Personal Assistance Services and Sexual Health in Norway—a Cross-Sectional Study of Disabled People's Experiences and Attitudes regarding Sexuality and Personal Assistants

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RESEARCH

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ABSTRACT

Many disabled people cannot live out their sexuality or exercise their sexual citizenship without assistance. There is a lack of knowledge concerning experiences and needs related to personal assistance to live out one's sexuality and how to support sexual citizenship when living with a disability and receiving personal assistance services in the Norwegian context. This study presents the experiences and attitudes of disabled people in Norway concerning personal assistance services and sexual citizenship. A cross-sectional quantitative survey was answered by 67 disabled people living with personal assistance services. The results show that 67.1% of the respondents would rather avoid sexual activity than receive assistance with these activities, 50% found it uncomfortable to talk about sexual health, and 76% feared that conversations about sexual health would make the personal assistant uncomfortable. Service providers and municipalities should acknowledge the sexual needs of disabled people and organize services to meet these needs without personal assistants feeling uncomfortable or exploited.

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INTRODUCTION

Disabled people in Norway have reported lower quality of life and higher rates of loneliness than the non-disabled population (Ramm & Otnes, 2017). In addition, disabled people face innumerable barriers when building relationships, being sexually active, and becoming parents (Gruskin et al. 2019; Rohleder et al. 2019; Shuttleworth & Sanders 2011). Accessing good sexual healthcare is difficult for many disabled people due to a lack of accessibility, information, and necessary support (Gruskin et al. 2019). Kulick and Rydström (2015) highlighted that the combination of bodies with impairments that needs assistance with activities that can transgress boundaries, may explain why the sexual lives of disabled people can be a challenge.[1] This article is the first Norwegian study investigating sexuality, sexual health, and intimacy for disabled people receiving personal assistance services. Often, research from other contexts demonstrated that disabled people are frequently met with the assumption that they do not have a sexuality or a sexual life and do not experience sexual pleasure (Bahner 2019; Rohleder et al. 2019), which is especially problematic for those who rely on support services, such as personal assistants (Bahner 2019). The mentioned barriers are presumably similar in Norway, but there is a lack of research in this field. However, there is also a lack of professional education in sexual health, which can further increase barriers to addressing sexual health with disabled people (Areskoug Josefsson & Solberg 2023).

The sexuality of disabled people is a taboo subject that most health service providers are unprepared to address (Bahner 2021; Shakespeare & Richardson 2018). If health professionals address sexual health and disability, the conversations are often aimed at treating sexual dysfunction or avoiding sexual abuse. Sexual pleasure, intimacy, and how sexuality can enhance the quality of life and happiness, help maintain a positive mood, and provide emotional wellness are rarely discussed in society (Gruskin et al. 2019; Mona et al. 2017; Sánchez-Fuentes et al. 2014). Sexual health is defined by the World Health Organization (WHO) as a state of physical, emotional, mental, and social well-being concerning sexuality (WHO 2006). Sexual health is essential for a good quality of life. For sexual health to be attained and maintained, sexual rights must be respected, protected, and fulfilled (Gruskin et al. 2019).

The article is based on The Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006) and the human rights approach to disability, focusing on citizenship (Degener 2016). When discussing sexual health and assistance, it is necessary to do so with an understanding of the human rights of disabled people. In this article, identity-first language (Shakespeare 2018) is chosen. Additionally, the term 'sexual citizenship' is used rather than 'intimate citizenship,' as 'intimate citizenship' may also include friendship, cohabitation, family life, and parenthood (Liddiard 2019).

AIM/RESEARCH QUESTIONS/PRESENTATION OF STUDY

As there are no previous studies on personal assistance, sexuality, and disability in the Norwegian context, the study aimed to describe the experiences and attitudes of disabled people in Norway concerning personal assistance and sexual citizenship. There is no previous knowledge of how disabled people in Norway negotiate sexual citizenship with their personal assistants, a topic that is highlighted and discussed in this article. This descriptive study explored the research question: 'What experiences and attitudes do disabled people in Norway receiving personal assistance services have regarding their own sexuality?' and 'How do these attitudes affect their possibilities to exercise their sexual citizenship?'.

PERSONAL ASSISTANCE SERVICES AND SEXUAL HEALTH IN THE NORWEGIAN WELFARE CONTEXT

The Norwegian context is a part of the Scandinavian welfare model, where the states use welfare to obtain equality among their citizens (Esping-Andersen 2015). Norway ratified CRPD in 2013 but has received criticism from the UN for not recognizing disabled people as equal citizens (Fjetland et al. 2022; United Nations 2020). The process of implementing the CRPD

1 Personal assistance service is defined as a service where the disabled person themselves must have the right to recruit, train, and manage their own personal assistants (European Network on Independent Living 2015).

in Norwegian law is assumed to be on the political agenda of 2024. In Norway, personal assistance service is a licensed welfare service for disabled people with extensive and long-term assistance needs (Health and Care Services Act 2011). The Norwegian personal assistance service's primary goal is to ensure disabled people can participate in society and be equal citizens. The local municipality pays for this personal assistance service, called 'BPA' (user-controlled personal assistance). Municipalities often pay a third party called a service provider[2] to operate the service.

