



The Journey to Life After High School

A Road Map for Parents of Children with Special Needs



A Report and Guide from AbilityPath.org
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Ponderosa High School Principal Lisa Garret presents Corrie McNamara with her high school graduation certificate. Photo courtesy of The Mountain Democrat

Foreword

By Anthony Shriver

As a parent with two children in college, I know how challenging the transition to life after high school can be. There are so many options, so many questions: Will my child go to college? Community college? Will he or she choose to begin a career or work right out of high school? Or volunteer for a year or two? These are just some of the questions we faced as a family when my children arrived at this life stage. It is exciting, frightening and can be overwhelming.

When your teenager or young adult has special needs, you experience the same emotions most parents go through when transitioning. However, those emotions are likely heightened and the challenges can be greater. Most families of children with special needs have an established routine, a set system that works for their child and the rest of the family. As the end of high school nears, this system will no longer work beyond graduation. The family is faced with all the same questions posed above but with additional concerns to think about. What government aid is available, if any? Will my child be able to work? Is my child ready for college? Are there programs that can help my child in college? Can my child live on his or her own? How do I prepare financially for my child's needs after high school? This process can feel overwhelming, but you are not alone.



Throughout my life, I have worked to ease this process and transition for children with special needs. As the Chairman and Founder of [Best Buddies International](#), I strive to make sure that people with special needs receive all the same opportunities and experiences as their peers. Whether it is through peer-to-peer friendships or job placements, I have dedicated my life to equalizing the circumstances for people with special needs. Through this work, I know it can be difficult to also prepare the family members for this life-altering transitional period.

Fortunately, there are several avenues of help for families going through this process. This step-by-step guide is a wonderful resource to help you through this process. Within this “Journey to Life after High School” guide, you will find a starting point; this guide will help you begin the process of planning for your child's transition. It will not have all the answers – no one document ever could – but it does give you a framework to begin: how to get organized, where to seek aid, and what options might be available to you. In this guide you will find real life stories from families who are probably no different than yours, and you will find encouragement from their solutions.

It is important that we help our children to live lives as full and rewarding as possible, while we continue to support and help facilitate their choices. This is the time to allow them to own their lives to the best of their abilities. As a parent, this is frightening – I've been through it. But after all is said and done, it is among the most rewarding aspects of being a parent – watching your child learn to fly.

In Friendship,
Anthony K. Shriver

A Journey to College: Kim & Alexis

Alexis Wineman, a 19 year old with an autism spectrum disorder (ASD), is excited about her future. In the fall of 2013, she started college at the university attended by her neurotypical twin sister. Having spent the past year serving as Miss Montana 2012 – the first Miss America contestant with autism – she has already discovered that she can do things and go places far outside her comfort zone. Even so, she began the year with her share of precollege jitters. How would she fare socially? How would she manage her time?

“I won’t have Mom and Dad to breathe down my neck and remind me of things,” she says as she gets ready to leave for school. “I have the most anxiety about the schoolwork itself and keeping up with it, because along with my autism is a lot of short-term memory problems.”

Kim Butterworth, Alexis’s mother, admits to being “a nervous wreck” as her daughter gets ready for her new life. For a long time she worried that Alexis, who has PDD-NOS,¹ wouldn’t graduate from high school. Now she has a host of new worries.

“I can see her being in a dorm room and not coming out of it for a couple days – she just doesn’t realize how much time has passed,” Kim says. While Alexis learned to advocate for herself during her year as Miss Montana, she will have far more self-advocacy to do as a college student.

“I’ve been her advocate,” Kim says. “I’ve been the one who tap danced on desks to get her what she needed. And now she’s going to have to do that herself.”

Still, Alexis and Kim agreed that they both underestimated Alexis’ abilities in the past, letting themselves be guided by her worst moments rather than her best.

“Sometimes the parents see it from such a different perspective,” Kim says. “They see the meltdowns, the struggles. But that’s not how those kids necessarily deal with the outside world. That’s how they act in a safe environment, not how they act when they walk out that door.”

Alexis agrees. Forging her way to adulthood hasn’t been easy, and there are sure to be plenty more pitfalls along the way. But she’s up for the challenge. “It can be scary, it can be frustrating, but life is like that. You can surprise yourself,” she says. For children with special needs, she says, “The path isn’t there. Your job is to make it.”



Alexis Wineman on her first day of college with her twin sister Amanda Wineman. Photo courtesy of the Wineman family.

¹ As defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM), PDD-NOS is the abbreviation of the diagnosis of pervasive developmental disorder – not otherwise specified, which is considered an autism spectrum disorder (ASD). With the 2013 release of DSM-5, the criteria set forth describing ASD were updated to be more consistent, creating one disorder – ASD – rather than the four branches that were present in DSM-IV. For more information, see the American Psychiatric Association’s [statement](#).

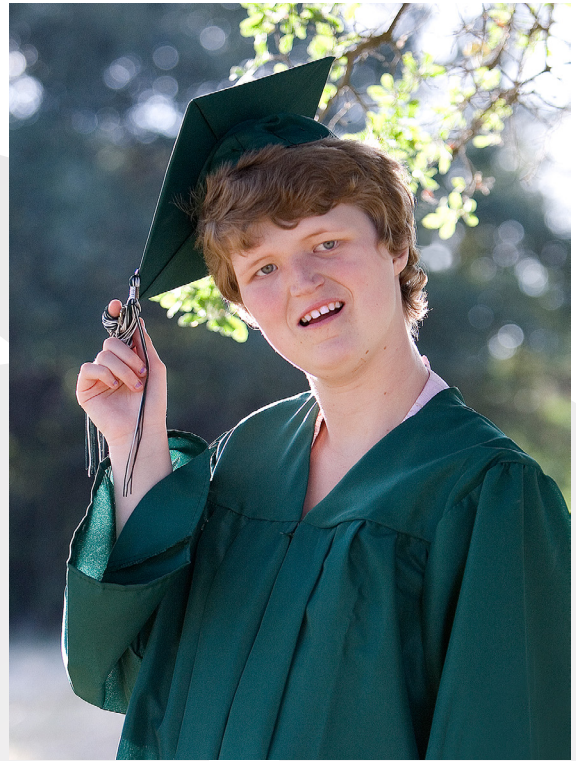
Introduction

Not every teenager with special needs will go on to a four-year college, of course. Some will choose community college; some will get vocational training; some will work; some will go into day programs; and some will stay home. Regardless of the path they take, teenagers with special needs will become adults, both physically and legally. For parents, that means preparing for profound changes in nearly every aspect of their children's lives – and for a sea changes in their own role as well.

Whatever the particulars of your situation, preparing for your child's transition to adulthood can feel daunting, even overwhelming. Many of the systems that have been in place to support both child and family are poised to disappear. Building a new support structure requires sorting through a maze of options while also learning about a variety of new laws, systems, benefits, and requirements. At the same time, young people with special needs are grappling with the physical and emotional changes brought about by adolescence just like their typically developing counterparts. Their feelings about the future may be complex or even contradictory. Parents too may feel pushed and pulled – not sure how or even whether to help their child move into the world.

“If you start thinking about all that's required, it's so huge and overwhelming,” says one mother of a son with ASD. “It's a monumental undertaking that people with typical children don't even grasp the enormosity of. It's critical to have some sort of road map.”

This aims to be that road map. Whether you have a [middle schooler](#) (11–14), a [high schooler](#) (14–18), or even a [young adult](#) (18–26), this is a tool for you to use as you begin planning your child's transition into adulthood. While it can't cover every detail or every situation, it will give you an overview of what lies ahead and a list of resources for where to go next.



*Corrie McNamara at Ponderosa High School graduation.
Photo by Shelly Thorene*

The report has four goals:

- To **inform** families about the components of the transition to adulthood
- To **encourage** families about the components of the transition to adulthood
- To **explain** the choices and changes that make up the transition process
- To **connect** families with the many resources available for helping them transition

Goal-Minded Planning: Lucie & Terri

At 25 Lucie is pretty clear about what she wants to do with her life. “I want to be a special ed teacher,” she says. “That’s my goal, to have my own preschool. But I don’t know if that will work.”

Lucie, who has an unspecified neurological disorder with a mild developmental delay, may or may not reach her goal of having her own school. But her parents have always encouraged her to think about what she wants to do and how to get there. “I followed Lucie’s lead,” her mother, Terri, says. “I would always ask her from the age of ten on up, ‘What are your dreams? What do you want to do?’ And I observed what her strong points were and took it from there.”

Because Lucie always loved being around younger children, Terri advocated to have her daughter’s child care ambitions included in her transition plan. She made sure that Lucie could do her WorkAbility training in a preschool rather than in her high school’s landscaping program. “Lucie’s not a fan of landscaping,” she says. “She hates doing physical work.”

After Lucie finished high school with a certificate of completion at age 18, she took community college classes that were designed for people with developmental delays. While she did well in those classes, she had a harder time with the community college classes she took to get certified as a child care assistant and eventually had to drop out of the program. “She couldn’t deal with the academics,” Terri explains.

While that was frustrating, Lucie hasn’t given up. She now works 3 days a week, for 1 1/2 hours a day, at a preschool for children with special needs. The position began as a volunteer job but she is now getting paid. Lucie probably will never be self-supporting – she is prone to anxiety and emotionally fragile, particularly if her environment isn’t controlled. “She’s not going to be giving up that SSI check anytime soon,” Terri says.

“I would always ask her from the age of ten on up, ‘What are your dreams? What do you want to do?’ And I observed what her strong points were and took it from there.”

All the same, Lucie is moving incrementally toward adulthood. She has a boyfriend and hopes to one day live on her own.

“I want to live in an apartment,” she says. “But it takes time to have my own apartment.” Sometimes, Lucie admits, she gets anxious about the future. “I worry about the disability and the money – I have to pay my bills and all that stuff,” she explains. So what does she do when she gets worried? “I tell myself that it will be okay,” she says. “I go to my room and listen to music.”

Getting Started

Preparation for the Journey

Looking ahead, it might seem overwhelming to already begin thinking about your child's transition from high school to adulthood. After all, he or she just started middle school. It is important to remember, though, that the years will go by quickly. Once your child starts high school, you will need to work with the school system to schedule meetings to plan your child's education program and future. Those years are not that far ahead. That is why it is best to get ahead and take advantage of these middle school years to learn as much as possible.

In an ideal world, every family would begin the discussions about self-advocacy and person-centered planning while their children are still in middle school or earlier, but the important thing is to start planning sometime; even if you do not begin planning until your child is in high school. This doesn't mean that you plan for your child, but that you plan with your child, helping them think about the best options for their future. Transition planning isn't a one-shot deal; it's a process that will continue long after your child is officially an adult. The most important thing is not to get discouraged. This may seem like a daunting process, but it is more than doable, and this guide will help!

SELF-ADVOCACY

Up until this point in your child's life, you have made all the decisions for them. You were the one advocating on their behalf, making sure your child's best interests were always met. Now that he or she has reached middle school, though, your student may be capable of also advocating on his or her behalf. It is important to teach your child how to advocate for themselves so that after the transition they can voice their concerns and so that you can see what their abilities truly are.

Throughout the transition process keep your child involved as much as possible with the decision-making. A great place to start is sitting them down to have a conversation about what they want for their future. While asking them questions about where they see themselves in five or ten years, teach them to continue to voice these desires.



STAYING ORGANIZED

There's no way around it, the transition process generates stacks of paperwork. You'll save yourself a good measure of time and frustration if you have a system for organizing both your electronic and your paper files. Some people find it works best to put information in binders. Others prefer to use hanging folders, perhaps in a portable file box so you can easily carry the files to meetings. Some people prefer to print out every electronic document so they have a paper record. Others prefer to scan every paper document so they have an electronic record. It doesn't matter what system you use, as long as you have a consistent method for keeping track of the documents. A good organizational system will allow you to use your time checking things off your list, rather than searching for documents or trying to recall what you've already done.

Remember to keep your computer files as well organized as your paper ones. To avoid having to search your hard drive every time you need to find something, create some electronic folders in advance, and make it a habit to put your electronic documents in them as you go.

You can create email folders as well. These will help you keep track of correspondence with various agencies and programs. Whatever email program you use, make it a habit to save copies of both the emails you've sent and the ones you've received into the appropriate folder so that you have records of what you've been told. Create folders for your bookmarks or favorites too, so that you can easily find the websites on which you've found useful information.

Finally, make sure to have a system for backing up your data on a regular basis. A hard drive failure can cause months of hard work to vanish. One strategy is to manually back up your data onto two external thumb drives, keeping one in the house and another in your purse or car. You can also back up onto cloud-based systems like Google Drive so that you can access documents from anywhere, even if you're not on your home computer. And there are many low-cost services that will back up your computer automatically every night so you don't have to remember to do so.

What is self-advocacy?

According to Dr. Valerie Paradiz from the School for Autistic Strength, Purpose and Independence in Education, self-advocacy is a lifelong endeavor.¹ Self-advocacy comes down to six key components:²

1. Understanding your disability and being able to explain your disability either through words, pictures, or gestures
2. Knowing your rights that are protected by law
3. Speaking up for yourself and your interests
4. Asking for what you need in order to live day-to-day
5. Negotiating on your own behalf so that your needs and wants are met
6. Utilizing the resources that are available to you

“Parents are the one constant in a disabled child’s life. Parents can set an example and promote positive attitudes for their disabled child regarding school and the need for an education. They can advocate for the continuity of services for their child between school and adult services. In many ways, the parent has the most to gain or lose when it comes to the progress their disabled child is able to make concerning academic, social and vocational skills.”

—James F. Austin,

[“The Role of Parents as Advocates for the Transition Rights of Their Disabled Youth”](#)

There is clear overlap in these areas, but that is because they are all needed in order for an individual to advocate for him or herself. It may seem difficult to teach your child to advocate for themselves, especially in the same way that you currently advocate for them. Remember, though, that you do not need to teach him or her everything at once. Self-advocacy can begin with small tasks, like allowing your child to decide what time they want to wake up in the morning or what they want to eat for breakfast. Starting with these small steps allows you to build upon the foundation and building blocks that you will continuously put into place. Eventually you will have a child that is confident in themselves, their wants and needs in life. And if your child can’t get that far, you have learned to what extent your child can self-advocate and what level of freedom he or she can have in life.



PERSON-CENTERED PLANNING

Part of the self-advocacy process is person-centered planning. It helps people with special needs shape their lives. For these young adults, it allows them to think about what is important to them, like their hopes for the future. While also learning about and discussing their lives, they get the opportunity to learn from the people closest to them about how to best approach their goals and reach them. The process allows you and your child to have focused discussions about both the details of everyday life and the large-scale dreams and values that make life meaningful and satisfying.

Ideally, person-centered planning is a facilitated process involving the people your child trusts and feels closest to. This means not just you and your spouse but also close friends, relatives, aides, teachers, or other professionals with a strong interest in your child's well-being.

"The process helps them paint the picture of who they are, with the majority of the data coming from them, not their family or their case managers," explains Eli Poblitz, transition specialist at the [San Mateo Union High School District](#) in California. "Once the student starts realizing who they are then I can start painting the picture of how the world connects to them."

Person-centered planning is a chance for your child to discuss things like:

- Where he or she hopes to live
- How he or she wants to spend their days
- Who he or she wants to spend their time with
- If he or she wants to go to college
- What type of job they see themselves having
- What his or her hobbies and passions are

Each of these questions will lead to more questions as you and your child discuss what he or she wants the future to be like, what steps are necessary to get there, and what support he or she will need in order to take those steps. The process will include a discussion of what your child does well and what they need help with. These factors will help you develop a plan for achieving your child's goals.

At these early stages of person-centered planning, it is important to remind yourself that your child may still be thinking as an adolescent and not in the long-term as adults do. If you ask them where they want to live in five years, they may say home. If you ask them what their passions are, they may say video games and the newest hot show on television. Such answers should not discourage you. It is likely that many of their typically developing peers would share similar answers.

It would be helpful to make these at least yearly discussions. When having these talks, provide your child with a work sheet to map out these answers. If he or she has difficulty writing, they can dictate the answers to you and you can write them down. If he or she would prefer drawing their plan, let them. The goal is to get them thinking about where they see their life going. While you are doing this, remind your child that they are not going to be held to these decisions and that they can change their mind at any time about what is most important to them and what they want for their future. By having your student create a physical copy of these thoughts and ideas, it provides a starting point for the following year and can show how he or she has grown and changed over time.

KNOW YOUR CHILD'S RIGHTS

In order to make sure you get the most out of the assistance granted to your child, you need to know the federal laws that protect your child and give them certain rights. The school system may not always be helpful in explaining to you what your child's rights are so you should take it upon yourself to learn them. It will also be important to teach your child these in order to help them fully understand the self-advocacy process.

