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Whose Sex is it Anyway?:
Freedom of Exploration and Expression
of Sexuality of an Individual Living
with Brain Injury in a Supported
Independent Living Environment

Dr. Karen L. Shue, C. Psych.
McMaster University
Departments of Psychiatry and Behavioural
Neurosciences and Psychology
Ana Flores, O.T. Reg. (Ont.)
University of Toronto
School of Rehabilitation Sciences

Abstract

Individuals living with the effects of a disability have varying degrees of access to sexual opportunities, i.e., "sexual access", when residing in institutions and more structured living environments. Individuals living with the effects of brain injury (BI) and living in a supported independent living environment (SIL) may face cognitive, behavioural, and psychosocial disabilities that present additional challenges to sexual expression and relationships. Issues relating to sexual accessibility in a SIL environment for individuals living with the effects of BI are discussed through a case study. Particular attention is paid to the impact on sexual accessibility of prior experience, legal competency, need for instrumental support, and attitudes of those working directly with these individuals. Ongoing education must address the attitudinal and societal perceptions that affect sexual accessibility for men and women with disabilities.

Individuals living with the effects of a disability have varying degrees of access to sexual opportunities, i.e., "sexual access", when residing in institutions and more structured living environments. Individuals living with the effects of brain injury (BI) may face additional cognitive, motor, behavioural and psychosocial disabilities that present challenges to sexual expression and relationships. Those persons who require direct support in the majority of activities of daily living are not afforded the same degree of

privacy in exploring and expressing their sexuality that individuals without a disability enjoy, especially when residing in supported independent living (SIL) settings. Issues relating to sexual accessibility for individuals living with BI in a SIL environment will be discussed as highlighted through one woman's experience.

In this paper we highlight the issues, challenges, and potential strategies to address the expression of sexual interest in a 30-year-old woman. This woman survived a serious brain injury in her late teens and currently lives in a SIL setting. While her details give a picture of the challenges particular to her situation, the overall issues she faces are generalizable to any adult with cognitive deficits who lives in a setting where some form of assistance from an agency is provided. We are presenting her case and the emerging issues in a non-academic way because the issue of sexuality and access to one's own sexuality is such an intimate and personal issue. We wanted to make sure that the intimacy was not lost in theoretical and academic jargon.

With her permission, we: (1) provide background information about "Jo's" injury and life; (2) highlight salient issues from the perspectives of each of the "stakeholders" involved in her life; (3) describe specific support issues and their applications to Jo's specific situation; and (4) finally discuss how Jo's issues are shared by individuals more generally.

Background Information About "Jo"

Jo is a 30 year old woman who was injured at 16 years of age in a motor vehicle collision. Following an intensive period of in-patient rehabilitation, she returned to her parents' home for approximately ten years with in-home attendant support provided by a local hospital rehabilitation pilot program. Approximately three years ago she moved into an apartment in a SIL setting that provides 24-hour support for activities of daily living (ADLs), community mobility, and activities both in and out of her apartment where she currently lives. There is no standardized policy relating to sexuality in this setting apart from recognizing the right of individuals to have a sexual life. Support needs are addressed in a way appropriate for each individual as they arise and if support is not requested or required, there are no intrusions into that sphere of an individual's life. In Jo's case, although she is living more independently, she is not legally her own decision-maker and her parents continue to be her legal guardians. They are quite concerned and cautious about her sexual access and have requested that SIL service providers monitor these activities to some extent.

Jo's brain injury has left her coping with significant cognitive impairments (i.e., memory, attention, "executive functions"), physical impairments (i.e., dysarthria, spasticity), and "inappropriate" behaviours (e.g., touching others without permission, making "disinhibited" comments to attractive strangers). She identified support to explore her

sexuality (e.g., flirting, finding a partner) as one of her support goals. Her pre-injury sexual experience was minimal. Due to her impairments, Jo requires one-to-one support to access the community.