The service provider is the formal employer for the personal assistants, while disabled people themselves take care of day-to-day management. Private and non-profit organizations can be the providers of the services, as well as the municipality itself. Through their obligations to the municipality, the service providers have a special responsibility to ensure that the services provided are safe, ethical, and health-promoting (Norwegian Standard 2017). The personal assistant is hired through a service provider to help the disabled person during their daily life. In Norwegian personal assistance services, the disabled person is the day-to-day manager of their personal assistants and, simultaneously, the care recipient. It is possible to have another person as a day-to-day manager of their personal assistants if needed, for example, due to intellectual disabilities. To the author's knowledge, Norway has no official policies regarding personal assistance services and sexuality.

SEXUAL CITIZENSHIP

Disability and sexuality cannot be seen as separate from the state's work with citizenship and equality; it must be seen in this context as sexuality is an integral part of life (Karlsson 2020). Sexuality cannot be isolated; according to Karlsson (2020), it must be included in the healthcare sector, economic politics, and as an overarching perspective. Disabled people are vulnerable to structural inequality that creates barriers to citizenship (Fjetland et al. 2022). Often, when discussing citizenship and disability, the focus is access to exercising their social rights (Sépulchre 2017). Sexual rights can be understood in a citizenship framework, which can be helpful when working with disabled people's rights (Liddiard 2019).

Disabled people have less access to exercising their social rights, making disabled people's sexual citizenship a complex relationship between national and international policies and disability rights (Bahner 2019; WHO 2011). Civil society has an important role besides the state to lift sexuality and empower disabled people to live out their desires/sexual identity and sexual rights.

Richardson (2000) defines sexual citizenship as having three main aspects: the right to engage in bodily activities related to sex, the right to express and assert one's own sexual identity, known as self-definition, the right to control one's sexual autonomy, and recognition of partners. For many disabled people, personal assistance services are crucial for them to be able to exercise their sexual citizenship. Since access to sexual citizenship should be seen as equally as important as accessing public spaces or work life, a part of the personal assistance service should be to offer guidelines, policies, and advice about sexuality (Kulick & Rydström 2015).

Bylund (2022) highlighted how the welfare state's changes would affect the individual possibilities to live out one's sexual life and sexual freedom. The disability movement in Norway has conducted several projects and campaigns to promote sexual citizenship for disabled people (Unge funksjonshemmede n.d.). In this article, the scope is to investigate how personal assistance services can be a barrier or a possibility for disabled people to live out their sexuality. This is important for the study since personal assistance services are seen as an essential tool for disabled people to exercise citizenship. However, it is less discussed whether personal assistants should also play a role in accessing sexual citizenship.

INDEPENDENT LIVING AS A TOOL TO ACQUIRE SEXUAL CITIZENSHIP

The independent living ideology represents a change from person-centered services to services where the goal is equal citizenship (Bartlett & O'Connor, 2010). Independent living means

2 The service provider is the formal employer for the personal assistants, while disabled people themselves take care of day-to-day management. The service provider can be a private company or a non-profit organization.

being free to choose and control one's life and lifestyle. A central tool for independent living is personal assistance services (Sépulchre 2019). Personal assistance services make it possible for disabled people to live like others and support achieving equality and equity for disabled people (European Network on Independent Living 2015; Sépulchre 2019).

Being able to utilize their personal assistants to maintain sexual citizenship can be crucial for many disabled people. Some disabled people are dependent on assistance to exercise their sexual citizenship (Bahner 2019; European Network on Independent Living 2016). As there are significant differences regarding what is considered intimate from one person to another, it may be difficult for disabled people and their personal assistants to set mutually agreed boundaries (Saxton et al. 2001). The fear of losing personal assistants may also keep disabled people from asking their personal assistants to aid in sexual tasks (Bahner 2016). Independent living theory is important for this study as Norwegian personal assistance services are built upon independent living ideology, so it is necessary to understand the pretext of the context.

Meeting disabled people's sexual rights must be aligned with the personal assistants' right to a safe work environment.

