



**Promising  
Youth  
Programs**

Personal Responsibility Education Program

January 2023

## **Sexual Health Resource Toolkit for Parents and Caregivers of Youth with Intellectual and Developmental Disabilities**



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## Introduction

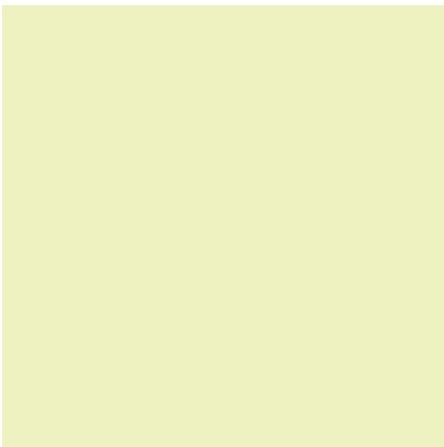
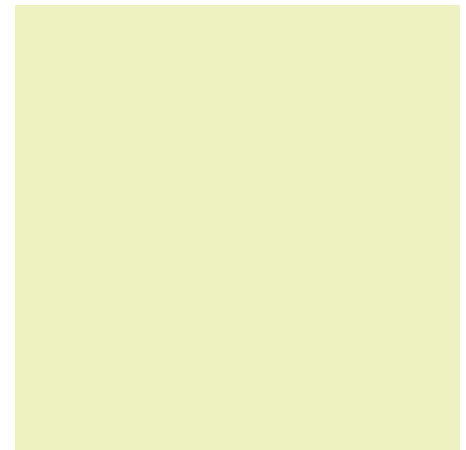
Parents and caregivers play an important role in helping youth with intellectual and developmental disabilities (IDD) learn about sexual health and relationships. This Sexual Health Resource Toolkit is designed to (1) raise parents' and caregivers' awareness about the importance of discussing these sensitive topics with their youth, (2) give them some tips to guide these conversations, and (3) provide additional resources for those who want more information. The toolkit is also intended to help organizations serving youth with IDD to connect with and support the parents of the youth they serve.

The toolkit has information on parent-child communication, adolescent development, internet safety and healthy online relationships, and sexual abuse prevention. For each topic, there are a set of social media memes, an audio clip, and an informational snapshot for parents and caregivers who want more information. The snapshots provide tips, information, and resources.



### Toolkit topics

- Parent-child communication
- Adolescent development
- Internet safety and healthy online relationships
- Sexual abuse prevention





## How to Use the Toolkit's Resources



### Social media memes

- Post the memes to your social media accounts to highlight the important role parents and caregivers play in the lives of youth and to give them information to support communication.
- Combine the meme with a link to the toolkit and a line or two about being available to help with any questions or concerns in a social media post. The post could also include URLs to the audio clips or informational snapshots below. For organizations, sharing useful resources can open the door to communication between your organization and parents and caregivers.
- Keep your posts fresh and your messaging consistent by choosing from a variety of memes for each topic.



### Audio clips

- Share the URLs for these short (3 minute) audio clips on your social media accounts. They're a great way to give a brief but powerful look at how parents and caregivers can support their youth's growth, promote their safety, and help them transition into the wider world. The clips can help parents and caregivers feel less alone and boost their confidence about discussing sensitive topics.



### Informational snapshots

- Share the URLs for the snapshots in your social media posts, download the pdf versions and email them to people in your personal or professional networks, or post a link as a resource on your organization's website. Sharing helpful information and resources is one of the most important ways to build a community of support around the youth we care so much about.
- Send the snapshots to any networks of parents, caregivers, or professionals that could benefit from the information, either for their own learning or as a resource they can share with their networks.

The memes and audio clips provide quick and easy-to-understand information for people on the go, and the snapshots are for parents and caregivers who want more information. And remember, repetition is a key to learning: posting each part of the toolkit repeatedly over time will make it easier for people to connect to and retain the information. You can also link to the toolkit materials on your website and refer people back to them. That way they continue to see you as a resource for useful information.



## Parent-child communication



Parents and caregivers play an important role in educating their youth with IDD about sexual health and relationships. You can be a safe person to discuss these sensitive topics with.

The resources in this section can help you raise awareness about this important topic and provide tips to help parents and caregivers guide these conversations.

## Social media memes

Post these memes to your social media accounts to highlight the important role parents and caregivers plan in discussing sexual health and relationships with their youth. Keep your posts fresh by choosing from the different memes below.

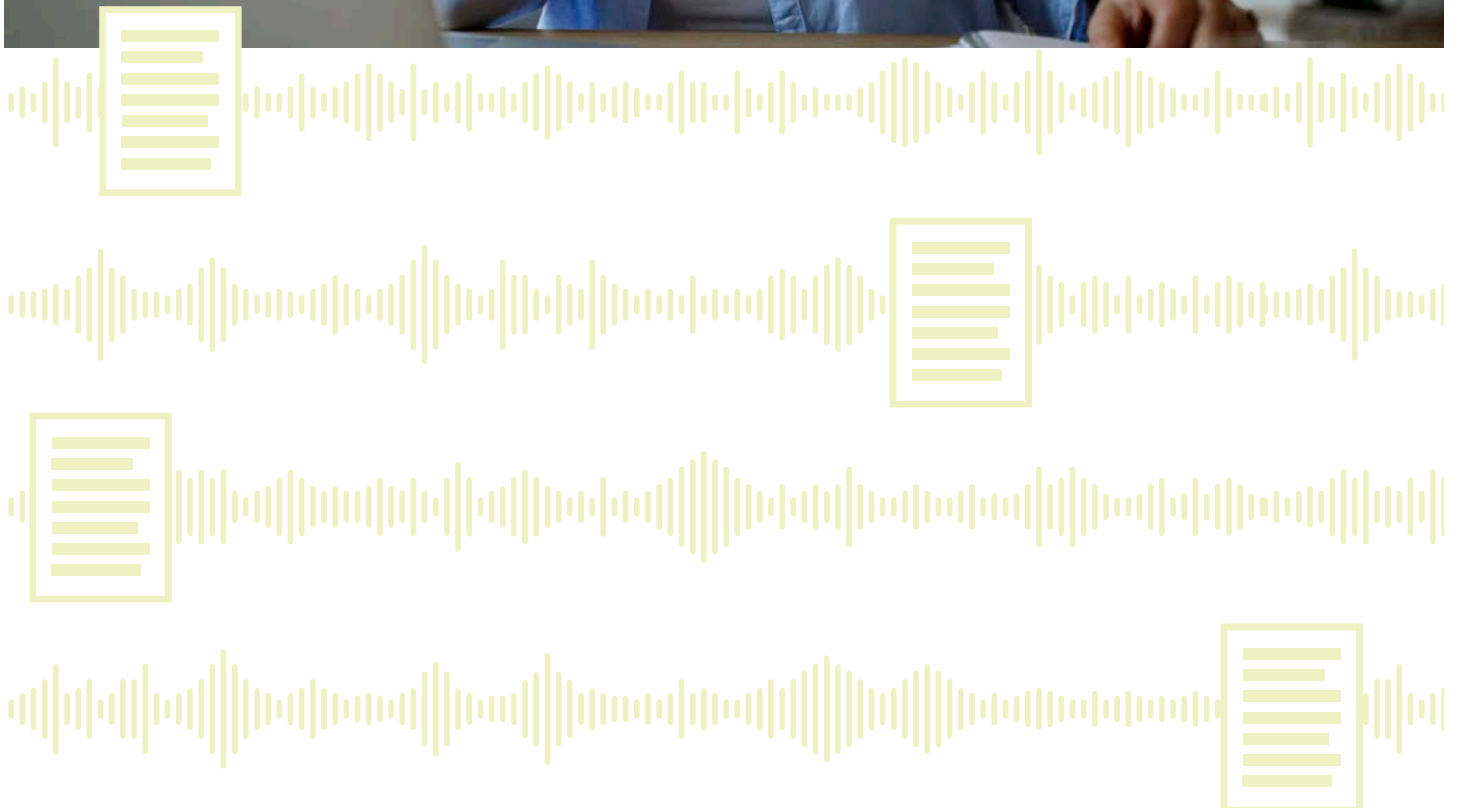
You can download high-resolution images of the individual memes [here](#).

