



**Anticipatory Guidance for Children with Developmental Disabilities**

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**Disclosure and Learning Objectives**

Ronda Franke DNP, CPNP-PC has no financial relationships with commercial interests to disclose

1. Identify common concerns parents of children with developmental disabilities have during key stages of development
2. Discuss adaptations of common anticipatory guidance topics for children with developmental disabilities
3. Discuss interventions and therapies and other supports that may be needed during different developmental stages for children with developmental disabilities



**Quick Facts**

- 1 in 6 children aged 3-17 years have developmental disabilities-conditions that affect how children play, learn, speak, act, or move.
- Many children with a developmental disability are not identified until after starting school.
- Nationally, only 17% of children younger than 5 years of age with developmental delays received services for those delays.
- Studies of children who are younger than 3 show that large numbers of presumably eligible children are not enrolled in early intervention. Despite high rates of developmental delays among children who receive Early Head Start, <5% of these children were also enrolled in early intervention (1)



**Infants and Toddlers**

- ❖ Often ages that developmental concerns emerge
- ❖ Listen to family's concerns
- ❖ Watch and Wait may not be best approach especially if child is in a high-risk group
- ❖ Parental concerns are highly accurate in identifiers for developmental disabilities



**Developmental Screening and Surveillance**

- ❖ American Academy of Pediatrics Recommendations
- ❖ Developmental Surveillance (informal process)
  - ❖ Occurs at ever well child visit
  - ❖ longitudinal process
  - ❖ eliciting concerns
  - ❖ Developmental Milestones
  - ❖ Observing Behaviors
  - ❖ Applying clinical judgement
- ❖ Developmental Screening (standardized process)



**Developmental Screening**

- ❖ Occurs at 9, 18, and, 30 month visits
- ❖ Standardized autism spectrum disorder screening at 18 and 24 months
  - ❖ Use specific ASD screening tool
  - ❖ Earlier screening does not identify children with mild symptoms and typical cognitive ability
- ❖ Any parent concerns—perform additional screening or refer



**Developmental Screening Tools**

- ❖ Ages and Stages
  - 2-60 months
  - Parent Questionnaire
  - Online Administration
  - Takes 10-15 min
  - 4-6<sup>th</sup> grade reading level
  - 21 questions
  - communication, gross motor, fine motor, problem solving, adaptive skills
- Results:
  - Pass- Care as Usual
  - Monitor- Scores were close to the cutoff, depending clinical judgement can rescreen in 2-3 months or refer
  - Refer- Scores were below cut off and referral is recommended

<https://agesandstages.com/>

**Developmental Screening Tools**

- ❖ Parent Evaluation of Developmental Status (PEDS-DM)
- ❖ Electronic Administration or parent Interview
  - 0-8 years
  - 4-5<sup>th</sup> grade reading level
  - 2-5 minutes to administer
- Domains : fine motor, gross motor, expressive language, receptive language, self-help, social-emotional, and for older children, reading and math
- Algorithm to guide need for referral, additional screening or continued surveillance

<https://www.pedstest.com/>

**Autism Screening**

- ❖ Recommended at 18 and 30 months
- ❖ MCHAT Revised with Follow up
- ❖ Valid for screening toddlers 16-30 months
- ❖ Primary Goal is early detection so intervention can start early which is associated with better long term outcomes
- ❖ Maximizes sensitivity meaning it will do better job of identifying children who have Autism (True Positives)
- ❖ Trade off is lower specificity with a higher number of False Positives in identifying children who do not have Autism
- ❖ Even though children will be over referred research has shown that children identified as false positives often have another developmental disorder and would also benefit from evaluation or intervention (Weitlauf)
- ❖ To deal with issue of false positives the original MCHAT was modified to provide follow up questions

