

# Sexuality and Access Project

## *Survey Summary*

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*For: Springtide Resources*



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# Table of Contents

<b>EXECUTIVE SUMMARY .....</b>	<b>V</b>
<b>METHODOLOGY .....</b>	<b>1</b>
ACCESS .....	1
LIMITATIONS OF THE SURVEY .....	2
READING THIS SUMMARY .....	2
<b>PART I: SURVEY DATA .....</b>	<b>4</b>
SURVEY QUESTIONS .....	4
<i>Sexuality and Sexual Support in Service Agreements and Job Contracts .....</i>	<i>4</i>
<i>The Right to Ask for Sexual Support/Attendants' Right to Refuse Sexual Support.....</i>	<i>5</i>
<i>Should Attendants Be Required to Assist with Sexual Expression? .....</i>	<i>5</i>
<i>Conversations between Attendants and Clients about Sex .....</i>	<i>6</i>
<i>Comfort Levels in Talking About Sex with Attendants.....</i>	<i>6</i>
<i>Examples of Sexual Support.....</i>	<i>7</i>
<i>Influence of Sexual Orientation and Gender Identity on Sexual Support .....</i>	<i>8</i>
<i>Conflicts between Attendant and Client Desires and Expectations.....</i>	<i>8</i>
<i>How Safe Do You Feel Talking about Sexual Support? .....</i>	<i>9</i>
<i>How Employers, Organizations, and Agencies Could Better Support Attendants .....</i>	<i>10</i>
<i>Suggestions from Attendants to Other Attendants on Providing Sexual Support .....</i>	<i>10</i>
<i>People's Experience Filling Out the Survey .....</i>	<i>11</i>
DEMOGRAPHICS .....	12
Age .....	12
Using/Providing Attendant Services.....	12
Funding.....	13
Education.....	13
Urban or Rural.....	13
Gender .....	13
Sexual Orientation .....	14
Living Arrangements .....	15
Relationship Status.....	15

<b>PART II: ANALYSIS OF SURVEY THEMES AND TOPICS .....</b>	<b>16</b>
GUIDING PRINCIPLES .....	16
<i>Intimacy.....</i>	<i>16</i>
<i>Sexuality Is Personal and Political, Always.....</i>	<i>17</i>
THEME 1: THE CARE RELATIONSHIP .....	18
<i>Topic 1.1: Sexual Rights.....</i>	<i>19</i>
<i>Topic 1.2: Here/Not Here.....</i>	<i>19</i>
<i>Topic 1.3: Ableism and Internalized Ableism.....</i>	<i>20</i>
<i>Topic 1.4: Power Dynamics.....</i>	<i>21</i>
THEME 2: LINES .....	22
<i>Topic 2.1: Non-Sexual Activities That in Other Contexts Are Sexual .....</i>	<i>22</i>
<i>Topic 2.2: Professional Boundaries .....</i>	<i>23</i>
<i>Topic 2.3: Falling for the Other .....</i>	<i>24</i>
<i>Topic 2.4: Job Descriptions and Contracts.....</i>	<i>24</i>
THEME 3: ESTABLISHING COMFORT.....	25
<i>Topic 3.1: Trust .....</i>	<i>26</i>
<i>Topic 3.2: Assumptions .....</i>	<i>27</i>
<i>Topic 3.3: Sameness and Difference .....</i>	<i>27</i>
<i>Topic 3.4: Humour .....</i>	<i>28</i>
THEME 4: COMMUNICATION .....	29
<i>Topic 4.1: Defining Sexual Support .....</i>	<i>30</i>
THEME 5: PERCEIVED SAFETY.....	30
<i>Topic 5.1: Abuse, Harassment, and Exploitation .....</i>	<i>31</i>
<i>Topic 5.2: Hiding.....</i>	<i>32</i>
<i>Topic 5.3: Protection, Paternalism, and the Dignity of Risk.....</i>	<i>32</i>
<i>Topic 5.4: Conflicts with Agencies/Employers.....</i>	<i>33</i>
<i>Topic 5.5: Homophobia/Transphobia.....</i>	<i>33</i>
THEME 6: REDUCED PRIVACY .....	34
<i>Topic 6.1: Gossip .....</i>	<i>35</i>
<b>CONCLUSION .....</b>	<b>36</b>
<i>The Attendant Service Relationship Is Unique .....</i>	<i>36</i>
<i>Sexuality Is about More than Abuse and Victimization.....</i>	<i>36</i>
<i>Everyone Wants to Talk, But No One Knows How to Start the Conversation.....</i>	<i>37</i>
<b>APPENDIX A: SURVEYS .....</b>	<b>38</b>
SURVEY FOR ATTENDANT SERVICE USERS .....	38
SURVEY FOR ATTENDANT SERVICE PROVIDERS .....	42

## Acknowledgements

We would not have been able to carry out the Sexuality and Access Project without the support of Springtide Resources and the support and funding of the Ontario Trillium Foundation.

Our greatest appreciation and thanks go to the over 400 people who agreed to participate in our survey, and the 14 people who further agreed to be interviewed on camera for the Sexuality and Access Project video. The topic of sexuality and disability remains underground for so many of us, and communicating honestly about it involves risk taking. The cumulative impact of multiple systems of power and marginalization leaves many of us feeling both ashamed and afraid to share our experiences. In sharing their stories with us the participants showed fierceness, generosity, and humour. We hope that this summary manages to convey at least some of what they have to say.

We are grateful to our advisory committee who helped us develop the questions that formed the basis of our survey, got the word out about the survey to a wide and diverse range of attendant and attendant service user communities, and provided valuable input as we worked to represent the rich and varied stories and experiences that participants shared. The summary is more thoughtful and nuanced for their participation.

The members of the advisory committee are as follows:

Anne Abbott, Community Member (former member)  
Jan Angus, University of Toronto (former member)  
Kirk Ashman, Community Member  
Sandra Carpenter, Centre for Independent Living Toronto  
Anne Marie Covello-Baxter, Niagara Centre for Independent Living  
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Dan Lajoie, Independent Living Centre of Waterloo Region  
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Valerie Scarfone, Independence Centre and Network  
Destiny Shackleton, Community Member  
Sandy Stauffer, Independent Living Centre of Waterloo Region  
Tracy Warne, Sherbourne Health Centre

We also want to acknowledge Lisa Seto, who prepared a careful and astute review of the available literature in the area of sexuality and attendant services.

The process of reading through the transcripts and responses of the over 400 people who we surveyed was both exciting and exhausting. Loree Erickson, Tracy Warne, Fran Odette, and Cory Silverberg formed a working group to organize the material. Our task was to sort the data with as minimal influence as possible, allowing perspectives to be documented

and voices to be heard. Loree and Tracy were patient and challenging collaborators in this process and we thank them for their contributions.

## EXECUTIVE SUMMARY

This report addresses the experience of people with disabilities who make use of attendant support in their daily lives and the experiences of those who provide these services and support. Attendant services have been traditionally understood to include supporting with activities such as cooking, cleaning, shopping, using the bathroom, bathing, and dressing.

The intimate nature of this working relationship means that sexual health will come up, and requests for sexual support will be made. While regional guidelines have been proposed for adults living in long-term care facilities, no framework for providing or requesting support for sexual activities or sexual expression for people with disabilities has been established, and as a result both support workers and people who use their services can find themselves in situations where they feel uncomfortable, afraid, frustrated, sexually harassed, exploited, or abused.

It is difficult to offer a simple definition of sexual support, as any definition must be grounded in the individual sexual expression from which it arises. Broadly speaking, sexual support describes the range of assistance that an individual may request and an attendant may provide, as well as an acknowledgement that sexuality is a part of life and may be an activity of daily living. Sexual support can be thought of along a continuum of involvement and intimacy, from assistance with cooking a romantic meal to assistance with shopping for sexual materials (e.g. sex toys or legal adult erotic material) to assistance with positioning for sexual activities.

This report summarizes the results of a year-long survey conducted by the Sexuality and Access Project and funded by the Ontario Trillium Foundation. The survey – the first of its kind ever undertaken – asked attendant service users and frontline providers to anonymously share their experiences with discussing, negotiating, and expressing their sexual and gender identities with each other in the context of their working relationship.

The project began with some basic truths that are simple, but are often simply ignored:

Sexual rights are human rights.

Sexual health is core component of general health.

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.

Attendants have sexual rights, which include the right to a workplace that is not sexualized.

The project also began with an understanding that societal shame around sexuality results in silence, and this silence is often compounded when it intersects with other socially taboo subjects, like disability and the details of personal support. The 464 people who participated in our survey (310 people using attendant services and 154 attendants) had plenty to tell us about this shaming silence and the impact it has on their lives.

### *Silence about Sexuality and Attendant Services Exists at All Levels*

People using attendant services were keenly aware of the systemic silence that surrounds their desire to express their sexuality, and attendants were equally aware of the silence they confront when they try to support this expression. Researchers, policy makers, agencies, and even advocate and activist organizations are often at a loss as to how they can address issues of sexuality and sexual health in attendant service relationships. The participants in this survey offered many suggestions.

