

A RESOURCE GUIDE FOR AMERICA'S CAREGIVERS

Caring for children with special needs: A guide for new parents and caregivers

Cynthia L. Hutchins, CRPC,[®] ChSNC[®]
Director of Financial Gerontology
Bank of America



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Introduction

There are 13.6 million children in the United States who have special health care needs, and one in four households (25%) has at least one child with a disability.¹ Every day, all parents step into the roles of teacher, advocate, provider, taxi driver, nutritionist, disciplinarian, coach, mentor and comforter in chief. Parents of children with special needs are no different — except that they take on all of these responsibilities and more.

Parents and caregivers of a child with special needs may face heightened stress and physical and mental challenges that include sleep deprivation, feelings of isolation and loneliness, depression, and anxiety, along with resulting physical health issues. They're challenged with finding appropriate and affordable child care, addressing medical concerns, and identifying the best health care providers, educators, advocates and friends. If they have more than one child, they've got to juggle the needs, emotions, health and well-being of their other children as well. They are resilient, tenacious, energetic, enduring, soothing and loving. They are, in short, superheroes.

With the current emphasis on diversity and inclusion in our society, it's important that we not lose sight of the extraordinary skills that many people with special needs possess. Consider Anthony Ianni, the first Division I scholarship basketball player diagnosed

“Special needs parents are the equivalent of Batman, Captain America and the Incredible Hulk combined with a side of Mary Poppins.”

–Unknown

with autism. Or the popular comedic actor Dan Aykroyd, who has been very open about discussing his experiences with mild Asperger's syndrome. President Theodore Roosevelt had epilepsy, as do rapper Lil Wayne and singer-songwriter Neil Young. Musicians Stevie Wonder, Ray Charles and Andrea Bocelli have struggled with blindness. Thomas Edison was completely deaf in one ear and had partial hearing loss in the other. In spite of becoming completely deaf at the age of 46, Ludwig van Beethoven continued to write music and perform publicly as a symphony conductor. Actress Kristen Bell has quite candidly discussed her struggles with anxiety and depression. Actress Catherine Zeta-Jones has battled bipolar disorder, and Olympic gold medalist Simone Biles has been diagnosed with ADHD.

Indeed, Hollywood has embraced the societal challenge of educating the public about the special needs community to help create a more inclusive environment. Movies like *Children of a Lesser God*, *Rain Man*, *Forrest Gump* and *The Peanut Butter Falcon* and television shows like *Breaking Bad*, *Parenthood*, *Speechless* and *Life Goes On* all highlight the abilities and talents of those with special needs while not ignoring the challenges that they face. For children with special needs, an emphasis on ability rather than disability can be the catalyst that leads them to thrive and excel throughout their lives.

“I’m grateful that the discussion regarding special needs has evolved over time to become more open and less stigmatic than when I was growing up. The more we can communicate on this topic, the greater the probability



of finding the right supports for our loved ones with special needs.”

Amy Ho, Managing Director, Business Strategies and Initiatives Executive at Bank of America

Amy Ho, Managing Director, Business Strategies and Initiatives Executive at Bank of America (and a parent of a child with special needs), believes that positive role models, access to resources, open and honest communication, and a supportive community are vitally important in helping families of a child with special needs to thrive. She also acknowledges that we’ve come a long way as a society in how we approach this sensitive topic. “I’m grateful that the discussion regarding special needs has evolved over time to become more open and less stigmatic than when I was growing up. The more we can communicate on this topic, the greater the probability of finding the right supports for our loved ones with special needs.”

We hope that this resource guide will help new parents and caregivers of a child with special needs feel they’re better equipped, better educated and more empowered to embark on their incredible journey with their very special child and family.



Categories of special needs

Special needs can be classified into four main categories: physical, developmental, behavior/emotional and sensory-impaired. Common physical special needs include allergies and asthma, limb differences, juvenile and chronic arthritis, multiple sclerosis, cerebral palsy, and epilepsy. Common developmental delays may include Down syndrome, autism spectrum disorder or dyslexia. Behavioral/emotional special needs can be difficult to diagnose and may include dissociation, obsessive-compulsive disorder, attention-deficit/hyperactivity disorder and eating disorders. Anxiety is included here as well but may be a special need itself or can be a symptom of another special need. Sensory-impaired special needs include sight impairment (including blindness) and being hard of hearing or deaf. Sensory processing disorder, where a person has difficulty receiving and responding to information from the senses, would also fall into this category. The next sections will look at a few of these disabilities in more detail.

Physical special needs — Epilepsy

Epilepsy is a neurological disorder that affects the central nervous system. The condition is characterized by seizures that disrupt the electrical activity in the brain. Most often, the cause of the seizures is unknown but may be related to a brain injury, brain structure, genetics or metabolic causes.² Currently, 65 million people worldwide are living with epilepsy. The United States is home to 3.4 million people with epilepsy, and 150,000 new cases occur each year. One in 26 people in the United States will develop epilepsy at some point in their life. The cause is unknown in approximately 60% of cases.³

For most people with epilepsy, medications can stop or control seizures. Uncontrolled seizures are seizures that continue despite taking one or several medications. For the caregiver, understanding what triggers a seizure, the symptoms of the seizure, and how to help during and after a seizure are critical and can save a life.

Seizure triggers

No two cases of epilepsy are exactly alike, and seizure triggers may be different from one person to another. There are, however, some common and well-known triggers:

- **Missed medication** — Missed medication is the most common reason why people with controlled seizures have sudden, unexpected seizures (called breakthrough seizures). For those with uncontrolled seizures, missing medication can cause more frequent and/or more intense seizures.⁴
- **Lack of sleep** — Proper rest is very important for a person with epilepsy. During sleep, the brain's electrical and hormonal activity changes. These changes in and of themselves can be triggers and can be the cause of seizures that occur during sleep. These hormonal and electrical changes can also trigger seizures in those who haven't gotten enough sleep. Unfortunately, epilepsy can disturb sleep, and sleep deprivation can cause seizures. On top of this, some epilepsy medication

can cause insomnia, aggravating the situation even more. Finally, people with epilepsy are more prone to sleep apnea. So, while the National Sleep Foundation recommends seven to nine hours of sleep per night (for those between the ages of 18 and 64), this can be easier said than done for a person with epilepsy.⁵

- **Stress** — It's common knowledge that prolonged stress can cause a whole host of unhealthy conditions, including heart disease and diabetes. For a person with epilepsy, stress can also trigger seizures. It's not known why this occurs, but there are some theories. Studies have shown that when people experience stress, they may feel a loss of control or develop anxiety. This can cause hyperventilation, which in turn can increase abnormal brain activity, which can provoke a seizure. For those with frequent or prolonged stress, it's advisable to talk to a doctor or mental health professional to learn stress management techniques.⁶
- **Alcohol** — Small amounts of alcohol don't typically cause seizures, but binge drinking (or having three or more drinks) can be a trigger. Many times, alcohol-related seizures occur during withdrawal. Withdrawal seizures can occur six to 72 hours after drinking. It's advisable to avoid being alone after drinking. It's also important to be aware that some seizure medications can lower one's tolerance for alcohol.⁷
- **Menstruation** — Many women have increased seizures during menstruation. This is most likely due to hormonal changes that occur during this time.⁸
- **Sickness (such as a cold, flu or sinus infection)** — Fever, dehydration, sleeplessness or insomnia, or the physical stress of being sick can trigger seizures. Medications used to treat an illness can also be triggers.⁹

- **Other triggers** — Though much less frequent than the aforementioned triggers, flashing lights, some herbal medications and dietary supplements, and some essential oils can trigger seizures. Nutrient deficiencies such as low levels of sodium, magnesium and calcium can as well. A Vitamin B6 deficiency can be a trigger in newborns and infants.¹⁰

Seizure symptoms

A seizure is a sudden, uncontrolled electrical disturbance in the brain that can cause changes in behavior, movement and consciousness. There are many types of seizures, and they vary according to where in the brain they begin and how far they spread. Typically, a seizure may last from 30 seconds to two minutes. Any seizure that's five minutes or longer in duration is a medical emergency.¹¹

Symptoms of a seizure can range from mild to severe and may vary according to the type of seizure. Typical symptoms may include confusion, staring, jerking movements of the limbs, loss of consciousness or awareness, and cognitive and emotional symptoms.¹²

The Mayo Clinic suggests that immediate medical help should be sought if any of the following occurs:¹³

- A seizure lasting longer than five minutes
- Breathing that does not return to normal after a seizure stops
- Not regaining normal consciousness after a seizure stops
- High fever
- Heat exhaustion
- A seizure experienced by someone who has diabetes or is pregnant
- Being injured during a seizure



