

Sexuality and Access Project (SAP) 2023

Summary Report December 2024

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Executive Summary

Highlights

- Most service users and providers reported that sexual support is excluded from service agreements and formal training and education, though informal discussions on the topic still occur within attendant care.
- Absent supports and resulting lack of conversations around sexuality and disability have contributed to ongoing gaps in accessing one's own sexuality and sexual health. Interview participants highlighted experiencing internalized stigma and shame, discomfort and dissociation with one's body, and challenges with heteronormative notions of intimacy and pleasure.
- Comfort levels with discussing sexual support varied based on the pre-existing service user-provider relationship.
- Users suggested that attendants could improve comfort by building rapport, setting clear boundaries, and normalizing these discussions as part of their role.
- Attendants suggested that employers could improve support by offering more education on sexual support, inclusion in service agreements, and clarifying rights and responsibilities.

Purpose

Our aim for the Sexuality and Access Project 2023 was to understand attendant service users' lived experiences with and service providers' perspectives around sexuality support and sexual health within the attendant care service dynamic with hopes to promote much needed conversations around sexuality and disability to combat ongoing stigma. Ultimately, the goal of this project is to provide updated research to inform the development of attendant service user and provider-informed care practices, ongoing community programming, and additional sexuality and disability-related resources tailored to the priorities, needs, and hopes of those receiving and providing attendant care services.

Methods

We first conducted online surveys with both attendant service users and providers across Canada from January 2023 to December 2023. Online surveys asked respondents about their experiences accessing sexual health support, attitudes towards sexual health support, and barriers to sexual health support within the attendant service dynamic. After data cleaning, we had a total of 22 attendant users and 20 attendants who completed the online surveys. Following the surveys, we conducted virtual interviews with attendant users across Canada. Each interview was 90 minutes long and asked participants to discuss the connection between sexuality and disability, within and beyond the service provision context. Between August 2023 and March 2024, we conducted six interviews with attendant users, who all had previously participated in our online survey.

Key Findings

The majority of attendant service users and service providers told us that sexuality or sexual support has never been a part of any service agreement they have signed. Further, over half of respondents reported never being told about their rights around asking for and providing sexual support, with a little over half of attendants reporting never receiving training or instruction on sexual support. Yet, the majority of respondents have had (a) prior experience(s) discussing sexual support within the attendant care context, suggesting that these discussions often happen informally.

We saw disproportionate experiences of conflict regarding sexual support within the service provider context, such that almost three times the amount of attendant service users reported experiencing conflict or disagreement compared to service providers. Further, almost half of attendant users shared that they have a request for sexual support refused, with many more having heard of stories of refused requests by others. Additionally, three times as many attendant users reported feeling unsafe during negotiations for sexual support compared to attendant providers. Attendant users highlighted how these findings are partly driven by biases and power dynamics, such that one's sexual and/or gender identity and orientation could influence discussions around providing sexual support. When asked if attendants should be required to assist with sexuality and sexual support, attendant users and attendants somewhat disagreed, further highlighting potential discrepancies in attitudes towards providing sexual support within the attendant provider context.

Comfort levels varied among attendant users and attendants and were dependent on the service user-provider relationship. For attendant users who did not feel comfortable talking to attendants about sexual support, they suggested that attendants could build rapport, be upfront about boundaries, and normalize discussions as part of their work.

A quarter of attendants reported feeling unsupported by their organization, with a little over half of attendants indicating that they think their employer could better support them. Attendants suggested that their employer or organization could better support them by providing more education on sexual support, introducing sexual support within signed agreements, and clarifying rights and responsibilities around providing sexual support.

Eight themes emerged from the interview data. We present these eight themes as either barriers or facilitators to accessing one's own sexuality. Although our purpose is focused on the service provision context, the final themes include experiences that transcended this context. We felt this was appropriate to still include as the service provision context does not exist in a vacuum and instead is entrenched within a larger sociocultural context. Barriers that participants encountered when accessing their sexuality included: (1) misconceptions that individual with disabilities are nonsexual; (2) missing an intersectional lens in education and discourse on sexuality and disability; (3) approaching disability and sexuality through Western medical perspectives; and (4) navigating systemic barriers with potential for harm. To challenge these barriers, participants shared: (1) using humour as an icebreaker when discussing disability and sexuality; (2) co-constructing sexual support when negotiating one's care; (3) centering diverse voices within discourse on disability and sexuality; and (4) expanding abled ideas of sexuality using knowledge produced from individuals with disabilities (IWD).

Discussion

Several themes were found across the survey and interview findings. Firstly, we found across both studies that IWD experienced ableism and medicalization within and beyond the service provider context, which ultimately impacted their access to their own sexuality and sexual health. Further, gender and sexuality were intertwined with sexual support, such that they could further influence related discussions and negotiations. Additionally, we found that establishing comfort and maintaining boundaries and clearly communicating expectations and boundaries were essential to successfully negotiating sexual support. Lastly, internal strategies (e.g. humour) and external supports (e.g. training and policies) can facilitate discussions around accessing and providing sexual support within the attendant care context.

Next Steps

Our research highlights the need for education, training, and other resources for service users and attendants related to negotiating sexual support within the attendant service user relationship. The next phase of the project will involve working closely with diverse disability communities and attendant service workers to develop and execute educational programs and other formal supports related to sexual support, with hopes of fostering long overdue conversations and positively impacting practices and experiences on all sides while centering IWD.

Acknowledgements

“Alone, we can do so little; together, we can do so much” – Helen Keller

When Wallace and I found one another, we found our partner in crime. We are a team concerned with social justice within the disability community. The two of us are fully flawed human beings looking to connect with others, and endeavour to be a part of some positive change.

When we reach out to others and begin building community, we can learn, support and celebrate one another. We can examine our biases as they pop up. We can learn from our mistakes, forgive ourselves, and grow. We need to be kind to ourselves so that we can be kind to others.

We believe everyone has a right to access their sexuality. It is a component of daily living that often gets ignored, and some people act like it is not (or should not) be a part of disabled people's lives. Disability and sexuality have always existed, but there is still a lack of conversation about how they intersect. As a result, many harmful myths still exist. How comfortable are you with your own sexuality? Expressing your needs and wants? Many of us are steeped in shame, uncomfortable with talking about our sexuality.

We would not have started the Sexuality and Access Project 2023 journey in 2021 (now called the Sexuality and Access Project 2.0), if it had not been for Julie Watson and Lubna Aslam. Julie Watson is a Peer Program Coordinator for Spinal Cord Injury Ontario (SCIO). In 2021, we were working with her on a 3-part presentation we called “Let's Talk About SCI and Intimacy”. Lubna Aslam, who was the Peer Program Manager for SCIO at the time, asked us to speak about the relationship between those who access attendant care services and those who provide these services. Specifically, she asked “How is a person's sexual health supported in this relationship?”. Julie and Lubna, thank you for the opportunity, and for asking the question.

We reached out to individuals, disability organizations, and academic institutions across North America, and beyond. We had many conversations about this specific relationship as it pertains to accessing one's sexuality.

To those who felt we should not be talking about this, thank you. Your discomfort with the topic further cemented our dedication to it. We will be circling back to you with an open invitation to join us. We hope that you do.

What we heard loud and clear from everyone else was a version of “Sounds great but you need to do a needs analysis, and who the hell are Wallace and Melanie?”. To this amazing group, Kevin Munn (Victoria Disability Resource Centre), Robin Green (Ottawa Independent Living Resource Centre), Kate Deacon and Laura Allen (Independent Living Centre Kingston), Dan Lajoie and Sheri Roberts (Independent Living Waterloo Region), Dr Stacy Elliot, Shea Hocaloski, Lesley Houle and Marie Carlson (The Vancouver Coastal Health Sexual Health Rehabilitation Service), Dr Amy Muise and Dr Jackie Kathnelson... thank you for supporting us, for seeing value in the project, for your time and introductions. Caveat: we recognize that some of you have retired or moved on to other positions since 2021.

We would like to highlight Dan Lajoie from the list above. Dan, thank you for pointing us towards the 2011 Sexuality & Access Project led by Fran Odette and Cory Silverberg. The link to the Survey Summary was a game changer. We found our starting point. Fran Odette and Cory



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Kayla Orr, as the new ED of SHORE Centre you did not miss a beat. When you joined the team, it was seamless – like you had always been there. Thank you for your commitment to the project and for your fierce determination. Vivila Yujuan Liu (Education and Outreach Manager, SHORE Centre). Viv, we are so grateful that you are a part of the team, and we look forward to collaborating with you on Phase 2.

To our friends and family... thank you for your donations! We could not have completed Phase 1 without you. The funds raised were used to support University of Guelph students working on the project, translations services, and gift cards for the people with lived experience who shared their invaluable life experiences with us during the consultation phase.

We are grateful to those of you with lived experience who completed a survey and/or participated in our qualitative interviews. Thank you for sharing your experiences, truths, desires and frustrations. The team is committed to this project, and to you. We look forward to working with you during Phase 2 of the Sexuality & Access Project 2.0.

Let's keep the conversation going!

Wallace (he/they) & Melanie (she/they)
t6talk

Introduction

Purpose

The aim of the Sexuality and Access Project 2023 is to promote crucial conversations around sexuality supports and sexual health within the attendant care service dynamic for both attendant service users (any individual who uses personal care services) and service providers (personal support workers, facility providers, family members).

Background

Individuals with disabilities (IWD) make up 22% of Canada's population (Morris et al., 2018) and are the largest minority group in the world (WHO, 2011). Still, the sexuality and sexual rights of IWD have long been undermined, while the general public tends to have more negative attitudes towards sexuality and disability (Pebdani & Tashjian, 2022).

According to Pebdani and Tashjian (2022), societal misconceptions are the largest barrier for IWD in accessing sexual support. Specifically, assumptions exist that IWD are not interested in or are not capable of sex. These false narratives continue to perpetuate discriminatory beliefs and need to be countered through engaging with the lived experiences of IWD. In response, Pebdani & Tashjian (2022) recommend analyzing current attitudes and experiences surrounding disability and sexuality to discover barriers and increase awareness of the sexual rights of IWD so they can be supported safely. The present study aims to investigate existing comfort levels and practices among service users and attendants, as well as open up further conversations about disability and sexuality supports within and beyond attendant care contexts.

Societal attitudes toward sexuality and disability have led to a lack of regulation and guidelines for the sexual support of IWD (Benoit et al., 2022). Personal topics and care needs related to sexuality for IWD are likely to arise within the intimate nature of attendant care dynamics, and yet current policies, guidelines, and trainings tend to focus exclusively on the prevention of abuse and sexual assault (Silverberg & Odette, 2011). Little information is provided for IWD and their support workers to help them navigate sexual support in a way that is safe and comfortable for both parties, potentially resulting in dangerous and unethical situations (Benoit et al., 2022). Furthermore, support staff and family members mainly report non-restrictive, positive attitudes towards the sexual rights of IWD, though a commonly expressed tension arises between supporting the sexuality and sexual expression of an IWD, while also considering safety and autonomy for both themselves as family and/or care attendants and the individual(s) they support (de Wit et al., 2022). This coupled with the precarious employment conditions attendants often face, including low wages, irregular or part-time hours, and a lack of job security, sick leave, and extended health benefits creates potential for harm (Pinto et al., 2022). In understanding this dilemma, the perspectives, needs, and rights of support workers and care providers are essential to understand how to provide safe sexual support for IWD.

While the rights of IWD and their support workers should align in both policy and practice (Benoit et al., 2022), research on sex and disability tends to separate these perspectives. Research on sex and disability also tends to compartmentalize various forms of disabilities to understand and address specific needs (Brown & McCann, 2019., Sellwood et al., 2017., Streur et al., 2018).

While there are advantages to these approaches, our project intentionally engaged with both service providers and service users regarding their experiences with sexuality supports within the attendant care dynamic, and also welcomed cross-disability perspectives of IWD, including folks who are multiply disabled and who embody a range of other social identities and lived experience.

The Sexuality and Access Project 2011

The Sexuality and Access Project 2023 (SAP 2023) aims to replicate and build upon the original Sexuality and Access Project (2011) conducted by Cory Silverberg and Fran Odette. Similarly, the 2011 project addressed the experiences of those who use attendant care and those who provide services with the goals of understanding and facilitating these working relationships when discussing, negotiating, and expressing sexuality and gender identities.

Silverberg and Odette (2011) defined sexual support as any act of service which acknowledges that sexuality is a core part of the service user's life, general well-being, and personhood. This could mean a range of things such as helping someone prepare for a date, asking sexuality related questions, and helping with positioning during intimate acts. The project's findings highlight the intimate nature of the relationship between service user and attendant, and the inevitability of sexual health topics and care needs arising during the regular program of supports (Silverberg & Odette, 2011).

Silverberg and Odette (2011) acknowledge that shame around sexuality tends to silence important issues related to sexuality – a silence which is exacerbated for IWD due to exclusionary, ableist societal attitudes and practices. In an attempt to combat this silence, the 2011 project followed four guiding principles, which informed our own project as well:

1. Sexual rights are human rights
2. Sexual health is a core component of general health
3. People with disabilities who use attendant services have a right to access information and resources about their sexual health and support in expressing their sexuality
4. Attendants have sexual rights, which include the right to a workplace that is not sexualized (Silverberg & Odette, 2011).

Our Mission

In 2021, Melanie Earle and Wallace Upper from t6talk, a peer connection and support resource within spinal cord injury and disability communities, were asked to do a 3-part series on sex and spinal cord injury for Spinal Cord Injury Ontario. They found it incredibly difficult to find research on sexuality within the attendant user and provider dynamic. They began expanding their network, having conversations with Independent Living Centres in Ontario and British Columbia (Waterloo, Kingston, Ottawa, and Victoria), along with the Sexual Health Team in BC (Blusson Spinal Cord Centre/GF Strong Rehabilitation Centre) and others until they came across the original 2011 Sexuality and Access Project. Melanie and Wallace had growing passion for



promoting conversations around sex and disability, as well as how the needs and experiences of individuals have changed over time. They began conceptualizing the Sexuality and Access Project 2023 as they felt replicating the survey, in collaboration with IWD and service providers, was an essential next step to providing still long overdue attention and consistent supports for sexual expression and well-being.