For example, she requires support to arrange transportation, to use a computer or telephone book to locate a specific wheelchair accessible store, to propel her wheelchair for moderate distances, and to communicate with strangers. Jo is considered legally "incapable" in Ontario of making independent decisions due to her difficulties in understanding information relevant to a decision and in demonstrating that she appreciates the likely consequences of her decisions (Substitute Decisions Act, 1994), both of these directly related to frontal lobe dysfunction resulting from the BI. Therefore, when health and safety issues are involved, she and the SIL service provider are required to consult the legal substitute decision maker (SDM), which in this case are her parents. She is encouraged in the SIL setting, however, to make decisions about her daily activities and overall priorities. Without support, and without specifically requesting this support from service providers, she would not be able to access resources to explore her sexuality.

Jo recently requested support to purchase a sexual device to aid masturbation. The difficulties faced by Jo and her support partners are a powerful illustration of the many influences impacting on such an apparently simple request. In the next section, we present some of the reactions to Jo's request from all the "stakeholders" (i.e., individuals affected by her request) beginning with Jo herself.

"Stakeholder" Perspectives

Personal Perspective

I am an adult woman with a strong, healthy interest in my own sexuality and in having sexual experiences. But I also have a brain injury that means I have ongoing motor problems and that people second-guess my choices and decisions all the time. I know I can be hard to understand because of the spasticity that affects my speech, but that doesn't mean they shouldn't try to see and hear me as the adult I am. I am told I am too "impulsive", too "disinhibited", too "direct" when I see a guy I think is hot. How am I ever supposed to get a guy's interest if I don't say it straight out?

I recently decided that at least I wanted to be able to pleasure myself, whether or not I'm going to be able to get a boyfriend in the near future. Well, wasn't that a ruckus! For my part, I thought it was a perfectly reasonable request that no one should have to be involved in. But everyone and their brother was involved! First, I had to ask my "Co-coordinator" to assist me to buy a stimulator. I can't get to a store on my own because of the wheelchair and needing to use disabled transit, so it's not like I could sneak off and just get one for myself.

Well, "supportive living" being what it is, my Co-

coordinator had to go to talk to her supervisor to get the ok. What ok? It's my body, isn't it? Well, next came the discussions with the supervisor about what I wanted to do and how I wanted to use it. How embarrassing to have to explain the intimate details to someone else! She said she needed to know because it would make a difference to what they needed to do to support me.

Everybody else can just go and buy the thing and have done with it, but I will have to have someone help use it in some way at least. I guess she's right, but I hate being at the mercy of all of these people and having to share every little private aspect of my life. She also talked about whether I or "we" would need to talk to my mother about it. I declined that opportunity - my mother would die thinking of her sweet brain-injured daughter masturbating! The supervisor can do it, if she must.

The supervisor was trying to convince me not to get the kind you insert, just a "stimulator" because she seemed to think it would be "safer" and that service providers would be more comfortable helping me with that. What's for them to be comfortable about? It's my sexuality we're talking about here! They just have to hand me the thing, make sure I reach myself, and go away. There didn't seem like one aspect of this whole idea I could keep private - from the notion of getting one to actually going shopping for one (they have to go with me, but maybe it will be someone fun and not someone "embarrassed" by the whole idea) to using it each time. I can have "private time" here, but even then I need to let someone know not to interrupt me. Is nothing sacred?

Parental/Guardian Perspective

I recently was informed that my daughter is interested in using some sort of device for personal sexual stimulation. I didn't know what to say. I was shocked and not eager to discuss this with the agency people. I don't think it is a good idea. I am afraid that having one of these things available will make her even more vulnerable to abuse. She can't use it independently and if someone has to help her, well, the risk of their abusing her directly or indirectly is obvious. I'm also not sure that I see how this will be helpful to her. I suspect that it will make her even more frustrated and disinhibited than she already is. And her disinhibition, making the wrong kinds of comments to the wrong sorts of people, is part of what makes her so vulnerable to start with.