Seizure first aid

Those who know or are caring for a person with epilepsy should familiarize themselves with the basic first aid procedures for their loved one. Knowing the basics could literally save a life. The Epilepsy Foundation suggests that there are three steps for general first aid for all seizures: Stay, Safe and Side.¹⁴

1. Stay

Remain with the person

and time the seizure (stay calm, check for medical ID).¹⁵



2. Safe

Keep the person safe

(guide them away from harmful objects and help the person steer clear of dangerous situations like traffic, heights and stairs). Ask others to stay back so as not to confuse or embarrass the person after the seizure is over.¹⁶



3. Side

Turn the person onto their side

if they're unaware or unconscious, and loosen the clothing around their neck. If they are aware, help them sit down in a safe place. If they're convulsing, lay them on the floor and turn them on their side to help them breathe more easily.¹⁷

Other first aid tips include:

- Don't put anything into the person's mouth. People can't swallow their tongue during a seizure, and putting something into their mouth (like a spoon or stick) could cause them to choke or swallow the object.
- Don't restrain the person. This won't stop a seizure and could result in injury, confusion, agitation or aggression.
- Stay with the person until he or she is awake, alert and responsive.
- Be sensitive and supportive.
- Call 911 if a seizure lasts longer than five minutes, there are repeated seizures, the person has difficulty breathing, or the seizure occurs in water. Also call 911 if the person is injured, sick or pregnant; the person doesn't return to a normal state; it's a first-time seizure; or the person asks for medical help.¹⁸



The Epilepsy Foundation offers a seizure first aid course, which can be accessed at [epilepsy.com](https://www.epilepsy.com).

Developmental needs — Down syndrome

Down syndrome is caused by an error in cell division that results in an embryo's having three copies of chromosome 21 instead of the usual two.¹⁹ It's named for the English physician John Langdon Down, who was the first to designate the condition as a separate and distinct syndrome and to accurately describe the traits associated with it. Down's work was published in 1866 and earned him the title of the "father" of Down syndrome.²⁰

A great deal of research has been done since then. In 1959, Jerome Lejeune, a French physician, identified Down syndrome as a chromosomal condition, and in 2000 an international team of research scientists was able to identify the roughly 329 genes on chromosome 21. This breakthrough has led to great advances in our understanding of Down syndrome.²¹

The cause of Down syndrome is still unknown. There is no indication that it's caused by environmental factors or is attributable to any activities that the parents may have engaged in before or during pregnancy. A woman over the age of 35 has an increased chance of giving birth to a baby with Down syndrome. The age of the mother is the only factor that's been identified as increasing the chances of a baby being born with Down syndrome, but it can originate with either parent, with 5% of cases being traced to the father.²²

In 2008, it was estimated that 250,700 people, or one out of every 1,200 people living in the United States, had Down syndrome.

Down syndrome is the most common chromosomal disorder. According to the Centers for Disease Control and Prevention (CDC), approximately 6,000 babies (about 1 in 700) in the United States are born with Down syndrome annually. In 2008, it was estimated that 250,700 people, or one out of every 1,200 people living in the United States, had Down syndrome.²³ Life expectancy has increased

significantly for people with Down syndrome, rising from about 10 years in 1960 to an average of 47 years in 1976.²⁴ A person with Down syndrome can now expect to live 60 years or more.²⁵

An individual with Down syndrome will have some typical but distinct facial features. These may include a flattened face, small head, short neck, protruding tongue, upward slanting eyes, or unusually shaped or small ears. Other features may include poor muscle tone, broad short hands with a single crease in the palm, small hands and feet, excessive flexibility, and short stature.²⁶

Health care costs are significantly higher for a child with Down syndrome. For a child up to 4 years old, they may be as much as 12 times higher compared with a child of the same age without Down syndrome. About 50% of infants who are born with Down syndrome are also born with a congenital heart defect. The health care costs for these infants are about five times higher in the first year of life than for infants with Down syndrome who don't have a heart defect.²⁷ While some children may have no significant health problems, others may experience health issues including obesity, asthma, seizure disorders, sleep apnea, thyroid disease and intestinal blockage at birth. Children with Down syndrome are at risk of developing pulmonary hypertension. About 50% will also have problems with hearing and vision.²⁸

Children with Down syndrome have a wide range of abilities, and each child learns in different ways. Most have mild to moderate intellectual impairment and will reach goals at a different pace from children who don't have Down syndrome. They can and will learn new skills throughout their lifetime, and it's impossible to tell at birth what they'll be capable of. Some children with Down syndrome have needs that are best met in a specialized program or school. Others, however, do very well in their neighborhood public school with children of their own age who don't have Down syndrome. A few people with Down syndrome will attend college, and many will transition to semi-independent living. While others may continue to live at home, they may still hold jobs and be successful contributors to their communities.

Developmental needs — Autism spectrum disorder

Autism spectrum disorder is a developmental disorder that, scientists believe, has multiple causes that act together to alter the way the brain develops. There's still a lot to learn about the causes of autism spectrum disorder. There are many subtypes of autism, and it's believed these are most likely influenced by genetic and environmental factors.²⁹

Autism spectrum disorder is an umbrella term used to include five pervasive developmental disorders (PDDs) including autistic disorder, Asperger's disorder, Rett's disorder, childhood disintegrative disorder and pervasive development disorder — not otherwise specified.³⁰ Because it's a spectrum disorder, there is a wide variation in symptoms, and each person with autism will have different developmental challenges, but they'll also have different abilities and strengths. The abilities of people with autism spectrum disorder can vary greatly. Some people with autism may be able to communicate very well, and others may be completely nonverbal. Some children with autism will grow up to live independently and hold a job with very little support or even no support at all. Others may need a lot of help on a daily basis for their entire lives.³¹

The core symptoms of autism are challenges with social communication skills and restricted and repetitive behavior. Many times, autism may be accompanied by sensory sensitivities or medical issues including gastrointestinal disorders, seizures and sleep disorders. Those with autism may also experience mental health challenges such as depression, anxiety and attention issues.³²

People with autism may experience social communication challenges as well as other challenges in social situations. Approximately one-third of people with autism are nonverbal. Others may have some difficulty with both verbal and nonverbal communication. They may have trouble with spoken language, use gestures inappropriately or have difficulty making eye contact. They may have challenges with understanding

facial expressions and understanding or using the appropriate tone of voice, and may misunderstand when an expression should not be taken literally. People with autism may also experience challenges in their emotional development. They may have difficulty recognizing their own emotions or the emotions or intentions of others and may be challenged when it comes to expressing their emotions. Some social situations may be overwhelming as well.³³

As is the case with social communication challenges, restricted and repetitive behaviors may vary greatly from person to person and may include repetitive body movements, repetitive motions with objects (such as spinning wheels or flipping levers) and staring at lights. Many times, a person with autism will have a need for a strict routine or schedule around daily activities, meal times and menus, and other frequent undertakings.³⁴

Signs of autism will usually appear at or before age 2 or 3. It's critical that children showing signs of autism receive a professional evaluation as early as possible. Children who receive early intervention will have the best outcomes as they grow up.³⁵

Autism doesn't change a baby's appearance, so it's especially important to understand signs or cues that could be an early indicator. For example, research has shown that babies who develop autism begin making less eye contact around the age of 2 months. This declining eye contact may be the earliest indicator of autism. Another indicator is not following you with their eyes. Children with autism may not show awareness of their own name at the appropriate age or may have delayed language or speech. Other signs and symptoms may show up as a child grows.³⁶ While all children grow at their own pace, the CDC offers a "Developmental Milestones

Guide” to get a general idea of the skills that should be developing and the appropriate age. They also offer a Milestone Tracker app that’s available for download.

The American Academy of Pediatrics recommends that children have developmental screenings at the ages of 9, 18 and 30 months, and additional screening for autism should occur at 18 and 24 months. As noted above, early intervention can significantly increase the chances of positive health outcomes for children with autism, largely due to the amazing adaptability of a child’s growing brain and nervous system.³⁷

Behavioral/emotional needs — Anxiety, OCD, bipolar, conduct, eating and psychotic disorders

The category of behavioral and emotional disorders, also referred to as mental illness, includes anxiety disorders, bipolar disorder, conduct disorders, eating disorders, obsessive-compulsive disorder and psychotic disorders.

Emotional disorders can have an effect on more than just emotional well-being. Depending on the disorder, a person’s physical, social and cognitive skills may be affected as well. The National Alliance on Mental Illness of Southern Arizona states, “Mental illnesses are medical conditions that disrupt a person’s thinking, feeling, mood, ability to relate to others and daily functioning.” In fact, mental illnesses can have the effect of diminishing a person’s capacity to cope with normal, everyday life.

