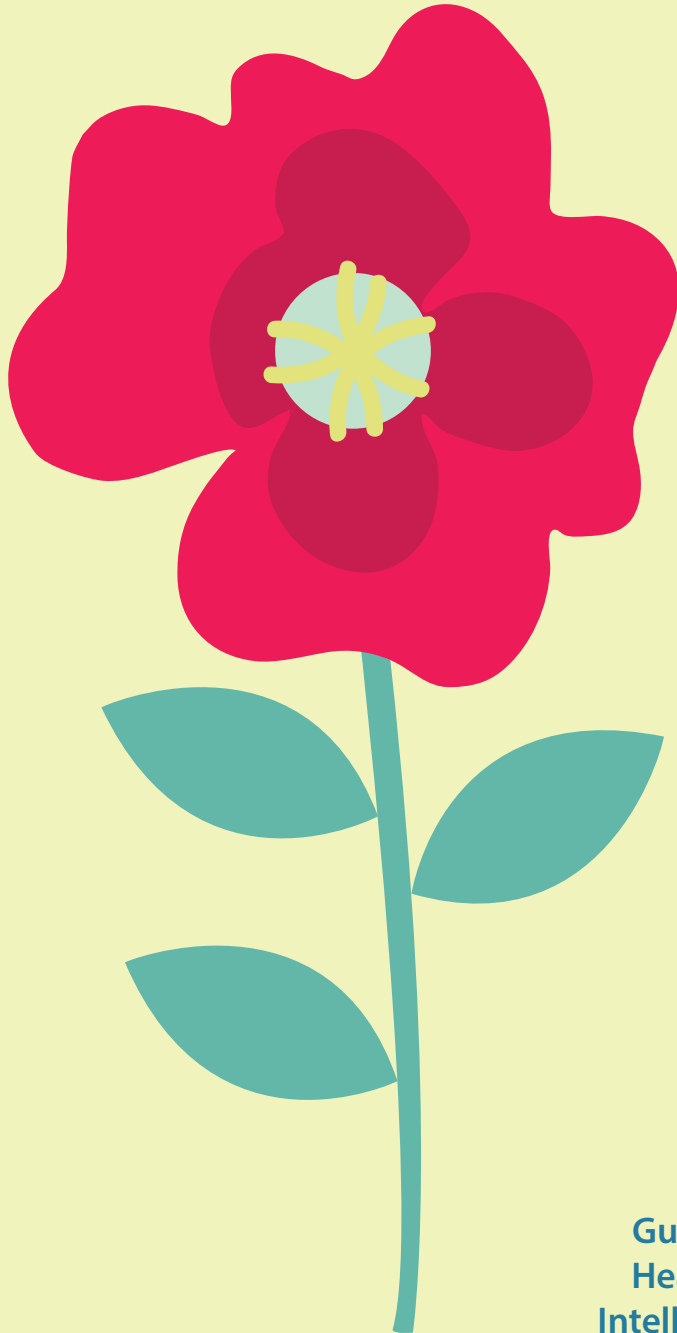


THE SEXUAL HEALTH EQUITY FOR INDIVIDUALS WITH
INTELLECTUAL/DEVELOPMENTAL DISABILITIES (SHEIDD) PROJECT
Growing Connection, Coordination and Support



IN THEIR OWN WORDS

Guidelines for Supporting the Sexual
Health of Young People Experiencing
Intellectual/Developmental Disabilities

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PART 1: EXECUTIVE SUMMARY

The Multnomah County Health Department’s (MCHD) Youth Sexual Health Equity Program (YSHEP) works with schools and community partners to provide age appropriate and culturally affirming comprehensive sexuality education to Multnomah County youth. In 2016, MCHD YSHEP received an Innovative Teen Pregnancy Prevention (ITP3) grant from the federal government to begin the Sexual Health Equity for Individuals with Intellectual/Developmental Disabilities (SHEIDD) project.

The SHEIDD (pronounced “sheed”) project seeks:

To promote comprehensive sexuality education and support for young people who experience intellectual/developmental disabilities (I/DD) by working together to build the skills of parents/guardians, caregivers, support workers, teachers, health care providers and others to provide sexual health education and support to the young people in their lives.

To learn more about the specific sexual health education needs of young people experiencing I/DD, as well as the training and technical assistance needs of members of their support networks (support people), we conducted a community needs assessment to help us answer the questions:

- Who is the community we serve?
- What sexual health education and help do young people experiencing I/DD need?
- What kinds of help do support people need to provide sexual health education and support to young people who experience I/DD?

Through surveys and sharing sessions, young people experiencing I/DD and support people outlined 13 guidelines to help youth experiencing I/DD get the sexual health education they need, want and deserve. These guidelines lead to the following key recommendations:

Support the Sexual Health of Young People Experiencing I/DD

1. Provide holistic sexual health education to young people experiencing I/DD.

Recognize young people experiencing I/DD as social and sexual beings by providing them with holistic sexual health education that helps them learn:

- Who they are
- What their rights are
- How to express themselves
- How to build healthy relationships

2. Learn about young peoples' goals.

Use person-centered processes to learn about young peoples' individual relationship, sexual and reproductive health goals and help them get the education and support they need and want.

3. Provide regular skill-building opportunities.

Support the self-determination of young people by helping them build relationship and sexual health skills in group and individual settings using a variety of methods, especially:

- Videos
- Group discussion
- Role plays/acting

4. Facilitate peer connection.

Enhance community inclusion by creating environments where young people have access to accurate, affirming sexual health information and can teach and learn from each other.

Build the Capacity of Support People to Provide Sexual Health Education and Support to Young People Experiencing I/DD

1. Put policies and procedures in place to support the relationships and sexuality of individuals experiencing I/DD.

Make it clear that your organization or practice understands the importance of supporting relationship, sexual and reproductive rights of the individuals you serve. Provide staff with clear and consistent guidelines and ongoing training on how to provide sexual health education and support that enhances individuals' quality of life.

2. Support collaboration around sexual health education and support.

Provide teams with tools and strategies to have conversations and make proactive plans around relationship and sexual health education and support.

3. Make inclusive and adaptable education materials and resources available.

Make sure support people have the resources and teaching tools to provide quality, holistic, affirming sexual health education.

4. Provide training opportunities.

Supporting the relationship, sexual and reproductive health of individuals experiencing I/DD is complicated. Help support people build the skills they need to put all the pieces in place to assist the young people in their lives. Skills-based training should include:

- Understanding the relationship, sexual and reproductive rights of individuals experiencing I/DD.
- Applying rights-affirming organizational policies and procedures.
- Exploring and clarifying personal and professional values around relationships, sexuality and disability.
- Strategies to clarify the rights of individuals with I/DD and the responsibilities of support people.
- Learning approaches for teaching sexual health education to individuals experiencing I/DD.
- Strategies to collaborate with teams to provide sexual health education to individuals experiencing I/DD.

When put into practice, these recommendations can help build a system of sexual health education and services supporting the full rights and experiences of individuals with I/DD by providing them with the knowledge and skills they need to make informed decisions about their health, increase safety, and seek mutually fulfilling relationships.



