



# How to Locate Services Available to Individuals with Developmental Disabilities: Caregiver Perspective

Having a child with developmental disabilities often causes unique stressors for parents. Many parents explain feeling overwhelmed with their lack of knowledge of support services, as well as uncertainty of their child's future<sup>4</sup>. In a national survey of 1,738 parents or caregivers of children with DD, 30.3% were not familiar at all with resources available for children with DD and 28.6% were only slightly familiar with these services<sup>6</sup>. To begin addressing this deficit, the following information sheet provides an overview of resources available for individuals with developmental disabilities across the lifespan and how parents can access them.

*Note: Many of the following services are funded through local and state governments and available resources likely vary from state to state. For this reason, the following contains information about programs available in the majority of states and how those resources can be accessed.*

## Developmental Stages

### Early Intervention

Identifying developmental disabilities at a young age can be difficult, but it is less complicated if resources are accessed early. Early intervention programs specialize in early identification of developmental disabilities and help provide programming to address the needs of these children. By beginning interventions early in a child's life, it is more likely that they will transition comfortably through later developmental stages<sup>8</sup>. Through a wide variety of experiences and interactions, infants and toddlers participating in early intervention programs directly improve their hearing, vision, and language development<sup>3</sup>.

In the U.S., Part C of the Individuals with Disabilities Education Act (2004)<sup>7</sup> authorizes grants to each state

to develop and maintain early intervention programs for toddlers and infants up to 3 years old with disabilities. These programs are free or available at a low cost for eligible children with intellectual or developmental disabilities. A directory of each state's services can be found on the [CDC early intervention webpage](#).

### School-Age Children

Children with developmental disabilities often struggle with the demands of learning: reading, writing, life skills, and other abstract concepts in the classroom<sup>13</sup>. In assisting children with their education, individualized support is often needed to help them reach their academic potential. By involving teachers, aids, and utilizing support programs, children with developmental disabilities will learn at their own pace while participating in a typical school setting. To support school-age children with developmental disabilities in school, consider accessing the following school-based resources.

**Individualized Education Programs (IEP).** IEPs help provide services for children who have one or more of the 13 disabilities listed in IDEA (2004)<sup>7</sup>. These disabilities are: Autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment (including ADHD), specific learning disability, speech/language impairment, traumatic brain injury, or visual impairment (including blindness).

IEPs help both parents and school staff support a child's unique educational needs. By mapping out an educational plan, these children are able to access school resources to support educational attainment, as well as plan for the child's transition to adulthood,

post-education<sup>17</sup>. Within the IEP, academic goals are set and reviewed annually, services to help support achieving these goals are discussed (when they will begin, where they will be provided, how long they will last, etc.), and decisions about how much time a child will spend both away from and within a typical classroom are made. Before attending school, the student, parents, and school staff should meet to establish an IEP for the school year.

Contact your school's counselor or special education teacher to find out more information about starting an IEP.

**504 Plans.** While similar to IEPs, 504 plans focus primarily on prohibiting discrimination against individuals with disabilities and are covered under section 504 of the Rehabilitation Act<sup>16</sup>. Unlike IEPs, 504 plans cover a wide range of disabilities or struggles that children may be having at school—meaning that those who do not qualify for an IEP may still qualify for 504 plans. Instead of changing the instruction in the classroom, 504 plans work to change the environment in order to give extra support and accommodations to the individual<sup>14</sup>. There are no set guidelines for 504 plans, giving school staff and parents the freedom to create a plan that will most benefit the child<sup>14</sup>.

Contact your school's counselor or special education teacher to find out more and begin your child's 504 Plan.