Children with emotional disorders may exhibit several behaviors, including hyperactivity; aggression; self-harm; withdrawal; excessive fear or anxiety; immature behavior, including temper tantrums; inappropriate crying; poor coping skills; and academic challenges that cause them to perform below their grade level.³⁸ While many children will exhibit some of these behaviors at different points in their development, children with an emotional disorder will exhibit these behaviors continuously over an extended period of time,

indicating that they’re having challenges coping with their environment or peers. While the actual causes of emotional and behavioral disturbances are not known, it’s believed that many factors, including heredity, dysfunctional family environment, diet and stress, may be contributing factors. However, no evidence has been found to support the notion that any of these factors are the direct cause of emotional or behavioral disorders.³⁹

More than 17.1 million children have or have had a psychiatric illness. Fifty percent of people who have a psychiatric illness experience it before the age of 14, and 75% will experience the illness by the age of 25.⁴⁰ The most common behavioral and emotional disorders experienced by children are anxiety disorders, attention deficit hyperactivity disorder (ADHD) and other disruptive behavior, depression, bipolar disorder, and eating disorders.⁴¹

Anxiety disorder

Anxiety disorder is a broad term that’s used to cover several different disabilities, with irrational fear being the common denominator. These include generalized anxiety disorder, panic disorder (including panic attacks), agoraphobia (an extreme fear of entering crowded places, of leaving home or of not being able to escape), social anxiety disorder, separation anxiety, obsessive-compulsive disorder (OCD), post-traumatic stress disorder (PTSD) and other specific phobias.⁴² According to the Anxiety Disorders Association of America, anxiety disorders are the most common psychiatric disorder affecting both children and adults. These are highly treatable with counseling and medication. Unfortunately, less than 40% of those needing treatment actually receive it.⁴³

Obsessive-compulsive disorder (OCD)

OCD is characterized by recurrent and unwanted thoughts (the obsession) and/or repetitive behaviors (the compulsion, such as cleaning or hand washing). The person engages in these behaviors in the hope of preventing or eliminating the obsessive thoughts. The compulsive behavior may provide temporary relief, and not performing these rituals markedly increases the person’s anxiety level.⁴⁴

Bipolar disorder

Bipolar disorder, also known as manic-depressive disorder, is a serious medical condition that causes dramatic mood swings. These mood swings will range from overly “high” to sadness and hopelessness and will go back and forth between the two extremes. Many times the mood will normalize for a period of time in between. Along with these mood swings, the person with bipolar disorder will experience severe changes in energy and behavior.⁴⁵

Conduct disorders

Conduct disorders is an umbrella term used to refer to a group of behavioral and emotional problems in children and adolescents. Those who are affected have difficulty following rules or behaving in a way that society deems acceptable. They may act out through aggression to people and animals, destruction of property, deceitfulness, lying, stealing, skipping school, and other rule violations. Treatment for these disorders is generally dependent upon a child’s age, symptoms and general health, and also on how severe the condition and behavior are. Children may be treated using cognitive-behavioral therapies, which might include treatment to help them become a better problem solver; family therapy; or peer group therapy to improve social and interpersonal skills.⁴⁶

Eating disorder(s)

Eating disorders are serious (and sometimes fatal) illnesses. They’re characterized by extreme eating behavior (eating too much or too little) or extreme feelings about body weight or shape. According to the National Institute on Mental Health, girls are more than twice as likely to develop an eating disorder (3.8%) as boys (1.5%). Common eating disorders include anorexia nervosa, bulimia nervosa and binge-eating disorder.⁴⁷

Anorexia involves self-starvation and dramatic weight loss, while bulimia involves binge eating and purging. Binge eating is also a disorder that’s characterized by excessive, out-of-control eating but doesn’t involve purging. Treatments for these eating disorders must be more comprehensive in scope, addressing not only the symptoms and

medical consequences, but also the psychological consequences. Treatment should also address the biological, interpersonal and cultural influences that contribute to the disorder. Therefore, a multifaceted approach involving a team of professionals may have the most successful outcomes.⁴⁸

Psychotic disorders

Psychotic disorders are severe mental disorders that cause abnormal thinking and perceptions. The main symptoms of psychotic disorders are delusions or false beliefs, and hallucinations or false perceptions. Schizophrenia is an example of a psychotic disorder. There are genetic, environmental, biological and psychological risk factors for developing a psychotic disorder. While treatment should be individualized, it typically is a combination of psychotherapy and medication.⁴⁹

As mentioned earlier, treatment for emotional and behavioral disorders will typically include a team of professionals from the medical and mental health fields. For children with behavioral or emotional disorders, everyone involved in their education and care should be included on that team. It’s important to coordinate services among school, home and the community and to develop strong lines of communication among all of the parties involved.



To locate systems of support in your community, check out:

- [Mental Health America](#)
800.969.6642
- [National Suicide Prevention Lifeline](#)
800.273.TALK (8255)
- [National Alliance on Mental Illness](#)
800.950.NAMI (6264)
- [National Mental Health Consumer’s Self-Help Clearinghouse](#)

Sensory impairment needs — Hearing and vision impairment

Hearing impairment/deafness

Hearing loss and deafness can affect children's communication and language skills as well as their social development. It can hinder their ability to learn as well as their ability to recognize everyday dangers. Many times, it's the child care provider who first notices that a small child has a hearing problem. Early detection and intervention are very important. The earlier children can begin to receive treatment and services, the more likely they'll be able to grow to their full potential. While some hearing issues may be temporary, many may be more permanent.

Parents who suspect that their child may have a hearing loss or impairment should first consult with the child's pediatrician. While not able to help with the hearing loss itself, the pediatrician can treat ear and upper respiratory infections and inflammations that may affect hearing. Following a visit to the pediatrician, parents will likely develop a team of specialized professionals. These include:⁵⁰

- **Audiologist** — A licensed and certified professional who specializes in the study of hearing disorders, an audiologist can identify and measure the hearing loss as well as recommend appropriate hearing aids.

- **Otorhinolaryngologist** — Commonly referred to as an ENT or otologist, an otorhinolaryngologist is a physician who specializes in diseases of the ear, nose and throat. **Federal regulation requires that an otorhinolaryngologist must examine the child to rule out any complications before parents purchase a hearing aid.**
- **Service coordinator** — This individual assists parents with locating and obtaining necessary services and providers.
- **Speech and language pathologist** — A specialist in the diagnosis and habilitation of speech and language issues, the speech pathologist is a licensed professional who will work with the child on, and teach parents how to help with, speech and language development.
- **Teacher of the deaf or hard of hearing** — It's recommended that parents consult with one of these state-certified teachers as early as possible, even if the child is an infant. The teacher may provide home visits and one-on-one early interventions.



There are several indications of hearing impairment that parents should be aware of.

They should take note if a child:⁵¹

- Does not respond when spoken to
- Does not progress from making sounds to saying words
- Interrupts conversations and/or seems unaware that others are talking
- Does not startle at loud noises
- Talks infrequently or not at all
- Turns one ear toward a speaker
- Does not turn toward sounds
- Cannot be understood when speaking
- Is alert and attentive to visual cues but is uninterested in or inattentive to things that can only be heard
- Does not wake up in response to sounds
- Leaves out sounds when talking
- May respond to loud sounds but not to softer, normal sounds
- Speaks in a monotone
- Cannot follow verbal instructions
- Cannot follow verbal instructions

Visual impairment/blindness

If a child is visually impaired, it means that the child's vision cannot be corrected to a normal level. There are many different causes of visual impairment, and the degree of the impairment can range from mild to severe (including blindness). Blindness doesn't necessarily mean that the child cannot see anything at all. In many cases, a child may see light, colors, shapes and indistinct objects but still be considered legally blind. This residual vision can be very helpful as a child navigates through life.

Children who are visually impaired are capable of learning and, in fact, do learn, very well. The challenge for them is that an enormous amount of learning takes place using vision, so they must learn to use their other senses or be taught using other methods. Therefore, children with a visual impairment will use their senses of hearing, touch, smell and taste as their primary information-gathering tools. A great amount of their learning is through the use of their hands. They'll learn a great deal if given opportunities to explore and experience objects directly. By holding an object in their hands, they explore its dimensions and learn the details to build an understanding of the whole object in their mind. Parents can support sensory learning by appealing to these other senses. For instance, encourage the child to smell, listen, taste (where appropriate) and touch.

While children with visual impairments need to learn the same subjects and skills as sighted children, they have the additional challenge of learning an expanded set of skills that are vision-related. They must learn to move around in their environment safely and independently. This is known as orientation and mobility (O&M). They must learn to use assistive technologies and any residual vision as efficiently and effectively as possible. If appropriate, they'll also learn to read and write Braille.

