



Who Counts as a Sexual Subject? The Impact of Ableist Rhetoric for People with Intellectual Disability in Sweden

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Accepted: 23 August 2023 / Published online: 1 September 2023
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Abstract

Introduction The ableist rhetoric around sexuality in disability services and beyond can hinder subjective sexual expression and have a powerful impact on health, self-esteem, and everyday life through internalized ableism, structural marginalization, and interpersonal discrimination. The aim of this study was to explore the ableist rhetoric of sexuality and its impact on sexual scripting for people with intellectual disability.

Methods A thematic analysis was carried out on data generated through ethnographic fieldwork at five sheltered accommodations and semi-structured interviews with ten individuals with intellectual disability.

Results The results show that people in Sweden with intellectual disability are desexualized within a moral order that is maintained in post-institutional social care. Through this moral order, which is deeply embedded in an ableist rhetoric about sexual relationships, sexual scripting for disabled people is constrained both inside post-institutional social care initiatives, and in the broader community of “ableist environments.” In response, disabled people employ various strategies of resistance.

Conclusions A rhetoric of positive sexuality should be a guiding principle for successfully supporting the development of sexual agency on each individual’s own term.

Policy Implications We conclude by encouraging the development of initiatives that will empower and support people with intellectual disability to learn about their sexual rights and to find solutions that allow for development of sexual agency and subjectivity.

Keywords Sexuality · Ableism · Sexual scripts · Post-institutional disability services · Intellectual disability

Introduction

There is often silence around positive aspects of sexuality and relationships within disability services—as in society as a whole—that can hinder sexual expression for disabled people in general and people with intellectual disability in particular (Black & Kammes, 2019; Gill, 2015). This silence can have a powerful impact on sexual health and well-being, self-esteem, and everyday life opportunities through processes of internalized ableism, structural marginalization, and interpersonal discrimination (Frawley et al., 2022; Peuravaara, 2013; Turner & Crane, 2016). These problems are generally grounded in prejudiced and paternalistic

views of and support practices for people with intellectual disability—becoming major obstacles to independence and social participation generally, and for sexual subjectivity specifically (Björnsdóttir et al., 2015). Although deinstitutionalization has gone far in Sweden and in other Western democracies, institutionalized attitudes still prevail in disability services and beyond (Altermark, 2017; Svanelöv, 2020). As Drinkwater (2015, 229) suggests from a UK perspective, “supported-living arrangements exemplify not an emancipation, nor even a humanitarian reform, as much as a new dispersal of power relations,” and these processes also influence sexuality (Feely, 2016; Wade, 2002). In Sweden, this can lead to ambiguities around recognizing the sexual rights of people with intellectual disability, even though such rights are indirectly secured in Swedish disability services law and the general state policy on “disabled people’s rights to live like others in society” (Kulick & Rydström, 2015).

In light of these considerations, discerning the scope of action people with intellectual disability have in constructing and laying claim to sexual identities is a pressing need.

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The aim of the present study is to explore the ableist rhetoric of sexuality and its impact on sexual scripting for people with intellectual disability; that is, the social construction of codes of conduct that form individuals' sexual behavior (Simon & Gagnon, 1984). Our approach is grounded in the hybrid political-relational model, meaning that we see the need to contextualize individuals' experiences within their social and political contexts (Kafer, 2013). As part of this approach, we focus on how power dynamics are (re)constructed in the various relationships that people with intellectual disability have with family members, disability services staff, and other people around them. We take up Alison Kafer's call to analyze how the category of disability is used "to justify the classification, supervision, segregation and oppression of certain people, bodies, and practices" (2013, 9) and to study the depoliticization of (positive) sexuality of people with intellectual disability, where we understand the right to sexual expression to be a structural issue rather than only an individual one. The concept of sexual citizenship highlights this specific socio-political, structural, and contextual nature of sexual rights and opportunities for disabled people (Bahner, 2020) and will be used as an overarching theme in the final part of the analysis.

We begin by contextualizing our study within the literature on sexuality and intellectual disability, with a focus on research studies that, like our own, are based on the voices of people who have been able to reflect on and discuss their experiences (which in some cases may be categorized as mild to moderate intellectual disability, although we have not used such diagnostic measures in our research), alongside studies of parents, teachers, and staff. We then offer a short introduction to the Swedish policy context relevant to this subject area, followed by theoretical and methodological considerations and a presentation of the study results.

Literature Review

Overall, research has shown that people with intellectual disability are frequently circumscribed by a restrictive rhetoric concerning opportunities for choice and control over their sexual lives—often under the banner of risk mitigation, resulting in paternalism and regulations (Bates et al., 2020; Grace et al., 2017; Hollomotz, 2011; Neuman, 2022). For instance, sexuality and relationships education (SRE) in special schools tends to focus on biology and risk awareness, whereas mainstream education uses a more holistic approach (Frawley & Wilson, 2016). Teachers generally lack training to deliver adequate SRE (Gill, 2015; Nelson et al., 2020), and some are ambivalent about whether SRE is even appropriate due to "concerns about unwanted pregnancies, sexual abuse and other sexual high-risk situations" (Löfgren-Mårtenson, 2012, 210). There are also gendered dimensions to these issues, with young men's sexuality often

pathologized and young women's sexuality conceptualized using a narrow focus on hygiene, self-protection, and pregnancy (Frawley & Wilson, 2016).

Similarly, in group homes or supported-living arrangements, habilitation centers, sheltered workshops, and activity programs, staff are seldom trained in and often feel insecure about dealing with issues around sexuality and relationships—even though they occur in the day-to-day lives of people with intellectual disability (Hamilton, 2009; Santinele & Perreault-Laird, 2019; Schaafsma et al., 2014). There seems to be an "apparent 'need' to regulate sexual expression of individuals with intellectual disabilities" and "professionals ... become authorized to regulate sexual behaviors, even if no behaviors are present" (Gill, 2015, xiif). A consequence of this is that staff rely primarily on their own values, rather than on professionalism for guidance (Neuman, 2022; Rushbrooke et al., 2014; Wilson & Frawley, 2016). These problems can be exacerbated when service users identify as lesbian, gay, or bisexual, in which cases a lack of policy and training may combine with prejudice among staff and parents or carers (Abbott, 2021; Löfgren-Mårtenson, 2009; Marks et al., 2020; McCann et al., 2016; Toft & Franklin, 2020; Wilson et al., 2018).

Family members have also been shown to restrict access to sexuality information and hinder development of sexual relationships (Feely, 2016; Foley, 2017; O'Shea & Frawley, 2020), including in the online content (Löfgren-Mårtenson et al., 2015; Santinele & David, 2022). Essentially, people who depend on others for support "often [find] themselves in a childlike role in relation to staff and family members who [view] them as vulnerable and consequently they [lack] status as autonomous agents"—including as sexual agents (Björnsdóttir et al., 2017, 306). Paradoxically, such attitudes and regulations may in fact lead individuals to take greater risks simply to be able to enjoy sexual relations (Santinele Martino, 2021).