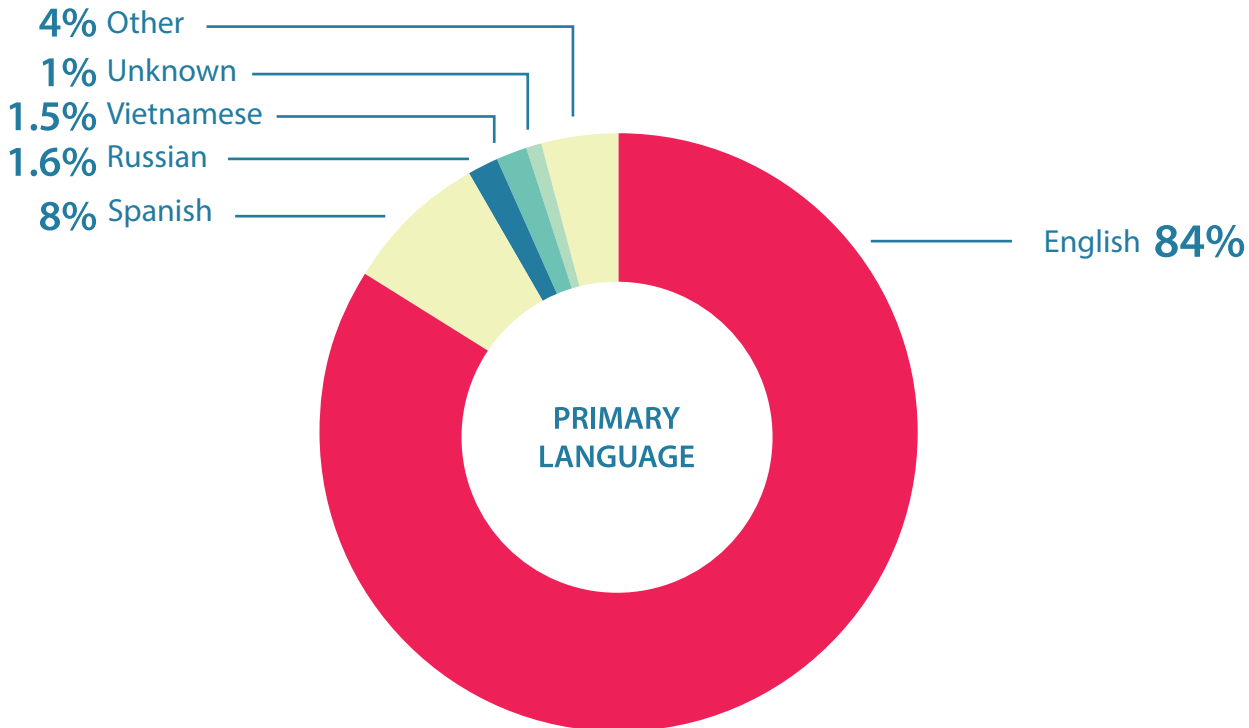
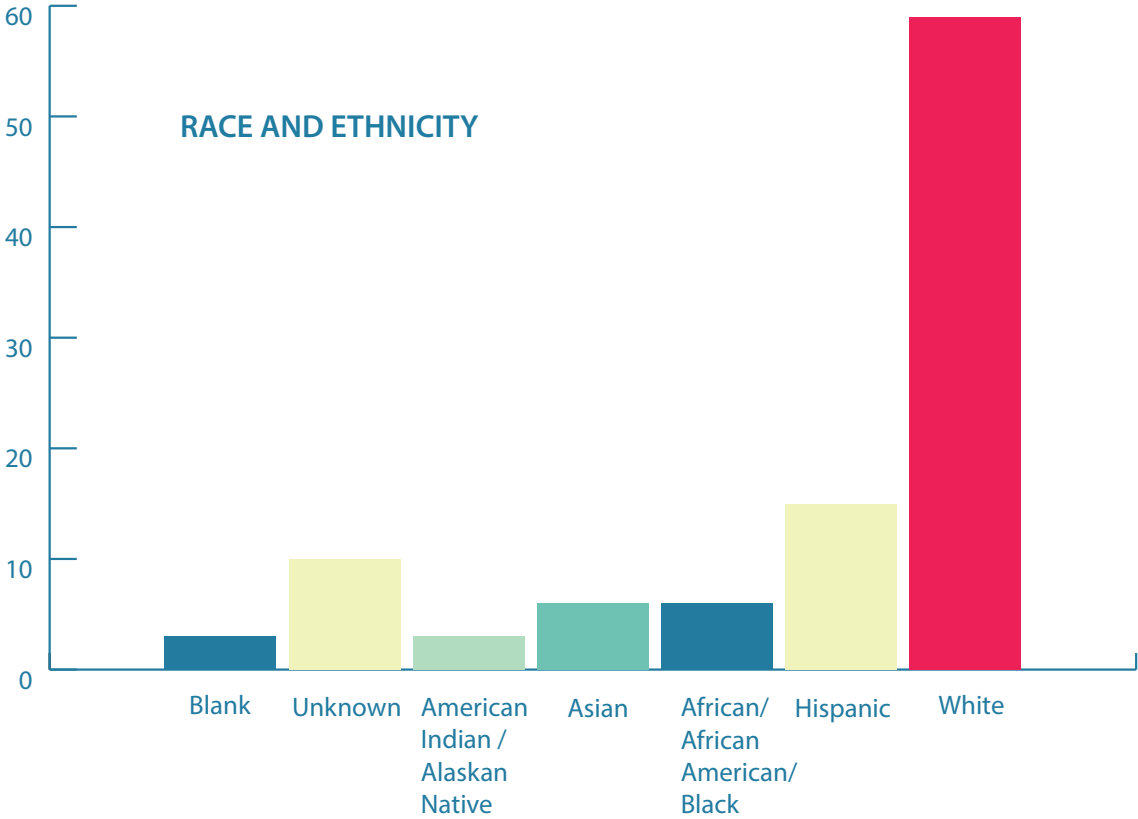
PART 2: INTRODUCTION

Why Focus on the Sexual Health of Young People Experiencing I/DD?

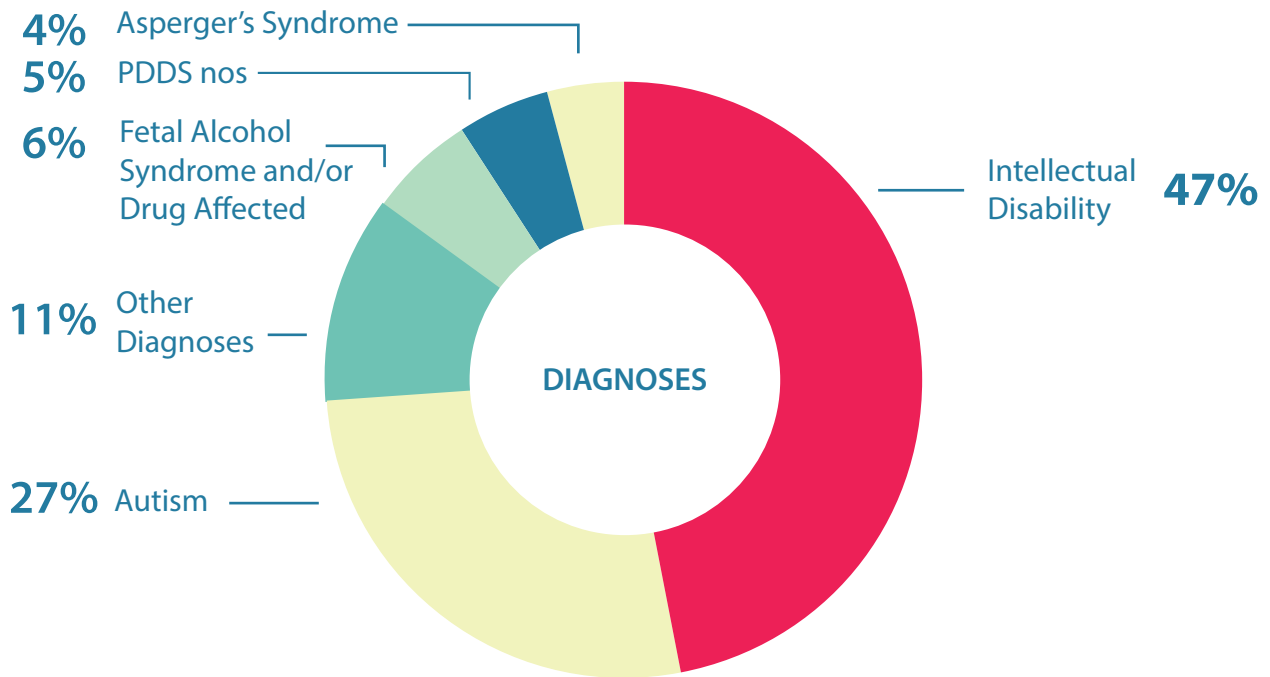
Many young people experience intellectual and/or developmental disabilities (I/DD). The Centers for Disease Control and Prevention (CDC, 2015) says that 1 out of 6 youth between ages 3-17 have an intellectual/developmental disability. In Multnomah County, we learned that young people with I/DD come from a variety of backgrounds: they can experience many types of disabilities, hold many identities at the same time, be a part of various cultures, live in many places and have a range of needs and goals when it comes to relationships and sexual health.

In 2016, 1,887 young people in Multnomah County between the ages of 10 and 24 years received I/DD services coordinated by the county or brokerages. This represents approximately 1.4% of the total population of young people in this age group in the county (Portland State University Population Research Center, 2016). The average age among these youth receiving services is 17. More than half of the young people identify as White, 15% as Hispanic, 13% as African/African American/Black, and 6% as Asian. At least 29 different languages are spoken, with English and Spanish being the most common. More young people who receive I/DD services live in East Multnomah County than any other part of the county (Multnomah County Developmental Services, 2015-2016).

Note: Multiple individuals who receive services indicated more than one race/ethnicity category.



The primary disability diagnoses for these young people are:



Research shows that young people with I/DD experience a greater burden of sexually transmitted infections (STIs), pregnancy, and sexual assault (Cheng & Udry, 2005; Gowen & Aue, 2011; Saxe & Flanagan, 2016; Shearer et al., 2002; Wings-Yanez, 2014). Eleventh grade students in Oregon with disabilities also experience poorer sexual and reproductive health and more abuse than students their age without disabilities (Oregon Health Authority [OHA], 2015).

HARMFUL MYTHS ABOUT SEXUALITY AND DISABILITY

There are many powerful myths about sexuality and disability (Gebb & Guthrie, 2015) that can keep the community from providing young people experiencing I/DD with sexual health education, support and services.



MYTH 1: People with disabilities are not sexual and do not experience sexual desire or have sexual relationships.



MYTH 2: People with disabilities are hypersexual and unable to control their sexuality.



MYTH 3: People with disabilities are “childlike” and dependent.



MYTH 4: People with disabilities have only abusive sexual relationships, or they are only involved in sexual relationships as victims or perpetrators of sexual violence.