Over the years, the US federal government has enacted several laws that grant rights to individuals with special needs that include a free and appropriate education and a lack of discrimination in the workplace. Four of these laws critical for families planning the transition to adulthood are described below:

1. [Section 504 of the Rehabilitation Act of 1973](#)
2. [The Americans with Disabilities Act of 1990](#)
3. [The Individuals with Disabilities Education Improvement Act of 2004](#)
4. [The Carl D. Perkins Vocational and Technical Education Act of 2006](#)

Section 504 of the Rehabilitation Act of 1973

- The Rehabilitation Act of 1973 was signed into law by President Richard Nixon.
- This act protects individuals from discrimination based on their disability.
- This was the first law of its kind to protect the rights of people with special needs.
- It applies to any program, organization, or employer that receives financial assistance from ANY federal department or agency.
- It also extends to any local education agency, vocational education system, or school system.
- Section 504 of the Rehabilitation Act establishes Free Appropriate Public Education (FAPE):
 - ◊ This provision requires school districts to provide FAPE to any “qualified person with a disability who is in the school district’s jurisdiction, regardless of the nature or severity of the person’s disability.” ³
- Who is entitled to FAPE?
 - ◊ All school-age children with special needs as defined by Section 504 and the [Individuals with Disabilities Education Act](#) (IDEA)
- What is an “appropriate education”?
 - ◊ Education services must be designed to meet the education needs of a student with a disability as adequately as they are designed to meet the education needs of a non special needs student.
 - ◊ The evaluation of proper placement procedures to protect against the misclassification and incorrect placement of students
 - ◊ Continuous and periodic reevaluation of students who receive special education and related services to ensure the placement meets their needs
- Ability of parents and guardians to review their child’s records, receive required notices, and challenge the identification, evaluation, and placement decisions in regard to their child.⁴
- FAPE also states that students with special needs must be placed in the same education settings as students without special needs as frequently as possible and as frequently as appropriate to the individual education needs of the special needs student.
- Students with special needs must receive specialized education services and support free of charge, just as a non special needs student would.

- Below is a chart from the [National Center for Learning Disabilities](#)⁵ that provides Free Appropriate Public Education (FAPE) Myths compared to FAPE Facts:

FAPE <i>Myths</i>	FAPE <i>Facts</i>
<p><i>Children with disabilities cannot be charged for</i></p> <ul style="list-style-type: none"> • Materials • Student fees • Any other costs that are requested of general education students. 	<p><i>Special education and related services are provided</i></p> <ul style="list-style-type: none"> • At public expense • Under public supervision and direction. • Without charge to the parent or guardian.
<p><i>Children with disabilities are not required to</i></p> <ul style="list-style-type: none"> • Complete basic requirements for graduation. • Pass state-approved assessments that demonstrate State standards. 	<p><i>Children with disabilities are provided</i></p> <ul style="list-style-type: none"> • Modifications • Accommodations • Support services under their Individual Education Programs (IEPs). <p><i>(These allow them to have access to and benefit from instruction so they can meet the standards of the State Education Authority.)</i></p>
<p><i>The district must provide</i></p> <ul style="list-style-type: none"> • A specific specialized program or school setting that is chosen by the parent • A program that provides the child greater access to educational materials than their non-disabled peers. <p><i>*FAPE also does not require that a school provide educational services that are superior to those provided to non-disabled peers.</i></p>	<p><i>The district must provide a program that</i></p> <ul style="list-style-type: none"> • Complies with the procedural requirements of IDEA • Addresses the child's unique needs as identified by evaluations, observation, and the child's educational team and, • Is coordinated to ensure the child is able to make adequate progress in the educational setting. <p><i>*FAPE requires that the quality of educational services provided to students with disabilities be equal to those provided to non-disabled students.</i></p>
<p><i>The student with a disability</i></p> <ul style="list-style-type: none"> • Must be provided preferential treatment or guaranteed placement in extracurricular activities; • Does not have to meet the basic requirements of participation that are required of non-disabled peers. 	<p><i>The district must provide a program that</i></p> <ul style="list-style-type: none"> • Must have access to nonacademic and extracurricular activities equal to those provided to non-disabled peers.

The Americans with Disabilities Act of 1990

- The Americans with Disabilities Act (ADA) was signed into law in 1990 by President George H. W. Bush.
- The act prohibits discrimination against persons with special needs and ensures that they receive equal opportunities in: employment (Title I), state and local government services (Title II), public accommodations (Title III), commercial facilities, and transportation.⁶ In 2008 major amendments were made to the law, and President George W. Bush signed into law the ADA Amendments Act of 2008.

The ADA Amendments Act of 2008 (ADAAA) expanded the definition of “disability” that applies to both the ADA and Section 504 of the Rehabilitation Act of 1973:

- It defines “disability” as:
 - ◊ “An impairment that substantially limits one or more major life activities, a record of such an impairment, or being regarded as having such an impairment.”⁷

- The ADAAA broadened the definition of “major life activities” to include “major bodily functions:”
 - ◊ Major life activities include but are not limited to “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.” ⁸
 - ◊ Major bodily functions include but are not limited to “functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.” ⁹
- While the ADAAA rejects the US Supreme Court’s definition of “substantially limits,” it does not provide a new definition.
- The ADAAA also provides rights for individuals with special needs who are not eligible for accommodations in school under IDEA:
 - ◊ These accommodations are the same as those set forth in Section 504 of the Rehabilitation Act of 1973.

The Individuals with Disabilities Education Improvement Act of 2004

- The Individuals with Disabilities Education Act (IDEA) was signed into law in 1990 by President George H. W. Bush.
- In 2004, the law was amended and reauthorized as the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) by President George W. Bush.
- A child with a disability is defined by the IDEA as:
 - ◊ General: “with intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this chapter as “emotional disturbance”), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services.” ¹⁰
- It requires public schools to create an Individualized Education Plan (IEP) for each student each year until the student is 22 years old, regardless of whether the student is enrolled in postsecondary education.
 - ◊ The IEP will be covered in greater detail on page [15](#) of this guide. In brief, it: ¹¹
 - Is a written statement of the uniquely designed education program to meet a child’s specific needs
 - States the services the school will provide for your child and the reasonable annual learning goals for your child



Includes your child's current academic performance and levels

- Says how your child's success and growth toward annual goals will be measured
- Explains how your child will participate in assessments – both statewide and district-wide – and the accommodations he or she will receive.

◇ Members of your child's IEP team include:

- The parents of the child
- Not less than one regular education teacher of the child (if the child is, or may be, participating in the regular education environment)
- Not less than one special education teacher of the child, or where appropriate, not less than one special education provider of the child
- A representative of the public agency (who has certain specific knowledge and qualifications)
- An individual who can interpret the instructional implications of evaluation results and who may also be one of the other listed members
- At the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the child, including related services personnel as appropriate
- Whenever appropriate, the child with a disability. ¹²

◇ The law requires that the IEP team begin no later than age 14 to address the student's need for instruction that will assist him or her in preparing for transition. Beginning at age 16 (or younger, if determined appropriate by the IEP team), the IEP must contain a statement of needed transition services for the student, including, if appropriate, a statement of interagency responsibilities. ¹³

◇ These rights are protected if your child transfers to a new school in the same state OR if your child transfers to a new school in a different state.

- For these regulations and rights, see numbers 8 through 10 on the US Department of Education's [website](#).

◇ It **must** be reviewed *at least* annually to see if your child is meeting the goals set forth and readjust if necessary.

- This is just a brief overview of what your child is entitled to. For a more in-depth look at what this law grants your child, visit the US Department of Education's [website](#). It provides a step-by-step list of the special education process and the ten topics that an IEP **must** include.

The Carl D. Perkins Vocational and Technical Education Act

- The Carl D. Perkins Vocational and Technical Education Act was signed into law in 2006 by President George W. Bush.
- This law states that individuals with special needs must be provided equal access to a vocational education.
- The funds made available through this law can be used to pay for the vocational education services laid forth in an IEP that was developed in accordance with IDEA.

A Transition in Progress: Lynne & David

When Lynne thinks about her 22-year-old son David's future, she pictures him living in an urban setting near public transit. She imagines him going to work each day doing something he loves and having friends and perhaps a girlfriend. "Being able to go out and do whatever young twenty-something adult males do, that's what I want him to do," she says.

Lynne started thinking about David's future when he was in high school, but the path to this ideal future is still murky. David is on the autism spectrum, but he doesn't self-identify as having ASD and gets angry when his parents try to talk with him about his diagnosis. While Lynne would like to see him eventually move into a supported living environment where he could have a richer social life, David doesn't want to leave home. He wouldn't mind if his parents moved out, but he's quite happy in the house where he grew up.

David had [WorkAbility](#) training and travel training and also took classes at community college. He loves animals and currently works as a volunteer at the local zoo one day a week, which is how often his parents can manage to drive him there. He also volunteers online, helping the Humane Society track down the sale of illegal animal products. But there aren't many paying jobs working with animals, particularly for someone with David's skills. While he wants variation in his workday, he can't handle complex tasks.

Lynne wishes David could be out in the world more. Now that he's done with school, he's at home on his computer all day. "I remember hearing someone say that about their kid and I thought, 'I'm not going to let that happen,'" she says. "And here I am – it's happened!" Finding the right path for David is still a challenge so his transition to adulthood is still a work in progress.



The High School Years

In the Beginning

Now that your child is in high school, you will need to start meeting annually with the school to create your child's Individualized Education Plan (IEP). You may have already begun the IEP process earlier in your child's life; however, a high school IEP is a little different. Children are encouraged to participate in their own IEP at the high school stage. If possible, you should include your child in this process. The high school level IEP should happen once your child turns 14. If they are capable of attending, they should be part of the discussion and planning of their education and goals for the year. Once he or she turns 16, the IEP needs to include transition steps to help them prepare for life after high school. This means talking about whether they will be going on to receive a postsecondary education or if they will be finding a job or enrolling in a day program. Through these decisions, the school is required to help you explore colleges, locate jobs, and find day programs for your child. As you explore these options, it is important to know most colleges and universities require students to have at least a standard diploma in order to attend. If your child wants to go to college, it is important to find out what [types of diplomas](#) are available at their school.

With so many different areas needing to be covered in the IEP, the background research conducted during your child's middle school years is important. It will help alleviate the stress that is sure to come with the first high school IEP. By going into this first meeting knowing what your child's rights are and what the school needs to help you with, you will be able to get more information from the school and create a constructive and beneficial IEP.

SIX SIMPLE THINGS YOU CAN DO

Transition is such a huge and overwhelming topic that it can be hard to know where to start, especially when your life is already so full. Here are six things you can do right now to begin the process:

- 1. Take stock of how much you already know.** Look back on the early years, before your child's diagnosis or immediately afterward. There was so much you didn't know about your child's disability and so much you didn't know about your child's capabilities. You've learned a lot since then and that knowledge is going to serve you well now, as you and your child move into the next stage together. Nobody is better equipped to help your child transition than you are. To help ease the stress of what you think you don't know, make a list of what you already know. Once you see how much you've learned, you will know that you can tackle these new tasks. "Find some peace and contentment in the fact that you've done a good job so far," Dr. Robert Naseef, author of *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability*, advises.
- 2. Face your fears. Anxiety can be paralyzing.** But it can also be informative. Naming your fears will help you understand both your bottom line and your priorities. If your biggest fears revolve around your child's medical condition, you know that transitioning their medical providers and medical benefits are first-order priorities – the rest can wait. If your biggest fears revolve around your child being bored and isolated after high school, then your first priority may be to focus on employment, education, or day programs.

3. **Establish your priorities.** You can't do everything at once. Use a list and a timeline to help you choose a small number of first-order tasks, questions, or issues. "Start with something small," advises Mary Anne Ehlert, CFP, whose company, [Protected Tomorrows](#), helps families navigate transition and future planning. "Choose one thing. Write it down and set a deadline. If you think of all the things you've got to do, you'll never do it. Just take it one step at a time."
4. **Start talking.** Having casual conversations about transition with your child and other members of the family will help normalize the topic and get everyone thinking about options. You might say to your child, "I've been thinking about what life is going to be like when you're an adult. What do you think it will be like?" "Anything out of the ordinary, we always talk about," says Mary Pilster, the mother of a young man with autism, "because with autism, it's important to give them a heads-up of what's coming."
5. **Find a mentor.** There's no reason to reinvent the wheel. Reach out to a family in your disability community who has gone through transition and talk to them about their experience. One good place to find mentors is through [Parent to Parent](#). "Always find someone who has been through it or is going through it now to mentor you through," says Teresa Jurado, who was a parent resource coordinator at Gatepath for many years. "There's nothing like sitting face-to-face with someone who can say, 'I did this and this is what happened.'"
6. **Work with other families.** You don't have to go it alone. Parents who work together can divide up tasks, share information, and advocate as a group. They can also give each other breaks as needed and – most importantly – devise new solutions. Dr. Naseef has seen families work together to create innovative answers for their children when the existing options weren't working. One group of families pooled their money to buy a franchise so that their children with developmental delays would have a place to work; a typically developing sibling with an interest in business is managing it. Others are setting up group living arrangements for their children or creating carpools and social groups. "There's power in community," Dr. Naseef says.



A SUCCESSFUL INDIVIDUALIZED EDUCATION PROGRAM (IEP)

While we covered the content of an IEP [above](#), for many the process of creating the first IEP for a student begins as early as middle school. Some of you may have begun this process at an earlier age. However, here we lay out the steps that a family should plan on taking as they embark on the IEP process in preparation for life after high school.

“A student-centered approach means finding out the student’s interests, their hobbies, and their skills and how they spend their time,” explains transition specialist Eli Poblitz. “It’s asking the student what they want to do. Sometimes they have no idea and we have to give them an idea how the world connects to them.”

First, know that you are not the only parent unsure of what to expect and ask during your child’s first IEP. Since preparing for an IEP seems daunting, many organizations have already stepped up to create guides to assist you with the process. Rather than creating yet another list of what to do and what not to do, we searched through the other lists and are providing you with their best advice, and letting you know where you can find even more information about the IEP. After all, it is impossible to be over-prepared for these meetings.

Before the Meeting ¹⁴

- **Plan ahead:** Write down the questions and thoughts you have about the IEP. This will help you remember what came across your mind during your research. It is natural for questions and concerns to slip your mind, especially since you are likely to be provided with so much information. By writing down what is important to you and your child, you are making sure these topics will be addressed during the conversation.
- **Get to know your child’s teachers:** There are several people included in the IEP. A couple of these people will be your child’s teachers. Make sure you get to know them before the meeting. You can talk to them about what you and your child want for his or her future, and the teacher can weigh in on what she thinks is best for your child. It will also make you more comfortable in the meeting if you know someone there. The teacher will also be more likely to advocate for your concerns and what you and your child want if you have established a personal relationship with them. The teacher will know what you want as a parent and understand more how your mind works. This relationship can also be built with your child’s school principal or school psychologist.
- **Review the materials:** If this isn’t your first IEP, review last year’s IEP so you can remember what was discussed and what the goals were. This will allow you to see how your child has progressed toward these goals and what needs to be adjusted. As a parent, you also should be sent a document of your rights and responsibilities annually. If you have not received this, make sure to reach out for it. When you do receive it, read it over so that you understand what you are entitled to as a parent, as well as your responsibilities.

During the Meeting

- **You are an important part of the team:** As the parent, you are allowed to be part of the IEP by law. You also know your child better than anyone else at the meeting. While you may not have the professional experience that your child’s teachers and school officials have, you have the personal experience. Do not feel like this makes your voice and opinion any less important.

- **Bring a support system:** Your child's other parent can also attend the meetings. It is important that you are both part of the decision-making process. You can also provide a support system for each other, making you feel more comfortable at the meeting. You both know what you want for your child and can ease each other's worries. Make sure you both know what you want to accomplish at the meeting so that you can work together as a team for what is in your child's best interest.
- **Bring your child:** More than anything, this meeting is about your child. While he or she has told you what they want from their education and what they want for their future, it is important to allow them to voice these desires. The law states that your child needs to be included, if possible, during these talks. By bringing him or her to the meetings, they will not only be able to advocate for themselves, but they will also learn what the goals are for their education that year. Give your child the chance to speak for him or herself so that their confidence can grow and so that the other members of the team can see that this is also what they want.
- **Ask questions:** You aren't expected to know everything going into this meeting. There are sure to be terms or facts stated that you haven't heard before. When this happens, don't be afraid to ask the others to clarify and explain what they mean. You may be afraid that asking such questions will make the professionals think you don't fully understand your child's disability. This is not the case. It will show them that you are invested in doing what is best for your child and want to understand as much as possible when it comes to bettering your child's life.
- **The key to success is compromise:** While you know what your child wants and what works best for him or her, the school officials and professionals also know what works best overall in the school environment. They will cite facts and statistics to prove their points while you cite experiences from your child's life to prove your points. What is best for your child is to try all angles. These professionals work with your child on a daily basis in the classroom. They see the larger picture of what the best options are. In order to make sure the goals you want reached in the year are met, you may need to let the professionals try their own tactics.
- **Look at the big picture:** You and your child are there to voice what you want to happen in the next year and what your child wants to do after high school. It is the job of the professionals to make a work plan to achieve these goals. Focus on the framework and the outcome, and let the professionals develop the strategies for how to arrive there.
- **Sign the show attendance:** You may not want to sign off saying you agree to the IEP yet, but it is important to sign off saying you attended the meeting. This will put it on record that you were there and part of the discussion.