Outside the immediate homes of and services for people with intellectual disability, more indirect restrictions also arise. For instance, Peuravaara (2013) demonstrates how young women with intellectual disability attending special needs classes in mainstream schools experience being mocked, laughed, or stared at on the bus and on the school grounds on the basis of being regarded as different. These experiences influence their identity formation, self-esteem, and felt opportunities for social participation in school and in the wider community, where they are often afraid of being "spotted" as disabled. Similar processes can relate to sexual identities specifically; for example, Blyth (2012) shows how gay men with intellectual disability are excluded from LGBT venues, both directly due to physical inaccessibility and indirectly because of prejudice and negative attitudes (see also Abbott, 2021).

In summary, international research has shown that there are many occurrences of prejudice, negative attitudes, and

restrictions in the sexual lives of people with intellectual disability; or *sexual ableism* in the words of Gill (2015), which works to hinder the development of their *sexual citizenship* (Bahner, 2020). We will develop these perspectives further below, but for now, we can concede that consequently, people with intellectual disability do not have the same opportunities to explore and experience sexual relationships because being regarded as capable and autonomous is closely related to being sexual, and how others view oneself influences whether one can identify as sexual at all.

Sexuality, Disability, and Post-institutionalization

In Sweden, the process of deinstitutionalization that began in the 1960s was propelled by government-commissioned investigations in the late 1980s and early 1990s conducted with more sensitivity and responsiveness to the needs of individuals living with disability (Tøssebro, 2016). These investigations eventually led to what is commonly referred to as the Disability Act, with its emphasis on promoting personal autonomy and goal of providing opportunities for disabled people to lead lives with a “good standard of living” (SFS 1993:387 §7). The services should further be characterized by an affirmation of each individual’s personal integrity, independence, equality, and possibilities to fully participate in society (Lewin, 2022). The Disability Act soon became integral in shaping how care and services for certain groups of disabled people are organized and provided in Sweden and remains so today. Some of the antecedents of the Disability Act were the independent living ideology advocated by disabled activists (Berg, 2005), every individual’s right to a private sphere (Grunewald, 2010), and people’s right to equal opportunities as to choices, control, and freedom (Pearson, 2019). Thus, the Disability Act and its goals and aspirations overlap significantly with the UN Convention on the Rights of Persons with Disabilities (CRPD, United Nations, 2006).

The sexuality of people with intellectual disability has not been high on the policy agenda in Sweden, at least not after eugenic policies and practices were ended along with forced institutional living arrangements, in the 1960s. Instead, the dominant discourse among policymakers, service managers, and staff on how to handle “issues” around sexuality has consisted of “letting sleeping dogs lie” and the view that “if we haven’t done anything, then at least we haven’t done anything wrong” (Kulick & Rydström, 2015, 23). These paternalistic attitudes can be explained by a culture of fear: on the one hand, a fear of sexual victimization and “unwanted” pregnancies among “vulnerable” groups, like women with intellectual disability; on the other, a fear of primarily intellectually disabled men’s “hypersexuality” and status as potential perpetrators (Löfgren-Mårtensson, 2004; Starke et al., 2016).

Preventing the realization of such fears has become the guiding principle for most policies and formal services relating to sexuality and disability, resulting in a lack of understanding of the value of and willingness to work with sexual health promotion and support for more positive and pleasure-focused aspects (Kulick & Rydström, 2015). For example, there is a specific research-based intervention for pupils in special schools using the toolkit “Children—What does it involve?” and a so-called baby simulator (Randell et al., 2021). Other examples include a municipal program for supporting parents with intellectual disability (Mc Hugh & Starke, 2015) and one aimed at violence prevention (Lindberg et al., 2019). However, interventions dealing specifically with topics of sexuality and relationship knowledge and skills, including aspects of pleasure and fun, have yet to be implemented on a national scale—even though such a focus has been shown to be valuable in violence prevention (Kulick & Rydström, 2015; Stevens, 2012). This can be contrasted with the disability policy of the Australian state of New South Wales, which includes sexual and reproductive rights as a core principle (Bahner, 2020). Policy implementation there also includes guidelines for practitioners that aid in securing service users’ sexual rights in practice, including specific sexual support and educational measures; see Kulick and Rydström’s (2015) study on a similar approach in Denmark.

In other words, the historical eugenic discourse may have taken new and less drastic but still powerful forms in today’s post-institutional service provision in Sweden (Altermark, 2017) with, for example, forced sterilizations replaced by non-consensual long-acting contraception use (Björnsdóttir et al., 2017; Desjardins, 2012; Tilley et al., 2012), various repressive ways of preventing sexual relationships (Feely, 2016), and legal boundaries based on ableist notions of consent (Clough, 2022; Kelly et al., 2009). These restrictions can be traced to international eugenic discourses (Aunos et al., 2020; Stefánsdóttir, 2022; Wade, 2002) that still legitimize the view that the sexual expression of people with intellectual disability must be highly regulated or even denied altogether (Feely, 2016; Gill, 2015).

As to Sweden’s widely acclaimed comprehensive and compulsory SRE agenda, alongside systematic work with youth sexuality centers and adult sexual health institutions, disabled people have been overlooked in sexual health and reproductive rights policy and practice (Löfgren-Mårtensson, 2020). For example, there are no national policies, regulations, or guidelines that grant disabled people the right to sexual expression or to guide disability services staff in how to work with such supports in practice (Kulick & Rydström, 2015). This is especially noteworthy considering that Sweden ratified the CRPD in 2008 (United Nations, 2006); Article 23 of that document urges states to “eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others,” while Article 25 detail rights regarding sexual health

information and services. However, the relevant state agency has not followed up on these articles, with the cryptic explanation that the articles are “outside the agency’s remit” and no further elaboration as to why that is so or whose remit it is instead (Swedish Agency for Participation, 2019).

Theoretical Framework

In relation to disabled people’s often restricted opportunities for developing sexual relationships and identities of their own choosing, the concept of ableism is crucial. We begin by discussing this perspective before moving on to a discussion of sexual script theory.