Following, t6talk partnered with the Sexual Health Options, Resources, and Education (SHORE) Centre, University of Guelph faculty member Dr. Adam Davies, University of Guelph's Community Engaged Scholarship Institute (CESI), and dedicated undergraduate and graduate students. Together, we are interested in continuing conversations around sexuality and disability to combat ongoing shame and silence. Our overall goals for the Sexuality and Access Project 2023 were to engage with the lived experience of IWD and service provider perspectives to further open space for mutual understanding and crucial conversations around sexuality and disability within and beyond attendant care dynamics. Ultimately, we aim to provide updated research to inform the development of IWD and provider-informed care practices, ongoing community programming, and additional sexuality and disability-related resources tailored to the priorities, needs, and hopes of those receiving and providing attendant care services.

Methods

Our study involved: (1) conducting online mixed methods surveys with both attendant users and attendants; and (2) conducting semi-structured virtual interviews with attendant users.

Ethics

This study was reviewed by the University of Guelph's Research Ethics Board for compliance with federal guidelines for research involving human participants. Due to the sensitive nature of topics relating to sexuality, participants were informed of subject matter and related benefits and potential risks before agreeing to participate and all questions were optional. Written and/or verbal consent was collected at the beginning of data collection. After interviews, participants also received a release form in which they were asked to consent to the ways that they were comfortable with having their data (i.e., demographics, direct quotes, etc.) shared publicly via academic and community-facing publications, websites, conferences, workshops, etc.

Recruitment Process

To participate in our study, participants were required to have had experience with accessing attendant care services or providing attendant care services. Participants were also required to be over 15 years of age and living in Canada at the time of the study to participate. Participants were required to be able to understand and respond in English or French, either orally or through written/typed responses.

Participants for our study were recruited through networks of connections made through t6talk, including independent living organizations, disability resource centres, and rehabilitation centres across Canada. If interested, participants were first directed to complete an online mixed method survey.

After completing an attendant service user survey, attendant users had the option to provide their email if they were interested in participating in a follow-up interview. Individuals who expressed interest were contacted by a member of the research team to set up an interview time.

Online Mixed Method Surveys

We first conducted online surveys with both attendant service users and providers via the Qualtrics survey platform. Surveys were offered in both English and French languages. The online format of our survey was an attempt for us to reach a much larger audience and potential participant pool, as well as to connect with individuals and organizations across Canada, while considering the priorities and needs of individuals with varying abilities. An online survey format allows participants to respond while minimizing social pressures and biases a research setting might induce for sensitive topics, such as sexuality and sexual support (Braun et al., 2021).

To accommodate and support various ranges of abilities and offer consideration for preferred communication methods, the survey was also offered over the phone/through video conference with a research team member, or through the option of having a hard copy of the survey sent by mail.

Participants

In total, we received completed survey responses from 22 attendant users and 20 attendants.

Data collections via online Qualtrics surveys initially garnered a much larger set of responses, which we quickly identified as bot responses. In total, 961 responses were submitted through the attendant users' survey and 2657 responses were received through the attendant's survey (demographic and main survey combined). Through review of the data set, we identified a problem with survey bots, a growing issue with online survey research (Imperva, 2022). Subsequently, this led to careful review of the data and elimination of any potential responses that could be identified as a bot. We took a conservative approach to removing participants. This involved various steps including eliminating any submissions that were under 60-seconds long, multiple or repeat responses that were submitted consecutively within a short period of time from the same IP address, and those that were recorded with an IP address outside of Canada. Remaining responses were carefully reviewed in terms of suspicious patterns in quantitative responses (e.g., those that selected only the first multiple choice response for the entire survey) and similarly for qualitative responses (e.g., those that only repeated language from questions asked, irrelevant responses, or those that did not fit with the question that was asked).

After this process, we were left with 22 attendant users and 20 attendants who completed the English survey. No responses from the French survey were included in our analyses, as response rates were very low and were all identified with a strong likelihood of being bot responses.

One attendant user also completed the surveys through a Zoom video conference with a research team member. The process for data collection and transcription can be found under 'Interview Details'.

Survey Details

Our surveys utilized both quantitative and qualitative items, as questions included both multiple choice response options and an open-ended text field. While we were interested in quantitative response trends across participants, we were also interested in the qualitative information respondents provided within each question. Including a qualitative component is appropriate for under-researched areas, such as sexuality and disability, as it allows us to prioritize the subjectiveness and complexities of individual experiences to form a comprehensive foundation of knowledge for topics receiving little attention in the literature (Braun et al., 2021). The qualitative survey components allowed us to expand upon and complement the quantitative pieces which were largely carried over from the original 2011 project.

Our surveys were adapted from the original 2011 survey and consist of a demographic questionnaire (12 questions) and a survey questionnaire (16 questions) for both attendant users and providers. Though we intended to keep both surveys as similar as possible, we made several changes, including:

1. Separating and switching the order of the demographic and survey questionnaires to ensure safe keeping of potentially identifying demographic information from potentially sensitive information related to sexuality and disability within the larger survey.
2. Adding additional demographic questions to gain a further range of information, including updating the language around gender identity in accordance with Rainbow Health Ontario guidelines (Bourns, 2023).
3. Clarifying any potentially ambiguous wording.

Demographic questions asked respondents about their identities (e.g., sex, gender, ethnicity), as well as other contextual details (e.g., relationship status, years using/providing services). Survey questions asked respondents to further expand upon their experiences accessing sexual health support, attitudes towards sexual health support, and barriers to sexual health support within the attendant service dynamic. Both questionnaires have been included at the end of this report (See Appendix A), with example questions also listed below:

- Have you ever received training or instruction on sexuality and sexual support as it applies to your work as an attendant? [Closed-ended and open-ended response options].
- Are the topics of sexuality and sexual support subjects that you have ever, or would ever, feel comfortable discussing with an attendant? [Closed-ended and open-ended response options].
- If you do not feel comfortable talking to attendants about sexuality and sexual support, what do you think an attendant could do to make you more comfortable? [Open-ended response option].

Semi-Structured Virtual Interviews

Following the surveys, we conducted semi-structured interviews with attendant users. Interviews were conducted virtually over Microsoft Teams or Zoom to allow for participation of attendant users across Canada.

Interviews took place between August 2023 and March 2024.

Participants

Six individuals with disabilities participated in an interview. Four participants live with Spastic Quadriplegia Cerebral Palsy. One participant lives with Spinal Muscular Atrophy Type II and one participant lives with an acquired Spinal Cord Injury. All participants are wheelchair users, and one participant is ventilator dependent. All participants currently utilize attendant service providers. All participants are Canadian and currently reside within Ontario or British Columbia. All participants describe their ethnic background as White European. Five participants described their gender as cisgender men, and one participant described their gender as non-binary. Four participants described their sexual orientation as heterosexual, with one participant describing their sexual orientation as queer and another as gay. Half of the interview participants indicated they were single, while the other half indicated they were partnered. One participant indicated that they are polyamorous. Polyamory is the orientation towards multiple simultaneous consensual intimate, sexual, and/or romantic relationships (The 519, 2020).

Interview Details

Each interview was 90 minutes (about 1 and a half hours) long. Two members of the research team were present during all interviews to ask questions and follow up with relevant probing questions.

Interviews began by asking participants to introduce themselves, their interest in participating in the study, and what is important to them about sex and sexuality and its connection to disability. Participants were then asked about the contexts they have spoken about sex and sexuality and its connection to disability. Interview questions also inquired about the information/education participants received around sex, sexuality, and disability over time, including whether participants had access to or participated in sex education growing up. Participants were then asked about how disability has affected their experience of sex and sexuality in the past and how the connection between sex and sexuality and disability impacts them now. Lastly, participants were asked about what barriers they experienced in accessing their sexual health and expression and what they would like to see in the future within and beyond attendant care dynamics.

Participants were often probed to think about the questions in the context of the service provider relationship, however, since interviews were semi-structured, we were also open and responsive to hearing about participants' experiences with sexual health and sexuality and disability across other relevant life contexts as well.

A list of interview questions and probes can be found in Appendix B.

Zoom and Microsoft Teams recorded both audio and visual data from the interviews. Interviews conducted through zoom were transcribed using Otter.ai, while interviews conducted through

Microsoft Teams were transcribed through Microsoft Streams. Following, a member of the research team watched each interview and edited the transcripts for all verbal utterances and nonverbal cues that these services could not capture.

Findings

Online Mixed Method Surveys

Demographics Survey

Age

Attendant users' ages ranged between 15 and 64 years old, while attendants ranged between 20 and 74 years of age.

Half of the attendant users (50%) were between the ages of 25 and 34. Following, 27% of attendant users were between the ages of 35 to 44, with 14% between the ages of 45 and 64. Five percent of attendant users were between the ages of 55 and 64, with an additional 5% between the ages of 15 and 19.

Similarly, half of the attendants (50%) were between the ages of 25 and 34, with an additional 35% of attendants between the ages of 35 to 44. Additionally, we had 1 attendant (5%) indicate they were between the ages of 20 and 24, another attendant indicate they were between 55 and 64 years old, and another within the age range of retirement (65 to 74 years old).

Table A.

Age Ranges of Participants

| Age ranges | Percentage of attendant users reported ages | Percentage of attendants reported ages |
|------------|---|--|
| 15-19 | 5% | NA* |
| 20-24 | 0% | 5% |
| 25-34 | 50% | 50% |
| 35-44 | 27% | 35% |
| 45-54 | 14% | 0% |
| 55-64 | 5% | 5% |
| 65-74 | 0% | 5% |
| 75-84 | 0% | 0% |
| 85-94 | 0% | NA* |

*Age range was not provided as a response option.

Education

For attendant service users, 41% of respondents had attained some post-secondary education, with 23% attaining a college diploma and 14% attaining an undergraduate degree. Some attendant users also reported either completing some (5%) or all of high school (9%). Additionally, 9% of attendant users reported less than high school as their highest level of education.

On the other hand, 21% of attendants attained a college diploma, 37% attained an undergraduate degree, and 21% attained a graduate degree. Additionally, 21% of attendants completed high school (16%) or some post-secondary education (5%).

Geographical Location

Just over two thirds (68%) of survey respondents using attendant services indicated that they were currently living in Ontario, with an 18% of attendant users residing in British Columbia. Following, attendant users reported living in Alberta (5%), Quebec (5%), and Nova Scotia (5%). No survey respondents reported living in the territories.

Similarly, attendants indicated that they mostly reside in Ontario (40%) or British Columbia (40%), with a smaller group residing in New Brunswick (10%) and one participant from Alberta (5%) and the Northwest Territories (5%).

Eighty-seven percent of attendant users estimated living in a city or town with populations greater than 10,000, with 27% of respondents estimating living in a city of 100,000 to 499,999 and 41% of respondents estimating living in a city greater than 500,000. On the other hand, 9% of attendant users estimated living in a town with a population size of 500 to 4999, with 5% of attendant users estimating living in a town with a population size of 5000 to 99,999. Similarly, 85% of attendants estimated living in a city or town with populations greater than 10,000, with 15% of respondents estimating living in a city of 50,000 to 99,999, 35% of respondents estimating living in a city of 100,000 to 499,999 and 20% of respondents estimating living in a city greater than 500,000. Conversely, 5% of attendants estimated living in a town with a population size of 500 to 4999, with 10% of attendants estimating living in a town with a population size of 5000 to 99,999.

Ethnicity

The majority of survey respondents using attendant services described their ethnic background as White European (73%) followed by users describing their ethnic background as Black/African/Caribbean (18%), South Asian (5%), and Indigenous (5%).

Similarly, 90% of attendants described their ethnic background to be White European. Following, attendants described their ethnic background as East Asian (5%), Black/African/Caribbean (5%), and Indigenous (5%).

Gender Identity

Eighty-seven percent of attendant service users indicated that they identify as cisgender, with 1 participant identifying as genderqueer, non-binary, and trans (5%). Sixty-four percent of attendant users described their gender as a woman, with 32% identifying as a man, and 5% as non-binary and genderqueer.

Similarly, 89% of attendants indicated that they identify as cisgender, with 11% of attendants indicating that they don't fully identify with any of the options or indicating not understanding the

terminology. Additionally, the majority of attendants described their gender as a woman (80%), with 20% identifying as a man, 5% as non-binary, and 5% as genderqueer.

More information regarding the definitions for sex and gender identities can be found on the Rainbow Health Ontario website (Bourns, 2023).

Sexual Orientation

When asked how participants would describe their sexual orientation, 86% of attendant users described themselves as heterosexual. Following, respondents also described themselves as bisexual (5%), queer (5%), and gay (5%).

Similarly, 70% of attendants described themselves as heterosexual, with additional 20% of attendants describing themselves as pansexual, 10% as bisexual, and 5% as queer.

Using/Providing Attendant Services

Fifty-five percent of attendant service users reported using services for 5 or more years, with 36% reporting using attendant services for 1 to 3 years. Additionally, 5% of attendant users reported using attendant services for 3 to 5 years, with 5% of respondents with less than 1 year of experience.

Experience Using Attendant Services

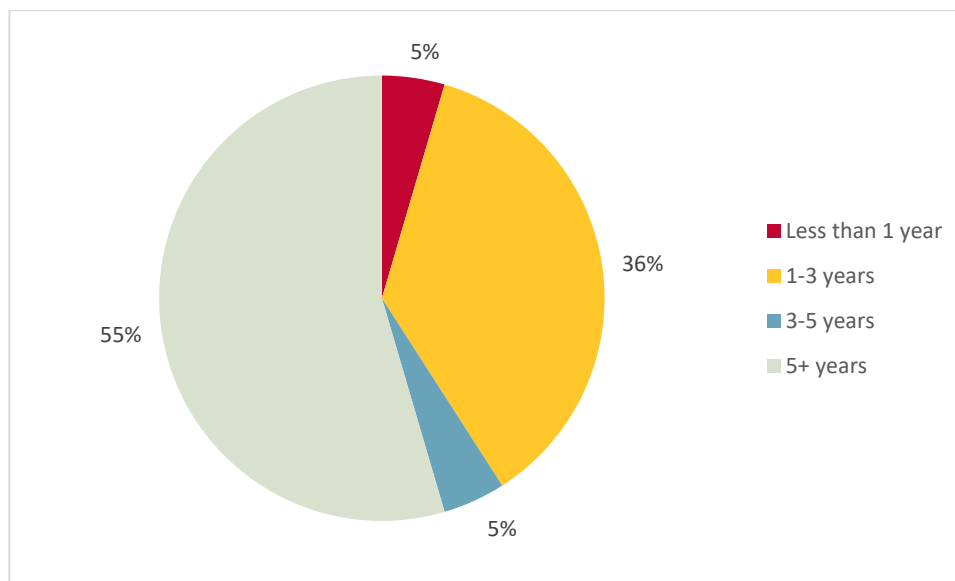


Figure 1

Experience Providing Attendant Services

There was more variation in responses across number of years of experience for attendants who responded to the survey, with 33% of attendants providing less than 3 years' experience, 28% providing 3 to 5 years of experience, and 39% providing more than 5 years of experience.