Intuitively, parents know that they'll need to make some adaptations to the child's home, school and play environment, but knowing which adaptations are necessary to keep the child safe while also encouraging and nurturing independence and confidence can be challenging.



To learn how to adapt the home, parents may want to consult Family Connect at [familyconnect](https://familyconnect.org).



Common signs of visual impairment in children include:⁵²

- Their eyes don't move together when following an object or face.
- Their eyes are crossed, turned out, turned in, flutter from side to side or up and down, or do not focus.
- Their eyes bulge, dance or bounce in rapid rhythmic movements.
- Their pupils are unequal in size or appear white instead of black.
- They repeatedly shut their eyes or cover one eye.
- They are unusually clumsy.
- They frequently squint, blink or rub their eyes, especially when there is no bright light present.
- They sit too close to the television or hold toys or books too close to the face.
- They avoid tasks that require good vision.

Educating the child with special needs

The Individuals with Disabilities Education Act (IDEA) and the individualize education plan (IEP)

The Education for All Handicapped Children Act (EHA) was enacted in 1975 to support states and municipalities in meeting the educational needs of children with disabilities and their families. The name was changed to the Individuals with Disabilities Education Act (IDEA) in 1990 when the act was reauthorized. Before the passage of EHA, many children with special needs were denied access to education. In 1970, only one in five children with special needs received education, and many states had laws excluding these children, including those who were deaf or blind, as well as those with emotional or intellectual disabilities.⁵³

In the 2018–19 school year, public schools in the United States have seen significant improvement from those dismal numbers, with special education and related services provided to more than 7.5 million children with special education needs.⁵⁴

Since then, significant progress has been made to develop and implement special education programs, including programs geared toward early intervention and related services.⁵⁵ In the 2018–19 school year, public schools in the United States have seen significant improvement from those dismal numbers, with special education and related services provided to more than 7.5 million children with special education needs.⁵⁴ More children with special needs are now being educated in their neighborhood schools (instead

of separate schools or institutions), and rates of high school graduation and postsecondary school enrollments have increased as well.⁵⁶

IDEA requires that each child with special needs must have an individualized education plan (IEP). The IEP is a written document that outlines the child’s education program and should be (as the name implies) tailored to the individual needs of the specific child. According to the U.S. Department of Education, “The IEP creates an opportunity for teachers, parents, school administrators, related services personnel and students (when appropriate) to work together to improve educational results for children with disabilities. The IEP is the cornerstone of a quality education for each child with a disability.”⁵⁷ There are several key members of the IEP team who come together to write the plan in order to derive the most benefit for the child. By law, the child’s parents, teachers, a representative of the local education agency and the child with special needs must be included in the IEP meeting. Other individuals may be invited at the discretion of the parent or the education agency.⁵⁸

IDEA requires that certain information be included in the IEP, including:⁵⁹

- **Current performance** — This information is derived from evaluation results using classroom assignments and tests, including tests given to decide eligibility for services. It will also include observations made by parents, teachers and other staff.
- **Annual goals** — These should be reasonable goals that can be accomplished for the year. They may address academic and social, behavioral and physical aims as well as other educational needs. These goals must be measurable to assess achievement.

- **Special education and related services** — This is a listing of education and services to be provided to the child.
- **Participation with nondisabled children** — The plan should specify the extent to which the child will not participate in regular classroom instruction and school activities.
- **Participation in state and districtwide tests** — The IEP must state modifications in the administration of standardized tests, if any, and the reason why any of these tests are inappropriate for the child as well as any provisions that will be made for alternative testing.
- **Dates and places** — Indicate when services will begin, how long they will last and the frequency with which they will be provided.
- **Transition services needed** — The plan should address the courses the child needs to reach the stated goals. A statement of needed transition services must be included with subsequent IEPs beginning at or before age 14.
- **Age of majority** — In states that transfer rights at the age of majority, a statement must be included in the IEP declaring that the student has been told of any rights that will transfer to them. This must be included at least one year before the child reaches the age of majority.
- **Measuring progress** — This is a statement that describes how the child's progress will be measured and reported to parents.

Under IDEA, children with special needs have the right to receive related services that will help them benefit from the educational programs detailed in the IEP. These services may include (but are not limited to) audiology, transportation, speech pathology, social work services, occupational therapy, physical therapy, recreation, psychological services, parent counseling and training, and more.⁶⁰



Government benefits for children with special needs

Supplemental Security Income payments

The Social Security Administration provides some income benefits for children with special needs or disabilities, but the eligibility requirements can be difficult to meet. Under the Supplemental Security Income (SSI) program, a minor child (under the age of 18) can qualify for benefits if they have a medical condition that meets the Social Security definition of disability for children and if the child's resources and income are within certain eligibility limits.⁶¹ The amount of the payment will be different from state to state, since some states supplement the SSI payment.

When determining income eligibility, the Social Security Administration will consider both the child's income and resources as well as the income and resources of family members living in the same household with the child. There is no minimum age for a child to be eligible to receive payments. Once the child reaches the age of 18, consideration of a parent's income ceases, and only the child's income and resources are considered in determining benefits. The Social Security website details the income eligibility limitations as well as a listing of states that supplement the SSI payments.⁶²

There are also disability standards that must be met:

- For children under the age of 18, there must be a “medically determinable physical or mental impairment or impairments which result in marked and severe functional limitations.”⁶³
- “The impairment(s) has lasted or can be expected to last for a continuous period of at least 12 months or be expected to result in death.”⁶⁴
- “[T]he child is blind or meets the same definition of ‘blind’ as applies to adults.”⁶⁵

The state agency determines whether the child meets the criteria for disability, and this process may take three to five months. However, there are some medical conditions that qualify to have payments made immediately, for up to six months, while the state agency determines whether the child has a qualifying disability. These include, but are not limited to, total blindness, total deafness, cerebral palsy, Down syndrome, muscular dystrophy, low birth weight (below two pounds, 10 ounces), symptomatic HIV infection and severe intellectual disability. In the event that the state agency determines that the child's condition does not qualify for SSI, the recipient doesn't have to pay back payments that have already been received.⁶⁶

Medicaid

Medicaid is a health care program for people who have limited income and few resources. It's administered by the state, and programs differ on a state-by-state basis. In most states, a child who is receiving SSI payments will automatically qualify for Medicaid. Other states require an application to receive health care under Medicaid. Some states allow all children to receive Medicaid benefits even if they don't qualify for SSI. It's important to check with your state Medicaid agency for more information and assistance in determining eligibility and benefits.⁶⁷

Legal and financial considerations

Every adult should make sure that they have a legally executed will, health care directive, health care proxy and power of attorney. A parent of a child with special needs should take care to consider a special needs trust, a guardianship and a letter of intent.

Special needs trust

SSI and Medicaid programs are needs-based and, as such, have strict asset and income limitations. In order to preserve a child's eligibility for these benefits, parents should consider creating a special needs trust (SNT). Instead of passing an estate directly to a child with special needs, the SNT can receive the estate for the benefit of the child. If administered properly, any funds left to the SNT will not be countable as assets when determining eligibility for government benefits. In addition, having an SNT can ensure that funds in the trust will be managed properly and benefit the child for his or her lifetime.

There are different types of SNTs, and each has its own benefits and drawbacks. It's recommended that the grantor of the trust consider consulting with an attorney who specializes in special needs planning to ensure that the trust is designed according to the intent of the grantor. The attorney will be able to explain each trust, the terms for governing how the trust funds can be used, how to determine which funds should go into the trust, and what happens to the remaining trust funds upon the death of the child for whom the trust has been set up.

Perhaps the most important and difficult decision that needs to be made when establishing an SNT is who to designate as the trustee. A trustee is charged with safeguarding the trust assets on behalf of the trust beneficiary. Like a trustee of every type of trust, trustees of an SNT have a duty of loyalty to the trust beneficiary and must act solely in the best interest of that beneficiary. They

have the responsibility of carrying out the terms of the trust agreement, keeping accurate records, filing tax returns and reporting to the beneficiaries as the trust or law requires. Trustees must not mix their own assets with the assets of the trust and must maintain separate checking and investment accounts. In general, trustees must not use the assets of the trust for their own benefit, and assets must be invested in a prudent manner.

The trustee of an SNT also has the additional responsibility of ensuring that the public benefits (SSI, Medicaid and subsidized housing) are maintained. Quite often, grantors of an SNT are inclined to choose a family member as the trustee. They feel that a family member will have an understanding of the child's needs and act in the best interest of their child. However, when considering a family member as the trustee, it's important to assess whether that person has the time, knowledge and skill to take on the responsibility. This is especially critical as it pertains to making distributions from the trust in such a way that the beneficiary doesn't lose eligibility for public benefits.