Ableism refers to “a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human” (Campbell, 2001, 44). We use this concept to reflect on how the ideal of the normative, able-mind/body is maintained and reproduced through naturalized, normalizing, and often governing social processes in the daily lives of people with intellectual disability. For our analytical purposes, we are inspired by Cherney’s (2011) use of ableism as a rhetorical concept:

[A]bleist culture sustains and perpetuates itself via rhetoric; the ways of interpreting disability and assumptions about bodies that produce ableism are learned. The previous generation teaches it to the next and cultures spread it to each other through modes of intercultural exchange. Adopting a rhetorical perspective to the problem of ableism thus exposes the social systems that keep it alive. (Sec. 2 Para. 1–5)

Normative institutional frames are still very much prevalent in post-institutional disability services, based on ableist norms of independence and autonomy that do not allow for the understanding and development of those essential human characteristics for people with intellectual disability. Peuravaara (2015, 283) refers to this as “ableist environments”; namely, “how some bodies are made visible for oneself and others depending on place and on the interactions that take place, where notions of normality are present.” Thus, in an ableist environment, through surveillance, intervention, classification, and labeling, norm-breaking individuals are devalued, dehumanized, and have restricted sexual access (Liddiard, 2017). In relation to sexuality specifically, we use the term sexual ableism to denote “the system of imbuing sexuality with determinations of qualification to be sexual based on criteria of ability, intellect, morality, physicality, appearance, age, race, social acceptability, and gender conformity” (Gill, 2015, 3). The ableist rhetoric expresses that disabled people lack bodily, intellectual, and cognitive

requirements to perform or express sexual agency (Liddiard, 2017), or as Waxman (2000, 169) eloquently puts it: “sexual rights have always and only been awarded to only those who are proclaimed to deliver quality offspring.”

To gain a deeper understanding of the processes by which sexual ableism, through ableist rhetoric and environments, is reproduced in practice among people with intellectual disability, staff, and others around them, we use the theory of sexual scripts (Simon & Gagnon, 1984).

Sexual scripts can be viewed as the conceptualization of socially constructed sexual behavior (Simon & Gagnon, 1984) or socially constructed codes of conduct that inform individuals’ sexual behavior, both consciously and unconsciously. According to Simon and Gagnon (1984), our scripted behavior is directed by different symbols and signs in collective societal arrangements and by the fact that how individuals’ different behaviors and roles are met is constituted by the interpersonal construction of discourses. That is, scripts are constructed within and by social interaction to clarify codes of conduct for certain behaviors and roles in specific contexts. Disabled people are assessed and scrutinized according to discourses of able-mindedness that form different kinds of contextual and role-specific types of belonging that may limit individual agency in the co-construction of personal scripts. A sexual script can be viewed as the normalization of sexual behavior, as something everybody should have (Simon & Gagnon, 1984). Thus, sexuality is constructed through discourses that ascribe (and deny) sexual scripts and in turn individuals’ rights to be decisive about and in control of one’s own body, feelings, relationships, and choices about identities (Plummer, 2003). In this way, sexual scripts can have a powerful influence on identity formation and on the construction and enforcement of different roles in various contexts.

The construction of sexual scripts can be viewed as the notion of the collective determination of appropriate behavior and attitudes (Simon & Gagnon, 1984). However, discourses of disability may place disabled people in a marginalized position in the interactional collective determination of sexual scripts (Kafer, 2013). A core aspect of the construction of and right to sexual scripts is to scrutinize both objectively and subjectively what Plummer (2003) calls “zones of intimacy”; that is, our innermost thoughts and feelings of knowing, caring, and being close to other people that may be contested due to cultural and contextual codes of conduct and pejorative labeling. While sexual scripting is an interpersonal and contextual journey experienced differently by different people, in the end, it comes down to the human dependence on social meaning (Simon & Gagnon, 1984). Our forthcoming analysis using sexual script theory thus serves to illuminate the interactionist nature of sexual identity formation, sexual expression, staff actions, and cultural beliefs based on sexual ableism.

Finally, we will use the concept of sexual citizenship (Bahner, 2020; Richardson, 2000) as a way of evaluating whether the

persons with intellectual disability whom we met throughout our research are awarded sexual rights and, as such, can become sexual citizens. Drawing on Richardson's (2000) framework developed for analyzing sexual citizenship in relation to non-heterosexual sexual identity and related practices, representations, and institutional limitations, Bahner (2020) shows specifically in relation to disability how state policies, regulations in disability services, and disabled people's organizations' advocacy are inextricably linked in a web of creating opportunities for exploring and expressing one's sexuality in practice.

Methods and Data

This study is based on samples of data collected from three different research projects studying the lived experiences of people with intellectual disability. The authors met in a Swedish network for critical disability studies; following discussions about their respective work, they realized that combining their research efforts could provide a deeper and more nuanced understanding of why the sexual rights of people with intellectual disability are such a marginalized topic in post-institutional disability services and society as a whole. The authors have, to varying degrees, prior experiences of working in different post-institutional disability services as well as taking part in activism and other types of engagements in the Swedish disability movement. As such, we consider ourselves primarily as allies and as researchers committed to their work having real-world impact in disabled people's lives in general, and disability services in particular.

Sampling, Recruitment, and Data Collection

The data were generated as part of fieldwork at sheltered accommodations for people with intellectual disability and through interviews with staff and individuals with intellectual disability who make use of a variety of post-institutional disability services. Fieldwork was conducted consistently throughout 2018 and interviews carried out periodically in 2020 and 2021.

Access was granted to five different sheltered accommodations selected using a purposeful sampling strategy (Patton, 2002). The sheltered accommodations—four group homes and one service housing unit—were distinguishable in terms of their relative scale (resident-to-staff ratio), scope (age and length of residency and employment among residents and staff, respectively), and service provider (privately or municipally operated). Each sheltered accommodation served as a residency for around 5 to 8 service users between the ages of 19 and 65 and employed around 6 to 9 staff members (not including substitute staff) between the ages of 24 and 63. Taken together, the length of residency among service users and the length of employment among staff members at the

given accommodations varied between 2 and 12 years. Fieldnotes were compiled in situ with the aid of mobile devices over a combined 280 h in the field using participant observation and shadowing techniques (Becker & Geer, 1957; McDonald, 2005). The observations focused on both individual and collective expressions of social selves as part of everyday care and service encounters between staff and disabled service users.

During the fieldwork, numerous informal interview-by-comment style discussions (Snow et al., 1982) were carried out face-to-face with both service users and staff members at the various residences. These were recounted and written down in the form of detailed fieldnotes by the researchers shortly after the fact, as opposed to during the actual interviews themselves. Additionally, potential interviewees were sought through advertisements in disability-focused Facebook groups and by contacting several disability service providers, which led to a self-selected sample of people self-identifying as labeled with intellectual disability. Semi-structured interviews conducted either face-to-face or through live video chat, depending on participant preferences and access needs, were carried out with ten individuals with intellectual disability between the ages of 25 and 48. These interviews, which were audio recorded and later transcribed with the consent of the interviewees, specifically addressed experiences of barriers to sexual expression.

In total, our data comprise individuals and organizations at multiple geographical locations across Sweden. The projects all received ethical approval, and we generally followed the ethical guidelines of the Swedish Research Council (2017) for good research practice and informed consent (Uppsala University, 2023).¹ Although all participants were able to communicate using speech and independently volunteered to take part in the interviews, we were attentive to ensuring continuous informed consent throughout and after the interview process, including opportunities to remain in touch with the researcher after the study conclusion (Foley, 2017; Gill, 2015).