She will never have a boyfriend or a husband and I just feel like it is cruel to encourage her to think about these things. But beyond that, I'm mostly worried about the idea of how she would use it. Who would be helping her? How would they be helping? What if she hurts herself with it? I wouldn't want her to hurt herself, but I also don't want someone else to be touching her there, especially in a sexual way - that just wouldn't be right. I just don't see how it can be done.

Direct Support Perspective

We are going to...what!? Oh no, I'm not going to help someone use one of those! What would I have to do? Put it in her? Hold her hand while she uses it? Clean it and her afterwards? Oh no, not me! How embarrassing would that be? And that would be another thing the guys here don't have to do, that I would. And what if she got an infection or something? Would I get it? I'm not even sure I'm comfortable with the whole idea - should she be masturbating when she says all these inappropriate things to people? I don't get it - they won't let us give her a hug good-night, but they want us to help her masturbate!? Give your head a shake, folks! This is even worse than letting Steve have the girlie magazines. I mean, I don't agree with that, pornography exploits women and I don't think we should be teaching him that it is ok by letting him have it, but at least I don't have to help him actually use it. At least he knows he needs to ask for private time. But this! She can't use it by herself, can she? So I'm going have to...no way!

Administrator Perspective

Oh my. Can we do this? The risks of having staff participate in helping a young woman masturbate...my blood is running cold. What if she accuses someone of abuse? She has in the past indicated that a professional touched her inappropriately and her parents are already concerned about the few occasions when a male staff needs to help her transfer to the toilet.

I seem to recall that in the past she needed to receive an internal examination to determine whether there was any abuse going on. If she is using a device, will this mask signs of abuse? Could she hurt herself or be rough enough to produce indicators that could seem to indicate abuse even in its absence? Surely, she shouldn't be able to get a device that would be internal, maybe that would avoid these kinds of problems.

But still, the staffing issues are very complex. I can't make people assist her if they don't want to, or can I? What will they have to do, exactly? Will they touch her? What if she complains about someone? Maybe there should always be a witness present when someone is assisting her with something as intimate as that? I wonder if this kind of activity is included in our insurance? Maybe I should write a policy and procedure regarding the type and level of support to provide? What if she gets hurt when someone is helping her? I heard she didn't want her parents to know, but as her guardians, they are the legal decision-makers for her, how could we not tell them? Maybe we would have to create a subteam of people trained in the use of the device? What would be the costs of that - what if one of them weren't available - we wouldn't be able to bring them in just for her.

While these "thoughts" do not necessarily represent the actual reactions of individuals in our setting, they are representative of the types of issues arising relevant to each stakeholder and were considered in developing means for

supporting Jo in this area. In the next section, we identify the issues to be considered to provide Jo with the support she requested. Following the identification of each issue, we describe how it applies specifically to Jo and share some of the problem-solving attempted in her situation.

Providing Support

When providing support to individuals living with the effects of a BI, service providers are obligated to consider cognitive, physical, emotional, and safety issues. Individuals access service providers because they are not able to complete an activity independently. This support, although provided as confidentially as possible, by definition impacts on individuals' privacy. In the area of sexuality, an individual is faced with many privacy intrusions and accessibility issues throughout the process of determining support needs, exploring and accessing sexuality resources, and implementing strategies. When an individual's pre-injury sexual experiences are minimal, the individual may also require support around "socializing" and learning interactional and sexual skills that were not acquired prior to the injury. Jo had minimal pre-injury experience and required a relative high degree of support to "access" her own sexuality.

An individual with significant cognitive disabilities resulting from BI is likely to experience challenges in the whole range of behaviours associated with sexuality (i.e., meeting people, flirting, dating, mutually satisfactory sexual responding). In situations where an individual acquired a cognitive disability prior to sexual experimentation, they may lack fundamental sexual knowledge in addition to a personal accumulation of past experience. Thus, service providers participate in linking the individual to resources to facilitate education as well as social experimentation.