Professional trustees, such as banks, trust companies or attorneys, may be a good alternative to consider when choosing a trustee for an SNT. An important consideration when looking at professional trustees is the fee they charge for their services. For larger trusts, these fees are typically reasonable, but for smaller trusts, there may be a minimum annual fee, and this fee may be high. While professional trustees would have expertise in trust management, they may not have the specific skill set needed to manage

an SNT. It's important to determine their area of specialization upfront. Beyond drafting and administering the actual trust document, it's advisable to consult your trusted Merrill financial advisor for advice and guidance on managing the investments within the trust.

Types of SNTs

There are a few different types of SNTs, and the type of trust that should be established is determined by where the property that's being used to fund the trust originates.⁶⁸

A first-party SNT is established if the property funding the trust originates with the beneficiary of the SNT.⁶⁹ These are most often used when the trust beneficiary inherits assets outright or receives a settlement in court. Many times, a first-party SNT is established when people own assets in their own name prior to becoming disabled, and on becoming disabled they need to qualify for public benefits.⁷⁰ An individual first-party SNT may be established only for individuals who meet the government definition of disabled and are under the age of 65 at the time the trust is created and funded.⁷¹

More often, a third-party SNT is created. These are typically used by parents who are planning in advance for the care of their child who has special needs, but may also be established by a grandparent, sibling or any other party as long as it's someone other than the beneficiary of the trust.⁷² These trusts are usually funded upon the death of the grantor of the trust.⁷³ A stand-alone SNT (an SNT not established under a will or as a subtrust within a living trust) exists during the lifetime of the grantor and therefore may receive gifts from any third-party source prior to the death of the grantor.⁷⁴

The most important difference between third-party SNTs and first-party SNTs is what happens to SNT property when the beneficiary dies. Upon the beneficiary's death, the third-party SNT is not required to use the remaining assets to reimburse

any state Medicaid benefits received by the beneficiary during his or her lifetime. As a result, this type of SNT is a useful planning tool for people who want to set aside property for a beneficiary with disabilities, preserve essential public benefits during that beneficiary's lifetime, and remain in full control of where all of the remaining SNT assets will go upon the beneficiary's death.⁷⁵

Guardianship

When children reach the age of 18, regardless of any disabilities they may have, the law considers them to be adults. Therefore, parents are the legal guardians of their child only until he or she reaches age 18. If children with special needs are unable to care for themselves or make financial and medical decisions on their own behalf, the parents will need to file a petition for guardianship with the court.

There are two types of guardianship: guardianship of the person and guardianship of financial matters.

- **Guardianship of the person** grants authority to decide where the child will live, make decisions about medical care, and provide for comfort and maintenance needs including food, clothing and other matters that contribute to the child's well-being.⁷⁶
- **Guardianship of the estate** is also called a conservatorship. The guardian will use the ward's assets to pay bills, apply for government benefits, in some states, and handle insurance issues and any other financial matters for the child with special needs.

There are different levels of guardianship as well. These include full or plenary guardianship (guardian has all of the powers allowed by law), a partial or limited guardianship (guardian has only some of the powers allowed by law), or a conservatorship (guardianship of financial matters).⁷⁷

Letter of intent

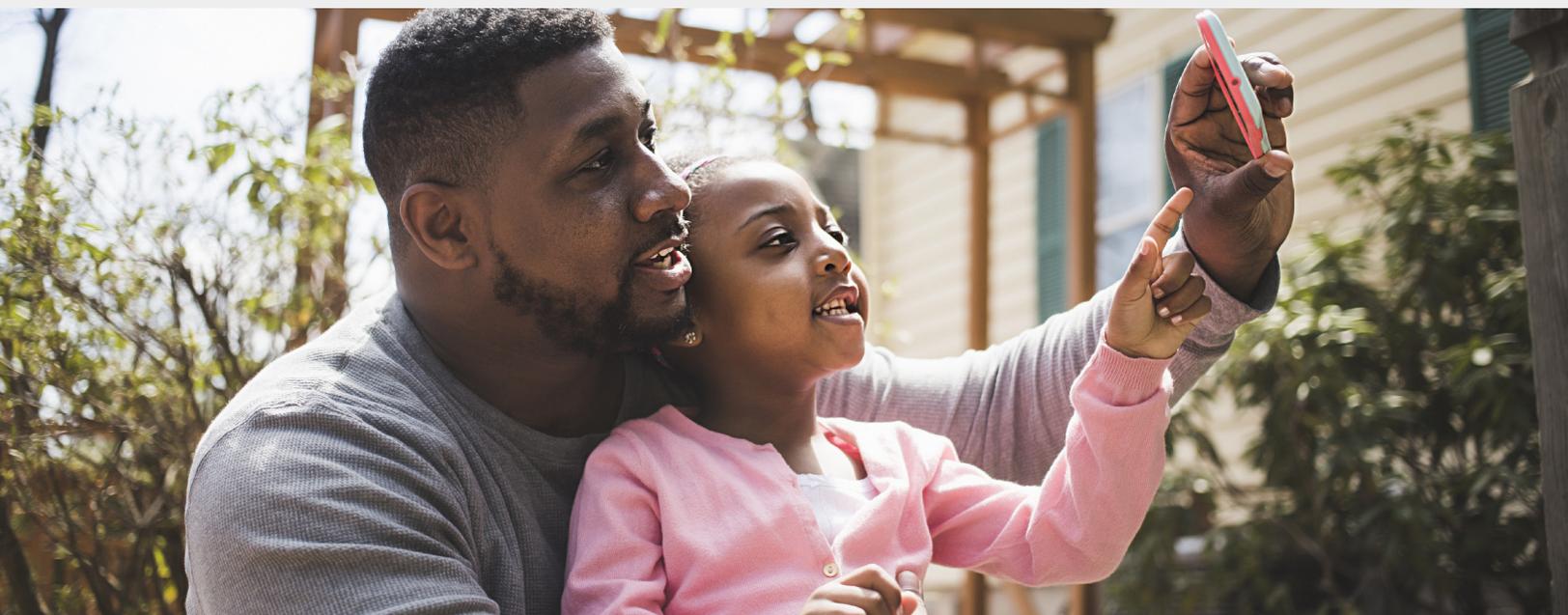
The letter of intent or letter of instruction is a document that informs a trustee about your child's functional abilities, routines, preferences, medical history, likes and dislikes, and any other information that will help your child live his or her best life. Parents have spent their child's lifetime gathering this information, and providing it to a future caregiver or trustee can be invaluable. This nonbinding document captures the information in one place and helps future trustees or caregivers avoid having to learn by trial and error.



A well-thought-out letter of intent might include:⁷⁸

- Family history
- Local resources
- Residential care needs
- Educational information, including past and current enrollment and future educational goals
- Special interests, talents and activities
- Employment guidance
- Important social, behavioral and personal relationships, including family, friends, teachers and caregivers
- Social and recreational activities
- Favorite foods, television shows, movies and books
- Routines
- Medical information (such as doctors and therapists)
- Medications, with an explanation of how they are administered
- Parents' final expression of love, hopes and desires for their child

Keep in mind that these three documents are a very basic starting point. There are several more complicated considerations that parents of a child with special needs will need to address, especially as the child grows up. Among the most important of these (and outside the scope of this paper) are planning for when the child reaches the age of majority and planning for care in the event that the parent(s) predeceases their child.



Selecting an attorney to help with your special needs trust and documents

While selecting an attorney for any purpose can be challenging, it's particularly challenging for new parents who need specialized guidance in order to make decisions that will affect not just their child with special needs, but their other children, other family members and even generations to come. According to the Special Needs Alliance, beyond recommendations and referrals from those in similar circumstances (which tend to be the best resource), there are three places that can be helpful in narrowing down your search: general public references, rating services and professional association memberships.⁷⁹

Many people will begin by searching the internet, and this can be helpful as a starting point. However, keep in mind that the internet will provide you with what basically amounts to the attorney's business card, access to a website, and the attorney's stated area of practice. It's essential to go beyond this information and research the attorney's qualifications and experience and verify their expertise in special needs legal planning.

As a next preliminary step, there are several rating services that may be useful. While not entirely flawless or objective, they are designed to provide information on the attorney's practice and reputation. Some of these services will provide peer reviews, and some even provide client comments. They should not, however, be used as the only gauge for evaluating an attorney's professionalism or ability.