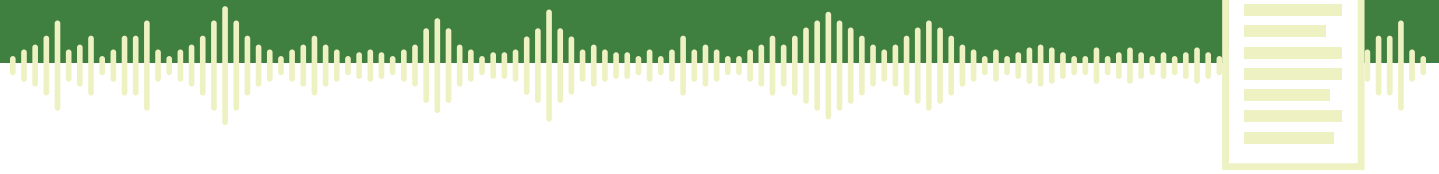




### Audio clip and script

Share the URL to [this audio clip](#) on your social media accounts. It provides a brief but powerful look at how parents and caregivers can talk to their youth about sexual health and relationships.





## **Script for parent-child communication audio clip**

Our kids with intellectual and developmental disabilities may learn in different ways or at different paces than our kids who don't have them. But that doesn't change our desire as parents and caregivers for them to have lives that are rich with learning and a full range of positive, healthy experiences. We are their most important teachers, and we have a prominent role to play in what they learn, how they learn it, and when those lessons happen for them.

Even though many of our kids with IDD will eventually have romantic relationships, they often don't get the same reproductive health and relationship education at school as their peers without disabilities do. Because these lessons are more complex and nuanced than many of those that we helped them learn earlier in life, teaching these things can feel like a much bigger ask of us. If like many people, we didn't get great education around puberty and romantic relationships ourselves, we may not feel as prepared to talk to our teens about these things as we have about others. But they need and want to know this stuff; and they need and want to know that we—the people they most trust—support them in this learning, too.

We can help them, even if we're not quite sure how. We don't have to know everything, but we do have to be open and remind them regularly that we are a safe place to ask questions and discuss ideas about sex and relationships. Using simple but concrete words and concepts instead of slang can help reduce confusion. Listening closely and repeating back what they've said shows them we really want to understand. And sharing with them our values about relationships and sexuality, even if theirs aren't exactly the same, helps them think through their own.

Finally, we don't have to do this alone. We can seek out information and tools for having these conversations, making sure we're getting the information and support we need from reputable sources.

We love our kids. We want them to have the kinds of happy and healthy relationships that will bring as much depth and warmth and support as possible to their whole lives. How they navigate and engage in romantic relationships—and how they protect themselves against relationships that might exploit or harm them—is really important information for them to have as they go through adolescence. Talking to them about it is key to making sure they get the relationship and reproductive health education and skills that they deserve. When we do this, we set them up for the kinds of rich, full, supportive relationships that we dream of for them and that they dream of for themselves.





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

*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).*

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.<sup>1</sup>

**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.<sup>2</sup>



### 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.

- 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.<sup>3</sup> 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.

**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 [link](#) 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.

## 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

- <sup>1</sup> 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.
- <sup>2</sup> 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
- <sup>3</sup> Maxey, M., & Beckert, T. E. (2017). *Adolescents with disabilities*. *Adolescent Research Review*, 2(2), 59-75.

## 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





## Adolescent development



Youth with IDD mature physically and sexually like adolescents without disabilities. Parents and caregivers can support youth through this phase by helping them learn about puberty and what physical and emotional changes to expect.

The resources in this section can be used to raise awareness about discussing puberty with youth with IDD as well as provide support to parents and caregivers who will have these conversations.

# Adolescent development

## Social media memes

Post these memes to your social media accounts to highlight how parents can support their youth with IDD during puberty. Keep your posts fresh by choosing from the different memes below.

You can download high-resolution images of the individual memes [here](#).

