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.

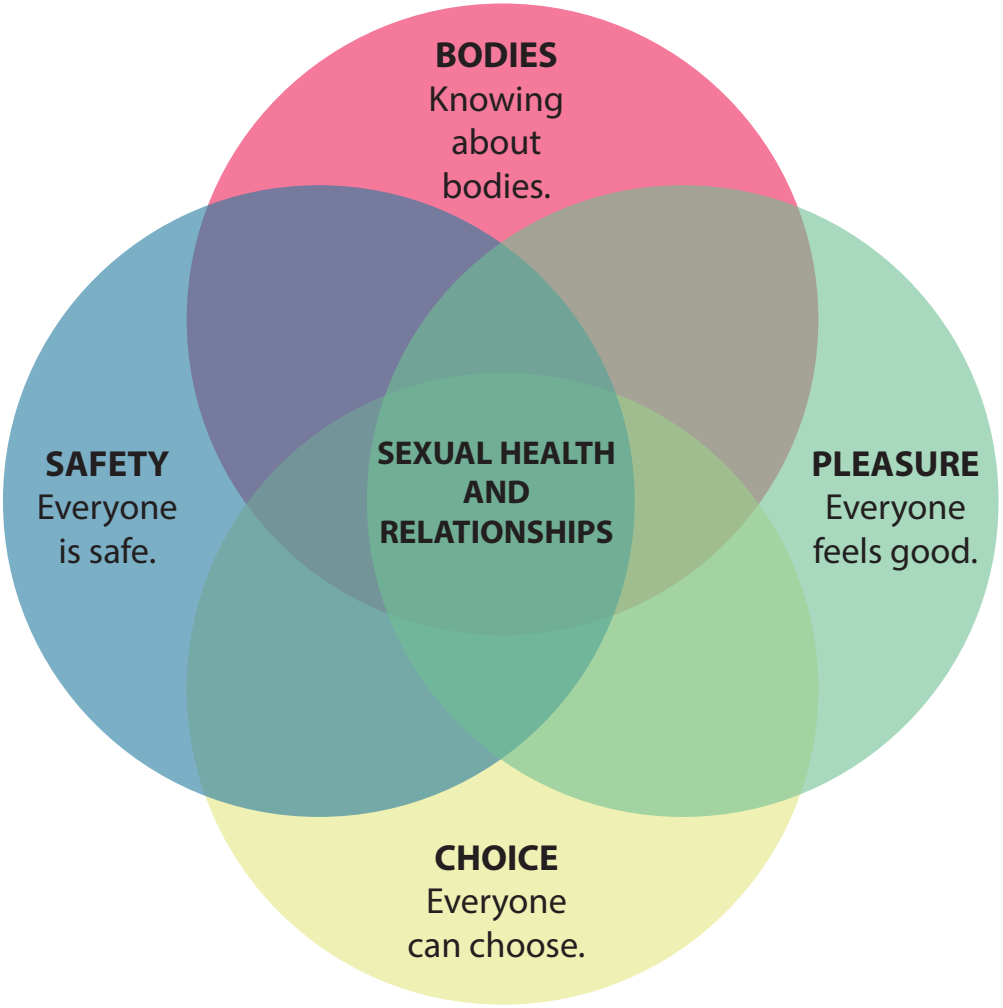
Study Limitations

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: • 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

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