Even if the individual acquired a disability after having had the opportunity to experiment with their own sexuality, they may have ongoing difficulty due to cognitive impairments (e.g., memory loss, social skills). In either scenario, there is commonly a need for services specific to sexual exploration and/or expression. These types of services are difficult to locate and even more difficult if the individual needs the consultant/counsellor to have knowledge or experience in working with individuals with a BI.

Application to Jo

Due to her lack of experience, Jo would benefit from access to specialized education and counseling regarding her sexuality. Unfortunately, there is a lack of these specialized counseling resources for persons living with a disability. Those that are available are generally through the private sector, thus are not financially accessible to Jo, or are focused on individuals adjusting to solely physical disabilities. In addition, Jo has had difficulty accessing counseling in the past due to cognitive challenges (i.e.,

limited attention; easy distractibility; sometimes tangential conversation) and to therapists' frustration understanding her dysarthric speech.

Developmental Expectations

If the individual was injured as a child or adolescent, there may be increased discomfort from the family of the person regarding support of sexual expression or exploration. That is, parents may continue to perceive the individual as "eternally a child" and to feel that either sexuality is not an issue or it should not be "encouraged" for fear that it will lead to further frustration for someone who is not expected to ever have a partner. Thus, another barrier can be the expectations and support from people close to the individual.

Application to Jo

Jo was injured in adolescence and is the daughter of fairly conservative parents. Many of the cognitive and behavioural impairments resulting from her injury meant that she required direct hands-on structuring of daily activities and feedback regarding "off-task" or "inappropriate" behaviours and comments. Thus, during the period she lived at home, her parents played a very "parent-to-young-child" role and were very alert to the differences from the maturing young woman that had been injured.

It has been difficult for them to perceive her as invested in her sexuality and to take that interest seriously or as anything other than another example of "disinhibition" associated with the results of the BI. Rather than assist Jo to "target" her interests productively, expressions of sexual interest were ignored or "treated" behaviorally to minimize their demonstration. Our support services, therefore, targeted education for the parents as well and to assist them to understand and accept their daughter's interest in sexual activities as well as provide reassurance that her safety and behaviors regarding sexuality with others would be "monitored".

Legal Capacity/Competency

Issues related to legal competency fall into two areas: (1) the individual's legal authority to make decisions related to expression of sexuality; and (2) concerns regarding the potential vulnerability of the individual and the obligation to provide some level of protection. These two areas are interdependent in that if the person is not considered legally capable, then it implies that their vulnerability is high and that others (SDMs; delegated service providers) must act in the best interests of the individual. Thus, there must be a balancing between protection and choice even for the person who has been legally determined as not capable of making independent decisions.

Service providers need to be mindful of providing education and being proactive in managing potential concerns

regarding risk of sexual abuse where the person is seen as vulnerable. While this is of greatest concern when the individual is seeking a sex partner, it also relates to situations where physical assistance is required to set-up for or actually use a sex device.

Decision-making capability plays a role in the decision to obtain and regularly use a device, what type of support is seen as appropriate and what type of device is acceptable. Where the individual is not their own legal decision-maker, the SDM must be involved in these decisions. Thus, whereas any other adult female would have been able to choose - on her own - the device she preferred and to explore its use without the need to communicate this information to a service provider or a legal substitute decision-maker, a woman, such as Jo, living with cognitive disabilities in a SIL environment cannot.

Application to Jo

Jo's situation in this respect was quite complicated. She is not her own legal decision-maker and, as noted, is seen by her parents (who are also her legal SDMs) as very vulnerable to abuse by others due to her high interest in sex and her general level of behavioural disinhibition. Thus, her parents were concerned about the potential for abuse by service providers assisting her in this area.