### *Where There Is Silence, Confusion, Fear, Harassment, and Abuse Can Flourish*

For people who use attendant services, the choice to reveal or conceal aspects of their sexuality was tied to concerns about feeling safe in the working relationship. Respondents told us that such decisions are often made out of fear of losing services and/or housing, or a fear of retaliation in other forms. Attendant service users also shared stories of harassment and abuse that they felt they could not talk about publically because of the climate of silence and shame around sexuality.

People providing attendant services shared stories about hiding aspects of who they were (specifically regarding sexual orientation and gender identity) for fear of losing employment, and reluctance to provide support without clear guidelines, for fear of retaliation from co-workers and/or employers. Attendants also shared stories of harassment and abuse that they felt they could not talk about publically in part because of a single focus in training around sexual abuse and no apparent space for other kinds of workplace conversations about sexual health.

### *The Rights of Attendant Service Users and Providers Are Not Diametrically Opposed*

Participants in this project told us in no uncertain terms that a model that pits “client” rights against attendant rights satisfies neither party. Any proposal to support the sexual health of attendant service users and the workplace safety of attendants needs to foreground the fact that it is a relationship and not simply two people working side by side but independently of each other. Many participants related stories of successful

negotiations around sexuality that showed that it is possible for both people in the relationship to feel safe, to feel respected, and to experience the working relationship as one that promotes health, including sexual health.

### *Attendants and Attendant Service Users Want to Talk*

The survey made it crystal clear that everyone involved wants to have a place to start professional and respectful conversations about sexuality. Survey responses emphasized that the elements necessary to successful negotiations of sexual support are comfort in the interpersonal dynamics, mutual understanding of boundaries, and trust that privacy will be respected. These elements cannot be established without clear lines of communication.

There is much work to do, and there is an urgent need to get it done to reduce the risk of sexual harassment and exploitation. There are many ways those of us working in policy, education, training, and advocacy can help fill the silence around sexuality in personal care attendant work and improve the health and lives of both attendants and people using attendant services.

But that work must include the people we say we want to support, and it must start with us learning from their experience. Here, we believe, is where the conversation should begin.

It is our hope that the Sexuality and Access Project will provide an entry point into a much bigger conversation about how people who use attendant services (however they use them) can gain greater and easier access to their basic human rights, including their sexual rights, and how people who provide attendant services (however they provide them) can ensure their own health and safety in the workplace.



## METHODOLOGY

In collaboration with our advisory committee we developed two surveys, one for people who use attendant services and one for attendants. A complete copy of the surveys can be found in Appendix A.

Because our questions related directly to the personal lives of people using attendant services but not to the personal lives of attendants, we asked a few questions about relationship status and living arrangements of attendant service users that we did not ask of attendant service providers.

We chose to ask demographic questions at the end of the survey, so as not to suggest or limit relevant identity categories for participants. We are also reporting them in this summary at the end, for the same reason.

A total of 475 people participated in the project. Four hundred and sixty-four people completed the survey: 310 people who use attendant services and 154 attendants. We also conducted phone and in-person interviews with 8 people, using the survey as a guide for questions. Finally, we conducted focus groups with both attendants and people using attendant services in Toronto and Sudbury. Twenty-three people participated in the focus groups.

### Access

Understanding that both attendants and people who use attendant services are often isolated, and that we were interested in hearing from people who are participating in attendant services in a wide range of settings, and not just institutionally, it was critical to offer the survey in as many formats as possible. This approach allowed us to connect with participants with a wide range of lived experience of disability, including augmentative and alternative communication (AAC) users. It also facilitated more participation from attendants whose work schedules often mean they are unable to participate in consultations of this kind.

We made the surveys available online where they could be completed anonymously using an accessible web-based survey tool. Four-hundred and thirty-three people participated through the online survey. We also made the survey available in a print version that could be mailed in.

## **Limitations of the Survey**

The Sexuality and Access Project was not conceived of as a scientific endeavour, and this summary should not be read as a collection of data that offers a definitive answer to questions about attendant services and sexual support.

We did not impose working, or operational, definitions of terms like “attendant services” “disability” or “sexual support” on participants filling out the survey.

This was an intentional choice that reflects our methodological approach. While we acknowledge that there is a place for such research, we do not believe that exploratory, community-based research benefits when it requires individuals to narrow their experience to a set of researcher-based expectations. Our goal was to let people share their stories in whatever way they chose, imposing the least amount of influence as possible.

One of the obvious limitations of this methodology is that responses cannot be understood as necessarily all the same, or generalizable, and many answers can only be fully appreciated in the context of the complete survey. While there are quantitative data in this report we caution against the use of this data to generalize about larger communities or specific individuals.

## **Reading This Summary**

The first part of this report summarizes responses to the specific questions that were asked of survey participants. Where we collected it, we include both quantitative and qualitative responses.

Of the 16 non-demographic questions in the survey, 9 were the same for both attendants and people using attendant services (only the words identifying the person as either a user or a provider of services were changed). Where questions were the same on both surveys we report user and provider results together

The second part of the summary offers a review of the major themes and topics that emerged as our working group reviewed the stories we were told.

Throughout the summary we have included quotes from responses to the survey’s open-ended questions. Each quote is followed by initials. The initials “AU” indicate that the quote is from someone who is an attendant service user. “AP” indicates that the person being

quoted is an attendant service provider. The quotes appear here as we received them, without editorial input from us.

## PART I

### Survey Data

#### Survey Questions

##### *Sexuality and Sexual Support in Service Agreements and Job Contracts*

Ninety-three percent of people using attendant services and 82% of attendants told us that sex or sexuality had never been part of any attendant service agreement they had signed.

Those few contracts and agreements that did include mention of sexuality or sexual support ranged from very general:<sup>1</sup>

*“That every client has the right to have sex and their sexuality and that if an attendant feels comfortable enough assisting the client with preparing for sex then they can. However they are not obligated.” (AU)*

*“It is expected that you follow direction given by the person with the disability, even if that means assisting them with the preparation of sexual matters.” (AP)*

to quite specific:

*“[Sexual support included] putting on sexy outfits, shaving, putting make-up on.” (AU)*

*“No formal contract was signed, but I was asked if I would feel comfortable assisting with masturbation. I was comfortable and did provide this assistance, usually once per week (as often as I worked).” (AP)*

While sexual support was not mentioned often in the context of service agreements and job contracts, sexual abuse and harassment was. For most participants the only reference to sexuality was in the context of negative or coercive acts:

*“Just the agreement of both employer and employee to abstain from sexual harassment.” (AU)*

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<sup>1</sup> The initials “AU” indicate that the quote is from someone who is an attendant service user. “AP” indicates that the person being quoted is an attendant service provider. The quotes appear here as we received them, without editorial input from us.

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

Ninety-four percent of people who use attendant services told us that they have never received any information about their rights to make requests for, or receive, sexual support.

Eighty-two percent of attendants told us that they have never received information or training about their rights to provide or refuse sexual support.

When information about sexual support was conveyed, it varied greatly in content and specificity. Here are a few examples of what people were told:

*"We have been told only to refuse work that is deemed to be unsafe." (AP)*

*"Attendants must provide preparation before and clean up after sex with some positioning. Anything further needs to be discussed with the attendant and is at their discretion." (AU)*

*"We have policy that prohibits sexual contact between clients and staff." (AP)*

*"I can refuse to provide sexual assistance or any service that makes me feel uncomfortable." (AP)*

## *Should Attendants Be Required to Assist with Sexual Expression?*

Both people receiving support services and support workers were asked if attendants should be required to assist with sexual expression.

**TABLE 1**

<b>Response</b>	<b>People Using Attendant Services</b>	<b>Attendants</b>
<b>Yes</b>	29%	23%
<b>No</b>	27%	35%
<b>Depends</b>	44%	42%

Participants were further prompted to elaborate on their response. The most common response from all participants was that people should have a right to sexual support, but no one should ever be “forced” to provide it:

*“They shouldn't be mandated to assist, as not everyone is comfortable with all expressions of sexual interests and lifestyles, but the opportunity of receiving assistance should be mandated.” (AU)*

*“I think that there are all kinds of different relationships that may fall under the umbrella of ‘care’. I think that people should definitely have access to care that assists with sexual expression. That said, I would be hesitant to declare that a requirement of all people who are attendants in some capacity.” (AP)*

The majority of both attendants and people using attendant services agree that sexual support is, or should be, a part of available services. However, the results also show that not all attendants are willing to provide sexual support.

### *Conversations between Attendants and Clients about Sex*

Seventy-eight percent of care workers participating in the survey reported that they have had conversations with the people they support about sex.

Seventy-six percent of survey respondents receiving care or support have had conversations with their attendants about sex.

While most people say they have talked about sex, the majority of participants agreed that they do not want to be the one to bring sex up the first time. Attendants told us they would only talk about it after a client brought it up. And people using attendant services often expressed the fear that raising it first could be seen as harassment.

The most common way sexuality was talked about was in the sharing of sexual jokes. While participants often saw this as a “safe” way to talk about sex, we also heard from both groups that sexual joking could often lead to unintended consequences, when the joke is at the expense of a particular group (e.g. sexist jokes, homophobic jokes, racist jokes).