Analytical Process

We were inspired by thematic analysis focusing on identifying patterns, similarities, and differences across our combined datasets (Braun & Victoria, 2006). All authors combed through their respective datasets with particular attention directed to the construction of sexual scripts and took note of emerging themes. This initial step of the analysis was primarily inductive and focused on how people with intellectual

¹ The projects were approved by the regional ethical review board in Uppsala, Sweden (Project 1, reg. no. 2015/39/1; Project 2, reg. no. 2017/488), or by the Swedish Ethical Review Authority (Project 3, reg. no. 2019-05817).

disability and those people who interact with them as part of everyday care and service provision talked about the former in relation to gender, sexuality, and relationships. In the next step, the authors met to compile and compare notes, with the goal of identifying commonalities and recurring patterns across the datasets. Once this step was concluded, attention returned to the individual datasets; the initial analytical step was repeated more deductively, as this time the analysis was informed by our shared notes and joint theorizing. As a final analytical step, the authors met in a series of sessions to compile and compare our revised notes and to discuss and collaboratively interpret selected excerpts from the data, which were immediately pseudonymized. During this process, the emerging main analytical themes took on several iterations before reaching their final form.

Findings

Below, we present our findings using three themes: “[Fostering deviant normality](#)” focuses on the symbolic level of restrictions; “[Disarming the uncomfortable](#)” scrutinizes staffs’ rhetoric around sexuality; and “Sexual scripts in action: Restriction and resistance,” which offers examples of resistance. Through this structure, we aim to highlight the multi-level character of sexual scripts and how they are (re)produced across contexts through both rhetorical and procedural processes. We do so in the hopes of illustrating how the political-relational model of disability can be used to analyze the various components that uphold sexual ableism (Kafer, 2013).

Fostering Deviant Normality

In post-institutional settings like group homes, several objects and symbols of power enable and hinder access to (un)desired activities and behaviors. They can provide comfort but at the same time limit the expressive freedom of disabled service users. Doors are one such symbol:

While sitting on the sofa in the common room area and concluding the day’s observations and conversations, I reflect upon the meaning and understanding of doors. Overall, doors to the residents’ apartments are open or closed depending on the time of day and amount of care interventions a given resident receives. In this group home, the staff conduct tightly scheduled care interventions, meaning that doors are often preventively opened to enable quick and easy access. In practice, this means that while I walk along the group home’s corridors with residents’ apartments on either side, I can look inside them, like a window into the residents’ “private” lives. (Fieldnote, sheltered accommodation A)

The doors function as mediators to both the private and the public, and in the post-institutional context of group homes, there are overlapping discourses about residents’ private lives and staff’s working conditions. An open door, from the resident’s perspective, could be an intrusion into private life and a restriction on behaving and being as one wants. At the same time, from the staff’s perspective, an open door can be an aid to having a private life and a support of individuals’ possibilities to behave and be who one wants. For example, Anna, a woman in her late 30 s, spoke about her past experiences with what she perceived to be staff members repeatedly infringing on her right to privacy:

Anna: The staff [at my previous group home] didn’t understand me at all. They came and bothered me constantly and it was really irritating. Someone [like me] would prefer not to be bothered all that much and if possible, not like, not as much as they did. It was a bit too much actually ...

Interviewer: Can you give an example of the kind of situation you have in mind?

Anna: Yeah, they [the staff] came and knocked on my door every time they were going to do something. Almost as if they thought I wanted to be with them all the time. But [someone like me] doesn’t want that. I’m not saying that [everyone] is like that, but I know that many are like me in that they want to make it known themselves when they want to be a part of something ... You know, they barely even bothered knocking at all. It was constant. Every time they were going to do something. And all I wanted was to be left alone in my apartment, but it felt like I wasn’t allowed to. I don’t know, they probably meant well and perhaps they thought I would want to participate and so on. It all depends on how you look at it.

That said, it is relevant to think about for whom and for what purpose doors or other symbols of power function, as they appear to be preconditions for residents’ sexual scripts and (un)privacy (see also Feely, 2016). The open door, as an ableist symbol of power, can function as an instrument for monitoring and controlling the expression or performance of sexual agency (see Liddiard, 2017), which in turn affects individual residents’ rights to freely construct their own identities (see Plummer, 2003).

Over the course of their fieldwork, the researchers experienced and talked with service users and staff about everything from competing in the Special Olympics to organizing music records but matters related to sexuality were rarely highlighted. The general absence of sexuality in the everyday lives of people who are labeled with intellectual disability says something about the status and availability of sexual expressions within sheltered accommodations. However, that is not to say that the topic of service users’ sexuality

never came up. For instance, one staff member mentioned in passing during a longer conversation about the problems and possibilities associated with independent living and the responsible freedom it entails that they felt an obligation to guide the residents toward desirable sexual scripts:

Most people have access to the Internet and that is very ... Well, you can find anything there, and it is easy to be influenced. And as I said, these people do not have very good consequences thinking, and then it can go wrong ... We have some information about sexuality and explain that “this is how it looks” and “this is okay, and this is not okay.” (Conversation with staff member, sheltered accommodation B)

Service users are in a disadvantaged social position and may miss the precedence of interpretation of one’s sexuality as a result of being labeled as disabled. An ableist rhetoric diminishing disabled people’s capabilities to be decisive regarding their own sexual scripting is prevalent in post-institutional settings (see Peuravaara, 2015). During fieldwork, in the few instances when matters of sexuality were discussed, it was often in the sense of educating disabled people about what is “right” and “wrong” sexual expression. Although staff members may find these types of educational interactions harmless and even necessary for proper online behavior, individuals with intellectual disability may internalize an inflated fear of Internet use. As argued by Gill (2015), sexual ableism takes the form of constructing a functional order of capability. Several of our interviewees mentioned that they were afraid of online dating because they had learned of “stranger danger.” For instance, Michael, a man in his 30 s living in his own flat with everyday support services, said:

Michael: There are no serious websites for dating. It’s only PM [private messaging] all the time. I want to meet people eye to eye. Anyone can hide behind the screen. There are some really nasty people out there, one needs to be vigilant.

Interviewer: Have you ever been in any situations like that?

Michael: No, no. I just think that one needs to be aware of the risks. Not to fall into every trap.

