



Puberty is a time of great changes physically and emotionally for every person. People with I/DD will go through these changes as well, and puberty can present some particularly confusing and/or challenging moments during this time of physical transition. Children with disabilities can go through these hormonal changes at different times than is typically expected, and the first resource for families regarding medical questions should be your primary care physician or pediatrician.

We have compiled some resources on puberty/adolescence that can help self-advocates and family members navigate this time of change.

This Fact Sheet provides a broad array of general, introductory information on the subject. Families should consult with their primary doctor, health clinic or counselor to determine what works best for your loved one.

Puberty Resources

Health systems and university medical centers have created resource guides for people with I/DD and their loved ones to help them understand and navigate the changes that occur during puberty.

Healthy Bodies Toolkit from Vanderbilt Kennedy Center. Separate publications for boys and girls. The links below include a web version of the Toolkit, as well as “Puberty, Sex and Sexuality: An Introduction for Autistic Teens and Adults Toolkit”.

English: [The Healthy Bodies Toolkit \(vumc.org\)](https://www.vumc.org/healthy-bodies-toolkit)

Spanish: [The Healthy Bodies Toolkit \(vumc.org\)](https://www.vumc.org/healthy-bodies-toolkit)

(Also available in Turkish and Thai)



Puberty Resources

From UWisconsin Health, written by physicians specializing in Adolescent Medicine. This covers the use of anatomically-correct language, accommodations at home/school/work that allows them to maintain proper hygiene & dignity, and communicating with medical providers.

[Puberty and Teens with Special Needs: Ensuring a Smooth Transition. Period. - Growing Up Healthy \(uwhealth.org\).](#)

Advocate Medical Group Adult Down Syndrome Center: terrific guides that include puberty-related topics [Families and Caregivers - Resources | Adult Down Syndrome Center \(advocatehealth.com\).](#)

The Illinois Service Resource Center has a library for students who are Blind, Hard of Hearing, or Visually Impaired. [Illinois Service Resource Center | ISRC \(nsseo.org\)](#). Illinois residents can request to borrow materials for four weeks. Link to the library website and instructions for requesting materials is here: [ISRC Library | Resources \(nsseo.org\)](#).

• The link to the ISRC resources on puberty is here:
[Puberty 2022.pdf - Google Drive](#)

Menstruation

The start of menstruation, or menarche, is an important topic for many parents of adolescent girls, with or without disabilities. Menstruation is covered in the toolkits above, and below are a few publications specifically for girls with disabilities and their caregivers.

Menstruation

The American Academy of Pediatrics published “Menstrual Management for Adolescents with Disabilities” in the journal Pediatrics on July 1, 2016.

[Menstrual Management for Adolescents With Disabilities | Pediatrics | American Academy of Pediatrics \(aap.org\)](#)

U of Michigan Health then created a family-friendly version to summarize the Pediatrics publication:

[Preparing for Puberty in Girls with Disabilities | Michigan Health Blog \(uofmhealth.org\)](#)

From Cincinnati Children’s Hospital: Defeating Period Problems in Girls with Disabilities:

[Defeating Period Problems in Girls with Disabilities - Cincinnati Children's Blog \(cincinnatichildrens.org\)](#)

From the website AboutKidsHealth.ca: Menstruation and Developmental Disability: Advice for Parents of Adolescent Girls: [Menstruation and developmental disability: Advice for parents of adolescent girls \(aboutkidshealth.ca\)](#)

Virtual Guides and Social Stories

Social stories and visuals can be helpful tools to help teach individuals with I/DD. Doing a web search for “puberty, disabilities, social stories” can result in numerous results. These below are comprehensive, providing both visuals and social stories.

Vanderbilt Kennedy Center Healthy Bodies Appendix for Boys. Includes both visual guides and social stories.

[HealthyBodiesAppendix-Boys.pdf \(vumc.org\)](#)

[Boys Healthy Bodies Toolkit \(vumc.org\)](#) (Spanish)

Virtual Guides and Social Stories

Vanderbilt Kennedy Center Healthy Bodies Appendix for Girls. Also includes both visual guides and social stories.

[HealthyBodiesAppendix-Girls.pdf \(vumc.org\)](#)

[Girls Healthy Bodies Toolkit \(vumc.org\)](#) (Spanish)

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Public vs Private Resources

Puberty is an especially important time to teach and reinforce the concepts of public behavior vs. private behavior.

From Autism Parenting Magazine: Teaching Private vs. Public Behaviors Introduces why this is important, and why it can be confusing.

[Teaching Private vs. Public Behaviors - Autism Parenting Magazine](#)

Organization for Autism Research Sex Ed for Self-Advocates: Public Versus Private training.

[Organization for Autism Research \(researchautism.org\)](#)

Sex Ed for Adults with I/DD

405 ILCS 5/4-211 requires the Illinois Department of Human Services (IDHS) to approve course material in sex education.

From Illinois Department of Human Services (IDHS):

Information about the approved curriculum from the National Council on Independent Living (NCIL):

[IDHS: Curriculum: SEX ED FOR I/DD ADULTS - NATIONAL COUNCIL ON INDEPENDENT LIVING \(NCIL\) \(state.il.us\)](#)

Sex Ed for Adults with I/DD

Sex Ed for People with Disabilities created by National Council on Independent Living (NCIL). This link is a list of videos, with one specifically on Puberty.

[Sex Ed for People With I/DD. - YouTube](#) (see video on Puberty)

From the Illinois Guardianship and Advocacy Commission. Documents available in English, Spanish, Polish and Chinese.

[Sex Education for Adults with ID/DD: Public Act 101-0506 \(illinois.gov\)](#)

Sexual Rights Statement:

[Sexual Rights \(illinois.gov\)](#)

[Sexual Rights Spanish \(illinois.gov\)](#)

FAQs from Self-Advocates about Sex Education:

[FAQ Sex Ed For Self-Advocates - March 2021 \(illinois.gov\)](#)

[FAQ Sex Ed For Self-Advocates - March 2021 - Spanish \(illinois.gov\)](#)

Three-Part Webinar series in Spanish on Puberty, Disability and Sexuality/Serie de seminarios web de tres partes en español sobre pubertad, discapacidad y sexualidad

Click on this link and scroll to the recorded webinars dated January 12 2023, February 9th 2023 and February 16th 2023. Haga clic en este enlace y desplácese hasta los seminarios web grabados del 12 de enero de 2023, 9 de febrero de 2023 y 16 de febrero de 2023. [Programación \(Webinars\) en Español - The Arc of Illinois](#)

Incontinence in people with I/DD during Puberty

For some individuals with I/DD, incontinence can continue through childhood and into puberty. Our Incontinence/Diaper Fact Sheet provides information on how to obtain diapers and support for those experiencing incontinence.

Diaper Fact Sheet from The Arc of Illinois: [DiaperFactSheetSept2022.pdf \(illinoislifespan.org\)](#)