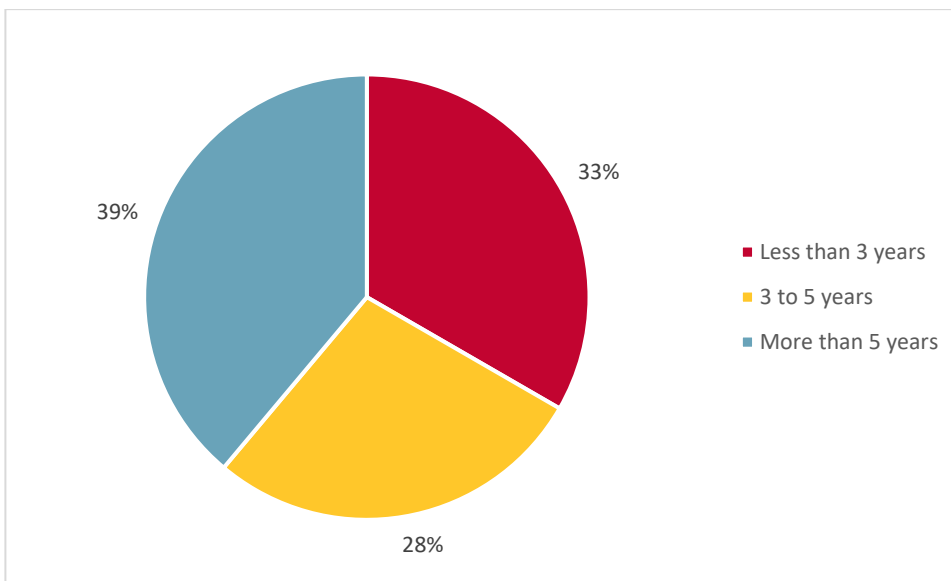


Figure 2

Disability Identity/Descriptor

Forty-five percent of attendant service users described their disability/disabilities as acquired physical, while 32% described their disability/disabilities as congenital physical. Following, 18% of respondents indicated an acquired mental disability, and 9% indicated an acquired communication disability. Additionally, respondents described their disability/disabilities as acquired sensory (5%), acquired learning (5%), congenital learning (5%), acquired cognitive (5%), congenital cognitive (5%), acquired intellectual (5%), congenital intellectual (5%), and congenital mental (5%). Thirty-six percent of attendant users identified as multiply disabled, meaning that they reported more than 2 disability descriptors. Table B presents this data on the following page.

Table B.

Disability Identity/Descriptor Used by Participants

| Disability/disabilities descriptors | Percentage of attendant users who used this description for their disability/disabilities |
|-------------------------------------|---|
| Congenital Physical | 32% |
| Acquired Physical | 45% |
| Congenital Mental | 5% |
| Acquired Mental | 18% |
| Congenital Intellectual | 5% |
| Acquired Intellectual | 5% |
| Congenital Cognitive | 5% |
| Acquired Cognitive | 5% |
| Congenital Learning | 5% |
| Acquired Learning | 5% |
| Congenital Communication | 0% |
| Acquired Communication | 9% |
| Congenital Sensory | 0% |
| Acquired Sensory | 5% |

Attendant service users who responded using the open-text box option, described their disability/disabilities as cerebral palsy and spinal cord injury and/or atrophy.

Funding

When we asked attendant services users about funding for their attendant services, respondents reported receiving attendant services through a community care access centre (41%), self-managing and receiving direct funding to hire and train their own attendants (36%), living in a supported living unit and provided attendant services through an agency (27%), and receiving support from non-formal services (18%).

Living Arrangements

When attendant users were asked about who they live with, 41% indicated living with family members, 32% indicated living alone, 14% indicated living with (a) partner(s) and/or spouse(s), and an additional 14% indicated 'other'. Those that indicated 'other' described their living arrangements as either receiving part-time care, living with children, or living with a partner in a group home.

Relationship Status

When attendant users were asked about their relationship status, 59% indicated they were single, 32% indicated they were partnered, 5% indicated they were in an open relationship, and 5% indicated they were polyamorous.

Sexuality and Access Survey

Sexuality and Sexual Support in Service Agreements and Job Contracts

Sixty-eight percent of respondents using attendant services and 75% of attendants told us that sexuality or sexual support has *never* been a part of any service agreement they have signed.

The Right to Ask for Sexual Support/Attendants' Right to Refuse Sexual Support

Forty-one percent of attendant users reported having conversations previously about their rights around asking for sexual support, including what they can and cannot ask for in a service agreement. Similarly, 45% of attendants reported being told about what services they are required to provide and what services they can refuse when it comes to sexuality and sexual support.

It seems however, the experiences respondents spoke to were often informal. For example, one attendant shared *"No authority has ever spoken to me about this, but I have spoken with my clients often about supporting them and we've discussed boundaries."*

Should Attendants Be Required to Assist with Sexual Expression?

When asked if attendants should be required to assist with sexuality and sexual support, attendant users and attendants somewhat disagreed as demonstrated in *Figure 3*.

While 55% of attendant service users think attendants *should be required* to assist with sexuality and sexual support, only 5% of attendants agree. Along the same lines, 9% of attendant users compared to 30% of attendants *do not think* attendants should be required to assist with sexuality and sexual support.

Do you think attendants should be required to assist with sexuality and sexual support?

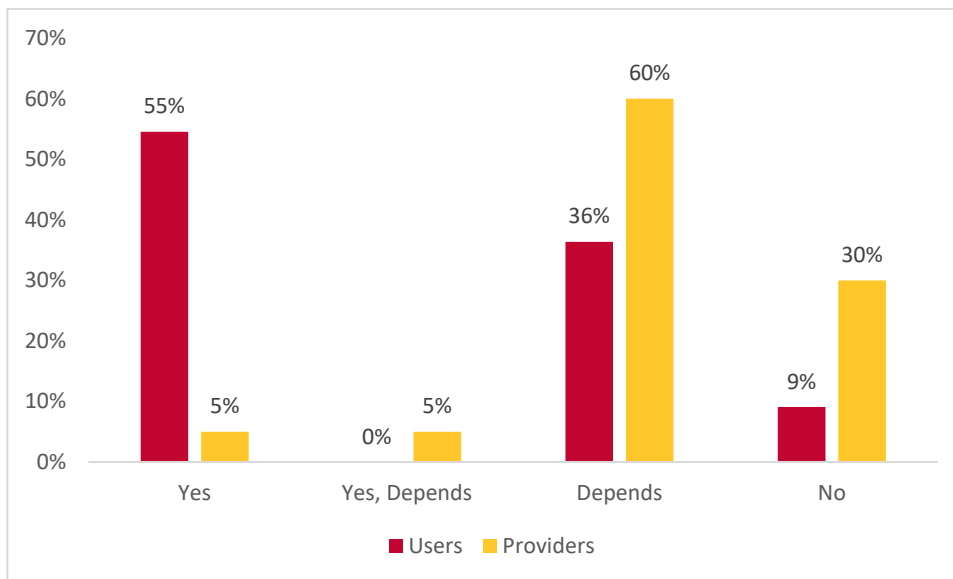


Figure 3

We do see, however, that 36% of attendant users and 60% of attendants believe that assistance is dependent on the situation. Very few participants selected 'yes, depends', with no service users and only 5% of attendants. When examining respondents' qualitative responses, respondents debated the ethics about requiring assistance for sexual support, potentially providing some insight into the disagreement we saw among respondents. One attendant user, for example, shared:

"I don't like the word "required" when speaking about sexual support."

Others acknowledged the complexity of the topic. One attendant user, for example, shared: *"I'm unsure right now. I don't think everyone should be *required* to provide these services, but I do think that there need to be options available for this, where everyone is informed and most importantly where users are safe and supported."*

Further, demonstrating the complexity of the topic, respondents discussed the implications of not being able to access their sexuality, with one user acknowledging the hypocrisy of sexual support being excluded from attendant care.

"Should be viewed as a need just like eating and shelter"

Comfort Levels in Talking About Sex with Attendants

Figure 4 highlights that 64% of attendant users and 65% of attendants reported feeling comfortable discussing the topics of sexuality and sexual support within the service provider context.

However, while only 5% of attendant users reported feeling uncomfortable discussing these topics within the service provider context, a quarter of attendants reported feeling uncomfortable (25%).

Are the topics of sexuality and sexual support subjects that you have ever, or would ever, feel comfortable discussing within the service provider context?

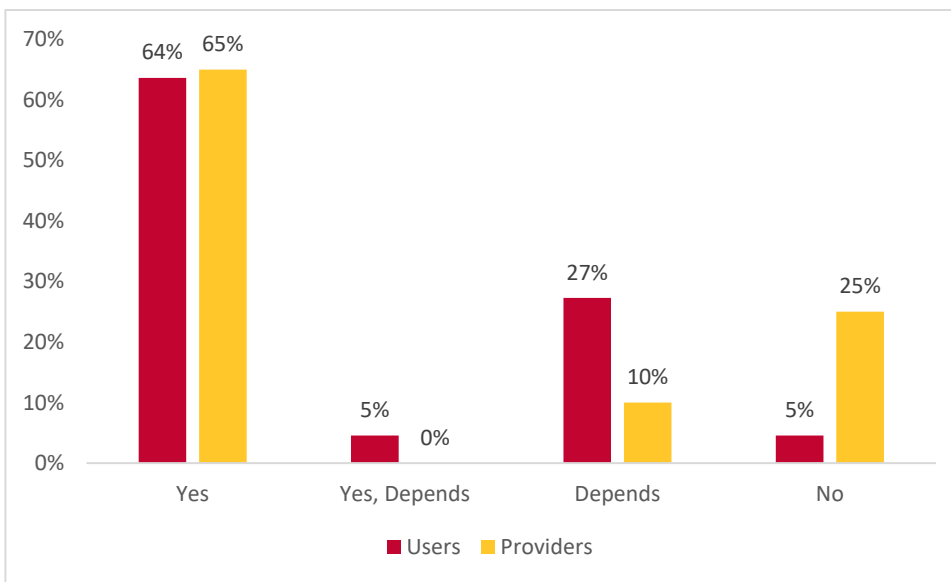


Figure 4

Further, 27% of attendant users and 10% of attendants reported that their comfort levels varied. Both attendant users and attendants provided some insights into when and why their comfort levels may change. Very few participants selected ‘yes, depends’, with no providers and only 5% of service users.

For example, attendant users shared how their comfort level depended on their rapport with their service provider.

“It would really depend on the attendant and whether it felt to me like a safe environment to discuss it.”

“It would completely depend on the person and how closely I am matched with age and personality.”

One attendant user also shared how considerations involve others outside of the service user-provider relationship:

“With that said, it is a very difficult conversation to have. It is one that [must] also consider the privacy and respect of the partner. It is not an easy relationship to manage.”

Attendants also highlighted how comfort levels can be built with time. Further, attendants noted that education and training can act as facilitators for comfort. For example, one attendant shared:

"I'm okay talking about it, but I am not yet comfortable with providing the service. I think proper training should be attained to maintain professionalism between client and caregiver."

Additionally, we asked attendant users whether they have ever worked with an attendant that they have felt comfortable talking to about sexuality and sexual support. Ninety percent of attendant users reported having at least one attendant where they felt comfortable talking about these topics with.

While the majority of attendant users reported at least one comfortable working relationship, users indicated preference for relationships outside of the service provider context to discuss sexuality supports, and felt they often provided a safer space for discussions. One user shared for example:

"It's a bit of a mix. Because [I]ve only really regularly accessed informal supports who tend to be friends/etc. or folks [I] know in-community, there can sometimes be more openness or feeling of safety there which [I] haven't experienced elsewhere, particularly as a fat queer and trans crip."

Users were also asked "if you do not feel comfortable talking to attendants about sexuality and sexual support, what do you think an attendant could do to make you more comfortable?"

Overwhelmingly participants' responses indicated preference for attendants to initiate conversations.

"If they were already knowledgeable and initiated the conversation, I would feel comfortable talking about it. I would not feel comfortable initiating the conversation without knowing that they are comfortable with it."

Users also shared some ways attendants can break down barriers including being upfront about boundaries, checking in regularly, and talking about it as part of the work. They can also make friends with the attendant user to build rapport.

Conversations between Attendants and Clients about Sex

Attendant service users and attendants reported differing prior experiences related to discussing sexuality and sexual support within the service provider context. For example, while 81% of attendant users have talked about these topics previously, only 55% of attendants have, as demonstrated by *Figure 5* on the following page.

Have you ever talked about sexuality and sexual supports within the service provider context?

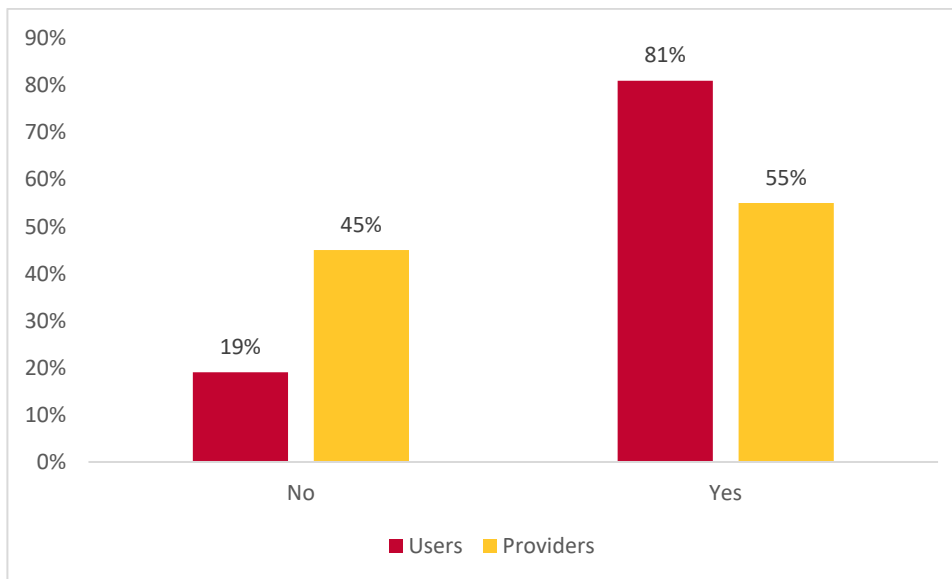


Figure 5

While this question helps understand whether these topics are being discussed within the service provider context, it doesn't provide insights into the frequency these conversations are happening. In fact, when probed, users' experiences varied from only two times ever during any attendant care relationship to this discussion occurring with every service provider they've encountered.