PEOPLE WITH DISABILITIES ARE SOCIAL AND SEXUAL BEINGS

The people and systems who support individuals with disabilities often deny their sexuality, though data shows they *are* sexual, experience sexual desire and have sexual relationships, like all people. For example, among Oregon youth (OHA, 2015):



Young people with disabilities have a range of sexual orientations:

84.2% of 11th graders experiencing any disability identify as heterosexual, 2.7% identify as gay or lesbian and 13.1% identify as bisexual.



Young people with disabilities are sexually active: 49.5% of 11th

graders who experience disability have had sexual intercourse, compared with 38% of students without disabilities.



Young people with disabilities had sexual contact for the first time at younger ages:

Of students who said they had had sexual intercourse, students with disabilities were more likely to have had sex for the first time at a younger age than their peers without disabilities.



Young people with disabilities are less likely to use condoms and birth control:

Of students who said they had had sexual intercourse, students with disabilities were less likely to have used condoms (57%) than their peers (65%) and less likely to have used a method to prevent pregnancy the last time they had sex. This can put them at higher risk of sexually transmitted infections (STIs) and unintended pregnancy.

Despite the fact that youth with disabilities are sexual beings, they often do not have access to education to help them make choices about their sexuality, health and safety (Murphy & Young, 2005). It is assumed that they are not able to understand or make decisions about their relationships and sexual health or control their behavior. Yet adapted sexuality education can actually improve the ability of people with I/DD to make sexuality-related decisions (Sinclair, Unruh, Lindstrom & Scanlon, 2015).

Youth with disabilities in Oregon are two to three times more likely than their peers without disabilities to experience sexual assault, dating violence and physical violence (OHA CD Summary, 2017), yet people with disabilities can and do have healthy intimate relationships. This is especially true when they get sexual health education that describes and promotes healthy relationships and includes healthy skills practice (Szydowski, 2016). Research has also shown that people with I/DD can learn how to recognize and protect themselves from abuse when taught how to make decisions effectively (Khemka, Hickson & Reynolds, 2005).

A decorative graphic of a teal branch with five leaves, extending from the left side of the page towards the right. The leaves are arranged in a slightly curved path, with one large leaf at the top left and four smaller ones following along the branch.

PART 3: COMMUNITY NEEDS ASSESSMENT

Who We Learned From and What We Asked Them

To learn more about how to better meet the sexual health needs of young people with I/DD in our county, the iTP3 SHEIDD project decided to do a community needs assessment. We asked young people with I/DD and people who support them to help us answer these questions:

What sexual health education and help do young people experiencing I/DD need?
What kinds of help do support people need to provide sexual health education and support to young people experiencing I/DD?

Multnomah County Health Department's Youth Sexual Health Equity Program worked closely with the iTP3 SHEIDD Community Advisory Group (CAG) to plan the community needs assessment. The CAG is the heart of the iTP3 SHEIDD project and guides its work. CAG members include young people experiencing I/DD, family members, service providers, health care providers, educators, and representatives of community-based organizations and research institutions committed to improving the sexual health education, supports, and services for young people with I/DD in Multnomah County.

Together, we developed two sets of guiding questions to help us design surveys and focus group discussions for **young people** with I/DD and for **support people** who are involved in the lives of young people with I/DD (for example family members, caregivers, service providers, healthcare providers, teachers, etc.). The design of our surveys and focus groups was based on similar work done by others (Evans, McGuire, Healy & Carley, 2009; Löfgren-Mårtenson, 2012; McCabe, 2011; Swango-Wilson, 2011). Once our community needs assessment study was approved by Institutional Review Boards (Appendix A), we invited young people and support people to take the surveys and participate in focus group discussions, or sharing sessions.

<p style="text-align: center;">Guiding Questions for Young People Experiencing I/DD (Ages 18-21)</p>	<p style="text-align: center;">Guiding Questions for Support People (Family members, caregivers, service providers, healthcare providers, teachers, etc.)</p>
<p>What do young people who experience I/DD know about sexual health?</p>	<p>What do support people know about the sexual health rights, needs and goals of young people who experience I/DD?</p>
<p>What experiences do young people who experience I/DD have of sexual health education?</p>	<p>What experiences do support people have of providing sexual health education and support to young people who experience I/DD?</p>
<p>What do young people who experience I/DD think that sexual health education should include?</p>	<p>What training/support do support people need to provide comprehensive sexual health education and support to young people who experience I/DD?</p>
<p>How and by whom do young people experiencing I/DD think that sexual health education should be taught?</p>	<p>How do support people want to receive training to prepare them to provide comprehensive sexual health education and from whom?</p>



PART 4: SURVEYS AND SHARING SESSIONS

Surveys

In-Person Survey with Young People

We invited young people to participate in an in-person survey exploring what they knew about sexual health. To be able to participate, the young person had to:

- Be 18-21 years old,
- Identify as a person experiencing disability,
- Live in or near Portland, Oregon (in Multnomah, Clackamas or Washington County)

Each of the 11 young people who completed the survey chose a safe, private and comfortable place to meet with a member of our community needs assessment team (made up of trained staff from MCHD YSHEP and the iTP3 SHEIDD CAG) to answer the questions. We decided to do this survey during an in-person meeting so that it would be easier to tell if the young person did not understand and needed us to ask the question a different way. We also wanted to be able to pay close attention to how the young person might be feeling and if they were comfortable answering the questions about topics that can be sensitive.

Online Surveys with Support People

We also invited different groups of support people to participate in 2 online surveys about sexual health education and support for young people who experience I/DD. There was one survey for parents/guardians and family members and another survey for support service providers. To be able to take the online surveys, support people had to:

- Be 18 years old or older,
- Support a young person who experiences intellectual/developmental disability,
- Live in or near Portland, Oregon (in Multnomah, Clackamas or Washington county)

Thirty-four people completed a support person survey, including 5 who identified as parents/guardians and 29 who identified as support service providers. Each support service provider shared their professional role in supporting young people with I/DD, including:

- Provider
- Service Coordinator/Personal Agent
- Special Education Teacher/School Staff
- Healthcare Provider/Staff
- Behavior Specialist/Therapist
- Personal Support Worker
- Domestic Violence/Sexual Assault Advocate
- Group Home Operator/Staff
- Mentor

Sharing Sessions

Young people and support people who completed a survey were also invited to participate in a sharing session about sexual health education. We hosted 3 sharing sessions, 2 with support people and 1 with young people.

Because we wanted to ask people to share their opinions about sexual health education and support during the session, we shared a poster with our definition of “sexual health” which includes many parts of sexuality and relationships. We explained that sexual health can be made up of 4 categories and gave examples of how different sexual health topics are related to these categories (Appendix A).

Support People Sharing Sessions

Eleven support people participated in 2 sharing sessions about providing sexual health education and support to young people who experience I/DD. Each sharing session lasted 3 hours. We asked the support people to share their opinions about (Appendix A):

- What young people (ages 14-21) who experience I/DD need the most help with when it comes to sexual health.
- What can make it hard for support people to provide this sexual health education and help.
- How various pretend scenarios about young people should be handled and what kind of support the youth in the situations needed.

Young People Sharing Session

Four young people participated in a sharing session about sexual health education. The sharing session lasted 4 hours. We asked the young people (Appendix A):

- To share their opinions about the best ways for young people to learn about sexual health and what kind of help young people need.
- To do activities that encouraged participants to share their opinions in different ways.
- How the same pretend scenarios we shared with support people should be handled and what kind of support the youth in the situations needed.

Guidelines for Providing Holistic Sexual Health Education and Support to Young People Experiencing I/DD

The input from young people and support people in the surveys and sharing sessions came together into 11 key guidelines that help us understand how to better provide young people experiencing I/DD with the affirming sexual health education they need, want and deserve.



1. *You* have a role to play in providing sexual health education to young people experiencing I/DD. Page 17



2. Re-frame sex ed: sexual health education is a basic human right. Page 19



3. Make sure young people know their relationship, sexual and reproductive rights. Page 20



4. Think of teaching about body parts as a starting point, not the end point. Page 21



5. Re-frame sex ed: sexual health education is an opportunity to help young people build a sense of self-worth. Page 22



6. Pay attention to building verbal and non-verbal communication skills. Page 23



7. Provide regular opportunities for young people to practice making decisions. Page 24



8. Practice setting and respecting boundaries. Page 25



9. Strengthen skills by teaching sexual health education in many ways, including videos, modeling, role-play and one-on-one support. Page 26



10. Facilitate positive peer connection. Page 27



11. Use person-centered planning processes to learn about young peoples' relationship goals and support sexual health education. Page 28



GUIDELINES SUPPORTING YOUTH EXPERIENCING I/DD



1. You have a role to play in providing sexual health education to young people experiencing I/DD.

Sexual health education doesn't just happen in the classroom. The support people in the sharing sessions agreed that "it takes a village" to provide consistent quality sexual health education and assistance to young people experiencing I/DD. All community members, including peers, parents/guardians, healthcare providers, teachers, support service coordinators and providers, have a part to play in helping young people with I/DD build the knowledge and skills to set and work toward their goals around relationships and sexual health. While young people may choose to talk with some people about sexual health more than others (Appendix C1), they value the support of people who are informed, respect their rights, are honest and trustworthy and assist them in difficult situations.