Just like in previous research, Michael has been taught about the risks of online dating, preventing him from even trying it—and without having been offered any other solutions or support (Gill, 2015; Löfgren-Mårtenson et al., 2015; Santinele & David, 2022). Above all, people with intellectual disability are socially fostered as not having any sexuality at all; as a result, individuals are fostered to learn the correct sexual conduct for disabled people and be careful because of vulnerability to abuse. There is thus an ableist rhetoric regarding sexuality and intellectual disability that

is woven into the very fabric of post-institutional social care interventions and that presents a paradoxical sexual scripting for these individuals (Cherney, 2011). This ableist rhetoric is not confined solely to bounded interventions such as sheltered accommodations but is also encountered by individuals with intellectual disability in the broader communities in which these interventions are often deeply embedded:

Many people think that people with a disability do not have any sexuality, that they do not have any sexual attractions. Or, well they, yes ... That they do not want a partner or that they cannot have a partner. But I think there is a lot of misunderstanding. And when we do talk about it [sexuality], then it’s like “Oh God! Why do you talk about that?” when it’s actually very normal. (Conversation with staff member, sheltered accommodation B)

The ambiguous attitude toward intellectual disability and sexuality creates an uncertainty within disability services (Santinele Martino, 2021). In an interview with Serena, who was again living with her parents after not having liked living in a group home, she described the revelatory experience of attending a lecture about sexual rights and disability by the civil society organization Swedish Association for Sexual Education (RFSU) in her city:

Serena: RFSU is great at showing regular people that here we [disabled people] are: “Here we come, and we’ll show you what we can do!” Because not many people know what impairment is or what RFSU is. So, it’s good to show regular people how it is and to see how they react. Because a lot of people say, “You can’t have sex ‘cause you’re handicapped.” “So what?” I say. How silly!

Interviewer: Has anyone ever said that to you?

Serena: Yes, many times. To my boyfriend too, but he doesn’t care; he shuts his ears. But I answer!

Interviewer: Who says such things?

Serena: Regular people when we’re out and about. When they see us, they ask “Are you a couple?” And I reply, “Yes, what about it?” [And they say] “Can’t you see that he’s got CP [cerebral palsy]!?” [And I reply] “So what? I love him as he is.”

Interviewer: But is it strangers who approach you like that?

Serena: Yes. A friend of mine was out with her boyfriend, who is also in a wheelchair; they were out dancing at [a local street festival] a couple of years ago, when suddenly two people came up to them saying that they shouldn’t be there [at the festival], that they should be locked up at home!

Interviewer: No!?

Serena: But some people don’t know what impairments are. And that’s why we have to go out and talk to regu-

lar people and tell them that they needn't be afraid of us. You know, there's that ... they are ashamed to look us in the eye. But unfortunately, there are people like that, and it's not only in Sweden but in the whole world.

Some participants had experienced similar situations where strangers had questioned them in public; however, that mostly involved those with more visible impairments than participants who were able to “pass” as non-disabled (see also Peuravaara, 2013). The notion of people with intellectual disability as lacking any form of sexual script is perceived as normal, especially among the “abled-community” (Feely, 2016). However, when that “normality” is disrupted and sexuality becomes explicitly related to disability, it becomes a deviant normality. This makes the impact of an ableist environment evident (Peuravaara, 2013), which reminds disabled people that they do not conform to the norms of either ability or sexuality (Gill, 2015).

Disarming the Uncomfortable

On the surface, life in sheltered accommodations like group homes and serviced housing units seems almost designed to facilitate the creation of close and intimate relationships because it involves relatively small and consistent groups of people living in close proximity to each other over extended periods of time. Upon closer inspection, however, rigid institutional frames and a strong ethos of professionalism that emphasizes the vulnerability of disabled service users as needing active monitoring and control appear to deeply influence social interactions in these kinds of settings. This includes tightly circumscribing any frolicking of a potentially sexual nature that might otherwise take place (Feely, 2016).

When the matter of viewing service users as sexual subjects surfaced as part of everyday interactions, staff members typically treated it as both serious and highly sensitive. It quickly became apparent over the course of fieldwork how different people came to be classified, primarily by the staff, as more or less appropriate recipients of service users' affections and desires. This was especially the case regarding the potential for infatuations or deeper amorous connections to develop between service users and staff members. Such emotional engagements were uniformly perceived by staff as threats to the moral order of the sheltered accommodations:

Sitting in the common living area of the residence, I happened to overhear resident Laura and a staff member as they were going over their plans to visit a gym not far from the residence. Realizing that I was listening in, Laura invited me to accompany them on this excursion. I proceeded to shadow them during this trip, and Laura invited me to come along again the following week.

[One week later], shortly after my arrival at the residence, I was informed by one of the staff members working today that resident Laura had fallen ill and would likely not be leaving her apartment. “What a shame!” I replied instinctively, “She had invited me to tag along for her accompanied visit to the gym today.” As I spoke these words, the staff member stopped what she was doing abruptly and turned to face me directly. “Ah, right, we were supposed to talk to you about Laura. She becomes easily infatuated with male staff members. Now, you're not exactly one of the staff, and she is aware that you're married and all that so there probably shouldn't be any problem. But just so you're on board with it.” (Fieldnotes, sheltered accommodation C)

In the above excerpt, the staff member in the second part of the field note can be seen to convey her concern about the service user's affectionate state. However, without overtly accusing the (male) researcher of being the type of person who would be suspected of knowingly taking advantage of someone in what is assumed to be a vulnerable position. The staff's explicit interest in getting the researcher “on board with” their shared view of the resident's vulnerability and deviant normality suggests that this was indeed an ableist environment (Peuravaara, 2013), marked by the salience of a moral order in which disabled service users' expressions of themselves as sexual subjects (whether actual or expected) are framed as problematic when oriented toward the “wrong” recipient. During an interview with Laura, she helped shed more light on the specifics of what the staff member had been alluding to—in response to a question on the role of staff members and if they could or perhaps should be expected to intervene in the personal relationships of service users:

There is something that everybody here knows about, but no one wants to talk about. It's kind of a little open secret here. I do not know if you've been told this already, but it was like this: I fell a little bit in love with one of the staff who used to work here, and obviously it ended with him not being allowed to work here anymore. Because that's the way it usually goes. It's one of those things that no one here wants to talk about ... As soon as I bring it up everyone tries to change the topic of conversation, because it's kind of taboo to talk about. I personally think that the staff reckons my feelings will disappear by not talking about it. But that's not really how it works.

But staff members were not the only ones to fall into the category of “wrong” recipients of affection within the sheltered accommodation context. As arbiters of these post-institutional spaces, the staff actively worked to ensure that any intimate behavior or displays of affection

between service users conformed, or at the very least paid lip service, to the institutionally sanctioned rules of engagement, in which expressions of love or longing of any kind were only acceptable when readable as being of a strictly familial (and non-incestuous) kind. This sexual ableism is reproduced in the culture of post-institutional disability services and its rhetoric about sexual identity (Cherney, 2011; Liddiard, 2017). Staff members' commonplace use of vernacular such as "the residents are like brothers and sisters" and their readily observable leniency toward service users addressing them joyously as if they were parental figures (e.g., "yes, mother/father") are taken to be indicative of this. Another indicator was reactions among staff to service users who openly challenged the moral order by either engaging in "indecent conduct" or giving voice to harbored "illicit motives":