After the Meeting

- **Review the IEP:** Ask for a copy of the IEP that has been developed. Take it home and read over what was decided. Your signature is needed in order for the plan to be set in motion. If you are uncertain of specific areas or want to review what is decided before signing off, let them know. It is good to review the material so that you can make sure you didn't miss anything and that you are okay with all the decisions. If you have any concerns about what is written in the plan, write a letter describing these concerns. Return these concerns and the unsigned IEP to the school so that an open discussion can be continued. You are allowed to ask for another meeting to discuss these concerns.

- **Discuss the meeting with your child:** Even if your child did attend, you want to sit down with him or her and explain what was decided. If there were terms or ideas you did not understand, then there are sure to be parts that they did not understand. Since the IEP is all about them, they need to know what the goals are and what they will be doing during the next academic year.
- **Mark your calendar:** During the meeting, you should have set markers for reports on your child. Make sure you have a calendar and can write down when you should be receiving these reports on your child's progress. This allows you to make sure the school is keeping you in the loop and letting you know about her or his progress.
- **Put in safekeeping:** Whether you keep a filing cabinet with all of your child's documents or an electronic copy of everything, file away the IEP some place [safe](#). This will be helpful when you are looking to review it before next year's IEP and in case you ever want to review it during the year.

Ten Common Mistakes

When preparing and going through the IEP, there is so much to remember. While it is likely that you will forget to ask a specific question in mind, you can always contact the professionals afterward for clarification. In the meeting, however, there are topics and areas you want to make sure are addressed. Below is a list compiled by the [Texas School for the Blind and Visually Impaired](#) of ten common mistakes that you want to avoid:

1. Believing the professionals are the only experts
2. Not making requests in writing
3. Being unfamiliar with the prior notice section of the procedural safeguards
4. Requesting a related service rather than an assessment
5. Accepting assessment results that do not recommend services you think your child needs
6. Allowing assessment information to be presented for the first time at the IEP
7. Accepting goals and objectives that cannot be measured
8. Allowing placement decisions to be made before IEP goals and objectives are written
9. Allowing your child's IEP meeting to be rushed
10. Not asking questions

To learn more about these mistakes in depth, read the School's [article](#). It is important to note that if your school does not have a program that works for your child, most schools will work with you develop a customized program. Be sure to ask about this option.

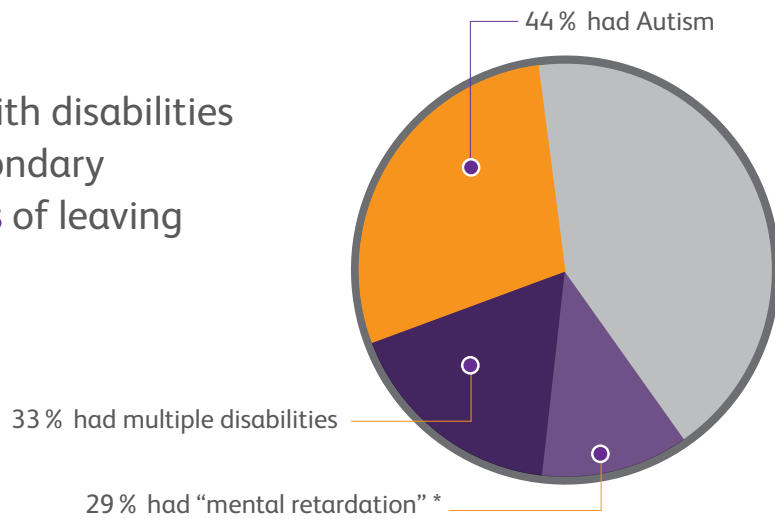
Nearing Graduation

When your child enters her or his junior and senior years of high school, it is officially time to start thinking about post-graduation. Like their peers, including those who are typically developing, the prospect of college comes into the picture. For the most part, colleges and universities require students to have at least a standard diploma in order to attend. If your child wants to go to college, it is important to find out what [types of diplomas](#) are available at their school.

In 2011 the [National Center for Special Education Research](#) issued a report, "[The Post-High School Outcomes of Young Adults With Disabilities up to 8 Years After High School](#)," which looked at a nationally representative sample of secondary school students with special needs who were receiving special education services in grade 7 or above.

Researchers followed these students for as long as eight years after graduation to see how they fared as young adults. While society still has a long way to go when it comes to providing support for people with special needs, the results of the study were encouraging.

60% of young adults with disabilities continued on to postsecondary education within **8 years** of leaving high school.



91% of young adults with disabilities reported having been employed at some time since leaving high school, including:

- **63%** of young adults with autism
- **63%** of those with multiple disabilities
- **76%** of those with "mental retardation" *

Within **8 Years** of leaving high school...

59%

of young adults with disabilities had lived independently (on their own or with a spouse, partner, or roommate).

77%

of young adults with disabilities reported seeing friends outside of organized activities at least weekly.

* This word choice is from the National Center for Special Education Research. In order to keep the statistics and findings as accurate as possible, the study's word choice was kept; however, it is not endorsed by AbilityPath.org.

Diploma Options

During an IEP, you need to discuss with the school what type of diploma option is best suited for your child. According to the [National Center on Secondary Education and Transition](#), there are six different options:

Diploma Option	Description
Honors diploma/diploma of high distinction	A student must achieve at a high academic level; often this diploma requires a certain grade-point average (GPA)
Standard diploma	A student must complete a certain number of credits and obtain a minimum GPA to receive a diploma
Certificate of completion/attendance	This option is for students who have not received the grades necessary to obtain a standard or honors diploma. It demonstrates that a student completed a set number of classes or that a student qualifies for a diploma because of sufficient attendance in a set period of time
Certificate of achievement	This demonstrates that a student has achieved a certain level of performance. This type of diploma certifies that the student was present and performed to the best of her ability but did not attain the necessary grades and/or credits to obtain a standard or honors diploma
IEP/special education diploma	This is an option for students receiving special education services and those who have an IEP. Requirements are usually set by the student's IEP team and are therefore unique to each student.
Occupational diploma	For students who are enrolled in vocational programs, this type of diploma certifies that a student has demonstrated a specific level of competence in an occupational area.

Not all states offer these options, though. Rather than offering multiple diploma options, some states offer the standard diploma with modifications to allow students with special needs the option of receiving it. In order to know if your state or school district offers modified standard diplomas, ask the school officials at your child's school or during one of the IEP meetings.

Looking for a College

If your child wants to continue her or his education after high school, there are several choices to make. Postsecondary education can be broken into three broad categories: four-year college or university, community college or associate's degree program, and vocational or technical school. Your child can become a full-time or part-time student. They can take classes with the aim of achieving a degree or simply for the purpose of learning what subjects interest them.

According to the [US Department of Education's Office of Civil Rights](#), postsecondary educational institutions are not required to provide free appropriate public education the way elementary and high schools are. Instead, they are required to provide appropriate academic adjustments to ensure that they don't discriminate on the basis of disability. These adjustments might include extended time for assignments and tests, providing note takers or readers, assistive technology, preferential seating, or use of a calculator. Schools must also provide convenient and accessible housing to special needs students if they provide housing to non special needs students.

Most universities and colleges have a disability services office that is responsible for complying with the ADA and Section 504. When visiting prospective colleges, it will be important to make an appointment to visit this office. As a college student, your child will have to advocate for him or herself in order to get the support and accommodations they need. Visiting the disability services office with a list of questions will be an important first step.

"People have been very accepting," says Mary Pilster, whose son Bobby has ASD and is now a student at San Francisco State University. She and Bobby met with the disability counselor when he started at community college and again when he transferred to a four-year university. In both cases, they showed the counselor Bobby's IEP and talked about what accommodations he might need, including more time for tests. "Don't sign off saying that you don't need your IEP during junior or senior year of high school," she advises. "It's hard to get it back if you need it for college."

Here is a list of questions incoming students might want to ask when they visit a college disability services office: [15](#)

1. What is the procedure for students to identify themselves and their disability if they want to receive accommodations? What documentation is required?
2. Are students required to be a full-time? If not, will this affect financial aid and the ability to live in the residence halls?
3. What experience does the college have in serving individuals with your child's disability?
4. How many students use the disability office's services?



TRAVELING WITH YOUR CHILD

In order to visit some of these colleges, you will need to travel around the country. Perhaps you have traveled before with your child and already know the best techniques for your family. Maybe you do all of your traveling by car so considering airplane travel is not necessary. If you are, however, looking into flying to certain locations to visit colleges with your child, know that there are ways to make the process easier. The Transportation Security Administration (TSA) has established ways to ensure that the process of security is as easy as possible.

All airports have security lines designated for people with disabilities and small children. If your child has trouble waiting in line, let the person checking you in to your flight at the airline desk know that you will need to go in this lane. She can direct you to where this line is and who you might need to let know that you are going in this lane. You can also tell one of the TSA agents that you need to go in this lane, and he can direct you to it as well. You can also ask the person at the airline desk if you can pre-board a plane with your child if she needs extra time getting settled.

With the advanced technology being used by the TSA at security checkpoints, it is rare that your child would need to be touched. If your child has a problem being touched, though, let the TSA agents know, and they can make sure she goes through the advanced imaging technology and the metal detector screening. If a pat down is needed, you can direct them on how best to conduct this search.

If you think you will require more assistance, you can call the airport ahead of time and let them know you will need a passenger support specialist when you arrive. By calling the TSA Cares hotline (855-787-2227) 72 hours before travel, they can ensure a specialist will be waiting for you and your child. You can also prepare this [TSA notification card](#) to provide the TSA agents with, letting them know about your child's disabilities.

5. What specific accommodations and services can be made for various types of special needs?
Is there a separate cost for any of these services? Are provisions available for:
 - Extended-time exams
 - Exemption from any exams/subject areas
 - Tutoring
 - Counseling
 - Readers and note takers
 - Interpreters for exams, class lectures, and texts
6. If a professor is not in compliance regarding the student's needed accommodations, how is the situation resolved?
7. Is there adaptive equipment (i.e., voice-synthesized computers and calculators, reading devices, tape recorders, hearing amplification systems) available for student use?
8. Does the school work closely with other support agencies, like vocational rehabilitation agencies?
9. Is the entire campus accessible?
10. Are there any student disability support groups on campus?
11. Are there any types of financial aid/scholarships specifically available for special needs students?
If yes, how do you apply for them?
12. What do they consider the most difficult majors/classes for special needs students, and what support is there on campus for them?

Searching online for colleges that properly accommodate your child's needs can be difficult. There are literally thousands of colleges available in the United States so it may seem impossible to find the ones that are the best fit for your child. A good place to start the search is with the College Board website. Visit their [college search](#) page and enter the types of special services you are looking for. The list will only show the colleges that offer these services. Other sources, like the [Huffington Post](#) and [U.S. News](#), provide their lists and advice. To help ease with the search, we've included a list in our [resource section](#) with the proper contact information.

It is important for your child to physically visit every school in which she or he is interested. While a college may look perfect on paper, it can appear less ideal in person. By visiting each school your child considers attending, they will get a better idea of what type of accommodations they truly need and which colleges meet these needs. While visiting these schools, try to set up an appointment to meet with the disability services office to talk about your concerns. At the end of the meeting, ask for a business card so that you can follow up with any future questions. It will also be good for your child to send a thank-you letter to the person who talked with you.

An Unexpected Path: Teresa & Tim

“We weren’t paying good attention until the last minute,” admits Teresa Jurado, whose son Tim has severe learning disabilities, chronic kidney disease, and cerebral palsy. Tim wasn’t expected to live past age 12, and for many years there seemed no reason to think long term. Instead, the family simply steeled themselves for the inevitable loss.

But by high school, Tim was still going strong, and his life had settled into a comfortable pattern. He had good medical care and supports services and enjoyed the special day class he attended at his local high school. Used to living day-to-day, the family kept on as they always had, enjoying time with their son that they never expected to have. “At 18, none of our transitions really happened,” Teresa explains.

Yet life changed anyway, whether or not Tim and his family were ready. When high school ended, Tim needed something to do during the day. That meant finding a day program for him, and Teresa quickly discovered that Tim was in an uncomfortable middle zone – he needed too much support for programs that were based in the community, yet he would be under stimulated by many of the center-based ones. Teresa hit on an unusual solution: signing him up to attend an Adult Day Health Center that serves senior citizens. The youngest participant by about sixty years, Tim sees himself as part of the staff and loves having a “job” – something he always wanted. The local regional center foots the bill. “He’s being beautifully taken care of and he’s learning new skills,” Teresa says. “Parents have to think creatively.”

But finding meaningful work for Tim wasn’t the only transition task ahead. Teresa learned that when he turned 21, Tim would lose the occupational and physical therapy services he’d been receiving through California Children’s Services. Nor could he still receive care from his beloved pediatrician and pediatric specialists; Tim was going to need doctors treating adults. That meant finding a whole new medical team. Teresa would also need to establish a conservatorship so that she and her husband could continue to make Tim’s medical decisions. The benefit landscape changed as well – some benefits were disappearing, some would have to be reapplied for and others were newly available.

There are long-term decisions to make as well. “He’s getting bigger, and I’m getting older, and that’s not a good match,” Teresa says. She and her husband have to think about getting help with Tim’s personal care in the short term, and about who will take care of him in the long term. Luckily he has an aunt, uncle, and cousins who are eager to fill that role. “Tim wasn’t supposed to live past 12,” Teresa says as she reflects on the transition process. “We prepared for that piece: ‘Oh my God, what are we going to do without him?’ Now we realize he has his own plan. So we’re just starting out.”





After Graduation

Whether your child goes on to a postsecondary education or not, he or she will need to transition into the “real world.” Depending on the level of their abilities, this may mean finding employment, enrolling them in a day program, or locating full-time housing. All three of these present their own challenges; ideally, you have already discussed these three prospects with your child’s IEP team during their high school years. Hopefully through these discussions, you became better prepared and understand your state or local landscape when it comes to searching for a day program or full-time housing. Before looking into these two options, though, understanding the employment landscape is necessary.

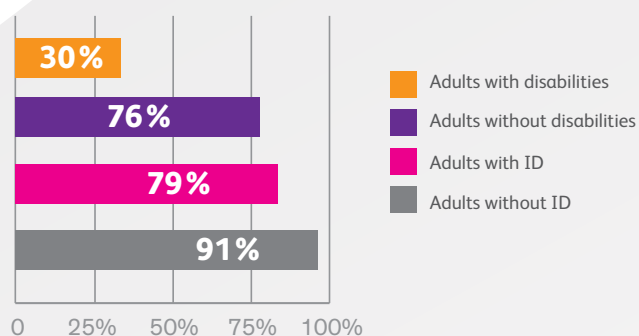
A STUDY OF EMPLOYMENT

In February 2014 the [Special Olympics](#) commissioned the University of Massachusetts Boston to conduct a [study](#) on adults with intellectual disabilities in the workforce. The research sheds some helpful light onto the possible work scenarios for your child.

“Our research shows that unemployment among people with intellectual disabilities is more than twice as high as for the general population. It’s critically important to know what the employment options are for someone with intellectual disabilities. Once this knowledge is gained, it is easier to align an individual’s desires and needs with what is available. It will also help with the transition period, allowing a high school and family to begin preparation or this post-graduation decision.”

— Tim Shriver, Chairman of the Board, Special Olympics International

Employment for Working-Age Adults with Disabilities versus Intellectual Disabilities (ID)



Competitively Employed



- Only a third of those competitively employed were offered health insurance from their place of employment.
- About a third of those competitively employed received support or employment services from a state or local agency.

Intellectual Disabilities (ID)

- Despite the financial investment being made and the investment in transition programming for youth with intellectual disabilities (ID), it appears that little has changed with regard to the employment rate of these individuals over the past decade.
- It has been noted that generally there are fewer individuals with ID working in sheltered settings today, although unfortunately there has not been a corresponding increase in the percentage working competitively.
- Another concern for those in the field is that most adults with ID who are employed in sheltered settings are unlikely to ever transition into a more inclusive competitive employment.

Special Olympics Study by University of Massachusetts Boston

SEEKING EMPLOYMENT

When looking for employment with your child, you need to think about what kind of job your child would be successful at as well as the level of support he/she will need to secure and maintain a job. There are five basic levels of employment support for individuals with developmental disabilities.

- **Competitive Employment:** a full-time or part-time job paid at market wages with no long-term support. The employer hires the individual based on their skillset and needs of the business.
- **Supported Employment:** a job in which the employee receives ongoing support that is funded through state developmental disabilities or vocational rehabilitation agencies. This job can be in an individual or group setting, depending on the support level needed. This type of position also meets the employer's business needs and can still include "job carving," where a job is created to meet the unique skillset of the individual.
- **Self-Employment:** a job someone does on his own that provides an income.
- **Production Employment:** a job in which employees with disabilities work at a site with other employees with disabilities and do defined tasks like collating, assembling, or packaging. This job setting provides a high level of supervision and job training.
- **Volunteer Employment:** a job that someone does without pay, usually to benefit the community. Volunteer jobs can lead to paid employment by providing work experience, or they can be an end to themselves, providing the volunteer with community and purpose.

