauma, but all of them at some point are very vulnerable.

In the extracts above, vulnerability is predicated on service users’ inability to make sound sexual decisions due to diminished cognitive capacity, rendering them vulnerable to sexual exploitation. The logic in Extract 1 is that if someone without cognitive impairment is susceptible to misinformation and media influence—and ensuing negative consequences—then someone whose “competence is quite low” would be more easily misled. Such depictions rely on the developmentalist discourse, as “sexual decision-making is conceptualized as being primarily dependent upon cognitive capacities, overlooking other relational and emotional/affective capacities” (Sandberg et al., 2021, p. 1430).

This developmentalist logic was common in discussions citing “the extent of, or the severity of the disorder” (Luna) as being the determinant of how much sexual expression or information to allow, as also noted in other research

(Charitou et al., 2021). For example, explaining the avoidance of sexual topics and restriction of information, Luna questioned, “Are they actually going to understand it or is it going to confuse them more?” These determinations are based on ill-defined assumptions regarding the relationship between intellectual disability and the inability to consent (Gill, 2016), particularly in the absence of policy and guidelines (Santinele Martino & Perreault-Laird, 2019). Such positioning supports the protectionist claim that women service users’ media consumption must be “controlled,” reflecting “an ableist trend to deny the sexual agency of individuals based on assumptions of inappropriateness and incompetency” (Gill, 2016, p. 1).

Extract 2 more clearly illustrates how such constructions of vulnerability are reinforced by heteronormative assumptions regarding gender roles and sexual conduct that shape perceptions of sexual risk and vulnerability in the context of cognitive impairment (Sandberg et al., 2021). Kylie’s story (Extract 2) about a particular woman she previously supported implies that all women with intellectual disabilities are similarly “very vulnerable.” In this account, the service user is at risk not (only) because of her past experiences of sexual harm but, more fundamentally, because of an inherent gendered inability to make sense of sexual issues correctly. In this description, cognitive incapacity and feminine sexual naiveté conflate, intensifying the usual gendered positioning of women as susceptible to male violence and heightening intellectually disabled women’s susceptibility to sexual risk. Kylie’s “story-worthy” case can therefore be read as a cautionary tale emphasizing the need to protect intellectually disabled women.

Such protectionism is reinforced by the dual infantilization of service users as intellectually disabled and as women. This infantilization is illustrated above as, drawing on the developmentalist discourse, intellectually disabled women are depicted as having childlike cognitive capacity and lacking cognitive capacity (i.e., abilities related to knowing, judging, and evaluating) to make (good) decisions (Daly et al., 2019). As a result, they are sexually innocent (Extract 1) and/or “hypersexualized” (Extract 2) or “oversexed” (Kahonde, 2023; Wiseman & Ferrie, 2020). Moreover, in emphasizing the women’s incapability and vulnerability, they are implicitly contrasted with ideal adulthood, which is conventionally associated with rationality and autonomy and coded as masculine (Daly et al., 2019; Sandberg et al., 2021).

Part of this dual infantilization involves the desexualization of intellectually disabled women, which draws on conventional hetero-gendered notions of women as naturally possessing less sexual drive and interest than men (Sandberg et al., 2021). In line with this infantilization, we note that as with constructions of *young* women’s sexuality, the discourse of desire is largely missing from this talk (Fine, 1988). Indeed, the participants commonly depicted female service users as having diminished or no sexual needs. For example:

Extract 3

Piper: As I said, these ones here, I haven’t seen that with them. I haven’t seen anything like kissing. ... One of the girls will give the boys a peck, but she does that to everyone,

or she tells you that she loves them and that sort of thing but there's no. ... I don't read anything else into it.

Extract 4

Researcher: And the women that you support, are they also encouraged to masturbate?

Luna: No, definitely not. It's not spoken about. It's not that it's prohibited or that they're not allowed to for whatever reason. It's just that it's just not talked about. The only thing really that, like I said, the only sign of having those kinds of needs is having some female clients who will go. "Oh. I want a boyfriend" or "So-and-so has a boyfriend, I want a boyfriend." Those kinds of things, but the concept of masturbation is just not talked about. With the client who was doing that, the only reason it was really talked about is because he was doing it either way. So it was, like, well we may as well talk about it and do this in a better way, go about it differently, but it wasn't talked about prior to that.