### *Comfort Levels in Talking About Sex with Attendants*

Sixty-five percent of survey respondents using attendant services said they had at least one working relationship where they were comfortable talking about sex. Their answers about what made them comfortable reveal much not only about what might make an attendant safe to talk to, but about respondents’ own values and beliefs:

*“Personality, openness, and rapport make it a lot easier to talk to someone. I’ve had ‘clinical’ assistance in the past and I wouldn’t have been comfortable talking with them about anything beyond the necessary ‘help me up here’ stuff.” (AU)*

*“Ultimately it boils down to their core reason on why they became a support worker, their general intelligence level, and their body language telling me if they’re a decent, open minded person or not.” (AU)*

*“They just struck me as someone who saw me as an individual and who realized that I had the same needs (and rights) as them.” (AU)*

*“I tend to be more comfortable with younger workers and workers who grew up here, because I feel more able to predict what they will be comfortable with and what might offend them.” (AU)*

*“The attendant was comfortable both with their own sexuality and their own sexual boundaries – so they were not confusing my talk of sexuality with any desire to be sexual with them.” (AU)*

## *Examples of Sexual Support*

We asked people using attendant services about the kinds of sexual support they have received. The most frequent responses were

Being accompanied when going out to clubs: 51%

Going out on a date: 46%

Positioning for sexual activities with partner: 31%

Purchasing a sex toy: 29%

Purchasing resources about sex: 28%

We also asked attendants about sexual support they have provided. The most frequent responses were:

Going to an event in the LGBTQ community: 37%

Positioning for solo sexual activities: 36%

Positioning for sexual activities with partner: 34%

Going out on a date: 34%

Going out to clubs to flirt, dance, socialize: 34%

## *Influence of Sexual Orientation and Gender Identity on Sexual Support*

We asked both attendants and people using attendant services whether their own or the other person's sexual orientation or gender identity impacted their ability or willingness to talk about or provide sexual support. The quantitative responses were:

**TABLE 2**

<b>Response</b>	<b>People Using Attendant Services</b>	<b>Attendants</b>
<b>Yes</b>	27%	5%
<b>No</b>	55%	76%
<b>Sometimes</b>	18%	19%

While this question did not specify particular orientations or identities, it is not surprising that people's responses to this question focused on orientations other than heterosexual:

*"Attendants' orientation definitely makes a big difference on their ability to speak calmly about sex, whether the subject is brought up by myself or them. Because I'm gay, it automatically creates issues with the staff in my building." (AU)*

*"As a heterosexual female, I have found that gay or lesbian attendants are generally less inhibited and easier to talk to. They are just more 'out' about everything." (AU)*

*"My sexual orientation should never affect a consumer. They have no need to know about or ask about my sex or sexuality." (AP)*

*"I have had to refrain with disclosing my sexual orientation to certain clients as I sensed that they would be uncomfortable with it – I respect that." (AP)*

## *Conflicts between Attendant and Client Desires and Expectations*

We asked people using attendant services if they had ever experienced conflicts between what they wanted to do and what an attendant thought they should be doing in a dating or sexual situation. We asked the same question of attendants.



Eighty percent of people using attendant services and 90% of attendants said they had not experienced conflict. However, it is not clear whether the lack of conflict responses represents a genuine working together, or whether it is a result of people avoiding conflict at all costs.

Stories suggest that ***people using attendant services regularly hide parts of themselves to avoid conflict or confrontation***. And while many attendants did tell stories of sharing their judgments, others reported holding them back:

*"They all make it officially or unofficially known that they disapprove of any kind of sexual activity – any kind of activity that would benefit us. They basically look at us as pets. The vast majority of attendants think that we are not sexual." (AU)*

*"Unless the activity is harmful to me, themselves, someone else, or is illegal, there should not be any conflict. The attendant's opinion or moral standing about the situation is irrelevant to the consumer/client, and in my opinion there are many attendants out there that could use some training on that as well." (AP)*

*"I have had attendants disagree with a lot of the decisions I have made, especially because I am in a relationship. It is hard because it hurts your feelings and makes you doubt yourself, after you have worked so hard to respect your own decisions." (AU)*

*"I was at a hotel for a conference and this girl was giving me that look and wanted to go back to my room with me. My aide at the time got a weird vibe about her and thought that she was after something else and did not trust her. He thought he was protecting me." (AU)*

*"I thought the young gay consumer's behaviours were really dangerous for him and I told him that. He respectfully responded with humor, 'Thank you, mother,' and I would say, 'Seriously it's because I care.' It was left at that. He would just smile and carry on." (AP)*

### *How Safe Do You Feel Talking about Sexual Support?*

Twelve percent of people using attendant services and 11% of attendants said that they had felt unsafe, unsure, or in danger when talking about sexual support (either making a request or receiving a request).

Based on the stories shared throughout the survey, we suspect that these numbers are low because people only ask for, or provide, sexual support once some sense of safety has been established.

When people reported not feeling safe, a lack of clarity was often the cause:

*"I felt unsure about their body language and personal opinions on subject matter. Unsafe or in danger of possibly losing my apartment due to conflicts of interest/opinions etc." (AU)*

*"It's always a tough spot. There is kind of an unwritten 'don't ask, don't tell' rule. We know clients aren't all virgins nor do they want to be, but we run a risk of our own when providing support, particularly with clients that are inconsistent – and impressionable. They may ask for something and then rescind that they requested it later, putting you in a tough spot." (AP)*

## *How Employers, Organizations, and Agencies Could Better Support Attendants*

***Eighty-two percent of attendants reported that they had never received training or instruction around issues of sexuality or sexual support.*** And 52% of attendants say they do not feel supported in their current workplace to respond to requests for sexual support.

We asked attendants what they thought employers or organizations/agencies could do to better support them. Suggestions included:

More education/training for staff around

- sexuality
- religious, cultural, and moral issues
- staff rights and client rights around sexual support

Development of guidelines and policies for staff around sexual support as a "designated act"

Information and seminars for parents that care for adult children

Funding for clients

Including sexual support in hiring and orientation processes

Designating a "resource person" in each agency

## *Suggestions from Attendants to Other Attendants on Providing Sexual Support*

We asked attendants who had provided sexual support what advice or tips they had for other attendants. Here are a few of the responses:

*"Establish a solid working relationship with the client before agreeing to provide [sexual support]." (AP)*

*"Get to know the client thoroughly." (AP)*

*“Have a proper conversation regarding the specific [sexual support service] required.” (AP)*

*“Keep your supervisor informed of what is going to happen, and make sure you have the management’s go ahead.” (AP)*

*“Be professional, objective, and detached without appearing to be cold or indifferent.” (AP)*

*“Safety in numbers. Have another staff member there when the request is made and carried out. Document it as necessary. With a private client make sure you know who may take issue with your compliance with the client’s request and your response, and know where you stand legally.” (AP)*

*“Just be open-minded. It will be awkward at first – just like the first time you provide bowel and bladder assistance. Just one more new thing – not a big deal when you actually do it.” (AP)*

*“Comfort with one’s own boundaries, knowledge, and comfort around sexuality as well as a sex-positive attitude, combined with the ability to say no when necessary are incredibly important in this work.” (AP)*

### *People’s Experience Filling Out the Survey*

Recognizing that this is a topic that is not often discussed and has not been researched in this way (to our knowledge), we wanted to find out what people thought of the survey itself, and we asked participants about their experience filling it out.

Responses were overwhelmingly positive regarding the need for this survey and for more training opportunities and conversations focusing on this issue. Many participants offered specific suggestions on how we might make future work more inclusive.

For example, participants commented that the language used for people in support working relationships often leaves out family members, friends, and other people who provide support for free or for barter. This is an important point to keep in mind for future work.

Here are a few of the responses:

*“I commend you for undertaking this sensitive topic – it’s one that even our primary care health professionals are generally not comfortable addressing, no matter how compassionate they are.” (AP)*

*“This survey, although appropriate for some, seemed absurd for those like myself, married with children.” (AU)*

*"Questions were clear and easy to understand, good order. The results should be interesting. Thank you for opening up dialogue about this important issue." (AP)*

*"Too short and too focused." (AU)*

*"Interesting survey. It made me think about the issue for the first time." (AU)*

*"Very well thought out. It's about time someone took on this subject." (AU)*

*"Great job, we need lots of research on this, lots of new information, and to change those brainwashed conservative health care workers so we don't have to suffer with our sex-related struggles." (AU)*

*"It was good to be asked relevant questions; it did feel a bit like it didn't recognize the institutional power people have when they are employers and instead responded as though the only power dynamic was able bodied/disabled. I did like the experience!" (AP)*

## **Demographics**

### *Age*

There was a greater range of ages among survey respondents using attendant services than among attendants. People using attendant services were, on average, slightly older than attendants.

The majority of survey respondents using attendant services were between 35 and 54 years of age, but ranged in age from 15 to over 65. The majority of attendants were between 25 and 44 years of age, with a range of 20 to 65+.

