



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.¹ 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.² On the other hand, many females with autism spectrum disorder or cerebral palsy start menstruating later than their peers.^{3,4}

What Changes to Expect During Puberty

Here are some examples of the physical changes youth will experience during puberty:⁵

- 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.⁶ 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.⁷
- **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.^{8,9} 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.¹⁰ 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.¹¹
- **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.**¹² 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

- ¹ 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.
- ² 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.
- ³ 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.jpog.2021.03.008.
- ⁴ Quint, Elisabeth H., and Rebecca F. O'Brien. "Menstrual Management for Adolescents With Disabilities." *Pediatrics*, vol. 138, no. 1, 2016, article e20160295.
- ⁵ 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.
- ⁶ 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.
- ⁷ 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.jpog.2021.03.008.
- ⁸ 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.
- ⁹ 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.
- ¹⁰ 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.
- ¹¹ 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.
- ¹² 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.