In these extracts, descriptions of chaste kisses and expressions of love or desire for "a boyfriend" signal innocent and childlike sexuality. This construction allows the women's sexuality to be trivialized: one need not "read anything else into" these innocuous behaviors. In turn, the notion that female service users may have genuine, adult sexual needs ("those kinds of needs") can be dismissed. This trivializing and desexualizing response arises in Extract 4 in response to a question about masturbation, prompted by the mention of the male service user Luna refers to. The implication in her response is that, unlike male service users, sexual release is unnecessary for female service users, justifying why masturbation would "definitely not" be encouraged. Intellectually disabled women's pleasure is rendered a non-issue rather than something "prohibited," avoiding giving the appearance of restricting or controlling service users' sexual expression, which conflicts with a sexual rights discourse.

"We Had Better Just Leave It at That"—Avoiding Sexuality

This theme captures a common positioning of the support worker primarily as a "risk assessor/protector" (Oloidi et al., 2022, p. 1041) in a way that ultimately justifies avoidance of sexual issues in the name of protection. The protector position relies on the sexual risk discourse—or what Daly et al. (2019) called a "discourse of sexual vulnerability" (p. 237). Positioning intellectually disabled women as vulnerable in this discourse renders their protection a key consideration in judgments about sexuality and reproductive health. Drawing on this discourse, supporting service users' sexuality was frequently described as "very complicated" (Kylie), "very complex" (Lilian), or "tricky" (Luna) due to job obligations and, importantly, the duty of care to keep women with intellectual disability safe.

For example, Lilian responded to a question about what is needed to support intellectually disabled women's sexual and reproductive health and rights. Her response below illustrates the common expression of uncertainty, ambivalence, and confusion regarding service users' sexual expression and their roles in supporting it.

Extract 5

Lilian: If I had the answer, I'd give it to you. Um, I don't know. It's something I always struggle with. I don't know what the right and wrong answer is. Um, I think they've got a voice that needs to be listened to and I don't think we ask them. I think we undervalue and undermine them. They may have an intellectual disability of some sort, shape, or form, [but they are] still smart people, at the end of the day, and they still have rights, and they still have responsibilities. [...] I remember [Janet] ... worked with a Down syndrome boy who became very sexualized, and she said to the parents, "You need to get a prostitute once a month so he can have sex and release that sexual tension and understand what an intimate relationship is." And it worked beautifully. So, why can't that happen more often? I don't, if ... I don't know how it would look ... in a perfect world.

Here, Lilian overtly condemns avoiding and overlooking intellectually disabled women's sexuality, citing their humanity and "rights." To support her claim that intellectually disabled people ought "to be listened to," she recounts a positive case (Extract 5) in which a support worker recognized the sexual needs of a "very sexualized" intellectually disabled "boy" and ensured that they were met. The support worker's solution (employing a sex worker) is described as having "worked beautifully." Yet, at the same time, the issue of supporting service users' sexuality is presented as something she "struggles" with and is not clear-cut. She expresses doubt that the scenario in her story could "happen more often," skeptically wondering how it could work in practice ("how it would look"), suggesting that it would only be feasible "in a perfect world."

Such talk reflects a tension between rights discourses and discourses focused on risk and safety, as highlighted in other qualitative studies (Kahonde, 2023; Pariseau-Legault et al., 2019). This excerpt illustrates how the notion of protection, inherent in the sexual risk discourse, helps reconcile the tension between discourses of rights and risk, which is expressed in the dilemma between the competing responsibilities alluded to by participants. As shown in Extract 5, supporting sexual rights can be considered ideal but impractical. By positioning the support worker chiefly as a protector, participants could endorse service users' sexual and reproductive health and rights in principle while construing support as unfeasible or needing to be limited in practice.

As part of this pattern of talk, participants frequently cited the potential for unknown negative consequences and complications, as shown in other research (Oloidi et al., 2022), as a deterrent to providing sexuality education or recognizing and allowing service users' sexuality. Risks were often deemed unknown but largely inevitable; as Hana remarked, "Bad things happen all the time." Drawing strongly on the sexual risk discourse, participants cited potential negative consequences such as exposure to abuse, unintended pregnancy, or provocation of uncontrollable sexual behavior. This is illustrated in Extract 6.

