



NAVIGATING THE SYSTEM

*A broadstroke overview of funding and services
for individuals with developmental disabilities
from birth forward*

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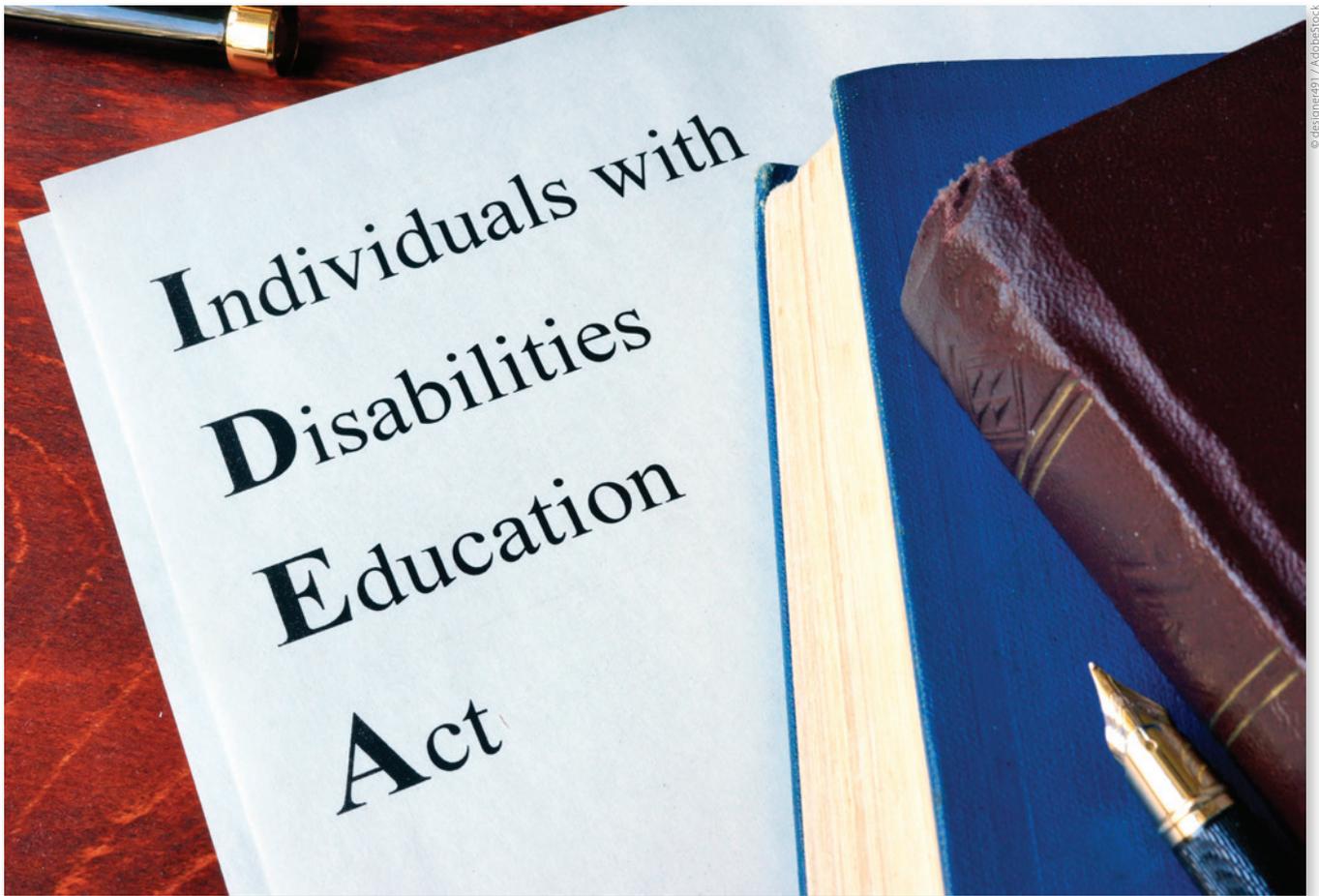
During the journey of raising a child with special needs, it's not unusual for parents to understand only a small segment of the services available to their child and family. It's also not unusual for the groups providing services to understand only a different segment of services. Very few truly know the full picture of supporting a child with disabilities throughout life or who to approach and from where the funding comes. The purpose of this article is to provide a broadstroke fundamental overview of this journey.