One means of determining whether an attorney specializes in SNTs or special needs legal issues is to look at professional organizations. The Special Needs Alliance is the only national membership organization for special needs planners. This is

an invitation-only organization focusing on training and professional development for its members. In order to be invited to join the Special Needs Alliance, the members must have a reputation for being among the best-qualified attorneys in their communities.

There are other specialized professional associations, including:

- **The American Bar Association (ABA).** It's the largest national bar group providing separate divisions according to specialization. There's a real property, trust and estate section (RPTE) that may be helpful, though these attorneys don't necessarily specialize in special needs planning.
- **The National Academy of Elder Law Attorneys (NAELA).** Although the name indicates "elder law," they are the largest national organization with a focus on special needs planning issues.
- **The National Organization of Social Security Claimants' Representatives (NOSSCR).** Members focus on advocacy before the Social Security Administration and don't necessarily focus on special needs planning.
- **The Academy of Special Needs Planners.** Any attorney who would like to acquire additional resources or training can join this organization. They focus on practice development and specialized programs, and membership in the Academy of Special Needs Planners indicates a strong interest in the field of special needs planning.

Before making a final selection, whittle down the list and interview each attorney to make sure you're compatible and that they can draft documents and make appropriate recommendations that will address your priorities and wishes.

Achieving a Better Life Experience (ABLE) accounts

The ABLE Act is considered to be the “most significant federal legislation addressing the needs of persons with disabilities since the Americans with Disabilities Act, passed over 25 years ago.”⁸⁰

Section 529 of the IRS code established the framework for education savings plans, originally designed to help families save for college. The 529 plan was expanded in 2017, under the Tax Cuts and Jobs Act, to allow for savings to cover the cost of private elementary and secondary school tuition. The ABLE Act is a provision of the 529 section of the IRS code that allows money to be set aside for a person with special needs in much the same way. The law allows a person who has been determined to have a disability (before the age of 26) to save money above the asset limit for SSI and Medicaid and not jeopardize those benefits. Contributions to an ABLE account can be made by any person and must be made using after-tax dollars. These contributions are not federally tax deductible, but some states allow for state income tax deductions for contributions. Currently, 43 states and the District of Columbia maintain ABLE programs. An ABLE account can be opened only through the state-designated program, and each program has an easily accessible website to facilitate opening an account online.

Contributions to an ABLE account are limited to \$15,000 per year in 2021, and this amount is based on the annual gift tax exclusion. The Able to Work Act allows working ABLE account owners who don't participate in an employer-sponsored retirement plan to contribute up to \$27,760 in 2021, depending on their income, and eligible individuals may make these additional contributions each year until the end of 2025, when the act expires.⁸¹ States have set limits for total allowable savings in an ABLE account. These limits range from \$235,000 to \$529,000. There are further limitations that apply to recipients of SSI. These limitations are critical to keep in mind, as SSI benefits could be affected. The first \$100,000 in ABLE accounts is exempt from the SSI resource limit. Once the account value exceeds \$100,000 (when combined with other resources), SSI benefits would be suspended. When resources fall below the \$100,000 threshold, benefits can be reinstated.

ABLE accounts are easy to set up and don't require the services of an attorney. They grow tax-deferred, and distributions will be tax-free as long as the distribution is used to pay for qualified disability expenses. Qualified expenses include the cost of education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative service, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and expenses approved under regulations.⁸²

Support for parents of children with special needs

Caring for the caregiver

Most parents have days filled with earning a living, coordinating schedules, driving the family “taxi,” grocery shopping, meal preparation, home maintenance, managing the family finances and being a hero on call... all while trying to achieve some semblance of work-life balance.

“Increased awareness of the diversity of these children’s needs, the unrelenting challenges their caregivers confront, and the important resources available to caregivers throughout their journeys is foundational to assuring that these



individuals can access the support they deserve.”

Mary D. Naylor,
a Marian S. Ware Professor
in Gerontology at the
University of Pennsylvania
School of Nursing

For a parent of a child with special needs, there is the added responsibility of managing doctor visits and therapy sessions, dealing with insurance companies, and overseeing the child’s education, to name a few. Add to that the endless worry: Am I doing everything I can to help my child grow and thrive? Am I doing it right? Am I maintaining my other relationships? Am I paying enough attention to my other children and to my spouse? Am I performing to the best of my ability at work? All of this can be not only exhausting, but can also

create an unmanageable and concerning level of stress. Mary D. Naylor, a Marian S. Ware Professor in Gerontology at the University of Pennsylvania School of Nursing, states it this way: “It’s impossible to overstate the superhuman role assumed by caregivers of children with special needs. Increased awareness of the diversity of these children’s needs, the unrelenting challenges their caregivers confront, and the important resources available to caregivers throughout their journeys is foundational to assuring that these individuals can access the support they deserve.”

Many times, you may not even be aware that you’re feeling stress and anxiety, so it’s critical to your own well-being that you be aware of the signs. Some common signs that you’re experiencing caregiver stress may include feeling overwhelmed or constantly worried, fatigue, sleeping too much or not enough, weight fluctuation (up or down), irritability, loss of interest in things that used to be enjoyable, sadness, headaches, body pain or other physical problems, and abuse of alcohol or drugs.

There are several things that parents and caregivers can do to alleviate their stress and, in general, declutter their lives. The biggest (and perhaps the hardest) thing you can do for yourself is to ask for and accept help from family and friends. Most people want to help but don’t know exactly what you need or when you need it. Don’t be afraid to ask for help and make specific requests. If your sister asks how she can help, tell her that you need a hand with meal preparation on a certain day every week if that’s what you need. Maybe you need someone to stay with the children for a few hours so that you can go to the gym or the spa, or just to go off into your quiet space to read a book or watch your favorite television show. Recharging your batteries is important so that you can bring your best self to all of your many roles. Your loved ones will, most likely, be happy to help!

Sometimes it's helpful to create a list of things that would make your daily life easier. Do you need help with picking up the kids from school? Put it on the list. Do you need someone who can help you with yardwork? Put it on the list. Once you've defined what your needs are, you can then delegate some of these things to those who offer to help. If your budget allows, consider some home health care assistance. Many insurance companies will cover this cost for a few hours a week (depending on the child's medical needs), and many employers have included this in their suite of employee benefits. In addition, many children with special needs will qualify for home and community-based Medicaid waivers that can cover the cost of respite care. Many of these programs have waiting lists, though, so it's important to apply early. Some members of the military also qualify for respite care as part of their child care benefits. In-home providers can give you the time you need to take care of your own well-being. Sometimes, they can even be hired for the overnight hours, giving you a rare opportunity to get away and reconnect with your spouse.

Many times, parents of children with special needs may feel as if they're the only people who can be trusted to handle their child's care. While this may be true to an extent, that doesn't mean that taking care of your own physical, mental, emotional and spiritual health and well-being should be neglected. If you're feeling this way, consider asking a trusted loved one or close friend to attend caregiver training. Many hospitals and social service agencies offer training at little or no cost, thus giving you the confidence that your child will be in good hands in your absence.

Oftentimes, parents of children with special needs don't need someone who can perform a specific task. It may be that some simple companionship will be just what the doctor ordered! Be sure to keep your relationships strong and thriving. If you can't get out of the house, invite a friend over for lunch or coffee. Ask them to watch a movie or join you in a hobby that you both enjoy. Be sure to laugh. Connect with them on a level that you reserve just for them.

Connect with support groups, both online and in person. It's very valuable (and inspiring) to connect with like-minded people who are in similar situations. It can be good for the soul when you know you're not alone.

And a few things you can do by yourself, for yourself:

- Stay positive!
- Set realistic expectations (for yourself and others).
- Take a few minutes each day to clear your head (try yoga or meditation).
- Get organized.
- Laugh. A lot!
- **REMEMBER:** You're not alone. You're a superhero!

Employer support for parents of children with special needs

Employers today recognize that parents of children with special needs face monumental challenges. Supporting these employee parents through a robust menu of benefits geared toward their unique needs can be mutually beneficial. The challenges facing parents of children with special needs include meeting financial demands such as higher health care costs; finding and accessing affordable, reliable child care; managing day-to-day schedules; and achieving a work-life balance that will increase the quality of life for themselves and their families.

When employers do not proactively address this need, it can cause a range of negative effects for both the employee and the organization: lost productivity, poor health and high medical costs, as well as recruitment and retention challenges, financial anxiety and, ultimately, intense competition for a shrinking pool of talent. However, employee caregiving also presents important opportunities for proactive employers that are willing to align their competitive advantage with employee needs. Those organizations that design and implement benefits to support their working caregivers can mitigate

“My parents are aging, and eventually I’ll be the primary caregiver for my younger sister, who has special needs. Knowing so many resources are available through my employer has allowed me to find comfort in



what will be a life-changing experience.”