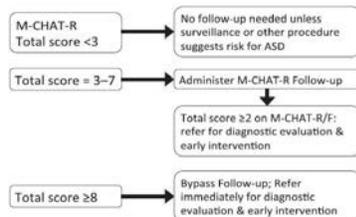
<https://mchatsscreen.com/>

**MCHAT Revised with Follow UP R/F (2014)**

- ❖ Follow up questions help clarify information and obtain additional information when a patient screens positive
- ❖ Some Emerging Evidence certain items may be more highly associated with a diagnosis of Autism
- ❖ Item 1: (Joint Attention) If you point at something across room does your child look at it
- ❖ Item 2: Does your child respond when you call his name
- ❖ Item 3: Have you wondered if your child might be deaf
- ❖ Item 4: Is your child interested in Peers



**MCHAT R/F (2014)**



**MCHAT R/F (2014)**





### Signs of Autism

### Resources for Online Parent Autism Training

HELP IS IN YOUR HANDS: 16 Video modules to help parents learn simple intervention practices they can use at home for their young children with autism. Based on Early Start Denver Model. Free, requires creation of an account.

<https://health.ucdenver.edu/news/headlines/help-is-in-your-hands-a-great-resource-for-families-with-young-kids-on-the-autism-spectrum/2020/03/>

ADEPT (Autism Distance Education Parent Training) MIND Institute/CEDD 10-lesson interactive, self-paced, online learning module providing parents with tools and training to more effectively teach their child with autism and other related neurodevelopmental disabilities functional skills using applied behavior analysis (ABA) techniques.

<https://health.ucdenver.edu/mandmh/department/earlychildhood.html>



### Preschoolers

- ❖ Initiative vs Guilt (3-5 years)
- ❖ Preoperational Stage (2-6 years)
- ❖ Increased interaction with their environment
- ❖ Learning about the world through experience
- ❖ Exploration through play
- ❖ Interaction with other children
- ❖ Elaborate Pretend Play
- ❖ Curiosity and want to learn
- ❖ Asking lots of questions

### Therapies and Services

- ❖ Adapted school environment is important for learning and experiencing success
- ❖ Families have questions about Public vs Private Preschool
- ❖ Transition from Early Intervention to School Services
- ❖ System can be challenging and frustrating for parents
- ❖ Language and cultural barriers
- ❖ Families often need assistance to identify and engage with community Agencies
- ❖ Connect to Community Centered Board for long term services and supports

### Therapies and Services

- ❖ Earlier Intervention results in better long-term outcomes
- ❖ Speech Therapy helps children build critical language and communication skills
- ❖ Occupational Therapy helps with motor skills, coordination, daily living, sensory differences and emotional regulation
- ❖ Behavior Therapy helps build daily living, communication skills as well as addressing problem behaviors like aggression
- ❖ Earlier Focus on building critical skills like functional communication can significantly decrease the potential for more serious behavior problems later on
- ❖ School Services vs Private Therapies
- ❖ Work to help families be good consumers of therapy
- ❖ Parent Training
- ❖ Davis Mind Institute has on online training for Parents called ADEPT
- ❖ Davis Mind Institute online Early Start Denver Model Help is in your Hands

### Education

- ❖ Transition from Early Intervention to Preschool
- ❖ Part C of IDEA (early Intervention)
- ❖ Part B of IDEA (preschool Services)
- ❖ Transition Evaluation to determine eligibility
- ❖ Evaluation for IEP in the Public School Setting
- ❖ Eligibility for Services may change
- ❖ Some children who were eligible for services in early intervention may not be eligible for an IEP
- ❖ Depending on new eligibility services received in Early intervention may change
- ❖ Process can be confusing

### Education Resources

Transition from Early Intervention to Preschool  
<https://www.vumc.org/assets/files/resources/etp-transition-toolkit.pdf>

Individuals with Disabilities Education Act  
<https://sites.ed.gov/idea/about-idea/>

Peak Parent Center  
<https://www.peakparent.org/search/site/idea>



### Potty Training

- ❖ Frequently have difficulties with Potty Training
- ❖ Usually occurs later and takes more structure and repetition
- ❖ Communication differences-less likely to initiate
- ❖ Thinking differences with more rigid less flexible thinking
- ❖ Difficulties with change
- ❖ Less likely to recognize their body's cues and initiate to use the toilet
- ❖ May hold both urine and stool especially when not at home or when not wearing a diaper
- ❖ GI differences predispose to constipation
- ❖ Stool holding makes constipation worse and the experience of painful bowel movements sets up cycle