To learn more about services that may be available for your child at school visit the [Understood webpage called School & Learning](#)

### *Post Highschool/Adulthood*

The post high school transition is a period of moving from the secure, protected life of a child to a more independent lifestyle of an adult<sup>5</sup>. While this change is difficult for all adolescents, those with developmental disabilities may be faced with additional barriers as they move from well-coordinated, entitlement-based services, provided through the K-12 education system, to a far less

coordinated, eligibility-based adult service system. Many of the free services provided by and coordinated through the K-12 education system (speech and language, occupational and physical therapy, special education, and pediatric services) do not automatically continue in the adult service system, which may involve waiting lists and additional costs for similar services, once they become a legal adult<sup>11</sup>. In order to ease this process, parents and children should start to explore the different options early and determine what is best for them as they transition into adulthood.

**Guardianship and supported decision-making.** When an individual turns 18 years old, all rights are typically transferred from the parent to the individual. It is during this time in an individual's life that questions including guardianship and supported decision making are raised. Guardianship is a legal procedure allowing a guardian to make decisions for another individual, while supported decision making allows those with disabilities to be proactive in making decisions while being supported by an informal group of advisors. In order to base these decisions on what is most beneficial to the person with a developmental disability, individuals should be informed about all options available before moving forward with any legal actions<sup>9</sup>.

For more information about what your state requires for guardianship or for other alternatives, go to the [National Disability Rights Network website](#) to find services close to you.

To obtain additional information on your state's options for supported decision making, visit the [National Resource Center for Supported Decision-Making website](#).

You can also learn more about guardianship and supported decision-making in the MHDD information sheet called [Guardianship and Supported Decision Making](#).

**Transition programs.** The Model Comprehensive Transition and Postsecondary Programs for Students

with Intellectual Disabilities (TPSID) awards grants to institutions of higher education for individuals with developmental disabilities<sup>15</sup>. With these grants, colleges and universities are able to create postsecondary/transition programs focusing on increased socialization, academic achievement, independent living skills, and integrated work experiences.

To browse and find out more about colleges that offer programs for individuals with developmental disabilities, go to the [Think College website](#) and take the time to see if this is the right option for your family.

## Additional Resources

While many resources apply to a specific developmental stage, there are other nationwide organizations that provide services throughout the lifespan (e.g., family support, employment, social interaction/friendship, residential programs, etc.). Consider the services offered by the local chapters of the following organizations.

**Parent Centers.** Parent centers are found in every state and provide information and resources specific to the needs of parents of children with disabilities. Getting involved with your parent center will help you get connected to local and state services that will be useful throughout your child's life. These centers receive federal funding through the Individuals with Disabilities Education Act (IDEA)<sup>10</sup>. Find your closest Parent Center on the [Center for Parent Information & Resources website](#). Once you find your center, check out their website and start getting involved with their programs and other services.

**Developmental Disabilities Council.** Every state has a federally funded Developmental Disabilities Council. These councils are meant to identify "the most pressing needs of people with developmental disabilities in their state or territory"<sup>12</sup>. These organizations are designed to help inform legislators about policy issues that affect people with developmental disabilities and encourage change that helps individuals gain more independence. They also teach people the skills to self-advocate and

support self-determination<sup>12</sup>.

**The Arc.** With over 700 local and state chapters, The Arc is the nation's leading advocate for people with developmental disabilities for nearly 60 years (Arc, n.d.). Striving to meet the needs of those with DD on an individual level, The Arc offers referral services, family support, residential support, employment programs, and individual advocacy initiatives<sup>1</sup>. For more information, contact a chapter near you. You can find your local chapter by going to The Arc's [find a chapter webpage](#).

**Best Buddies.** Dedicated to eliminating physical, social, and vocational isolation of individuals with developmental disabilities, Best Buddies is an international nonprofit organization striving to help individuals create friendships, receive employment, and gain opportunities for leadership responsibilities<sup>2</sup>. With chapters found in all 50 states and 53 countries, Best Buddies' goal is to empower individuals with developmental disabilities all over the world, helping them become independent and valued by society<sup>2</sup>. To contact your state chapter, go to the [Best Buddies United States Programs webpage](#).

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