Extract 6

Madison: It's a really hard area to talk about, because some people might be feeling that people with intellectual disability shouldn't have any sexual interactions. ... I don't know how we support them, because we don't know how much they understand and how much we should go for it, push to talk. So, it's quite [a] hard topic. [laughs] [...] [pause] If I

gave that information, it could be too much and they might be overwhelmed, and they could go to the extreme outside of this. We don't know how much they are really, fully understanding. [...] Yeah, confusion, and, I don't know ... probably, they could be too curious if we give a lot of information. It is just a really hard one [laughs].

Once again, the speaker presents herself as uncertain about the role of a support worker in helping service users realize their sexual rights. The focus here is specifically on providing information, with concern expressed that offering too much information could cause negative outcomes: rousing service users' sexual curiosity and inciting "extreme" (i.e., uncontrolled) sexual behavior. This logic is reminiscent of arguments against providing children with sexuality education for fear of potentially sexualizing them or promoting sexual precocity. As in arguments against sexuality education for children, intellectually disabled women's capacity to comprehend sex-related information is highlighted.

The issue of service users' diminished cognitive capacities and their uncertain ability to "fully" comprehend sex-related information was frequently raised by other participants. With the possibility of harm rendered ever-present, limited support is justified based on practicability rather than the support worker's reluctance or unwillingness. Participants can thereby maintain a position of supporting intellectually disabled women's sexual rights while at the same time rationalizing limited or no action, with some arguing that their actions could do more harm, concluding that it might sometimes be best to leave well enough alone.

Avoiding risking the service user's safety was also partly related to accountability to others and, implicitly, jeopardizing their employment. Echoing other qualitative findings, "fear and/or concerns regarding accountability" (Oloidi et al., 2022, p. 1041) were reported as hindering efforts to support sexual and relationship rights. The following extract shows, for example, how some participants spoke about answerability to others, in this case, the service user's family, as a deterrent to providing service users with support or information for their sexual needs. This excerpt is part of a discussion about a scenario presented by Olivia involving family members requesting support workers not to allow a service user to pursue an intimate relationship and sexual expression.

Extract 7

Luna: I think your role is always going to be overruled or compounded by their family members. A lot of them, as much as they are adults, their parents are still very involved because they care [...] and their core beliefs on sexual health and needs, most of the time I would say, is more skewed toward like the case that you're describing. I think it comes from fear of the unknown. If we let them have sex or if we let her masturbate, 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 [intellectual disability] having sex or masturbating or oral sex or whatever it might be. I think it's that fear, that anxiety, of "we don't want anything to happen to this person." So, we just don't want them to kind of delve into that at all.

Here, Luna positions support workers as not necessarily opposed to supporting a service user's sexual rights and needs but as being obstructed by family members who have more say and to whom they are ultimately answerable. This extract illustrates how female service users are commonly positioned as de facto children ("as much as they are adults"), as commonly reported in the literature (Gill, 2016; O'Shea & Frawley, 2020; Stefánsdóttir, 2014), with guardians/families as default sexual decision makers to whom institutions and individual support workers are answerable as paid service providers.

The above depiction of the family's conservative and restrictive actions is not unsympathetic, however. Here, "involved" families are depicted as motivated by "care," and their actions are attributed to legitimate concerns about the inevitable dangers ("risks that naturally come") of an intellectually disabled person's sexual expression. Moreover, as the extract continues, it appears that the staff is presented as sharing families' apprehension ("fear," "anxiety") of "what's going to happen" to service users who are allowed sexual expression. Consequently, allowing sexual expression is rendered too risky, and restriction is justified by drawing on the sexual risk discourse and its ableist constructions of intellectually disabled women as vulnerable and incapable.

The uncertainty and risk described by these support workers as paid employees were related to the ambiguity regarding supporting service users' sexual and reproductive health and rights, which Luna described as "a grey area." All participants mentioned risk-averse organizational cultures, limited resources, and lack of guidance as factors that necessitated support workers to use their discretion in sexual and reproductive matters. Lack of guidance has also been noted in other settings, such as Canada (Pariseau-Legault et al., 2019) and the UK (Bates et al., 2020).