Resident David excuses himself and prepares to leave the common living room area. Resident Jennifer calls out after him, "I'll come to tuck you in later!" Sudden outbursts of half-muffled chuckles erupt from the crowd sitting around the coffee table. Not long thereafter, resident Kevin excuses himself and begins heading off toward the hallway. Jennifer calls out once more, "I'll come to tuck you in later, too," to which Kevin replies by flashing a wide grin and gesturing with both of his hands. As Kevin disappears from view, one of the staff members asks the rest of the group about what he had gestured. Most of us feel unsure about this as no one seems to have been able to catch a good enough glimpse. That is, apart from resident Samuel, who loudly announces to the group "Kevin did this!" moving his right index finger in and out of the circle that he has formed by pressing his left index finger and thumb together [a gesture that is commonly associated with sexual penetration]. The staff members who are present quickly jump to their feet, loudly protesting that this most certainly was not the case and positioning themselves between Samuel and Jennifer in what looks like a uniform attempt to block him from her view. Staff member Yasmine speaks up in a clear yet firm voice "No he didn't! He did something like this," placing three fingers from one hand on the back of the other, creating a non-sexual symbol. The other staff members quickly sound off in agreement: "Yes, he did something more like that!" (Fieldnote, sheltered accommodation D)

The type of comment uttered by the service user, "I'll come to tuck you in," is typically reserved for parents addressing young children. The amused reactions to this comment from the crowd of people around the coffee table provide further support that expressions of familial (and non-incestuous) love are indeed acceptable within this space.

In stark contrast, the reactions of the staff to resident Samuel's interpretation of resident Kevin's gesture as signaling lustful intent and a possible desire for sexual intercourse suggests that even the very thought that a service user might harbor such feelings warrants response as if it were a profane affront to the moral order.

The possibility of service users feeling enamored about or directing lustful feelings at the "wrong" recipient or of being interpreted as harboring such feelings is viewed by the staff as problematic in both the situations described above. This holds true whether the recipient is a staff member or another service user. To manage this "problem," staff members in both instances adopted strategies that allowed them to avoid engaging directly with the matter of service users' sexuality (see also Kulick & Rydström, 2015). The mere notion that service users might experience feelings of this kind is a double threat from the staff's perspective: both a palpable danger to the personal well-being of vulnerable service users themselves and a threat to the stability of the moral order of the sheltered accommodations—and by extension to the interests of everyone involved (Altermark, 2017). This raises the question of who the "right," "appropriate," or "legitimate" recipient of disabled service users' affections might be given the normative institutional frames at play and their associated moral order. The following fieldnote helps illuminate at least part of an answer:

I am sitting in the shared kitchen talking to staff member Maria when we are joined by resident Sophie, who sits down and gently rests her head upon the former's shoulder. Shortly thereafter, Maria initiates a conversation on the topic of Sophie's so-called "love interests." Earlier that same day, I had mentioned to Maria in passing how I had observed that several of the male residents appeared eager to approach and show Sophie noticeably more attention than they did other female residents. Maria had responded by reassuring me that Sophie and the other residents were simply "very good friends" without romantic interests in one another and "almost like siblings." As she brings up the topic once more, this time in the presence of Sophie herself, Maria asks her if the two of them should show me "the pictures." A few moments later, I find myself being given an impromptu tour of Sophie's apartment. With Sophie silently hanging on to one of her arms, Maria ushers me around while pointing out and enthusiastically informing me about the many posters and photographs of young male pop stars that decorate the interior walls, shelves, and tabletops in the space. (Fieldnote, sheltered accommodation D)

In this excerpt, the staff member is shown to reject the researcher's interpretation that several of the service

users may have harbored amorous feelings toward one of their own, so to speak, by ascribing (non-sexual) scripts of being “sibling-like” to service users. By doing so, other service users who reside in the same sheltered accommodation and with whom frequent and repeated contact can be expected are, like the staff, framed as the “wrong” or “illegitimate” objects of disabled service users’ sexual desires. In contrast, individuals who are spatially removed from the sheltered accommodations—like pop stars and other celebrities—with whom the feared dangers associated with sexual relationships, whether physical or emotional, are deemed slim in comparison or even non-existent become framed as the preferred (or “right”) alternative.

The occurrence of labeling practices such as those discussed above does not mean that disabled service users never develop affectionate and reciprocal relationships with those with whom they share close and recurring contact. However, labels of this kind do go a long way to circumscribe relationships between service users as being strictly platonic in nature and thus contribute to both limiting and controlling how relationships of these kinds can be articulated within the sheltered accommodation context. The ableist rhetoric of sexuality makes it clear that normative functionality has precedence when it comes to sexual scripts (Waxman, 2000). By disavowing or even demonizing disabled service users’ capacities for harboring amorous feelings and desires toward individuals who work at, live in, or frequently visit the bounded liminal spaces of sheltered accommodations, the staff actively work to disarm the perceived double threat posed by disabled service users’ sexual identities.

Similarly, the rhetoric around parenthood can be interpreted as part of the fear of where sexual relations can lead. When Daniel, an interviewee in his 40 s, was asked about his wishes for the future, he talked about a previous long-term relationship where parenthood had been dismissed:

Daniel: It was [my girlfriend’s] mother who thought that she wouldn’t be able to take care of a child. She has Asperger’s, so ...

Interviewer: But it’s your right to decide ...

Daniel: Yes, but her mother decided a lot. [My girlfriend] got sterilized.

Sabina, another interviewee, also talked about how her parents had urged her not to have children in the future. But staff in her previous serviced housing unit had also tried to dissuade her from parenthood: “[The staff member] said that I shouldn’t have kids considering my mental health and that I’m on medications. At the time I was nineteen and got very frightened.” Sabina, who was thirty when interviewed, was now certain that she was not fit for parenting: “I want children, but at the same time I don’t, ‘cause I had such a tough childhood.” She thought that her experiences with mental

health problems in her youth, although they were currently under control, would prevent her from managing as a parent. Thus, when service users are surrounded by one-sidedly negative sexual scripts, it is not surprising that they can internalize such sexually ableist views of themselves. This happens in processes of interaction whereby staff members are trying to disarm what for them is regarded as uncomfortable situations, at the same time they work to uphold a culturally pervasive sexually ableist moral order (Gill, 2015).

Sexual Scripts in Action: Restriction and Resistance

Post-institutionalism occurs not only in sheltered accommodations but also in other types of disability services and in family relationships—and, as previous sections show, ableist environments across the community can influence everyday interactions. Moving on from the symbolic and rhetorical levels, we now discuss examples of how restrictive scripts are felt at a psycho-emotional level (Peuravaara, 2013) and examples of how participants resist such restrictions.

Two respondents, Sabina and Myriam, discussed dating and talked about how self-conscious they felt about being perceived as disabled by a potential date (see also Santinele & David, 2022). However, their fear of disability prejudice was not connected to their disabilities per se but rather to their reliance on disability support. Sabina said that she would like to meet men in “mainstream environments” rather than in disability communities, but that she was afraid that non-disabled men would look down on her for being unemployed or having “only” supported employment. She also talked about how her work situation influenced her financial situation: “It’s tough going on a date when you have less money.” Myriam talked about this similarly, but she was also concerned about how she would be perceived if a potential date found out that she had been appointed a limited guardian, which resulted from her becoming indebted:

I’m ashamed. I can’t just say on the first date that I have a limited guardian, because then I’m really ashamed. Then maybe he [the date] thinks that I’m completely stupid. Maybe [he] believes that I’m completely incapable. But it’s the opposite: I can do a lot of things! And that’s the kind of person I am; I don’t like lying on dates and stuff, but I’m forced to.