METHOD

The research questions were explored using a descriptive study with a cross-sectional quantitative design (Creswell & Hirose 2019) based on an online survey. The survey aimed to uncover experiences and attitudes that disabled people had concerning topics around sexuality and personal assistance services. The survey was distributed through service providers of personal assistance and social media. The different service providers were asked to share the survey. The study population was disabled people who themselves had personal assistance from a private service provider.[3] The following criteria were set for the participants:

- Have had a personal assistant for at least six months
- Function as day-to-day managers for their personal assistants
- 18–67 years old
- Use private/non-profit service providers for the BPA service

The first author identifies as a disabled person and has received personal assistance services for 12 years. The second author works as an associate professor and has a background as a social educator working within the disability field. The last author is a senior researcher and previous rehabilitation professional.

SURVEY DEVELOPMENT

There were no validated surveys suitable for exploring the research questions. Therefore, a survey was developed. The different questions and areas of interest were identified through previous research in the field and the authors' experiences. A human rights approach was emphasized in the survey questions, and the articles in the convention determined how the questions were formulated. To distribute the survey, www.nettskjema.no was used.[4] The survey also contained eight demographic questions to ensure the respondents met the inclusion criteria.

SURVEY CATEGORIES

The survey contained 30 questions divided into five categories, starting with eight demographic questions. Four of the demographic questions asked about the participants' gender, age, sexual identity, and how long they have received personal assistance services. The other four demographic questions concerned the level of personal assistance service. When approving personal assistance services, the municipality focuses on how complex the need for assistance is, not necessarily on diagnosis or type of disability. Therefore, the type of disability was not

3 This project's focus is on private suppliers due to their similar delivery methods.

4 Nettskjema is a web-based survey tool developed by the University of Oslo that allows you to create, store, and manage surveys and data collections. In short, Nettskjema is a robust and secure data capture tool that offers a range of features for collecting, storing, and analyzing data from the desired audience. Retrieved from nettskjema.no.

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categorized in the survey. Instead, questions regarding the number of hours of assistance per week and the visibility of the disability were used. The rest of the survey contained questions exploring disabled people's experiences of and feelings regarding assistance with sexual and intimate tasks. The questions were separated into four subcategories: 'advice and knowledge,' 'communication about sexual health,' 'specific sexual activities,' and 'fears and worries'.[5] In 'advice and knowledge,' the questions concerned how much advice the respondents were given and their understanding of assistance and sexuality. 'Communication about sexual health' contained several questions about different aspects of sexual health and sexuality with their personal assistants. The survey also contained questions about specific sexual activities and experiences and covered the respondent's experiences and how they viewed assistance with specific activities. 'Worries and fears' covered possible fears or concerns that they might have regarding receiving assistance with sexual health.

PILOT TESTING

Pilot survey testing was performed to ensure that the representative respondents perceived the survey as desired. Before pilot testing with disabled people, the authors and a colleague tested the survey. The questions were then discussed, and minor changes were made before the pilot testing. The pilot testers were recruited through service providers of personal assistance. All ten pilot testers were disabled people who had been living with personal assistance services for 2–15 years. The disabled people who participated in the pilot testing were representative of the target group of the survey, ranging in age from 18–56 years, including male, female, and non-binary people.

After the pilot study, minor improvements were made to the survey. The original survey did not include any examples, and all pilot testers agreed/suggested that examples were necessary to understand the questions. For example, romantic activities were specified as 'for example, to go on a date, being on dating apps/online dating, or finding a partner offline.' Examples were used for all questions about specific activities to ensure the respondents understood what was included in the questions.

All the disabled people in the pilot study viewed the survey positively. They scored each question on a content validity index scale from 1–4, where one was deemed irrelevant, and four were highly relevant (Polit & Beck 2006). All questions had an average score between 3.5 and 4.0, indicating that the questions were relevant and representative.

DATA COLLECTION

The first author approached all major providers of personal assistance services in Norway, sending them an email about the survey with an attached invitation to participate. The service providers were asked to distribute the survey to their clients who were receiving personal assistance. All but two service providers shared the survey, and most of them also shared the survey multiple times. The invitational email included information about the study and that participation was voluntary. A link to the online survey was included in the email. After four weeks, additional recruitment via social media was added to increase the number of respondents.

An invitational post was published in multiple Facebook groups for disabled people, support groups for disabled people, NGO-related groups, and groups associated with the BPA service in Norway. The invitation was also sent by email or personal message to around 20 disabled people, including the pilot testers, at their request (they contacted the first author to request this). The survey was also shared on the webpage and social media of 'Unge Funksjonshemmede,' an umbrella organization with 38 member organizations for disabled and chronically ill youth. The organization works against discrimination and for universal design in all areas of society (Unge Funksjonshemmede n.d). Two disability influencers shared an Instagram post about the project in Norway. The survey was available for respondents from December 6, 2022, until March 1, 2023, and had 68 respondents. However, one respondent was excluded due to lack of explicit consent. Thus, the total sample contained 67 respondents.

5 Sexual activities in this article and the survey used in data collection are defined as dating, kissing, touching, masturbation, sex with partners, and/or engaging in romantic relationships.

