



Welcomes



you to the family!



For additional resources, please contact the National Down Syndrome Congress at 800-232-6372 or [info@ndsccenter.org](mailto:info@ndsccenter.org).

# TABLE OF CONTENTS

A letter from the NDSC.....	3
Congratulations .....	4
A Baby is a Baby First.....	4
Understanding Down syndrome.....	6
Talking about Down syndrome .....	8
Developmental expectations and medical issues.....	9
“What Parents Wish They'd Known” .....	12
The important role of siblings.....	13
Welcome to Holland.....	14
Early intervention and services.....	15
Your child's education .....	16
Waiver information .....	17
Additional resources .....	18
Bibliography .....	20



# A letter from the NDSC

---

On behalf of the National Down Syndrome Congress, we want to welcome you to the family. The birth of a child brings joy and excitement, concerns, and challenges. This is no less true when the child happens to have Down syndrome. Becoming a parent is life-changing - becoming the parent of an individual with Down syndrome may bring changes that you did not anticipate. As a new parent, you may be unfamiliar with Down syndrome – what it is and how it will affect your new baby and family. You most likely have concerns about your baby's well-being and your ability to cope and provide for every need of your child. We want you to know that we are here for you. As you adjust, please know that our staff and medical and education experts, researchers, and advocates are here to support you and your family.

The NDSC is perhaps best known for what many refer to as the Down syndrome community's "giant family reunion." The annual 4-day NDSC Convention is the world's largest gathering of people with Down syndrome, their families, and the professionals who serve them and has something for everyone. During the general conference, world-renowned experts present nearly 100 workshops for parents and professionals who care for those with Down syndrome. The event also hosts the Youth & Adults Conference produced for and by individuals with Down syndrome age 15 years and older and the Siblings Conference, designed specifically for school-age siblings of children with Down syndrome. Of course, there are also plenty of social and networking opportunities for everyone to enjoy!

In addition to our member families, there are nearly 300 local and regional organizations across the U.S. that provide support, information, and awareness opportunities for families. To find the one closest to you, please visit <https://www.ndsccenter.org/programs-resources/affiliate-organizations/local-and-national-support-networks/>.

Our mission is to provide information, advocacy, and support concerning all aspects of life for individuals with Down syndrome. We want to make the transition to parenting a child with Down syndrome easy, joyful, and fun and be with you through your child's life.

Again, congratulations on your new baby, and welcome to the family!

Sincerely,

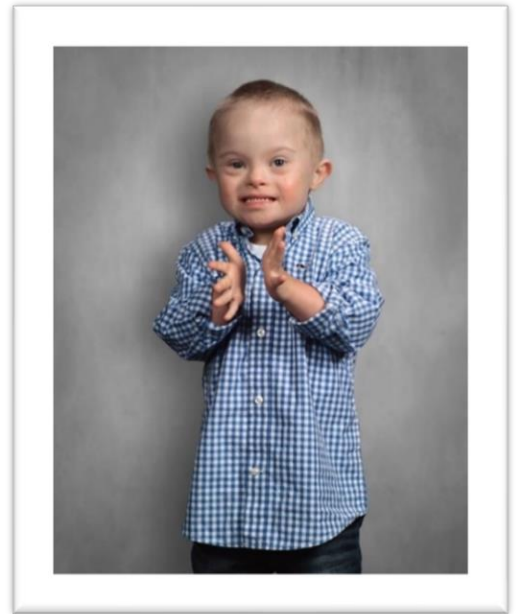
The NDSC Staff



# Congratulations!

Whether you are celebrating your child's birth or anticipating his or her arrival; we want to congratulate you!

We know this journey is not without its unique challenges and new experiences, but rest assured, you are not alone. Instead, you have become part of a large, deeply caring, and warmly welcoming community.



## A Baby is a Baby First

*By Kate Sefton, Master Development Therapist*

There is nothing quite like a baby ... there's a lurch in the heart when we touch the beginning of life in a the small person of an infant. For some parents, the lurch is made more poignant, even painful, by the fact of their baby's diagnosis of Down syndrome.

Recently, I've had the great pleasure of holding several soft, beautiful new babies who have Down syndrome. Their parents want to find out what it all means, what they can do, what to think about the future. Many times first professional to talk to parents of babies with Down syndrome tend to discuss the differences parents may see, difficulties babies will encounter. Armed with information about what milestones their child may not reach, what problems she may have, what services they should obtain to avoid potential problems, new parent want to help their babies as soon as possible. So they come to me (and to numerous others) to get this help ... to find therapy, activities, solutions to problems that may or may not exist. We just don't know, at an early age, in exactly which ways Down syndrome may affect a child.

She may be really good at cognitive activities, but have significant delays in movement ... thereby falling behind her peers in playground and paper-and-pencil activities.

He may be fairly good at gross motor, excelling in sports. Ocular control may be an area of need, or may be perfect.



Language may be good, or may need lots of work. However, one thing we know for certain ... babies don't deal with these things no matter what their chromosomes look like. They lie down and expect to be carried, cuddled, talked to, fed, and generally catered to. They learn they are lovable, cute and the center of the universe. They begin to know who their family members are, and who is the soft touch in the house in the middle of the night.