Additionally, attendants have noted that topics have varied. For example, one provider shared that they discussed the broader topic of sexual support within the service provider context, but not regarding their own relationship with the client.

Examples of Sexual Support

We asked survey respondents about the kinds of sexual support they have requested or received. *Table C* on the following page presents these findings.

Table C.
Examples of Sexual Supports

| Examples of Sexual Supports | Percentage of attendant users requesting this sexual support | Percentage of attendants who received requests for this sexual support |
|---|--|--|
| Dressing up as a form of sexual expression (e.g. leather, lingerie). | 13% | 18% |
| Finding, calling, or arranging for a sex worker/escort. | 56% | 29% |
| Going into online dating or chat rooms. | 6% | 41% |
| Going out on a date. | 63% | 53% |
| Going out to clubs to flirt, dance, socialize. | 31% | 24% |
| Going to a strip club. | 19% | 18% |
| Going to an event in the lesbian, gay, bisexual, trans, or queer community. | 13% | 18% |
| Going to workshops or trade shows about sex. | 38% | 24% |
| Helping with vocabulary, supporting you to find people to talk to, and opportunities to communicate about sexuality and intimacy. | 6% | 18% |
| Positioning for sexual activities with (a) partner(s). | 56% | 12% |
| Positioning for solo sexual activities (e.g. masturbation). | 31% | 59% |
| Purchasing a sex toy. | 25% | 18% |
| Purchasing resources about sex (e.g. books, DVDs, websites). | 31% | 18% |
| Renting/ purchasing erotica/ pornography. | 25% | 35% |
| Using a sex toy. | 31% | 24% |
| Watching or reading erotica/ pornography. | 13% | 24% |

Influence of Sexual Orientation and Gender Identity on Sexual Support

Attendant users and attendants had somewhat different experiences when asked whether sexual orientation, gender identity, or sexual interests have made it easier or more difficult for them to talk about sexuality and sexual supports.

For example, as highlighted in *Figure 6*, 43% of attendant users indicated ‘yes’, that sexual orientation, gender identity, and sexual interests have impacted discussions around sexual supports, while only 10% of attendants shared the same perspective. Similarly, 29% of attendant users indicated ‘no’, that sexual orientation, gender identity, and sexual interests *have not* impacted conversations around sexual supports, while a much larger 70% of attendants shared the same perspective. Additionally, 29% of attendant users and 20% of attendants indicated that sexual orientation, gender identity, and sexual interests have impacted discussions around sexual supports.

Has sexual orientation, gender identity, or sexual interests made it easier or more difficult for you to talk about sexuality and sexual support?

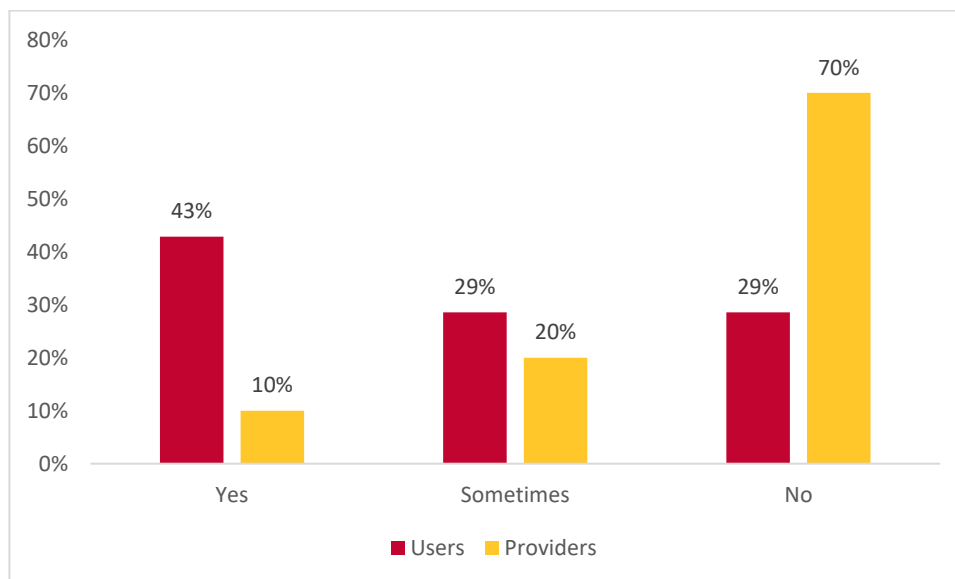


Figure 6

Even if respondents did not have their own experiences they could speak to in which sexual orientation or gender identity made it easier or more difficult, they still acknowledged that sexual orientation and gender identity were intertwined with sexual support, such that, one’s identity or orientation could influence discussions around sexuality and sexual support.

For example, one attendant user shared:

“having some similarities with folks has definitely helped create a more safe environment around this stuff.”

While, one service provider, shared:

“If my client was heterosexual and I am of the opposite sex it could make the discussion slightly different.”

Consequently, attendant users reported disclosing their sexual orientation, gender identity, or sexual interests only when needed. Two attendant users shared for example:

“Of course when I think it's appropriate to have an escort with me”

“I will when I need to.”

A service provider also noted additional factors beyond gender or sexual orientation that have influenced discussions around sexuality and sexual support, such that *“Their religion or home situation may have been an obstacle, but not their gender or sexual orientation.”*

Conflicts between Attendant and Service User Desires and Expectations

Survey respondents reported varied experiences when asked if they have ever experienced conflict or disagreement regarding sexuality or sexual support within the attendant service provider context (findings presented in Figure 7 below). For example, 59% of attendant users compared to 20% of attendants reported experiencing conflict or disagreement.

Have you experienced conflict or disagreement in regard to sexuality or sexual supports within the attendant service provider context?

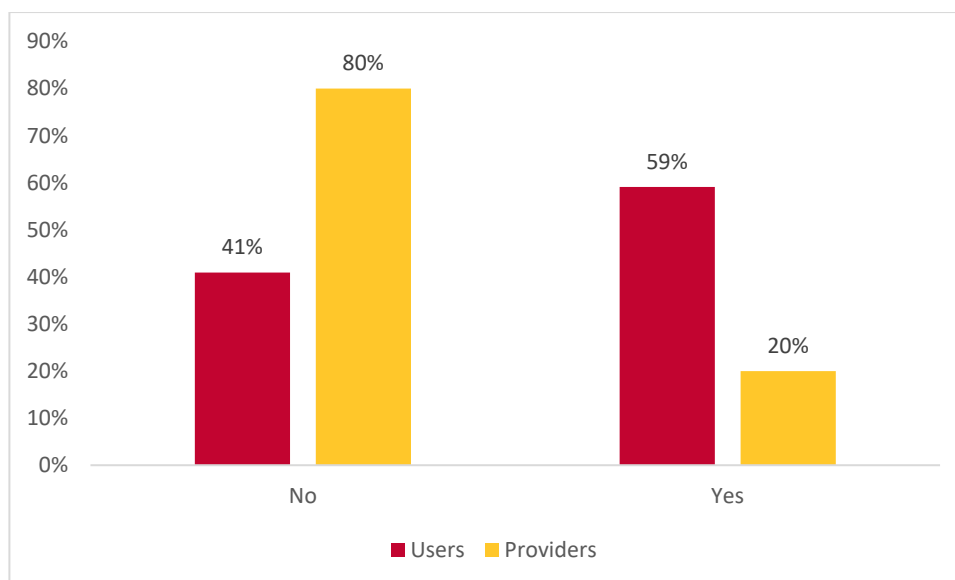


Figure 7

Further, attendant users reported variability in the frequency of conflict or disagreement, from one interaction, to once in a while, to on a regular basis.

There were also differences in experiences regarding the degree of conflict. For example, one attendant user shared their experience as *“unpleasant”* while an attendant shared *“Occasionally boundaries have been overstepped but it was nothing a conversation couldn't fix”*.

Attendant users were also asked “Do you have a story of your own experience where you asked for sexual support and the request was refused?” Forty-five percent of attendant users indicated that they did have a story of their own experience where their request for sexual support was refused, while 55% did not. However, while attendant users may not have their own stories where a request was refused, they have heard “*many tales*” shared by others.

How Safe Do You Feel Talking about Sexual Support?

As demonstrated in Figure 8 below, 36% of attendant users and 11% of attendants reported having felt unsafe, unsure, or in danger when trying to negotiate for sexual support within the service provider context.

Have you felt unsafe, unsure, or in danger when trying to negotiate sexual support?

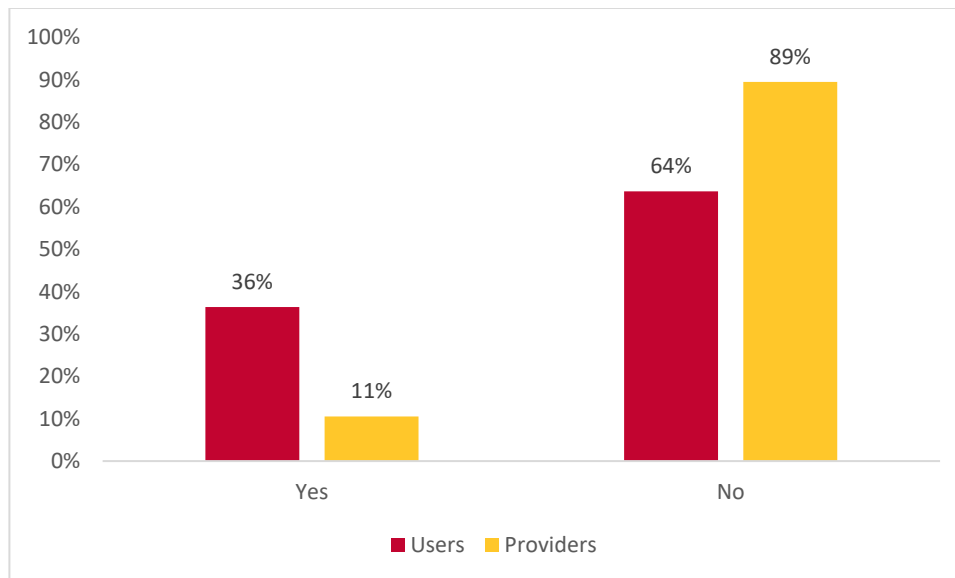


Figure 8

Attendant users and attendants alike shared they do not engage in discussions or look to exit conversations, when feeling unsure or unsafe.

Users highlighted some of the contributors and consequences from their experiences, including power dynamics, ingroup bias (that is favouring one’s own group and/or devaluing a group to which one does not belong; Hewstone et al., 2002), and potential impact for future service provision.

*“Although having a shared identity doesn’t guarantee a smooth experience, this has for sure happened when it’s an attendant who [I] didn’t share community with (but it’s also pretty exposing when it *is* someone [I] share community with lol). There’s a lot of assumption about crip sexuality (or the supposed lack thereof), what we should/n’t be into/ etc. Navigating that stuff with folks who don’t have any experience in queer and especially trans community, can be scary.”*

“They have all the informational, physical, and social power; what if my funding was threatened by a mis-step or accusation, real or not?”

How Employers, Organizations, and Agencies Could Better Support Attendants

A little over half (53%) of attendants reported never receiving training or instruction on sexuality and sexual support as it applies to their work as an attendant.

For those who did receive training or instruction on sexuality and sexual support within the service provider context (47%), it seems that many of the experiences took place outside of their organization and out of their own professional interest. As one attendant shared:

“The subject is very taboo in my role...it is only addressed if a client demands it be, or a staff is a great advocate”

We also asked attendants whether they have ever experienced any positive or negative consequences after a request has been made by a consumer/client for sexual support. Thirty-two percent of attendants indicated that they experienced either a positive or negative consequence from a request that has been made for sexual support from a client. Attendant’s responses demonstrated consequences for both attendants themselves and their clients. Attendants noted:

“Lots of positive feedback and more work”

“Always appreciative of information/assistance provided”

“Client’s mood and physical challenges improved immensely.”

“Client was able to trial new medication to support him with sexual performance. It also strengthened my rapport with patients, [and built] more trust.”

Additionally, we asked attendants “In your most recent workplace, do/did you feel supported by management and other staff to respond to consumer/client requests for sexual support?” While 75% of attendants do/did feel supported within their organization, 25% of attendants indicated that they did not.

Attendants shared how their organization’s structures and (lack of) policies acted as barriers to feeling supported. For example, one attendant shared that their agency did not have a management team, while another attendant shared how their organization followed bureaucratic procedures. Both users highlighted how these structures acted as a barrier to implementing much needed resources.

“Not really, it took a lot of time to get them on board with it. They wanted to create policies, rules, making sure staff felt comfortable with it.”

Lastly, we asked attendants if there are ways they think their employer or organization could be supporting them better around requests for sexual support. A little over half (53%) of attendants indicated that yes, there are ways they think their employer or organization could better support them, including:

- More education provided or opportunities to engage in self-directed education
- Introducing sexual support topics within signed attendant-user agreements
- Providing clear instruction around job responsibilities
- Fighting misconceptions around what sexual support looks like

Suggestions from Attendants to Other Attendants on Providing Sexual Support

Over half (55%) of attendant survey respondents shared tips with other attendants based off their past experiences, including:

“Be clear and compassionate with your boundaries and respect their right to sexuality while also insisting they respect your right to protecting your own sexuality, physical and mental health.”

“All touch requires consent, ongoing. Explain and clarify.”

“Listen with an open mind. Be willing to try, have a sense of humour, do your own work around your own sexual issues, and leave your personal opinions, beliefs outside the door and pick them up, or not, on your way home.”

Attendants with previous experiences providing sexual support also highlighted the importance of education around sexual health and pleasure. Attendants encouraged others to learn and implement sex-positive approaches to care, including the Permission-Limited Information-Specific Suggestions-Intensive Therapy (PLISSIT) model as recommended by one attendant.

The Importance of Research and Education Related to Sexual Supports within and Beyond the Attendant Care Provider Context

Attendant users and attendants alike highlighted the importance of researching sexual support and the implications it can have within the service provider context.

For attendant users, they reported experiencing barriers to accessing their own sexuality. For example, one attendant user highlighted that while sexual support may not be a part of their care, access outside of their care may also be limited, due to barriers such as the criminalization of sex work. Attendant users highlighted how these barriers are perpetuated by stigmas around sexuality that are harmful to individuals with disabilities. In response, attendant users and attendants highlighted the importance of discourse and education to disrupting the status quo and normalizing these topics.

“I think it's critically important that these discussions are happening. We need to teach staff to leave their own values at the door and remember the focus is on the client. We need to learn to stop "medicalizing" people's need for sex.”