There had also been inconsistent past complaints by Jo about sexual molestation in the past and thus there was also concern about the impact of using a device on the ability of a physician to physically confirm or disconfirm abuse. Her SDM's concerns around sexual abuse led us to engage in discussion with Jo around the type of device to be purchased (i.e., penetrating vs. nonpenetrating) and whether to share her decision with the SDM. Consequently, Jo's lack of legal decision-making capability and our need to initiate this discussion, stemming from service delivery and potential liability issues, impeded Jo's unencumbered sexual access to obtaining the device of her choice.

Requiring Instrumental Support

Instrumental support required (e.g., transportation, locating an accessible store, researching a usable device) may be needed through the SIL service provider. This is the most commonly considered area of impeded accessibility. Yet beyond not being able to access resources or requiring physical assistance to use a sexual device, privacy is also significantly compromised. Individuals with cognitive impairments may need not only to request support from the service provider for the actual instrumental assistance to use a device, but may also require support to make decisions around experimentation and how to consult with the SDM, if applicable.

Privacy and personal preference is always weighed in the context of potential health and safety issues for the individual and liability and staffing issues for the agency. Without natural connections (e.g., friends) or opportunities

(e.g., exploring relationships, "dating"), individuals are left no choice but to request more "public" support. How many people and who assist in this most private of domains is typically inconsistent and also has an impact on the person's access to preferences for how services are delivered.

Application to Jo

Due to physical, communication, and cognitive impairments, Jo required support around most areas of instrumental ADL's. Areas of support for actually purchasing and using a sexual device included: (1) researching a device that would meet her sexual aims and be manageable given her fine motor difficulties; (2) finding a wheelchair-accessible shop; (3) booking and accessing wheelchair-accessible transportation; (4) communicating with clerks at the shop; (5) communicating wants, needs, and concerns to parents; (6) preparing the device for use; (7) identifying and recalling a private storage location that could also be accessible to her without assistance; and (8) recalling and getting assistance to clean the device regularly and sufficiently.

To minimize the number of service providers with access to information about her private preferences and needs, a single SIL service provider of her choice facilitated her research for a suitable shop that would be physically accessible and understand her unique needs as well as facilitating transportation and communication needs while at the shop with the sales clerk and after the fact with her mother. Accessibility to the store was not a factor for Jo due to the preliminary research and the salesperson was helpful. The same service provider provided the fine motor support to assist Jo to open the packaging and arrange an accessible private storage area. Skill teaching in managing motor barriers to learn to use the device correctly was also provided. Specific parameters around support services by other service providers were developed to ensure Jo's privacy and service providers' professional boundaries.

Without this type of support, Jo would not be able to access the device she was looking for nor would have she been able to try the device. Even though supporting individuals to explore their sexuality and access resources as required is a desired outcome of support services in a SIL environment, this support is provided at the detriment of the individual's privacy and may limit access to preferred options. The individual living with the effects of a BI has few options but to enlist the support of service providers if she does not have friends or other non-paid relationships that will provide that support. Although Jo received the support she needed, a closer approximation to inclusion would have been for her to access a friend or partner with whom to discuss issues of sexuality.

Relationships with Family Members, Parents, Service Providers

To access services to explore sexuality, an individual requiring support is faced with potential attitudinal and

interpersonal barriers related to service providers, family and friends, and SDMs. Adults without support needs do not have to share private information about their sexuality or "get permission" to experiment. When parents are also legal SDMs, there is a risk of a certain kind of "conflict of interest" in so far as they wish to protect their "vulnerable child" versus assisting her adult independence and exploratory risk-taking.

Sexual values and experiences of front-line service providers (for themselves as well as their attitudes toward their customers) also impacts on the accessibility of sexual exploration and expression of the individual. If service providers are not comfortable with discussing and supporting personal activities such as masturbation, use of stimulatory devices or other erotic materials, sexual preferences, etc., they may directly or indirectly limit the person's access to exploring these avenues for themselves.

Application to Jo.