ANALYSIS

Statistical analyses were performed with IBM SPSS version 28 (IBM, Crop, Armonk, NY USA). The values on the variables in the survey were either ordinal or nominal. Descriptive statistics are shown in frequencies and percentages; they are presented in the results as tables. The subgroups were not further divided due to the small samples. The open questions were analyzed separately using content analysis (Elo et al. 2014).

ETHICAL IMPLICATIONS

The Norwegian Social Science Data Service approved the project. The project was evaluated by REK (Regional Committees for Medical and Health Research Ethics) in Norway, who concluded that it was not necessary to apply for further approval as the project did not qualify as medical and health research. The participants had to give informed consent before starting the survey, and the survey could be ended at any time without any data being saved. The survey contained an explicit question about consent to ensure active/informed consent from all participants. All surveys were anonymized.

One respondent highlighted that the link between VID Specialised University and the private service provider Medvind Assistance AS was unclear; therefore, this is clarified as follows. The Norwegian Research Council funds the research project as a collaboration between VID Specialised University and a service provider of personal assistance, Medvind Assistance AS, the workplace of the first author. The research process is part of the first author´s PhD project at VID Specialised University and was separate from the private service provider. The private service provider was not involved in the research process. The first author is a PhD student who works 25% for Medvind Assistance AS and is one of the company's founders.

RESULTS

The results are presented in the following categories: The respondents, advice and knowledge, specific sexual activities and experiences, fears, and worries. After each category in the survey, the respondents could write a comment related to the category.

THE RESPONDENTS

All 67 respondents answered every question included in the survey, and the demographics of the respondents are described in Table 1. Most of the respondents were female. As many as 19.4% of the respondents identified as non-heterosexual, and 6.0% of the respondents were non-binary.

Table 1 Characteristics of participants.

DEMOGRAPHIC VARIABLE	*N*	%
Gender		
Non-binary	4	6.0
Female	42	62.7
Male	21	31.3
Age		
18–25 years	8	11.9
26–34 years	26	38.8
35–45 years	22	32.8
46–55 years	6	9.0
56–67 years	5	7.5

(Contd.)

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DEMOGRAPHIC		
VARIABLE	***N***	**%**
How long have you had BPA?		
Six months–less than a year	3	4.5
1–2 years	4	6
2.5–5 years	20	29.9
More than five years	40	59.7
What BPA company do you use?		
Non-profit service provider	19	28.4
Private service provider	48	71.6
How many hours of BPA do you have each week?		
Less than 25 hours	17	25.4
25–34 Hours	4	6.0
35–50 Hours	12	17.9
51–99 Hours	12	17.9
100–168 Hours	15	22.4
More than 168 hours	7	10.4
Would you say that your disability is visible to others?		
No, not at all	3	4.5
Yes, in some situations	11	16.4
Yes, all or most of the time	53	79.1
Sexual orientation		
Bisexual	7	10.4
Heterosexual	53	79.1
Lesbian/homosexual	3	4.5
Queer	3	4.5
Do not want to answer	1	1.5
Sexually active		
Yes, both alone and with others	21	31.3
Yes, with myself (masturbation)	22	32.8
Yes, with partner(s)	15	22.4
No, I do not want it	1	1.5
No, but I wish I was	8	11.9

ADVICE AND KNOWLEDGE

Only eight respondents had been counseled about sexuality and assistance from their service provider. When responding 'yes' to having been advised, there was an option to state what type of advice they were given. The respondents reported that they had received less advice than they wished for, and mostly, the advice was centered around what was legal or not. One respondent said they had been to a sex fair and spoken to a sexologist, which was helpful.

Over 76.2% of the respondents believed that they should be able to receive advice on sexuality and personal assistance services from their service provider if they wanted it. 67.1% of the

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respondents reported that, to some extent, they would rather avoid sexual activities than receive assistance with them (Table 2).

QUESTION	YES		NO		
Have you received counseling about 'sexuality and assistance' from your current or former service provider?	11.9% (8)		88.1% (59)		
Statement	Strongly disagree	Disagree	Partially agree	Agree	Strongly agree
I believe that as a disabled person, I should be able to receive advice on sexuality and assistance from my service provider.	16.4% (11)	7.5% (5)	26.9% (18)	20.9% (14)	28.4% (19)
I have sufficient knowledge about what is permissible to get help with when it comes to facilitating sexual activities (for example, masturbation and sex with partner(s))	17.9% (12)	13.4% (9)	23.9% (16)	14.9% (10)	28.4% (19)
I would rather avoid sexual activities (such as sex and masturbation) than receive assistance for these tasks.	13.4% (9)	17.9% (12)	17.9% (12)	14.9% (10)	34.3% (23)
I do not use personal assistants to facilitate sexual activities.	4.5% (3)	7.5% (5)	10.4% (7)	7.5% (5)	68.7% (46)
If I need assistance in facilitating sexual activities, I receive this from my partner(s) or others such as a friend or a family member.	34.3% (23)	4.5% (3)	14.9% (10)	10.4% (7)	35.8% (24)
I feel comfortable initiating a conversation with my BPA assistant(s) about sexual health and sexuality	25.4% (17)	11.9% (8)	28.4% (19)	19.4% (13)	14.9% (10)

Table 2 Advice and knowledge.