"It doesn't matter if you have I/DD or not, it shouldn't just be the teachers, it shouldn't just be your doctor, it shouldn't just be your parents. It shouldn't just be your society and your social media. It's all of it. And so it's not any different from this population as it is for any other population out there." - **support person**

"It's essentially their [healthcare providers] job to take care of you in the event of something like that to make sure you don't screw up in some bad way. Getting pregnant when you don't want to or contracting STDs because you didn't receive the proper education. And it's going to be them, in the case that you do, that are going to be giving you the suggested ways on how to resolve the situation. I mean it's kind of their job... They are going to be a very reliable source. In fact, they're probably going to be one of those must haves when it comes to staying healthy." - **young person**

"I would hope parents are allowing their youth to be the human being they want to be. And not try to put what their preconception... One would hope that they would want their youth to grow in whatever direction that is healthy and positive for that youth. However they want to express themselves. And their sexual identity. And it goes with a lot of other things. They own that. They should be able to be whoever they can be." - **support person**

"Talk to your parents about it too. Because they can give you the honest opinion even though it can be a little bit nervous and a little bit awkward to ask your parents. But your parents can give you the right way to do it and the wrong way and stuff." - **young person**

"I don't really talk to my dad about some things. Some things I don't like to open up because I'm afraid of him can judge to not being honest. My dad said you don't need to worry about that. You don't need to worry about any of that [sexual health] stuff. You're too young. You don't need to worry." - **young person**

"If these families can get behavior support services through DD and brokerage, there should be some specialists that can cover some of these topics so that it's not on the behavior specialist to try to make it up as they go along." - **support person**



2. Re-frame sex ed: sexual health education is a basic human right.

Providing holistic sexual health education to young people experiencing I/DD can challenge harmful myths by affirming their full humanity as social and sexual beings. Supporting their rights to build knowledge and skills around relationships and sexual health reinforces their right to make informed choices about their lives and participate in the community (Appendix B).

“And I would say what makes it hard for us to support people is even that belief system that they have a right. That they are entitled to choice, that they’re entitled to pleasure. A lot of the focus is on safety...and we can teach about bodies pretty easy...But what really gets in my way is believing that these kids are entitled to those choice and pleasure just like everyone else.” - **support person**

“...(young people experiencing I/DD) feel extremely undervalued in the community and in the school. If they don’t feel valued and they don’t have that identity, how are they supposed to practice all of the other things with their body?” - **support person**

“But I think...having comprehensive, and including sexual reproductive health education benefits all of us. Not just youth with I/DD.” - **support person**



3. Make sure young people know their relationship, sexual and reproductive rights.

In order for young people experiencing I/DD to develop goals around their relationship, sexual and reproductive health, they need to know their rights and responsibilities (Appendices B, C2). Holistic, affirming sexual health education provides youth with ongoing opportunities to learn their relationship, sexual and reproductive rights as well as develop skills to exercise them and respect the rights of others.

“...if you’re in a sexual relationship that doesn’t feel good then... if they...don’t know they have the right to be in a relationship like that, they’re not going to know to make things better for themselves.” - **young person**

“Because when you’re young, you tend to have a lot of certain qualities and stuff that you need to be aware of like you kind of need to know a lot of societies’ laws, expectations, and rules. And to be able to have a lot of personal skills and I feel like sometimes not everybody gets taught these things.” - **young person**

“...really empowering young people to name what it is that they want...clinicians actually asking young people, do you know what your rights are around your sexual health? And do you know this conversation is confidential?” - **support person**



4. Think of teaching about body parts as a starting point, not the end point.

Young people experiencing I/DD say it's important that sexual health education help them learn more about who they are, which includes learning about their body parts and how they work (Appendix C2). Teaching about human sexual and reproductive systems helps young people make sense of their experiences and can be the beginning of bigger conversations about self-identity, self-awareness and self-acceptance.

"I mean a lot of kids...you go through puberty or anything because you don't really understand what's going on with your body, which you need to talk to someone you can trust and not have a worry about that." - **young person**

"...starting with the body parts, it gives you a direction...for your conversation. If there's a feeling that they're having with those body parts, you're able to describe why there's that feeling and you can go from there." - **support person**

"...I think the how to take care of your body and just knowing about bodies is really important for that. That establishment of identity helps to create a value for that thing. And it's hard to advocate for something or want to be safe with something if you don't value it." - **support person**



5. Re-frame sex ed: sexual health education is an opportunity to help young people build a sense of self-worth.

The young people we talked to explained that youth experiencing I/DD can feel a lot of pressure to be someone they are not in order to fit in. They say it is important to be themselves both in and out of intimate relationships. Holistic sexual health education goes beyond teaching about body parts and sexual behavior and provides opportunities for youth to develop social and emotional skills, including opportunities to develop a strong sense of self, learn about their own interests and goals, explore their genders and sexual orientations and grow the self-confidence that can help them build healthy relationships.

*“At the end of the day, you should always be your own person, do your own things, have your own life. At the end of the day, a person has friends and stuff...stuff that they want to do, too... It should never be your goal to strive just to be in a relationship. That should be part of something but...you should always be doing your own thing. The other person is just a part of it...just a part of the ride.” - **young person***

*“I purposely do not send my kids to a couple of the teachers because they teach it in the science way. Here’s the answers for these. Here’s the answers for this. Well they didn’t even get to talk about the fact that they have emotions around sex. Because he’s not willing to have that conversation with him.” - **support person***



6. Pay attention to building verbal and non-verbal communication skills.

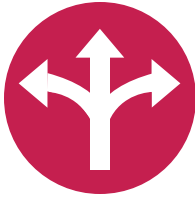
Young people experiencing I/DD can feel isolated and unsafe in a society where they're often excluded. This can be worse when they don't know how to express themselves or understand others. To build healthy relationships, including healthy sexual relationships, youth need opportunities to learn many ways to express who they are and communicate what they think, feel, need and want in socially acceptable ways (Appendix C2).

"I feel like some people, they like they have certain things that they may want or need but they feel either too shy or too humiliated or something or too awkward to just state said want or need. And that may eventually just go completely unnoticed." - **young person**

"If they are special in some ways, it's hard for them to communicate in a relationship. Because they don't know what to say...Because they can't understand needs of someone like that. And trying to understand but they can't really understand the proper needs and stuff." - **young person**

"...learning to be able to talk to people. Learning be able to act... how to act around people. How to treat people that would be polite or proper. Like different...like maybe how to talk to a person to get that first date." - **young person**

"And how to send the nonverbal messages he wants to send. "I'm interested" in friendly but non-threatening...the whole series of skills that Coby [scenario character] might need help to develop in order to do this successfully." - **support person**



7. Provide regular opportunities for young people to practice making decisions.

People experiencing disability have historically been given few opportunities to make choices about their lives and young people with I/DD may have many decisions made for them. Providing youth with regular opportunities to understand and explore their options, develop decision-making skills and learn from their experiences helps them build the skills they need to exercise their relationship, sexual and reproductive rights, protect their health and work toward their goals.

“...the young people that we work with...many times they’re not given any decision making process. They’re not given the power to make decisions so then like sexual health and relationships is all about making decisions and if they can’t make decisions on what they’re eating or a class they want to take or these type of things, then they don’t understand that there’s multiple solutions.” - **support person**

“... so many young people aren’t given the option to practice making decisions...when I’m working with young people I always keep in mind what I call successful risk taking and that’s... normal adolescent development for all young people around successful risk taking.” - **support person**



8. Practice setting and respecting boundaries.

All of the young people we talked to understood that they have the right to set boundaries in relationships (Appendices C3-4). The youth in the sharing session explained that it's important for youth experiencing I/DD to learn how to communicate their limits and respect others' (Appendix C2). Providing youth with regular opportunities to make choices about their bodies, communicate them to others and have them respected -- and learn how to do the same for others -- teaches them important qualities of healthy relationships.

"It can be a communication thing. Or certain places where people don't like to be touched. That's just what I'm thinking. People should learn boundaries with body feeling."

- **young person**

"And learning about advocacy...for themselves at that very moment. Like no please don't. Even it's like I don't want my mom to help me in my shower anymore. It doesn't matter. That's kind of that same idea like who's allowed and when and why."

- **support person**



9. Strengthen skills by teaching sexual health education in many ways, including videos, modeling, role-play and one-on-one support.

Young people experiencing I/DD need concrete examples of healthy relationships that affirm who they are. They want clear models of healthy behaviors and communication skills along with opportunities to develop their own interpersonal skills in a supportive environment. Short videos can provide simple visuals and explanations and positive models of relationship and sexual health skills that youth can watch as many times as they need. Role-play, which can be supported with scripts, gives them the opportunity to try out new interpersonal skills that can be used in many situations. Creating options for one-on-one teaching or coaching allows support people to make adaptations to best meet individual needs and goals.