Amelie, another interviewee, complained about the lack of accessibility in online dating environments, as she needed easy-to-read text, but above all she said, “I have difficulties getting to know new friends and partners because of scars in my soul after tough bullying.” In other words, the psycho-emotional effects of ableist environments continued to influence her current sexual expression. Cassandra also mentioned similar experiences and she was currently

undergoing psychotherapy, including sexological counseling, to work through a long history of bullying and build up her sexual self-esteem and desires.

Like Sabina and Myriam, Cassandra mentioned disability shame, but her experiences were grounded in her family. She said that she was afraid of coming out as bisexual to her father, who had previously expressed shame at having a disabled daughter. Cassandra attributed this to his own upbringing and a general culture in which disability was not spoken of openly in the same way as it is today. And even though she now felt confident in his love for her, she was afraid that adding the aspect of non-normative sexuality would reawaken his resentment. This was one of the reasons that she participated in disability rights organizations and in a political party: to work for increased understanding of and respect for disability rights. She said that her work in these organizations was important to her feeling like “everyone else” and that she mattered in society.

Penny, another young woman, used the same kind of strategy to counter disability prejudice: “When I am not working at the preschool, I give talks about my life with diagnoses to spread knowledge so that we can have a better society for people with diagnoses. People don’t intend to be mean; they just don’t have the right understanding. I’m also currently writing a book on the subject.” As to sexuality, she mostly struggled with her parents’ lack of understanding, as she lived with them. They often had opinions on her boyfriends, and she said that she did not want to “disappoint them” by talking about problems in relationships. She wished there was “a manual” for how to handle sexual relationship issues.

Interviewee Stella talked about how she was fighting with her limited guardian for the opportunity to move in with her husband, who currently lived in a group home in another city. The problem was that his limited guardian would not allow it: “It feels like we are growing apart now that we can’t meet as often [and] only talk on the phone.” Compared to her husband, Stella knew her rights after having been involved with a project undertaken by a civil society organization. Apart from being educated about her rights, she had also made sure that the staff in her group home were educated, and that she could talk to them and ask for their help around sexuality and relationships.

However, not all participants had these kinds of resources or were in a position to confidently demand recognition and rights around their sexual expression. When asked about his experiences of sexual autonomy in daily life, Daniel, a man in his late thirties, recounted that his parents and brother, along with support workers, commonly decided things for him. When asked to give an example, he said that they decided what clothing he can and cannot wear, such as female-coded underwear: “They think that it’s sick.” He talked about situations such as going on family vacations and having his brother urge him not to bring female-coded

underwear or not be allowed to come along: “He thinks it’s embarrassing. When I pack, I have to lie.” Also, when going swimming, his assigned contact person demanded that he bring shorts and not a bikini; which is one reason why he now wanted a new contact person. He did not see any way to change people’s minds; about his parents, he said that “They are so old, so I’d rather lie about it. It [underwear] isn’t visible anyway.” By contrast, Daniel is thankful for his limited guardian, with whom he can “talk about anything, I like her.” In other words, Daniel used different strategies to counter the restricting scripts that people tried to impose on him.

In a similar way, Laura, whose experience of disclosing her felt attraction toward a male staff member was discussed above, sought out ways to work around the restricting scripts imposed on her by the majority of staff at her sheltered accommodation:

Interviewer: After what has happened and what you have been through, does it affect what you decide to share with the staff or what you choose not to share?

Laura: Well, I consider whom I talk to about these things. For example, when it comes to talking about guys and dates and stuff like that, I usually just talk to [a particular staff member]. Because I know she’s the only one with whom you can talk about those things in a relaxed way, without it getting awkward or strange or with the added nervous laughter. We’re on the same page when it comes to these things. But there aren’t that many [staff] here who are.

To summarize, these interviewees all had experienced ableist environments (Peuravaara, 2013), whether they were going on dates or simply interacting with their families or living in their serviced accommodations. Those who had met sexual rights activists were more knowledgeable about their rights but could not always put them into practice when encountering ableist environments. Restrictive sexual scripts were thus continuously reproduced, resulting in a repression of sexual expression, including gender non-conforming identities (see also Abbott, 2021; Toft & Franklin, 2020). However, engaging in activism helped some interviewees gain strategies for resistance and empowerment as sexual subjects, while others resisted by more covert strategies. In other words, limiting sexual scripts are not all encompassing—agency and resistance are also evident (Löfgren-Mårtenson, 2020; Santinele & David, 2022).

Discussion

The aim of this study was to explore the ableist rhetoric of sexuality and its impact on sexual scripting for people with intellectual disability and thus shed light on what

consequences may ensue for how individuals feel about themselves and their opportunities in the sexual realm. Additionally, we aimed to analyze the political-relational character of the rhetoric around sexuality and intellectual disability using the concept of sexual citizenship.

First, our results confirm earlier research both from Sweden and internationally about people with intellectual disability being desexualized within the moral order in post-institutional social care (Black & Kammes, 2019). When interacting with other people, both within post-institutional settings and when out and about in public, the sexuality of people with intellectual disability is a heavily gated, deeply moralized, and zealously controlled matter (Feely, 2016; Gill, 2015). The areas of public and private life are inter-mixed, hindering free sexual expression even in the private sphere (Foley, 2017). Ableist environments are thus omnipresent, whether they are explicitly restrictive or more indirectly employed by influencing the self-governing of sexual expression (Peuravaara, 2013).

The post-institutional spaces (re)created for people with intellectual disability shape, through institutionalized attitudes and rigid normative frames, certain desirable behaviors and influence what is considered right and wrong (Altermark, 2017; Gädman Johansson, 2021). Via objects and symbols of power, certain types of sexual scripts are either enabled or hindered (Simon & Gagnon, 1984), essentially fostering a deviant normality in which sexual expression is repressed unless it is institutionally sanctioned as “appropriate” (Feely, 2016; Santinele Martino, 2021). The forceful labeling and categorization processes make the identity of “disabled” affect or completely overshadow other identifications (Altermark, 2017; Svanelöv, 2021). Sexual expression, behaviors, and identities thus reflect an ableist rhetoric about what “disability” essentially entails, illuminating the power of sexual ableism (Gill, 2015; Kafer, 2013).