Deciding what type of employment is best for your child can be included in his or her IEP. The professionals can help you and your child figure out where the best place to start is. It is also important to note that where they start is not where they will be the rest of their life. If your child wants competitive employment but you or the IEP team believes he or she is best suited for supported employment, it does not mean they can never move over to competitive employment. Let your child know that this is just the starting point and that they can always change their course later.

Mary Pilster says that when Bobby first went out into the work world things didn't go very well. "He got interviews, but his lack of eye contact and sitting kind of squirrely in his seat didn't allow them to see his potential," she says.

Eventually Bobby joined [Gatepath's Autism Works](#) program, where he got help with his resume and was able to practice interview skills through workshops and role-playing. A staff member went with him to his first job interview with a Safeway supermarket, and another staff member accompanied him to his training after he landed a job as a courtesy clerk. At Safeway, Bobby bagged groceries, retrieved shopping carts, helped customers find things, and cleaned up around the store. For the first six weeks of employment, he had a job coach available to help him when he ran into rough spots.

Eventually, he was transferred to another store, where the management wasn't as used to working with people with disabilities. Bobby felt he was being yelled at all the time and his self-esteem plummeted. But Bobby was able to find seasonal employment working as a loader for Lowe's, a big home improvement store. This time, Mary says, "he didn't need a job coach – he was very confident." The job became permanent after a few months, and Bobby has now had it for over a year.

“The advice I give parents is that if something doesn’t work out the way you planned, that’s OK,” says Laura Dana, Community Services Manager at Community Gatepath. “There are programs for wherever your kid is at.” Paths can change or be recharted over time – no decision is permanent. The key is for your child to develop the skills and experience they need in order to reach their goals.

Here are five ways to prepare your child for a successful experience in the work world:

1. Talk with your child about the kinds of jobs he would like to have and what kinds of skills he will need to do that work. Help him think realistically and strategically about employment goals so that he can find work that he enjoys and is qualified to do. Transition specialist Eli Poblitz cites the example of a teenager who loves playing with younger relatives or caring for neighbors’ pets. “A lot of times they don’t think [of] that as a job, but when you ask them about that experience they kind of glow,” he says. “Then you realize that person is a helping person, they really like to help. And then you can tell them there are lots of helping jobs that don’t need college.”
2. Include both travel and WorkAbility training in your transition plan, and advocate for longer hours of coaching and practice. “One hour a day twice a week wasn’t enough time to prepare for even part-time work,” one mother observes.
3. Encourage your child to do volunteer work, internships, or summer jobs so that she or he develops work experience and skills and can discover what they like.
4. Take advantage of the services offered by your local Vocational Rehabilitation agency and any screenings and assessments offered by local nonprofits. These assessments will help identify both what your young adult wants to do and what supports their needs. These can be used to anticipate problems before they happen.
5. Once your child has landed a job, you may also want to consider hiring a private job coach who can act as a liaison between your young adult and his or her employer to help design supports to help with their specific deficits.

“The reality of the workforce is that everyone will be expected to meet and perform at competitive levels, whether your child has a special need or not. This can be difficult to face if you are not prepared for it.”

—Tracey Fecher, VP of Programs at Community Gatepath

The Vocation Rehabilitation (VR) Agency

Under the US Department of Education, each state has a [Vocation Rehabilitation Agency](#) with regional and local offices that help people with disabilities find work. While each office is different, VR services may include:

- Vocational guidance and counseling
- Job development and placement
- Skills training
- Job coaching
- Help with transportation
- Adaptive devices, tools, equipment, and supplies

- Apprenticeship programs
- Interpreter services for people who are deaf or hard of hearing
- Orientation and mobility services
- Transition services for young adults
- Support, advocacy, and follow-up services once work has started

To be eligible for VR services, your child must be an “individual with a disability,” defined as having a physical or mental impairment that is a barrier to employment and can benefit from VR services, meaning that they are not too special needs to be able to work. If your child receives [Supplemental Security Income \(SSI\)](#) and/or [Social Security Disability Insurance \(SSDI\)](#) benefits, they are presumed to be eligible for VR services.

Because VR offices are government agencies, you should expect that your child will need to deploy his or her budding self-advocacy skills in order to get the most out of the services offered. That means being prepared, proactive, and persistent.

Best Buddies

Another great option to help your child find a job is Best Buddies. Unlike other organizations, your child can become involved in Best Buddies starting in middle school. The goal of this organization is to pair an individual with disabilities with a peer who does not have disabilities. As your child moves on to high school and college, he or she can continue to grow with Best Buddies. Overall, [Best Buddies](#) offers eight programs to help your child at each stage of their development: middle schools, high schools, colleges, promoters, citizens, ambassadors, jobs, and e-Buddies. By becoming involved in Best Buddies, your child can gain social skills from and develop friendships with peers who do not have disabilities.



*Lauren Potter, Glee Actress and Maria Shriver, Journalist, Author & Activist.
Photo by Stephen Simons*

Your child does not need to join Best Buddies in middle school to become involved in the organization’s jobs program, which assists individuals with disabilities in locating competitive employment. Best Buddies partners with various businesses and employers, and they all work together to find jobs for individuals. Not only does Best Buddies help with locating a job but they also assist with the hiring process, and once a job is secured, they maintain support for both the employee and the employer.

DAY PROGRAMS

Not every young adult is suited for postsecondary school or employment. Some will be better suited to a day program. These programs vary in their emphasis, with some taking participants out into the community and others offering most of their services in a center. Laura Dana, Community Services Manager at Community Gatepath, suggests that parents tour different programs to get a sense of the options. “Parents should see whether the program offers some sort of a trial period, so that the individual looking for services can try out the program,” she advises.

There are three broad categories of programs:

1. Community Integration(CI) programs

In these programs, participants spend the majority of each day in the community. They may be involved in volunteer work, participate in recreation opportunities, or engage in other activities. They are best for people who like variety and activity and enjoy being in the community.

Participants might take art or cooking classes, visit senior centers, or help out in an elementary school. Dana notes that one advantage of these programs is that by bringing people with intellectual disabilities into the world, they help create a more tolerant and welcoming society.

“People with special needs are just like you and me, and want to be a part of the community. Community inclusion is a key component of our work and we strive to create this for everyone.”

—Sheryl Young, CEO Community Gatepath

2. Center-Based programs

In these programs, participants spend the majority of their time at a center or home base. The range of activities usually includes arts and crafts, exercise, and volunteer work along with a couple of community trips each month. These programs are good for people who do not like much change in their routine and feel less comfortable out in the community. Parents should see if there’s a clear continuum of growth in the program, with demonstrated goals and outcomes.

3. Adult Day Health Care (ADHC)

Services in these programs are provided at a home base and often include health monitoring, socialization, recreation, dietary consultation, and rehabilitative training. ADHC programs have a diverse group of adults, as many of the programs enroll persons who are elderly and/or people who need close supervision to remain safe.

When exploring the different day programs for your child, you will want to compare what each of them offers. While visiting them, bring a notepad with you and take notes about what you like and don’t like. You can also keep to standard questions you would like to ask at each of them so that you can find out the same information from each.

The [Special School District of St. Louis County](#) in Missouri provides five important areas for you to examine when visiting day programs: ¹⁶

1. **Funding:** How is the program paid for? Are there costs to the individual?
2. **Transportation:** Does the program provide transportation to and from home?
3. **Experience:** How long has the program been around? Do they have any big changes planned?
How long have their most senior staff members been in the field?
4. **Staff-to-Client Ratio:** How many clients/participants does each staffer supervise?
5. **Community Experiences:** Do they take their clients into the community and if so, how often and for how long each time?

In addition to these five areas, we have added on five more that are important:

6. **Types of Activities:** What kinds of things do clients do each day? What are the program goals for the participants? Is activity varied and challenging?
7. **Hours of Operation:** What time does the program start and end each day? How many days a year is the program closed?
8. **Age and Ability:** What is the age range of the participants? What is the ability range of participants?
9. **Eligibility:** What are the entrance/eligibility requirements? What is the application process? Is there a waiting list?
10. **Length of Stay:** What is the average length of stay for the participants? Do participants often move to other types of programs after a period of time? What indicators does the program have of client outcomes and satisfaction?

FULL-TIME HOUSING

Even if it works well for your child to continue living at home now, it may not work as she or he matures and as you grow older. Since supported living arrangements often have long waiting lists, it's important to think about housing options well before you need them.

There are many different kinds of housing options, with varying levels of support. They include:

- Independent living in a house or apartment, alone or with a roommate
- Transitional residential programs offering short-term residential experience for people who need support, intervention or instruction while learning to live independently
- Supported living programs
- Supervised living programs
- Group homes
- Intermediate care facilities

New models are being developed all the time, including cohousing arrangements and farmstead programs.

As you think about your child's future living arrangements, it's important to remember that every option has pros and cons. A study of the feelings that mothers of adult children with special needs had about having their child live at home or in a residential facility found that mothers whose children lived away from home felt pleased that their children were developing new skills and friends, but they also worried more about their child's future than the mothers whose children stayed at home. On the other hand, as Dr. Robert Naseef explains in his book *Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability*, families with a son or daughter at home tended to have more peace of mind about their child's safety, but they did not feel that their child was necessarily benefiting from opportunities for growth and development.

Some questions to ask yourself as you consider your options:

- What kind of living arrangements does my child prefer?
- What kind of housing arrangements would work best for my child's physical care and emotional well-being?
- What kinds of support would my child need to live away from home?

- What kind of living arrangement would work best for my child's other goals, needs, and desires, including education, employment, recreational activities and socializing?
- What kind of housing will make it possible for my child to have adequate access to transportation? Are there bus lines? Services within walking distance? Adequate parking for a van?
- What kind of housing arrangements can we afford?
- What kind of housing arrangements will work best as my partner and I age?

Six Steps for Exploring Housing Options

1. Discuss the topic with your child and other members of his or her circle of support. Make sure housing is part of the person-centered planning process.
2. Include the development of independent living skills in your child's transition plan. These might include:
 - Safety skills
 - Phone skills
 - Housecleaning
 - Laundry
 - Budgeting
 - Nutrition and cooking
 - Grocery shopping
 - Travel training
3. Discuss housing options and benefits with your regional center and with others in your disability community. Be sure to [read](#) about your child's federal and state housing benefits.
4. Create a checklist of things you and your child want to find out before you visit apartments, group homes, or care facilities.
5. Create a housing budget that includes not just the monthly cost of the housing itself, but also any associated costs like:
 - Furnishings
 - Transportation
 - Supportive services
 - Utilities
 - Groceries
 - Incidental Expenses
6. List the sources available for paying for housing. These might include:
 - Social Security income
 - Disability benefits
 - Your income
 - Your child's income
 - Money from a trust or legal settlement
 - State and county benefits

Additional assistance might come in the form of In-Home Supportive Services, which can be used to provide personal assistance and other services.

Securing Benefits

Of all the things that parents worry about as their child approaches transition, the future of their child's financial and medical benefits may be the most nerve racking. While you can think about housing and employment when you're ready, medical care and financial benefits are tied to the calendar, and they will disappear or convert whether or not you're ready for them to do so.

To prepare for this transition, start by getting organized:

- Make a list of all of the benefits your child receives, whether they are in the form of monetary payments or support services.
- Make a list of all the medical providers your child sees and the therapies your child receives.
- Make a list of your child's current medications.
- Organize your paperwork in one place, including medical records and school records, your child's birth certificate and social security card, contact information for the medical providers, therapists and services you use, and any other documents documenting your child's disability.

HEALTH AND MEDICAL CARE

Begin preparing for the transition to adult care in early adolescence, if possible. Now is the time to start asking questions about your child's future care and receiving recommendations of doctors, therapists, and specialists that can provide it. It's also important for your child to begin assuming responsibility for his or her medical conditions, perhaps going into the doctor's office without you there.

Here are four areas to think about as you search for new medical providers:

1. Location
 - Is the office easy to get to?
 - Can your child get there on his or her own?
 - Is it wheelchair accessible?
2. Relationship
 - Does this doctor explain things clearly?
 - Does this doctor have a good rapport with your child?
3. Convenience
 - Are office hours convenient?
 - Can you reach the doctor or staff during off-hours?
4. Reputation
 - Does this provider come recommended?
 - Does this provider have expertise or experience with my child's disability?
 - At what hospital does this provider have admitting privileges?



Social Security Benefits

Social Security benefits are the most important benefit your child can receive as an adult, not only for their own sake, but also because SSI eligibility is often a prerequisite for other benefits.

- **Supplemental Security Income (SSI)**

When your child turns 18, he or she becomes eligible for SSI regardless of the parent's income. SSI is a needs-based program that provides monthly payments to people with disabilities who have limited income and resources. While monthly SSI payments are fairly small, SSI eligibility is the gateway to other important programs, particularly access to the Medicaid health care program, which will be discussed more below. It can also be the entry into a variety of vocational training and group housing programs. In addition, many states also provide a supplemental monetary benefit that is added to the SSI benefit. All of these factors make it important to apply for SSI. You can complete much of the SSI application [online](#). If your child was already receiving SSI payments before their 18th birthday, they will need to go through a redetermination of eligibility at age 18.

Because SSI is only available to people with fewer than \$2,000 in assets, it is important to safeguard your child's eligibility by putting any money you are setting aside for him or, including inheritance, life insurance payment, or legal settlement in a [Special Needs Trust](#).

There are a number of Work Incentive programs that allow your child to work and continue receiving SSI benefits, both while he or she is a student and afterward. The Work Incentive program may also allow your child to deduct certain disability-related expenses from their income total, including attendant care, transportation, assistive devices, or job coaches.

- **Social Security Disability Insurance (SSDI)**

Unlike SSI, which is needs based, SSDI is an entitlement program. This means that assets do not determine eligibility. An unmarried adult who had special needs before age 22 may be able to receive child's benefits if a parent is deceased or has started collecting retirement or disability benefits. It is considered a "child's benefit" because it is paid based on the parent's Social Security earnings record. The "adult disabled child" of someone who is collecting social security can receive a monthly benefit check as long as he or she is not earning more than \$940 a month. After two years of collecting SSDI payments, the adult special needs child will also receive Medicare. In many cases, an adult who has had special needs since childhood will receive SSI benefits until his or her parents retire and then switch to the SSDI program, which has a higher benefit and more flexible rules about income and assets.

Medical Coverage

- **Private Health Insurance**

If you have private insurance, it's important to review your policy carefully so that you know what will be covered when your child reaches age 18. Under the 2010 Patient Protection and Affordable Care Act ("Obamacare"), private insurance policies will continue to cover your child under your policy until age 26.¹⁷ Some states require insurance companies to continue covering special needs adult children past that age. If you get insurance through work, check with your Human Resources department to find out if this is true in your state, or check with your state's Department of Insurance. Because your private insurance policy may not cover all the drugs or services your child needs, it may be important to have Medicaid or Medicare coverage to fill these gaps. For that reason, make sure that claiming your child as a dependent will not jeopardize their eligibility for those programs.

- **Medicaid**

Medicaid is a government-sponsored insurance program for people of all ages who lack the income or resources to pay for health care. Access to Medicaid is granted when an adult begins receiving SSI. These benefits are particularly important if your child has medical needs because Medicaid may pay for medication and equipment that insurance doesn't cover. If your child is already receiving Medicaid benefits, he or she will have to reapply after they turn 18.

- **Medicare**

Medicare is a government-sponsored insurance program for people over 65 and some younger people with disabilities. Access to Medicare is granted two years after a special needs adult child begins receiving SSDI. While not every medical provider accepts Medicaid, most everyone accepts Medicare. "If I have a choice between Medicare and Medicaid, I want to be on Medicare," says Mary Anne Ehlert.

LEGAL DECISIONS

Once your child turns 18, the law presumes that he has the capacity to make his own medical, personal, and financial decisions, regardless of disability. If you feel that your child does not have the ability to make safe and informed decisions, there are a variety of legal options.

- **Guardianship & Conservatorship**

A guardian or conservator – terminology varies from state to state – has received legal authority to make certain decisions on behalf of a person with a disability who has been deemed "incapacitated," meaning that she or he can't participate meaningfully in decisions about their life. The arrangement is usually done with the help of an attorney, as it requires court appearances and ongoing interaction with the court. Guardianship or conservatorship can be limited to certain areas such as medical care.

- **Durable Power of Attorney**

Durable Power of Attorney allows a person with a disability to give someone else the power to make financial or health care decisions for her or him. It is simpler and less costly to set up than guardianship or conservatorship.

- **Advanced Medical Directives & Living Wills**

Advanced Medical Directives and Living Wills allow a person with a disability to state their intentions about medical treatment in the event they become too ill or incapacitated to participate in decisions about their care.

- **Trusts**

Setting up a Special Needs Trust, sometimes called a Supplemental Needs Trust, will create financial stability for both your child and for future caregivers. Find more information on page [37](#).