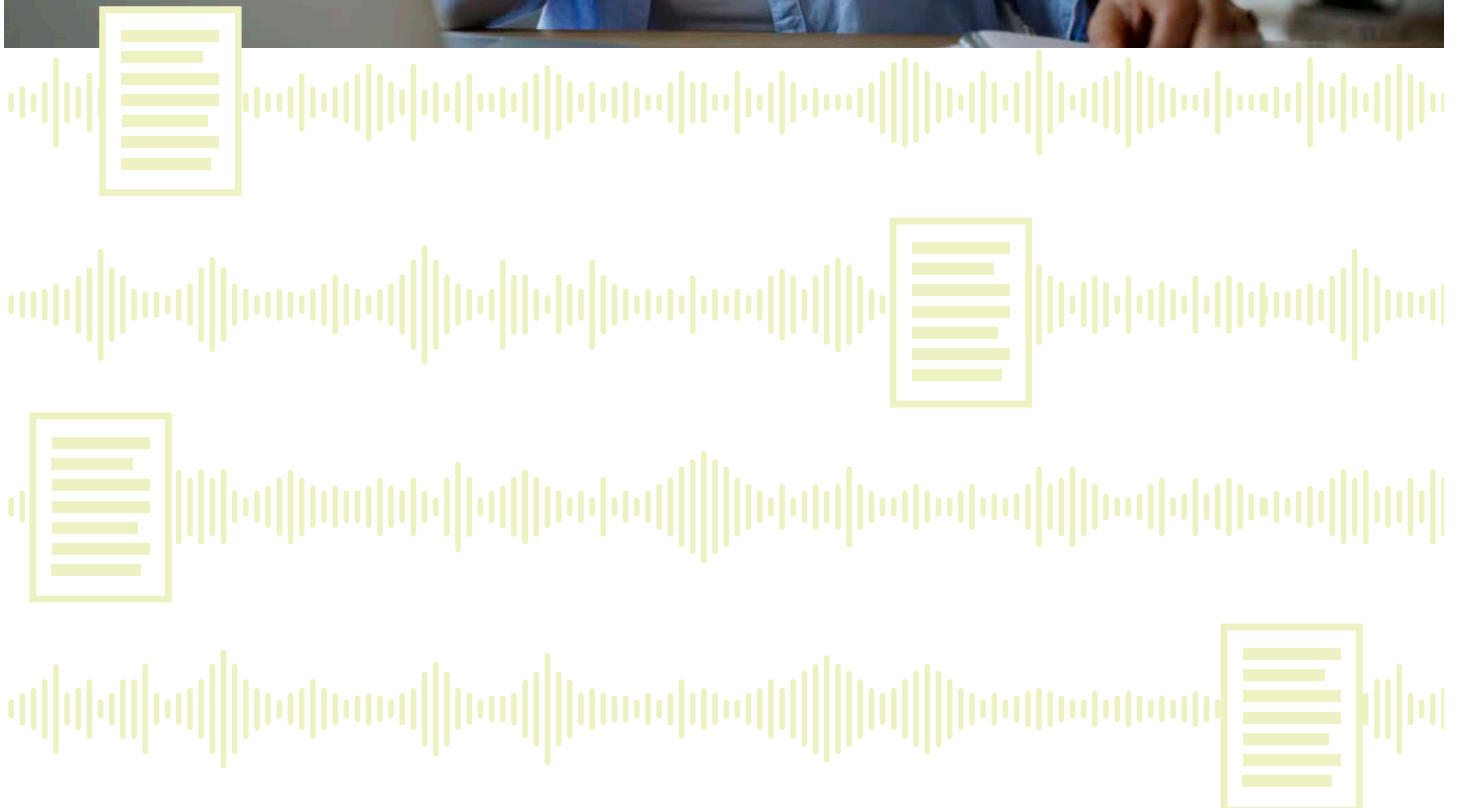
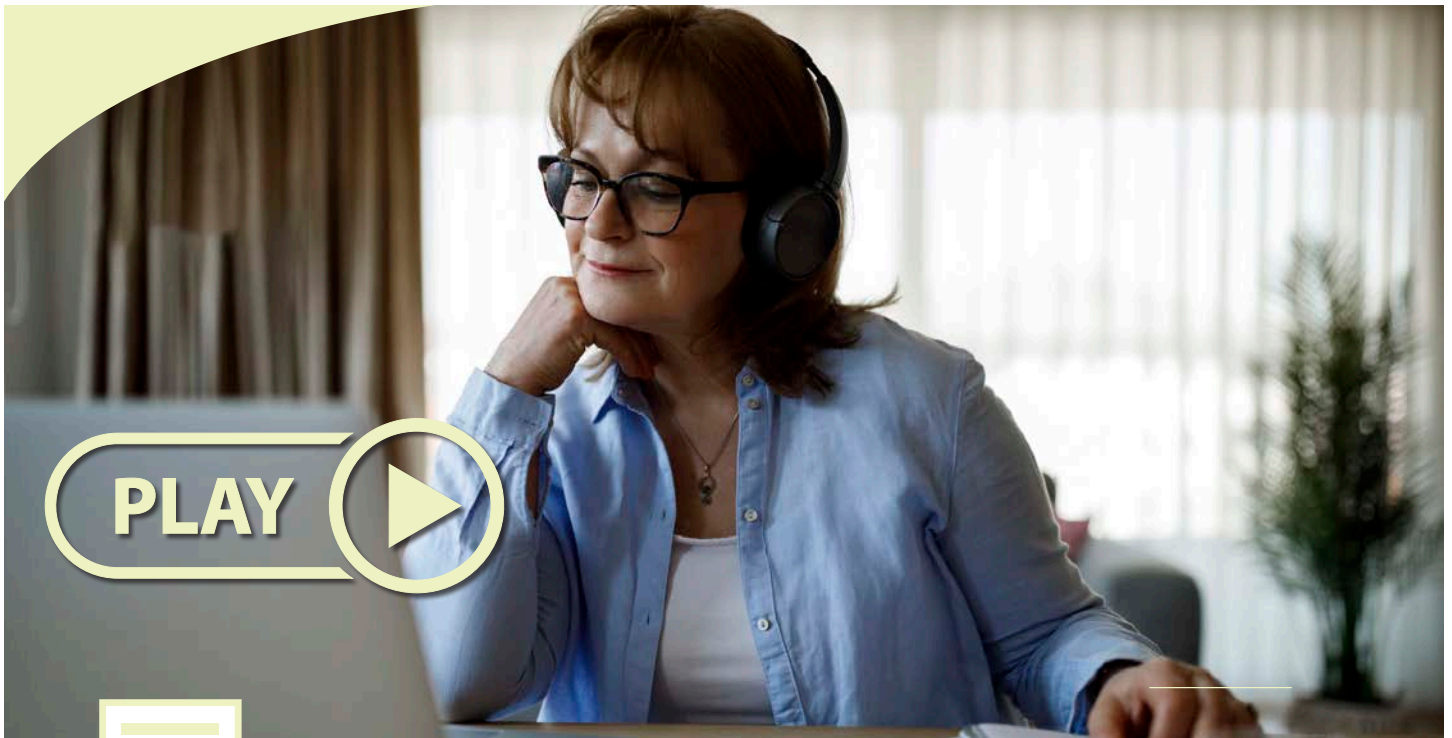


The **support** parents and caregivers provide helps teens feel more **confident and secure** as they move into young adulthood.

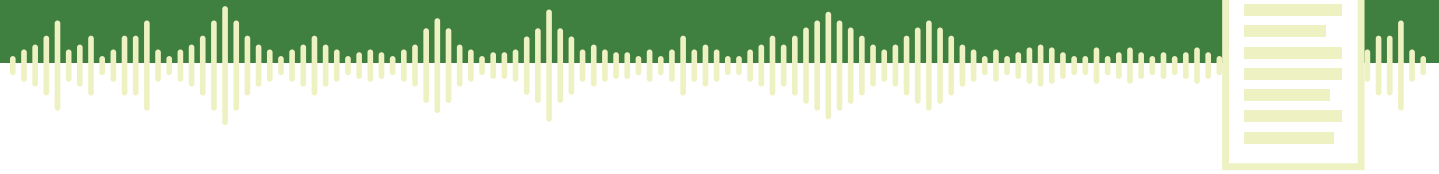


## Audio clip and script

Share the URL to [this audio clip](#) on your social media account. It provides a brief but powerful look at how parents and caregivers can support their youth through the physical and emotional changes of puberty.







## **Script for adolescent development audio clip**

Being a parent or caregiver of a child with an intellectual or developmental disability is different in some ways from parenting a child without one. The general wisdom and child-rearing advice don't always translate well to the unique challenges we and our children experience. This can be especially true when our kids with intellectual or developmental disabilities become teenagers and move into the complex stage of puberty. But the physical changes of puberty aren't very different for our children than for their peers without intellectual or developmental disabilities.

For the most part, our kids reach puberty at the same time as other kids. The support we provide during this time in their lives can help our kids feel more confident and secure as they move through puberty and into young adulthood.

We're all probably familiar with the physical changes that come with puberty. What might not always be as clear are the social and emotional changes that our kids also go through. Some young people in this stage start showing a desire for more privacy and independence. Some also experience and express their emotions more strongly. Like most things related to kids, these social and emotional changes will probably be a little unique to each individual.

It's a good idea to start talking to our kids about puberty before it begins, so these changes don't come as a surprise to them. This gives them time to think about the changes and ask any questions they may have. It also gives us the opportunity to reassure them that all of this is normal, healthy, and okay to talk about.

Other changes during puberty are about behavior, so it's important we make sure our kids are clear on what's okay for public spaces and what needs to be done in private. We also play an important role in helping our kids understand the sexual and romantic feelings they start to have and how to appropriately express them. We go a long way to helping our kids through puberty by creating opportunities for them to talk to us about everything from healthy relationships to setting boundaries to the importance of consent.

Puberty can be challenging for young people and for the adults who love them. We can make it more manageable by finding balance between their growing and healthy need for privacy and independence and our desire and responsibility to keep them safe. We're their biggest cheerleaders and their strongest allies. Their health, well-being, and dignity are worth our best effort.



## Supporting Youth with Intellectual and Developmental Disabilities Through Puberty and Early Adolescence

*The emotional and physical changes that happen during adolescence can make youth feel excited, confused, or anxious.*



Adolescence is the phase of life when youth begin transitioning into adulthood. During this time, they will experience physical, sexual, social, and emotional changes caused by hormonal changes in their body.<sup>1</sup> Puberty occurs during adolescence and is when a youth's body becomes physically able to have youth. For most youth, puberty begins at ages 9 to 14.

Youth with intellectual and developmental disabilities (IDD) mature physically and sexually like adolescents without disabilities, although sometimes the timing can differ depending on the type of disability. For example, youth with severe cognitive disabilities are more likely to experience puberty earlier than youth without these disabilities.<sup>2</sup> On the other hand, many females with autism spectrum disorder or cerebral palsy start menstruating later than their peers.<sup>3,4</sup>

## What Changes to Expect During Puberty

Here are some examples of the physical changes youth will experience during puberty:<sup>5</sup>

- Both females and males: growth spurts, body hair growth, excess sweating
- For females: breast growth, menstruation, vaginal discharge
- For males: enlargement of the penis and testes, nocturnal emissions (wet dreams), involuntary erections, deeper voice

**Social and emotional changes** during puberty can include things like the desire for more privacy and an increasing need for independence. During puberty, you might notice that your youth's feelings and expressions of those feelings are more intense. These changes might be large or small depending on the youth's developmental disability.

