

Developmental Disabilities

- 1. Understanding Developmental Disabilities.** Developmental disabilities are a group of conditions with a variety of causes that include language, behavioral, physical and mental impairments. About 15 percent of children aged 3 through 17 years old have one or more disabilities that began during the developmental period of a child's life and will usually last through their lifetime. Developmental disabilities are divided into specific conditions, including: Autism spectrum disorders, cerebral palsy, epilepsy, Down syndrome and others. These types of disabilities may cause limitations in major life activities such as caring for oneself, learning or living independently. Kids with developmental disabilities experience delays in reaching milestones such as taking first steps, smiling and learning to speak, or show other signs. Children should be monitored by their parents and primary care providers for possible developmental disabilities. If you or your child's doctor has concerns about the child's growth, he or she should be screened for developmental disabilities at 9, 18 and 24 or 30 months old.
- 2. Essential Early Interventions.** While not all children meet each developmental milestone at the same pace, extreme delays in reaching these markers may be a sign of a developmental disability. Parents should learn the signs of childhood development so they can act early if they are concerned. Families on Medicaid can take advantage of the Early and Periodic Screening, Diagnosis, and Treatment program. Seeking services as soon as possible about possible developmental disabilities means your child will receive essential early interventions. Early interventions are intended for infants and toddlers who have a developmental delay or disability that is determined by evaluating the child. When the early intervention system receives a referral about a child with a suspected disability or delay, there are 45 days to complete critical steps. Learn how your state defines developmental delays so you can get the best possible treatment as soon as possible. Find your state's early intervention contact to get the process started and familiarize yourself with key terms and language.
- 3. Special Education and Related Services.** Students with developmental disabilities may be eligible for special education and related services that provide Individualized Education Programs (IEPs). The Center for Parent Information and Resources breaks the IEP process down into 10 basic steps. A teacher, parent or doctor noting that a child struggles in the classroom will kick off the referral process for an IEP, during which the student is evaluated with parental consent. The update to the Individuals with Disabilities Education Act (IDEA) made parents a member of their child's education team. Now, within 30 days of your child becoming eligible, you can partner with the school to develop an IEP that outlines goals and supports to help your child succeed. Assistive technology is often used in the classroom to benefit students of all ages with a developmental disability. For more information, Understood.org's extensive section on school and learning has details on your child's rights in the classroom, choosing or changing schools, tutoring and more. If you still have questions about special education read "Questions Often Asked by Parents about Special Education Services."
- 4. Children with Special Health Care Needs.** Children with disabilities face special health considerations, from the types of health problems that may arise due to their disabilities to determining how to pay for healthcare. Many children are eligible for the Children's Health Insurance Program (CHIP). Learn about programs in your state, call **1-877-KIDS-NOW (1-877-543-7669)** or submit an application through HealthCare.gov. Having a disability doesn't prevent a child from being healthy – it just means that staying well

and living an active life, in addition to regularly seeing a health care provider, is especially important. It can sometimes feel like a full-time job coordinating care for your child; consider building a care notebook for your child and developing a care plan. In addition to physical health, daily dental care is important for children with developmental disabilities. Find a dentist through the American Academy of Pediatric Dentistry. If you need financial assistance, contact your state dental society for information on care in your area.