### Potty Training

- ❖ Prepare parents that potty training will most likely take longer, in some patients we see the process may take months
- ❖ Toilet Training for urine is usually accomplished more easily
- ❖ Due to difficulties with change need to take process slow and follow child's lead
- ❖ Treat constipation as hard uncomfortable bowel movements make the child more fearful and resistant
- ❖ Most children require the use of a timed schedule or trip training
- ❖ Families can start by changing diapers or pull ups in the bathroom and completing the potty routine each time they change their child
- ❖ This helps to scaffold environmental cues for the child
- ❖ Therapy providers like OT and ABA can help
- ❖ For children over 4 years will developmental disability Medicaid will usually cover the cost of diapers or pull ups



### Feeding

- ❖ More challenging especially with kids who have a lot rigidity and sensory differences
- ❖ Higher Incidence of Medical Comorbidities that contribute to feeding problems
- ❖ May pocket food and be at risk for choking
- ❖ May overstuff or eat too fast
- ❖ Often very limited variety of foods they will eat
- ❖ Prefer foods high in carbs and fats as these foods often have a more bland taste and neutral color
- ❖ Non preferred foods may trigger gagging or throwing up
- ❖ Parents need to understand this is not their child being spoiled or uncooperative this is related to brain differences in how they experience food
- ❖ Growth concerns like being underweight or overweight
- ❖ Often have nutrient deficiencies in Vitamin D and Iron



### School Age

- ❖ Industry Vs Inferiority
- ❖ Concrete Operations
- ❖ Developing Friendships
- ❖ Understanding and mastering basic academic concepts
- ❖ Working on Achieving goals
- ❖ Competition and success
- ❖ Develop a sense of pride and accomplishment in various areas like academics, sports and social



### School Age

- ❖ Skills in many areas lag behind peers
- ❖ Recognize this by may not understand why
- ❖ Parents and children compare themselves with others
- ❖ Develop feelings of being inferior, decreased self esteem
- ❖ This can lead to other mental health disorders like depression and anxiety
- ❖ Want to support these kids in finding things they are good at and interested in
- ❖ Want to encourage independence and skill building
- ❖ This can be hard for families



### Social Skills

- ❖ Gaps in Social Skills widen and become more evident
- ❖ Often seen as different by peers
- ❖ Interests may not align with peers
- ❖ Parents will tell you they don't have any friends
- ❖ Often become isolated and retreat to screens
- ❖ Parents often need to be more involved and help facilitate social interactions
- ❖ Find avenues where their kids can connect with kids who have similar interests like Lego Club
- ❖ Social Skills Groups either in community or School



### Bullying

- ❖ Bullying becomes more prevalent
- ❖ Kids with Autism and ID are 2-3 times more likely to be bullied
- ❖ Easy target for bullies
- ❖ Easily led and manipulated
- ❖ Communication deficits
- ❖ Lack of understanding social cues
- ❖ Lack of cognitive flexibility
- ❖ Often don't tell anyone
- ❖ Often feel helpless and may become anxious and depressed



### Social Media

- ❖ Want to be like others
- ❖ Don't understand nuances or consequences of social media
- ❖ Encourage Parents to know what is happening at school
- ❖ Be involved, supervise social media use, and dialogue about social media
- ❖ Social Stories can be helpful
- ❖ Monitor Screen Time
- ❖ Create very specific rules



### Social Stories

- ❖ Used to teach what is expected in a specific social situation
- ❖ Combination of pictures and words
- ❖ How to for specific situations
- ❖ A set of instructions
- ❖ Can be individualized