In the open comment questions, the respondents agreed that the service providers should offer advice and courses about sexuality and personal assistance services. However, many of the respondents were insecure around the topic and reflected on boundaries concerning their personal assistants, as this comment shows:

> 'My assistance needs have so far not included sexual activity, but I am aware of the boundaries, and I avoid, for example, taking my personal assistant to a sex shop.'

COMMUNICATION ABOUT SEXUAL HEALTH

In this section, communication about sexual health was addressed regarding how the respondents felt towards communication and how they perceived their personal assistant(s) would react if they spoke about sexual health. When asked if they were worried that their personal assistant might feel uncomfortable if they spoke about sexual health and facilitation needs, 76.2% agreed. Around 50.7% felt uncomfortable discussing their needs for facilitation or assistance with specific sexual activities (Table 3).

Table 3 Communication about sexual health.

STATEMENT	STRONGLY DISAGREE	DISAGREE	PARTIALLY AGREE	AGREE	STRONGLY AGREE
I feel comfortable discussing my facilitation needs for specific sexual activities with my personal assistant(s)	31.3% (21)	19.4% (13)	26.9% (18)	10.4% (7)	11.9% (8)

(Contd.)

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STATEMENT	STRONGLY DISAGREE	DISAGREE	PARTIALLY AGREE	AGREE	STRONGLY AGREE
I have enough knowledge to talk about my sexual health and any facilitation needs around sexuality with my personal assistants(s)	16.4% (11)	16.4% (11)	25.4% (17)	20.9% (14)	20.9% (14)
I believe that I may feel uncomfortable if the personal assistant(s) ask questions about my sexuality and/or sexual health.	20.9% (14)	13.4% (9)	23.9% (16)	20.9% (14)	20.9% (14)
I am worried that the BPA assistant(s) may feel uncomfortable if I talk about sexual health and any facilitation needs around sexuality	7.5% (5)	16.4% (11)	25.4% (17)	20.9% (14)	29.9% (20)

In the open comment questions, many respondents said that talking about sexuality with their personal assistants was hard and that they wanted the service provider to take more responsibility regarding this issue.

> 'I would never discuss my sexuality and sexual health with my personal assistant.'

SPECIFIC SEXUAL ACTIVITIES AND EXPERIENCES

When those who used assistance for sexual activities were asked how many personal assistants were involved in the procedure, 58.2% said none. When asked about specific activities, 47.8% had received assistance with romantic activities, while 20.9% had received assistance with facilitating masturbation and sex with partners. When presented with statements about sexuality and assistance, the respondents seemed more open to receiving assistance for romantic activities than various sexual activities (Table 4).

Table 4 Specific sexual activities and experiences.

STATEMENT	NONE	ONE ASSISTANT	A SELECT FEW ASSISTANTS	ALMOST ALL ASSISTANTS	ALL ASSISTANTS
If you have received assistance with sexuality, how many of the current employees assist with this?	58.2% (39)	4.5% (3)	17.9% (12)	10.4% (7)	1.5% (1)
Question	Yes			No	
Have you received assistance with romantic activities from your BPA assistants?	47.8% (32)			52.2% (35)	
Have you received assistance from your BPA assistants with facilitating masturbation?	20.9% (14)			79.1% (53)	
Have you received assistance from your BPA assistant(s) with facilitating sex with your partner(s)?	20.9% (14)			79.1% (53)	

(Contd.)

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STATEMENT	STRONGLY DISAGREE	DISAGREE	PARTIALLY DISAGREE	AGREE	STRONGLY AGREE
Consider the following statement: I think it is unproblematic to get BPA assistance with romantic activities (dating, swiping on dating apps (Tinder, etc.), making a move, or finding a partner(s))	16.4% (11)	10.4% (7)	35.8% (24)	13.4% (9)	23.9% (16)
Consider the following statement: I do not care if the BPA assistant(s) handle my sexuality aids.	41.8% (28)	20.9% (14)	14.9% (10)	9.0% (6)	13.4% (9)
Consider the following statement: I think it is unproblematic to receive assistance with practicing sexuality with a partner(s)	41.8% (28)	16.4% (11)	26.9% (18)	6.0% (4)	9.0% (6)
I think it is unproblematic to receive assistance with facilitation when it comes to masturbation/self-pleasure	47.8% (32)	17.9% (12)	19.4% (13)	6.0% (4)	9.0% (6)

WORRIES AND FEARS

The questions centered around the respondents' fears and worries about sexual abuse and developing romantic feelings. Of the respondents, 82.1% disagreed with the statement, 'I am worried that I may be subject to sexual assault or sexual abuse if I receive assistance related to sexuality' (Table 5).