Determining whether you should pursue guardianship or conservatorship is "a hard decision for people because what they're doing is taking people's rights away," Ehlert says. She advises parents to think through various scenarios. For example, if your young adult needs surgery, would he or she be able to assess the benefits and risks on their own? Could she or he make a decision after getting advice from you or other trusted adults? Or would you need to make the decision for her or him?

[Autism Speaks](#) has created a useful checklist to use when assessing what kinds of decisions a young adult with special needs can handle on their own and what aspects of their life you may need to retain authority over. For each area, ask yourself whether your child can do the following on their own:

Medical

- Seek medical care when he or she is sick or injured
- Weigh the risks and benefits of any particular medical procedure that is being proposed
- Understand the need for routine medical care
- Understand that even if a medical procedure is painful or unpleasant, it may still be necessary
- Assess whether a particular medication is desirable, even though it may have unpleasant side effects
- Provide accurate information about his or her medical condition
- Follow medical advice

Education

- Grasp the essentials of his or her learning problems and understand the services needed to learn effectively
- Advocate for himself or herself to obtain necessary education services

Finances

- Understand money basics, including the purpose of money, how to count money, and how to make change
- Safeguard his or her money so that it is not lost or stolen
- Budget money so that some funds are available to pay expenses at the end of the month

Vocational/Adult Services

- Apply for services from the Department of Disability Services, Department of Mental Health, or other agency that serves people with disabilities
- Access necessary services and supports, such as job training, employment support, or a day habilitation program
- Negotiate with the agency overseeing his or her care to obtain the best possible services

Living Arrangements

- Provide for his or her own physical care and well-being, such as purchasing proper food, clothing, and shelter
- Live harmoniously in a group setting, respecting others' needs for quiet, privacy, and cleanliness

Legal and Decision-Making

- Understand the implications of signing documents
- Make sound decisions in important areas such as living arrangements, school, and work

Self-Care and Safety

- Have personal safety skills, such as staying out of dangerous areas, not talking to strangers, and keeping doors locked
- Know how to summon help in an emergency, such as a fire or accident
- Have basic safety skills, such as being careful around fires, stoves, candles, etc.

Communication

- Communicate effectively (verbally or by other means)
- Understand that he or she has choices and is able to express themselves



A Lifelong Support Network

Since birth, you have been your child's passionate advocate and constant companion. But while no one may ever have the same bond that you have with your child, it is essential to widen the circle. As children move toward adulthood, they must have other competent and caring adults in their lives who will be there for them – as friends, mentors, guardians or caregivers. Now is the time to begin thinking about who will be part of your child's life for the long term – people who can age with your child and are able and willing to accept responsibility for his care if that becomes necessary.

Mary Anne Ehler, Founder and President of Protected Tomorrows, says that parents can often become paralyzed by the prospect of appointing a future caregiver and end up not formalizing their plans. In the absence of any instruction from parents, however, courts are left to make the decision. Ehler advises parents to simply tackle the question head on without over-thinking it. "In one minute, write down everybody you know who is loving and caring," she says. "Circle the ones who have a relationship with your child. Choose the top three. You're done. That's the best you can do."

Here are seven questions to ask yourself as you think about your child's future support network:

- Which adults are part of my child's current support network?
- Who among them might be right to take on a long-term role?
- Have I spoken with my child about the people who will be involved in her or his future care?
- Have I spoken to these people about taking on formal or informal roles in the future?
- Do the people in my child's support network have all the information they need to take on the role I have in mind for them?
- Have I formalized my plans with legal documents, such as a will and letter of . . . intent?
- Do I have a backup plan?

Talking with Siblings

According to a study conducted by [MassMutual](#) and [Easter Seals](#),¹⁸ almost a quarter of adults with special needs siblings serve as their sibling's primary caregiver. Nearly a third expects to play that role in the future.

But the study found that many were not prepared for the role, which is often more expensive and time-consuming than they realized. While 75 percent of current caregivers feel caring for their sibling is a full-time job, for example, only 55 percent of future caregivers expect it to be one. And while 67 percent of future caregivers expect to receive the financial, emotional, and physical support they need, only 57 percent of current caregivers feel they actually receive that same support. In addition, only 33

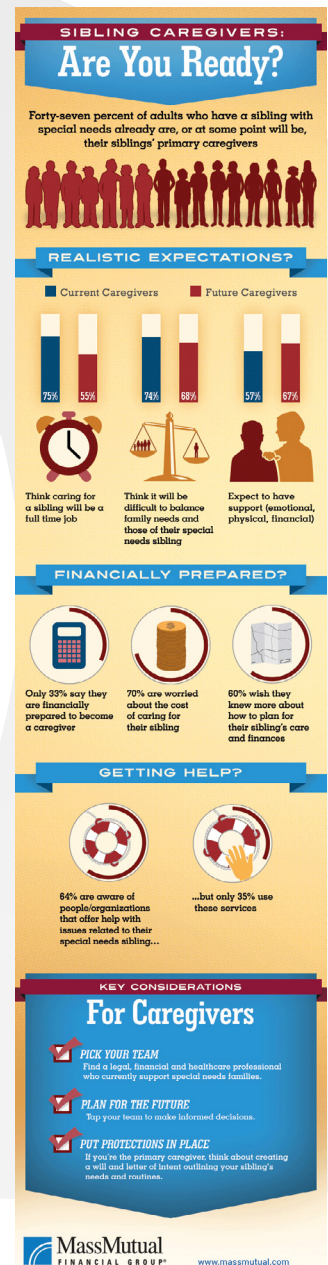


Image from MassMutual

percent of future caregivers feel financially prepared to care for siblings, and 60 percent wish they knew more about planning for their sibling's care and finances.

Don Meyer, director of the [Sibling Support Project](#) in Seattle, says that parents should start talking about the future with typically developing siblings as early as possible. Often, siblings will assume that they will need to take on the responsibility for their special needs sibling whether or not that's actually true. That can mean that they curtail their own transition into adulthood, fearing that if they pursue their own aspirations they will be putting their special needs sibling at risk.

"Kids are thinking about it," he says. "If parents don't share their plans with the typically-developing brother or sister, kids will make their own plans."

Five Important Steps to Preparing for Your Child's Long-Term Future

1. Start talking

Talk early and keep the lines of dialogue open. Make discussions about the future part of everyday conversation and recognize that your plans may need to change as circumstances change. "Normalize that everybody's got a future in this family and we're all thinking about everybody's future," Meyer suggests.

2. Consult with an attorney

Make sure that your intentions have been documented in a properly executed will and that you have the legal power to make any decisions you plan to make. Look into acquiring legal guardianship for siblings or other future caregivers. Attorneys who specialize in special needs can be found through the Special Needs Alliance's "[Find an Attorney](#)" page.

3. Protect your money

Setting up a Special Needs Trust, sometimes called a Supplemental Needs Trust, will create financial stability for both your child and for future caregivers. A trust allows someone with a disability to receive a life insurance payout, legal settlement, or inheritance money without losing their eligibility for benefits like SSI and Medicaid. It also ensures that any money you set aside for your child's future care is only used for that purpose. Without the protection of a trust, money left to a caregiver can be lost in a divorce or other litigation. There are a variety of trusts, each of which has different requirements and advantages. Work with an attorney who specializes in setting up Special Needs Trusts to set up the right kind for you, and make sure that any life insurance policy you have pays into the trust.

4. Share responsibilities now

The best transitions happen gradually, over time. Rather than hoping that future caregivers will assume full responsibility at some point in the distant future, give both your child and future caregivers a chance to try things out slowly. That might mean having siblings or other caregivers take your child on regular outings or come over for the day or evening while you go out. Or it might mean that you have your child transition into an independent or supported living arrangement where both parents and future caregivers can visit frequently. Your child will navigate changes in his or her care better if you are there to help, rather than being plunged into a new and potentially frightening arrangement after your death.

5. Write A Letter of Intent

A Letter of Intent is not a legal document but simply a way of documenting the hopes and plans you and your child have for the future and the important details of your child's life in the present. What does your child like to eat? What medications does he or she take? Who is your child's doctor? What's soothing to them when their upset? Where do you keep his or her financial records? There's so much that you know that others don't; make sure it's written down and that future caregivers know where to find it.



A Happy Ending: Carolyn & Connor

Connor is a young man with learning disabilities and an anxiety/panic disorder. He struggled to keep up at his academically oriented high school but didn't identify as having a disability or special need, dismissing his one special education class as a "waste of time." Because his friends were focused on college, he assumed he would go to college too. But college turned out to be a mistake. The friends who helped him through his classes in high school weren't with him in college to help him make sense of his assignments, and he soon stopped going to class, winding up on academic probation. It was then that his mother, Carolyn, told him that it was okay with her if he didn't go to college.

"I think it was a relief for him to realize he wasn't letting me down," she says now.

Connor then applied for a job at a sporting goods store and had a friend go with him to the interview. He got the job, but on his first day of work he was so overcome with anxiety that he stayed home. He stayed home the next day as well. At last his parents convinced him to try going to work for just one day. Six years later, he is still working for the same chain and is now the manager of his own store.

"He's passionate about his job," Carolyn says. "He can tell you about every type of shoe and the type you should wear because of the kind of foot you have." Her advice for families facing the transition process: "Do your research and follow your gut instinct."



Conclusion

“Professionals often state that parents and family members are the most important elements in the transition from school to adult life process, because they are the only people to have continuous and stable contact with the student throughout the entire process.”

— Everson and Moon, 1987 ¹⁹

Having a child with special needs reach adulthood means taking stock of your own life and trying to envision what the next stage will look like. No matter what your situation is, this time is almost guaranteed to generate some emotional turmoil. While parents with typically developing children may be thinking about an empty nest, many parents of special-needs children are realizing that their responsibilities are unlikely to ease up. That can mean a fresh period of grieving as you come to terms with the prospect of being a lifelong caretaker.

“It’s difficult for parents of special-needs kids because they see their friends who have typically developing kids who are leaving the nest,” observes Lynne, whose son David has an autism spectrum disorder. “And they’re like, ‘I’d like to be able to start thinking about myself, especially after all these years in the trenches, but it’s not realistic.’ It’s like when your child first gets diagnosed and you realize this is forever. You start thinking, ‘What’s going to happen when I’m gone? Who’s going to look after my child when I’m no longer around?’”

Parents of special-needs children who are ready to leave the nest may experience another kind of grief. As their child becomes more independent, they may find themselves mourning the loss or diminishment of a role that was as fulfilling as it was challenging. It isn’t easy to let go of a job that has been your life’s mission for so many years. What will you do with yourself? How will you manage the fears and anxieties you have about your child’s welfare? After spending years as your child’s most devoted champion, it can be hard to dismount from your white horse. You may feel guilty about asking your child to start assuming responsibility for his or her future, as if you are shirking your duty. And you may worry that your child will be physically or emotionally hurt by an outside world that doesn’t understand or cherish him or her the way you do.

“Letting go is terrifying because we’re talking about kids who couldn’t have progressed to where they are if their parents, particularly their moms, hadn’t put in a whole lot of effort,” says Dr. Robert Naseef. “But if you can loosen your grip a little, you start to get a better idea of what your child can handle. It’s not just a transition for this child with special needs but for the family as a whole.”

Rest assured you are not abandoning your role as your child’s advocate. But you are changing it. This is a time of new beginnings. Your child is transitioning into a new role as a young adult. You are transitioning into a new role too – the parent of a young adult. It will take time to reach a new equilibrium. “We’re parents all our lives,” observes Dr. Naseef. “As our children get older, we might not have to do as much for them, but be there as they need us.”

Resources

STAYING ORGANIZED

- Checklist for the First 21 Years – a [checklist](#) created by the Special School District of St. Louis County to help with the years leading up to transition
- “Transition Tool Kit” – a [guide](#) created by Autism Speaks to assist families with the transition from adolescence to adulthood
- “SSD Transition Guidebook” – [guidebook](#) made by the Special School District of St. Louis County to help with the move into adulthood
- Find Your Parent Center – a [list](#) compiled by the Center for Parent Information and Resources of the parent training and information centers in the United States
- State Agencies – an [interactive guide](#) that provides the contact information for the intellectual/developmental disability agencies in each state created by the National Association of State Directors of Developmental Disabilities Services

PERSON-CENTERED PLANNING

- *It’s My Choice...* by William T. Allen, PhD – a [workbook](#) for helping your child think and talk about her future
- *Guiding Your Teenager with Special Needs through the Transition from School to Adult Life...* by Mary Kopi

KNOW YOUR CHILD’S RIGHTS

- For a list of all the federal laws, and an overview of each, that apply to the rights of the special needs, visit www.ada.gov/cguide.htm
- For more information on FAPE, please refer to: www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

SIX SIMPLE THINGS

- Parent Transition Survey – created by Transition Coalition, this [survey](#) allows parents to take stock of what they already know when it comes to their child’s transition

A SUCCESSFUL INDIVIDUALIZED EDUCATION PROGRAM

- “Your First IEP” by SchwabLearning.org – prepared for the San Francisco United School District, this [guide](#) provides step-by-step preparation for the IEP and work sheets to help you prepare for the meeting
- NSTTAC Indicator 13 – intended for the school district to use, the National Secondary Transition Technical Assistance Center created two checklists ([A](#) and [B](#)) that help to make sure an IEP was completed in accordance with IDEA
- Ten Common Mistakes – a [look](#) at ten mistakes parents make during their child’s IEP

DIPLOMA OPTIONS

- “Diploma Options for Students with Disabilities” – compiled by the National Center on Secondary Education and Transition, this [briefing](#) provides an overview of the different diploma options and the benefits of a state offering multiple options versus one option
- “Diploma Options and Graduation Policies for Students with Disabilities” – created by the National Center on Educational Outcomes, this [guide](#) looks at the positives and negatives of the different diploma options, helping to make a decision on which is best for your child
- “Graduation Requirements and Diploma Options for Students with Disabilities: What Families and Advocates Need to Know” – published by the US Department of Labor, this [informational brief](#) examines the different diploma options and the need to align IEP goals with postsecondary goals concerning a diploma

LOOKING FOR A COLLEGE

- Colleges with Programs for Students with Learning Disabilities – a [list](#) of colleges in the United States that provide programs for students with disabilities; includes links to the specific program pages on the college’s website

TRAVELING WITH YOUR CHILD

- Children with Disabilities – TSA travel [information](#) about their accommodations when you travel with your child
- Travelers with Disabilities or Medical Conditions – TSA travel [information](#) specific to travelers with autism or an intellectual disability

SEEKING EMPLOYMENT

- Vocational Rehabilitation Agencies – a [list](#) of the VR agencies in each state
- “Getting the Most from VR” – an [article](#) that discusses how you can get the best out of VR agencies
- Best Buddies Programs – a master [list](#) of all the Best Buddies programs, specifically for colleges, high schools, and middle schools around the world and a [description](#) of the different programs that Best Buddies offer (click on your state in the left sidebar to see all the programs located in your state)

DAY PROGRAMS

- Services for Younger Adults – a [page](#) with information about the day programs offered by Easter Seals

FULL-TIME HOUSING

- When Choosing a Home – a [work sheet](#) created by the Regional Center of Orange County in California to help you and your child look for full-time care; it provides questions that are helpful to ask when searching
- State Associations of Independent Living – a [list](#) of the contact information for state independent living centers compiled by Independent Living Research Utilization
- Choosing a Residential Service Provider – a [guide](#) to residential options for people with autism created by the Foundation for Autism Support and Training

HEALTH AND MEDICAL CARE

- Moving from Pediatric to Adult Healthcare – a [compilation](#) of resources on how to create a smooth transition to adult health care
- “Working While Disabled” – a [brochure](#) on how your child can work and continue to receive Social Security benefits

LEGAL DECISIONS

- Legal Matters to Consider – a [look](#) at the legal matters a parent needs to consider when deciding whether to become a guardian, conservator, or other for an adult child; provides questions and scenarios to consider in the decision-making process
- The Special Needs Trust – an [article](#) by Richard W. Fee about questions surrounding the special needs trust for the National Institute on Life Planning for Persons with Disabilities

TALKING WITH SIBLINGS

- The Special Needs Trust – a [guide](#) from the National Institute on Life Planning for Persons with Disabilities on the process of creating one of these trusts
- Sample Letter of Intent – a [sample](#) version of a Letter of Intent to help you with writing your own
- What to Record – a [list](#) of topics to document for future caregivers
- My Special Life – a [workbook](#) from Protected Tomorrows where you can document the important information in your child’s life

Appendices

WHAT TO DO AND WHEN TO DO IT

Before Age 14:

- Begin transition planning through the IEP process. An IEP must include transition-planning services starting at age 16, but the process should ideally begin at age 14.
- Find out about diploma types and their requirements and discuss the options with your child and the IEP team.
- Talk to your child about puberty and sexuality.

Before Age 16:

- Begin thinking about long-term housing because waiting lists can be several years long, consider adding your child's name to the waiting list for residential programs. That will give you more options later.
- Make sure your child is receiving WorkAbility and life skills training as part of their transition plan.
- Learn about the admission requirements and funding options for any college or vocational training program your child is interested in.
- Begin talking with medical providers about the transition to doctors and specialists treating adults. If your child has complex medical issues, you will want to begin finding new medical providers now.
- Make sure your child has an understanding of any chronic health problems he/she has and how to manage them.