### *Using/Providing Attendant Services*

Sixty percent of survey participants using attendant services had done so for five years or more, while 16% had been using services for three years or less.

Forty-four percent of attendants had been working for 5 years or more, while 32% of attendants had been working for three years or less.

## *Funding*

Forty percent of survey participants using attendant services identified as “self managers receiving direct funding to hire and train” attendants.

Twenty-four percent lived in supported living units and received services through an agency, 17% received services through a community care access centre, and 20% indicated “other.”

This last figure is worth noting, since several people indicated that their ***attendant services were not provided through a single source*** and included a mix of services, some of which were paid for and others of which were volunteer services provided by friends and family members and/or through other arrangements.

## *Education*

Sixty-one percent of attendants participating in the survey had attained a college diploma, 24% had an undergraduate university degree, and 15% held a graduate degree.

Sixty percent of survey respondents using attendant services had attained a college diploma, 22% had an undergraduate degree, and 22% held a graduate degree.

## *Urban or Rural*

Survey participants were largely from urban areas. Eighty-two percent of people using attendant services, and 92% of attendants, currently live in a city or town with populations greater than 10,000.

## *Gender*

We asked participants to tell us how they describe their gender; the results are summarized in Table 3, below.

**TABLE 3**

	People Using Attendant Services	Attendants
<b>Female</b>	45%	80%
<b>Male</b>	52%	17%
<b>Trans*</b>	1%	3%
<b>Prefer Not to Answer</b>	2%	0%

*\* The survey allowed for trans people to identify as male-to-female (MtF) or female-to-male (FtM). Because of the relatively small number of people who identified as trans we collapsed the numbers in this chart.*

### *Sexual Orientation*

We asked participants to self-identify how they describe their sexual orientation.

**TABLE 4**

	People Using Attendant Services	Attendants
<b>Heterosexual</b>	80%	80%
<b>Gay</b>	3%	5%
<b>Lesbian</b>	6%	6%
<b>Bisexual</b>	4%	6%
<b>Unsure or Prefer Not to Answer</b>	7%	3%

### *Living Arrangements*

This question was only asked of people using attendant services. Of these survey participants, 49% live alone, 28% live with a partner/spouse, 16% live with family members, 4% live in a group home.

### *Relationship Status*

This question was only asked of people using attendant services. Of these survey participants, 65% were single, 33% were partnered, and 2% preferred not to answer.

## PART II

### Analysis of Survey Themes and Topics

After reviewing all the data, our four-person work group focused on the qualitative responses to questions and from those developed the following six themes and topics:

- The care relationship
- Lines
- Establishing comfort
- Communication
- Perceived safety
- Reduced privacy

The themes are “bigger picture” issues that came up in many topic areas and ran throughout responses from both attendants and people using attendant services.

Each theme is subdivided into separate topics that provide more concrete examples of what both attendants and people using attendant services identified as important to the conversation about sexuality and sexual health. Most topics are relevant to both people using attendant services and attendants, but some are more relevant to one group than the other.

To illustrate the ways in which the themes appeared in the survey, we include sample quotes from the surveys.

Themes and topics are not presented in order of importance or relevance.

### Guiding Principles

Before we get into the specific themes and topics we derived from the survey responses, we want to share two overall principles that underlie much of what we were told by attendants and people using attendant services: intimacy is a part of every working care/support relationship, and sexuality is always both personal and political.

#### *Intimacy*

*Whether or not they considered the relationship to be working well, most participants talked about the **unique challenge of a working relationship that involves a high degree of physical intimacy**: “I think we already provide very intimate care to our clients; I do more for my clients than I would for my husband and I believe that if we*



*also assist them with any form of sexual intimacy we are crossing the line. We should leave that to the professionals who are prepared to deal with the psychological ramifications.” (AP)*

*“I want to be treated as a human being rather than an object needing services. There is more to life than getting services met. Moving from the servant mode to a family/familiar mode is a large jump. It is not so much that we need sexual servicing as much as we need intimacy.” (AU)*

*“Be aware of how your body is interacting with the other person’s, how they might be reading your body language and how you want them to be. This is really important in moments of intimacy which are on some level moments of vulnerability (physical or emotional) for both parties.” (AP)*

In some ways, intimacy offers a connection between how we think about “care” and how we think about “work.” Whether we are comfortable with it or not, it is the intimacy of the relationship that makes it unique. Intimacy is what makes “care work” powerful but also, at times, confusing.

Giving both attendants and people who use attendant services the opportunity to talk explicitly about intimacy, and hear what the other has to say, may improve the working relationship and could be useful as an advocacy tool for both groups.

As you read through this section you will see the word intimacy a lot, but even when you do not read it on the page, we want you to be thinking of how intimacy informs each theme and topic.

### *Sexuality Is Personal and Political, Always*

Regardless of our specific upbringing, we were all raised in societies and cultures that hold some shame and fear about sexuality. From an early age most of us are taught that sex is private, personal, and not to be talked about with others, except those we are “intimate” with.

This message can lead us to think that sexuality is only a personal, individual issue, and that it is not related to the social, cultural, and political world around us.

In fact, ***how we develop sexually, as well as our sexual options and choices, are heavily influenced by the world around us***; this world includes family, society, religion, politics, education, and more. Our sexual options are related not just to how we talk and move, but to how others treat us and laws that govern our rights to be in relationships, to engage in particular sexual activities, and to marry.

As you read through these themes and topics we encourage you to think not only about the personal stories, but also about the world that they take place in.

## Theme 1: The Care Relationship

*“Some [attendants] are not comfortable with their own bodies. When you’re doing this kind of care, you have to shut yourself off. They have to maintain their professionalism, so it can become very cold, impersonal, personal care. [Independent Living] assumes you can speak for yourself.” (AU)*

*“For me it is a matter of the heart – you may provide physical assistance, but you end up supporting each other emotionally.” (AP)*

*“I can’t even imagine arranging any [sexual support] with my caregiver; I don’t have the energy to explain/train.” (AU)*

When agencies and organizations talk about attendant services, the relationship between the person using attendant services and the attendant often takes a back seat to discussions of work flow and safety. However, when you ask people who are in these working relationships to talk, they usually talk about the unique nature of the relationship itself; a relationship that is at one level emotional and intimate while also being professional and at times mechanical.

Attendants and people using attendant services may or may not experience the working relationship as caring or as a “care relationship.” Care is often mentioned either as something that is missing, or as something that is not possible given the nature of a particular agency or working relationship. People’s stories demonstrated that ***the experience of attendant service as a care relationship depends on many things***, including how support is received, negotiated, and paid for, what sort of rapport there is between the individuals involved, and the kind of “connection” people have.

Many attendants and people using attendant services described ***feeling as if the other person did not see the relationship the same way they did***. These differences in expectations – and also in basic definitions of what is meant by attendant care or attendant services – can become flash points for conflict around service delivery. These points of conflict can become heightened when sexual support is discussed, requested, or provided.

## *Topic 1.1: Sexual Rights*

***In order to talk about sexual support, one must first agree that people who use attendant services have basic sexual rights.*** Not all participants adhered to this principle, but in the cases where sexual support was a part of a healthy professional relationship, all parties involved made it clear that they believed sexuality to be a basic right.

***Unfortunately, the model of rights often used in the care relationship is an either/or model.*** One person's rights are protected at the expense of the other's. In terms of sexual support, this debate pits the right to sexual expression against the right to a workplace that is free of sexual harassment or fear.

In this model of looking at sexual rights someone always loses, and it is most often the person who either has, or is perceived to have, less power. Establishing a different way of thinking about sexual rights will not happen easily, but we can start by asking the basic questions that underlie this model:

What constitutes a person's right to sexual expression, and what does sexual expression involve?

If an attendant cannot be required to provide sexual support, and yet someone using attendant services has the right to receive it, how are we to make sense of the situation?

One of the obstacles to establishing the sexual rights of people using attendant services is that many attendants may not experience themselves as having sexual rights, and they bring this personal framework to their jobs. In the survey, some attendants expressed doubt as to the fairness of asking them to assist others with sexual support when they feel unsupported in their own lives. One participant said, "no one helps me with my sex life, so why should I have to help others?"

## *Topic 1.2: Here/Not Here*

One of the more subtle experiences described by both attendants and people who use attendant services is a feeling of "disconnectedness" or "invisibility" when they are together. This was described as happening when you are in a room with someone else who does not fully acknowledge you as having an active presence in space or in the relationship. People described this as ***the feeling of being "here but not here."***

In the ***independent living model***, there is one agent: the person directing care. ***Attendants can sometimes feel as if they are reduced to being a machine, or just arms or legs or hands.*** Because they are not the "agent," it can be unclear what they are and are not responsible for. Attendants working in agencies may be guided by policies that dictate the scope of their work, but these may not always match their own sense of moral or ethical

obligation or responsibility. In this model, attendants are not allowed to acknowledge their own knowledge or skills, except when they fits with clients' needs or expectations.