### Growth

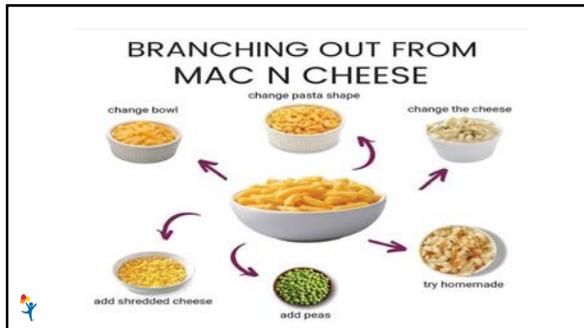
- ❖ Growth differences are frequently seen on both ends of the continuum
- ❖ Impact of Genetic influences
- ❖ Increased risk of obesity in developmental disabilities
- ❖ Can more difficult in developmental disabilities due to numerous factors
- ❖ Very Limited Diets
- ❖ Prefer Unhealthy Foods
- ❖ Rigid Thinking
- ❖ Sensory Differences
- ❖ Oral Motor Challenges
- ❖ Typical strategies often don't work
- ❖ Often need more formal intervention
- ❖ Multi Disciplinary Team approach



### Food Chaining

- ❖ Adding very small amounts of non preferred foods to a preferred food
  - ❖ Adding meat or veggies to Rice or Mac and Cheese
  - ❖ Diluting milk or Sugary Beverages with very small amounts of water
- ❖ Over time slowly increase the amount of the non preferred food
- ❖ Or changing a food gradually from one food to another





**Physical Activity**

- ❖ Difficulties with motor coordination
- ❖ More tiring and get fatigued more easily
- ❖ Social challenges related to group sports
- ❖ Families may have negative past experiences with team sports
- ❖ Gravitate to sedentary activities
- ❖ Simple Activities like walking, even riding a bike can be hard
- ❖ Try to make activity part of a routine
- ❖ Individual sports like swimming may be better
- ❖ Some evidence that activities like Hippotherapy (horse therapy) can improve communication, sensory symptoms and coordination
- ❖ Some evidence martial arts therapies can help with hyperactivity and attention
- ❖ Consider Physical Therapy to help
- ❖ Adaptive programs like Special Olympics
- ❖ Waiver funds can pay for activities

**Adolescents**

- ❖ Identity vs Role Confusion
- ❖ Who am I/Sense of Self
- ❖ Developing Abstract Reasoning Skills
- ❖ Developing Goals
- ❖ Fitting in
- ❖ Develop Competence
- ❖ Find way to contribute
- ❖ Autonomy and Independence

**Independence**

- ❖ Encourage as much independence as possible
- ❖ Can be hard for some families as their identity can become linked to caring for and protecting their child
- ❖ Talking with families about ways they can begin taking small steps to being more independent, like having chores around the house, using public transportation
- ❖ Know what life skills they may be working on at school and reinforce these at home
- ❖ Many children receive services through IEP in Public school until 21 years
- ❖ At 14 years of age families need to ask to have their child placed on adult services wait list with their local CCB so they are eligible to receive adult services

**School Transitions**

- ❖ Transition to Middle and High School
- ❖ Help Families be PROACTIVE and think about this transition ahead of time
- ❖ IEP is usually redone prior to starting middle or high school
- ❖ Encourage families to understand the IEP and know what services are being provided
- ❖ This is especially important for non English speaking families and lower SES families as they often may blindly trust what the school says and don't realize they have a voice to advocate for their child

**Physical Changes**

- ❖ Hormonal Changes can worsen behaviors
- ❖ If not in therapy may need to discuss resumption
- ❖ Females will begin menses and families often unprepared for this and how to manage
- ❖ Family may be interested in menstrual suppression so referral to a GYN provider to discuss
- ❖ Changes to body are scary and kiddo may not understand
- ❖ Encourage parents to take multiple opportunities to talk about this over time
- ❖ Don't do well with hygiene aspects and need much more explicit instruction on this. Simple things like wearing deodorant, bra or taking shower can be really challenging

