

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.



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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**