Table 5 worries and fears.

STATEMENT	STRONGLY DISAGREE	DISAGREE	PARTIALLY AGREE	AGREE	STRONGLY AGREE
I am worried that the personal assistant(s) may develop sexual and/or romantic feelings for me if they assist with tasks related to sexuality.	71.6% (48)	16.4% (11)	6.0% (4)	3.0% (2)	3.0% (2)
I am worried that I will develop sexual and/or romantic feelings for the personal assistant(s) if they assist with tasks related to sexuality.	59.7% (40)	19.4% (13)	13.4% (9)	4.5% (3)	3.0% (2)
I am worried that I may be subjected to sexual assault and/or sexual abuse if I receive assistance related to sexuality	68.7% (46)	13.4% (9)	13.4% (9)	1.5% (1)	3.0% (2)

In the open questions, the respondents stressed the importance of the service provider's responsibility to ensure that the disabled person and their personal assistants feel confident about their sexuality. One respondent said:

> 'I think the providers should have a better follow-up on the issue of sexuality and personal assistants; my adviser at the provider knows nothing and has no suggestions on what we can do to find good solutions.'

Also, some respondents were worried about how their personal assistants would feel if they were asked for assistance with sexual activities. One respondent even claimed that getting help for sexual matters crosses the professional boundary between the employee and the disabled person.

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POSSIBILITIES OF EXERCISING SEXUAL CITIZENSHIP WHEN LIVING WITH PERSONAL ASSISTANCE SERVICES IN NORWAY

In line with previous research on the lack of sexual advice and information (Gruskin 2019), this study shows that only a small proportion of the respondents had received counseling about sexuality and personal assistance. In this study, only eight of 67 respondents reported that they had been counseled about sexuality and personal assistance. Out of those who had received counseling, all reported that they were given less advice than they wanted and that most of the dialogue was centered around legal issues.

Sexual facilitation by personal assistants is a complex operation with personal, emotional, and political aspects (Bahner 2019; Rohleder et al. 2019). As illustrated in the results of the present study, some disabled people might prefer to keep their sexual life apart from their personal assistants, which may be easier for those receiving only a few hours of assistance per week than for those with round-the-clock assistance. In other countries, there are examples of how the sexual needs of disabled people are covered through services such as sex therapists, sex surrogates, sex assistants, and sex workers (Bahner 2021), services which are hindered by Norwegian legislation (The Criminal Code 2009: 316).

ASSISTANCE AS A TOOL TO ACCESS SEXUAL CITIZENSHIP

The findings of the present study suggest that it may be challenging for disabled people to communicate their needs around sexuality and how to start a conversation about this with their personal assistants. Approximately half of the respondents found it hard to communicate with their personal assistants about sexual health and facilitation. Therefore, it is essential that disabled people and personal assistants can access respectful support and knowledge about how personal assistance services with sexual tasks can be communicated and organized to support sexual citizenship for disabled people. For disabled people, all three aspects of sexual citizenship (Richardson 2000) can be challenging to meet without adequate personal assistance services, including sexual needs. A majority of the respondents would rather avoid sexual activity than receive assistance from their personal assistants, and one respondent even stated that they would never bring this up with their assistant due to this being considered unprofessional when being the manager of their own assistants. As sexual health is closely linked with the quality of life, contentment, and happiness (GAB 2016), this is an important finding, especially as disabled people in Norway have reported lower quality of life and more loneliness than the non-disabled population (Ramm & Otnes 2017). It is necessary to explore further why disabled people in Norway would rather avoid sexual activity than receive assistance with it, even if the findings of this study support the barriers found by Bahner (2021) when negotiating sexual support with personal assistants: staff attitudes, lack of disability and sexuality policy, lack of accessible information, and the clients' fears. Concerning client's fears, the results of this study showed low levels of fear of abuse or romantic interest between clients and personal assistants. Instead, a fear of being perceived as an unprofessional manager and losing staff was more prevalent.

THE COMPLEXITY OF MANAGERSHIP, BOTH MANAGER AND SERVICE RECIPIENT

In the Norwegian personal assistance service, the disabled person is the day-to-day manager of their personal assistants and, simultaneously, the care recipient. When having personal assistance services, it is the individual disabled person's responsibility to communicate their needs to their personal assistants (Askheim 2019; Ministry of Health and Care 2015). The findings of the present study show that a majority of the respondents were afraid of making the personal assistant uncomfortable. The complexity of being the manager of their own personal assistants while also being the service recipient might be an explanation as to why a majority of the respondents would rather avoid sexual activities than receive assistance with them.