In the **medical model**, people using attendant services often get reduced to an object, or a task that needs to get done. **People using attendant services can feel like they become a thing to “set up” and “clean up.”** Although they are the ones directing the care, the knowledge and skills that get brought into that relationship can be dismissed by attendants as a “know-it-all” attitude. This approach does not just happen at the attendant level; it is often reflected in written policies and contracts at the level of attendant service agencies.

Ironically, **both attendants and people using attendant services share this experience of feeling like they aren't really there.** However, attendants and people using attendant services rarely talk about it, either with each other or with colleagues.

Because this experience evolves in part from the very models that guide the care relationship, many feel as if there is no point in talking about it. We disagree, and we think that discussion-based workshops are a great space to begin to unpack these feelings and talk about how feelings can be discussed with the other person in the relationship.

### *Topic 1.3: Ableism and Internalized Ableism*

“Ableism” refers to the physical and social ways that people with impairments and lived experience of disability are marginalized, excluded, or otherwise prevented from participating in the broader community and accessing their basic rights.

In the context of sexuality, **ableism includes beliefs that people living with disabilities are not sexy or sexual and are not capable of having a healthy sexuality or healthy relationships**, specifically because of their disabilities. Ableism fails to acknowledge that people with disabilities are systemically marginalized and discriminated against in ways that make it more difficult for them to express and explore their sexuality, find sexual partners, and experience healthy sexual relationships.

“Internalized ableism” refers to the way that people with disabilities come to accept these same attitudes, even though they conflict with their own feelings of self-worth and desires to be sexual and to have intimate relationships.

Ableism impacts sexual support by influencing what attendants expect and pay attention to. Attendants who assume the person they are working with is not sexual, or that sex is not important to that person, express that through their actions. They are less likely to start or pick up on conversations about sexual support, as they do not perceive it as an issue. They also send non-verbal messages that they are not someone with whom it is safe to discuss sexuality. **Ableism takes sexuality off the table before a conversation even starts.**

Internalized ableism has a similar impact on the ability or willingness of someone who uses attendant services to raise questions about sexuality in the working relationship.

Internalized ableism shapes interactions by influencing what a person may feel like they can or cannot ask about or express with an attendant.

### *Topic 1.4: Power Dynamics*

Probably the most obvious power dynamic in an attendant/client relationship is the dynamic of disabled versus non-disabled. To the outside world, this dynamic may seem simple: the disabled person has no power and the non-disabled person has all the power. But ***people in these working relationships describe a much more complicated power dynamic.***

Both attendants and people using attendant services share stories of other power differences that they experience across a range of roles and identities, including (but not limited to):

- Employee/employer
- Race
- Class
- Gender
- Education
- Sexual identity
- Sexual orientation

Both attendants and people who use attendant services can be marginalized in multiple ways, often based on the identities listed above. But these experiences of being marginalized are rarely made explicit. Society pressures us not to talk about the ways that we are left out. We are supposed to stay silent and simply try to fit in. This, of course, never fully works.

Instead of being a source of connection and strength, the ways in which both attendants and people using attendant services have been marginalized often become a site of conflict and resentment.

There is a long history of casting the roles of attendant and client as "us" versus "them." There are few opportunities to talk about how attendant and client experiences of power and marginalization are connected to sexuality and how these experiences impact the way they interact with each other when the topic of sex comes up.

## Theme 2: Lines

*“The goal of attendant care services is to enable independent living – sexual expression is part of that. That’s the theory. The practical application of this theory would likely be difficult – where do you draw the line? Is there a line? Should attendants assist in preparing you for sex/masturbation (washing, positioning, making sexual aids available within easy reach) only, or also be present during sex/masturbation?” (AU)*

*“Professionalism and privacy is very very important when assisting with intimacy. Since there doesn’t seem to be a drawn line of when assisting becomes participating, you have to decide what you are willing and not willing to do. You should discuss this as well with the client beforehand, and use common sense.” (AP)*

People using attendant services and attendants often used the concept of “lines” when describing their experiences of thinking about, providing, or accessing sexual support. Lines are similar to boundaries, but are different from the kind of professional boundaries that may be a topic of training and discussion. Rather, these lines often became apparent in a surprising way, usually after someone has crossed one (as in, “they crossed a line when they did that”). Some of the lines people talked about included:

The line between what is sexual and not sexual

The line between what is appropriate and inappropriate

The line between personal and professional

The line between wanted sexual comments or actions and unwanted sexual comments or actions

The line between assisting in sexual expression and participating in sexual expression

These lines are not always straight or clear. They move and change, depending on past experiences, the particular situation, and the people involved. Project participants described the position of their lines as being related to many things, including age, culture, and faith.

### *Topic 2.1: Non-Sexual Activities That in Other Contexts Are Sexual*

It is not uncommon for attendants and people using attendant services to have encounters that involve the kind of touching one usually only does during sex. Transfers and assisting with bathing and going to the bathroom can all involve touch which, in most other contexts, would be happening as a form of intimacy or for sexual pleasure. In these moments two bodies are working together, essentially working together as one body.

These moments can create awkwardness that few attendants or persons using attendant services are prepared for. And while attendants may receive training on the mechanics of these activities (e.g. how to do a transfer, how to assist with bowel or bladder care), neither attendants nor people using attendant services receive any formal support or training on how to navigate personal feelings and communicating with the other person.

Both attendants and people using attendant services talked about experiencing a ***desexualizing of the body*** in these moments. Sometimes they felt they were desexualizing the other person, sometimes they described desexualizing themselves, and sometimes they described feeling desexualized by the other's actions or attitude. How, and if, attendants and people using attendant services manage to desexualize these situations may have an impact on how they feel about themselves as sexual. This is a topic that needs to be further explored.

Additionally, in the context of attendant care, attention is usually focused solely on disabled people's bodies. ***We cannot forget that the body of another person, the attendant, is also present.*** We need to be mindful of this and make room for attendants to explore their experience in these moments.

## *Topic 2.2: Professional Boundaries*

Asking for, and providing, sexual support in the context of a work relationship requires clear boundaries. But how does one find, establish, and maintain those boundaries? This is not a question with a single answer.

In our survey, people providing and receiving attendant services shared more stories of boundaries being crossed than of boundaries being respected. The result is often a violation of basic rights for people using attendant services, and sometimes a loss of employment for the attendant.

The importance of professional boundaries becomes immediately apparent when a topic like sexual support is raised. Without professional boundaries, both the person requesting sexual support and the attendant receiving that request can lose sight of context. This means they miss an opportunity to make sexual support happen in a way that is safe for all parties and contributes to both life and work satisfaction.

Both attendants and people using attendant services need support, not only in learning how to maintain professional boundaries, but also in developing boundaries that are personally relevant and realistic. The diversity of opinions expressed and the range of activities that were disclosed in our survey indicate that without personal "buy in" from both attendants and people using attendant services, government and agency policies and guidelines will have little impact, regardless of how they are enforced or used.

### *Topic 2.3: Falling for the Other*

Many people in the survey spoke about one fear in particular when talking about crossing a line: the potential that one person in the working relationship will “fall for” (as in, fall in love with) the other person. Usually the assumption was that the person receiving attendant services would fall for the attendant, and the fear was that providing any sexual support would lead to these kinds of emotions.

In fact, ***most of the stories we heard that described sexual support didn’t include anyone “falling for” anyone else.*** Still, both attendants and people using attendant services may benefit from a discussion of what underlies this fear or concern, and how the fear or concern itself may influence decisions to ask for or provide sexual support.

It is possible that this fear is tied to a larger idea that sex and love always go together. If one believes that where there is sex there must be love, and where there is love, there must be sexual feelings or activities, it would make sense that providing sexual support would almost inevitably lead to feelings of love.

This may be a common belief, but it is a value-laden belief, not a fact. Many people have the experience of enjoying sex without love and of having loving, intimate relationships that do not involve sex.

This topic raises other connected questions about our ability to separate sex from love and how sexual support, which for most is experienced as intimate and vulnerable-making, can be understood outside the context of intimacy or love.

The communication required for sexual support builds intimacy, and intimacy may create a space where love (though not necessarily of a sexual sort) can develop. Yet it seems equally clear that neither intimacy nor love precludes the ability to be professional and maintain boundaries.

### *Topic 2.4: Job Descriptions and Contracts*

Job descriptions and contracts are, in part, attempts to clarify things for the purposes of safety and satisfaction for both employer and employee. To the extent that job descriptions and contracts do this, they are useful. However, the expectation that all aspects of the working relationship be documented bumps up against several problems when it comes to sexual support.

The silence in society about sexuality in general is clearly reflected in the silence about sexual support in job descriptions, contracts, and service agreements.



Since participants in the survey received and provided attendant services in so many different contexts (direct service, through agencies, outreach, family members, for pay and barter, etc.), it is difficult to speak generally about job descriptions and contracts. Some people have no control or input while others have total control, and some fall in between those two extremes.