## How Can Parents and Caregivers Help Youth with IDD Navigate Puberty?

### Overall support

As a parent or caregiver, you can support your youth through this phase by helping them learn about puberty and what physical and emotional changes to expect.<sup>6</sup> Here are some general tips when approaching puberty with your youth:

- **Use direct, anatomically correct language** to avoid confusion and make youth more comfortable with all their body parts.
- **Discuss the physical and emotional changes** with your youth in early adolescence, ideally before they have experienced them. This will give them time to think about what is going to happen and ask questions. Tell them these changes they will experience or are experiencing now are normal and they shouldn't be ashamed of them. If your youth tends to worry a lot, it might be good to have these discussions gradually.
- **Teach your youth about appropriate behavior** in private and public spaces. This can be a difficult concept for some youth with IDD to understand, so it is important to reinforce it. For example, always close the door when getting dressed and going to the bathroom.

### Be sure to see our other snapshots:

Talking to Your Youth with IDD About Sexual Health and Relationships

Keeping Youth With IDD Safe Online

The Role of Parents and Caregivers in Preventing and Responding to Sexual Assault and Abuse

*"[My child and I] agree on cues between parent and child in social situations to guide behavior. I give him 'the mom look' when he's violating standards of appropriate social conduct or boundaries."*

-Parent of youth with IDD



### Support for Physical Changes

You can help your youth feel more prepared for the physical changes they will experience during puberty. Here are some ways to help prepare both you and them for these changes:

- **Talk to your youth's doctor.** Your youth's doctor can be an important resource for both you and your youth during puberty. For example, if your youth is having a hard time dealing with menstruation (also called their period), their doctor might have options to help with pain management or control the flow of menstruation. A doctor can also help address other changes during puberty, such as acne. You can also meet with a doctor before your youth goes through puberty to discuss what to expect and think about ways to help you and your youth with the physical and behavioral changes.<sup>7</sup>
- **Encourage and support good hygiene.** Like their non-IDD peers, youth with IDD will likely need your help learning about new hygiene needs, such as using deodorant. In addition, females might need information about menstrual products such as pads and tampons and how to find a product they are comfortable using. Males might need information about what to do if they have a wet dream and how to take care of new body hair. All youth need to know about how their bodies are growing and changing and how to care for them as they transition into adulthood.
- **Work with caregivers and schools** to ensure youth have accommodations to support proper hygiene with dignity.<sup>8,9</sup> For example, ensure youth have privacy in the bathroom, even if they need support from you or another caregiver.

Help youth find puberty-related products they like. It might take some trial and error to find the products that work for their bodies.

### Support for Social and Emotional Changes

Increasing independence and opportunities for social interaction are an important part of transitioning to adulthood. It is an exciting time, and youth with IDD might need extra help to navigate this independence and these opportunities.<sup>10</sup> Here are some ways you can support your youth as they encounter the social and emotional changes of puberty.

Help your youth name the different emotions they might be experiencing during puberty.

- **Find ways for your youth to gain independence and take part in social activities.** For example, help them plan a trip to the movies with friends. With practice, youth with IDD can gain valuable social skills such as greeting people, using eye contact and appropriate body language, respecting personal space, standing up for themselves, and understanding customs for telephone and computer use.<sup>11</sup>
- **Expect some conflict and approach it calmly.** As your youth seeks more independence, your relationship with them could start to include more conflict. During puberty, some youth rebel against their parents or other caregivers, which is normal and usually will decrease over time. Parents and caregivers might have to find ways to balance their youth's privacy and independence while also keeping their youth safe. For example, you may talk to your youth about when they can have alone time in their room without being interrupted.
- **Acknowledge that youth will begin to experience sexual and romantic feelings during puberty.**<sup>12</sup> Support your youth in understanding these new feelings by talking to them about healthy relationships, the qualities they

might look for in a partner, consent, and boundaries. For example, you might ask your youth about what personality traits they think would make the perfect partner for them. Also, some youth with IDD may not experience feelings or emotions in the same way a youth without IDD does. As a parent you might need to discuss feelings in a way that feels safe to your youth and meets them there they are developmentally.

*"When I think about my kid with IDD...he doesn't understand social cues and doesn't have the same type of emotional feelings as others do. When I talk to him about his feelings, he pushes back against that, so recognizing that [talking about feelings] might be different for him than my neurotypical kid is important."*

-Parent of youth with IDD

### Want to Learn More? Here are Some Resources that Can Help

- Tip sheet for navigating puberty for youth with special needs: <https://parenting.uwhealth.org/2018/08/puberty-teens-special-needs/>
- Parent's guide to puberty and adolescence for youth with autism: <https://www.autismspeaks.org/sites/default/files/2018-08/Puberty%20and%20Adolescence%20Resource.pdf>
- Preparing for puberty in females with disabilities: <https://healthblog.uofmhealth.org/youths-healthpreparing-for-puberty-females-disabilities>
- First-hand account about finding love and a healthy relationship from a person with a physical disability: <https://www.youtube.com/watch?v=UjmhDyJhgvs>
- Informational videos on puberty for youth, parents and caregivers: <https://amaze.org/?topic=puberty>

### Endnotes

- <sup>1</sup> Allen, Brittany, and Helen Waterman. "Stages of Adolescence." Itasca, IL: American Academy of Pediatrics, March 28, 2019. Available at <https://www.healthyyouth.org/English/ages-stages/teen/Pages/Stages-of-Adolescence.aspx>. Accessed February 17, 2022.
- <sup>2</sup> Houtrow, Amy, Ellen Roy Elias, Beth Ellen Davis, and Council on Youth with Disabilities. "Promoting Healthy Sexuality for Youth and Adolescents With Disabilities." *Pediatrics*, vol. 148, no. 1, 2021, article e2021052043. doi:10.1542/peds.2021-052043.
- <sup>3</sup> Fei, Y. Frances, Susan D. Ernst, Melina L. Dendrinis, and Elisabeth H. Quint. "Preparing for Puberty in Females With Special Needs: A Cohort Study of Caregiver Concerns and Patient Outcomes." *Journal of Pediatric and Adolescent Gynecology*, vol. 34, no. 4, 2021, pp. 471-476. doi:10.1016/j.jpag.2021.03.008.
- <sup>4</sup> Quint, Elisabeth H., and Rebecca F. O'Brien. "Menstrual Management for Adolescents With Disabilities." *Pediatrics*, vol. 138, no. 1, 2016, article e20160295.
- <sup>5</sup> Allen, Brittany, and Katy Miller. "Physical Development in Females: What to Expect During Puberty." Itasca, IL: American Academy of Pediatrics, June 4, 2019. Available at <https://www.healthyyouth.org/English/ages-stages/gradeschool/puberty/Pages/Physical-Development-Females-What-to-Expect.aspx>. Accessed February 17, 2022.
- <sup>6</sup> Allen, Brittany, and Helen Waterman. "Stages of Adolescence." Itasca, IL: American Academy of Pediatrics, March 28, 2019. Available at <https://www.healthyyouth.org/English/ages-stages/teen/Pages/Stages-of-Adolescence.aspx>. Accessed February 17, 2022.
- <sup>7</sup> Fei, Y. Frances, Susan D. Ernst, Melina L. Dendrinis, and Elisabeth H. Quint. "Preparing for Puberty in Females with Special Needs: A Cohort Study of Caregiver Concerns and Patient Outcomes." *Journal of Pediatric and Adolescent Gynecology*, vol. 34, no. 4, 2021, pp. 471-476. doi:10.1016/j.jpag.2021.03.008.
- <sup>8</sup> Houtrow, Amy, Ellen Roy Elias, Beth Ellen Davis, and Council on Youth with Disabilities. "Promoting Healthy Sexuality for Youth and Adolescents with Disabilities." *Pediatrics*, vol. 148, no. 1, 2021, article e2021052043. doi:10.1542/peds.2021-052043.
- <sup>9</sup> Kramolis, Kali, and Paula Cody. "Puberty and Teens with Special Needs: Ensuring a Smooth Transition." Madison, WI: University of Wisconsin-Madison, August 16, 2018. Available at <https://parenting.uwhealth.org/2018/08/puberty-teens-special-needs/>. Accessed February 17, 2022.
- <sup>10</sup> Houtrow, Amy, Ellen Roy Elias, Beth Ellen Davis, and Council on Youth with Disabilities. "Promoting Healthy Sexuality for Youth and Adolescents with Disabilities." *Pediatrics*, vol. 148, no. 1, 2021, article e2021052043. doi:10.1542/peds.2021-052043.
- <sup>11</sup> Houtrow, Amy, Ellen Roy Elias, Beth Ellen Davis, and Council on Youth with Disabilities. "Promoting Healthy Sexuality for Youth and Adolescents with Disabilities." *Pediatrics*, vol. 148, no. 1, 2021, article e2021052043. doi:10.1542/peds.2021-052043.
- <sup>12</sup> Allen, Brittany, and Katy Miller. "Physical Development in Females: What to Expect During Puberty." Itasca, IL: American Academy of Pediatrics, June 4, 2019. Available at <https://www.healthyyouth.org/English/ages-stages/gradeschool/puberty/Pages/Physical-Development-Females-What-to-Expect.aspx>. Accessed February 17, 2022.