Second, since sexual scripting is a central part of identity formation and for finding one’s role within a given context, the rules of engagement and rhetoric about sexuality in post-institutional social care limit service users’ own formation of themselves as sexual subjects (Cherney, 2011). Indeed, the emphasis here is on *limitation*, as individuals continuously internalize cultural and societal discourses of sexuality through symbols and signs that are steered by moral codes and rhetoric about appropriate sexual behavior (Feely, 2016; Turner & Crane, 2016). Disabled service users’ possible expressions of either harboring affectionate feelings or amorous desires directed toward the “wrong” kind of recipient are actively rejected and reframed by support workers, families, and members of the general public. At the same time, expressed yearnings for or infatuations with the “right” kind of recipient—someone who is deemed unlikely to engage in actual sexual activities with a given disabled service user—are, in contrast, both endorsed and positively reinforced

through everyday interactions with social care professionals and frontline support workers (Foley, 2017). In these instances, it becomes clear how sexual ableism permeates the interactionist level of sexual scripting for service users.

Furthermore, sexual scripting for people with intellectual disability is often depicted as a sensitive and serious matter fraught with danger (Grace et al., 2017; Neuman, 2022). Sexuality becomes a double threat of sorts, perceived by support workers as a danger both to individual service users and to the continued stability of the moral order itself. As a result, support workers actively ascribe institutionally sanctioned restrictive sexual scripts to disabled service users and may attempt to influence and reformulate the meaning of scripts invoked by others, all on the premise of disarming the uncomfortable and protecting individuals from the presumed dangers associated with intimate or sexual contact with another person (Gill, 2015). This is also done by support workers as a way of maintaining the stability of the moral order on which both service users and support workers depend to inform their conduct and the presentation of their social selves, including for assessing the nature and quality of their mutual engagements and working relationships (Altermark, 2017).

Third, cultural and societal discourses depicting disability as synonymous with dependency or infancy, inability to consent to sexual relations, or sexual deviance create pressures and restrictions on identifying as a sexual subject (Kafer, 2013; Turner & Crane, 2016). The sexual-ableist rhetoric diminishes the presence of positive sexuality, affecting possibilities to self-determined sexual scripting, including potentially desired identifications such as being a parent, and may enforce undesired identifications, such as heteronormative sexuality (Löfgren-Mårtenson, 2009; Rushbrooke et al., 2014; Turner & Crane, 2016). In post-institutional disability services, many find themselves trapped in segregated contexts and marginalized citizenship (Abbott, 2021). This cannot be understood without acknowledging the overarching ableist rhetoric that results in both disability-specific segregated environments that are ableist in themselves (Cherney, 2011) and in ableist environments in which people with intellectual disability are “spotted” and sometimes even called out as not belonging (Peuravaara, 2015). Thus, sexual ableism is present at every level of daily life: the individual, the social, and the cultural (Gill, 2015).

In the absence of policies and guidelines dealing explicitly with sexual rights, our study and research in other contexts show that it is more difficult for people with intellectual disability to develop empowering and positive sexual scripts, and thus become sexual citizens (Bahner, 2020; Gill, 2015). Awareness among disability services staff needs to be raised about the power of ableist rhetoric to counter the value-laden “support” around sexuality (Santinele & Perreault-Laird, 2019). Policy development on sexual rights in line

with the CRPD is also urgently needed, including work against disability prejudice more generally. This is of course not a new finding; in fact, some local disability rights and sexual rights organizations in Sweden have been conducting projects about sex education, LGBTQ identity, and gender equality from a more sex-positive approach during the last twenty years (Bahner, 2021). The problem with such project-based approaches, however, is that when the funding runs out after two to three years, the work stops with the knowledge produced seldom widely operationalized.

But as our research shows, some of the interviewees had empowering experiences from such projects, which offers one possible counter to sexual ableism and the possibility to develop alternative sexual scripts where they are indeed sexual subjects in their own right. This result is in line with international studies in which self-advocacy among people with intellectual disability, including support to learn together and from one another about sexuality and relationships, can foster empowerment and feelings of community and entitlement to sexual rights (Azzopardi-Lane & Callus, 2014; Frawley & O’Shea, 2020; Martino & Campbell, 2020). This can be especially important for sexual minorities (Abbott, 2021). Connected to this is a need for increased cultural visibility and representation of people with intellectual disability as competent sexual agents whose voices are listened to, and who can act as role models to their peers, and thereby work toward rewriting dominant sexually ableist narratives (Santinele, 2020; Withers et al., 2020).

By highlighting several examples of agency among our interviewees, we have also shown that even in repressive frameworks there is room for resistance and constructive strategies. Interviewees thereby also influence the level of interpersonal scripting, demanding rights to privacy and support—or in the words of Gill (2015, 7): “Failure to recognize an individual’s sexual agency might deny recognition of sexual citizenship but not sexual activity.” Although not all strategies are explicitly empowering regarding sexual subjectivity but intended as more covert ways of navigating restrictions, they are nevertheless important examples.

Finally, our research confirms that the invisibility of sexual agency is a considerable barrier to achieving opportunities for “meaningful choice” under the banner of the principles of rights and inclusion (Löfgren-Mårtenson, 2020, 252). Incorporating support for developing sexual subjectivity within existing disability services could be one way forward in developing more rights-based service approaches in contexts that lack national policies or guidelines (see Schaafsma & Wernaart, 2022). Although our participants exhibit various strategies of countering sexual ableism and desexualization, and thereby securing certain sexual rights in their daily lives, they cannot be seen to have full sexual citizenship in the meaning of being able to decide over and be recognized as competent subjects in all aspects of their

sexual lives. Therefore, in line with previous research, we see the need for policy recognition as an important component for securing sexual citizenship in both rhetoric and practice (Bahner, 2020; Kulick & Rydström, 2015). The *repoliticization* (Kafer, 2013) of the sexual rights of people with intellectual disability can take many forms, but a rhetoric of positive sexuality should be a guiding principle for successfully supporting the development of sexual agency on each individual’s own terms.

Limitations and Directions for Future Research

The study’s data partly consisted of participant observations without the specific aim to observe discourses and situations of sexuality or intimacy, and a more direct focus on this topic would be beneficial for future research. Furthermore, the interviewed research participants were not the same as the observed, and some of the interviewed participants did not live in sheltered accommodations. Thus, directions for future research could have more coherent context-bound observations and interviews, with a specific aim to observe discourses and situations of sexuality and intimacy.

Acknowledgements The authors express their gratitude to the participants in the three projects for sharing their experiences with us. They also thank the anonymous reviewers for input that was helpful in refining the final version, as well as members of the Welfare Research Group based in the Department of Sociology, Uppsala University, for constructive feedback and comments on an earlier draft of this article.

Author Contribution All authors have contributed equally and are listed alphabetically.

Funding Open access funding provided by Mälardalen University. Funding for this research was provided in part by a municipally financed doctoral candidate position at the School of Health, Care and Social Welfare, Division of Social Work, Mälardalen University, a faculty-financed doctoral candidate position at the Department of Sociology, Uppsala University, and FORTE: Swedish Research Council for Health, Working Life and Welfare (reg. no. 2018–01830) along with stipends from the Swedish foundation Ottarfonden.

Declarations

Competing Interests The authors declare no competing interests.

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