Mary Krupinski,
Senior Vice President,
Senior Audit Director,
Corporate Audit and Credit
Review at Bank of America

productivity losses, recruit and retain valuable talent, and realize a vital competitive advantage. By taking some of the worry off of employees’ shoulders, they can experience heightened employee morale, loyalty and productivity as well as a reduction in absenteeism and negative employee health consequences. Mary Krupinski, Senior Vice President, Senior Audit Director, Corporate Audit and Credit Review at Bank of America, reflected on how valuable this employer support can be. “My parents are aging, and eventually I’ll be the primary caregiver for my younger sister, who has special needs. Having conversations with my parents on how to be prepared has at times been challenging. Knowing so many resources are available through my employer has allowed me to find comfort in what will be a life-changing experience.”

Just as employers recognized the need to develop benefits that catered to young parents and to employees who are caregivers for older adults, they’re now developing benefits specific to parents with children who have special needs. Some of the benefits that employers might offer include:

Employee assistance programs

An employee assistance program (EAP) is a workplace-based program that helps employees resolve issues that are affecting their professional performance, such as alcohol or drug abuse. The EAP has evolved in recent years, and many now cover a broad range of issues including child care, elder care, legal services, employee wellness programs and issues, and counseling for personal or relationship issues. They may also offer referral services to find child care and special needs resources. EAP services are usually offered at no cost to the employee; delivered via phone, online, by email or in person; and are usually offered to employees, their spouses and their children.

Increased paid time off

Many companies are providing increased paid time off, including increasing the number of days allowed for family leave, medical leave, maternity leave and paternity leave. They’re also allowing paid time off to be used for multiple purposes. For example, allowing sick days to be used as personal days off can free up time for parents to address a child’s special needs. Some companies are allowing workers to “donate” their days off to another employee who needs them. Organizations may also address the need for additional time off on a case-by-case basis, giving the employees the assurance that if an emergency arises, the employer will likely work with them to address their needs.

Flexible work schedules

Many organizations offer work-from-home options, hybrid options (a combination of work from home and onsite), flexible hours/shifts, job sharing and more. These arrangements can be very beneficial to parents who are juggling doctor’s appointments and other issues that require them to be away from the job during normal working hours.

Child care arrangements

Many companies offer benefits that subsidize child care costs. Larger organizations may offer onsite child care centers. These centers may even hire professionals who are trained to care for children with special needs. Knowing that your child is close by and having the ability to check in during the course of the workday can provide immeasurable peace of mind to parents.

Flexible spending accounts and health savings accounts

These accounts are designed to allow employees to contribute pretax dollars that grow tax-deferred and come out tax-free if used to pay for health care expenses. These funds can be used to cover the expenses of all members of the household, not just the employees themselves.

Respite care/emergency backup care

Companies are now offering employees the ability to take advantage of emergency backup care and respite care at a greatly reduced cost. These services can be used in emergency situations so that employees can have professional care instead of missing work to provide the care themselves. This can also be very beneficial for the stressed-out parent who just needs a few hours away to refuel and refresh.

Access to legal services

Many benefit plans offer access to legal services such as preparation of a will, special needs trust, health care proxy, power of attorney or other document. These are just a few of the offerings that are now becoming commonplace, especially in larger organizations. There's little doubt that, as employers start to realize the mutual benefits that can be derived from these offerings, benefits packages will expand and become broader and more innovative in scope.

A word about neurodiversity in the workplace

Neurodiversity—the idea that there’s a range of neurological differences that should be regarded as part of normal variation in the population—is a concept that some large companies are beginning to embrace. Adopting the belief that, with some help and accommodation, people who are differently abled can contribute greatly to an organization, these employers have launched programs to diversify their workforces to include those on the autism spectrum as well as those with other developmental challenges like ADHD.



According to the *Harvard Business Review*, the neurodiverse population is an untapped resource, with an unemployment rate as high as

80%.⁸³

Many of those who are working are underemployed, settling for jobs that are normally given to students, even though many have advanced degrees in such fields as engineering, statistics, computer science and mathematics.⁸⁴ Given the skills shortage that has emerged in certain industries, including technology, data analytics and cybersecurity, why aren’t more employers tapping into this largely overlooked segment of the population?

One reason may be that large corporations use structured hiring methods and processes that are developed to be scalable and apply across the entire organization. For many in the neurodiverse population, rising to the top of the applicant pool can be difficult under these traditional guidelines.

As an example, many neurodiverse applicants may not possess solid communication skills, be good conversationalists or make strong eye contact—qualities that are needed to come across well in an interview. Other companies may not be aware of the accommodations that may be needed in order to help neurodiverse applicants thrive and excel in the traditional workplace.

Many neurodiverse employees will require some deviation from established workplace norms and practices. Most of these accommodations are relatively simple and inexpensive, including providing noise-cancelling headphones or enhanced lighting. Some will require some individualization in an employee’s workspace.

Employers that have reimagined their hiring policies to benefit neurodiverse individuals include Hewlett Packard, Microsoft, SAP, IBM, Deloitte, Caterpillar and Dell Technologies. Although these programs haven’t been in existence for very long, companies report that they’ve seen increases in productivity, quality of output, innovation and employee engagement.⁸⁵

Conclusion



“We meet no ordinary people in our lives. If you give them a chance, everyone has something amazing to offer.”

– Ryan Seacrest

Children with special needs have amazing things to offer, talents to share and lessons to teach us. Through the years, they’ve taught us to never give up, to be patient and accepting, to glory in our differences, and to think positively about the future. They’ve taught us to accept without conditions and to love with our whole hearts. With the right planning, information and support, parents of children with special needs can be better equipped to handle the unique challenges that come with this role and to focus on the joys of raising their very special child.

It’s our hope that this paper and the comprehensive resource guide beginning on the next page will help parents and families to prepare, adapt and thrive.

Helpful resources

Following is a list of helpful resources with their web addresses:

Financial resources

- **Social Security Administration** – ssa.gov
- **SSI Income Limits for Children** – ssa.gov/ssi/text-child-ussi.htm
- **List of SSA Offices** – disability-benefits-help.org/social-security-disability-locations
- **Government Benefits for Children with Special Needs** – ssa.gov/pubs/EN-05-10026.pdf
- **ABLE NOW** – able-now.com
- **ABLE National Resource Center** – ablenrc.org

General resources

- **The ARC** (thearc.org) is an organization dedicated to the promotion and protection of the human rights of people with intellectual and developmental disabilities. It provides families with access to information, advocacy and skills that support full inclusion and participation at every age. There are more than 700 ARC chapters throughout the United States, and its website provides a directory to find local support and guidance.
- **Parenting Special Needs Magazine** (parentingspecialneeds.org) is a free, interactive and informative magazine for parents of children with special needs. The magazine provides articles, tips, videos and stories to inform, encourage, empower and inspire parents.
- **KidsHealth** (kidshealth.org) is an information site that aims to give families the tools and confidence to make the best health choices. It offers doctor-reviewed advice on physical, emotional and behavioral topics; separate sections for parents, younger kids and teens; and articles, slideshows, videos and health tools designed to help families learn and make informed decisions.

- **Parent to Parent USA** (p2pusa.org) matches each parent with a fellow parent who has a child with the same special health care need. This allows parents to have a contact for sharing information, receiving support and creating new friendships. The group provides local support in almost every state.
- **National Youth Leadership Network** (nyln.org) works to break isolation among people with disabilities between the ages of 16 and 28. It hosts workshops for young people to develop leadership skills and promote inclusion.
- **The M.O.R.G.A.N. Project** (Making Opportunities Reality Granting Assistance Nationwide) (themorganproject.org) offers a large library of resources and information. It also assists families with travel expenses for medical treatments and gifts of medical equipment not covered by insurance.
- **The Federation for Children With Special Needs** (fcsn.org) provides information, support and assistance to parents of children with disabilities, their professional partners and their communities. It also promotes participation among parents in shaping and influencing public policies that affect their families and offers a peer support network.
- **Best Buddies** (bestbuddies.org), founded by Anthony Kennedy Shriver, is an international organization dedicated to helping children with special needs develop friendships and stay social. They work to help children with special needs improve their communication skills, secure jobs and develop the necessary skills to live independently.
- **Friendship Circle** (friendshipcircle.org) emphasizes, like Best Buddies, the importance of friendships in the special needs community. It has locations across the United States and pairs teen volunteers with a child with special needs in order to form lasting friendships.