It was beneficial to share Jo's information only on a "need to know" basis with SDM, specifically given parents' stated perception that their daughter is not aware of issues of sexuality because she is disabled and their initial disinclination to "encourage" her in this area. This was possible due to preliminary agreements before and after Jo moved into the SIL that she would take the lead in making day-to-day decisions and they would be consulted only where significant health or safety risks existed.

Due to the parents' perception of Jo's increased vulnerability, it was necessary to encourage and support Jo to raise the topic with her mother, but she was supported to plan what she wished to share and how she wished to accomplish it. In addition, our SIL setting promotes ongoing value discussions among service providers regarding empowerment and inclusion that addresses sexuality and other personal value decisions made by customers. Support responsibilities are explicitly clarified with respect to Jo and other individuals requiring support in the sexual domain.

Access to Health Care

Significant attitudinal, social and architectural barriers may also be present when an individual needs to discuss sexual health and options with a family physician. Barriers may stem from inability to access the physician's office, to communication issues, to attitudinal and value judgments made by the physician that impacts on the advice and care provided.

Application to Jo

Jo was provided support to access her family physician to clarify medical, health, and safety issues. Although access to the physician's office was manageable, the examination table was not designed to facilitate transfers from a wheelchair and the physician tended to speak to the service provider rather

than to Jo.

The family physician was clearly uncomfortable discussing the issues of concern and, although Jo advocated for herself, the physician provided minimal assistance. The physician clearly communicated her perception that a woman using a wheelchair, having communication impairments, and who was injured prior to "sexual maturity or sexual involvement" is not a sexual being. Jo advocated for herself by describing herself as "normal", as a person who has sexual drives and who also requires regular examinations - like any post-pubescent woman. The family physician lacked insight and experience in addressing questions that Jo asked (i.e., responding to a woman with cognitive and physical disabilities). Jo is receiving support to locate a family physician more sensitive to her needs.

As noted under Experience, other specific education around devices and expression/exploration of sexuality has not yet been accessed. A community partner/service provider who specializes in interpersonal relationships and sexuality is being sought since, as a SIL provider, we felt that this service (i.e., "consulting" on issues related to sexual exploration and sexual pleasure) were beyond our scope of practice. Accessibility to such services is virtually nil for the reasons already described above.

Summary

Jo is living with the effects of a severe BI. She copes with motor, communication, cognitive, and behavioural disabilities. Due to having a legal guardian appointed for her and the need to ensure ethical quality service delivery by direct line support providers, her privacy and easy accessibility to sexual exploration has been unavoidably impacted as support efforts have been put in place. To try to minimize this intrusiveness, the service delivery model in this SIL environment enabled the individual to gain support from the single service provider with whom she was most comfortable to: (1) decide whether to discuss the issue with her SDM, (2) research options for a suitable device, (3) purchase a suitable device of her choice, (4) develop parameters for support from her support team in the SIL environment, and (5) use the device and determine its effectiveness/comfort. Ongoing support is required to locate a more "progressive" female family physician; to locate a counsellor specifically experienced in working with individuals with BI and issues of sexuality, relationships, and sexual expression; to continue to dialogue with the SDMs; and to facilitate exploration of sexuality while confronting Jo's implicit experience through others that she "should" be asexual due to her range of impairments.

Discussion

The barriers discussed (i.e., physical, cognitive, developmental, legal, societal) are indicative of many other barriers to "sexual access" that are present for individuals living with the effects of a cognitive disability striving for inclusion. In what ways can service providers decrease the barriers, facilitate inclusion, and empower the individual to maintain privacy while expressing sexuality? How can service providers provide support, maintain their legal responsibilities, and facilitate sexual expression?

One of the areas that is critical and rarely considered in terms of "accessibility" is that of legal decision-making capacity in the case where the person has a cognitive disability. The individual is likely to retain their interest in having sexual partners and want to pursue some type of sexuality in their life, either with a partner and/or solo, but the decisions related to these activities may rest with another party.