Many people with input or control over job descriptions and contracts say they would never include the term “sexual support” in a job description, while others insist on bringing it up in interviews. ***Attendants responding to the survey were divided on how they would respond if sexual support were listed in a job posting, even while they acknowledged that it may be part of the job.***

This topic can quickly become a point of conflict. If sexual support is mentioned, does that mean it is required? Would that be desirable or even legal? Here is where the right to access sexual support as someone using attendant services can be pitted against the right to be protected from sexual exploitation as someone providing those services. The challenge is to ***find a way of talking about this that puts people on the same side of the issue and does not automatically set up the dynamic of “the attendant” versus “the client.”***

### **Theme 3: Establishing Comfort**

*“I think someone being comfortable with the fact that someone with a disability might be sexual is much different than being comfortable with actually assisting a disabled person. I expect the first in all my attendants, but not the second.” (AU)*

*“I can refuse to provide sexual assistance or any service that makes me feel uncomfortable.” (AP)*

For survey respondents, feeling comfortable with the person you are working with and in the working relationship was often considered a prerequisite before any request for sexual support would be made or offered. ***Many attendants and people using attendant services reported a lack of comfort as a reason for not requesting or providing sexual support and/or for not talking about sexuality at all.***

But what does it mean to be comfortable with sex? Some people are comfortable with their own sex lives, but not comfortable talking about sex with others. Some people talk about sex with friends and strangers and seem comfortable when in public, but can feel uncomfortable and threatened if a conversation ventures beyond joking when in private.

An attendant’s comfort with sex in their own lives may or may not have an impact on their ability or willingness to acknowledge that the people they work with are sexual beings and

the bodies they work with are sexual bodies. People who use attendant services may be comfortable with themselves sexually, but this doesn't mean they will find it easy or desirable to negotiate sexual support if it involves disclosing aspects of their sexual desires to someone they work with. ***For both parties, sex may be an important topic of conversation and one they are usually comfortable discussing, but having (or being) an attendant as a second or third person in the room when sex is about to happen, or is happening, may require a different kind of comfort.***

There is no one way to create comfort in a working relationship. Some people told us that comfort came from treating the working relationship more as a friendship, whereas others were most comfortable after professional boundaries were identified and maintained.

### *Topic 3.1: Trust*

From their first interaction, an attendant and the person accessing attendant support are required to put their trust in each other. This is not so much a choice as it is a necessity. If you require attendant services, you rely on attendants to do their job safely and professionally. If you are an attendant, you rely on the person using services to provide instruction so that you may do your job.

At the same time, most people who responded to the survey told us they wouldn't request sexual support or consider providing sexual support unless they trusted the person they work with.

So it seems that there is trust, and then there is trust. Responses indicated that people are aware of different levels and even kinds of trust. Trusting someone in one area does not always translate into trust in another area. There is a level of trust related to the basic professional services the worker provides – for example, a person receiving attendant services may trust that the worker will not drop them during a transfer. However, there is another level of trust that is more difficult to define. The person receiving attendant services also needs to trust that the worker has their best interests at heart and that they respect them as a whole person. We should be asking ourselves and others how the kind of requirement of trust that takes place in an attendant client working relationship might impact other or deeper kinds of trust that make sexual support feel possible and safe.

We should be mindful of the imbalance in the opportunity to choose to trust when one is reliant on attendant services that are not managed through direct funding.

And finally, because the topic of sexuality always holds the possibility of accusations of harassment or abuse (for both the attendant and the person using attendant services), the issue of trust in the relationship becomes even more important when broaching the subject of sexual support.

### *Topic 3.2: Assumptions*

Assumptions about people we work with can have a huge impact on comfort in the workplace. Consider these two examples:

An attendant feels comfortable with someone they are providing services to, and thinks sexual support will never be an issue because they assume the client is a “good girl” based on what they understand to be the gender, ethnicity, age, and religion of the individual.

An individual using attendant services says he does not want to be supported by a particular attendant because he assumes the attendant is gay, and believes that this means the attendant will want to talk about sex or will be promiscuous and unhealthy.

In these examples, assumptions are being made about sexuality based on what one person thinks they know about another person and on their value-laden beliefs about certain socially salient categories. An attendant assumes that a young, Christian, female client is not going to be interested in sex. A person using attendant services assumes that a gay attendant is going to be overly interested in sex. In both cases the person making the assumption is filling in what they do not know with their own beliefs and whatever stereotypes they were raised with.

One of the greatest dangers of not communicating about sexuality is that we fill in what we do not know with assumptions. When we never learn about another person’s sexuality it is easy to make assumptions about what it must be like.

But how do we begin to challenge our assumptions about people and their sexual values when things like sexual orientation, gender, class, race, ethnicity, and religion are often considered taboo topics of conversation in the workplace?

People using attendant services and attendants need a space where it is safe to talk about their assumptions and figure out a way to check them when possible without intentionally offending the other in the process.

### *Topic 3.3: Sameness and Difference*

Many respondents described those with whom they felt comfortable working somewhere on a continuum of similarity and difference from themselves. People indicated that they felt more comfortable working with someone they considered to be “the same as me” and less comfortable with people they considered to be “different from me.”

For both attendants and people using attendant services, sameness was tied to perceptions of race, age, religion, orientation, sexual and gender identity, class, and education. And when sameness was perceived to be there, an assumption was made that there would be shared values and beliefs around sexuality. Of course, this is not always the case.

Two people who come from the same country, go to the same church, and have the same perceived gender identity and sexual orientation may hold very different sexual values and beliefs about sexual rights. And two people who appear to be different on the surface in all sorts of ways may think the same way about sexuality. However, assumptions about sameness or difference, regardless of their accuracy, can have a profound impact on decisions to ask for or provide sexual support.

### *Topic 3.4: Humour*

Based on responses to our survey, sharing sexual jokes is a common form of sexual communication between attendants and people using attendant services.

Humour is used to “test the waters” of whether or not a working relationship can safely include sexual support. Humour may also be used to deal with a situation that feels awkward, uncomfortable, or tense. And humour is used as a defence or way of retracting when the other person reacts negatively to a request or suggestion (for example, “I was just joking, I didn’t really want to go to the sex store”).

Humour is subjective and it can easily result in marginalizing one group or another. Attempts at jokes are not always received in the ways they are intended.

The use of humour (whether successful or not) is a rich topic to unpack, and it raises many questions:

What is the intention of using humour?

When is humour a good idea and when is it a bad idea?

When people use humour, are they trying to make themselves or others feel more comfortable?

When can humour open up a conversation and when can it shut it down, or make someone feel offended or upset?

How do you address humour that you do not like or find offensive?

## Theme 4: Communication

*“Since it is an employer-employee relationship, one has to be very careful not to make the other uncomfortable when [communicating about sexuality] and create a hostile work environment.” (AU)*

*“My experiences in this regard have been positive – it makes me feel good that people are comfortable asking me for assistance and I am an open person – I like discussing things with people.” (AP)*

Communication is required for any form of attendant support to occur. Individuals and agencies promoting an “independent living model” often say that an attendant’s job is simply to follow direction. The implication is that instructions can be conveyed neutrally. This idea ignores something essential about communication, which is that **we are always whole human beings when we communicate**. The words we use and how we convey instructions matters. We bring our experiences and our mood and our awareness to communication in the moment. And there is another human being (with their own set of experiences, moods, and understandings) there to take in the information and respond. In other words, communication is always complicated.

Add to this the fact that most of us carry some ignorance, shame, and silence around sexuality and you can imagine how talking about sex in a working relationship can seem not only difficult but, at times, impossible.

Sexual communication encompasses a wide range of interactions, from sexual joke telling, to disclosure of past sexual experiences, to the giving of sexual advice. Most attendants and people using attendant services told us that they usually wait for the other person to bring up the topic of sex, especially if it has not been spoken about before. Both groups suggested that raising sex could be perceived as a form of harassment or viewed as simply not appropriate. Therefore, it feels safer to let the other person bring it up. This is just one of many obstacles to accessing sexual support, as ***even those who might agree that sexual support is a part of attendant services may be wary of bringing up the topic altogether.***

This theme inspires many questions; for example:

How do honest conversations about sex ever get started?

How do you move from making a sexual comment or sexual joke to having an “honest” conversation about sex?

Do you need to talk about sex in order to ask for or provide sexual support?

### *Topic 4.1: Defining Sexual Support*

While sexual conversations, particularly of a joking kind, may be common, it is rare for people using attendant services to communicate a clear definition of what sexual support means to them, and it is just as rare for an attendant and/or an attendant service agency to communicate a definition of sexual support for the people accessing their services.

Sexual support, like all other aspects of attendant services, requires communication. One important difference is that while many of us learn (formally or informally) how to communicate about other aspects of life in order to potentially direct someone to complete the task (cooking, shopping, etc.), few of us get the opportunity or develop the skills to talk about sex.

There is no single definition of sexual support. Some view sexual support like any other kind of “private” support (often bowel and bladder care gets mentioned in this category). Others consider it “special work” requiring specialized outside training. And still others talk about it happening mostly in working relationships that were more “like friendships.”

Whatever an individual’s definition of sexual support may be, ***both attendants and people using attendant services need the opportunity to discuss their definitions.*** Without this, when trying to negotiate sexual support, the result will be at best confusion and at worst an experience of feeling violated by someone with whom one has had a working, trusting relationship.