## Internet safety and healthy online relationships



The internet can create a sense of community for youth with IDD. Parents and caregivers can help youth learn how to navigate the internet safely so they can have positive experiences online.

The resources in this section can help you raise awareness of how to help youth safely navigate digital spaces.



# Internet safety and healthy online relationships

## Social media memes


Post these memes to your social media accounts to highlight how parents and caregivers can help their youth with IDD have positive experiences online. Keep your posts fresh by choosing from the different memes below.

You can download high-resolution images of the individual memes [here](#).




**The internet can be a place for youth with intellectual and developmental disabilities to connect with others and find community.**

Parents and caregivers can help by teaching their youth **how to be safe online.**



**The text-based posts, pictures, and GIFs of social media posts can be easier than social cues for some youth with intellectual and developmental disabilities to understand and respond to.**

Help your youth stay safe online by working with them to set healthy online habits and boundaries.



**The text-based posts, pictures, and GIFs of social media posts can be easier than social cues for some youth with intellectual and developmental disabilities to understand and respond to.**

Help your youth stay safe online by working with them to set healthy online habits and boundaries.



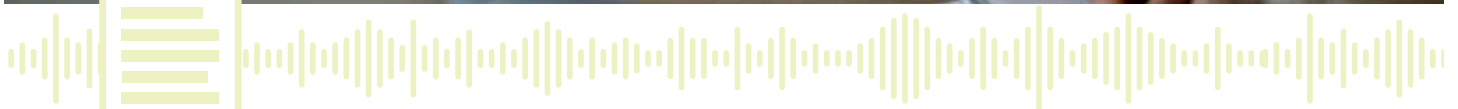
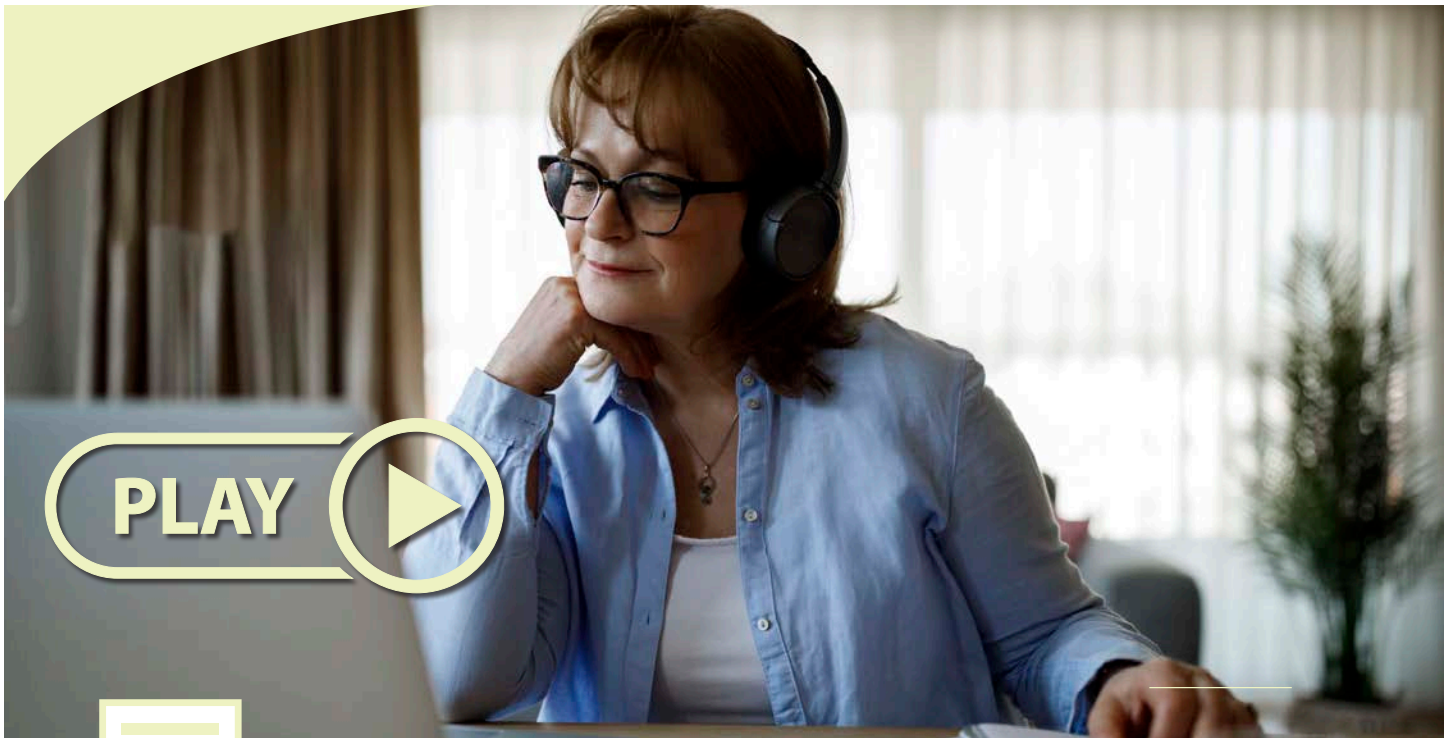
**The internet can be a place for youth with intellectual and developmental disabilities to connect with others and find community.**

Parents and caregivers can help by teaching their youth **how to be safe online.**



## Audio clip and script

Share the URL to [this audio clip](#) on your social media accounts. It provides a brief but powerful look at how parents and caregivers can help their youth with IDD have positive experiences online.





## Script for internet safety audio clip

Modern life can be tough for parents and caregivers, especially when it comes to technology. We have to think about not only where our kids are physically, but also where they are online. And because the internet can take our kids anywhere, and connect them to anyone, it's a lot for us to figure out. For those of us who have kids with intellectual or developmental disabilities, the complexities can feel even more challenging. But technology and social media have some upsides for our kids as well.