“...there’s other videos that actually show what a good relationship looks like, what a bad relationship looks like. So that kind of helps people understand oh, you’re to be nice to this person – respect their boundaries. And then what it doesn’t look like...it’s...you hurt that person when you don’t respect their boundaries.” - **young person**

“So as a behaviorist, the first thing that I think of in a situation like this is helping to provide...some scripts to use and doing some role-play scenarios...because especially with, if either one of them has autism, some of the social cues and some of the social niceties that might come really natural to somebody won’t be as obvious. And so practicing the asking of [someone]...out, practicing some things that you might talk about on a date that would be appropriate. Some appropriate conversation topics and things. Because sometimes conversation skills can be really difficult for individuals that are I/DD. You want it to be a good experience for them.” - **support person**



10. Facilitate positive peer connection.

Young people experiencing I/DD can feel alone in their experiences and may have few opportunities to both get and *give* support to their peers with and without disabilities. All but one (91%) of the young people we talked to said that they had talked about sex, sexuality and sexual health with their friends (Appendix C1). They value peers', friends' and siblings' ability to understand their experiences, empathize with them and give advice and ongoing support in ways that other people cannot. Support people can facilitate peer connection and community inclusion by bringing youth together, ensuring they have accurate and affirming sexual health information and helping them have open and honest conversations about relationships and sexual health.

"I think it's good to discuss in a group because then you can know like everyone will know where everyone is at. And then we can talk about what kind of things they can get through if they're having a hard time in that situation. If someone is more experienced than that in there." - **young person**

"I chose my brother not just because of the sexual stuff but like relationships. He's taught me a lot about life and people." - **young person**

"...young people with disabilities as well as their peers without disabilities together. ...my kids don't need special ed. It's the other kids that need special ed. How can we also integrate more that like a peer would be really willing to talk to their other buddy with intellectual disability? And say like this is my understanding of the world. And so they're gaining more knowledge from all over." - **support person**

"Peer-to-peer education can also be beneficial for moving our society forward to making sure we're recognizing all members as...able to access sexual health and relationships." - **support person**



11. Use person-centered planning processes to learn about young peoples' relationship goals and support sexual health education.

In order to support the relationship and sexual health of young people experiencing I/DD, they need opportunities to set and share their goals with the people who support them. Person-centered plans, including the Individualized Education Program (IEP) and the Individual Support Plan (ISP), can include relationship and sexual health education, goals and support. Person-centered planning approaches can also help support teams explore and define their roles and responsibilities in supporting the relationship and sexual health of the young people in their lives.

"He [scenario character] might need help regarding proper ways of treating a lady. So that'll be starting a relationships. He might need a little bit of education of what's appropriate versus not appropriate." - **young person**

"...making sure that Coby [scenario character] knows that he's allowed to ask his parents to call an IEP meeting if he feels that he needs some support. IEP educational plan in schools, point person to be saying like Coby's really interested in making sure that he's able to ask some people out on some dates this year. And like how, where is his level of communication, and what does he know about dates? And getting all that information so that way the students have voice within what they want to do..." - **support person**

Guidelines for Helping Support People Provide Holistic Sexual Health Education and Support to Young People Experiencing I/DD

The input from young people and support people helped us understand how to provide young people experiencing I/DD with holistic, affirming sexual health education. Additional input from support people outlined 2 key supports they need to help build their capacity to provide young people experiencing I/DD with the sexual health education they need, want and deserve: 1) policies and procedures and 2) skills-based training.



Put policies and procedures in place to support the relationships and sexuality of individuals experiencing I/DD. Reinforce the importance of these policies with regular communication and staff training.

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Provide skills-based training.

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Training Component 1: Understanding the relationship, sexual and reproductive rights of individuals experiencing I/DD.

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Training Component 2: Applying organizational policies and procedures.

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- Navigating personal and professional values
- Balancing rights and responsibilities



Training Component 3: Teaching approaches, tools and resources for providing rights-based, affirming, holistic sexual health education to individuals experiencing I/DD.

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Training Component 4: Tools and strategies to collaborate with teams to provide sexual health education to individuals experiencing I/DD.

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GUIDELINES HELPING SUPPORT PEOPLE SUPPORT YOUTH

Put policies and procedures in place to support the relationships and sexuality of individuals experiencing I/DD. Reinforce the importance of these policies with regular communication and staff training.

The majority of those who participated in the staff/professionals survey (55%) were not aware of any organizational guidelines on the personal relationships or sexuality of people experiencing I/DD (Appendix C5). Providing staff with clear and consistent guidelines and training on how to provide sexual health education and assistance that enhances individuals' quality of life makes it clear that your organization understands the importance of supporting relationship, sexual and reproductive rights of the individuals you serve. According to the support people we talked to, policies and procedures that support both staff and clients:

- Are clear, consistent and communicated across organizations and systems.
- Are explicitly supported by organizational leadership.
- Explain to both clients and staff that staff are expected to support the relationship, sexual and reproductive rights of the individuals they work with.
- Provide guidance to staff on how to support the relationship, sexual and reproductive rights of the individuals they work with, including by providing sexual health education.
- Help members of individuals' support teams explore and define their roles in providing sexual health education and support.

(Continued)

“One of the core issues here is that there are no expectations set up to begin with so the general teacher doesn’t know your expectations and you don’t know theirs. And the kids don’t know...and no one knows anyone’s expectations of what they’re supposed to be learning in the first place. If those things are established I think it would reduce the amount of people that are calling you up and saying why are you saying this? ... transparency, that’s a huge part of like minimizing miscommunication. Because I think that’s where I think a lot of these issues come up...It’s that the expectations of what they’re doing aren’t communicated to begin with.” - **support person**

“Helpful for employees to be really clear around what are the state statutes, what’s the wiggle room, what are the rules around mandatory reporting, and then to have management support employees to meet the needs of the clients. And follow the law and follow the policies and for that all to be very, very transparent...have a course of action...” - **support person**

“The (support) people would be less scared about ‘I might break the law and get in trouble’ if they had some clear guideline that we could point them to and say this is what you can do and this is what you should do. And this is who is responsible...whose role is responsible for which role of providing sexual health education.” - **support person**

Provide skills-based training.

Supporting the relationship, sexual and reproductive health of individuals experiencing I/DD is complicated and support people want training to help them navigate these complexities. Only about 1/3 of staff/professionals who took the survey had ever received training about discussing romantic and/or sexual relationships and sexual health with young people experiencing I/DD, and nearly all of them (97%) were interested in receiving such training. Four out of 5 parents/guardians who took the survey had had training on discussing romantic/sexual relationships and sexual health with their family member and 3 out of 5 were interested in receiving training in this area (Appendices C6-8).

Seek and devote funding to help support people build the many skills they need to provide holistic, affirming sexual health education to the young people in their lives. Provide interactive, skills-based training including 4 key components:



Training Component 1: Understanding the relationship, sexual and reproductive rights of individuals experiencing I/DD.

Young people think it is important that sexual health education is rights-based, person-centered, and holistic. Support people feel that their trainings should have those same qualities and focus on the rights, stories, experiences and quality of life of individuals experiencing I/DD.

“...I think that one 30 minute training that I went to years ago has stuck with me more than any of the like, here’s what you should teach. But actually like listening to them and saying this was my story. This was really hard...no one wanted me to do this. They thought I couldn’t get married. They told me I couldn’t. So at some point they hear these stories and they know...they hear this information. And then in the end he was like but we did because this is the person that I love. And in that moment it kind of makes you think, oh right, no matter what, they’re a human first. They have their own emotions and their own feelings. It doesn’t matter what all of this and jargon and information we put on it. Their stories’ first.” - **support person**

Support people need more information about the relationship, sexual and reproductive rights, including rights to privacy, of individuals experiencing I/DD to be able to better support them. While almost all of the staff/professionals who took the survey thought individuals with I/DD should be allowed to have all types of relationships, including sexual relationships and marriage (Appendices C9-10), many (12 out of 29 or 41%) also did not know the legal rights of people with I/DD when it came to romantic and/or sexual relationships.



Training Component 2: Applying organizational policies and procedures.

While putting in place organizational policies and procedures on personal relationships and sexuality is important to supporting the quality of life of individuals with I/DD, staff also need training and ongoing support on how to apply these guidelines in a way that affirms the rights of the individuals they serve. Forty-six percent of the staff/professionals whose organizations did have guidelines on relationships and sexuality reported that they had not received any training on applying the guidelines and 39% also reported that they found the guidelines difficult to apply (Appendix C5). Support people experience 2 key challenges when it comes to applying rights-based organizational policies and procedures: 1) navigating their personal and professional values and 2) balancing the rights of the individuals they serve with their responsibility to keep them safe.

Navigating personal and professional values: Provide training that allows support people to explore and understand their personal and professional values around relationships, sexuality and disability. Help them build skills to learn about the values of the individuals they serve as well as the values of their cultures and communities and members of their support teams.

“I want to make sure it’s not just me imposing my values about sexuality on this person. Because they might have different values and they have a right to have that supported.” - **support person**

Balancing rights and responsibilities: Help support people develop strategies to clarify the rights of the individuals they serve, including the right to make mistakes, and their responsibility to keep them and others safe. Provide opportunities for them to build skills to put proactive sexual health education and support plans in place, clarify their support role as well as navigate challenges that can come up around relationships, sexuality and disability. Ensure ongoing support is available to staff as they have questions and address ethical and legal challenges.

