

The International Journal for Direct Support Professionals

Changing the Conversation: Let's Talk Disability and Sex

By Amy McPherson and Christine Provvidenza

Think back. How did you first learn about sex? From a friend? In a class? During an awkward talk with your parents? It's likely that you were curious and found the information you wanted – whether that was from formal or informal sources. However, opportunities to access accurate and tailored information about sex are often more limited for youth with disabilities.

Although sexuality is much less of a taboo topic these days, many of us still feel awkward talking about it. This article provides some guidance for healthcare professionals, including direct support professionals (DSPs), to consider when talking about sexuality with the people they support. While a youth's capacity to consent is an important issue when considering sexuality, other articles have covered this in detail (for example, see Dominguez & Hermans, 2022, and Esmail & Concannon, 2022). Instead, this article provides some guiding principles for discussing sexuality. These principles are drawn from literature across a range of disabilities, including youth with intellectual and developmental disabilities (IDD), and can be adapted as appropriate to different settings and populations.

What do we mean by 'sexuality'?

The terms 'sex,' 'sexual health,' and 'sexuality' are often used interchangeably. The World Health Organization (WHO) defines sexuality as "a natural part of a person's life and can include: sex, gender identity and expression, sexual orientation, pleasure, intimacy and reproduction. Sexuality is experienced and expressed through thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed" (WHO, 2006, p.5). Sexuality, then, is much more than "having sex" and also includes things like how you see yourself and others, whether you are attracted to other people and who those people are, and how you feel about your body. We, therefore, use the term 'sexuality' to represent a holistic view of a person's identity, emotions, attraction, relationships (including friendships), body image, reproduction, and much more, which will not look the same for different individuals.

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Why is this important?

We all have rights related to our sexuality. This includes the right to accurate, timely information, and appropriate support to make choices around our sexuality. Unfortunately, the sexual rights of people with a disability (especially young people) are often denied. This is due, in large part, to the misconception that youth with disabilities are not sexual beings and, therefore, do not need to be taught about sexuality. When the topic of sex *is* raised, the focus (especially with youth with IDD) is typically on issues such as risk of abuse, sexually transmitted infections, and contraception. While these are all important, where is the discussion about pleasure, desire, and choice?

Broadly, youth with disabilities experience the same sexual desires as any other youth, but may experience low self-esteem, loneliness, a lack of belonging, anxiety, and confusion if not supported with their sexuality. However, complicated medical histories and/or daily care needs often become the primary focus of interactions. Youth may be unsure about their sexual abilities or what sexuality means for them in their body, especially if they have multiple medical issues. Yet leaving youth without appropriate information on sexuality-related topics, can result in an inability to construct a healthy sexual identity, fulfill their sexual needs, or develop the skills required to navigate sexual situations safely and appropriately. If they *do* receive information, it is rarely tailored to their specific needs, goals, and abilities. Unfortunately, we've heard from many youth with disabilities that they experience a lack of recognition and support around their sexuality by family, friends, and professional caregivers (Bonder et al., 2021). They've called for *more conversations, more often*.

Why aren't professionals having these conversations?

While talking more about sexuality with youth with disabilities might be the goal, these conversations can sometimes feel awkward – for both youth and healthcare professionals.

Some of the challenges that healthcare professionals report facing include:

- Fear of offending the youth and/or their parents;
- Lack of knowledge and training;
- Uncertainty regarding who should initiate the conversation, and
- Lack of clarity if providing sex-related information to youth with disabilities is within their scope of practice.

Below, we've provided five principles to help address some of these challenges.

1. Create a safe and comfortable environment

A trusting relationship between DSPs and the people they support is fundamental to all good care, but this is particularly important when approaching conversations about sexuality. Being respectful, honest, supportive, friendly, and non-judgmental are characteristics that youth greatly value in professionals who care for them. This helps establish an environment where youth feel safe to talk about sensitive topics, including sexuality.

