This guide is for health providers and advocates who work with teens and young adults. Staff can use the ideas and tools with youth who have disabilities. All youth can benefit from information that is easy to understand. Counseling and education delivered in plain language helps staff and youth to reach their goals.

Sexuality is a part of life for all people.

Plain language means speaking in every day words. Medical words are not every day words. Use clear words and give resources that are easy to understand.

Use plain language every time you work with youth. This guide models plain language.

Youth that you work with each have their own strengths. It is important to focus on their talents and skills. Try not to focus on their problems or disabilities. Focus on what a person can do. Think about ways to change tools and resources to meet the needs of all youth. It is a practice that all youth may benefit from. Focus on what a person can do.
Sexuality and Youth with Disabilities

Youth may not learn about sexuality or sexual health at school or home. Adults may also not have this information. They may not know how to help a young person with a disability learn about sexual health or sexuality. Health providers and advocates may provide facts and options that youth may not get in other ways.

Sexuality is more than sexual feelings or sex. Youth with disabilities have the same rights as others. Young people with disabilities need facts about sexual health. They need a person who they can trust and talk to. Youth with disabilities are at a higher risk for sexual abuse. Education and information can lower this risk.

Practice Tools

You can adapt tools that you use now for youth with disabilities. You may find some new tools in this guide. You cannot see most disabilities by looking at a person. All youth may benefit from learning the same things about sexual health and options.

Head Heart Body is a tool to talk about giving a yes or no. There is a drawing of a head a heart and a body. Words and questions give the young person things to think about. A young person can use Head Heart Body to see if they are ready for sexual activity.

Circles Curriculum is a tool to talk about social boundaries with a circle drawing. The circles show relationships that a young person may have in daily life. The circles have different colors to show closeness in different relationships. Self is the first circle and then family, friends and others.

Affirm Clarify Answer gives three steps to supporting a young person. Affirm the question and the person. Let them know they made the right choice by asking you. Clarify the question to be clear about what they are asking. It will also be clear if they have any wrong information. Answer the question with facts, feelings and values. Thank them for talking with you. This will encourage future questions about sexual health and relationships.

Advocacy can be big or small. Advocates may talk with young people about their rights and options. They may talk to adults about ways to support young people. Parents, guardians, and co-workers may learn from information about options and ways to be safe and have healthy relationships. Advocates support the sexual health rights of youth with disabilities and all youth.

Engaging Parents and Guardians

Young people have relationships with their parents, guardians and natural supports. These relationships are important to their well-being. A natural support is anyone that is not paid to be in a person’s life. Natural supports can be family, friends and people from community programs. Keep a young person connected to safe natural supports. Be an active listener and give information and resources. Take the time to learn how to have healthier relationships and model them as much as you can.

Pennsylvania Law

Sexual health services are confidential. This means youth have the right to receive services and have the information be kept private. Health providers are mandated reporters. The exception to confidential services is when mandated reporters by law must report child abuse. A report may be made to ChildLine online or 1-800-932-0313.
Take time to learn the legal rights of youth including youth with disabilities. This may include information about guardianship or what choices a person can legally make. Youth with disabilities have the same rights to sexual health information as youth without disabilities.

**Topic Specific Webinars**

**The Touchy Topic: Sexual Consent and Engaging Adolescents with Disabilities**
This recorded webinar talks about sexual health and sexuality for youth with disabilities in a trauma informed way. It addresses ideas, thoughts and feelings about sexuality and people with disabilities. [Data edit: Researchers have found that 1 in 6 men have had abusive sexual experiences before the age of 18. 1 in 6.org]

**The Three Cs: Creating a Culture of Consent, Capacity, and Comfort**
This recorded Live Stream event increases comfort in talking about sexuality and healthy relationships with youth with disabilities. It talks about ways to adapt relationship safety cards.

**Beyond the Birds and the Bees: Teaching Sexual Health Education to Adolescents with Disabilities**
This recorded Live Stream event shares an adapted sexual health curriculum for youth with disabilities. It includes tools to teach boundaries and developmentally appropriate information.