For instance, for our kids who struggle to read social cues or body gestures, text-based communication—like text messages and social media posts—can be easier to understand and respond to. Texting and online communication also give our kids more control over how fast a conversation takes place, giving them time to think about the messages coming in and the ones they want to send out. In many ways, technology opens avenues for our kids to feel more a part of their peer groups and the world around them. These are all good things.

As parents and caregivers then, our job becomes helping them use these technologies and digital spaces safely. We can work with our kids to create healthy online habits in lots of different ways.

We can teach them not to give out personal information to someone online who they've never met in person. We can encourage them to talk to a trusted adult about anything that happens online or messages they receive that make them uncomfortable, worried, or upset. And we can remind them that pictures and social media posts can be impossible to delete once someone else receives or shares them.

Unfortunately, there are also some scary online realities. Kids with intellectual and developmental disabilities are at higher risk of cyberbullying and receiving sexual requests online, and they are less likely to learn about social media safety at school. As parents and caregivers, we should balance these realities by seeking out reliable sources of information and support and educating ourselves and our kids about these risks.

Technology and social media can open important doors of community for our kids with intellectual and developmental disabilities. Working with them to create healthy online habits and boundaries empowers them to walk through those doors safely and grow strong into a wider, more connected world.



## Sexual Health Resource Toolkit for Parents and Caregivers of Youth with IDD

# Keep Youth with Intellectual and Developmental Disabilities Safe Online

*Safe internet use equals knowledge and skills to cautiously navigate digital spaces such as email, direct messaging, websites, social media, online dating apps, chat rooms, and cell phones.*

### Safe Internet Use Can Provide Positive Online Experiences

The internet can connect people all over the world who share similar life experiences. It can help youth create a sense of community for themselves, for example, by connecting with others who have a similar developmental disability.

Like all youth, many youth with intellectual and developmental disabilities access the internet through multiple devices in the home and at school.<sup>1</sup> Communicating online or by text gives youth with IDD more control over:

*"I really love the idea that social media can be an asset for my kids."*

Parent of youth with IDD



- The pace of conversations
- Additional ways to communicate nonverbally
- Communication without having to rely on face-to-face social cues<sup>2</sup>

Learning how to use the internet safely can guide youth to positive experiences online!

*Used safely, the internet can be a great place for youth to connect with other people, learn new information, and access entertainment. Parents and caregivers can help make this happen!*

## Tips to Help Youth Learn to Stay Safe on the Internet

Now that we know how online communication can be a positive experience for youth with IDD, let's talk about how you can help create an environment for a healthy online community by working with your youth as a TEAM:

### Teach

- Your youth not to overshare.<sup>3</sup> Explain that it is not safe to share personal information like their address or last name with someone they have never met in person.
- Your youth what "red-flag feelings" are, such as when something online makes them uncomfortable or upset. However, be aware that some youth with IDD might have a hard time identifying a red-flag feeling. Red-flag feelings are a warning sign of potential danger. For example, a request to meet secretly or to share pictures of themselves partially clothed (or worse—unclothed) should cause a red-flag feeling. Encourage your youth to discuss these feelings with you or another trusted adult.

*"My kid has a hard time distinguishing feelings so I ask if he has 'funny tummy feelings' to understand if he might feel uncomfortable."*

-Parent of youth with IDD

- Your youth to think about how they present themselves online. Remind them that pictures and social media posts can be difficult to delete, especially if other people reshare the content on their social media feeds. Remind them it's also important to be respectful of other people, like their friends, when posting on social media.

### Explore Together

- Best practices for internet safety. This can be fun! For example, try out [Interland](#), an online game to help explore why and how to set internet boundaries. You can also ask your youth to show you what they've learned or know about the internet. You might learn something from them!
- A shared list of family internet rules and displaying it in a common space, such as the door of your refrigerator or by a shared computer. For example, not letting your youth use the internet or phones at night. There are other examples available online, such as the [Family Media Agreement](#) developed by Common Sense Media.

### Awareness of Common Issues

- Be aware of cyberbullying. Youth with disabilities are 1.8 times more likely to be victims of cyberbullying than youth without disabilities.<sup>4</sup> Youth with IDD can be victims of false rumors or insults online. Some have received threats of harm.<sup>5</sup> Youth with IDD also have a higher risk of being prey to sexual solicitation on the internet.<sup>6</sup>
- Know what social media and gaming sites your youth frequents online. This can help you be aware of where they go online and be able to help them avoid negative experiences, since youth with IDD receive less training on social media safety than their peers do.<sup>7</sup> Counteract that with your TEAM.

## Work as a TEAM!

Teach

Explore together

Awareness of common problems

Monitor

## Be sure to see our other snapshots:

- Talking to Your Youth with IDD About Sexual Health and Relationships
- Supporting Youth with IDD through Puberty and Early Adolescence
- The Role of Parents and Caregivers in Preventing and Responding to Abuse



### Monitor

- The websites, social media platforms, and apps your youth uses regularly, which can change often.
- Warning signs that an online predator is targeting your youth. For example, is your youth spending long hours online, especially at night; turning the computer or device off when you walk in the room; withdrawing from family life; or showing a reluctance to discuss online activities?<sup>8</sup>
- Ongoing needs for privacy. It is OK for most youth to have some privacy online. Establish guidelines together about when you will check their digital devices. This helps provide a trusting relationship as youth become more independent.<sup>9</sup>

### Take Action If You Think Your Youth Is at Risk

Talk to youth about what to do if they are bullied online and teach them how to stay safe. For example, they can tell a trusted adult, take screenshots to save evidence, and block the bully. Organizations such as [Young Adults: Disabled and Proud](#) have resources and tips to help.

**Ask your youthren to tell a trusted adult if someone upsets them online.**

Take it seriously if your youth reports uncomfortable exchanges or bullying online or by text. Familiarize yourself with resources such as the reporting line for the [National Center for Missing and Exploited Youth](#) (800.843.5678) in case you have concerns about online relationships and need help.

### Resources:

Click links for more information

- [Stopbullying.gov](#): U.S. Department of Health and Human Services provides general tips to keep your youth safe on the internet.
- [Youth Organizing! Disabled and Proud](#): An advocacy group that connects, organizes and educates youth with disabilities.
- [ConnectSafely](#): An organization dedicated to educating people about safety, privacy, and digital wellness.
- [Common Sense Media](#): An organization focused on the digital well-being of youthren and teens, with many resources for parents, caregivers and teachers on internet safety.
- [KidsHealth Internet Safety Guidance](#): Quick tips for parents and caregivers on internet safety.