“It’s often very difficult to know when we’ve gotten to the point that it’s necessary, or what exactly we legally and ethically can and should do to intervene. On the one hand, there’s dignity of risk to consider - people have the right to make poor decisions and to be in relationships that aren’t healthy. On the other hand, due to the person’s lagging cognitive skills and social awareness, they’re often at much higher risk of abuse and exploitation, particularly sexually, than a neurotypical person, and their teams bear a responsibility to ensure they are protected from abuse and exploitation.” - **support person**

“I think what’s hard on our end is that balance of overstepping and being reported as an abuse when you’re trying to help teach someone sexual education. That’s one of the biggest obstacles that I think that we struggle with at least in the company I work for. Where it’s...it’d be really easy for someone to deem it inappropriate and for you to suddenly be investigated and you’re out of the job. So trying to find that balance I think is really important.” - **support person**



Training Component 3: Teaching approaches, tools and resources for providing rights-based, affirming, holistic sexual health education to individuals experiencing I/DD.

Provide training opportunities designed to reach “the village,” or all support people, so they can collectively build the knowledge, skills, comfort and confidence to provide rights-based, holistic and inclusive sexual health education to young people with I/DD. Topics should include 1) strategies for talking with young people about relationships, sexuality and sexual health, 2) the most effective approaches for teaching sexual health education to individuals experiencing I/DD and 3) strategies for adapting and individualizing sexual health education. A variety of resources and teaching tools should be made available, including videos, curricula, handouts, and resource lists that can be used to support the sexual health of youth with I/DD as well as improve the communication and education skills of support people.

“...usually it’s the people around this table that are asked to provide it [sexual health education] and often I’ve personally felt like I’m flying by the seat of my pants and giving my best guess at how to provide it appropriately.” - **support person**

“...some kind of resource list where families or support people or educators that are uncomfortable. But like an evidence-based, accurate, medically up to date, if I could dream, clearinghouse of where people could go to get information to then go talk to their kids.” - **support person**

“Maybe developing a curriculum that’s adapted...Adapted to a different level that has contingencies [a wide range of activities] in it for different scenarios...bring it to a level that’s accessible for people with disabilities.” - **support person**

“A short series of videos that’s parents can watch at home with their kids. With so many young people preferring video or the technology part, to have educational messages that are 5-7 minutes...best practice. But keeping them short and to the point.” - **support person**

“I would take some video modeling or some scenarios like as an educator and adult support person. Like so if I were to be able to maybe see how do other people respond and to kind of be given a script of what is appropriate or what are some ways that I could address or define some things that are positive and would hopefully not make the individual feel worse. But then if I could see that...see someone else do it and kind of practice that in my head, I would feel better prepared because the truth of it is when you’re in these situations and especially if you’re in public, it’s really very stressful.” - **support person**



Training Component 4: Tools and strategies to collaborate with teams to provide sexual health education to individuals experiencing I/DD.

While support people agree that “it takes a village” to provide consistent sexual health education and assistance to young people experiencing I/DD, they’re not always sure how to collaborate with that village and help everyone play their part. Support people may recognize opportunities to focus on relationships and sexual health education and support, for example as part of person-centered planning processes like the IEP and ISP, but may not have the skills and confidence to have constructive conversations about relationship and sexual health with other members of individuals’ support teams. Help bridge this gap by providing support teams with tools and skill-building opportunities that will help them have conversations and collaborate to make proactive plans around the relationship and sexual health education goals and needs of individuals experiencing I/DD in their communities.

“Ideally, everyone involved in this person’s team and everyone is involved in this person’s support should be working together so that they (young people) get a consistent clear message. Because a lot of times we confuse the hell out of people with different messages from different sources. And that’s difficult to do so usually they go ‘behavior specialist, what do we do?’ Or ‘sex educator, what do we do?’ And sometimes we go, ‘hell if I know.’” - **support person**

"I think...a good way to provide support for support people is to have more community...have a chance to talk with other providers and have a lot of discussion around it because like anything with relationships, I mean, this stuff is tricky. It's not clear cut. But if we can have education and discussion then we can, then I think people can be equipped to also be more confident in and of themselves. Because you know a lot of people are not sure about how to talk about these topics to young people." - **support person**

"...if there were a question on a student's IEP... plan that really addressed if whether or not this student was getting information about their sexual health and relationships. And who was responsible to provide that and what were the next steps or activities to support that. That forces teams to ask the question and then it kind of mandates school districts, agencies, and programs to make sure that they are considering it. It triggers that responsibility..." - **support person**

"Family engagement...that's a key. Because too many times parents or family who have kids or people with disability...we feel like the school is fight. Because you're always fighting for the IEP, for the placement, for this, for this. So this never, I mean not never, but too many times it's like a war in between. So why can you call families and say you know we want to teach this, how do you think it's appropriate for us to teach your kids? So getting that information and for parents to be involved too." - **support person**



PART 5: RECOMMENDATIONS

Through surveys and sharing sessions, young people experiencing I/DD and support people outlined 13 guidelines to help young people experiencing I/DD get the sexual health education they need, want and deserve. When put into practice, these recommendations can help build a system of sexual health education and services supporting the full rights and experiences of individuals with I/DD by providing them with the knowledge and skills they need to make informed decisions about their health, increase safety, and seek mutually fulfilling relationships. The 13 guidelines lead to the following key recommendations:

Support the Sexual Health of Young People Experiencing I/DD

1. Provide holistic sexual health education to young people experiencing I/DD.

Recognize young people experiencing I/DD as social and sexual beings by providing them with holistic sexual health education that helps them learn:

- Who they are
- What their rights are
- How to express themselves
- How to build healthy relationships

2. Learn about young peoples' goals.

Use person-centered processes to learn about young peoples' individual relationship, sexual and reproductive health goals and help them get the education and support they need and want.

3. Provide regular skill-building opportunities.

Support the self-determination of young people by helping them build relationship and sexual health skills in group and individual settings using a variety of methods, especially:

- Videos
- Group discussion
- Role plays/acting

4. Facilitate peer connection.

Enhance community inclusion by creating environments where young people have access to accurate, affirming sexual health information and can teach and learn from each other.

Build the Capacity of Support People to Provide Sexual Health Education and Support to Young People Experiencing I/DD

1. Put policies and procedures in place to support the relationships and sexuality of individuals experiencing I/DD.

Make it clear that your organization or practice understands the importance of supporting relationship, sexual and reproductive rights of the individuals you serve. Provide staff with clear and consistent guidelines and ongoing training on how to provide sexual health education and support that enhances individuals' quality of life.

2. Support collaboration around sexual health education and support.

Provide teams with tools and strategies to have conversations and make proactive plans around relationship and sexual health education and support.

3. Make inclusive and adaptable education materials and resources available.

Make sure support people have the resources and teaching tools to provide quality, holistic, affirming sexual health education.

4. Provide training opportunities.

Supporting the relationship, sexual and reproductive health of individuals experiencing I/DD is complicated. Help support people build the skills they need to put all the pieces in place to assist the young people in their lives. Skills-based training should include:

- Understanding the relationship, sexual and reproductive rights of individuals experiencing I/DD.
- Applying rights-affirming organizational policies and procedures.
- Exploring and clarifying personal and professional values around relationships, sexuality and disability.
- Strategies to clarify the rights of individuals with I/DD and the responsibilities of support people.
- Learning approaches for teaching sexual health education to individuals experiencing I/DD.
- Strategies to collaborate with teams to provide sexual health education to individuals experiencing I/DD.

APPENDICES

Appendix A: Additional Study Information

This community needs assessment study was approved by Institutional Review Boards at Texas A&M University (TAMU IRB 2016-0620) and Oregon Public Health Division (PH IRB 16-25), with Daesha Ramachandran, PhD serving as Principle Investigator and Kim Toevs, MPH as the Co-Principle Investigator. Young people who participated in the in-person surveys and the youth and support people who participated in the sharing sessions received a gift card for their time.