**Enhancing Natural Supports and Navigating Complex Systems for Adolescents with Disabilities**
This recorded Live Stream event talks about advocating for the sexual health rights of youth with disabilities. It includes focusing on parents and others to support healthy relationships.

**Putting It All Together: The Normalization of Consent, Sexuality, and Healthy Relationships for Adolescents with Disabilities**
This recorded Live Stream event reviews ways to teach youth with disabilities about healthy relationships and sexuality. It talks about ways to make an action plan to use tools in a trauma informed way.

**Additional Resources**

Advocates for Youth: An Explanation of the Circles of Sexuality [https://www.advocatesforyouth.org/for-professionals/lesson-plans-professionals/200](https://www.advocatesforyouth.org/for-professionals/lesson-plans-professionals/200)


Centers for Disease Control and Prevention: Plain Language Materials and Resources [https://www.cdc.gov/healthliteracy/developmaterials/plainlanguage.html](https://www.cdc.gov/healthliteracy/developmaterials/plainlanguage.html)


Family Acceptance Project [https://familyproject.sfsu.edu/](https://familyproject.sfsu.edu/)


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Supporting Consent, Healthy Relationships, & Healthy Sexuality for Adolescents with Disabilities
Sexuality, Sexual Health, Sexual Rights

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction. Sexuality is experienced and expressed in 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. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious, and spiritual factors.

Sexual Health is a state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absences of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and realized.

Sexual Rights embrace human rights that are already recognized in national laws, international human rights documents, and other consensus statements. They include the right of all persons, free of coercion, discrimination, and violence, to:

- the highest attainable standard of sexual health, including access to sexual and reproductive health care services;
- seek, receive, and impart information related to sexuality;
- sexuality educators;
- respect for bodily integrity;
- choose their partner;
- decide to be sexually active or not;
- consensual sexual relations;
- consensual marriage
- decide whether or not, and when, to have children;
- pursue a satisfying, safe, and pleasurable sexual life.

The responsible exercise of human rights requires that all persons respect the rights of others.

What are we striving for?

What is a sexually healthy person?

It is important to remember in our work with all people, but especially when supporting those with disabilities, that striving indicates we have a goal to work towards continually. Each individual has different abilities and requires different support to become a sexually healthy individual.

Therefore, the list of characteristics on the following page should be seen as a guideline to direct us in our support of any individual. Traditionally, there has been a reluctance to recognize people with disabilities as capable of making healthy and informed sexual decisions. We know that with ongoing and non-judgmental support people can build the capacities they need in order to make healthy and safe sexual decisions.
Profile of a Sexually Healthy Person

Body and Self Awareness

- Understands how the male and female reproductive systems function
- Knows own genital area and does not feel ashamed of genitals
- Has a realistic and positive image of own body
- Knows about and practices health promoting behaviors, i.e. safer sex practices, using birth control, practices abstinence, regular medical check ups
- Has a clear sense of own values
- Knows sexual limits
- Understands own gender and sexual orientation

Decision Making and Communication Skills

- Acts in accordance with personal values
- Has decided ahead of time what is or is not okay sexually
- Understands the consequences of sexual activity, both positive and negative
- Takes responsibility for own actions
- Is able to communicate and negotiate limits and personal needs to partners
- Is able to ask questions and seek support from parents and others about sexuality
- Demonstrates respect for others values, needs, and limits

Canadian Guidelines for Sexual Health Education, 2009

How are we doing?
Sexual Health

While there are piles of statistics to tell us how we are doing in our work with neuro-typical youth, adults and even older adults, bodies of research concerning people with disabilities and sexual health are lacking in Canada. With so little to draw on it is difficult to have even baseline data to share.

Most of the work that has been done regarding sexuality and disability is in the field of sexual assault/abuse. We do know:

- The degree of risk for women with disabilities appears to be about 150% higher than the risk for women without a disability
- In 1988 40% of respondents to a survey of women with disabilities indicated they had been raped, sexually assaulted, or abused
- It is estimated that only 20% of sexual abuse cases are reported to the police or authorities


Research shows that increased awareness of sexuality and open and honest sexual education reduces rates of abuse for all people.