"We Have to Correct Them to Make It the Safest"—Directing Sexuality

Talk in this theme draws on a more affirmative view of intellectually disabled women's sexuality than those discussed above. A rights discourse is prominent in this theme as participants invoke service users' rights to sexual pleasure and expression, albeit within certain bounds and emphasizing the right to consensual sex. The following comment illustrates this discourse: "I'm more than happy to talk to people with disability about what's the best way, what'd be the safe way, and you have a right to say no" (Madison). Interwoven with such talk is the notion that the support worker's role is to help foster service users' sexuality. This was most frequently envisaged, according to a developmentalist discourse, as encouraging "normal" sexual development toward an ideal sexual subject (Sandberg et al., 2021). The effect of these two discourses (rights and developmentalist) working in tandem, as we show in this section, is to advocate for fostering intellectually disabled women's sexuality insofar as it can be channeled in socially acceptable ways.

This channeling of sexuality is illustrated in the following extracts in which the support worker's role is constructed as one of educating service users about appropriate, healthy, and acceptable sexual behaviors.

Extract 8

Kylie: For example, she was masturbating herself with objects—like a hairbrush, vegetables—and she got a lot of infections because it's not the healthy thing to do. So, we tried to contact *Oranga Tamariki* [Child Welfare] to see if she can have a vibrator. She's 17 anyway, she can buy [one] with her own money if she wants. So, the social worker bought one to give her a healthy option if she wants to masturbate or have pleasure. Because [her] body is not to make babies, [but] she can feel pleasure, and if you want to feel pleasure, you have the right to have the right things to do it. [...] And she was very open to talk to me about it. [She said], "Thank you very much." I feel she feels comfortable when you talk to her about sexuality, without shame or embarrassment. With most of them, it's not just about the body, sometimes we talk about relationships as well. What is a nice relationship, what's kind of controlling or respectful in our relationships? [...] Because, when they're teenagers, sometimes they don't know how to say no to many, many situations. And, not saying "no" doesn't mean "yes."

Extract 9

Lilian: ((*Discussion of the extent to which it's her role to support and educate service users around sexual health and rights*)) Well, I'll be just, I don't know, educating informed decisions and the right way to go around things and relationships. Lots of them have come from trauma background, so they're very skewed [regarding] what is healthy and what's not healthy in terms of relationships and facilitating that. They've got very, very sexualized behavior in terms of the opposite sex. They don't realize that that's not necessarily appropriate. So just helping them understand what's appropriate and what's not appropriate. [...] So probably more about the social standing and how we deal with it on a day-to-day basis. But, you know, we don't instigate dating. We don't take them to Family Planning or anything along those lines. [...] I guess at the end of the day it's all about informed choices, is it not? If we're not giving these people all the information that they need, we're doing them a bit of a [dis]service really, aren't we? [...] I think the people assume because they've got an ID [intellectual disability] that they're not sexual beings and that they don't want sex. ... It's about setting boundaries, like: "Masturbation is OK, but you do that in your room, you don't do it in a public area."

In these extracts, we see that intellectually disabled women are permitted sexual desire and expression to some extent. This stance is particularly clear in Extract 8, in which the desexualization and infantilization of intellectually disabled women are challenged and the service user's sexual desire and right to satisfy it are acknowledged. The request for a vibrator for the service user is predicated on her right to pleasure, drawing on a sexual rights discourse. Yet, at the same time, providing appropriate ("the right") means for the service user to satisfy her desires also necessitates intervention from support workers. Though the intervention is overtly related to keeping the service user "healthy" (by preventing "infections"), the notion of in/correct or un/healthy means of gaining sexual pleasure is introduced along with the suggestion that the task of determining what is correct or healthy is best left to knowledgeable individuals around the service user, rather than the service user themselves.