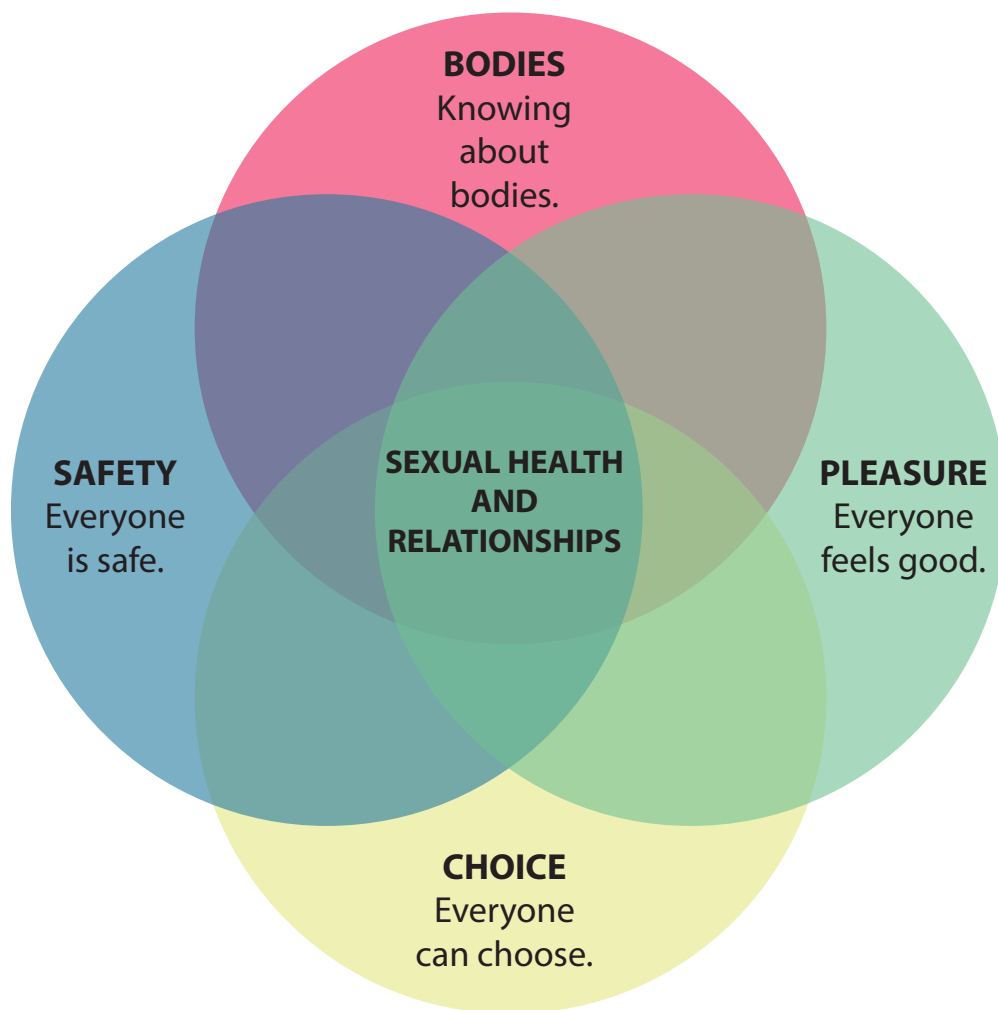
Study Limitations

This community needs assessment study was limited in a number of ways. It included a small number of youth and support people from the tri-county area. Parents/guardians and support service providers who participated in the online surveys were self-selected. While we wanted to learn about the sexual health education needs and wants of young people experiencing I/DD ages 14-21, we chose to only talk with older youth ages 18-21, which may have limited our understanding of the needs and wants of younger youth. In order for a young person to participate in the in-person survey, they had to show they understood and agreed to participate in the survey by completing a consent process. This limited who was able to participate as some young people who were interested in participating in the survey were not able to complete the consent process. All the young people who completed the in-person survey and sharing session were high school graduates participating in transition programs that were supportive of sexuality education.

Sharing Session Facilitator Guide Examples

Poster of Definition of Sexual Health Categories

As part of the introduction to each sharing session, we gave a definition sexual health based on the Sexuality Information and Education Council of the United States' (SIECUS) Guidelines for Comprehensive Sexuality Education (2004). We used a poster with the image below to explain that sexual health can be made up of 4 categories and gave examples of how different sexual health topics are related to these categories.



Sharing Session Questions and Scenarios

Below are the questions and scenarios from the focus group/sharing sessions that were co-developed with the iTP3 SHEIDD Community Advisory Group.

Support People Sharing Session Questions

1. What do young people need the most help with when it comes to sexual health (refer to list from definition)? Why?

Follow-up questions:

- Who should provide this education/support? Why?
2. What can make it hard for support people to provide sexual health education and help to young people with I/DD? Why?

Follow-up questions:

- How could these challenges be addressed? What would make it easier for support people to provide sexual health education and help to young people with I/DD? Why?

Youth Sharing Session Questions

Note: These questions were accompanied by activities and follow-up questions.

1. What are the best ways for young people to learn about sexual health (refer to definition: bodies, choice, safety, pleasure)?

Alternative wording options:

- How do you think young people need to learn about sexual health?
 - How do young people learn best about sexual health?
2. Who are the best people to teach young people about sexual health?
 3. What do young people need the most help with when it comes to sexual health (refer to list from sexual health definition)?

Alternative wording options:

- What things are the most important for young people to know about (refer to list from definition)?
- What sexual health topics do young people need the most help with (refer to list from definition)?
- What sexual health subjects are the most important for young people to know about (refer to list from definition)?

4. What can make it hard for young people to talk about sexual health?

Alternative wording options:

- What can make it uncomfortable for young people to talk about sexual health?

5. What help do young people need to have healthy (dating/intimate/romantic) relationships?

Alternative wording options:

- What do young people need to have healthy relationships?
- What help do young people need to have the kind of (dating/intimate/romantic) relationships they want?
- What do young people need to have the kind of relationships they want?

Scenarios Discussed in Youth and Support People Sharing Sessions

1. Coby is 17 years old and in high school. He has a crush on another student at his school, Madison, who is 15 years old. Madison seems to like Coby, too. Coby wants to ask Madison out on a date.
2. Shelby is 14 years old and is becoming sexually excited more and more lately. When Shelby wakes up in the morning and feels sexually excited, they stay in bed and touch their body/masturbate until they feel calm. When Shelby feels sexually aroused at other times, like at school and at the park, they put their hand down their pants to masturbate. Shelby has been told that they're only supposed to masturbate at home and doesn't know what to do when they feel sexually excited and aren't at home.
3. Maria is 20 years old and lives in a group home with two other men and a woman. Maria has a job and her parents visit her every weekend. One weekend, Maria tells her parents that one of the men in the house, John, who's 21 years old, is her boyfriend. Before then, Maria's parents and the group home staff thought that Maria and John were just friends. Now, Maria says she has missed her period. She takes a pregnancy test and finds out she is pregnant. It turns out that Maria and John have been having consensual sex and made the pregnancy happen together.

Appendix B: Relationship, Sexual and Reproductive Rights of Individuals with Disabilities

In order for a people to experience sexual and reproductive health, including people with disabilities the United Nations (Article 25 – Health) recognizes that their rights must be affirmed, respected and protected. According to the World Health Organization (2018), sexual health can be defined as "...a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence 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..." Examples of human rights related to people being able to control and protect their bodies and experience relationship, sexual and reproductive health, include:

- the rights to equality and non-discrimination
- the right to be free from torture or cruel, inhumane or degrading treatment or punishment
- the right to privacy
- the rights to the highest attainable standard of health (including sexual health) and social security
- the right to marry and to found a family and enter into marriage with the free and full consent of the intending spouses, and to equality in and at the dissolution of marriage
- the right to decide the number and spacing of one's children
- the rights to information, as well as education
- the rights to freedom of opinion and expression, and
- the right to an effective remedy for violations of fundamental rights (World Health Organization, 2018).

The Arc and the American Association of Intellectual and Developmental Disabilities have issued a position statement on sexuality to affirm that "Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality" (The Arc, 2008). Among the rights it affirms are every person's right to:

- develop interpersonal relationships, including friendships and emotional and sexual relationships;
- sexual expression and education, reflective of their own cultural, religious and moral values and of social responsibility;
- individualized education and information to encourage informed

decision-making, including education about such issues as reproduction, marriage and family life, abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases;

- education and information about having and raising children that is individualized to reflect each person's unique ability to understand;
- make their own decisions related to having and raising children with supports as necessary;
- make their own decisions related to using birth control methods within the context of their personal or religious beliefs;
- have control over their own bodies;
- protection from sexual harassment and from physical, sexual, and emotional abuse; and
- protection from sterilization solely because of their disability.

All people also have the responsibility to respect the rights of every other person.

Appendix C: Tables

Youth Survey: Talking about Sexual Health, Sex and Sexuality

Table C1 – Talking to Others About Sexual Health, Sex and Sexuality (n = 11)					
How often do you talk to the following people about sexual health, sex and sexuality?	% Youth All the time	% Youth Sometimes	% Youth Once in awhile	% Youth Never	% Youth Did not answer
Doctors / Nurses	27%	9%	46%	9%	9%
Friends	18%	27%	46%	0%	9%
Family	18%	18%	0%	46%	18%
Teachers	0%	9%	36%	46%	9%
Case Coordinators	0%	0%	9%	82%	9%

Youth Sharing Session: Sexual Health Topics Votes

Young people in the sharing session were asked to look at 39 different sexual health topics adapted from the Sexuality Information and Education Council of the United States' (SIECUS) Guidelines for Comprehensive Sexuality Education (2004) and vote for those that youth experiencing I/DD need the most help with. All 4 young people who participated in the sharing session said youth experiencing I/DD need a lot of help with the 18 different topics highlighted in green:

Table C2 – Sexual Health Topics
Do teenagers and people your age need help knowing about:
How bodies grow and change?
Becoming an adult?
Names of body parts?
How bodies work?
How to take care of their bodies?
Appreciating their bodies?
Gender (who we are and how we feel as a boy, girl, man, woman or another gender)?
How pregnancy happens?
How babies are made?
Having babies/childbirth?
Parenting?
Adoption?
Ending a pregnancy/abortion?
Keeping unwanted pregnancy from happening/birth control?
What's important to them when it comes to relationships, sex and sexuality?
What's important to their family, community and society when it comes to relationships, sex and sexuality?
Family life?
Consent/agreeing to have a sexual relationship?
Unwanted touch and sexual abuse?