This does not mean that knowing the individual for a long time is always necessary. Aspects of the environment within which you are meeting the youth can communicate openness to the topic of sexuality, even if this is the first time you have met them personally. For example, visual

displays such as “safe zone” signs or rainbow stickers in offices/meeting spaces can quickly convey that topics such as gender identity and sexual orientation are welcome. Youth may not feel that they can discuss more mature topics when spaces are designed for younger children (e.g., bright colours, cartoon characters, etc.). Even then, practices such as introducing yourself with your pronouns and enquiring about their preferred pronouns – rather than assuming from their visual appearance or health chart – can demonstrate that you understand and respect diverse identities, and are a ‘safe’ person to talk to about sexuality (for more information on pronouns and how to use them, see [Dominguez & Hermans article in Volume 11, Issue 2](#)). Youth are often more willing to talk about sexuality and other sensitive topics when they don’t feel rushed, so very brief encounters are not optimal for discussing the topic. However, using these strategies demonstrates openness and respect, which leaves the door open for any future questions youth may have.

2. Initiate the conversation

Even when youth are interested in discussing sexuality, many prefer that the professional initiates the conversation. There are several strategies that professionals can use to do this, depending upon the context. These include:

- Putting time aside during each shift, meeting, or appointment (depending upon how frequently you are providing support to the person or meeting) to specifically address any concerns/questions about sexuality.
- Explaining that sexuality discussions are part of routine care. This can help normalise the topic and also allows youth to think of questions in advance if they are expecting to be asked (although it may take multiple interactions before a youth feels comfortable enough to ask their questions or have a conversation).
- Ensuring youth know that they have a choice about whether they talk about sexuality (unless abuse or other safety issues are suspected).
- Asking about their peers’ experiences (e.g., if any of their friends/classmates are dating) and what they think about that. This may feel less awkward to the youth than if asked directly.

Box 1 suggests some other ‘sentence starters’ to help professionals initiate a conversation about different aspects of sexuality.

Box 1: Sentence starters

- Sexuality can be a sensitive topic for many young people and families. Is it OK if we talk about it today?
- It’s OK to have sexual thoughts and feelings. Do you want to talk about dating, relationships, your body, or your feelings?
- Growing up can be exciting but scary too. What’s the best/worst thing about puberty and growing up?
- Sometimes ideas about sex that you see online or in the media aren't real. Do you have any questions about what you’ve heard or seen?
- Young people get their sexuality information from many different places. Where do you get your information?

Source: Holland Bloorview Kids Rehabilitation Hospital (2002). Let’s Talk Disability and Sex: Sentence Starters for Healthcare Providers. Accessed from: Hollandbloorview.ca/sexuality

3. Think about sexuality broadly and take a staged approach

Despite sexuality being multi-faceted, it is often addressed from only a biomedical perspective (e.g., contraception, sexually transmitted diseases). It's important for professionals to also understand and address the psychosocial concerns that youth with disabilities may have, such as around friendships and identity. For example, youth with IDD who identify as part of the LGBTQ2S+ community are at higher risk of bullying and harassment (McCann et al., 2016), so exploring available social supports is particularly important to help mitigate risks to their mental health (see Abou-Chacra et al., 2017, for more detailed guidance on this topic). Too often, the topic of sexuality is only raised when a youth is in their teens and/or is displaying potentially risky or harmful sexual behaviours (**Note:** The differences between harmful/risky sexual behaviours and natural sexual expression is beyond the scope of this article. Readers are directed to Esmail & Concannon, 2022 and Martino, 2022 for more information on this topic).

Professionals are encouraged to start talking with children/youth about developmentally appropriate sexuality concepts early. It can be useful to consider the many areas highlighted earlier in the definition of sexuality (e.g., feelings toward self and others, body image, gender identity and expression, meaningful relationships including friendships, etc.) and using them as 'building blocks.' Taking this approach helps youth understand sexuality as they grow and develop and will not focus on 'sex' at all initially. For example, talking about topics such as trust and honesty in the context of friendships (e.g., 'How do you want to feel when you are around a friend?' 'How do you think friends like to be treated?' etc.) can create the foundation for later discussions of consent in romantic/sexual relationships and awareness of coercion. Similarly, teaching the proper names for body parts can be helpful when later discussing puberty-related body changes, and even supporting youth to learn how to do breast or testicular self-examinations. The learning strategies of repeating information, using real-world examples, and building on previous knowledge can be employed when discussing sexuality concepts, as with any other topic.

