

Personal Responsibility Education Program

Sexual Health Resource Toolkit for Parents of Youth with IDD

Parents and caregivers play an important role in educating their youth about sexual health and relationships.

Parents and caregivers can begin talking with their youth about sexual health before or during puberty (usually sometime between the ages of 8 and 14).

Tips for Talking to Your Youth with Intellectual and Developmental Disabilities About Sexual Health and Relationships

Do you feel comfortable talking about sex and relationships with your youth? Do you want more guidance about how to talk to youth with intellectual and developmental disabilities (IDD) about relationships and sex? You are not alone!

Fact: Many youth with IDD will eventually have romantic relationships. They need and want information and life skills on sexual health and relationships, like any other youth their age.¹

Fact: Sometimes youth with IDD are not offered sexual health education at school. Parents and caregivers can help fill this gap by sharing their values and expectations for how their youth can stay safe and healthy.²



How do you start the conversation? Be open

- Remind your youth that you ARE a safe place to discuss their questions about sex and relationships.
- You don't have to know it all. If you don't know the
 answer to a question or aren't ready to talk about it
 right then, make eye contact and tell them that you
 will get more information and follow up. Remember
 that there are resources available to you like the ones
 listed below.

Practice a positive approach

• Use eye contact and open body language, like a relaxed but attentive posture leaning slightly in to the youth. If eye contact is difficult for your youth, as it often is for youth with IDD, try talking while you're in the car or on the couch watching TV, when the youth can focus their eyes elsewhere.







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- Use simple, concrete words and concepts. For example, use the correct terms for body parts (e.g., penis and vagina) instead of slang terms.
- Give verbal cues such as "okay" and "uh huh" to show you are listening.
- Try to stay calm and take a deep breath before responding to a question or comment.
- Occasionally say "tell me what you understand..." to make sure they have the same understanding about terms and concepts as you.
- Repeat back and paraphrase to show you want to understand, using phrases like,
 "What I hear you saying is...."

"I find myself repeating back what I think I heard [my son say], which is often not what he meant. So I use paraphrasing to check my understanding."

-Parent of youth with IDD

What is important to talk about?

- Physical and emotional development, including puberty.³ Please see our snapshot on adolescent development for more information.
- Expectations about what it means to be in a healthy romantic relationship, like how to decide and communicate what you want and need.
 What consent or "saying yes" looks like and how to give and get consent before sexual activity.
- Setting boundaries in relationships to stay safe and healthy. Also teach them to respect other people's boundaries.
- How to access sexual health services, such as where to get contraception and/or HIV/STI testing.

Discuss your values and hopes for them

Communicate your values about relationships and sexuality, but realize that your youth may hold different values.

"Talk about what dating looks like from an early age, like going to a dance [with someone], and keep talking over time."

-Parent of youth with IDD

Conversation starters

- Do you hope to be in a relationship one day?
- What kinds of fun activities would you like to do with a romantic partner?
- What are some characteristics you are looking for in a romantic partner?
- Do you think you will get married one day?
- Do you want to have youth? Why or why not?

Many youth with developmental disabilities want to learn more about dating, contraception, and pregnancy.

Talk about pregnancy and STI prevention

- Talk about how a pregnancy or STI could affect your youth. Use simple language to help youth understand what it is like to be pregnant, give birth, and raise a youth.
- There are many safe and effective methods to prevent unintended pregnancy and STIs. Some methods are more effective and easier to use than others. You and your youth can talk with a medical professional about the method that might work best.

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Do: Include your youth when deciding whether birth control is appropriate now. Openly discuss the birth control options with your youth and their doctor. Here is a <u>link</u> that you can review for more information before your doctor's visit.

Do: Remember that only the correct and consistent use of condoms prevent STIs. Condoms and contraception should be used together every time someone has sex to avoid unintended pregnancy and STIs. Your medical provider may be able to demonstrate correct condom use.

Some final tips

Find a co-pilot

- Engage another adult caregiver in your youth's life, like your partner, a healthcare provider, or your youth's teacher, to support your efforts to communicate openly and honestly about sex and relationships. Make sure they are giving similar messages about sexual health as you are.
- Model healthy relationships in your home with your family and friends, so your youth can learn what healthy relationships look like through example.
- Many schools, religious institutions, or community-based groups offer relationship and sexual health education to supplement what you are discussing at home. Typically, these programs offer a variety of approaches to help align with your family's values.

Use the moments you have

- Some parents and caregivers find it helpful to use situations about dating, love, or sex that come up while watching TV or listening to the radio in the car.
- Talk about sexual health and relationships

 a little bit at a time. It is important for parents
 and caregivers to cover topics more than
 once to make sure their youth understands.

 Conversations about sexual health are not a one-time conversation. There isn't one time where you give "the talk." Instead, think of these evolving conversations as ongoing starting in early adolescence and continuing into adulthood.
- If your youth is attending a course on sexual health...You can ask your youth to "teach you" what they learned and listen without judgment. Ask specific questions. Instead of, "How was your school class today?" say, "Tell me one thing you learned in your 'learning about my body' class today."

Be sure to see our other snapshots:

- Supporting Youth with IDD through
 Puberty and Early Adolescence
- Keep Youth With IDD Safe Online
- The Role of Parents and Caregivers in Preventing and Responding to Abuse

Resources:

Click links for more information

Tips for talking with your youth about sexuality

List of resources for teens and young adults with autism from the Kennedy Krieger Institute

Endnotes

- Retznik, L., Wienholz, S., Höltermann, A., Conrad, I., & Riedel-Heller, S. G. (2022). Young People with Intellectual Disability and Their Experiences with Intimate Relationships: a Follow-up Analysis of Parents' and Caregivers' Perspectives. Sexuality and Disability, 1-16.
- Schaafsma, D., Kok, G., Stoffelen, J. M. T., & Curfs, L. M. G. (2015). Identifying effective methods for teaching sex education to individuals with intellectual disabilities: A systematic review. Journal of Sex Research, 52(4), 412–432
- ³ Maxey, M., & Beckert, T. E. (2017). Adolescents with disabilities. Adolescent Research Review, 2(2), 59-75.