Having different kinds of healthy relationships, including healthy intimate and sexual relationships?
Starting, keeping and ending relationships?
Communicating what they need and want?
Expressing feelings in appropriate ways?
Setting limits/boundaries?
Making decisions?
How people have the right to have opportunities to build relationships, including romantic and sexual relationships?
How people have the right to decide whether or not to have children?
How people have the right to decide whether or not to get married?
How people have the right to have sexual relationships that feel good?
How people have the right to have sexual relationships that are safe: <ul style="list-style-type: none">• Where everyone agrees.• Where everyone feels good.• Everyone's rights are respected.• No one is pressured.• No one is getting hurt.
How people have the responsibility to respect other peoples' rights?
Sexually transmitted diseases or sexually transmitted infections (STD/STIs)?
HIV/AIDS?
Protecting the body from diseases and infections?
Sexual attraction and desire?
Emotional/romantic attraction and desire?
Dating and boyfriend/girlfriend/partner(s)?
Sexual feelings/feeling turned on?
Masturbation: when a person touches their own body to make it feel good?

Youth Survey: Consent and Boundaries

In the youth survey, all the participants showed that they know they have the right to set boundaries in relationships when they answered that they have a right to say “no” if someone wants to touch them and they don’t want them to. The majority, but not all, also demonstrated an understanding of sexual consent, or agreeing to sexual behavior, when they said that someone needs permission to touch a romantic or sexual partner in a sexual way. The majority also shared their ideas of how they would know if they had permission to touch another person (for example by asking the other person or when the other person says it’s okay, gives permission or consents).

Table C3 – Consent & Boundaries (n=11)	
Does someone need permission to touch a romantic or sexual partner sexually?	% Youth
Yes	73%
No	9%
I don’t know	9%
Did not answer	9%

Table C4 – Consent & Boundaries (n=11)	
How would you know if you had permission to touch another person?	% Youth
When they say it’s okay, give permission, straight up answer or consent	64%
Ask them	27%
I don’t know	9%

Staff/Professionals Survey: Organizational Guidelines on Personal Relationships and Sexuality of People Experiencing I/DD

Table C5 - Organizational Guidelines (n = 29)	
Staff / Professionals:	Percentage
NOT aware of any current guidelines their organization has on personal relationships and sexuality for people experiencing I/DD	55%
Aware of guidelines and have NOT received training on how to apply them	46%
Aware of guidelines and believe they are difficult or very difficult to apply	39%

Support People Surveys: Confidence in Ability to Discuss Relationships and Sexual Health

Table C6 - Confidence in Ability to Discuss Relationships and Sexual Health		
	% Staff/ Professionals (n = 29)	% Parents/ Guardians (n = 5)
Confident/very confident in their ability to discuss issues of romantic and/or sexual relationships with the people you support who experience I/DD.	66%	60%
Confident/very confident in their ability to discuss issues of sexual health with the people they support who experience I/DD.	66%	80%

Support People Surveys: Training Experiences

Table C7 - Sexual Health Support Training Experiences (n = 29)	
Staff / Professionals:	Percentage
Who have NOT received any training in how to discuss romantic and/or sexual relationships with people who experience I/DD.	62%
Interested in receiving such training in the future.	97%
Who have NOT received any training in how to discuss sexual health with people who experience I/DD.	66%
Interested in receiving such training in the future.	97%

Table C8 - Sexual Health Support Training Experiences (n = 5)

Parents/Guardians:	Percentage
Who have NOT received any training in how to discuss personal relationships/sexuality/sexual health with their family member.	20%
Interested in receiving such training in the future.	60%

Support People Surveys: Rights of People Who Experience I/DD

Table C9 – Belief in Types of Allowable/Capable Relationships

	% Staff/Professionals believe the people they support who experience I/DD should be allowed to have (n = 29)	% Parents/Guardians believe their family member is capable of having (n = 5)
Friendship	100%	100%
A boyfriend/girlfriend/dating partner (non-sexual)	100%	60%
A boyfriend/girlfriend/dating partner (sexual)	100%	20%
Marriage	97%	20%

Table C10 – The Right to Privacy for Adults 18+ Using Adult Foster / Group Home Services

	% Staff/ Professionals (n = 29)	% Parents/ Guardians (n = 5)
Believe entitled to privacy in terms of unsupervised romantic and/or sexual relationships	83%	40%
Believe entitled to privacy in terms of not having their parents/guardians informed about their romantic and/or sexual relationships	72%	40%

Appendix D: References

Centers for Disease Control and Prevention (CDC). (2015, July 09). Developmental Disabilities. Retrieved from <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>

Cheng, M.M. & Udry, J.R. (2005). Sexual experiences of adolescents with low cognitive abilities in the U.S. *Journal of Developmental and Physical Disabilities*, 17(2), 155-172.

Evans, D.S., McGuire, B.E., Healy, E., & Carley, S.N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: service-user perspectives. Part II: staff and family career perspectives. *Journal of Intellectual Disability Research*, 53(11), 913-921.

Gebb, A. & Guthrie, S. (2015). Sexual health education curriculum for students with moderate to severe disabilities (Master's thesis). Retrieved from <https://www.teacherspayteachers.com/Product/SAFE-SECS-Curriculum-2237249>

Gowen, L. K., & Aue, N. (Eds.) (2011). *Sexual Health Disparities Among Disenfranchised Youth*. Portland, OR: Public Health Division, Oregon Health Authority and Research and Training Center for Pathways to Positive Futures, Portland State University.

Khemka, I., Hickson, L., & Reynolds, G. (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. *American Journal of Mental Retardation*, 110(3), 193-204.

Löfgren-Mårtenson, L. (2012). "I want to do it right!": a pilot study of Swedish sex education and young people with intellectual disabilities. *Sexuality and Disability*, 30, 209-225.

McCabe, M.P. (1999). Sexual knowledge, experience and feelings among people with disability. *Sexuality and Disability*, 17(2), 157-170.

Multnomah County Developmental Services (FY2016). Youth ages 10-24 with intellectual/developmental disabilities. [Data set].

Murphy, N., & Young, P. (2005). Sexuality in children and adolescents with disabilities. *Developmental Medicine & Child Neurology*, 47, 640-644.

Oregon Health Authority (OHA), CD Summary (2017). Oregon Teens with Disabilities: Addressing Health and Safety Needs. Retrieved November 15, 2017 from <http://www.oregon.gov/oha/PH/DISEASES/CONDITIONS/COMMUNICABLEDISEASE/CDSUMMARYNEWSLETTER/Documents/2017/ohd6610.pdf>

Oregon Health Authority (OHA), Oregon Healthy Teens Survey (2015). Disability Status [Data set].

Portland State University College of Urban & Public Affairs: Population Research Center (2016). *Youth ages 10-24 in Multnomah County*. Retrieved November 27, 2017 from <https://ophat.public.health.oregon.gov/Account/LogOn>

Saxe, A. & Flanagan, T. (2016). Unprepared: an appeal for sex education training for support workers of adults with developmental disabilities. *Sexuality and Disability, 34(4)*, 443-454.

Sexuality Information and Education Council of the United States. (2004). *Guidelines for Comprehensive Sexuality Education* (3rd Edition). Retrieved from http://siecus.org/_data/global/images/guidelines.pdf

Shearer, D.L., Mulvihill, B.A., Klerman, L.V., Wallander, J.L., Hovinga, M.E., & Redden, D.T. (2002). Association of early childbearing and low cognitive ability. *Perspectives on Sexual and Reproductive Health, 34(5)*, 236-243.

Sinclair, J., Unruh, D., Lindstrom, L., & Scanlon, D. (2015). Barriers to Sexuality for Individuals with Intellectual and Developmental Disabilities: A Literature Review. *Education and Training in Autism and Developmental Disabilities, 50(1)*, 3-16.

Swango-Wilson, A. (2011). Meaningful sex education programs for Individuals with intellectual/developmental disabilities. *Sexuality and Disability, 29*, 113-118.

Szydlowski, M.B. (2016, February). *Sexual health education for young people with disabilities*. Retrieved from <http://www.advocatesforyouth.org/storage/advfy/documents/Factsheets/sexual-health-education-for-young-people-with-disabilities-educators.pdf>

The Arc. (2008). *Sexuality*. Retrieved from <http://www.thearc.org/who-we-are/position-statements/life-in-the-community/sexuality>

United Nations. *Article 25 – Health*. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html>

Winges-Yanez, N. (2014). Why all the talk about sex? An autoethnography identifying the troubling discourse of sexuality and intellectual disability. *Sexuality and Disability, 32(1)*, 107-116.

World Health Organization. (2018). *Sexual and reproductive health*. Retrieved from http://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/

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Growing Connection, Coordination and Support

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