4. Be transparent about confidentiality

Youth are generally reluctant to discuss sexuality if they are worried that their parents or other caregivers will find out what they have said. It is critical that professionals clearly explain (and repeat) what they can and cannot keep confidential when discussing sexuality. This will be influenced by several things, including the youth's capacity to make decisions and provide sexual consent (readers are again directed to Dominguez & Hermans, 2022 and Esmail & Concannon, 2022 for in-depth information on consent in youth with IDD). Different healthcare regulatory bodies also have their own requirements around mandatory reporting. Providing examples of the information you would have to tell someone else about may be helpful – for example, a general conversation about what makes a good friend is different than a disclosure that a youth is being severely bullied. Refer to **Box 2** for some sample language that can be adapted to your own context and regulatory body. Also take time to ensure that the youth understands what different words mean (e.g., confidential, private, hurt, etc.)

Box 2. Keeping conversations private

I will keep our conversations private/confidential unless you want me to talk to your parent/caregiver about a particular issue. I would also have to tell someone if I thought someone was hurting you, or if I thought you might hurt yourself or someone else.

Source: Holland Bloorview Kids Rehabilitation Hospital (2002). Let's Talk Disability and Sex: Sentence Starters for Healthcare Providers. Accessed from: Hollandbloorview.ca/sexuality

When discussing sexuality, it is also important to ensure a youth's privacy. For youth living in group homes or semi-independent living, ensure that there is privacy from fellow residents or roommates before discussing sexuality. Similarly, if the topic arises while you are out in a public space, suggest that you move to a private area before starting the conversation. This should not be done in a way that may suggest it's a 'bad' topic, just one that people usually have in private.

Meetings that include parents or other caregivers can be a source of discomfort for youth when discussing sexuality. Professionals can consider routinely asking parents to step outside for part of an appointment, although this should come with an explanation for both youth and parents about the topics that will be discussed, along with what information will be shared with the parent. Youth may feel pressured to say, 'no' if asked whether they want their parents to step out of an appointment. So, it is important to explain to youth and parents that it is routine and appropriate for emerging adults to have some privacy. Of course, this may not be appropriate in some situations and a parent should not be made to leave if this distresses the youth.

5. Use inclusive language

As Dominguez & Hermans's article discusses, our language and the words we use are powerful. Terminology, tone, and body language can convey openness and acceptance, or reinforce stigma and shame. We can communicate assumptions and judgment without intending to. For example, rather than assuming a youth is heterosexual when discussing romantic partners and sexual orientation (e.g., asking whether they are dating someone of the opposite sex), use gender-neutral terms (e.g., the person you're dating, partner, significant other, anybody, someone, anyone). Because youth sexual preferences are often still developing and may be fluid, it is better to focus more on attraction rather than orientation and understand that this can change over time. Similarly, youth pronouns may change, so it is important to re-confirm their preferences. Many professionals avoid discussing sexuality in case they say something 'wrong.' However, we have an obligation to understand contemporary, inclusive language in order to provide high-quality care (a glossary of important terms can be found at the back of the book *"Becoming You: Exploring sexuality and disability for pre-teens"*). But it is also important to remember that everyone makes mistakes! If you use the wrong pronoun, apologize, and move on. If you are unsure how best to answer a question, acknowledge this, commit to look into it, and come back to them. If a youth is uncomfortable with using a particular term, ask what they would prefer to use. Educate yourself, and then be curious and authentic.

Conclusion

Our best hope is that this article highlights the importance of discussing sexuality when working with youth with disabilities, including those with IDD. By recognizing these youth as sexual beings, we can help them exercise their sexual rights. Taking a holistic approach to sexuality, starting conversations early, tailoring information to their unique needs, and demonstrating a willingness to learn can all support youth to have satisfying and safe sexual lives – whatever that looks like to them.

About the Authors

Amy McPherson, PhD, RP: Amy McPherson leads the ProFILE (Promoting an Inclusive healthy Lifestyle for Everyone) lab at the Bloorview Research Institute and conducts research addressing the inequities experienced by youth with disabilities in accessing information that supports their health, focusing on sexuality, eating disorders, body image, and mental health. Amy is also a registered psychotherapist who works with adults experiencing a range of mental health issues and has her own private practice.