Resources to help find respite care

- **Lifespan Respite Care Program** (acl.gov/programs/support-caregivers/lifespan-respite-care-program) offers coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. The Lifespan Respite Care Program is a federally funded grant program that assists states with improving access to respite care, and may provide financial assistance. The program is offered in many states and the District of Columbia. Check the website to see whether there's a program in your state.
- **ARCH National Respite Network** (archrespite.org) can supply a list of providers in your area for visiting nurses, child care centers and sleep-away camps.
- **Some members of the military may qualify for respite care as part of their child care benefit.** Visit Child Care Aware of America (childcareaware.org) or Tricare (tricare.mil).
- **The American Camp Association** (acacamps.org) has an online listing of camps for children with special needs broken down by type of camp, cost, length of stay, state/region and camper's age. The site also offers general and age-appropriate advice for parents.
- For more information on selecting a camp for your child with special needs, read the article titled "Camps for Kids With Special Needs" by KidsHealth Medical Experts at kidshealth.org.

Mental and behavioral health resources

- **The National Alliance on Mental Illness (NAMI)** (nami.org) is a leading voice on mental health. It's a community-based alliance of more than 600 local affiliates and 48 state organizations that raise awareness and provide support and education.
- **The American Academy of Child and Adolescent Psychiatry (AACAP)** (aacap.org) provides education advocacy and research to child psychiatrists, families and youth to promote the healthy development of children, adolescents and families.

- **The Anxiety and Depression Association of America (ADAA)** (adaa.org) focuses on improving the quality of life for those with anxiety, depression, OCD and PTSD. It provides education and can assist in finding treatment, resources and support.
- **The National Eating Disorders Association (NEDA)** (nationaleatingdisorders.org) is a nonprofit organization supporting families and individuals affected by eating disorders.
- **The International OCD Foundation** (iocdf.org) is a nonprofit dedicated to helping those with OCD and related disorders. Through education, research and training, it strives to provide a supportive community for those affected by OCD so that they can live full and productive lives.
- **The American Psychological Association** (apa.org) provides information and support on specific emotional disturbances.
- **The National Institute of Mental Health** (nimh.nih.gov; 866.615.6464) offers authoritative information, tips and resources on mental health disorders in English and Spanish.
- To locate systems of support in your area:
 - **Mental Health America** (arc.mentalhealthamerica.net/find-an-affiliate; 800.969.6642)
 - **National Suicide Prevention Lifeline** (suicidepreventionlifeline.org; 800.273.TALK (800.273.8255))
 - **The National Alliance on Mental Illness** (nami.org/Find-Your-Local-NAMI; 800.950.NAMI (800.950.6264))
 - **The National Mental Health Consumer's Self-Help Clearinghouse** (cddirectory.org)

Resources for epilepsy

- **The Epilepsy Foundation** (epilepsy.com) offers information, resources, training and comprehensive expert information on epilepsy and seizures as well as online management tools. There's also a section to help find a doctor who specializes in epilepsy and a tools and resources section geared toward both patients and caregivers.
- **The Managing Epilepsy Well Network** (managingepilepsywell.org) provides self-management programs to help people with epilepsy learn more about their condition and develop skills to help manage their health. Some of the programs offered include:
 - **HOBSCOTCH** (Home Based Self-Management and Cognitive Training Changes Lives) teaches memory skills to people with epilepsy. Instruction can be delivered in person or via telephone.
 - **PACES in Epilepsy** (Program for Active Consumer Engagement in Self-Management) improves self-management, confidence and quality of life. The program can be offered in person, in a community setting or by phone.
 - **Project UPLIFE** (Using Practice and Learning to Increase Favorable Thoughts) uses cognitive behavioral and mindfulness therapies to reduce depressive symptoms and improve depression management. This is an eight-week program that's delivered over the phone.

Resources for autism spectrum disorder

- **Autism Speaks** (autismspeaks.org) provides education, resources, tools and support according to life stage (ages 0–3, 4–12, 13–17, 18–21 and adults age 22+) as well as resources specifically geared to the person with autism, parents, siblings, grandparents, educators, employers, health care professionals and researchers.

- **The Autism Society of America** (autism-society.org) provides advocacy, education, information and referral, and community at the national, state and local levels (through a network of affiliates). It also hosts a comprehensive national conference each year.

Resources for hearing impairment

- **The Alexander Graham Bell Association** (agbell.org) is a national organization for parents and professionals providing information, support, training and resources to help guide families through their journey with their hearing-impaired child.
- **The American Society for Deaf Children (ASDC)** (deafchildren.org) provides support, education and resources to families of children who are deaf or hard of hearing. They are especially focused on providing full communication access to children through the use of sign language.
- **Hands and Voices** (handsandvoices.org) provides information and resources to support communication without regard to modes or methodologies.
- **Parent to Parent** (p2pusa.org) is a national organization that aligns parents and families with another family who has a child with the same health need or disability in order to provide emotional and informational support.
- **State Early Hearing Detection and Intervention Program (EHDI)** (infanthearing.org/status/cnhs.php). Each state has an EHDI program. The state coordinator is familiar with resources in that state.
- **Hearing First** (hearingfirst.org) is an interactive website, available in both English and Spanish, that promotes listening and spoken language development. Offerings include video tutorials, language activities, webinars and access to current research.

Resources for vision impairment

- **Family Connect** (familyconnect.org) is a service offered by the American Printing House for the Blind that provides resources, support and information for parents of children who are blind or visually impaired.
- **The American Council of the Blind** (acb.org; 800.424.8666) provides education, resources and advocacy for the blind or visually impaired and their families.
- **Parent to Parent** (p2pusa.org) is a national organization that aligns parents and families with another family who has a child with the same health need or disability in order to provide emotional and informational support.
- **The American Foundation for the Blind** (afb.org/directory.aspx) provides assistance with finding services in your area.

Additional resources include:

The American Printing House for the Blind – aph.org; 800.223.1839

Lighthouse Guild – lighthouseguild.org; 800.284.4422

The National Braille Association – nationalbraille.org

National Braille Press – nbp.org; 888.965.8965

The National Federation of the Blind – nfb.org

National Library Service for the Blind and Physically Handicapped, Library of Congress – loc.gov/nls

The National Eye Institute, National Institutes of Health – nei.nih.gov (English); nei.nih.gov/health/espanol (Spanish)

Prevent Blindness America – preventblindness.org; 800.331.2020

Resources for Down syndrome

- **The National Down Syndrome Congress (NDSC)** (ndscenter.org) is the oldest organization and support group in the United States for those affected by Down syndrome. The organization focuses on those with the disorder, their relatives and the professionals who work with them. It advocates for those with Down syndrome through education, legislation, medical care and disability awareness.
- **The National Down Syndrome Society (NDDS)** (ndss.org) is known as the national advocate for the value, acceptance and inclusion of those living with Down syndrome. The website offers informative articles, personal stories that seek to raise funds for Down syndrome research and awareness, and help finding support groups in your area.
- **The National Association for Down Syndrome (NADS)** (nads.org) offers specific support for parents and grandparents of children with Down syndrome as well as support for health care professionals. It provides mentoring programs, parent support groups, parent workshops and family retreats. Their website contains educational information and helpful links to information related to Down syndrome.
- **The Down Syndrome Resource Foundation** (dsrf.org) helps people with Down syndrome reach their full potential through educational programs and services. It focuses on understanding the learning style of those with Down syndrome as well as support for parents of children with Down syndrome. Children can enroll in a variety of classes specifically designed for them, including reading, music, and communication and language programs.

Suggested reading

Following is a list of books that may be useful, informative, supportive or inspirational:

- *Being the Other One: Growing Up With a Brother or Sister Who Has Special Needs* by Kate Strohm
- *Different Dream Parenting: A Practical Guide to Raising A Child With Special Needs* by Jolene Philo
- *Different Dreams: Reflections and Realities of Raising A Child With Developmental Disabilities* by Mary Kay DeGenova, Ph.D.
- *One Step at a Time* by Jennifer Smith and Bradie Kvinsland
- *Parenting an Adult With Disabilities or Special Needs: Everything You Need to Know to Plan for and Protect Your Child's Future* by Peggy Lou Morgan
- *Ten Things Every Child With Autism Wishes You Knew* by Ellen Notbohm
- *The Reason I Jump: The Inner Voice of a Thirteen-Year-Old Boy With Autism* by Naoki Higashida
- *What to Expect When Parenting Children With ADHD: A 9-Step Plan to Master the Struggles and Triumphs of Parenting a Child With ADHD* by Penny Williams
- *Will My Kid Grow Out of It?: A Child Psychologist's Guide to Understanding Worrisome Behavior* by Bonny J. Forrest, J.D., Ph.D.
- *You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children With Disabilities* by Stanley D. Klein, Ph.D., and Kim Schive

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