**Sexuality**

- ❖ Many families don't think about this especially when their teen has Intellectual Disability
- ❖ Teens with Developmental Disabilities are interested in Romantic Relationships
- ❖ They need a lot more instruction and direction on how to go about this
- ❖ Inappropriate touching of others can become a big problem
- ❖ Inappropriate Self Touching very distressing to families especially when done in public
- ❖ Talking about Public Vs Private
- ❖ Getting therapy providers involved to help with this if parents are not comfortable
- ❖ Social Stories can be helpful tools
- ❖ Dev Pediatrics runs a class for families on Sexuality and covers a wide range of topics

**Social Media**

- ❖ Need support to use social media safely
- ❖ Research has shown adolescents and adults with Autism who use social media in moderation tend to be happier
- ❖ Friendships online may be easier and more rewarding
- ❖ May be especially vulnerable due to not understanding social rules
- ❖ May need much more explicit rules about things that are appropriate
  - Don't post compromising pictures even if people ask you to
  - Don't give out personal information
  - Just because someone says they are a friend on social media does not mean they are
  - Talk about rules for accepting friend requests
- ❖ People with Autism often like rules so creating and writing these down may help
- ❖ People with autism often don't understand emotions and may be very concrete and too honest in things that they post which can lead to others attacking them
- ❖ rough\_guide\_to\_social\_media\_use.pdf (ucl.ac.uk)

**Guardianship**

- ❖ Early on begin a dialogue with the family about what their hopes and expectations are for their child's future
- ❖ Dialogue about realistic expectations
- ❖ There are many options for independent living but not all families want this
- ❖ Guardianship is a legal process
- ❖ Process and takes time and needs to begin well before child's 18<sup>th</sup> birthday
- ❖ Healthcare proxies may be needed so parents can have access to medical records and be involved in medical decision making
- ❖ Young Adults with Autism may not need guardianship but may need help making decisions so arrangements like Shared Decision making should be discussed

**Options other than Guardianship**

Power of Attorney- Appoints someone for certain aspects of legal decision making	Supported Decision Making Instead of naming a guardian or POA, individuals will create a supportive community that names specific individuals in their life that can help them make decision (SB 075 in Colorado)	Conservatorship- person assigned by courts to make financial decisions
Representative Payee- Person assigned to manage benefits assigned to an individual	Medical Proxy- Person designated to make medical decision	Releases of Information- allow designated person to access protected health information

**References**

CDC: Celebrating Children's Development and Improving Early Identification About "Learn the Signs. Act Early." Program <https://www.cdc.gov/ncbddd/actearly/pdf/LTASE-program-one-paper-P.pdf>

Promoting Optimal Development: Identifying Infants and Young Children with Developmental Disorders through Surveillance and Screening. *Pediatrics*, 145(1)e20193449 <https://doi.org/10.1542/peds.2019-3449>

Sturner R, Howard B, Bergmann P, Stewart L, Afarian TE. Comparison of Autism Screening in Younger and Older Toddlers. *J Autism Dev Disord*. 2017 Oct;47(10):3180-3188. <https://doi.org/10.1007/s10803-017-3230-1>

Schwarz SM, Corredor J, Fisher-Medina J, Cohen J, Rabinowitz S. Diagnosis and treatment of feeding disorders in children with developmental disabilities. *Pediatrics*. 2001 Sep;108(3):671-6. <https://doi.org/10.1542/peds.108.3.671>

### References

Must A, Curtin C, Hubbard K, Sikich L, Bedford J, Bandini L. Obesity Prevention for Children with Developmental Disabilities. *Curr Obes Rep*. 2014 Jun;3(2):156-70. Doi: 10.1007/s13679-014-0098-7. <https://pubmed.ncbi.nlm.nih.gov/25530916/>