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References and Resources

Articles

- Abou-Chacra, M., Lunsky, Y., & Hingsburger, D. (2017). [Speaking OUT: Understanding Sexuality and Diversity in LGBTQ+ Individuals with Developmental Disabilities](#). *The International Journal for Direct Support Professionals*, 6(6): 1-6.
- Bonder, R., Wincentak, J., Gan, C., Kingsnorth, S., Provvidenza, C., & McPherson, A.C. (2021). They assume that you're not having sex: A qualitative exploration of how healthcare providers can have positive sexuality-related conversations with youth with disabilities. *Sexuality and Disability*, 39: 579-594. <https://doi.org/10.1007/s11195-021-09686-z>
- Dominguez, E. & Hermans, H. (2022). [Relationships & Rollercoasters Supporting People with IDD throughout Relationships: A Trauma-Informed Approach](#). *The International Journal for Direct Support Professionals*, 11(2): 1-5.
- Esmail, S., & Concannon, B. (2022). Approaches to determine and manage sexual consent abilities for people with cognitive disabilities: systematic review. *Interactive journal of medical research*, 11(1): e28137, <https://doi.org/10.2196%2F28137>
- Martino, A.S. (2022). The intersection of sexuality and intellectual disabilities: Shattering the taboo. In N.L. Fischer, L. Westbrook, & S. Seidman (Eds.), *Introducing the new sexuality studies* (pp. 460-469). Routledge. <https://doi.org/10.4324/9781003163329>

McCann, E., Lee, R., & Brown, M. (2016). The experiences and support needs of people with intellectual disabilities who identify as LGBT: A review of the literature. *Research in Developmental Disabilities, 57*:39-53. <https://doi.org/10.1016/j.ridd.2016.06.013>

World Health Organization (WHO). (2006). *Defining sexual health. Report of a technical consultation on sexual health 28-31 January 2002, Geneva.* https://www3.paho.org/hq/dmdocuments/2009/defining_sexual_health.pdf

Body of Research

The following are publications from members of the ProFILE Lab's program of research on disability and sexuality and, in part, informed this article:

1. Bonder, R., Wincentak, J., Gan, C., Kingsnorth, S., Provvidenza, C., & McPherson, A.C. (2021). They assume that you're not having sex: A qualitative exploration of how healthcare providers can have positive sexuality-related conversations with youth with disabilities. *Sexuality and Disability, 39*: 579-594. <https://doi.org/10.1007/s11195-021-09686-z>
2. Heller, M. K., Gambino, S., Church, P., Lindsay, S., Kaufman, M., & McPherson, A. C. (2016). Sexuality and relationships in young people with spina bifida and their partners. *Journal of Adolescent Health, 59*(2), 182–188. <https://doi.org/10.1016/j.jadohealth.2016.03.037>
3. Lung, S.M. Wincentak, J., Gan, C., Kingsnorth, S., Provvidenza, C., & McPherson, A.C. (2022). A scoping review of suggested practices for healthcare providers when discussing sexuality with youth. *The Canadian Journal of Human Sexuality, 31*(1):143-160. <https://doi.org/10.3138/cjhs.2021-0058>
4. Lung, S.M. Wincentak, J., Gan, C., Kingsnorth, S., Provvidenza, C., & McPherson, A.C. (2021). Are healthcare providers and young people talking about sexuality? A scoping review to characterize conversations and identify barriers. *Child: Care, Health and Development, 47*(6):744-757. <https://doi.org/10.1111/cch.12892>
5. Giles, M. L., Juando-Prats, C., McPherson, A. C., & Gesink, D. (2023). "But, You're in a Wheelchair!": A Systematic Review Exploring the Sexuality of Youth with Physical Disabilities. *Sexuality and Disability, 41*(1), 141-171. <https://doi.org/10.1007/s11195-022-09769-5>

Resources

Resources for healthcare professionals, families and young people can be found on the Let's Talk Disability and Sex online Hub from Holland Bloorview Kids Rehabilitation Hospital:

1. "Let's Talk Disability & Sex" Online Hub
 - a. Section: Conversation Guides, Books, and Infographics
2. Teens, Sex and Neuromuscular Conditions: A Practical Guide for Clinicians
3. Sex Information & Education Council of Canada
 - a. Resources

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