If these adorable creates have Down syndrome they are at risk for certain physical and cognitive delays. It behooves parents to keep an eye open for problems that could arise. It's important that they know something about their child's diagnosis so that they can be alert and helpful. But my belief is that the most important things that parents of babies with Down syndrome can do are exactly those things that all parents do. You know: they cuddle, feed, sing and love. Not the kind of things you need a Developmental Therapist for ... or any other therapist, for that matter.

I want to be clear. Young children with Down syndrome often show delays that need to be remedied so that these kids can be happy with themselves and do their very best. Very young babies with Down syndrome should be evaluated if their parents or doctors have specific concerns about early development. And doubtless, parents will find themselves driving this child about for ear infections, speech therapy, developmental evaluations, etc. But the main advice I have for parents of new babies with Down syndrome boils down this:

*“ You have a beautiful new baby.*

*There will be some areas that need work, but what you have right now is precious and perfectly right. ”*





# Understanding Down syndrome

According to a CDC study report, it is estimated to be 1 in every 691 babies are born with Down syndrome. There are believed to be roughly 250,000 families in the United States affected by Down syndrome.

**So, what exactly is Down syndrome?** Down syndrome is one of the most common genetic variations and occurs in approximately one in every 700 live births in the United States. For most people, each cell in the body has 23 pairs of chromosomes. One chromosome in each pair comes from the mother and the other comes from the father. But sometimes, during cell division, an extra copy of the 21st chromosome is present. As the cells multiply and the pregnancy is carried to term, a baby with Down syndrome is born.

**What causes Down syndrome?** Scientists have investigated the causes of Down syndrome for the past century. So far, its exact cause has eluded discovery. Doctors aren't sure why this happens. There's no link to any environmental factors or anything the parents did or didn't do. Although many factors have been considered possible causes, the mother's age is the most often discussed factor related to the likelihood of having a baby with Down syndrome because older eggs have a greater risk of improper chromosome division. It has been known for some time that the risk of having a child with Down syndrome increases with the mother's advancing age. For instance, the risk of a 20-year-old mother giving birth to a child with Down syndrome is about 1 in 1600, the risk at age 35 is 1 in 365, and the risk at age 40 increases to 1 in 100. However, the majority of babies with Down syndrome are born to mothers less than 35 years old. This is because there are many more births among younger women.

**Are there different types of Down syndrome?** According to the CDC, there are three types of Down syndrome: Trisomy 21, Translocation Down syndrome, and Mosaic Down syndrome. The difference between each type can only be determined by looking at the chromosomes under a microscope as the physical features and behaviors are similar.<sup>1</sup>

**Trisomy 21:** About 95% of people with Down syndrome have Trisomy 21. In this type of Down syndrome, each cell in the body has three separate copies of chromosome 21 instead of the usual two copies.



**Translocation Down syndrome:** This type accounts for about 3% of people with Down syndrome. It occurs when an extra part or a whole extra chromosome 21 is present, but it is attached or "trans-located" to a different chromosome rather than being a separate chromosome 21.

**Mosaic Down syndrome:** This type affects about 2% of the people with Down syndrome. Mosaic means mixture or combination. For children with mosaic Down syndrome, some of their cells have three copies of chromosome 21, but other cells have the typical two copies of chromosome 21. Children with Mosaic Down syndrome may have the same features as other children with Down syndrome. However, they may have fewer characteristics of the condition due to the presence of some (or many) cells with a typical number of chromosomes.

**What are the physical characteristics of Down syndrome?** There are various common physical features among babies with Down syndrome. Not every baby born with Down syndrome will possess each of the characteristics. Many characteristics most commonly associated with Down syndrome can also be found in the general population. Some more noticeable common physical features found in babies with Down syndrome include:

- Low muscle tone (hypotonia) which makes muscles appear relaxed or "floppy"
- Loose joints
- Almond-shaped upward slanting eyes
- A flattened face and/or nose bridge
- Smaller ears, hands, and/or feet
- Small pinky fingers that sometimes curve toward the thumb
- A single crease across the palm of the hand (palmar crease)
- A deep groove between the first and second toes
- A short neck
- A protruding or larger tongue
- Tiny white spots on the colored part of the eye (Brushfield spots)

It should be noted that there is no correlation between the number of characteristic features a baby has and the child's cognitive ability.

**Can Down syndrome be treated or cured?** Down syndrome is a lifelong condition. Although it cannot be cured, medical professionals know more about it now than ever. Getting the best care early on can make a big difference for individuals with Down syndrome and improves the likelihood of a full and meaningful life.

**How will having Down syndrome affect my baby?** Babies born with Down syndrome will grow and develop like all the other babies, but those with Down syndrome generally develop at a somewhat slower pace. Children with Down syndrome may be delayed in achieving milestones such as walking, talking, and eating



compared to typically developing children. Children who have Down syndrome may also face intellectual and behavioral delays. Having a loving home environment and early intervention and special education services will positively influence a child's development in all areas.

**What is the life expectancy of people with Down syndrome?** Over the years, medical research, technology, and practices have helped prolong individuals with Down syndrome's life span. Today the majority of individuals will live upwards of age 60 or 70.