The didactic or instructive role of support workers becomes clearer as Kylie segues into an explanation of what constitutes “a nice relationship” for service users. The support worker’s role is thus construed as instructing service users regarding preferred relationship norms, as indexed by distinctions between “controlling” and “respectful” relationships. This didactic role is evident in Extract 9. Here the education that Lilian is willing to provide centers around what she refers to as “the right way to go about things” and “social standing,” referring, we infer, to social norms related to sexuality and relationships. She constructs the support worker’s role as involving teaching service users “appropriate” and “healthy” sexual expression, positioning service users as having a distorted (“skewed”) understanding of sexuality and as being unable to control their sexuality due to past abuse.

These examples illustrate how participants commonly advocate that support workers must direct intellectually disabled women’s sexuality in line with “normative assumptions regarding ‘good’, ‘desirable’ and ‘healthy’ sexuality” (Sandberg et al., 2021, p. 1426), which is, of course, changeable and value laden. As the extracts above show, talk centered on the binary of “appropriate,” “healthy,” and “right” versus “inappropriate,” “unhealthy,” and “wrong” sexual practices and behaviors indexes normative sexuality. The extracts above illustrate how even when a more affirming view of intellectually disabled women’s sexuality is upheld (albeit to varying degrees), it is still assumed that their sexuality needs to be taught and defined by the cognitively able (Sandberg et al., 2021). This assumption is supported by a developmentalist discourse, which prescribes the fostering of “normal” sexual development toward an ideal sexual subject (Liddiard, 2018). Such language is found throughout the data set as participants describe their work as being “about modeling and talking to them [service users] about these things earlier” (Luna).

Importantly, it becomes apparent that even in recognizing the sexual needs and desires of intellectually disabled women, they are allowed only to be “conditionally sexual” (Wilson et al., 2011). In Extract 8, the participant states, “[Her] body is not to make babies, [but] she can feel pleasure,” thereby granting the service user a right to sexual pleasure but only insofar as it relates to nonreproductive sexual practice. This statement invokes “the regulation of ‘othered’ women’s reproductive decision-making” as demanded by normative ideals (Wiseman & Ferrie, 2020, p. 320).

In Extract 9, this conditionality is even clearer. The participant nominally supports the view that intellectually disabled women are “sexual beings” who “want sex” while positioning herself as willing to support service users’ sexuality only “to a certain degree.” The support worker’s role is presented as reactive and reparative; it does not include proactive support, such as taking service users to sexual health services or facilitating intimate relationships, as in Kylie’s account. These examples reinforce the support worker’s role as boundary setting: directing service users’ sexual expression. These examples demonstrate the variation in the extent to which participants affirmed their service users’ sexuality.

Despite differences in the degree of recognition and support, the focus of the support worker in both of these examples is facilitating service users’ appropriate sexual development and conduct. This didactic role may, in part, also be envisaged as protective, based on the assumption that “the lack of such education puts people with cognitive

disabilities at risk of entering into sexually abusive relations from a lack of sexual self-responsibility or maturity or at risk of engaging in risky sexual practices from a lack of sexual knowledge or low self-esteem” (Sandberg et al., 2021, p. 1425). This is suggested by Kylie’s remarks about consent and Lilian’s opinion about failing to educate service users being “a disservice,” which imply susceptibility to exploitation. Of course, the protective function of educating service users is not in dispute. However, this emphasis reinforces the overarching sexual risk discourse and its positioning of intellectually disabled women’s sexuality as risky and support workers as primarily responsible for risk management and protecting service users, with sexual pleasure acknowledged but conditional upon safety.

Conclusions

Our analysis of support workers’ accounts generated three themes representing distinct patterns of talk about supporting clients’ sexuality and reproductive rights. We conclude that the objective in all of these ways of speaking—even of more progressive talk that overtly champions intellectually disabled women’s sexual rights—is the management of service users’ sexuality, whether through denial or allowing “conditional sexuality” (Wilson et al., 2011). Such regulation is most apparent in the first two themes, which either support the limitation of intellectually disabled women’s sexual expression or ignore it as a potentially integral aspect of their lives. These discursive effects clearly serve the ableist status quo (Alexander & Gomez, 2017).