In the case of BI, where the person injured is likely to be a young adult, the SDM is likely to be a parent. Even in the case of a young adult without identified disabilities, parents are notoriously reluctant to see their child as a sexual being. When the "child" has cognitive or interpersonal impairments that the parent sees as increasing their vulnerability or risk of harming others, this reluctance is increased many-fold.

An SDM is supposed to make the same decisions that an individual would make if personally able to do so. Yet all too often SDMs make decisions that they believe are in the person's best interests without recourse to that individual's preferences or values as expressed verbally or behaviorally prior to the injury or after the injury in so far as the person is able to express them. The service provider may feel caught between a rock and a hard place. They can hear the preferences and desires of the person and feel an obligation to assist them to live as independently and inclusively as possible. Yet they have a legal obligation to follow the decisions made by the SDM unless these are blatantly in contradiction to the person's best interests. Challenging the decisions of the SDM risks disrupting what needs to be an effective and collaborative partnership between the parties and would not be done lightly or frequently. What to do? At present, many facilities and/or health care professionals actually do nothing at all.

Along a similar vein, the experiences and expectations of the individual with a disability must be considered in providing support or deciding whether to assist the individual to press for more autonomy. The kinds of questions that should be asked include the experience of the individual prior to the injury. Were they at an age where they had experimented and were familiar with their own preferences, knowledge about sexuality, safe sex, birth control, gender issues, etc.? In situations where a parental SDM is involved, what are the parental feelings about sexuality, the sexual experiences of their children, their comfort level with "readiness" for their

child's explorations or even awareness of explorations that were already occurring? Have there been any experiences post-injury and again, if so, was the parent aware of this? What were their feelings about it?

In many situations where young women are involved in sexual activities following a brain injury, parents are quick to assume that some sort of abuse or poor "supervision" of the individual was involved and that it should not have been allowed to happen. Parents tend to focus more on the vulnerability and need to protect their "child" from harm than on being able to see their "child" as a young adult needing to take "normal" risks and explore themselves and their relationships.

There certainly are interpersonal situations however, where impairments associated with BI (e.g., impulsivity, disinhibition, poor problem-solving) may put the person at risk for increased vulnerability (e.g., meeting someone new in a bar; bringing a stranger into their apartment). These same impairments are associated with a decreased capacity to understand and appreciate the nature and probability of the risks. It may also be hard for the person to gauge how much or what of their thoughts, desires, and experiences to share with others.

Men and women living with the effects of an acquired BI are faced with significant challenges in expressing their sexuality. Individuals who require one-to-one support in the majority of activities of daily living, including support in communication, are not afforded the privacy in exploring and expressing their sexuality that individuals without a disability enjoy. Support needs as simple as making a telephone call and accessing the community outside the living environment preclude the individual from maintaining privacy about sexual needs and relationship wants as support is requested and required. Balancing support needs, access, and privacy is an ongoing challenge to a SIL service provider.

Independence of one's sexuality from one's parents may also be at risk if the individual, as in this case, has a SDM who is also the parent. The individual may not perceive any risk where the SDM may perceive a significant risk. Negotiating this discrepancy requires openness, a perception of the individual as having a sexual identity, and an ability to tolerate risk. The individual may also request or benefit from sexually-related skill development (e.g., flirting, masturbation, preparing for erotic activities with a partner) by a service provider with this area of expertise.

The individual with a disability faces challenges in accessing services specific to skill teaching and having opportunities for practice. Research is needed to determine effective ways to facilitate sexual expression for those with disabilities. For example, qualitative studies exploring sexual accessibility barriers and the most effective support models from the perspective of both individual with an injury and their partners (sexual and otherwise) may assist in refining existing services or in developing new approaches

that will more effectively address sexual access needs. Ongoing education must address the attitudinal and societal perceptions that affect sexual accessibility for men and women with disabilities.

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