Paul H. Lipkin, Michelle M. Macias, COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS, Kenneth W. Norwood, Timothy J. Brei, Lynn F. Davidson, Beth Ellen Davis, Kathryn A. Ellerbeck, Amy J. Houtrow, Susan L. Hyman, Dennis Z. Kuo, Garey H. Noritz, Larry Yin, Nancy A. Murphy, Susan E. Levy, Carol C. Weitzman, Nerissa S. Bauer, David O. Childers Jr, Jack M. Levine, Ada Myriam Peralta-Carcelen, Peter J. Smith, Nathan L. Blum, Stephen H. Contompaslis, Damon R. Korb, Laura J. McGulnn, Robert G. Voljt; Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening. *Pediatrics* January 2020; 145 (1): e20193449. 10.1542/peds.2019-3449

<https://publications.aap.org/pediatrics/article/145/1/e20193449/36971/Promoting-Optimal-Development-Identifying-Infants>

### Resources Developmental Screening

Ages and Stages Questionnaires:

<https://agesandstages.com/about-asq/>

Parents Evaluation of Developmental Status:

<https://www.pedstest.com/>

MCHAT-R Screen

<https://mchatscreen.com/mchat-rf/>

### Resources for Online Parent Autism Training

HELP IS IN YOUR HANDS: 16 Video modules to help parents learn simple intervention practices they can use at home for their young children with autism. Based on Early Start Denver Model. Free, requires creation of an account.

<https://health.ucdavis.edu/news/headlines/help-is-in-your-hands--a-great-resource-for-families-with-young-kids-on-the-autism-spectrum/2020/03>

ADEPT (Autism Distance Education Parent Training) MIND Institute/CEDD 10-lesson interactive, self-paced, online learning module providing parents with tools and training to more effectively teach their child with autism and other related neurodevelopmental disabilities functional skills using applied behavior analysis (ABA) techniques.

<https://health.ucdavis.edu/mindinstitute/centers/cedd/adept.html>

### Education Resources

Transition from Early Intervention to Preschool

<https://vkc.vumc.org/assets/files/resources/ei-transition-toolkit.pdf>

Individuals with Disabilities Education Act

<https://sites.ed.gov/idea/about-idea/>

Peak Parent Center

<https://www.peakparent.org/search/site/idea>

### Resources for Toilet Training

Autism Speaks Toilet Training Tool Kit:

<https://www.autismspeaks.org/tool-kit/atnair-p-toilet-training-guide>

Autism Speaks Constipation Tool Kit:

<https://www.autismspeaks.org/sites/default/files/2018-08/Constipation%20Guide.pdf>

Toilet Training for Children with Special Needs by Hepburn, S. (2009):

<http://www.ucdenver.edu/academics/colleges/medicalschool/programs/JFKPartners/products/Pages/Toilet-Training-for-Children-with-Special-Needs.aspx>

The Poo in You: A wonderful video that explains for children and parents why a child is having problems with soiling accidents and constipation. This interactive, animated video explains what causes the accidents and constipation why they happen so often, and how it can be treated.

[https://www.youtube.com/watch?v=SgBj7Mc\\_4sc](https://www.youtube.com/watch?v=SgBj7Mc_4sc)

### Resources for Toilet Training

**Squatty Potty** It is important to have your knees slightly above your hips with sitting on the toilet this allows the muscles of the pelvis to relax. You can use a foot stool or the Squatty Potty. This fun, interactive video explains the importance of having your feet well supported while sitting on the toilet. <https://www.youtube.com/watch?v=6vWdLD44>

GI Kids: This website provides children and families with resources and easy-to-understand information on the diagnosis and management of pediatric digestive disorders.

<https://gikids.org/constipation/>

**Healthy Eating:** <https://gikids.org/nutrition/healthy-eating/>

### Resources for Feeding and Obesity

Guide to Exploring Feeding Behavior in Autism

<https://www.autismspeaks.org/tool-kit/atnair-p-guide-exploring-feeding-behavior-autism>

Ellen Satter Institute of Feeding

<https://www.ellynsatterinstitute.org/>

Improving Food Selectivity in Children with Autism

<https://asatonline.org/research-treatment/clinical-corner/improving-food-selectivity/?eclid=EA1aQobChMlobKQnJPg->