People with disabilities are at a higher risk of sexual abuse or assault.
Getting Started - Being Prepared

**Acquire a broad foundation of factual information** about sexuality from books, courses, the internet, journals. Remember that sexuality is a much larger topic than intercourse. It includes emotions, physiology, values, knowledge, attitudes, relationships.

**Learn the correct terminology.** If you have difficulty saying some words without embarrassment, find a private place with a mirror and practice saying these words until you are as comfortable with them as you are with non-sexual words.

**Thoughtfully explore your own feelings, values, and biases** about sexuality. Think about current sexuality issues, such as contraceptive use, gender issues, sexual orientation, masturbation. You must be aware of how you feel before you can effectively communicate with others.

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**Where do you stand?**

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Appendix: Supporting Sexuality in People with Developmental Disabilities
So how do you talk about sex?

- **Be proactive** - open the lines of communication. Start the discussion. Don’t wait for a crisis.

- **Listen** - to what the person is saying. Don’t make assumptions. Only they can tell you what they know, what they want to know, and what they need. Include them in the conversation.

- **Create a safe and comfortable environment** - use correct and inclusive language. Set up ground rules. Enforce them. Don’t tolerate sexism, racism, homophobia. Challenge it!

- **Be concrete** - give clear guidelines and scenarios to help people understand what is acceptable and what is not. The Circles Program© provides an excellent outline for teaching about relationships.

- **Answer all questions correctly and thoughtfully** - a good process to follow includes validating, clarifying, and answering the question, and addressing the facts, feelings, and values behind the question. Normalizing is important. Be age and culturally appropriate.

- **Give all information** - believe that people are capable of making mature, responsible decisions, especially when they have all the pertinent facts and opportunities to discuss the options with a supportive adult. They will trust and respect you more for it.

- **Be consistent**:
  - Make sure all support people in the individual’s life are giving clear and consistent messages about sexuality.
  - Have conversations with parents, teachers, the organization you work for, so you understand what your role is in the individual’s learning about sexuality.
  - Remember that sometimes your client needs an advocate, sometimes that might be you.

Don’t wait for a crisis, start having conversations now.
Head

- I think it is a good idea.
- I think I am old enough.
- We talked about birth control and pregnancy.
- My partner said YES to using condoms.
- Having sex will be ok with my values and/or religion
- We have privacy

Heart

- I feel that I can trust this person
- I feel like it is my choice - no pressure.
- I feel happy about having sex.
- It feels safe. I’m not worried about anything.
- My heart will feel good after.

Body

- My whole body feels excited.
- I have butterflies in my stomach.
- My body feels tingly.
- My genitals are excited (hard/wet).
- I’m feeling very sexual and my body feels respected and safe.

Head, Heart, Body

Head Heart Body is a framework for having conversations about consent. IF used appropriately, people can assess their readiness to engage in sexual activity in each new situation.

Below is the image used to visually represent the different aspects of consent, the following pages detail things to think about when exploring each aspect of consent.
Formula for Conversations

Before doing anything else...

Take a deep breath! You can prepare yourself for talking about sexuality by reading up on the answers to some key questions, clarifying your values, having resources ready, and looking for conversational opportunities.

Sometimes a person may ask a question because they think it will be shocking. It is important to respond to questions in a way that does not encourage the person to feel shame.

When one of those questions does fall in your lap, there are three steps to starting a conversation that supports the person in learning and growing as a sexually healthy person. **Affirm** the question and the person, **Clarify** the question, **Answer** the question.

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A Word About Sexual Coercion...

**Sexual Assault Disclosure:**

- Tell them it was not their fault
- Acknowledge that they were brave to talk about it; that it’s important
- Ask if they’d be willing to talk to a doctor/nurse or counselor

**Do Not:**

- Freak out
- Force them to do anything unwillingly
- Ask any question that implies that it was their fault, e.g. “Why did you go...”