## **Theme 5: Perceived Safety**

*“It is too difficult to find good attendants at the best of times. If sexual expression is listed in the job description, one would probably have no applicants. If anyone did agree to this requirement, I would be very wary of that person, wondering if he or she were safe to have around.” (AU)*

*“Assisting with sexual expression would be acceptable to me if it were structured in a way that maintained the dignity of all parties involved and was safe for attendants.” (AP)*

As the first quote above highlights definitions of safety are intimately connected to sexuality. In this quote the individual using attendant services is in a sense, trapped. They can’t bring up sex because they think it would be perceived as unsafe by prospective attendants. But they also would be unlikely to trust any attendant who was comfortable enough with sex to respond to an ad that mentions sexual support. ***Sex itself is experienced as something to be wary of, something that is fundamentally unsafe.***

Safety means many things. Safety is the state of being safe, the condition of being protected against physical, psychological, emotional harm, or a combination of the three. It also speaks to consequences which could be considered non-desirable and which leave one feeling at risk.

Feeling safe may also mean feeling comfortable with what is or isn't occurring in one's immediate environment or perceived environment. Safety may refer to components of a government or agency policy that is intended to keep staff and clients safe. Safety may also refer to what is legal. An activity may feel safe, but if it is the kind of activity one could be fired, or sued, for, then the activity may be called unsafe.

Some attendants in our survey distinguished personal safety from workplace safety. They may refuse to do something that they feel is unsafe, even if it's part of their employer's idea of what is required. They might also do things in the workplace that their employer might not deem as safe, as long as they feel safe doing it.

For people using attendant services the workplace is usually their home so the line between work and personal is fuzzier.

This theme is called "perceived safety" to highlight the fact that nothing is every 100% safe and all action comes with risks. This theme speaks to the experience individuals have of feeling safe or unsafe, and the way they evaluate, or perceive, their own safety and the safety of others in the world.

### *Topic 5.1: Abuse, Harassment, and Exploitation*

Many people experience sexual harassment, abuse, and exploitation in their personal lives and in their work lives. While participants shared many stories that the working group identified as examples of abuse, harassment, or exploitation, the situations described were not always named that way by the people describing them.

It was more common for people to describe something as "potential harassment" or something else as being "mistaken" for abuse.

The lack of clarity in the responses highlights the need to start talking about what these words mean and who defines them. Questions to consider include:

How is harassment defined by attendants and how is it defined by the people they are working with?

What makes harassment "harassment"? Where, for example, is the line between joking and unwanted flirtation or between harassment and assault?

Based on the responses to our survey, we must conclude that individuals do not always have strong feelings about what is and is not problematic behaviour, and what one person reads as acceptable another may experience as abusive. When, for example, might the

sincere asking of a question about sex, or the request for sexual support, be experienced as harassment? Is it possible to have any kind of sexual interaction in a work setting that is not considered or experienced as harassment or as abusive?

### *Topic 5.2: Hiding*

Participants shared many stories of hiding parts of themselves to keep safe, or at least to feel safe. We often hide the things we are told to feel shame about and in the context of sexuality participants shared stories about hiding non-heterosexual sexual orientations, sexual identities, and so-called alternative sexual activities, that they felt would put them at risk of losing support or losing a job.

Hiding may be a practical way of staying safe, but it can come with a price: a sense of powerlessness and fear; fear of being found out, fear of gossip, fear of retaliation.

### *Topic 5.3: Protection, Paternalism, and the Dignity of Risk*

Many attendants consider it part of their job to protect the people they work with from harm. In stories from both attendants and people using attendant services, we saw how an attitude of paternalism prevails in many working relationships and how this idea of protection can easily lead to over-protection.

When it comes to requests for sexual support, the attendant's need to protect the person receiving services, and the pitfalls of over-protection, are often amplified. This is due in part to the idea that sex is always a bit dangerous. Ableism and internalized ableism encourage us to think of disabled people as asexual and/or fragile. The idea of disabled people being sexual or having sex is often considered doubly dangerous and full of potential for harm.

People who use attendant services shared stories in our survey about attendants getting in the way of them exploring or expressing their sexuality out of a fear that they would get hurt or disappointed.

Many attendants responding to the survey seemed unaware of the complicated position they are in as people who can have the power to limit an individual's access to activities and services. Attendants often spoke of people they worked with as incapable of making informed decisions. Attendants may also have the attitude that "nothing bad will happen on my shift."

What is missing is the understanding that the choice to take a risk is a question of human autonomy and dignity; to make this choice for another person denies them this autonomy and dignity. People who use attendant services have the right to take risks. Those risks may



have potential negative consequences, but dignity comes with exercising the right to make mistakes and learning from every outcome, good, bad, or neutral.

#### *Topic 5.4: Conflicts with Agencies/Employers*

Attendants will inevitably experience conflicts with employers, co-workers, and/or managers around the topic of sexuality or sexual support. Conflicts may arise from a fear of losing one's job or a fear of being accused of abuse or harassment. It may also arise from a disagreement with a fellow staff member who is dealing with sexual support in a different way. These conflicts can result in people who use attendant services not getting access to the sexual support they have requested; these conflicts may even lead to people being threatened with losing services altogether.

Each working relationship and work setting will require a unique approach to dealing with conflict. People may find friends or co-workers to commiserate with about these conflicts, but few people are given an opportunity to have a constructive conversation about them.

The specific conflicts that arise around sexual support raise questions that are valuable for everyone involved to consider:

Whose job is it to advocate for the right to receive sexual support?

In what ways are attendants being put in a vulnerable position when they provide sexual support?

Are there situations where it is clearly unsafe for them to do so?

#### *Topic 5.5: Homophobia/Transphobia*

Both attendants and people using attendant services identified homophobia and transphobia as something that reduced their sense of safety in their lives and/or workplaces.

“Homophobia” refers to feelings of fear, disgust, or hatred that come from stereotyping people because of their perceived or actual sexual orientation. “Transphobia” refers to feelings of fear, disgust, or hatred that come from stereotyping people who are perceived to be or identify as transgender or transsexual, or who are otherwise considered to have a non-conforming gender presentation.

Homophobia and transphobia can take the form of words, actions, lack of action, attitudes, and more. These manifestations of homophobia and transphobia can occur whether or not someone who identifies as, or appears to be, gay, lesbian, bisexual, transgender, or transsexual is present.

Respondents discussed dealing with homophobic or transphobic remarks, having sexual support denied specifically because it related to same-sex sexual interests or activities, and being afraid of losing a job if the client were to find out that the attendant identified as gay/lesbian/bisexual/queer. These experiences speak to the need for both attendants and people using attendant services to receive basic information about homophobia and transphobia and about their legal rights under Human Rights legislation.

## **Theme 6: Reduced Privacy**

*"[My attendant] has helped me get my apartment and dinner ready for my boyfriend coming over. She has also, in cleaning up, ended up putting away sex toys that I forgot I left out, which was really embarrassing!" (AU)*

*"I have not had any of these issues. I have a husband and we prefer privacy in the matter." (AU)*

*"When I come in, in the morning, and I know they've had sex, I'll just make a joke or comment, I think it makes everyone feel more comfortable and breaks the tension." (AP)*

There are many ways that using attendant services means living with reduced privacy. Having someone in your space first thing in the morning and last thing at night, having someone in the bathroom with you when you bathe or use the toilet, or even just having someone there whether you feel like being around people or not are all areas where privacy is negotiated.

In the context of sexual support, reduced privacy may mean that someone you work with, or someone who works for you, is a witness to your sexual interests, desires, partners, fantasies, and more. This may be direct, if they are supporting some part of a sexual activity, or indirect, as when an attendant "comes across" something related to the sex life of the person they are working with (e.g. condom wrappers, sex toys in a drawer, or erotic material on a shelf or on a computer).

While both attendants and people using attendant services may get used to reduced privacy in some areas (like dressing or bowel and bladder support), attendants may become so accustomed to being in a client's space that they forget that privacy is not a single experience and that some things can feel more private than others.

The kind of reduction in privacy that receiving sexual support entails can, for some, be considered too high a price. Sexual support may not be requested (or offered) because of a perception that bringing a second or third person, who is not a sexual partner but a worker, into one's sex life represents too great a loss of privacy.

Because reduced privacy is perceived to be something that is non-negotiable and inevitable, both attendants and people who use attendant services may simply not talk about it: If it cannot be “fixed,” then why discuss it? But some responses to the survey suggest that people do want to talk about it, and that it is possible to maximize privacy. Even where people feel that maintaining their privacy is not possible, the opportunity to talk about privacy and have the challenge acknowledged can be helpful.

### *Topic 6.1: Gossip*

Gossip is an issue for everyone involved in attendant services. It may seem like a larger issue in agencies, group homes, and supported living unit settings, but it is equally relevant to people who manage their own attendant support, as this often takes place in the context of a small community, even though that community may be located within a large urban centre. Maintaining privacy and boundaries in the face of gossip is a huge struggle.

Gossip includes attendants sharing conversations they have or things they saw during a booking with other attendants and other people they work with. People who use attendant services do not want their personal lives gossiped about by their attendants, nor spoken about to other clients.