Interviews

Data Analytic Approach

We conducted a Thematic Analysis to analyze the interview data. Thematic Analysis is a strategy of looking for patterns of meaning, called "themes," in qualitative data (Clarke & Braun,

2017). Thematic Analysis allows us to find common patterns among the interviews, but it can also be used to look at individual experiences as well (Braun & Clarke, 2021). Further, Thematic Analysis can help address questions around people's experiences, with particular focus on specific groups like those with disabilities, while also considering how societal and cultural factors influence their experiences (Braun & Clarke, 2021).

To conduct a Thematic Analysis, we followed the steps as suggested by Braun and Clarke (2006). These steps involved familiarizing ourselves with each transcript, looking for interesting features in the data (called "codes"), and grouping features into potential themes (Braun & Clarke, 2006). However, as noted by Braun and Clarke (2006), the process was iterative, meaning that we moved back and forth between each step to make sure our themes were captured by what participants said (Braun & Clarke, 2006).

The dataset was coded and analyzed within Microsoft Word to allow for features such as commenting and highlighting extracts of the transcripts.

Themes

When we set out to conduct this research, we were originally interested in understanding the experiences and needs of attendant service users in regard to their sexual health and sexuality within the attendant service provider relationship. During data collection, however, participants overwhelmingly shared experiences and needs in regard to their sexual health and sexuality that transcended the attendant service provider relationship. We felt when creating themes, it was important to still include these experiences and needs, even if they did not directly address our research questions. Similarly, to Braun and Clarke (2023), we felt the need to embrace the shift in focus because we recognize that the attendant service provider relationship does not exist in a vacuum and operates within a larger sociocultural context.

Eight themes were generated from our list of codes that we identify as either barriers or facilitators to accessing one's own sexual health and sexuality. It should be noted that themes are not presented in order of importance or relevance.

Barriers to Accessing One's Own Sexual Health and Sexuality

Misconceptions that Individuals with Disabilities are Non-Sexual

Participants overwhelmingly shared how stigmatized attitudes towards individuals with disabilities acted as a barrier towards accessing one's own sexuality and sexual health. These attitudes and stigmas existed structurally, publicly, and internally.

First, participants discussed how structural stigma (i.e., societal, cultural, and institutional practices) impacted their access to their sexuality. Participants shared their experiences with ableism within various contexts, including healthcare and attendant care. These biases revealed themselves in the forms of treatment by medical staff and professionals and through access to care. Participants shared stories of how they were infantilized and desexualized by providers, including being treated with condescension and staff disregarding their preferences for care. However, these experiences are not always as overt.

"I was in a relationship, and I had a box of condoms in my closet [...] it wasn't hidden, but it also wasn't just like out in plain sight, [and] she asked me if I would mind hiding them somewhere because it made her uncomfortable [...] and so me being nosy I was like well, 'Sure, but why does it make you uncomfortable? Like do you have an issue with me like having sex'? And she

said 'No'. And then I said, 'Well do you have an issue with me having safe sex'? And she said 'No'. And she honestly couldn't give me an answer. [It] just made her uncomfortable."

Participants also highlighted how bias impacted their access to care. Participants highlighted how accommodations for medical testing and procedures were often an afterthought. For example, multiple participants shared difficulty accessing STI testing, due to providers hesitancy or lack of ability to test for STI's. Participants shared that at the center of these experiences is the perception that individuals with disabilities are non-sexual. This misconception acted as an attitudinal barrier for participants in accessing their sexual health and had potential health repercussions.

"For 10 years I was having unprotected sex. [I] didn't get tested, cause the first time I went to the [health clinic] I said, 'Oh, I had, I had somebody [give] me a hand job. Should I get a test?' And the nurse was like, 'Oh no, you don't need that. You'll be fine.' [...] I was like, 'OK, well, I guess I won't test. The nurse told me no, so I guess I'm OK.' And so, for years I just had sex and didn't worry about it because I was like, 'OK, they told me I'd be fine.'"

Participants also shared experiences in which they encountered negative attitudes from the public, including experiences with their peers and sexual and/or romantic partners. Similarly, participants shared how the public perceives individuals with disabilities as non-sexual.

"One time we kissed in public and there were a few teenagers [...] and they go, 'I think they kissed? Oh, they can do that?' And I said, 'Oh, and sometimes we have sex too.'"

In response to these pervasive beliefs, participants shared the emotional labour they take on advocating that they are sexual beings.

"It's exhausting to constantly have to prove to you that I'm also a sexual person. It's really tiring ... you constantly have to put on this air of 'Oh, no, it's OK. Your ableism is totally fine. Doesn't bother me one bit.' And then they leave, and you break down, 'cause you're safe to do that. But when they're there, you have to pretend like it's no problem. It's no big deal."

Participants also shared how these stigmas have been internalized. Some participants spoke about how they believed that sex wasn't for them or that sexual feelings were unnatural. Others shared experiences in which they encountered ableism from other individuals with disabilities. For example, one participant shared a sexual encounter with another individual with a disability: *"And then so when we were done, I said, like, 'Do you want to hang out? Do you want to go on a date?' [...] and he said, 'Oh no, you're too disabled for me, you're too much work.'"*

The Exclusion of Disability within Discourse on Sex and Sexuality

Participants shared when growing up, there was no discourse (i.e., written or verbal communication) or education around disability and sexuality. Participants noted that often the only sex education they received was through schooling. However, participants highlighted how the curriculum lacked an intersectional lens, as it assumes heteronormativity, able-bodiedness, and neurotypicality. This gap left participants wondering about sex in the context of their disability.

"It was, like, showing with a banana how to put a condom on. And I was like, 'OK, how does somebody that can't use their hands put the condom on?' [...] things like that weren't visible." Consequently, one participant shared how they didn't pay attention to the information presented. Others shared how they were either dismissed from sex education or left out of it altogether, due to prevailing myths about individuals with disabilities being nonsexual.

“There’s, like normal, like high school health class thing, but even that, it was weird ... I don’t know [if] this is true, so, but to my recollection, it was almost like, well, you don’t need to do this. You don’t need to know this so ... you don’t have to be in this class.”

Another participant shared similar sentiments, as they were given the option to leave sex education class. They noted at the time they wanted to have a “free period” however, they later came to regret their decision as they had little knowledge of safe sex practices, which left them at risk for STI’s and sexual abuse.

Further, participants shared how the exclusion of disability within discourse on sexuality continued beyond and outside of educational institutions. For example, participants reported experiencing physical and attitudinal barriers to accessing spaces that encourage discourse on sex and sexuality, such as queer clubs and kink groups. Participants shared how this often left them excluded from participating in said spaces.

“And it speaks volumes that in every queer club that I’ve had access to, I’ve had to go in through the garbage chute [...] it tells me that they don’t give a shit that I’m there and they could care less.”

This occurs not only in physical spaces but in virtual spaces as well. Many participants emphasized the significance of the internet, social media, and pornography as avenues for learning about sex and sexuality, due to its accessibility. However, they all noted how individuals with disabilities were invisible within said spaces. One participant, for instance, highlighted the absence of disability representation within the “gay aesthetic” that is perpetuated within queer social media and how this left them feeling further excluded from the community. Additionally, participants pointed out how virtual sources often perpetuate misinformation and unrealistic notions about disability and sexual expression. One participant shared how they try to challenge and dispel misinformation:

“I was like, Jesus, like, we should put this on Pornhub, because if you go on Pornhub and type in quadriplegics [...] it’s terrible trope shit. And what we’re doing here, it’s pretty hot.”

Impacts of Western Medical Understandings and Practices Related to Disability, Sexuality, and Bodies

Participants noted experiences in which their bodies have been medicalized¹ by healthcare and/or service providers. The core themes participants shared were around touch and privacy and how that impacted their experiences of pleasure.

Participants discussed the disconnect they feel when it comes to touch and pleasure. For them, they noted how touch is often associated with pleasure, yet they reported experiencing frequent touching by providers, often at the provider’s discretion. Furthermore, participants acknowledged how this normalized overstepping boundaries when it comes to touch.

“Because I think for a lot of kids, when you see so many doctors and so many specialists, they touch you without even thinking [...] But wouldn’t it be great if the doctor stopped and said, ‘Hey, is it all right if I touch you now?’”

Participants discussed how these experiences have impacted their experiences and understanding of pleasure. For some, they experienced heightened or misplaced pleasure with experiences of touch, while others discussed losing the feeling of pleasure altogether.

“It’s something that [I] call being touched out constantly; being touched with gloves and with care and touched in ways that are not – that are not rough but they’re not pleasant either. And you just deal with it because it is what it is, but it doesn’t mean you like it. So, when you get touched with desire, that can be overwhelming.”

“But that happens a lot now with my body. And [I] feel shame around that [...] When we think about orgasm, when we think about climax, where you immediately think about, ‘Oh, pleasure – you brought yourself there’. And so, I’m experiencing kind of the other way of there’s no pleasure there, there’s no excitement.”

Participants also highlighted their loss of privacy, often due to the intimate nature of the working relationship between service provider and user. One participant noted their experiences of discomfort as an adolescent going through puberty, and how it is normalized within the service provider context.

“Man, I remember especially [as] a younger guy going through puberty and having all these random people bathing me. It like, it – it sucked. It was a horribly uncomfortable experience, right? You just get used to it.”

Other participants shared similar sentiments about the discomfort they sometimes experience within their care. One participant further noted how this discomfort led them to dissociate from their body.

“You reach this place of really stark disassociation [...] you’re like, ‘OK, well, washing my genitals now...’ I guess – I guess I got to check out for a minute [...] It just becomes a part of care. So, when somebody touches with desire, that’s like, ‘What the fuck are you doing? What’s this?’” Participants described several emotional impacts that these experiences have had on them, including feelings of betrayal and shame.

“I feel like my body betrays me a lot. And it’s really, it’s really hard to put that into words. But it’s true. I feel like my body really doesn’t let me have even those moments of joy anymore. And it’s kind of like, how do you live in a body that doesn’t ever do what you want it to do [...] And so that that’s what’s hard about it is that even though I can still ejaculate, I can still do the things physically – I can’t enjoy it.”

Navigating Systemic Barriers and Potential for Harm

Participants highlighted that discussing sex and sexuality can potentially carry a lot of risk, particularly within the service provision context. Some participants shared a hesitancy to request sexual support from service providers, despite wanting to, out of fear that their request might be misconstrued as inappropriate, potentially impacting their future care.

“I’m terrified of people misunderstanding what I’m saying [...] If I do ask and they’re [like] ‘Eww, what the hell!’ [...] I have this vision of it spreading.”

Participants acknowledged that gender and sexuality are intertwined with requesting and providing sexual support. For one participant who is not out, they shared concern about their providers maintaining confidentiality about their sexuality. They mentioned a hesitancy to disclose their sexuality within the service provision context due to assumptions of heterosexuality and being unsure as to how accepting attendants are of queer sexualities.

"I still get PSWs who I haven't come out yet to. Because I don't plan on, to this particular one. But, the individual goes, 'Why don't your girlfriend's ...' like [you] have to play that off and [that] just gets uncomfortable."

Further, participants acknowledged a unique power dynamic between themselves as users and attendants who are providing the care. For one participant, they highlight their hesitancy to request sexual support due to the gender imbalance within the working relationship. *"Every one of them is a female who's had nothing but dick thrown at them all their lives."*

Others spoke about how they were quite open about sex and sexuality and felt comfortable broaching these topics with their service providers. In discussions with them, it became clear that having agency over hiring service providers provided some security. Unlike those who were fearful of requesting sexual support assistance, those who could choose to hire like-minded individuals could thereby minimize potential risk.

"Getting back to being able to – to hire my own staff [and] find people that are a good fit [...] it would be more awkward to ask my caregivers to help me with sex toys and whatnot if they were, you know, 80 years old and reminded me of my grandma. Right? Like [it's] nice that I [have] the ability to hire people that are around my own age and - and so that that makes me a lot more comfortable as well."

Beyond the service provision context, participants shared that they rely on sexual partners for support sometimes because it was too risky to ask their service providers. However, participants shared how this left them at risk financially, legally, physically, and emotionally.

For one, participants acknowledged how accessing sex work has a lot of risk associated to it due to its legal and financial barriers. Participants acknowledged legislation within Canada that makes seeking sex work illegal criminalizing individuals with disabilities who seek out support. Further, participants acknowledged how limited governmental income support meant limited access to receiving sexual support through these means.

"It's like the wild, wild west of sex work [and] it's still seen as this dirty, inappropriate thing where a lot of disabled folks use it to have their needs met."

Participants also shared how seeking sexual partners has risk associated, including potential for abuse. For example, one participant recalls a sexual encounter in which the sexual partner walks out and almost leaves the participant without support (such as getting back in their chair and getting stuck in the door). The participant later in the interview acknowledges that if they had sexual support from a service provider, they believed that this interaction would not have impacted them as much, as the sexual partner would have been able to leave instead of needing to stick around for support.

"I'm realizing that [I] had to rely on others, on sexual partners, for a lot of things [...] I feel like they have to be totally on board [and] a lot of it falls on the other person, which is tough [...] if they don't have the best of intentions then you're just super vulnerable."

This vulnerability extends beyond sexual partners that do not have the best of intentions to also include loved ones who they trust and support. For those having established trust in long-term relationships, while participants appreciated their partners' reassurance and support, they also expressed concerns or doubts from relying on their partners for physical assistance. For example, one participant discussed their distress on relying on their partner for lifting, transferring, and positioning.

“I want my partner to feel like we're [in] a relationship together and, like, sometimes I feel like he is doing all the heavy lifting. Although pun intended, as well [...] I don't know if he's getting as much out of the experiences [as] I would hope that he would. So, I think that's how it affects me now. Knowing that I have to rely so much on the other person in the relationship [for] sexuality stuff.”

Facilitators to Accessing One's Own Sexual Health and Sexuality

Using Humour as an Icebreaker When Discussing Disability, Sex, and Sexuality

Participants reported using humour when discussing the relationship between disability and sex and sexuality. Participants acknowledged that initiating discussions around disability, sex, and sexuality can be scary for both service attendant workers and users and shared that humour can be used as a tool to help “break the ice”. Participants highlighted that initial discussions around disability, sex, and sexuality can be awkward and uncomfortable, but suggested that once the “ice is broken” it helps to relieve some of the awkwardness. Participants also noted that often discourse around disability, sex, and sexuality is seen as heavy and serious. Therefore, participants suggested using humour to lighten conversations.