*All the way -- Sex for the first time by Kim Martyn, 2003*

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**Assumptions to Avoid**

- All people come from traditional nuclear families
- All people are heterosexual (be aware of the overwhelming heterosexism that exists in our culture)
- All people are sexually active
- All people are not sexually active
- All people’s involvement in sexual activity is consensual
- All people who are sexually active are having intercourse
- All people have the same cultural and religious beliefs and values
- All people are embarrassed to talk about sexuality
When they don’t ask...

If people do not ask questions, you are responsible for encouraging conversations about sexual health. Don’t assume they don’t want to talk or know all the answers because they haven’t asked. Work at making sexual health a conversational topic. Consider asking open, encouraging questions to begin talking:

- What do you think of...?
- Do you feel you have enough information about condoms, STI’s, etc.?

Ensure there are visual reminders of sexual health topics in your space, e.g. posters, condoms, brochures. Be sure these visual pieces include diverse images and messages: gender, sexual orientation, ethnicity. This demonstrates that conversations on the topic of sexual health are encouraged and apply to everyone. It also provides openers to conversations.

Because people with disabilities have traditionally been denied the opportunity to learn about and talk about sexuality it is even more important to encourage conversations.

When teaching about sexual health, be sure to:

- Use concrete information and props where necessary
- Help people search for information if they need it
- Provide context and scenarios to talk about new situations
- Repeat, repeat, repeat the information

**Affirm** - Start by letting the person know that it’s great that they asked the question - we all need good information. They chose to bring their question to you, which shows their trust in you. Reassure them that you are a good person to ask.

**Clarify** - Ask any clarifying questions if you are not sure what they are asking. A clarifying question could be, “Do you want to know about...” or, “Are you asking about...” You might also ask what they already know about the subject. That way if they are starting out with any wrong information, you can provide accurate information to help clarify their understanding.

**Answer** - When you answer the question, address the facts, feelings, and values that it brings up. Encourage the conversation by saying, “What do you think or feel about that?” “That is an interesting perspective.” “Here are some resources to help you in your decision making.” “Where are you with this?”

Thank them for talking with you. You want to encourage them to seek out information and discussions about sexuality and relationships.
What is good advocacy?

Advocacy works best when based on a sound knowledge of the relevant person or group of people, and a thorough understanding of their lives, their fundamental needs, and their various interests.

No advocacy happens in a vacuum, but should emerge instead from an informed understanding of the vulnerable person or group. This means understanding the person as a person, not simply as a collection of un-met needs.

Genuine respect for the individuals with whom we interact in our advocacy will improve the likelihood of a successful outcome, and is more likely to safeguard the rights and interests of a vulnerable person or group of people over the long term.

Advocacy is most effective when based on an understanding of and respect for the people one is advocating to as well as the people you are advocating for. Understanding their specific roles, the limitations of their power, and the particular economic, administrative, and philosophical imperatives that govern their work will enable you to better position your advocacy efforts for success.

("Reflections on Advocacy" Speech by Ian Boardman Public Advocate - Queensland, 11 March 200)

Notes:

Private Conversations

Discussion Questions:

• How did you respond to the situation?
• What were the biggest challenges?
• What are the most important things to remember each time you have a conversation with a client abut sexual health?

Making a Referral:

• After engaging the client in a conversation you may discover they need further information or services.
• Know the available resources that are client friendly (use Quick Reference List provided.)
• Describe the organization or service; reassure them.
• Assess if you are able or if it is necessary for you to accompany them.

Right to Love’s Top Ten Ways to be an Ally

1. Educate yourself.
2. Challenge your own and others’ beliefs about people with disabilities.
3. Listen.
4. Invite people with disabilities to hang out
5. Prevent abuse by talking openly and honestly about love and relationships
6. Talk about why sexuality and relationships are important for everyone.
7. Know that sharing experiences means trust - not attraction
8. Look for everyday opportunities to teach about boundaries and relationships.
9. Participate in and plan inclusive events
10. Believe that all people, regardless of ability, gender, identity, and sexual orientation should be treated
Action Plan

What can you do to integrate sexual health into your daily practice?

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