The issue of gossip is complicated by the process of staff documentation, which is required by many agencies providing attendant services. Attendants will often be encouraged to “cover themselves” by documenting events that may or may not be appropriate or relevant. At these times a staff person’s safety or job security may be pitted against the right to privacy of people using attendant services. The people using the services are never there to advocate for themselves when something is being documented, making this an unequal and unfair process.

Attendants may also have concerns about gossip. Those who provide sexual support may not want other attendants or employers knowing about details of their lives that they might share in a conversation with someone during a booking. For example, attendants who may be “out” to clients but not to employers or co-workers are made vulnerable if a client chooses to gossip about them.

Gossip in a workplace is practically unavoidable, but it can seriously impact a workplace and everyone involved. Discussion groups can offer a space to talk about how actual gossip, or even just the fear of gossip, affects how we talk and act and how safe we feel in our homes and workplaces.

## CONCLUSION

The Sexuality and Access Project survey was conceived of as the beginning of a much bigger conversation about how to support the health of Ontarians living with disabilities who use attendant services and the health, workplace satisfaction, and safety of people providing attendant services.

As is often the case when people are given the opportunity to speak without being interrupted, what we heard was not a single voice reporting a clearly articulated set of obstacles, but instead a chorus of voices speaking about complicated, often messy, experiences that are difficult to reduce to easily digestible action points. Nonetheless, as we worked through the responses we were left with some clear messages.

### *The Attendant Service Relationship Is Unique*

The amount of intimate touch that occurs between a person receiving and a person providing attendant services makes the relationship unlike any other professional exchange. Workplace responses intended to support both workers and those who receive services need to be keenly aware of these differences. They should also take into consideration the context of the support, whether it takes place in an institutional setting, through outreach, or in the community.

### *Sexuality Is about More than Abuse and Victimization*

The only policies or formal support mechanisms currently in place focus on sexual abuse and sexual victimization. While guidelines to reduce sexual exploitation are a crucial part of any agency or system response, both attendants and people using attendant services are dealing with a much wider range of questions and experiences when it comes to sexuality and sexual health.

Where training sessions and policies exist around sexual abuse, they need to be expanded to include positive aspects of sexual health, per the *Canadian Guidelines for Sexual Health*. This material should be integrated across agency policy and training documents.

## *Everyone Wants to Talk, But No One Knows How to Start the Conversation*

Project participants made it clear that dealing with sexuality issues in attendant care relationships without adequate opportunity to discuss these issues (both among peers and across divides of power) is an experience that is at best uncomfortable and at worst dangerous.

Both attendants and people using attendant services need safer spaces to talk with peers about their experiences: what works, what does not work, and what they can do to integrate sexual health into their work and lives. The second phase of the Sexuality and Access Project will begin this work by training people across the province to be “peer discussion leaders,” individuals who will facilitate just these kinds of discussions in their communities.

These conversations need to happen not only among frontline workers and people receiving services but also among managerial and executive staff members of support agencies. Currently most workers and people accessing attendant services through agencies feel alone and unsupported by the agencies. Before policies are developed, managers and executives need to talk about the ways that their organizational culture can support the health of their workers and clients, including sexual health and sexual expression.

Establishing policies may not be advisable in all contexts; however, in many settings, developing policies may be a helpful starting point for opening discussions about the ways that sexual health may be supported by attendant services.<sup>2</sup>

There is much work to be done. The status quo finds both workers and clients at a loss for how to deal with sexual health issues in a way that supports both rights and responsibilities. Ultimately, this leaves everyone, including the agencies that manage these services and funders who pay for them, at risk.

It is our hope that the Sexuality and Access Project will provide an entry point into these larger conversations about how people who use attendant services (however they use them) can gain greater and easier access to their basic human rights, including their sexual rights, and how people who provide attendant services (however they provide them) can ensure their own health and safety in the workplace.

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<sup>2</sup> We recommend starting the policy development process by reading the Vancouver Coastal Health Authority's *Supporting Sexual Health and Intimacy in Care Facilities*. While this document is specific to adults living in long-term care facilities in British Columbia, it proposes guidelines that may be applicable or adaptable to individuals living with disabilities in Ontario.

## **APPENDIX A**

### **Surveys**

#### **Survey for Attendant Service Users**

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

Yes / No

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

Less than 1 year

1-3 years

3-5 years

5 + years

3. How are your attendant services funded?

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).

Other (please specify)

4. Has assistance with sex or sexuality been part of any attendant service agreement you have signed?

Yes / No

If you answered yes, what was included in the contract?

5. Has anyone ever talked to you about what you can, and cannot, ask for in a service agreement when it comes to sex?

Yes / No

If you answered yes, please tell us what you were told.

6. Do you think attendants should be required to assist with sexual expression? (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 explain your answer(s).

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

Yes / No / Depends

Please explain your answer(s).

8. Have you ever worked with an attendant you felt comfortable talking to about sex?

Yes / No

If you answered yes, what do you think it was about them that made you feel comfortable?

Did they provide you with sexuality assistance? What sort of assistance did they provide?

9. If you do not feel comfortable talking to attendants about sex, what do you think an attendant could do to make you more comfortable?

10. Have you ever talked with your attendants about sex? (for example: making sexual jokes, talking about dating or your sex lives, asking for sexual advice, talking about being attracted to someone else).

Yes / No

If you have ever talked with an attendant about sex, please give us some examples?

11. There are many ways that attendants are involved in facilitating sexual expression. Using the list below, please check off any of the situations you have requested and/or received assistance with.

Going out to clubs to flirt, dance, socialize.

Going out on a date.

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

Positioning for sexual activities with a partner.

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 use the space below to share any stories about your experiences.

12. 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 sex and sexuality?

Yes / Sometimes / No

If your answer is yes or sometimes, please give us some examples of when you felt it was an issue and what, if anything, happened.

13. Have you ever experienced conflict or disagreement in a dating or sexual 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

If you answered yes, please share any stories you have.

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

Yes / No

If you answered yes, was the refusal followed by negative consequences? Please elaborate.

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

Yes / No

If you answered yes, please elaborate on your experience.

16. Are there any questions we missed or anything else you'd like to share?

17. Please tell us your age.

15-19

20-24

25-34

35-44

45-54

55-64

65 and over

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

some high school

completed high school

some post secondary education

college diploma

undergraduate degree

graduate degree or greater

19. Do you currently live in the province of Ontario, Canada?

Yes / No

20. Does the city or town you live in have less than 10,000 people?

Yes / No

21. 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/spouse.

I live in a group home.



22. Please tell us how you describe your gender.

Male

Female

Trans (FtM)

Trans (MtF)

I prefer not to answer

Other (please specify)

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

Heterosexual

Gay

Lesbian

Bisexual

Questioning

Unsure

I prefer not to answer

Other (please specify)

24. What is your relationship status?

Single

Partnered

I prefer not to answer

Other (please specify)

## **Survey for Attendant Service Providers**

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

Less than 3 years

3 to 5 years

More than 5 years

I don't work as an attendant

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

Yes / No

If you answered yes, please tell us what you remember about the expectations regarding assistance with sexuality?

3. 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 sex ?

Yes / No

If you answered yes, please tell us what you were told?

4. Have you ever received training or instruction on sexuality as it applies to your work as an attendant?

Yes / No

If you answered yes, please tell us what topics were addressed in the training?

5. Do you think attendants should be required to assist with sexual expression? (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.)

Yes / No / Depends

Please expand on your answer(s).

6. Are sexuality and sexual support topics you talk with consumers/clients about?

Yes / No / Depends

Please expand on your answer(s).

7. Have you ever talked with a consumer/client about sex? (some examples include: making sexual jokes, talking about dating or your sex lives, asking for sexual advice, talking about being attracted to someone else).

Yes / No

If you answered yes, please give us some examples?

8. 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 sex and sexuality?

Yes / Sometimes / No

If your answer is yes or sometimes, please give us some examples.

9. 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.

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

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

Helping with positioning for sexual activities with a partner.

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 use this space to provide additional details about your experience.

10. 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 a dating or sexual situation?

Yes / No

Please tell us about one or more situations you've been in.

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

Yes / No

If you answered yes, can you describe whether the request was granted or not, and what the consequences were.

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

Yes / No

If your answer is yes, please tell us more.

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

Yes / No

14. Are there ways you think your employer or organization could be supporting you better around these issues?

Yes / No

If you answered yes, can you give us some examples of what would help?

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

Yes / No

Please expand on your answer.

16. Are there any questions we missed or anything else you would like to add?

17. Please tell us your age.

15-19

20-24

25-34

35-44

45-54

55-64

65 and over

18. 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

19. Do you currently live in the province of Ontario, Canada?

Yes / No

20. Does the city or town you live in have less than 10,000 people?

Yes / No

21. Tell us how you describe your gender.

Male

Female

Trans (FtM)

Trans (MtF)

Prefer not to answer

Other (please specify)

22. Tell us how you describe your sexual orientation.

Heterosexual

Gay

Lesbian

Bisexual

Questioning

Unsure

Prefer not to answer

Other (please specify)