“Over time, I've learned that the best way to feel comfortable about something is you [have] to talk about it and to make it less of a serious topic and make it more fun and sometimes comedic. And then I think that really helps me through those awkward stages or awkward discussions in life.”

One participant put forward that some of this fear is driven by misconceptions of what sex means when you are disabled. They highlight that sex when disabled are seen as “work”, and to dispel these misconceptions we need to make these discussions more fun.

“And once you broach that fear and make it a joke and play with it a little bit, then it becomes less scary. That's not always easy to do. But I think it's so heavy, this discussion of sex and disabilities – so, like, intense all the time and it needs to be a little bit lighter and [if] anything we need to find avenues to make it fun ... I think when people think about sex and disability, they don't think fun. They think [it's] work.”

Co-constructing the Meaning of Care in the Attendant Provider Relationship

Participants recognized the unique dynamics of the attendant provider relationship. For one, participants recognized that this is a working relationship – in which both attendant service workers and users may abuse their power over one another. Second, participants acknowledged the intimate nature of their working relationship, as they often received care for daily living activities, such as bathing. Even so, sexual support is often not included in the understanding of care in this relationship, often out of fear of abuse. Yet, this can leave participants at a loss as to how to access their own sexuality.

“But I think the fear of, again, the abuse, it'd be on both sides, is too scary for them to even broach. So, they don't even bother touching it because it's too - they're just there to provide care. That's it. Nothing else. Goodbye. And I - so I get it. I understand where that comes from, but it leaves [the] client, at a loss for support when they want to access [their] own body and own sexuality.”

Therefore, participants suggest that attendant workers and users need to work together to co-construct what care means. Participants noted several challenges to incorporating sexual support within their care, noting that sexual support is often misunderstood. For example,

participants shared that sexual support is often misunderstood as sexual assistance. As one participant shared *“some of my buddies, they dream about [how] amazing it would be to be in a wheelchair and have the caregivers helping them and [give] like sponge baths and – and sex toys. And it’s like, ‘No, it’s not like that man.’”*

It also was emphasized that sexual supports exist on a continuum and are not an either-or situation. Participants acknowledged that both attendant workers and users will have different comfort levels with supporting and receiving sexual support. One participant, shared for example, how some providers were comfortable with them using sex toys, but were uncomfortable assisting with said use of the toys, while others were not. This participant later highlights how they broach negotiating sexual support within their care while both challenging misconceptions with respecting boundaries.

“I just broached it like a part of care. Like, I never say, ‘You’re helping me get off’ [...] I say it very clinically like, ‘I’m testing a product now. Can you put me in bed and give me the product and then come back in 20 minutes? Bye. Thank you.’ Like, I keep it very boundaried, so they feel safe and so that I’m not crossing anything and so that it’s comfortable for them.”

Similarly, across participants, communication was viewed as essential to clarifying misconceptions and fostering a safe space to negotiate care. Participants highlighted that transparency, agency, and safety are central to successful communication. First, participants highlighted how clear communication of their needs and boundaries is central to negotiating sexual support. Further, communication skills can ensure that requests are communicated in a safe and non-threatening way.

“I can’t get to masturbation though without somebody else helping. So, I’m gonna ask for help. So, [I] learned communication techniques and learn how to not be a douchebag - [to be] not threatening and how to be ethical.”

Rapport building and psychological safety were further acknowledged by participants as essential to fostering clear and safe communication. Participants highlighted that they would not feel comfortable discussing sexual support if they felt it was unsafe to do so.

“Like they’re helping with activities of daily living, so I think, [if] they just they made it known that they were comfortable having those conversations. But it’s weird, because they [can’t] automatically jump into that topic right away [...] So, like, I think there has to be a rapport there.”

Participants also highlighted how external parties can support the safe negotiation of sexual support within the attendant-client relationship. Participants suggested training, certifications, and formally integrating conversations within the intake process. Participants highlighted how training and certifications not only provided education, but reassurance for their comfort. *“I don’t know why that piece of paper makes it better. In some way, [it’s] knowing that they were open”.*

“Let’s say you ask someone who is just like a regular PSW, that could be risky for – for both individuals. So yeah, [I] would say, I’d feel more comfortable asking if, if they did complete that hypothetical training.”

Further, participants highlighted how the initial intake meeting is *“as good of [a] place as any to have that conversation”* as other aspects of care are already being discussed and negotiated.

Further, it was suggested that the process could be overseen by an external party who could match service users with providers based on their matching interests.

Lastly, central to the co-construction of care, is the framework or approach taken. Participants highlighted two components that should drive the framework: (1) the approach being service user driven and (2) the approach being grounded in the Independent Living Model. One participant shared an example organization that is goal oriented, and therefore focuses on what the service user wishes to get out of the program. As highlighted by the participant, doing so fosters an openness to approach these conversations. Another participant highlighted that without the basic foundations of the individual model from the independent living movement, it makes it much more challenging to engage in discussions about sexual support.

“But if that is like algebra, then we needed to teach the simple mathematics of independent living.”

Representation Matters! Centering Diverse Voices

Participants stressed the importance of applying a disability centric lens within education and discourse on sexual health and sexuality. Participants discussed how various marginalized identities affect people, and ultimately, their sexuality. Therefore, participants emphasized intersectionality as an essential building block to education². One participant discussed, for example, how sex education needs to go beyond simply the “mechanics” of sexuality.

“And before you jump into, ‘And here’s a penis, let’s talk about that’. Like, ‘OK, great’, but until you know all of the things that are connected to the person that’s connected to that penis, like, [you’re] not really getting an education.”

Participants also discussed the need to de-center non-disabled folks in discourse around disability. For example, one participant spoke about the anger they feel seeing non-disabled folks at the forefront of policy decision-making for individuals with disabilities. For them, having no diverse representation meant that false promises were being made and therefore meaningful change wasn’t happening. Another participant spoke about the impacts of the lack of representation within their attendant care.

“Where I live right now, there are a lovely bunch of folks, but there’s not one person in that office that has a disability that I know of. They might, but I’m pretty sure they don’t. And so, because I don’t see myself represented there when I have an issue with my care, I think you have no idea what I need. You have no idea what that feels like. You have no idea what it is [to] need that. So, the care needs a liaison between the disabled client and the care working team, somebody who can be like, ‘OK, I’m disabled, I understand.”

As highlighted, lived experience can foster a shared understanding. Centering diverse voices within decision-making means that an individual’s needs, feelings, and concerns are more deeply and genuinely understood.

The benefits of centering diverse voices in conversations about disability, sex, and sexuality were further highlighted. Participants shared how representation within discourse helped them feel seen, ultimately fostering a sense of inclusion. For example, one participant shared the impact hearing from and meeting their role model had on their self-esteem.

“When I was [a] little kid and met Rick Hansen for the first time I was like, ‘this guy’s freaking cool’ [...] I don’t know if I’d go as far as to call him a hero, but [it] made me appreciate the fact [that] here’s a guy in a wheelchair that people, including myself, are - are looking up to [and] it made me feel just a little bit better about myself.”

Participants highlighted how centering individuals with disabilities within conversations about disability and sexuality offered a non-clinical perspective that countered the frequent medicalization of disabled bodies.

Participants also spoke about the benefits representation has for everyone, including those who do not live with a disability. Participants acknowledged the power that discussions have on normalizing their experiences and to help dispel misconceptions. Further, participants shared how education on disability and sexuality is important for everyone, as it helps to promote dignity and respect.

However, participants also cautioned that when centering diverse voices, it must be done in a way that does not tokenize the individual nor exploit them. Participants shared stories in which they were expected to educate others for free or were severely underpaid. As one participant shared *“Yeah, that’s one of the things they think about in DEI³ spaces. They never want to pay enough. They can’t tell you [how] many times a month I’m asked ‘Hey, could you – could you work for free? Could you just, could you work for 100 bucks? Could you just,’ And it’s like, ‘No, [I] have to feed myself.”* Ultimately, participants discussed the tension they experience between engaging in advocacy work because of its impacts dispelling stigma while also being unfairly compensated for their work.

Disability Knowledge: Expanding Abled Ideas of Sex and Relationships

Participants shared how they resisted western colonial ideas of disability and sex, including the medical model of disability. Participants shared how resistance took many forms, from redefining independence and intimacy to exploring and celebrating one’s sexuality.

Participants shared how ableism perpetuates a myth of independence. Participants acknowledged how dependence is pathologized within Western society and how this impacts their sexuality and relationships, including dating.

“So, it just, it’s hard, because I’m so severely disabled that even the idea of going on a date with somebody, people get scared of the idea of, like, feeding me or me needing help on the date or supporting me, they get really scared. And so, the whole mythology of independence on a date that we’ve kind of cemented in our society, when you go on a date, you’re your own person, you’re independent, you’re showing off your best side. And then for me, it’s like [there’s] a whole other piece to it.”

Participants discussed how abled ideas of intimacy have also impacted their understanding of disability and sexuality. Participants discussed abled ideas of what intimacy means, including spontaneity, independence, and touch. For participants, they discussed how prep work, including transferring into and positioning, can “kill the mood”.

“Like sex is supposed to be in the moment but we can’t do that because there’s a lot of prep work before that [...] Sometimes it puts it off, like the moment is gone because we need to do all these other things that is not sexual that is important for [the] sexual encounter.”

Further, one participant shared how *“able-bodied individuals take for granted having independence”* in regard to positioning and cleaning up from sexual encounters. Participants

acknowledged that able-bodiedness is assumed to be the default and therefore experienced related stigmatization and marginalization. To challenge stigmatization, this involved, for example, exploring one's own internalized stigmas regarding ability and dependence.

"I was forced to confront all my thoughts about disability and what I could or couldn't do."

Touch was also seen as central to intimacy by participants. However, participants reported experiencing barriers to being touched and touching when engaging in sexual activities, such as limited movement or positioning.

"I'm just figuring out, like, even to be with a partner, like, what positions will work and what doesn't. It also doesn't help being on a ventilator and having all these hoses connected to me [can] also limit the amount of, like, positions and whatnot that I can be placed into [...] There's so much about, like, about sex or even just like being with a partner is that intimacy of that touch. And so not being able to, like, independently touch somebody also it's hard, like, those are things that I've learnt from other people with disabilities how they get around that, right? Like, yeah, what do you say to your partner when you would want to be into that or when [there's] cues that I see able bodied people doing, like growing up, and you know? Like, giving their partner a massage, or something like that. And that's just not an option for me."

For participants, exploration of one's sexuality was an act of resistance against ableism as they learned about and redefined their sexuality. This was especially important, given that participants acknowledged that the definition of intimacy should be individualized to that person. Consequently, participants reported celebrating their expanded ideas of sexuality, beyond able-bodiedness and heteronormativity.

"I've had an incredible sex life since I broke my neck. I have better sex than ever before in my life, since I broke my neck and in so many ways, but you know, it took a lot, in the right partners in this life, doing it wrong, figuring [it] out and stuff."

Discussion

Comparison of the 2023 Survey and the Original 2011 Survey

Demographics

Both the 2023 and 2011 survey found that majority of respondents were:

- Young adults to middle age (ages 25 to 44)
- Attained at least some post-secondary education
- Resided in urban areas
- Described themselves as heterosexual

We are unable to make comparisons with the 2011 survey regarding the ethnicity and gender identities of survey respondents, due to either missing data or changed language. Additionally, we found some similarities between the 2023 and 2011 survey respondents when asked about the years they have been using attendant services, source of funding, and living arrangements. However, some differences were found for some response options including:

- While our survey found that 41% of survey respondents had been using attendant services for 3 years or less, the 2011 survey reported only 16% of survey respondents had been.
- While our survey found that 41% of respondents received attendant services through a community care access centre, only 17% of respondents reported so in the 2011 survey.
- While we found that 41% of respondents lived with family members, only 16% from the 2011 survey reported doing so.

Therefore, it's important to note that the comparisons made below with the 2011 survey may not be as reliable due to differences in the years of service use, sources of funding, and living arrangements.

Survey Responses

Sixty-eight percent of attendant users and 75% of attendants told us that sexuality or sexual support has never been a part of any service agreement they have signed. This is somewhat lower than respondents also addressed in the 2011 survey, which found that 93% of service users and 82% of attendants never had sexual support being a part of any attendant service agreement they had signed. It is difficult to know if the current numbers represent any meaningful change over time, however, the significant proportion of attendant users and attendants indicating that sexual supports are often still not a part of service agreements demonstrates an ongoing need for education and resources related to sexual supports.

We also found that 90% of people using attendant services said they had at least one working relationship where they were comfortable talking about sex. This is higher than the 2011 survey which found that only 65% of attendant users reported having at least one attendant where they felt comfortable talking about these topics with. While this makes us hopeful, it should be noted that we found comparable findings regarding comfort discussing topics within the service provision context (64%), suggesting more work still needs to be done.

While we found discrepancies between attendant users (81%) and attendants (55%) in their prior experiences discussing sexual support within the service provision context, this was not observed in the 2011 survey. Instead, the 2011 survey found that 77% of attendant users and 78% of attendants reported having had these conversations within the service provider context. The discrepancies observed in the current survey provide interesting points to explore and address further in upcoming program and resource development phases.

Further, we also found disagreement among attendant users (55%) and attendants (5%) regarding their attitudes towards requiring sexual support assistance. This was not observed in the 2011 survey, which found that 29% of users and 23% of attendants think attendants should be required to assist with sexual support. However, the 2011 and 2023 survey respondents largely agreed that it depends. The 2011 report similarly found that while participants acknowledged everyone's right to sexual support, they also believed that no one should be required to provide it. Exploring contextual factors influencing these differences of perspective within and beyond the attendant care dynamic will be important to explore in the next phase of education and resource development.

Next, when we asked people using attendant services about the kinds of sexual support they have requested or received, the most frequent responses were:

1. Going out on a date: 63%
2. Finding, calling, or arranging for a sex worker/escort: 56%
3. Positioning for sexual activities with (a) partner(s): 56%
4. Going to workshops or trade shows about sex: 38%
5. Using a sex toy: 31%

In comparison, the most frequent responses among attendant users from the 2011 survey were:

1. Being accompanied when going out to clubs: 51%
2. Going out on a date: 46%
3. Positioning for sexual activities with partner: 31%
4. Purchasing a sex toy: 29%
5. Purchasing resources about sex: 28%

When we asked attendants about sexual support they have provided or received requests for help with, the most frequent responses were:

1. Providing or helping purchase resources about sex (e.g. books, websites): 59%
2. Going out to clubs to flirt, dance, socialize: 53%
3. Going out on a date: 41%
4. Supporting a person with a communication disability in communicating with someone (e.g. partner, doctor, teacher) about sexuality and intimacy: 35%
5. Finding, calling, or arranging for a sex worker/escort: 29%

While the most frequent responses among attendants from the 2011 survey were:

1. Going to an event in the LGBTQ community: 37%
2. Positioning for solo sexual activities: 36%
3. Positioning for sexual activities with partner: 34%
4. Going out on a date: 34%
5. Going out to clubs to flirt, dance, socialize: 34%

We found that 43% of attendant users and 10% of attendants agreed that sexual orientation, gender identity, and sexual interests impacts discussions around sexuality and sexual support. This is up from the 2011 survey, which found that 27% of attendant users and 5% of attendants

said sexual orientation, gender identity, or sexual interests has made it either easier or more difficult for them to talk about sexuality and sexual support.