As a manager, it might be natural to focus on the personal assistant's needs over one's own. In the open-ended questions, several respondents highlighted that receiving assistance with sexual activities would be crossing the professional boundary between employees and them as managers. The respondents also expressed the need for training to balance managership's complexity with maintaining good sexual health and accessing sexual citizenship. It could be

argued that it is not possible to maintain a managership role while receiving intimate assistance, as a traditional manager needs to keep the worker-manager relationship professional. Since personal assistance service at its core is considered a grey area between the personal and the professional (Askheim 2019; Bahner 2016), it could be interesting to explore the possibility of redefining what is deemed professional in this worker-manager relationship to ensure that disabled people who are managers could both be professional and receive facilitation of their sexual health. The balancing act between being a professional manager and living an independent life is one of the core challenges and main complexities of personal assistance service. The goal of the personal assistance service in Norway is for the disabled person to live an active and equal life (Askheim 2019; The Norwegian Ministry of Health and Care 2015). Concerning sexual citizenship, there is a need for better support, including follow-ups with providers, as was described by respondents of the present study.

AUTONOMY AND BOUNDARIES WHEN HAVING PERSONAL ASSISTANCE SERVICES

Many respondents reported being insecure about boundaries concerning their personal assistants, leading them to avoid all sexuality-related issues, as they were unsure about how to navigate and exercise their sexual citizenship.

Boundaries were considered a key concern by the respondents related to sexual citizenship. Bodily autonomy, ownership, and boundaries may be hard to achieve for disabled people who need assistance with personal and intimate tasks. For many disabled people, personal assistance service is a service that empowers them to take ownership of their bodies as they manage their own personal assistants. Gundersen et al. (2014) found that the quality of the relationship between a disabled person and their personal assistants is decisive for body perception and experiences with intimacy and personal hygiene. Thunem (2020) found that disabled people felt more in control of their bodies when having personal assistance services than when receiving traditional services, such as home health nursing. Only approximately a fifth of the respondents of the present study were worried about sexual abuse from their personal assistants, which may be related to their ability to hire and manage their own personal assistants, which acts as a protective factor against the risk of being subjected to abuse (Shakespeare 2006).

Since a common misconception is that disabled people do not have sex (Gruskin et al. 2019; Rohleder et al. 2019; Shakespeare & Richardson 2018), personal assistants might have the same misconceptions; however, this is a topic that calls for future research, in a Norwegian context. However, internalized prejudices against their own sexuality might be a possible explanation for why a majority of the respondents would rather avoid sexual activities than receive assistance with these activities.

Prejudice can make it difficult for disabled people to both set boundaries and find a way to discuss sexual health and sexual activities (Saxton et al. 2001). Since there are significant differences in the topics different people consider intimate (ibid), it can be challenging for the disabled person to predict what might make their personal assistants uncomfortable. This aligns with the results of the present study, which suggested that respondents were worried about how their personal assistants would react if they were asked to assist with sexual activities. Most of the respondents were afraid to make their personal assistants uncomfortable if they spoke about sexual needs. Not knowing the personal assistant's boundaries might lead to the disabled person not addressing the topic for fear of losing their personal assistant (Bahner 2019), a fear also identified in the present study. If the personal assistant quits, the disabled person might face an acute lack of daily activity support. When faced with the fear of insufficient services in their daily life, it is reasonable to understand why some disabled people would rather avoid living out their sexuality. However, more research should be conducted on this topic. A possible solution to the dilemma could be to disclose that sexual health is a part of the job when hiring. This might be uncomfortable for the disabled person conducting the interview, but it may decrease the risk of the personal assistant leaving when sexual facilitation is brought up.

When analyzing the results of this study, it seems like talking about romance is easier for the respondents than talking about sexuality with their personal assistants. Regarding specific

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activities, most respondents were also positive concerning assistance with romantic activities, such as being assisted with dating, using dating apps, and finding a partner. A possible explanation is that it might seem more personal and private to facilitate sexual activities compared to facilitating romantic activity. In order to establish boundaries and agree on how sexual facilitation should be organized, both the disabled person and the personal assistant need to have a description of how the facilitation should occur (Mona et al. 2017).

The relationship between the disabled person and their personal assistant involves touch, conversation, and shared activities, where managing the boundaries and keeping the relationship professional can be challenging (Ungerson 1999). Gender, disability, and work relations can put both personal assistants and disabled persons in vulnerable positions (Askheim 2019; Bahner 2019). The goal of personal assistance services is for the disabled person to have bodily autonomy and control over their own life, but the liberation of disabled people should not depend on suppressing or exploiting their personal assistants. When receiving assistance with sexuality, it is important not to cross the boundaries of the personal assistants. In the personal assistance service, the personal assistants can be seen as vulnerable due to their employment being decided by the disabled person (Askheim 2019). When discussing sexual health, it might be difficult for the personal assistant to set boundaries if they are dependent on the job; they might feel they cannot refuse the disabled person's requests. There is a need for more research on how disabled people and personal assistants understand and navigate boundaries regarding sexuality in the Norwegian context.