Before Age 18:

- Determine what adult services your child is eligible for and apply for them.
- Organize your child's medical records and other documents.
- Find out if there is an age cutoff for any of the therapies your child receives and, if so, get recommendations for providers working with adults.
- Apply for SSI.
- Apply or reapply for Medicaid.
- Find adult medical providers to replace your pediatrician and pediatric specialists.
- Get legal advice about conservatorship and guardianship.
- Speak with your health insurance agent about medical coverage for your child after s/he turns 18.
- Check with Durable Medical Equipment (DME) vendors and home care agencies to see if there are age cutoffs and, if so, what agencies can continue to provide the necessary care.
- If appropriate, have discussions with family about advanced directives, including Allow Natural Death/Do Not Resuscitate (AND/DNR) orders.
- If you have a daughter, arrange for her to have a gynecological examination with a gynecologist who understands her disability.
- If you have a son, he must register with Selective Service. He may register at the post office or online at www.sss.gov.
- Help your child register to vote.
- Determine whether or not your child will need a Special Needs Trust (SNT) or other financial plan.

Before Age 21:

- Take advantage of IDEA-funded special education services that run through age 21, particularly transition services.

Before Age 26:

- Determine whether your child will continue to be covered through your health insurance policy after they turn 26, and if not, what insurance they will need.

EMPLOYMENT OPTIONS

AbilityPath has spent a year conducting a national search on the best practices to date on various employment models for individuals with special needs. Below are the findings:

What to look for: key lessons learned

- The programs only succeed if there is a tireless champion at the employer
- The best programs involve collaboration between companies looking to hire and community organizations who identify and train potential employees
- It needs to make business sense for the hiring organization, like:
 - ◊ Good workers who are more productive
 - ◊ Help your company meet compliance standards
- Even the most successful programs are placing relatively few people: a highly scalable model is yet to be developed

Health services jobs

- [Project Search](#), Cincinnati & across U.S.
 - ◊ Training and internships for high school seniors
 - ◊ At hospitals, on-site classrooms and on the job training
 - ◊ Funded by school districts out of senior year budget
 - ◊ Detail-oriented jobs like surgical set preparation, stocking drugs by bedsides

Medical and telecommunications jobs

- [Launchability](#), Dallas, Texas
 - ◊ Pre-hire training program to make the developmentally special needs young adults competitive.
 - ◊ Trains on specific work skills for specific jobs plus soft skills that keep them from interviewing well or doing the job
 - Embedded within the company, utilize existing employees as mentors
 - 5-6 week training to go into medical and telecommunications jobs
 - ◊ State vocational rehabilitation pays for training

Service jobs in corporate setting

- [Microsoft](#) Supported Employment Program
 - ◊ Real estate and facilities division: goal to hire 200 in Redmond, WA campus
 - ◊ Partnering with Washington Initiative for Supported Employment
 - ◊ Service jobs to be offered by Microsoft suppliers
 - Food service, transportation, mail, office relocation
 - ◊ Collaborate with local disability organizations to recruit

Software testing jobs

- [Specialists Guild](#), San Francisco
 - ◊ For young people in their 20's on the autism spectrum
 - ◊ Train, assess their abilities and give them real world experience to build a resume and get work
 - ◊ When hired, can work from home if transportation or being in an office are problematic

- [Aspiritech](#), Highland Park, Illinois
 - ◊ Workshop that provides training to do technology work, software debugging, for young people with developmental disabilities who can't function well onsite
 - ◊ Combined project manager/coach/trainer model
 - Test to see if they can work in a group setting
 - Creates a social context for the workers who work together, also improved quality because they collaborate as a team
 - They are a social enterprise, a non profit, but they are the employer who contracts with companies
- [Specialisterne](#), coming to Silicon Valley in 2014
 - ◊ Adults on high functioning autism spectrum (37 total in Denmark)
 - ◊ Identifying opportunities and placing consultants in companies
 - ◊ Assessment via building Lego Robot, training, and placement in software testing and other detail work
 - ◊ Assessment, training at Specialisterne offices; job placement on site

Software and game development jobs

- [Nonpareil](#), Plano, Texas
 - ◊ Supports an exclusive segment of autism: could not make it in university environment, could not do calculus, and can't get a standard programming degree
 - ◊ College level education for IT programming, video graphics, gaming, and apps
 - The students become professional game and app designers
 - Design products that will sustain the organization
 - Their goal is some will work for Google or EA, some will work for non profits become professors there or do programming to sustain
 - ◊ Looking to build a campus community where people can train, develop software and game products, either from campus or moving to companies, and perhaps teach new recruits. Want them to be able to live there if they choose

NATIONAL DIRECTORY OF STATE AGENCIES

ALABAMA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Alabama Council of Developmental Disabilities (ACDD)	100 North Union Street, Montgomery, AL 36104 334-242-3973 800-232-2158 info@acdd.org	ACDD has a mission to support independence, advocacy, productivity, and inclusion for Alabamians with developmental disabilities.
Department of Mental Health, Division of Developmental Disabilities	100 North Union Street, Montgomery, AL 36104 800-361-4491 Alabama.DMH@mh. alabama.gov	The Department is dedicated to efforts to enhance the health and well-being of those impacted by mental illnesses, developmental disabilities, and substance abuse and addiction.

REGIONAL CENTERS:

<http://www.mh.alabama.gov/ID/RegionalOffices.aspx>

ALASKA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Health & Social Services–Senior & Disabilities Services Anchorage Office	550 West 8th Avenue, Anchorage, AK 99501 907-269-3666 800-478-9996	The Department’s mission is to promote health, well-being, and safety for individuals with disabilities, seniors, and vulnerable adults by facilitating access to quality services and supports that foster independence, personal choice and dignity.
Department of Health & Social Services–Senior & Disabilities Services Juneau Office	240 Main Street, Suite 601, Juneau, AK 99811 907-465-3372 866-465-3165	

Department of Health & Social Services–Senior & Disabilities Services Fairbanks Office

751 Old Richardson Highway, Suite 100A, Fairbanks, AK 99701

907-451-5045
800-770-1672

ARIZONA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Arizona Department of Economic Security Division of Developmental Disabilities	1789 West Jefferson Avenue, Phoenix, AZ 85007 602-542-0419 866-229-5553 DDDWeb@azdes.gov	The Division provides supports and services to more than 32,000 people with developmental disabilities and their families throughout Arizona. DES strives to support the choices of individuals with disabilities and their families by promoting and providing within communities, flexible, quality, consumer-driven services and supports.

ARKANSAS

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Arkansas Developmental Disabilities Council	5800 West 10th Street, Suite 805, Little Rock, AR 72204 501-661-2589 800-462-0599 teresa.sander@arkansas.gov	The Council's main objective is to improve the independence and productivity of people with developmental disabilities and to ensure their integration and inclusion into the community.
Arkansas Disability Coalition	1501 North University Avenue, Suite 268, Little Rock, AR 72207 501-614-7020 800-223-1330 http://www.adcpti.org/content/arkansas_disabi/email_adc.as	The Coalition is a statewide organization that assists families and individuals with all types of disabilities by providing information, support, resources, and training.

Department of Human Services, Division of Developmental Disabilities Services

PO Box 1437, Slot N505,
Little Rock, AR 72203

501-683-0870

<https://dhs.arkansas.gov/ost/contactforms/ContactUs.aspx>

The Division believes individuals and their families should have choices when selecting the appropriate services in their local community. This allows each individual to maximize his or her abilities while enjoying a quality of life that matches those abilities. It also will prevent individuals from being forced to access more expensive and intrusive services. The Division is responsible for the overall coordination of services for Arkansans with developmental disabilities.

CALIFORNIA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Resources for Independent Living (RIL)	420 I Street, Suite 3, Sacramento, CA 95814 916-446-3074 http://www.ril-sacramento.org/contact-us/	RIL promotes the socioeconomic independence of persons with disabilities by providing peer-supported, consumer-directed independent living services and advocacy.
California Foundation for Independent Living Centers (CFILC)	1234 H Street, Suite 100, Sacramento, CA 95814 916-325-1690 http://www.cfilc.org/contact-us/	The mission of CFILC is increasing access and equal opportunity for people with disabilities by building the capacity of Independent Living Centers.
State Council on Developmental Disabilities (SCDD)	1507 21st Street, Suite 210, Sacramento, CA 95811 916-322-8481 866-802-0514 council@scdd.ca.gov	SCDD is established by state and federal law to ensure that individuals with developmental disabilities and their families participate in the planning, design, and receipt of the services and supports they need, which promote increased independence, productivity, inclusion, and self-determination.

Department of Developmental Services (DDS)

1600 9th Street, Sacramento, CA 95814

916-654-1690

rgeditor@dds.ca.gov

DDS is the agency through which the State of California provides services and supports to individuals with developmental disabilities.

REGIONAL CENTERS:

Regional centers are nonprofit private corporations that contract with the Department of Developmental Services to provide or coordinate services and supports for individuals with developmental disabilities. They have offices throughout California to provide a local resource to help find and access the many services available to individuals and their families.

<http://www.dds.ca.gov/RC/RCList.cfm>

COLORADO

ORGANIZATION	CONTACT	DESCRIPTION
Division for Developmental Disabilities	1570 Grant Street, Denver, CO 80203 303-866-2993 Roberta.Aceves@state.co.us	The mission for the Division is to join with others to offer the necessary supports with which all people with developmental disabilities have their rightful chance to be included in Colorado community life, make increasingly responsible choices, exert greater control over their life circumstances, establish and maintain relationships and a sense of belonging, develop and exercise their competencies and talents, and experience personal security and self-respect.

REGIONAL CENTERS:

Regional centers serve persons with developmental disabilities who have the most intensive needs. Their services include: 24-hour supervision, residential services, day programming, habilitation, medical, training, and behavioral intervention, plus short-term emergency/crisis support to the community system.

<http://www.colorado.gov/cs/Satellite/CDHS-VetDis/CBON/1251579354640>

CONNECTICUT

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Council on Developmental Disabilities	460 Capitol Avenue, Hartford, CT 06106 800-653-1134 Molly.Cole@ct.gov	The mission of the Council is to promote the full inclusion of all people with disabilities in community life.
Department of Developmental Services	460 Capitol Avenue, Hartford, CT 06106 860-418-6000 866-737-0330 ddsct.co@ct.gov	The Department is responsible for the planning, development, and administration of complete, comprehensive, and integrated statewide services for persons with intellectual disability and persons medically diagnosed as having Prader-Willi Syndrome.

DELAWARE

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Division of Developmental Disabilities Services	1052 South Governor's Avenue, Suite 101, Dover, DE 19904 866-552-5758	The Department is responsible for the planning, development, and administration of complete, comprehensive, and integrated statewide services for persons with intellectual disability and persons medically diagnosed as having Prader-Willi Syndrome.

FLORIDA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Florida Developmental Disabilities Council (FDDC)	124 Marriott Drive, Suite 203, Tallahassee, FL 32301 850-488-4180 800-580-7801 fddc@fddc.org	The Council was established in 1971 to help plan individual and family-centered supports for persons with disabilities in Florida. FDDC also guides the development and administration of services for people with developmental disabilities by planning and funding research, innovations, and programs designed to improve the quality of their lives.

Agency for Persons with Disabilities (APD)

4030 Esplanade Way,
Suite 380, Tallahassee, FL
32399

850-488-4257
866-273-2273

apd.info@apdcares.org

The Agency works in partnership with local communities and private providers to assist people who have developmental disabilities and their families. APD also provides assistance in identifying the needs of people with developmental disabilities for supports and services.

REGIONAL CENTERS:

<http://apd.myflorida.com/region/>

GEORGIA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Georgia Council on Developmental Disabilities (GCDD)	2 Peachtree Street NW , Suite 26-246, Atlanta, GA 30303 404-657-2126 888-275-4233 vmsuber@dhr.state.ga.us	GCDD is charged with creating systems change for people with developmental disabilities and their families by increasing opportunities for independence, inclusion, integration, productivity, and self-determination.
Department of Behavioral Health and Development Disabilities (DBHDD)	2 Peachtree Street NW, Atlanta, GA 30303 404-657-2252	DBHDD provides treatment and support services to people with behavioral health challenges and addictive diseases, and assists individuals who live with developmental disabilities.

HAWAII

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Development Disabilities Division	1250 Punchbowl Street, Room 463, Honolulu, HI 96813 808-586-5840	The mission of the Division is to assure there is a state system of supports and services for persons with developmental disabilities or intellectual disabilities, which includes principles of self-determination and incorporates individualized funding, person-centered planning and community services.

IDAHO

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Council on Developmental Disabilities	700 West State Street, 1st Floor, West Boise, ID 83702 208-334-2178 800-544-2433 info@icdd.idaho.gov	The mission of the Council is to promote the capacity of people with developmental disabilities and their families to determine, access, and direct the services and/or support they need to live the lives they choose, and to build the communities' ability to support their choices.
Able to Work	http://www.abletowork.idaho.gov/contact.html	The purpose of the website is to promote more and better employment opportunities for people with disabilities in Idaho.

ILLINOIS

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Council on Developmental Disabilities	101 West Randolph, Suite 10-600, Chicago, IL 60601 312-814-2080	The Council is dedicated to leading change in Illinois so that all people with developmental disabilities are able to exercise their rights to freedom and equal opportunity.
Department of Human Services–Developmental Disabilities Division	319 East Madison, Suite 4N, Springfield, IL 62701 217-524-7065 DHS.WebBits@illinois.gov	The Department provides leadership for the effective management of the design and delivery of quality outcome-based, person-centered services and supports for individuals who have developmental disabilities. These services and supports will be: appropriate to their needs, gifts, talents, and strengths; accessible; life-spanning; based on informed choice; and monitored to ensure individual progress, quality of life, and safety.

INDIANA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Bureau of Developmental Disabilities Services	800-545-7763 BQIS.Help@fssa.IN.gov	The Bureau provides services for individuals with developmental disabilities that enable them to live as independently as possible in their communities.

REGIONAL OFFICES:

<http://www.in.gov/fssa/ddrs/4088.htm>

IOWA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Division of Mental Health and Disability Services (MHDS)	5 SE, 1305 East Walnut Street, Des Moines, IA 50319 515-281-7277 rshults@dhs.state.ia.us	MHDS is responsible for planning, coordinating, monitoring, improving, and partially funding mental health and disability services for the State of Iowa.

KANSAS

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department for Aging and Disability Services	503 South Kansas Avenue, Topeka, KS 66603-3404 785-296-4986 800-432-3535 wwwmail@kdads.ks.gov	The Department envisions a community that empowers Kansas older adults and persons with disabilities to make choices about their lives.

KENTUCKY

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Learning Disabilities Association of Kentucky, Inc.	2210 Goldsmith Lane, #118, Louisville, KY 40218 502-473-1256 LDAofKY@yahoo.com	The Association is a nonprofit organization of individuals with learning differences and attention difficulties, their parents, educators, and other service providers. This organization has been a continuous voice in this state for those who learn differently since 1966.

Department of Behavioral Health, Developmental and Intellectual Disabilities

100 Fair Oaks Lane 4E-B,
Frankfort, KY 40621

502-564-4527

<http://dbhdid.ky.gov/contact.aspx?p=1>

The Department's mission is to provide leadership, in partnership with others, to prevent disability, build resilience in individuals and their communities, and facilitate recovery for people whose lives have been affected by mental illness, intellectual disability or other developmental disability, or substance abuse.

LOUISIANA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Office for Citizens with Developmental Disabilities (OCDD)	628 North 4th Street, Baton Rouge, LA 70802 225-342-0095 866-783-5553 ocddinfo@la.gov	OCDD is committed to ensuring quality services, serving as the single point of entry into the developmental disabilities services system.

REGIONAL CENTERS:

<http://new.dhh.louisiana.gov/index.cfm/directory/category/146>

MAINE

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Office of Aging and Disability Services (OADS)	41 Anthony Avenue, Augusta, ME 04333 207-287-4242	The Office is responsible for planning, developing, managing, and providing services to promote independence for elders and adults with brain injuries, intellectual disabilities, and physical disabilities through the provision of services. These include evidence-based prevention programs and comprehensive home and community-based services, including Adult Protective Services and Public Guardianship and Conservatorship Programs. OADS fulfills its mission through: Policy and Prevention, Intervention and Care Management, Community Partnerships, and Accountability and Information Services.

MARYLAND

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Disabilities	217 East Redwood Street, Suite 1300, Baltimore, MD 21202 410-767-3660 800-637-4113 MDOD@mdod.state. md.us	The Department advances the rights and interests of people with disabilities so they may fully participate in their communities.
Transitioning Youth	217 East Redwood Street, Suite 1300, Baltimore, MD 21202 410-767-3660 800-637-4113 MDOD@mdod.state. md.us	Their mission is to ensure effective interagency planning and delivery of services for secondary students with disabilities.