In theme 1, “They’re just so vulnerable,” the emphasis on vulnerability tightly restricts sexual expression to practices deemed “safe” by support workers (usually non-procreative, solitary, and private). Infantilizing these women as unable to exercise sexual control in certain instances or as sexually naïve renders them incapable of being “good” sexual decision makers. This reinforces their position of vulnerability within the sexual risk discourse. In this way, ensuring that service users’ sexual behavior is “controlled” (Extract 1), the restriction of sexual information, opportunities, and behaviors can be construed as being in intellectually disabled women’s best interests and thereby subtly regulated. The effect of this positioning is the restriction of service users’ sexuality.

In theme 2, “We had better just leave it at that,” sexuality is not restricted outright but rather side-stepped, mirroring a common response in disability support services. The lack of institutional discussion and guidance raised by all of the participants indicates the common tendency in disability organizations to overlook service users’ sexual and reproductive health and rights (Alexander & Gomez, 2017). As a result of institutional barriers, participants described support for service users’ sexual and reproductive health and rights as too challenging to implement and/or manage and ultimately too risky for them to undertake to any significant extent or at all. The effect of this talk is, therefore, avoiding the service user’s sexuality.

In contrast, the third theme, “We have to correct them to make it the safest,” comprises seemingly more progressive talk, supportive of service users’ sexual rights and pleasure beyond love or procreation (Alexander & Gomez, 2017). However, the sexual risk discourse ultimately undercuts this support as well, also only allowing sexuality based on ableist ideas regarding what is ab/normal, in/appropriate, and un/healthy

sexual expression and practice. The sexuality of service users is therefore directed toward normative expression. The subtlety of this talk indicates the pervasive, sometimes insidious nature of sexual ableism and the key role played by the sexual risk discourse in upholding it, such that it undermines even more progressive approaches to the sexuality of intellectually disabled women.

Consequently, all three patterns of talk draw on the sexual risk discourse, invoking notions of safety and normative ideals to rationalize and justify the management and regulation of sexuality—albeit in more or less restrictive ways. As such, each upholds and reinforces uneven power relations rooted in sexual ableism and constrains service users' sexual agency to some extent. As Gill (2016, p. 176) maintained, “Professional able-bodied authority connected to paternalism and harm reduction of sexuality ... is a key component in upholding the primacy of sexual ableism” in the lives of intellectually disabled people. Ironically, though notions of risk and protection inform all of these themes, they ultimately expose intellectually disabled women to harm through the diminishment of their sexual agency, silencing of their needs and concerns, and reinforcement of deleterious norms and power relations (Daly et al., 2019; Meer & Combrinck, 2015).

A sexual risk discourse allows regulation to pass as protection, which is commonly justified as being in the best interests of service users. The role of the supporting developmentalist and gendered discourses is also significant in masking power relations. The embodied and intrinsic character of both cognitive capacity and gender allow supposed heightened risk to be constructed as originating from within the woman rather than owing to social and institutional arrangements and power relations that disadvantage disabled women (Daly et al., 2019). The solution then becomes one of managing individual service users rather than challenging the status quo.

Supporting the sexual and reproductive agency of service users—and intellectually disabled women more broadly—requires a fundamental shift from a risk-oriented to a human rights perspective. However, our findings also demonstrate the limitations of a solely rights-based focus. As we showed in theme 3, support for sexual and reproductive rights can be sidelined by paternalistic notions of service users' best interests, supported by discourses of sexual risk, developmentalism, and gender. We advocate instead for the expanded view of *human rights* teamed with a social justice orientation offered by the reproductive justice approach.

In addition to a theoretical lens, reproductive justice offers a holistic, intersectional framework for policy and programming that emphasizes “the human right to make personal decisions about one's life, and the obligation of government and society to ensure that the conditions are suitable for implementing one's decisions” (Ross, 2017, p. 174). This framework can help to challenge individualistic constructions of disability and risk—in line with the social model of disability—and expose and challenge protectionist discourses and underlying sexual ableism. The latter is achieved by its ability to highlight the crucial role played by the social context, including that of relationality and sustaining environments—aspects that are crucial to everyone's sexual agency but obscured by individualizing discourses locating risk and disability *within* individuals (Jarman, 2015; Wu et al., 2019). Disability, sexual health, and associated services should commit to a reproductive justice perspective from policy to implementation to address the

oppression that intellectually disabled women continue to experience despite appeals to their rights.

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