[FyCtBh0GbQqEAAAYvAAEgK5PFD\\_BwE](https://asatonline.org/research-treatment/clinical-corner/improving-food-selectivity/?eclid=EA1aQobChMlobKQnJPg-)



### Resources for Feeding and Obesity

Obesity

Lifestyle Medicine Program- Contact Us: 720-777-3352

Children's Hospital Colorado Lifestyle Medicine Clinic is a comprehensive program to treat obesity or co-morbid conditions, motivation of child or family, abilities of child or family and geographical locations. Our goal is to provide a tailored program to each individual. After an initial medical evaluation, each patient meets with a team of providers, including a dietitian and an exercise physiologist to address the individual needs of each child and/or family.



### Resources on Bullying

Bullying and Autism Spectrum Disorders: A Guide for School Staff

<http://www.autismspeaks.org/family-services/bullying>

Friendship Circle

Friendship Circle is a program that bring together teenage and adult volunteers in helping children, teens, and adults with special needs and their families. Our unique formula introduces teenage and young adult volunteers to our friends and through shared experiences both are enriched. Friendship Circle is made up of five parts: **volunteers, special friends, parents, staff, and supporters**. The true beauty of the circle is how we all link together to form a seamless circle of friendship. Together, we can perform miracles.

[https://www.friendshipcirclemiami.org/templates/articlecco\\_cdo/aid/97459/jewish/About-Us.htm](https://www.friendshipcirclemiami.org/templates/articlecco_cdo/aid/97459/jewish/About-Us.htm)



### Resources on Bullying

Committee For Children Creating Safe Spaces in Learning

<https://www.cfchildren.org/programs/bullying-prevention/>



### Resources Puberty

Puberty and Children on the Autism Spectrum is part of The Autism Society of America's (ASA) Living with Autism Series.

[http://www.autism-society.org/wp-content/uploads/2014/04/LWA\\_Puberty.pdf](http://www.autism-society.org/wp-content/uploads/2014/04/LWA_Puberty.pdf)

Boys

<https://kidshealth.org/en/teens/autism-puberty-boys.html>

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

Girls

<https://kidshealth.org/en/kids/autism-puberty.html?ref=search>

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



### Resources Puberty

Parents Guide

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

Spanish

<https://vkc.mc.vanderbilt.edu/HealthyBodies/Sp-index.html>

[Tool Kit \(social stories handouts\)](#)

[Navigating Puberty, Sex, & Sexuality \(vumc.org\)](#)

Taking Care of Myself: A Hygiene, Puberty and Personal Curriculum for Young People with Autism by Mary Wrobel

Social Stories

<https://raisingchildren.net.au/autism/therapies-guide/social-stories>



### Resources Puberty and Sexuality

Sexuality of Children and Adolescents With Developmental Disabilities - a 2006 policy statement from the American Academy of Pediatrics (AAP).

<http://pediatrics.aappublications.org/content/117/1/171>

Sexuality Education for Children Students with Disabilities - A thorough overview of the topic, covering such issues as: the definition of *sexuality*, social skills, developmental stages, particular disabilities, sexual orientation, reproduction, birth control, STDs, and sexual exploitation.

<http://www.bornwithadifference.org/sexuality/>



### Resources Puberty and Sexuality

Puberty and Children on the Autism Spectrum is part of The Autism Society of America's (ASA) Living with Autism Series.

<http://www.autismspeaks.org>  
[http://www.autismspeaks.org/content/dam/autism/2014/02/07/07\\_LWA\\_Puberty.pdf](http://www.autismspeaks.org/content/dam/autism/2014/02/07/07_LWA_Puberty.pdf)

Relationships and Sexuality - "A handbook for and by Autistic People." Autobiographical accounts from individuals with autism spectrum disorders on a number of topics related to puberty, sexuality and romantic partnership. <http://autismnow.org/news>

<http://www.autismnow.org/news/content/uploads/2015/07/07-Relationships-and-Sexuality-Web.pdf>

Developmental Pediatrics Children's Colorado  
Birds and Bees Program on Puberty and Sexuality  
Call 720-777-6630



### Resources Puberty and Sexuality

Abuse of Children and Adults With Disabilities: A Risk Reduction and Intervention Guidebook for Parents and Other Advocates, by Nora Baladerian.