MASSACHUSETTS

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Developmental Services	500 Harrison Avenue, Boston, MA 02118 617-727-5608 http://www.mass.gov/ eohhs/gov/departments/ mcdhh/contact-us/ques- tion-about-our-services. html	The Department is dedicated to creating, in partnership with others, innovative and genuine opportunities for individuals with intellectual disabilities to participate fully and meaningfully in, and contribute to, their communities as valued members.

MICHIGAN

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Michigan Development Disabilities Council	201 Townsend Street, Suite 120, Lansing, MI 48913 517-335-3158 mdch-dd-council@michigan.gov	The Council's mission is to support people with developmental disabilities to achieve life dreams.

MINNESOTA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Council on Developmental Disabilities	658 Cedar Street, St. Paul, MN 55155 651-296-4018 877-348-0505 admin.dd@state.mn.us	The Council serves as an advocate for all persons with developmental disabilities by carrying out activities in major areas of emphasis.
Department of Human Services	651-431-2400 800-747-5484 dhs.info@state.mn.us	The Department helps people with disabilities live as independently as possible so they can be a part of the communities in which they live.

MISSISSIPPI

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Mental Health	239 North Lamar Street, Jackson, MS 39201 877-210-8513	The Department is supporting a better tomorrow by making a difference in the lives of Mississippians with mental illness, substance abuse problems and intellectual/developmental disabilities one person at a time.

Mississippi Society for Disabilities (MSD)

500-G East Woodrow
Wilson Drive, PO Box 4958,
Jackson, MS 39296

601-982-7051

<http://msdisabilities.com/contact/>

The mission of MSD is to provide a broad spectrum of programs and services to meet the needs of Mississippi children and adults with disabilities, thus enabling them to achieve maximum independence and gain the greatest possible quality of life.

MISSOURI

ORGANIZATION

**Department of Mental Health,
Division of Developmental
Disabilities**

CONTACT

1706 East Elm, PO Box
687, Jefferson City, MS
65102

573-751-3070

ddmail@dmh.mo.gov

DESCRIPTION

The Division serves a population that has developmental disabilities such as intellectual disabilities, cerebral palsy, head injuries, autism, epilepsy, and certain learning disabilities. Their mission is to improve lives of Missourians with developmental disabilities through supports and services that foster self-determination.

REGIONAL OFFICES:

<http://dmh.mo.gov/dd/facilities/>

MONTANA

ORGANIZATION

**Developmental Disabilities
Program**

CONTACT

111 Sanders, Suite 305,
PO Box 4210,
Helena, MT 59604-4210

406-444-2995

<http://www.dphhs.mt.gov/dsd/contactus.shtml>

DESCRIPTION

The Program is dedicated to creating a system that coordinates resources, supports, and services for people to have meaningful lives in their communities.

REGIONAL OFFICES:

<http://www.dphhs.mt.gov/dsd/ddp/regionaloffices.shtml>

NEBRASKA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Division of Developmental Disabilities	301 Centennial Mall South, Lincoln, NE 68509 402-471-8501 dhhs.developmentaldisabilities@nebraska.gov	The Division administers the Beatrice State Developmental Center and publicly funded community based developmental disability services. Their responsibilities include certification, technical assistance, regulations and payment for providers of community-based developmental disabilities services, and operation of the Beatrice State Developmental Center (a 24-hour intermediate care facility for persons with developmental disabilities).

NEVADA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Aging and Disability Services Programs	1010 Ruby Vista Drive, Suite 104, Elko, NV 89801 775-738-1966 adsd@adsd.nv.gov	Aging and Disability Services provides resources at the community level that promote equal opportunity and life choices for people with disabilities through which they may positively contribute to Nevada.

NEW HAMPSHIRE

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Bureau of Developmental Services	105 Pleasant Street, Concord, NH 03301 603-271-5034 800-852-3345, ext. 5034 http://apps.dhhs.nh.gov/EmailContact/EmailContact.aspx?a=bds&b=Bureau%20of%20Developmental%20Services	The Bureau will join with local communities to support individuals of all ages with developmental disabilities or acquired brain disorders and their families to experience as much freedom, choice, control, and responsibility over the services and supports they receive as desired.

NEW JERSEY

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Division of Developmental Disabilities	195 Gateway, Suite 100, 5 Commerce Way, Hamilton, NJ 08691 800-832-9173 http://nj.gov/humanservices/ddd/staff/email/index.html	Some of the most basic aspects of the Division's mission are protecting the health and safety of the individuals it serves, promoting equity and fairness, and spending state dollars responsibly. The Division also continues to strive to expand the type and number of services available in the community. In this way it is not only able to help individuals avoid unnecessary institutional placements but also help make it possible for them to remain at home with their families for as long as possible.

DEVELOPMENTAL CENTERS:

<http://nj.gov/humanservices/ddd/home/centers/>

NEW MEXICO

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Developmental Disabilities Planning Council	625 Silver Avenue SW, Suite 100, Albuquerque, NM 87102 505-841-4519 Justin.Moore@state.nm.us	The Council will promote advocacy, capacity building, and systemic change to improve the quality of life for individuals with developmental disabilities and their families.

NEW YORK

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Office for People with Developmental Disabilities (OPWDD)	44 Holland Avenue, Albany, NY 12229 866-946-9733 people.first@opwdd.ny.gov	OPWDD is responsible for coordinating services for more than 126,000 New Yorkers with developmental disabilities, including intellectual disabilities, cerebral palsy, Down syndrome, autism spectrum disorders, and other neurological impairments. It provides services directly and through a network of approximately 700 nonprofit service-providing agencies, with about 80 percent of services provided by the private nonprofits and 20 percent provided by state-run services.

NORTH CAROLINA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Division of Mental Health, Developmental Disabilities and Substance Abuse Services	Albemarle Building, 325 North Salisbury Street, Raleigh, NC 27699 919-733-7011 contactdmh@dhhs.nc.gov	The Division's mission is to promote excellence in prevention, treatment, and rehabilitation programs for persons with mental illness, developmental disabilities, and substance abuse disorders in North Carolina.

NORTH DAKOTA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Developmental Disabilities Services	600 East Boulevard Avenue, Department 325, Bismarck, ND 58505 701-328-2310 800-472-2622 dhseo@nd.gov	Developmental Disabilities provides support and training to individuals and families in order to maximize community and family inclusion, independence, and self-sufficiency; to prevent institutionalization; and to enable institutionalized individuals to return to the community.

REGIONAL CENTERS:

<http://www.nd.gov/dhs/locations/regionalhsc/>

OHIO

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Developmental Disabilities	30 East Broad Street, Columbus, OH 43215 800-617-6733 John.Martin@dodd.ohio.gov	The Department is responsible for overseeing a statewide system of supports and services for people with developmental disabilities and their families.

OKLAHOMA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Developmental Disabilities Services	2400 North Lincoln Boulevard, Oklahoma City, OK 73105 405-521-6267	The mission of Developmental Disabilities is to help individuals with developmental disabilities and their families help themselves to lead safer, healthier, more independent and productive lives.

OREGON

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Developmental Disability Services	500 Summer Street NE E02, Salem, OR 97301 503-945-5811 800-282-8096 ODDS.INFO@state.or.us	Developmental Disability Services strive to support choices of individuals with disabilities and their families within communities by promoting and providing services that are person centered and directed, flexible, community inclusive, and supportive of the discovery and development of each individual's unique gifts, talents, and abilities.
Oregon Council on Developmental Disabilities	540 24th Place NE, Salem, OR 97301-4517 503-945-9941 800-292-4154 ocdd@ocdd.org	The mission of the Council is to create change that improves the lives of Oregonians with developmental disabilities.

PENNSYLVANIA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Public Welfare (DPW), Intellectual Disabilities Services	717-265-7427 888-565-9435 http://www.dpw.state.pa.us/Feedback/index.htm?ContactCode=OLT-L&Subject=Disability % 20 Assistance	The Department supports programs for individuals with disabilities throughout the state with a focus on individualized care and benefits programs designed to meet the specific needs of each person. From assisted living and personal care homes, to individual supports plans for community services, to medical assistance, DPW seeks to meet the needs of individuals with disabilities throughout the community.

RHODE ISLAND

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Division of Developmental Disabilities	6 Harrington Road, Cranston, RI 02920 401-462-3421 CStenning@bhddh.ri.gov	The Division is responsible for planning, providing, and administering a community system of services and supports for adults with developmental disabilities.

SOUTH CAROLINA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Disabilities and Special Needs	3440 Harden Street Ext., Columbia, SC 29203 803-898-9600 888-376-4636 http://www.ddsn.sc.gov/about/Pages/ContactUs2.aspx	The Department serves persons with intellectual disability, autism, traumatic brain injury, and spinal cord injury and conditions related to each of these four disabilities.

SOUTH DAKOTA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Division of Developmental Disabilities	Hillsview Plaza, East Highway 34, c/o 500 East Capitol, Pierre, SD 57501- 5070 605-773-3438 infodd@state.sd.us	The Division ensures that people with developmental disabilities have equal opportunities and receive the services and supports they need to live and work in South Dakota communities.

TENNESSEE

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Intellectual and Developmental Disabilities	400 Deaderick Street, Nashville, TN 37243 615-532-6530 800-535-9725 PUBLIKAFFAIRS.DIDD@tn.gov	The Department supports all Tennesseans with intellectual and developmental disabilities to live fulfilling and rewarding lives.

REGIONAL CENTERS:

The regional offices are responsible for the enrollment of individuals with intellectual disabilities into a service delivery system that best meets their individual needs for support. It is the mission of these offices to develop and support opportunities for persons with intellectual disabilities to live as contributing members of their chosen home community.

http://www.tn.gov/didd/regional_offices/locations.shtml

TEXAS

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Aging and Disability Services (DADS)	701 West 51st Street, Austin, TX 78751 512-438-3011	DADS was created to administer long-term services and supports for people who are aging as well as for people with intellectual and physical disabilities.

UTAH

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Division of Services for People with Disabilities	195 North 1950 West, Salt Lake City, UT 84116 801-538-4200 800-837-6811 dspd@utah.gov	The Division promotes opportunities and provides supports for people with disabilities to lead self-determined lives by overseeing home- and community-based services for more than 5,000 people who have disabilities. Support includes community living, day services, and supported employment services.

VERMONT

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Disabilities, Aging & Independent Living	103 South Main Street, Weeks Building, Waterbury, VT 05671 802-871-3350 http://www.ddas.vermont.gov/ddas-contact-us/ddas-on-line-contact-form1	The mission of the Department is to make Vermont the best state in which to grow old or to live with a disability with dignity, respect, and independence.

VIRGINIA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Behavioral Health and Developmental Services	1220 Bank Street, Richmond, VA 23219 804-786-3921 jim.martinez@dbhds.virginia.gov	The Department provides leadership and service to improve Virginia's system of quality treatment, habilitation, and prevention services for individuals and their families whose lives are affected by behavioral health disorders or developmental disabilities.

INTELLECTUAL STATE DISABILITY FACILITIES:

<https://www.dbhds.virginia.gov/SVC-StateFacilities.htm#MR>

WASHINGTON

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Developmental Disabilities Administration	4450 10th Avenue SE, Lacey, WA 98503 360-725-3413 dddcoreception@dshs.wa.gov	The Administration strives to develop and implement public policies that will promote individual worth, self-respect, and dignity such that each individual is valued as a contributing member of the community.

WEST VIRGINIA

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Division of Intellectual and Developmental Disabilities	Room 350, 350 Capitol Street, Charleston, WV 25304 304-356-4811 http://www.dhr.wv.gov/bhhf/Pages/contact.aspx	The Division provides leadership, facilitation, technical assistance, and funding to support children and adults who have intellectual/developmental disabilities.

WISCONSIN

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Department of Health Services Bureau of Long-Term Support	1 West Wilson Street, Room 418, PO Box 7851, Madison, WI 53707-7851 608-266-8560 dhswebmaster@wisconsin.gov	The Department is the primary state agency responsible for the development and implementation of statewide policy, services, and supports for people with developmental disabilities.

REGIONAL CENTERS:

http://www.dhs.wisconsin.gov/disabilities/dd_ctr/index.htm

WYOMING

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Behavioral Health Division, Developmental Disabilities Division	6101 North Yellowstone Road, 259A, Cheyenne, WY 82002 307-777-7115 800-510-0280 bhdmail@wyo.gov	The Division's mission is to promote, protect, and enhance the health of all Wyoming citizens.
Council on Developmental Disabilities	122 West 25th Street, 1st Floor West, Herschler Building, Room 1608, Cheyenne, WY 82002 307-777-7230 800-438-5791 wgcdd@wyo.gov	The Council's purpose is to assure that individuals with developmental disabilities and their families participate in and have access to needed community services, individualized supports, and other forms of assistance that promote independence, productivity, integration, and inclusion in all facets of community life.

OTHER

<u>ORGANIZATION</u>	<u>CONTACT</u>	<u>DESCRIPTION</u>
Learning Disabilities Association of America (LDA)	4156 Library Road, Pittsburgh, PA 15234-1349 412-341-1515 info@LDAAmerica.org	LDA visualizes a world in which: all individuals with learning disabilities are empowered to thrive and participate fully in society; the incidence of learning disabilities is reduced; and learning disabilities are universally understood and effectively addressed. LDA's mission is to create opportunities for success for all individuals affected by learning disabilities and to reduce the incidence of learning disabilities in future generations.

The Arc

1825 K Street NW, Suite
1200, Washington, DC
20006

202-534-3700
800-433-5255

info@thearc.org

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families. They encompass all ages and all spectrums from autism, Down syndrome, fragile X, and various other developmental disabilities.

Best Buddies

100 Southeast Second
Street, Suite 2200,
Miami, FL 33131

305-374-2233
800-892-8339

info@bestbuddies.org

Best Buddies is a nonprofit 501 (c)(3) organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment, and leadership development for people with intellectual and developmental disabilities.

Special Olympics

1133 19th Street NW
Washington, DC 20036-3604
USA

+1 (202) 628-3630
+1 (800) 700-8585
+1 (202) 824-0200 (Fax)

info@specialolympics.org

Special Olympics transforms lives through the joy of sport, every day, everywhere. They are the world's largest sports organization for people with intellectual disabilities: with 4.4 million athletes in 170 countries -- and millions more volunteers and supporters. They are also a global social movement.

Center for Independent Living of Broward

4800 N. State Road 7,
Suite 102 Ft. Lauderdale,
FL 33319

Voice: 954-722-6400

TTY: 954-735-0963

Fax: 954-735-1958

Toll Free: 888-722-6400

Under the Rehabilitation Act of 1978, Congress established the Center for Independent Living in response to individuals with disabilities need for core services focused on independent living skills training, peer support, information and referral, and advocacy. Since 1991, The Center for Independent Living of Broward (CILB) has served more than 60,000 individuals with disabilities in fulfilling their goals of independence and self-sufficiency. CILB strives to enhance the lives of people with disabilities, regardless of age, in Broward, Charlotte, Collier, Glades, Hendry, and Lee counties.

Autism's Got Talent

44 020 8882 0629

info@autismshow.co.uk

The Autism Show deserves the same production values and levels of marketing spend as other more mainstream events. They strive every year to stage a high quality and busy event while trying to keep their costs for visitors and exhibitors to a minimum. As a result they feel that they offer good value for money.

They enjoy working in partnership with others to ensure that they fully understand the needs of their visitor audience. The National Autistic Society has supported The Autism Show since its birth.

Erik's Ranch and Retreats

Minnesota contact:
3420 Heritage Dr.
Edina, MN 55435

612-401-3080

Montana contact:
1627 West Main St. #340
Bozeman, MT 59715

406-451-2722

Erik's Ranch & Retreats provides safe and unequalled living, working, social and recreational environments for young adults with autism, using its guiding principles of lifelong learning, individual community building and bidirectional integration through voluntourism. They're committed to giving these individuals a rewarding life on their own terms, experiencing dignity, compassion and the joy of continuing possibility.

Ability Catcher

AbilityCatcher
9921 Carmel Mountain
Road, #128
San Diego, CA 92129

AbilityCatcher has a mission to “humanize the way the world thinks and treats individuals with differing abilities.” The stories – both collective and individual – are the collateral behind this business. They are a creative think tank and production company that aims to cleverly and accurately portray rich stories in the ability space through a wide-variety of mediums.

Easter Seals

233 South Wacker Drive,
Suite 2400, Chicago, IL
60606

800-221-6827 (toll-free)

Easter Seals provides exceptional services, education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in their communities. Easter Seals has been helping individuals with disabilities and special needs, and their families, live better lives for more than 90 years. From child development centers to physical rehabilitation and job training for people with disabilities, Easter Seals offers a variety of services to help people with disabilities address life’s challenges and achieve personal goals.

American Association for Physical Activity & Recreation (Special Needs)

1900 Association Drive
Reston, VA 20191-1599

Telephone : 7034763431
Fax : 7034769527

MNelson@aahperd.org

AAPAR is dedicated to enhancing quality of life by promoting creative and active lifestyles through meaningful, inclusive physical activity, recreation and fitness experiences across the lifespan with particular focus on community-based programs.