5. **The Transition to Adulthood** for children with developmental disabilities is the time to consider options for post-secondary education, employment and independent living. Disability.gov's Guide to Student Transition Planning is a good starting point for students with disabilities and their parents or guardians to find information and resources. Learn about options for life after high school and plan for the transition to college or technical school. You may be wondering how to decide between college and an apprenticeship or training program. Find and compare information on colleges with programs for students with intellectual disabilities and download the Navigating College Handbook. Once you get to school, you'll need to know how to advocate for your rights on campus. Young adults who want to work can find information about job training programs, working and preparing for a career. Part of the transition to adulthood may include living independently and advocating for yourself. There are many resources available to help young adults with disabilities succeed in these areas of adult life, which include finding housing, managing healthcare and more.
6. **Self-Determination** refers to a person's freedom to make their own choices and decisions based on their personal preferences and interests. Self-determination can begin at a young age – parents who feel their child is ready to be involved in the IEP process, for example, can help set the foundation for further developing these skills. As the child ages, self-determination is a key part of growing up that involves mentoring and family support. Teaching these strategies to middle and high school students prepares them for the college experience and the transition to adulthood, when they will have more independence and will need to be self-advocates. As young adults begin to advocate for themselves, they will be able to make their own decisions, including choosing their home and community-based services. The Autistic Self Advocacy Network has published a helpful guide for self-advocates seeking these services that allow them to live how and where they choose.
7. **Housing and Transportation Options:** Learner's permit, driver's license, first apartment – before you know it, your child has grown up, moved out and started life as an adult. When considering housing options for your young adult with a disability, there are a couple of things to keep in mind: types of housing, services and supports, funding and rights. Review this guide to determining appropriate housing for your young adult with a disability, which outlines types of housing, questions to ask and how to involve your son or daughter in the process. A young adult living on his or her own and paying rent may need financial assistance. Also consider transportation options when choosing housing – will your child drive, take public transportation or use alternative options? Public transportation varies depending on where you live and is sometimes non-existent in rural areas. For young people with disabilities who do use public or "fixed-route" transportation, travel training is critical. Those who choose to purchase a vehicle may need to consider vehicle modifications so they can drive safely and effectively.
8. **Securing Your Child's Future:** A little foresight goes a long way in planning for your child's future. Although parents hope to support their children for a long time as they age, preparing ahead of time can ease worries. You may want to create a special needs trust and write a will to specify where your finances will go and who will care for your child. Learn about guardianship laws by state and determine whether you will appoint a guardian or an alternative caretaker for your child. Read this overview of financial options for parents of young children with disabilities. The PACER Center's Possibilities: A Financial Resource for Parents of Children with Disabilities offers additional financial and guardianship information while preparing for your child's future. The Arc's Family Handbook on Future Planning is an in-depth guide to help families develop future plans for their children with developmental disabilities.
9. **Organizations for Children and Their Families.** Along the way, there are many national, state and local organizations willing and available to answer questions and provide support. The federal Administration on Intellectual and Developmental Disabilities works to ensure that those with developmental disabilities and their families can fully participate in all aspects of community life. State governments each have their own agency that supports citizens with disabilities. You can also find your state's Council on Developmental Disabilities,



Protection and Advocacy System, University Center for Excellence or Parent Centers. The Arc is a long-standing national organization that supports individuals with developmental disabilities through local chapters. The American Association on Intellectual and Developmental Disabilities advocates for rights and quality of life for people with disabilities. Transitioning young adults can find support through the Association on University Centers on Disability. Founded and led by people with autism, the Autistic Self Advocacy Network provides resource and information for people with autism spectrum disorders. Other national organizations of note are United Cerebral Palsy and the Special Olympics. Although there is only room to list a few of these, there are many more which you can search for on Disability.gov.

- 10. Rights of Parents and Children with Disabilities.** There are several laws in place that protect the rights of people with disabilities. First and foremost is Americans with Disabilities Act, which celebrates its 25th anniversary in July. The Individuals with Disabilities Education Act (IDEA) ensures services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities. The Developmental Disabilities Assistance and Bill of Rights Act promotes the rights of people with developmental disabilities so they can live independently as productive community members with access to needed forms of assistance. Students with disabilities in public elementary and secondary schools have rights under Section 504 of the Rehabilitation Act of 1973. Youth preparing for post-secondary education have similar rights and responsibilities.

Disability.gov; June 2015; <https://www.disability.gov/disability-connection-newsletter-june-2015/>

 The contents of this publication were developed under a grant from the US Department of Education, H328M150022 (PATH), H328M150023 (PEN), & H328M150024 (TEAM). However, those contents do not necessarily represent the policy of the US Department of Education, and you should not assume endorsement by the Federal Government.



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