

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.

Page 30



Provide skills-based training.

Page 32



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

Page 32



Training Component 2: Applying organizational policies and procedures.

Page 33

- 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.

Page 34



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

Page 35



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**