We also found that 59% of attendant users and 20% of attendants reported experiencing conflict or disagreement. This is up from the 2011 survey, which found that 20% of attendant users and 10% of attendants said they had experienced conflict. Although we saw an increase in reported experiences of conflict in the 2023 survey, it does not necessarily indicate disagreements are more likely to occur. For example, the 2011 survey concluded that it is unclear whether a reported lack of conflict represents people agreeing and working in harmony or whether it represents people avoiding conflict. In fact, the qualitative responses from the 2011 survey suggested that attendant users attempted to avoid conflict by hiding parts of themselves. These issues are complex and will need to be further explored and addressed in the upcoming education and resource development phase.

Thirty-six percent of attendant users and 11% of attendants reported in the 2023 survey having felt unsafe, unsure, or in danger when trying to negotiate for sexual support within the service provider context. In comparison, the 2011 survey found that 12% of attendant users and 11% of attendants said that they had felt unsafe, unsure, or in danger when making or receiving a request for sexual support. Even though we saw an increase in attendant users who reported experiencing feeling unsafe, unsure, or in danger in the 2023 survey, this increase could be for a multitude of reasons. For example, it could mean that attendant users are initiating discussions more frequently or that our sample felt more comfortable disclosing their experiences. In the 2011 report they conclude that the low numbers may be because “people only ask for, or provide, sexual support once some sense of safety has been established.”

While we found that 47% of attendants reported never receiving training or instruction, the 2011 survey found that 82% percent of attendants reported never receiving training or instruction on sexuality and sexual support as it applies to their work as an attendant. There was also a decline in attendants’ responses when asked whether they felt supported by management and staff, with 25% of attendants from the 2023 indicating that they did not, from 52% of attendants in the 2011 survey.

Lastly, we found that 59% of attendant users and 55% of attendants reported that they were never informed about their rights around asking for or providing sexual support. This is lower than the 2011 survey, which found 94% of attendant users had never received any information about their rights to make requests for, or receive, sexual support, while 82% of attendants had never received information or training about their rights to provide or refuse sexual support.

Contextualizing our Interview Findings

Below we present several themes that emerged across interviews and the 2023 and 2011 survey.

Ableism

Interview participants discussed the many forms of ableism they experienced within the service provision context and beyond. For example, participants shared the attitudinal, physical, legal, and financial barriers they experienced when accessing their sexuality, including STI testing and sex work. Participants shared how these discriminatory and exclusionary practices are perpetuated by discriminatory attitudes, presuming that IWD are non-sexual. Participants also shared how these stigmas have been internalized, such that they experienced shame for their sexuality.

Similarly, our survey respondents who use attendant services reported experiencing barriers in accessing their sexuality both within and outside the service provision context. Outside of service provision, respondents acknowledged criminalization of sex work as one barrier, for example. Further, survey respondents acknowledged how these barriers are perpetuated by stigmas around sexuality and disability.

Survey respondents from the 2011 survey reported similar experiences of ableism within the service provision context. Experiences shared in the 2011 report included encountering and internalizing beliefs that IWD are not sexy or sexual. The 2011 survey reported that this impacted attendant users' assurance and attendants' expectations for requesting and providing sexual support. Further, the 2011 report acknowledges how this perpetuates fear of discourse as they conclude that it "takes sexuality off the table before a conversation even starts". Addressing stigma and related ableist attitudes (with attention to intersectionality) is a topic in need of significant attention in upcoming education and resource development phases.

Medical Model of Disability

The Medical Model of Disability approaches disability biologically, focused on treatment and intervention. It, however, pathologizes IWD and overlooks systemic barriers that IWD face. Interview participants shared experiences in which they have been medicalized, infantilized, and desexualized within service provision context. Participants reported how this impacted their experiences of pleasure and their relationship with their body.

Similarly, the 2011 survey acknowledged a western medical approach to disability and sexuality within the service provision context. For one, the 2011 survey reported how attendant users become objectified by attendants as they are seen as a "task to be done", rather than having an individualized and humanized approach to their care. Users also shared how their autonomy was undermined by attendants with a "know-it-all" attitude. Further, themes around touch and reduced privacy also came up in the 2011 survey. Respondents of the 2011 survey shared how they experience frequent touch and limited privacy within the service provision context, that would be considered a form of intimacy in another context. Following, respondents from the 2011 survey reported feeling awkward and desexualized. Further, they shared becoming accustomed to these experiences. Similar to the themes discussed above, it may be of great benefit to address the experiences of IWD related to their medicalization and dehumanization in the context of bodily touch practices of healthcare providers, which represent a lack of understanding or regard for the boundaries and humanity of IWD.

Intersections of Disability, Gender, and Sexuality

Interview participants acknowledged that gender and sexuality are intertwined and can influence their sense of safety. For example, one participant who identified as a heterosexual man, shared that they were hesitant to request sexual support, as their service providers were all women. Another participant shared their hesitancy to disclose their sexual orientation to their service providers, as their service providers may not be accepting.

Interview participants shared additional examples of how disability, gender, and sexuality intersected within other contexts. One participant shared, for example, their exclusion from the queer community, both when accessing physical (such as queer clubs) and virtual spaces (such as social media).

Survey respondents similarly acknowledged that sexual orientation and gender identity were intertwined with sexual support. Respondents shared, for example, how one's identity or orientation could influence discussions around sexuality and sexual support. Consequently, survey respondents reported disclosing their sexual orientation, gender identity, or sexual interests only when needed. Similarly, survey respondents from the 2011 survey shared that they would hide parts of themselves, including their sexuality, as a safeguard. Given these common experiences, it is crucial that education and resources related to sexual supports in the attendant care context address diversity in gender and sexual identities.

Comfort and Boundaries

Interview participants highlighted how comfort depended on their relationship with their service provider, such that they would not feel comfortable discussing sexual support if they felt it was unsafe to do so. While rapport building and psychological safety can foster comfort, interview participants discussed their hesitancy to initiate discussions of these topics within the attendant care context, due to fear of crossing boundaries with their service provider. Ultimately, interview participants acknowledged how individuals will have different levels of comfort providing and/or receiving sexual support. Further, while interview participants acknowledged their right to access their sexuality, they also stressed the importance of respecting their attendants' boundaries. Survey respondents from the 2023 survey similarly shared how their comfort level depended on their relationship with their service provider. Survey respondents shared how rapport and similarity made an attendant safe to talk to. Additionally, attendant users' answers from the 2011 survey mapped onto these facilitators.

Survey respondents from the 2023 survey indicated their preference for attendants to initiate conversations because fear of crossing a boundary. Similarly, the 2011 survey found that service users preferred to not initiate requests for sexual support, as it could be viewed as harassment or inappropriate. However, while the 2011 survey also found respecting boundaries as a theme to emerge from their data, they preferred the term "lines" as this terminology represents that boundaries are not always clear or straightforward and can change and move. In fact, the 2011 survey found that expectations around receiving and providing care are individualized. Developing rapport and navigating boundaries/lines in conversations and general practices related to sexual supports are important topics to address in the development of education and other resources within the attendant care relationship.

Humour

Interview participants reported using humour as an "icebreaker" to help combat their fears when approaching service providers about sexual support. Further, humour was used as a tool by interview participants to cope with the awkwardness they experienced discussing these topics. Lastly, participants reported using humour as a way to make conversations more fun to engage in, ultimately, dispelling conceptions that sexual support is "work".

Similarly, in the 2011 survey, they found that making sexual jokes was the most common way sexuality was talked about. Participants in the 2011 survey saw this as a safe way to approach conversations, as they could use it to "test the waters". Further, participants from the 2011 survey shared how they used humour as a way to cope with any potential awkwardness. However, the 2011 survey found that joking about sex was not always received well, especially when it was at the expense of others. Continuing discussions about the role of humour in 'lightening' and sparking conversations about sexual supports in the attendant care dynamic is another key to navigating learning and practice on all sides.

Communication

Communication was seen as essential, by interview participants, to safely and successfully negotiate sexual support. Participants highlighted that central to successful communication is transparency and safety. Firstly, participants highlighted how clear communication of their needs and boundaries is central to negotiating sexual support. Further, communication skills can ensure that requests are communicated in a safe and non-threatening way.

Attendants who responded to the 2023 survey shared several practical tips to improve communication skills, including actively listening without judgement and clearly explaining their responsibilities and boundaries in a way that is respectful of the client.

The 2011 report also stressed the importance of communication when negotiating sexual support. In fact, the 2011 survey found that when people reported not feeling safe, a lack of clarity was often the cause. Providing educational and practice-related opportunities to build skills in clear and effective communication around sexual supports, including navigating conflict, continues to be crucial within the attendant care dynamic.

Institutional Support

Interview participants highlighted how organizations and agencies can support the safe negotiation of sexual support within the attendant-client relationship. For one, interview participants suggested that sexual support negotiations could be integrated formally with practices and policies, such as in the intake process. Further, interview participants recommended offering training and certifications for both attendant users and attendants alike. Ultimately, education was seen as a powerful tool, by interview participants, for fostering understanding and inclusion. This is not surprising, given that attendant education and training programs in Canada lack a national standardized curriculum, with requirements varying by province and often excluding topics like sexuality and aging (Lum et al., 2010; CIHI, 2023).

Survey respondents similarly suggested that their organization/agency could provide opportunities for education, introduce topics within signed agreements, and clarify rights and responsibilities. Further, in the 2011 survey, attendants suggested offering education and training on topics, such as sexuality, religious, cultural, and moral issues, and staff and client rights around sexual support. Attendants, who participated in the 2011 survey, also suggested that their employer could support them by developing clear guidelines and policies for staff around providing sexual support. These insights highlight the many points of care where opportunities exist to significantly shift education and practices related to sexual supports and the related potential for positive impacts. Ultimately, advocacy efforts around sexuality within attendant care must account for the broader healthcare context, including considering the needs and perspectives of attendant providers who experience a lack of autonomy and uncertainty when supporting sexuality (Maguire et al., 2019).

Limitations of Current Research and Hopes for the Future

We wish to acknowledge several limitations we encountered in our study that bear on our findings and the overall conclusions we may draw.

First, our survey and interview samples were largely homogeneous. Our survey sample was largely white European, heterosexual, cisgender, and young to middle adults. Further, our survey

captured a population that largely resided within Ontario and British Columbia in urban areas. Our study sample differs slightly from the broader demographic makeup of attendant providers in Canada, where the workforce is predominantly female, often over the age of 45, lives in rural areas, and includes a disproportionately high percentage of visible minorities (Lum et al., 2010; Newfoundland & Labrador Centre for Health Information, 2019).

Similarly, our interview sample was largely white European, heterosexual, cisgender, and men. Further, all interview participants currently resided in Ontario and British Columbia. The depth of critical reflections, insights, and promising practices noted by participants in the attendant care dynamics is truly remarkable even within relatively small numbers of participants. At the same time, while we have scratched the surface of some nuances which exist in experiences within and across different identities, due to a small and relatively homogenous sample we are unable to make strong statistical inferences or conclusions across specific intersections. However, qualitative interviews with service users provided deeper insights into varied and nuanced lived experiences, including how power dynamics impact upon the experiences of service users in terms of gender and sexual orientation in particular.

While our intention when collecting data was to recruit a diverse sample of participants, regarding race, ethnicity, disability, sexuality, and gender, to gain a comprehensive understanding of the diverse experiences and needs of attendant service users, this proved challenging given our limited time and resources on the project. Missing voices, including from Black, Indigenous, and people of colour, means that we may be missing experiences that are unique to intersections of race and disability. Future collaborative research and programming by our current team and others should delve deeper into the varied experiences, priorities, and needed supports of folks who use and provide attendant care so we may better understand and address power dynamics related to disability, sexuality, gender, culture, race, and more.

Additionally, our approach to reviewing for survey bots has the possibility for exclusion of genuine responses, even with careful data cleaning. Given that we took a conservative approach to eliminating responses, it's possible that some responses may have been eliminated for not meeting our inclusion criteria, such as having a short response time and not providing qualitative responses. This meant that our final sample size was much smaller than we intended. A small sample size may impact our conclusions, as we may have captured only a subset of broader attitudes and experiences. For example, while some of our results might suggest an improvement from the 2011 survey in people's experiences and attitudes regarding using/providing sexual support within the service provider context, it may also be possible that our results are skewed positively to those who are most interested and comfortable speaking to these topics.

Additionally, while our qualitative analysis was driven by the data instead of pre-existing theory, it should be noted that Thematic Analysis can never be fully inductive. This is because as researchers we bring in our own pre-conceptions and assumptions that shape our interpretation of the data (Braun & Clarke, 2006).

Even given these limitations, we believe that the updated survey data and additional qualitative interviews offer much in continuing and expanding current knowledge and conversations related to sexuality and disability within and beyond the attendant care dynamic. We also intend to foster ongoing learning in the next phase of resource and program development alongside diverse community partners.

Next Steps: Community Action

While our findings add to limited research, they will also be used to guide a second action-oriented project phase where we will work closely with the SHORE Centre, disability communities and attendant service workers to develop and execute educational programs and other formal supports related to sexual supports in the attendant care dynamic. The next phase will begin by forming an advisory committee to review our work and provide input. Our team will be seeking people with lived experience, across disability and across Canada for this advisory committee.

If you are interested in participating in the next phase of our project, please reach out to Melanie and Wallace of t6talk at t6talk@gmail.com.

Conclusion

Attitudinal and physical barriers exist for individuals with disabilities when accessing their sexual health and sexuality within and beyond the attendant care dynamic. These attitudinal and physical barriers are entrenched within institutions, including within the attendant service provider context. These barriers in accessing care leaves individuals with disabilities vulnerable to physical, emotional, and relational harm.

At the same time, IWD hold deep knowledge and experience in pushing back against ableist attitudes and practices at multiple levels, and there is much to celebrate in the existing care relationships that many IWD, care providers, and loved ones hold.