When children are diagnosed with a developmental or intellectual disability, they may be registered prior to the age of 18 with their state agency. This agency may be called something similar to the Developmental Disabilities Agency. Parents should register their child as soon as they have a diagnosis regardless of what advisers may say. It takes about six months and requires that you stay on top of the agency.

It's important to understand that this registration does several things. It allows the state to recognize that the individual will require SSI (Supplemental Security Income) and SSDI (Social Security Disability Insurance) for their disability starting at the age of 18. It will also place the child on a waiting list for future services. Here's where it gets grey, though: The agency may say that they do not provide any services to the child until they are 21 or 22 (state dependent for transition). However, if you read your state law, the age is not mentioned. Additionally, there may be waiver or other funds available which will be further explained in this overview.

EDUCATING YOURSELF

It's crucial that parents understand the education system. Each state's Board of Education is responsible for providing services to our children with disabilities in the least restrictive setting. IDEA (Individuals with Disabilities Education Act), first adopted in 1975 as the Education for All Handicapped Children Act and modified most recently in 2004, set forth that all children with disabilities should have a free and appropriate education. IDEA covers children from infancy through high school graduation or age 21, whichever comes first. The Act also gives parents a voice in their child's education.



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What is most important to understand is that it's the responsibility of the Board of Education to fundamentally prepare our children for independence and employment. Again, read the law. Further, IDEA requires the school system to prepare our children to lead productive and independent lives to the maximum extent possible.

Now let's apply this. My son with special needs was failing at home but succeeding at school. This was because he had a highly structured environment at school with 1:1 oversight most of his day. At home, he had two younger siblings, and we did not have the structure or constant oversight ability. So, together, not independently, we were failing our son in the endeavor to prepare him for independence and employment. My argument was that the Board of Education, therefore, was failing my son because

he could not successfully transition from the school to the home environment. This led to funding for a full special education school. We needed a better education program for him.

Your child will receive an IEP (Individualized Education Plan) during the school years. This plan will define the goals and modifications for your child's education. If you aren't good at advocating and researching yourself, then hire a qualified educational advocate. A comprehensive IEP is crucial. Understand, as a parent, it is your right to call for an IEP meeting anytime you want. If you feel the plan needs adjusting or isn't being implemented, call a meeting. Being bold is a necessary skill for raising a child with special needs. Being united as parents is also imperative.

KNOW WHAT'S OUTSIDE THE SYSTEM TOO

During the school years, it's important to know what other services or funding are available to help your child and your family. Look at local agencies such as the ARC for possible respite grants. Seek after-school social group opportunities at local churches or within the special needs public schools.

Determine if waivers are available within your state and dissect how these waiver dollars can be used. Often, autism waivers are available. There may also be additional waivers through the local Department of Social Services. These waivers may provide dollars for bringing qualified help into your home or allowing your child to attend appropriate summer camp programs.

These waivers may also make your child eligible for Medicaid. As a side note, know that this then covers all orthodontics until the age of 21 as well as all other medical and dental costs. Family counseling may also be a part of these services.

Be cautious not to allow these services to lapse. If you don't use them, you may be dropped out of the program and lose the related funding. Limited dollar requested funds for specific needs, such as camp, home modifications or technology products, may also be available. Specifically, these are one time requests made annually to the state developmental disabilities agency while a child is still under 21. Understand, if these funds are available, they run out fast and often are allocated on a first come, first serve basis. Learn the agency's fiscal year and make the timing of the request before the start of the new fiscal year.

PREPARING FOR ADULTHOOD

Okay, now onto transition. This is the time in which a child with special needs prepares for adulthood. IDEA requires transition planning to start by age 16 within the school. However, each state may modify this to start earlier. Virginia, for example, begins transition at age 14.

While in school, your child will be on one of two tracks—diploma bound or certificate bound. Diploma bound means your child has the ability to complete the minimal testing to graduate from school with a diploma. Certificate bound means your child will not receive a diploma. Typically, a certificate bound child has more severe challenges and requires more time in the school system to prepare for adulthood. A certificate bound child may

attend school through the age of 21 or 22. The exact age and date is state specific. Some states stop the education on the actual birthday. Some go to the end of the academic year after the birthday.

Do not allow your child to be pushed out of school. There is often a big black hole in services between the age of 18 and 21. Don't do your child's homework in pursuit of a diploma for him or her. Ultimately, you will do your child a huge disservice. If you believe your child can benefit from additional years of educational or vocational support, keep him or her in school. You may also seek additional assessments for employment at this time from DARS (Department of Aging and Rehabilitation Services) or other similar agencies (DORS) depending on your state.