THE SERVICE PROVIDER'S ROLE

The respondents highlighted the role of the service provider, and a large majority felt that the service provider should offer advice, guidance, and training courses on sexuality and assistance. This coincides with previous research, which has identified that many disabled people want personal assistance services to also include their sexual needs but have been unable to find anyone to turn to for advice and often have unmet needs instead of asking out of fear and insecurity (Bahner 2019). When faced with a challenge with personal assistance services, the disabled person can usually turn to their service provider for advice. The service provider is obligated by the contract with the municipality to offer support, counseling, and advice for disabled persons and their personal assistants (Norwegian Standard 2017). However, it seems that the topic of sexual health is rarely touched upon by the service providers. When checking the websites of the largest service providers of personal assistance in Norway (June 2023), only one mentioned sexuality.

The common assumption among respondents was that their service providers should be able to guide them in talking to their personal assistants about sexual health-related tasks. In the national standard contract between the service provider and the municipality, sexuality is usually not addressed unless specified in a separate contract (Norwegian Standard 2017). In the CRPD convention, article 19, sexuality and sexual health are emphasized as rights for disabled people (United Nations 2006). When the service providers are not offering training or information about sexual health, they are also amplifying the barriers for disabled people to receive assistance with sexual health, sexuality, and intimacy. Not addressing sexuality and personal assistance services can hinder the sexual citizenship of disabled people (Mona et al. 2017; Richardson 2000). Suppose conversations about sexual health were part of the mandatory follow-up from the service providers. In that case, this might decrease the stigma around sexual needs and encourage disabled people to discuss their concerns about sexual health. If disabled people with personal assistance services know that they can seek advice and knowledge from their service providers, this could make it easier to address these issues. Knowing that the service provider acknowledges their sexual health might make it easier for disabled people to seek guidance and find a way to maintain professionalism when receiving assistance with sexual facilitation.

METHODOLOGICAL DISCUSSION

As the other Nordic countries have a similar social welfare model, the results might be relevant in the Nordic context. However, increased knowledge of how disabled people experience their sexual citizenship might be applicable outside the Nordic context as well.

In this study, the proportion of respondents identifying as non-binary and non-heterosexual was higher (19.6%) than for the non-disabled population of Norway, where around 6.9% has been found to be non-heterosexual (Støren et al. 2020). When discussing personal assistance services and sexuality, an intersectional approach is essential, as gender identity, ethnicity, religion, age, socioeconomic status, and sexual orientation can affect sexual opportunities and sexual health (Bahner 2019). For disabled people who identify as queer, their personal assistants' attitudes towards queer people might affect their sexual citizenship. For future research, it would be of interest to investigate the link between queerness, disability, and personal assistance services. As many of the respondents highlighted the responsibilities of the service providers of personal assistance services to address sexual health, sexual facilitation research regarding the service providers would be a natural next step. A limitation of the present study is that no validated survey was available. Thus, a survey had to be developed, and the questions may be interpreted differently by the respondents. However, the comments given by the respondents indicate a correct interpretation of the questions. The pilot study was also conducted to improve the quality of the survey questions and was discussed with other researchers who knew the Norwegian context of disability. The survey was developed for the Norwegian context, which is a strength, as the survey used words and expressions that would be familiar to the respondents. Another limitation is that the survey was conducted on a sensitive topic, and it could be challenging to reach informants willing to participate.

CONCLUSION

As the first Norwegian study investigating sexuality, sexual health, and intimacy for disabled people receiving personal assistance services, the findings are important. Overall, the results highlight a need for more research and conversations around sexual health and personal assistance services, along with official policies and guidelines regarding sexual health and personal assistants. A central finding was that 67% of disabled people with personal assistants would rather avoid sexual activity than receive assistance with these tasks. In addition, 76% thought the service providers of personal assistance should offer courses, guidance, and advice on sexual health both for disabled people and their personal assistants. The service providers and the municipality should acknowledge the sexual needs of disabled people as a natural part of their citizenship and participation in society and ensure that the services are organized in a way that allows disabled people to have their sexual needs met without personal assistance feeling uncomfortable or exploited. The results also show the need for further research in this field.

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AUTHORS CONTRIBUTIONS

All authors were involved in the study's conception and design. The first author performed the data collection and the data extraction, analysis, and interpretation of results. The first author conducted the draft manuscript preparation. All authors reviewed the results, approved the final version of the manuscript, and agreed to be accountable for all aspects of the Work.

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