To combat barriers and build caring practices for all those involved, individuals may hone diverse knowledges and skills related to intersectionality, independent living, informed consent, building rapport, and effective communication. Organizations may foster knowledge and skill development through offering training and resources. Further, governed processes can be put in place by organizations to ensure clarity and accountability in care, thereby minimizing potential risks and providing strong foundational supports for attendant-service user relationships.

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Appendix A: Survey Instruments

Service Users – Demographic questionnaire

Q1. Please tell us your age.

15-19

20-24

25-34

35-44

45-54

55-64

65-74

75-84

85-94

95 and over

Q2. What is the highest level of formal education you have completed?

Less than high school

Some high school

Completed high school

Some post secondary education

College diploma

Undergraduate degree

Graduate degree or greater

Q3. Where are you currently living in Canada?

Alberta

SAP 2023

British Columbia

Manitoba

New Brunswick

Newfoundland and Labrador

Northwest Territories

Nova Scotia

Nunavut

Ontario

Prince Edward Island

Quebec

Saskatchewan

Yukon

Q4. Please provide an estimate population size of the town/city you currently live in.

0-499

500-4999

5000-9999

10 000-29 999

30 000-49 999

50 000-99 999

100 000-499 999

500 000 and over

Q5. How would you describe your disability/disabilities? (Please select all that apply)

Congenital Physical

Acquired Physical

Congenital Mental

Acquired Mental

Congenital Intellectual

Acquired Intellectual

Congenital Cognitive

Acquired Cognitive

Congenital Learning

Acquired Learning

Congenital Communication

Acquired Communication

Congenital Sensory

Acquired Sensory

Please provide detail (e.g. depression, spinal cord injury, autism, cerebral palsy...) (Optional)

If you don't fully identify with the options above, how do you identify?

Q6. Tell us about who you live with.

I live alone.

I live with family members.

I live with friends or roommates.

I live with (a) partner(s)/spouse(s).

I live in a group home/supportive housing.

Other (please specify)

Q7. Which of the following BEST describes your ethnic background? (Please select all that apply)

Indigenous (Please feel free to name the nation, if desired)

White European

Black/African/Caribbean

East Asian (e.g., Chinese, Japanese, Korean, etc.)

Southeast Asian (Thai, Indonesian, Cambodian, Filipino, etc.)

South Asian (East Indian, Sri Lankan, etc.)

West Asian (Iranian, Afghani, etc.)

Arab (Saudi Arabian, Palestinian, Iraqi, etc.)

Latin American (Costa Rican, Guatemalan, Brazilian, Columbian, etc.)

If you don't fully identify with the options above, how do you identify?

Q8. Please indicate how you identify (More information regarding the terms below can be found on the Website for Rainbow Health Ontario):

Cisgender

Transgender

Prefer not to answer

If you don't fully identify with the options above, how do you identify?

Q9. Please tell us how you describe your gender. (Please select all that apply)

Woman

Man

Non-binary

Femme

Masc

Genderqueer

Two-spirit

Neuroqueer

Autigender

Prefer not to answer

If you don't fully identify with the options above, how do you identify?

Q10. Please tell us how you describe your sexual orientation.

Heterosexual

Gay

Lesbian

Queer

Bisexual

Pansexual

Asexual

Neuroqueer

Indigiqueer

Questioning

Unsure

I prefer not to answer

If you don't fully identify with the options above, how do you identify?

Q11. What is your relationship status?

Single

Partnered

Polyamorous

Open relationship

I prefer not to answer

If you don't fully identify with the options above, how do you identify?

Service Providers – Demographic questionnaire

Q1. Please tell us your age.

(Multiple choice, one answer allowed)

15-19

20-24

25-34

35-44

45-54

55-64

65-74

75-84

85-94

95 and over

Q2. What is the highest level of formal education you have completed?

(Multiple choice, one answer allowed)

Less than high school

Some high school

Completed high school

Some post-secondary education

College diploma

Undergraduate degree

Graduate degree or greater

Q3. Where are you currently living in Canada?

(Multiple choice, one answer allowed)

Alberta

British Columbia

Manitoba

New Brunswick

Newfoundland and Labrador

Northwest Territories

Nova Scotia

Nunavut

Ontario

Prince Edward Island

Quebec

Saskatchewan

Yukon

Q4. Please provide an estimate population size of the town/city you currently live in.

(Multiple choice, one answer allowed)

0-499

500-4999

5000-9999

10 000-29 999

30 000-49 999

50 000-99 999

100 000-499 999

500 000 and over

Q5. Which of the following BEST describes your ethnic background? (Please select all that apply)

(Multiple choice, multiple answers allowed)

Indigenous (Please feel free to name the nation, if desired)

White European

Black/African/Caribbean

East Asian (e.g., Chinese, Japanese, Korean, etc.)

Southeast Asian (Thai, Indonesian, Cambodian, Filipino, etc.)

South Asian (East Indian, Sri Lankan, etc.)

West Asian (Iranian, Afghani, etc.)

Arab (Saudi Arabian, Palestinian, Iraqi, etc.)

Latin American (Costa Rican, Guatemalan, Brazilian, Columbian, etc.)

If you don't fully identify with the options above, how do you identify?

Q6. Please indicate how you identify (More information regarding the terms below can be found on the Website for Rainbow Health Ontario):

(Multiple choice, multiple answers allowed)

Cisgender

Transgender

Prefer not to answer

If you don't fully identify with the options above, how do you identify?

Q7. Tell us how you describe your gender (Please select all that apply)

(Multiple choice, multiple answers allowed)

Woman

Man

Non-binary

Femme

Masc

Genderqueer

Two-spirit

Neuroqueer

Autigender

Prefer not to answer

If you don't fully identify with the options above, how do you identify?

Q8. Tell us how you describe your sexual orientation.

(Multiple choice, multiple answers allowed)

Heterosexual

Gay

Lesbian

Queer

Bisexual

Pansexual

Asexual

Neuroqueer

Indigiqueer

Questioning

Unsure

Prefer not to answer

If you don't fully identify with the options above, how do you identify?

Service Users – Survey Questionnaire

Q1. Do you live with one or more disabilities or physical differences?

Yes

No

If you do not identify as living with a disability, please provide information on why you use attendant care services.

Q2. As of right now, how long have you been using attendant services?

Less than 1 year

1-3 years

3-5 years

5+ years

Q3. How are your attendant services funded? (Please select all that apply)

I am a self manager and receive direct funding to hire and train my own attendants.

I live in a supported living unit (SLU) and my attendant services are provided through an agency.

I receive my attendant services through community care access centre (CCAC).

I receive support from non-formal services i.e. family/friends/community members

Other (please specify)

Q4. Has assistance with sexuality and sexual support been part of any attendant service agreement you have signed?

Yes

No

Please provide detail (Optional).

Q5. Has anyone ever talked to you about what you can, and cannot, ask for in a service agreement when it comes to sexuality and sexual support?

Yes

No

Unsure

Please provide detail (Optional).

Q6. Do you think attendants should be required to assist with sexuality and sexual support? (this does not include having sex with you, but does include assisting you in having sex on your own or with someone else).

Yes

No

Depends

Please provide detail (Optional).

Q7. Are the topics of sexuality and sexual support subjects that you have ever, or would ever, feel comfortable discussing with an attendant?

Yes

No

Depends

Please provide detail (Optional).

Q8. Have you ever worked with an attendant you felt comfortable talking to about sexuality and sexual support?

Yes

No

Please provide detail (Optional).

Q9. If you do not feel comfortable talking to attendants about sexuality and sexual support, what do you think an attendant could do to make you more comfortable? (Response is optional)

Q10. There are many ways that attendants are involved in facilitating sexual support. Using the list below, please check off any of the situations you have requested and/or received assistance with. (Please select all that apply)

Going out to clubs to flirt, dance, socialize.

Going out on a date.

Going to an event in the lesbian, gay, bisexual, trans, or queer community.

Positioning for sexual activities with (a) partner(s).

Positioning for solo sexual activities (e.g. masturbation).

Going to workshops or trade shows about sex.

Purchasing resources about sex (e.g. books, DVDs, websites).

Purchasing a sex toy.

Using a sex toy.

Renting/ purchasing erotica/ pornography.

Watching or reading erotica/ pornography.

Going into online dating or chat rooms.

Going to a strip club.

Dressing up as a form of sexual expression (e.g. leather, lingerie).

Finding, calling, or arranging for a sex worker/escort.

Helping with vocabulary, supporting you to find people to talk to, and opportunities to communicate about sexuality and intimacy.

Please provide detail (Optional).

Q11. Have you ever talked with your attendants about sexuality and sexual support (for example: items listed above).

Yes

No

Please provide detail (Optional).

Q12. Have you ever felt that your (or an attendant's) sexual orientation, gender identity, or sexual interests have made it either easier or more difficult for you to talk about sexuality and sexual support

Yes

Sometimes

No

Please provide detail (Optional).

Q13. Have you ever experienced conflict or disagreement in a sexuality or sexual support situation between what you wanted to do and what an attendant thought you should be doing? For example: an attendant disagreeing with your desire to flirt, have sex, masturbate, hire an escort, or something similar?

Yes

No

Please provide detail (Optional).

Q14. Do you have a story of your own experience where you asked for sexual support and the request was refused?

Yes

No

Please provide detail (Optional).

Q15. Have you ever felt unsafe, unsure, or in danger when trying to negotiate with an attendant for sexual support?

Yes

No

Please provide detail (Optional).

Q16. Are there any questions we missed or anything else you'd like to share (Please refrain from sharing identifiable information about yourself or others)?

Service Providers – Survey Questionnaire

Q1. How long have you been working as an attendant?

(Multiple choice, one answer allowed)

Less than 3 years

3 to 5 years

More than 5 years

I don't work as an attendant

Q2. Has assistance with sexuality or sexual support been a part of any attendant service agreement you've ever signed?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q3. Has anyone ever talked to you about what services you are required to provide and what services you can refuse to provide when it comes to sexuality and sexual support?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q4. Have you ever received training or instruction on sexuality and sexual support as it applies to your work as an attendant?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q5. Do you think attendants should be required to assist with sexuality and sexual support?
(This does not include having sex with consumers/ clients, but it does include assisting them in having sex on their own or with someone else.)

(Multiple choice, multiple answers allowed)

Yes

No

Depends

Please provide detail (Optional).

Q6. Are the topics of sexuality and sexual support subjects that you have ever, or would ever, feel comfortable discussing with a service user?

(Multiple choice, multiple answers allowed)

Yes

No

Depends

Please provide detail (Optional).

Q7. Have you ever talked with a consumer/client about sexuality and sexual support?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q8. Have you ever felt that your (or a client's) sexual orientation and/or gender identity has impacted your ability to talk about, or support with, requests about sexuality and sexual support?

(Multiple choice, multiple answers allowed)

Yes

Sometimes

No

Please provide detail (Optional).

Q9. There are many ways that consumers/clients can request support for sexual expression. Below are some examples. Please let us know if you have experience with, or have received requests for help with, any of these situations. (Please select all that apply)

(Multiple choice, multiple answers allowed)

Providing or helping purchase resources about sex (e.g. books, websites).

Going to an event in the lesbian, gay, bisexual, trans, or queer community.

Helping with positioning for sexual activities with (a) partner(s).

Help with positioning for solo sexual activities (e.g. masturbation)

Going to workshops or trade shows about sex.

Going out to clubs to flirt, dance, socialize.

Going out on a date.

Purchasing a sex toy.

Using a sex toy.

Renting/ purchasing erotica/ pornography.

Watching or reading erotica/ pornography.

Online dating or chat rooms.

Going to a strip club.

Dressing up as a form of sexual expression (e.g. leather, lingerie).

Finding, calling, or arranging for a sex worker/escort.

Supporting a person with a communication disability in communicating with someone (e.g. partner, doctor, teacher) about sexuality and intimacy.

Please provide detail (Optional).

Q10. Have you ever experienced a conflict or disagreement between what you thought a consumer/client should do and what the consumer/client wanted to do with regards to sexuality and sexual support?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q11. Have you ever experienced any positive or negative consequences after a request has been made by a consumer/ client for sexual support?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q12. Have you ever felt unsafe, unsure, or in danger when trying to negotiate with a client around a request for sexual support?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q13. In your most recent workplace, do/did you feel supported by management and other staff to respond to consumer/client requests for sexual support?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q14. Are there ways you think your employer or organization could be supporting you better around these issues (Your employer may be considered an institution/ agency, or could simply be one person who utilizes attendant services)?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q15. If you have supported consumers/clients around sexuality and sexual support in the past, do you have any tips or suggestions for other attendants to do this work safely and well?

(Multiple choice, multiple answers allowed)

Yes

No

Please provide detail (Optional).

Q16. Are there any questions we missed or anything else you would like to add (Please refrain from sharing identifiable information about yourself or others)?

Appendix B: Interview Questions

1. Tell us about yourself.
 - a. Consider: name, age, pronouns, nature of disability/neurodivergence, any other identities that are important to you, where are you located etc.
2. What is your interest in participating in the interview today? Choose all that apply.
 - a. Contributing to a knowledge base,
 - b. Connecting with peers,
 - c. Interested in the topic,
 - d. Other:
3. Have you spoken about sexuality and its connection to disability/neurodivergence before?
 - a. Consider: What was the context? Who was your audience? How did it go?
4. What is important to you about sexuality and its connection to disability/neurodivergence?
 - a. Consider: What do you value? How do you identify? Are there societal norms that impact or shape your experience of disability/neurodivergence and sexuality?
5. What information/education did you get around sexuality and disability/neurodivergence, and the relationship between the two, growing up?
 - a. Consider: messaging from family, peers, community, cultural, church, school
6. Did you have access to/participate in sex education as a child/youth?
 - a. Consider: in school, outside of school
7. How has your disability/neurodivergence affected your experience of sex and your sexuality?
 - a. Consider: If your disability/neurodivergence is acquired or if your disability/neurodivergence is congenital how does that factor in (change in function, position in the life cycle/milestones)?
8. How does the connection between disability/neurodivergence and sexuality impact you now?

- a. Consider: How, where, and with whom are you currently able to express yourself? Solo, with another and/or others, with sex workers, with sexual surrogates etc.
9. What barriers do you experience, or perceive, accessing your sexual health?
 - a. Consider: Attitudinal, physical, opportunity, systemic, faith, professional etc.
10. What would you like to see in the future?
 - a. Consider: How would you change things? Or keep things the same?
 - b. If educational programming was developed for service providers to support people's sexual health in the disability/neurodivergence communities, what would you like to see included?
11. Is there anything else you'd like to share that we haven't asked?