### Endnotes

- <sup>1</sup> Alfredsson Ågren, K., A. Kjellberg, and H. Hemmingsson. "Access to and Use of the Internet Among Adolescents and Young Adults with Intellectual Disabilities in Everyday Settings." *Journal of Intellectual & Developmental Disability*, vol. 45, no. 1, 2020, pp. 89–98.
- <sup>2</sup> Alper, Meryl. "Digital Youth with Disabilities." John D. and Catherine T. MacArthur Foundation Reports on Digital Media and Learning. Cambridge, MA: MIT Press, 2014.
- <sup>3</sup> Nesi, Jacqueline. "The Impact of Social Media on Youth Mental Health." *North Carolina Medical Journal*. vol. 81, no. 2, March 2020, pp. 116–121
- <sup>4</sup> Fuxman, S., S. Kessel Schneider, and M. Heyman. "The Ruderman White Paper on Social Media, Cyberbullying, and Mental Health: A Comparison of Adolescents With and Without Disabilities." Ruderman Family Foundation, n.d. Available at [https://rudermanfoundation.org/white\\_papers/ruderman-white-paper-reveals-students-with-disabilities-are-almost-twice-as-likely-to-be-victims-of-cyberbullying/](https://rudermanfoundation.org/white_papers/ruderman-white-paper-reveals-students-with-disabilities-are-almost-twice-as-likely-to-be-victims-of-cyberbullying/). Accessed October 20, 2021.
- <sup>5</sup> Sallafranque-St-Louis, F., and C.L. Normand. "From Solitude to Solicitation: How People with Intellectual Disability or Autism Spectrum Disorder Use the Internet." *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, vol. 11, no. 1, 2017.
- <sup>6</sup> Normand, C.L., and F. Sallafranque-St-Louis. "Cybervictimization of Young People with an Intellectual or Developmental Disability: Risks Specific to Sexual Solicitation." *Journal of Applied Research on Intellectual Disabilities*, vol. 29, no. 2, March 2016, pp. 99–110. doi: 10.1111/jar.12163. Epub 2015 Apr 13. PMID: 25871891.
- <sup>7</sup> Fisher, K. W., H. Williamson, and N. Guerra. "Technology and Social Inclusion: Technology Training and Usage by Youth with IDD in the National Longitudinal Transition Study of 2012." *Inclusion*, vol. 8, no. 1, 2020, pp. 43–57.
- <sup>8</sup> KidsHealth. "Internet Safety." Website, Nemours Youthren's Health. Available at <https://kidshealth.org/en/parents/net-safety.html>. Accessed August 3, 2021.
- <sup>9</sup> KidsHealth. "Internet Safety." Website, Nemours Youthren's Health. Available at <https://kidshealth.org/en/parents/net-safety.html>. Accessed August 3, 2021.



## Sexual abuse prevention



Sexual abuse can happen to anyone, including youth with IDD. Parents and caregivers can help prevent abuse by teaching youth about sexual boundaries and advocating for their youth if they suspect abuse.

The resources in this section can help you raise awareness of the importance of talking to youth about this important topic and tips for how to have these sometimes challenging conversations.

# Sexual abuse prevention

## Social media memes

Post these memes to your social media accounts to highlight how parents and caregivers can help youth with IDD prevent sexual abuse. Keep your posts fresh by choosing from the different memes below.

You can download high-resolution versions of the individual memes [here](#).



**You've taught them to be fearless.**

**Now teach them to be safe.**

Youth with intellectual and developmental disabilities are more likely to be victims of sexual abuse or assault. Talk to your youth and teach them how to protect themselves.



**You've taught them to be fearless.**

**Now teach them to be safe.**

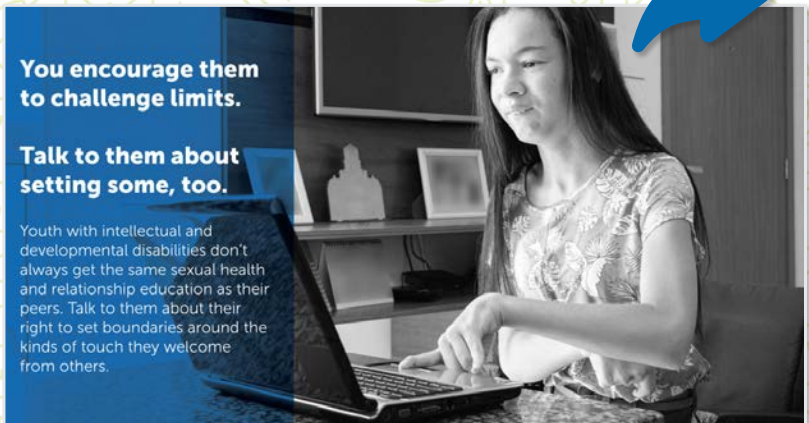
Youth with intellectual and developmental disabilities are more likely to be victims of sexual abuse or assault. Talk to your youth and teach them how to protect themselves.



**You encourage them to challenge limits.**

**Talk to them about setting some, too.**

Youth with intellectual and developmental disabilities don't always get the same sexual health and relationship education as their peers. Talk to them about their right to set boundaries around the kinds of touch they welcome from others.



**You encourage them to challenge limits.**

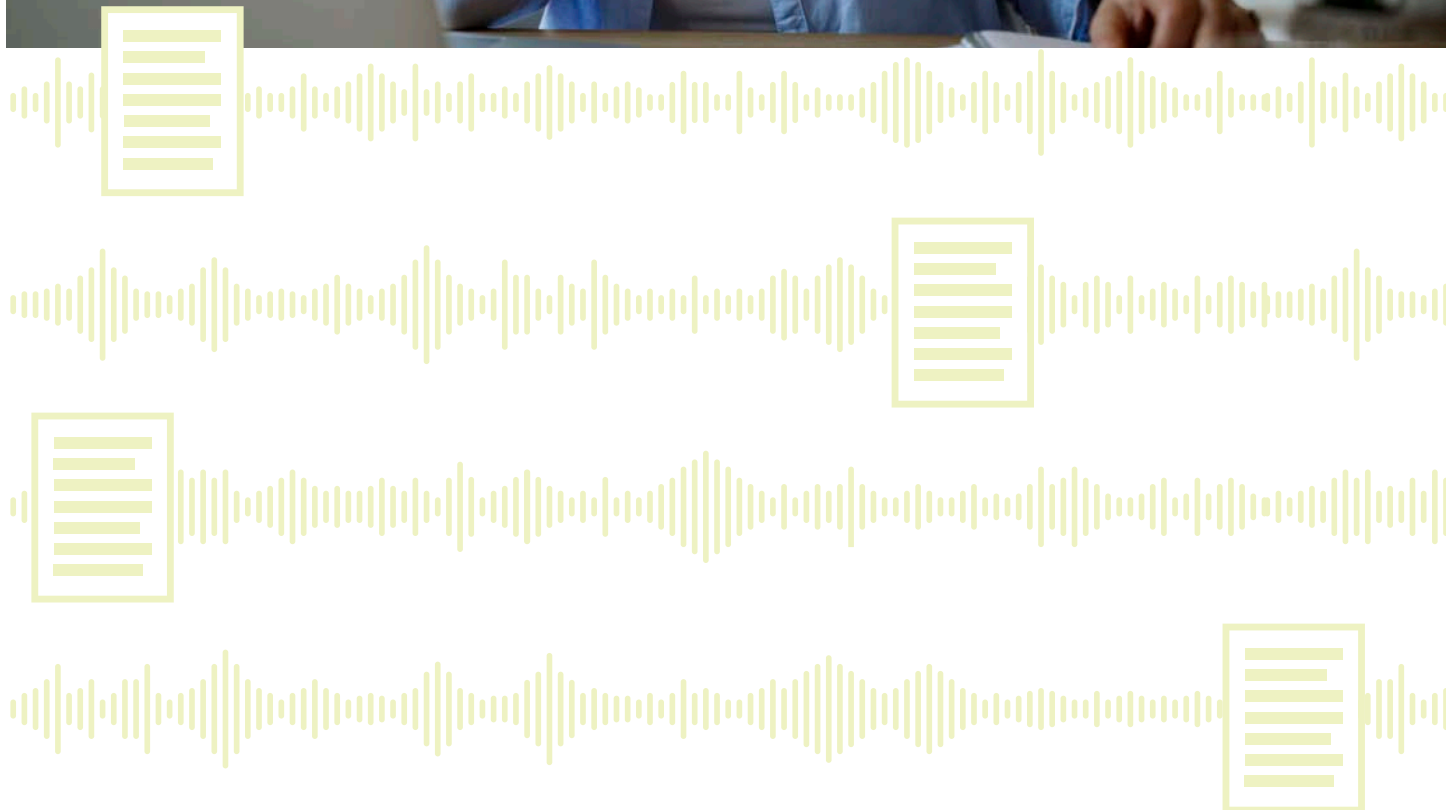
**Talk to them about setting some, too.**

Youth with intellectual and developmental disabilities don't always get the same sexual health and relationship education as their peers. Talk to them about their right to set boundaries around the kinds of touch they welcome from others.