*Discusses the signs, symptoms and consequences of abuse, the abusers, how to report suspected abuse, intervention and provides examples of how to lower the risk of abuse.*

Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality (Topics in Down Syndrome) by Terri Couwenhoven.

*Easy-to-read guide that covers topics important for children of all ages, like emotions, personal space, self-care, appropriate levels of affection, and topics important for teens and young adults, like puberty, fertility, periods, bras, erections, and relating to the opposite sex.*



### Resources Puberty and Sexuality

An Easy Guide for Caring Parents: Sexuality and Socialization: A Book for Parents of People with Mental Handicaps, by Lynn McKee and Virginia Blackledge.

*Addresses the social needs of kids with mental disabilities. Discusses the role of parents in their children's sexuality education. Includes a thorough discussion of sexual development and discusses topics like growing up, responsible sexual behavior, masturbation, social life, sexual orientation, fertility and birth control, sexual abuse, and marriage.*

Sex Education for Parents of Children with Autism Spectrum Disorder, by Mark Steege and Shannon L. Peck.



### Transition to Adulthood

Exceptional Lives-Resources for Families caring for Children with Disabilities

<https://www.exceptionallives.org/transition-to-adulthood-for-youth-with-disabilities/>

Got Transition:  
[gottransition.org](http://gottransition.org)

Autism Speaks Transition Toolkit:  
[Transition Tool Kit | Autism Speaks](http://transitiontoolkit.autismspeaks.org)

Start Here: A Resource Guide.



<http://www.colorado.gov/cs/Satellite/CDHSVetDis/CBON/1251586995868>

### Transition to Adulthood

Transition & Adult Resources | Ability Connection Colorado  
<https://www.abilityconnectioncolorado.org/>

Family Voices of Colorado Transition Guide  
<http://familyvoicesco.org/transitions/>

Toolkit for Primary Care Providers on Managing Patients with Developmental Disabilities (Vanderbilt University):  
[IDD Healthcare E-Toolkit now available online \(vumc.org\)](http://iddhealthcare.org/Toolkit_now_available_online_vumc.org)

Guardianship Alliance of Colorado:

[www.guardianshipallianceofcolorado.org](http://www.guardianshipallianceofcolorado.org)



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### Transition to Adulthood

Tips for Transition to Adulthood  
<https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/helping-teens-on-the-autism-spectrum-transition-to-adulthood-tips-for-parents-&-caregivers.aspx>

American Academy of Pediatrics-Autism  
<https://www.aap.org/en/patient-care/autism/>



### General Resources

Colorado Community Centered Boards  
[Community Centered Boards | Colorado Department of Health Care Policy & Financing](http://www.cco.gov)

American Association on Intellectual and Developmental Disabilities  
<https://www.aaidd.org/>

American Academy for Cerebral Palsy and Developmental Medicine  
<https://www.aacpdm.org/>

Society for Developmental Behavioral Pediatrics  
<https://sdbp.org/>



### General Resources

Healthy Children.org  
[https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/default.aspx? ga=2.199034287.1686469262.1657975600-1540926268.1657302195&\\_gl=1\\*izq4dj\\*\\_ga\\*MTU0MDkyNjI2OC4xNjU3MzAyMTk1\\*\\_ga\\_FD9D3XZVQQ\\*MTY1Nzk3NTYwMC4yLjEuMTY1Nzk3NTYzMS4w](https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/default.aspx?ga=2.199034287.1686469262.1657975600-1540926268.1657302195&_gl=1*izq4dj*_ga*MTU0MDkyNjI2OC4xNjU3MzAyMTk1*_ga_FD9D3XZVQQ*MTY1Nzk3NTYwMC4yLjEuMTY1Nzk3NTYzMS4w)