When a child moves into transition, depending upon his or her academic level, you may see a shift towards emphasis on developing life and vocational skills. Prepare your child for this by providing these opportunities at home at an early age. Do not assume your child isn't capable. Repetition and role play are often what they need to learn. If you feel your child is simply repeating the same school work, force change. Know that there are different learning environments available. Visit other programs. Some of the special needs public schools focus more on vocational learning and run specific programs such as culinary, horticulture and mechanical shop. No one knows your child better than you. Therefore, speak up for what you think is best for him or her. Your voice carries weight, especially if you are loud.

Now, while your child is in school and living at home, know that if you experience incredibly complex behaviors at home or if your child has extreme behaviors at school, you may ultimately need to seek residential school placement. If you feel this is the case and you have the documentation to support this need, your state will either use Department of Social Services with child support co-pays or Department of Health and Mental Hygiene funding. If your child is still in a residential school at age 18, this is where your child becomes an adult and is no longer dependent upon you. No funding co-pay for child support is required after this age. This is where you may need to re-read the law about the responsibility of the developmental disabilities agency. Don't allow your state to tell you that you must pay for the residential stay.

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BEYOND HIGH SCHOOL

Now, let's transition your child to adulthood after school. First, your adult child (18 and older) cannot have any more than \$2000 in their name or their services will be nullified. Make sure that your child is not listed as the beneficiary of any wills or investments. Meet with an experienced attorney to discuss possibly establishing a special needs trust.

The recent adoption of the ABLE Act (Achieving a Better Life Experience) has provided families and individuals the ability to create ABLE tax-advantaged savings accounts for individuals with disabilities. These savings only cover qualified expenses. Read the act. When your child comes out of school, if they received a diploma, they will start collecting SSI/SSDI and may also qualify for transportation vouchers, food stamps and some minimal level of day supports such as job coaching.

If your child is more challenged and exits school after age 21, he will have been collecting SSI/SSDI because you will have made that appointment with your local office before his 18th birthday. This is where you begin to charge your child rent and living expenses if he is still at home. Your adult child will receive day supports that can look like supported employment in community, or day services within a specific day facility. This usually provides for activities or employment approximately four to six hours during the full weekday.

The next thing most parents assume is that their child will get placement in a group home or funding for residential services. This is a very wrong assumption. Let's review how residential services work. There are typically three classification levels for residential services—future need, crisis prevention, and crisis resolution. Check with

your state. When your child was registered with the state as having a disability at an early age, he was placed on a state list. These wait lists can be massively long. Each state only has so much residential funding with limited placements. The only way a place opens up is when another resident passes away, moves back home or moves out of the state.

An adult with special needs is likely to live at home for a very long time unless there is a medical or extreme behavioral reason that he or she cannot live at home or if the parents are very old or very ill. If your child is in a residen-

tial program when aging out of school, he should roll over into an adult residential placement. This is simply because if your child needed residential placement as a student, then that need does not go away simply because of a program change.

FUNDING SOURCES

Where does the money come from for our kids' services? Each year, the federal government allocates money to each state. The state then matches those dollars to create the funds that are allocated to support special needs individuals for services and programs.

The federal government adopts the CMS (Center for

Medicaid & Medicare Services) language. Read this too! It is crucial to understanding adult services. Also know that services DO NOT cross state lines. You start over if you move. If your child is a fully-funded adult, assume he or she will never move. If you yourself move, ideally you will be connected by a single flight or a direct train. This will allow your child to live an independent life while accessing easily managed transportation to visit you! I fundamentally believe all parents want their children to live full and independent lives. ◀



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Parent Stages

1

Diagnosis

During this time, we may initially be scared and overwhelmed. We might also believe there is something we can do to “fix” the situation. In addition, we are relieved to have a diagnosis that defines a clear path for us.

2

Seeking

As parents, we start reading everything and talking to everybody seeking answers. This continues during all the school age years.

3

Adolescent

This can be a difficult time because of changes happening to our kids. It can almost create the same anxiety for us as the initial diagnosis.

4

Advocacy

A sense of urgency overwhelms us as we look to the future for our children. This is where we really hone our advocacy skills.

5

Full Acceptance

Lastly, we have settled into a solid understanding of our children’s rest of life. As a post-adolescent adult, all of our children’s abilities are fully understood by us as parents.