### Audio clip and script

Share the URL to [this audio clip](#) on your social media accounts. It provides a brief but powerful look at how parents and caregivers can help youth with IDD prevent sexual abuse.







## **Script for sexual abuse prevention audio clip**

Being a parent or a caregiver is a big job. It requires us to learn how to do it over and over again as our kids move through different developmental stages: what we needed to know and do to be a good at this when they were little can be pretty different from what they need our help with as they get older.

For those of us with kids with intellectual and developmental disabilities, helping them sort it all out can be an even heavier lift. We have to figure out how to explain things to them in a language or a way and at a level they can understand. As they get older and start to interact more with the wider world—something that is entirely normal and healthy for them to do—we lose some ability to control who and what they encounter, and that’s not easy, particularly as they move into adolescence.

The simple and worrisome fact is that kids with intellectual and developmental disabilities are at a higher risk for being sexually assaulted than other kids. That’s really scary for us. Our kids typically depend more on adults than youth without intellectual and developmental disabilities. They might have difficulty understanding or communicating what’s happening to them. It’s possible they don’t get the same school-based education or support around sexual health and safety that their peers do.

How do we help our kids understand the dangers of being assaulted and how to protect themselves? We aren’t powerless. There are lots of things we can do.

We can talk to our kids about these things, like we have about others: keeping it in line with the language and types of ideas they can understand. We can take steps to make sure the people providing care for them are safe and trustworthy. We can also make sure our kids know they can tell us anything, even if someone else told them to keep it secret. We can keep the lines of communication between us open, so we can be aware when they have additional questions or might be trying to tell us indirectly that something isn’t right. And we can get more information and support from reputable sources on how to talk about these matters with them.

There’s no way to keep our kids in a protective bubble and help them navigate into adulthood and some degree of independence. We balance independence with safety by teaching them about the risks, providing them with a space where they can talk and we will listen, and supporting them through all of it.

Along the way, we watch them bloom into the adult lives they’ve dreamed of.



## The Role of Parents and Caregivers in Preventing and Responding to Sexual Abuse

*Attempted rape, unwanted sexual touching, and forcing victims to perform sex acts are all types of sexual violence.*

*The best time to start talking to your youth about sexual boundaries is between the ages 5 and 14. The second best time?*

**Right now!**

Sexual abuse can happen to anyone, including youth with intellectual and developmental disabilities (IDD). Sexual assault is sexual contact or behavior that occurs without the explicit consent of the victim.

**Fact:** Youth with IDD are at a higher risk for sexual abuse than youth without IDD.<sup>1</sup> They are also less likely to report assault to parents and caregivers, as well as the police.<sup>2</sup>

Why? One reason might be that youth with IDD might have increased dependence on adults. They might not be able to understand or communicate what's happening to them. They also might have less access to sexuality education at school.



### Here is How You Can Help Prevent Abuse

#### Talk to your youth

- Talk with your youth in a developmentally appropriate way about personal safety and consent.
- Help youth understand that some parts of the body are private and people should not look at or touch them. Tell them that they have a right to decide who touches their bodies.
- Identify which caregivers or medical staff may touch areas typically covered by a bathing suit with their permission and the situations when they may need to do this. Also mention that youth can ask to have someone else in the room with them during medical exams.
- Help your youth identify what makes them uncomfortable. Emphasizing to them what is and isn't appropriate behavior will help them know when it's abuse.
- Remind them that it is okay to politely say no even to nonsexual touching, like hugs.

- Discuss what to do when using the restroom when you are outside the home, such as:
  - Using public restrooms independently if possible
  - Closing and locking bathroom or stall doors
  - Restricting nudity to appropriate spaces such as a bathroom, bedroom, or a changing room in a locker room<sup>3</sup>
- Let your youth know they can talk to you about anything, even if someone told them to keep something a secret or private.

### Advocate for Your Youth

- Understand that most youth are abused by someone they know and trust. Avoid focusing exclusively on “stranger danger” or the idea that assault is only perpetrated by someone the youth doesn’t know.<sup>4</sup>
- Evaluate the caregivers who care for your youth. For example, contact multiple references, conduct a background check, and drop in unexpectedly when they are providing care.<sup>5</sup>
- Seek educational opportunities on sexual health outside the home. Make sure that your youth learns basic facts about sex.<sup>6</sup>

### Parents and Caregivers Might be Able to Recognize Signs of Abuse in Their Youth

Recognizing sexual assault and ongoing sexual abuse can be more difficult in youth who are nonverbal or otherwise cognitively delayed. Parents can look for new or more frequent self-stimulatory behaviors, such as repetitive movements or sounds (known as “stimming”) and new or more frequent behaviors leading to self-injury.<sup>7</sup>

Youth might or may not disclose abuse to you. If they do, it could happen by telling you directly or indirectly by mentioning something like “a friend told me ...”. You can support your youth by:

- Believing them
- Never blaming them
- Providing a safe environment
- Reassuring them that they did nothing wrong<sup>8</sup>

### Some Signs of Abuse or Assault\*

**Physical:** difficulty sitting or walking, bruises or pain in genital areas, headaches, stomach aches, or sexually transmitted diseases.

**Behavioral:** depression, substance abuse, withdrawal, avoids specific setting or people, sleep or appetite changes, crying spells, seizures, phobias, regression, guilt or shame feelings, self-destructive behavior, feelings of panic, sexually inappropriate behaviors, severe anxiety or worry, resists physical exams, learning difficulties, irritability, or a change in habits or moods.

**\* Look for repeated or multiple signs since these signs can also appear in youth who are not being abused. For example, a youth might feel depressed or have headaches due to another reason than abuse.**

## Report Suspected Abuse Immediately by Calling:

**911** for emergencies

Your youth's health care provider or a national resource such as **1-800-4AYouth (1-800-422-4453)** for the Youthhelp National Youth Abuse Hotline or **1-800-656-HOPE (1-800-656-4673)** for the National Sexual Assault Hotline.

### TAKE ACTION!

*Talk to your youth about sexual abuse right away. If you suspect abuse, ensure your youth gets help immediately.*

### Be sure to see our other snapshots:

- Talking to Your Youth with IDD About Sexual Health and Relationships
- Supporting Youth with IDD through Puberty and Early Adolescence
- Keep Youth With IDD Safe Online

### Resources:

Click links for more information

- Tips from RAINN (Rape, Abuse & Incest National Network) [on talking to kids about sexual assault](#)
- Article from The Arc on [people with intellectual disabilities and sexual violence](#)
- Resources from the Youth Welfare Information Gateway on [responding to youth abuse and neglect](#)
- State-by-state listing from the National Youth's Alliance [of accredited Youth's Advocacy Centers](#) that offer coordinated support and services for victims of youth abuse, including sexual abuse

### Endnotes:

- <sup>1</sup> National Public Radio. *The Sexual Assault Epidemic that No One Talks About*. January 28, 2018. <https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about>. Accessed September 1, 2022.
- <sup>2</sup> California Youth Abuse Training and Technical Assistance Centers Youth with Disabilities and Sexual Assault Fact Sheet. [https://cirinc.org/file\\_download/284a5f31-04d4-4b3d-97d9-84fa73862bea](https://cirinc.org/file_download/284a5f31-04d4-4b3d-97d9-84fa73862bea). Accessed September 1, 2022.
- <sup>3</sup> Autism Speaks. "Recognizing and Preventing Sexual Abuse." n.d. Available at <https://www.autismspeaks.org/recognizing-and-preventing-sexual-abuse>. Accessed July 14, 2022.
- <sup>4</sup> National Public Radio. *The Sexual Assault Epidemic that No One Talks About*. January 28, 2018.
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# Promising Youth Programs

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Personal Responsibility Education Program