The National Ability Center

Mailing Address:
National Ability Center
PO Box 682799
Park City, UT 84068

Physical Address:
National Ability Center
1000 Ability Way
Park City, UT 84060

Phone: 435.649.3991
Fax: 435.658.3992
Email: info@DiscoverNAC.org

The National Ability Center offers a wide variety of programs both seasonally and year-round. Activities include alpine and Nordic skiing, snowboarding, snowshoeing, horseback riding, hippotherapy, indoor rock climbing, swimming, archery, sled hockey, cycling, water-skiing, wakeboarding, kayaking, canoeing, paddle boarding, and challenge course activities.

The National Center on Physical Activity & Disability

4000 Ridgeway Drive
Birmingham, Alabama -
35209

1-800-900-8086
1-205-313-7475

email@nchpad.org

The National Center on Health, Physical Activity and Disability (NCHPAD) is positioned to effect change in health promotion/obesity management among people with disabilities through its existing 15-year history of providing advocacy, services and programs to numerous organizations and people throughout the country. The primary focus of the Center's approach is to collaborate with the nation's leading health advocacy and disability organizations in linking them to the hundreds of program initiatives ongoing across the nation, and using this framework to build inclusion and integration into these existing programs.

Autism Community Network

4242 Woodcock Drive,
Suite 101
San Antonio, TX 78228

Phone: (210) 435-1000
Fax: (210) 200-6056

The mission of Autism Community Network is to maximize the potential of children with autism by increasing autism awareness and services for families throughout the San Antonio area with an emphasis on collaboration with autism service providers, early diagnosis, and providing services to underserved young children and their families.

The Foundation School for Autism

2235 Thousand Oaks,
Suite 130
San Antonio, TX 78232

210-402-0253

Rheatha Miller
rlmiller@responsiveed.com
Campus Director

The ResponsiveEd community of schools is tuition-free, public charter schools dedicated to helping students of all ages achieve their full potential. At ResponsiveEd, They're all about options in education. Strongly tied to the communities they serve, the mission of their schools is to provide hope for students through an encouraging, innovative environment where they are academically successful and develop into lifelong learners.

Arts 'n Autism

P.O. Box 20111
Tuscaloosa, AL 35402

(205) 247-4990

artsnautism@gmail.com

The Arts 'n Autism after school and summer camp program was initiated in March 2004. It provides services to children from preschool to young adults with autism in the Tuscaloosa, Alabama area and surrounding counties. Arts 'n Autism was conceived by a veteran teacher of children with autism in the local public schools and a parent of a child with autism. Both founding members are still actively involved in the development and growth of Arts 'n Autism.

Spare Some for Autism

7474 Creedmoor Road
#125
Raleigh NC 27613
Telephone: (919) 844-1960
www.sparesomeforautism.org

Spare Some for Autism seeks to support families affected by ASD by educating them on such topics as literacy and coping with disabilities so that families will be better prepared to support each other.

Autism Family Foundation

Wanda Malone
Founder/Executive Director
wanda@autismfamily-foundation.net
630-803-8471

Autism Family Foundation was founded in 2010 and is a 501 (c) (3). AFF was created to provide resources, networking opportunities and financial assistance to local families impacted by Autism/ADHD.

Autism Speaks

New York
1 East 33rd Street
4th Floor
New York, NY 10016
Phone: (212) 252-8584
Fax: (212) 252-8676
Princeton
1060 State Road, 2nd Floor
Princeton, NJ 08540
Phone: (609) 228-7310
Fax #1: (609) 430-9163
Fax #2: (609) 430-9505
Los Angeles
6330 San Vicente Blvd.,
Suite 401
Los Angeles, CA 90048
Phone: (323) 549-0500
Fax: (323) 549-0547

Autism Speaks was founded in February 2005 by Bob and Suzanne Wright, grandparents of a child with autism. Their longtime friend Bernie Marcus donated \$25 million to help financially launch the organization. Since then, Autism Speaks has grown into the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. They are proud of what They've been able to accomplish and look forward to continued successes in the years ahead.

Autism Science Foundation

28 West 39th Street, Suite
#502
New York, NY 10018

Phone: 212 391 3913
Fax: 212 391 3954

Email: contactus@autism-sciencefoundation.org

The Autism Science Foundation is a nonprofit corporation organized for charitable and educational purposes, and exempt from taxation under section 501(c)(3) of the IRS code.

The Autism Science Foundation's mission is to support autism research by providing funding and other assistance to scientists and organizations conducting, facilitating, publicizing and disseminating autism research. The organization also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism.

Golden Hat Foundation

7301 Ranch Road 620 N
Suite 155, #111
Austin, TX 78726-4537

info@goldenhatfoundation.org

The mission of the Golden Hat Foundation is to change the way people on the autism spectrum are perceived, by shining a light on their abilities and emphasizing their great potential. With proper education and career training, these individuals can truly realize their dreams.

In addition to ongoing unique awareness initiatives that highlight capabilities of those on the autism spectrum and their free meetup groups that provide monthly outings and support meetings for autistic individuals and their families, their long-term goals include the establishment of innovative post-high school campuses designed to truly honor all autistic individuals - not just those considered "higher-functioning" - by creating an environment that supports and respects their individual needs and strengths.

The Center for Autism and Related Disorders, Inc.

19019 Ventura Blvd. Suite 300
Tarzana, CA 91356
Phone: (818) 345-2345
Fax: (818) 758-8015

CARD is committed to remaining at the forefront of research on ABA-based methods of autism assessment and treatment. CARD is equally committed to developing technology to make autism recovery available to professionals and families around the world. Based on over 30 years of research on child development and autism, CARD's breakthrough Web-based tool, Skills®, provides comprehensive skill assessment, individualized curriculum design, and the ability to track treatment progress with automatically-generated graphs and clinical timeline charts. Skills™ is designed to teach over 4,000 age-appropriate skills to children with autism, making it the most in-depth, multidisciplinary system of its kind in the world.

Families for Early Autism Treatment

P. O. Box 255722
Sacramento, CA 95865-5722

(916) 303-7405

feat@feat.org

Families for Early Autism Treatment, Inc. (FEAT) is a non-profit organization of parents, family members, and treatment professionals, designed to help families with children of all ages who have an Autism Spectrum Disorder (ASD), which includes Autistic Disorder, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), and Asperger's Disorder (AS). It offers a network of support where families can meet each other to discuss issues surrounding autism and treatment options. FEAT has a Board of Directors that meets monthly to discuss issues, establish priorities, and vote on the direction of the organization.

National Down Syndrome Society

800-221-4602

info@ndss.org

The mission of the National Down Syndrome Society is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.

Spina Bifida Association

Street Address:
1600 Wilson Blvd.
Suite 800
Arlington, VA 22209

Please send all correspondence to:
P.O. Box 17427
Arlington, VA 22216

Phone:
Main (202) 944-3285
Fax (202) 944-3295

Email:
sbaa@sbaa.org

The Spina Bifida Association (SBA) serves adults and children who live with the challenges of Spina Bifida. Since 1973, SBA has been the only national voluntary health agency solely dedicated to enhancing the lives of those with Spina Bifida and those whose lives are touched by this challenging birth defect. Its tools are education, advocacy, research, and service.

Through its network of [Chapters](#), SBA has a presence in more than 125 communities nationwide and touches thousands of people each year. Lives are changed by the programs SBA has created, the services provided, and the results of their advocacy efforts.

Shining Through Center

7365 Martin Grove Road
Woodbridge, Ontario L4L
9E4

Phone: 905-851-7955
Fax: 905-851-1132

250 Beecroft Road
Toronto, Ontario M2N
6W3

Phone: 416-782-4816

The Shining Through Centre for Children with Autism, a not-for-profit charitable organization, is a recognized leader in the field of autism, providing service excellence in therapy, education, research, and awareness to affected children and their families. Through their work, they provide intensive, comprehensive, and individualized therapeutic and educational programs to each of their children, based on the recognized principles of Applied Behaviour Analysis (ABA). ABA is the only scientifically-validated mode of engagement with children who have Autism that has been demonstrated to produce long-term and permanent learning.

Lucile Packard Foundation for Children's Health

400 Hamilton Avenue,
Suite 340
Palo Alto, CA 94301

(650) 497-8365

info@lpfch.org
www.lpfch.org

The vision of the Lucile Packard Foundation for Children's Health is that all children in the communities they serve are able to reach their maximum health potential.

The Six Degree Project

They are a grassroots student organization committed to improving the lives of children and youth with autism around the world, by providing awareness and knowledge. The six degree project is a student driven mission to get celebrities to participate in helping to create and to generate awareness around autism. By having community members and their networks connect to these celebrities, it will allow them to make a greater impact around the world.

Organization for Autism Research

2000 North 14th Street,
Suite 240, Arlington, VA
22201

Tel: 703.243.9710

The Organization for Autism Research (OAR) was created in December 2001—the product of the shared vision and unique life experiences of OAR’s seven founders. Led by these parents and grandparents of children and adults on the autism spectrum, OAR set out to use applied science to answer questions that parents, families, individuals with autism, teachers and caregivers confront daily. No other autism organization has this singular focus.

Kids Peace

4085 Independence Drive
Schnecksville, PA 18078-
2574

800-25PEACE (800-257-
3223)

kpinfo@KidsPeace.org

KidsPeace is a private charity dedicated to serving the behavioral and mental health needs of children, families and communities.

KidsPeace provides a unique psychiatric hospital; a comprehensive range of residential treatment programs; accredited educational services; and a variety of foster care and community-based treatment programs to help people in need overcome challenges and transform their lives. KidsPeace provides emotional and physical health care and educational services in an atmosphere of teamwork, compassion and creativity.

Paper Clouds Apparel

3434 North 11th Street
Suite 9
Phoenix, AZ 85014

[602-525-1315](tel:602-525-1315) - Robert
Thornton

Info@PaperCloudsApparel.com

Paper Clouds Apparel was formed to showcase the creative minds and artistic abilities of individuals with special needs while raising funds to provide financial support for special needs schools and organizations. They achieve this goal by selling t-shirts, hats and totes featuring artwork designed by individuals with special needs. Paper Clouds Apparel also hires individuals with special needs to package all of their sensory-friendly clothing. Fifty percent of the net proceeds from the sale of all merchandise is given to the cause they are promoting in each campaign.

Generation Rescue

13636 Ventura Blvd. #259
Sherman Oaks, CA 91423

877-98-AUTISM

Generation Rescue is the leading national organization that provides hope, information and immediate treatment assistance to families affected by autism spectrum disorders.

STRIVE U

28 Foden Road
South Portland, ME 04106

Phone: 207-774-6278
Fax: 207-774-7695

E-mail: info@pslstrive.org

STRIVE U provides post-secondary education and training to young adults with developmental disabilities in the realms of residential, employment, and community skills with the goal of enabling its graduates to live and work as full community members with maximum independence and productivity.

Unicorn Children’s Foundation

21100 Ruth & Baron Coleman Blvd. , Suite 250
Boca Raton, FL 33428

Phone: 561-620-9377
Fax: 561-620-9376

1350 Sherbrooke Street
West, Suite 700
Montreal, Quebec
H3G 2T4 Canada

Unicorn Children’s Foundation is an international non-profit organization dedicated to children and young adults with developmental, communication, and learning disorders through education, awareness, and research so that they have every opportunity to lead productive and fulfilling lives.

Unicorn Children’s Foundation’s key initiatives include: promoting early identification of symptoms associated with ADHD, autism, bipolar, dyslexia and other learning disorders; developing and disseminating worldwide ground-breaking and extensive evaluation and treatment guidelines; fostering communication and collaboration between parents, professionals and policy makers to promote learning and increased awareness; and to provide adequate tools and resources to better meet the needs of their beneficiaries.

Doug Flutie Foundation

PO Box 767
Framingham, MA 01701

508-270-8855 (Phone)
508-270-6868 (Fax)

The goal of the Flutie Foundation is to improve the quality of life for people and families living with autism.

They are dedicated to increasing the awareness of autism and the unique challenges of families who are faced with it every day. Their commitment is to support these families by helping them find the resources they need and by funding advocacy programs as well as educational, therapeutic and recreational opportunities.

Lindamood-Bell Learning Processes

1610 Arden Way #277,
Sacramento, CA 95815

Phone:(916) 929-8183

Lindamood-Bell helps children and adults improve language processing — the foundation of all communication and learning. For over 25 years, their intensive, process-based instruction has been used in Lindamood-Bell Learning Centers to strengthen the sensory-cognitive functions needed for reading and comprehension, and has proven successful for individuals with learning challenges, including dyslexia, ADHD, CAPD, and ASD.

Endnotes

- 1 Paradiz, Valerie, Ph.D. "Developing Self-Advocacy Skills: An Integral Aspect of Transition Planning." *Asperger's Association of New England*. Asperger's Association of New England, n.d. Web. 9 June 2014. www.aane.org/asperger_resources/articles/teens/developing_self_advocacy_skills.html.
- 2 "Transition Tool Kit." *Autism Speaks*. Autism Speaks, n.d. Web. 9 June 2014. www.autismspeaks.org/family-services/tool-kits/transition-tool-kit.
- 3 U.S. Department of Education Office for Civil Rights. "Free Appropriate Public Education for Students with Disabilities: Requirements under Section 504 of the Rehabilitation Act of 1973." *Office of Civil Rights*. U.S. Department of Education, Aug. 2010. Web. 9 June 2014. www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html.
- 4 Ibid.
- 5 NCLD Editorial Team. "What Is FAPE, and What Can It Mean to My Child?" *National Center for Learning Disabilities*. National Center for Learning Disabilities, n.d. Web. 9 June 2014. ncl.org/parents-child-disabilities/ld-rights/what-is-fape-what-can-it-mean-my-child.
- 6 "The Americans with Disabilities Act of 1990 and Revised ADA Regulations Implementing Title II and Title III." *Information and Technical Assistance on Americans with Disabilities Act*. United States Department of Justice Civil Rights Division, n.d. Web. 9 June 2014. www.ada.gov/2010_regs.htm.
- 7 "The ADA Amendments Act of 2008: Frequently Asked Questions." *Office of Federal Contract Compliance Programs*. U.S. Department of Labor, n.d. Web. 9 June 2014. www.dol.gov/ofccp/regs/compliance/faqs/ADAFaqs.htm.
- 8 Ibid.
- 9 Ibid.
- 10 "20 U.S. Code § 1401 - Definitions." *Legal Information Institute*. Cornell University Law School, n.d. Web. 9 June 2014. www.law.cornell.edu/uscode/text/20/1401.
- 11 NICHCY. "The Short-and-sweet IEP Overview." *Center for Parent Information and Resources*. Center for Parent Information and Resources, Mar. 2013. Web. 9 June 2014. www.parentcenterhub.org/repository/iep-overview/.
- 12 U.S. Department of Education, Office of Special Education Programs. "Individualized Education Program (IEP), Team Meetings and Changes to the IEP." *Building the Legacy: IDEA 2004*. U.S. Department of Education, 4 Oct. 2006. Web. 9 June 2014. <http://idea.ed.gov/explore/view/pl/%2Croot%2Cdynamic%2CTopicalBrief%2C9%2C>.
- 13 Ibid.
- 14 San Francisco Unified School District, Special Education Services. "Your First IEP Meeting." *E-ssential Guide*. San Francisco Unified School District, n.d. Web. 9 June 2014. www.sfusd.edu/en/assets/sfusd-staff/programs/files/special-education/First%20IEPfinalIEP.pdf.
- 15 "Questions to Ask College Disability Services Staff." *Oregon Student Access Commission*. Oregon Student Access Commission, n.d. Web. 9 June 2014. <http://oregonstudentaid.gov/aspire-students-disabilities-questions.aspx>.
O'Shaughnessy, Lynn. "12 Questions to Ask about a College's Disability Services." *The College Solution*. College Solution, 15 Aug. 2012. Web. 9 June 2014. www.thecollegesolution.com/12-questions-to-ask-about-a-colleges-disability-services/.
- 16 "Beginning the Search — Tips and Questions." *Partners for Student Success*. Special School District of St. Louis County, n.d. Web. 9 June 2014. www.ssdmo.org/step3/beginning_search.html.
- 17 "Can Children Stay on a Parent's Plan until Age 26?" *HealthCare.gov*. U.S. Centers for Medicare & Medicaid Service, n.d. Web. 9 June 2014. www.healthcare.gov/can-i-keep-my-child-on-my-insurance-until-age-26/.
- 18 "Sibling Caregivers Meet Unexpected Challenges." *MassMutual Financial Group*. Massachusetts Mutual Life Insurance Company, 21 Feb. 2013. Web. 9 June 2014. www.massmutual.com/aboutmassmutual/newscenter/pressreleases/articledisplay?mmcom_articleid=34b89774b4dfc310VgnVCM100000d47106aaRCRD.
- 19 Everson, J. M., and Moon, M. S. (1987). "Transition services for young adults with severe disabilities: Defining professional and parental roles and responsibilities." *Journal of the Association for Persons with Severe Handicaps*, 12 (2): 87–95.