## Talking about Down syndrome

**T**he correct name of the diagnosis is Down syndrome. Although named for the French physician Jérôme Lejeune, who identified Down syndrome as a chromosomal condition, no apostrophe denoting ownership is used in the United States, nor is the s in syndrome capitalized. The proper way to say and write the diagnosis is Down syndrome.

An individual with Down syndrome is an individual first and foremost. Thus, when speaking of a person with Down syndrome, the emphasis should be on the person, not the disability. This is referred to as person-first language.

### **Put people first, not their disability**

- A person with a disability, **not** a disabled person.
- A child with Down syndrome, **not** a Down's child.

### **Use emotionally neutral expressions**

- A person with Down syndrome, **not** a person afflicted with Down syndrome.
- An individual who has Down syndrome, not a Down syndrome victim or patient.
- A person has Down syndrome, **not** one who suffers from Down syndrome.

### **Emphasize abilities, not limitations**

- A child who receives special education services, **not** a special ed child.

### **Adopt preferred language**

- A person with a cognitive or intellectual disability is preferred language. It is **NEVER** acceptable to use the words mentally retarded.
- Typically developing or typical is preferred over normal.
- Accessible parking space or hotel room is preferred over handicapped.

Words can create barriers. The words you use and the way you use them matter. A person with Down syndrome has many other qualities and attributes that can be used to describe them, so it is important to learn, practice, and promote the use of person-first language. When speaking of a person with Down syndrome, they should be referred to as just that, not the Down syndrome person or a person with Downs.







It is also vital to use the correct terminology when referring to a person's diagnosis. It is accurate to say a person has Down syndrome, rather than suffers from, is a victim of, is diseased with, or is afflicted by Down syndrome.

It is essential to recognize that children with Down syndrome grow into adults with Down syndrome; they do not remain eternal children. Adults who enjoy activities and companionship with other adults. When speaking with adults with Down syndrome, the tone used should be the same as when talking with a person who does not have Down syndrome, being sure not to talk down to or use baby talk.

Each person has their own unique strengths, capabilities, and talents. Try not to use the clichés that are so common when describing an individual with Down syndrome. To assume all people have the same characteristics or abilities is demeaning. It reinforces the stereotype that all people with Down syndrome are the same.

## Developmental expectations and medical issues

Most human beings have 23 separate pairs of chromosomes in each of their cells. Chromosomes carry our genetic information (our genes), which determines whether we will have brown hair, blue eyes, or dark skin, for example. Generally, people inherit one copy (half of the pair) of each chromosome from each parent, resulting in 46 total chromosomes. People with Down syndrome are born with an extra 21st chromosome. This extra chromosome can have consequences that may lead to different medical or developmental challenges but can also lead to a lot of positive things as well.

Children with Down syndrome typically have some delays in the different areas of development. Gross motor delays involve skills like sitting, crawling, and walking. Fine motor delays are seen in the purposeful coordination of the movements of the hands and fingers. Speech delays affect the onset and quality of speech development. All children develop at a different pace, and some may not have as many delays as others in these development areas. On average, most children with Down syndrome reach their developmental milestones about 1.5 to 2 times later than other children. It is important to remember that almost all children with Down syndrome will reach the developmental milestones. Parents just have to be patient while waiting!



## Developmental Skills

Skill	Typical Child average (months)	Child with Down Syndrome average (months)
Finger Feeding	8	12
Using spoon/fork	13	20
Bowel Control	29	42
Bladder control	32	48
Undressing self	32	40

## Developmental Milestones

Milestone	Typical Child average (months)	Child with Down Syndrome average (months)
Smiling	1	2
Rolling Over	5	8
Sitting Alone	7	10
Crawling	8	12
Talking (words)	10	16
Standing	11	20
Walking	13	24
Talking (phrases)	21	28



Certain medical conditions occur more commonly in people with Down syndrome. This section provides an overview of potential issues that *could* develop and does not mean that every child will have all of these problems. The vast majority of children with Down syndrome are indeed healthy and thriving.

- **Cardiac** – Roughly half of all newborns with Down syndrome are born with a heart condition. Adolescents and adults with Down syndrome can develop leaky heart valves that may result in a heart murmur that was not previously present.
- **Gastrointestinal** (G.I.) - About 5% of infants with Down syndrome will be born with an obstruction of their intestinal tract. Gastrointestinal issues usually include reflux, constipation, celiac disease, or chewing/swallowing difficulties.
- **Respiratory/Ear, Nose, Throat** - Many people with Down syndrome have what is called mid-face hypoplasia. This simply means that the middle part of their face may be narrowed and can result in difficulty draining the fluids in that part of the face. Therefore, they may develop recurring ear infections, sinus infections, croup, and sometimes hearing loss. Another common issue related to the airway narrowing seen in people with Down syndrome is obstructive sleep apnea (OSA).
- **Endocrinologic** - Children with Down syndrome can be born with hypothyroidism (underactive thyroid) which is usually detected during the newborn screening done on all children born in U.S. hospitals. Hypothyroidism may also develop later in life.

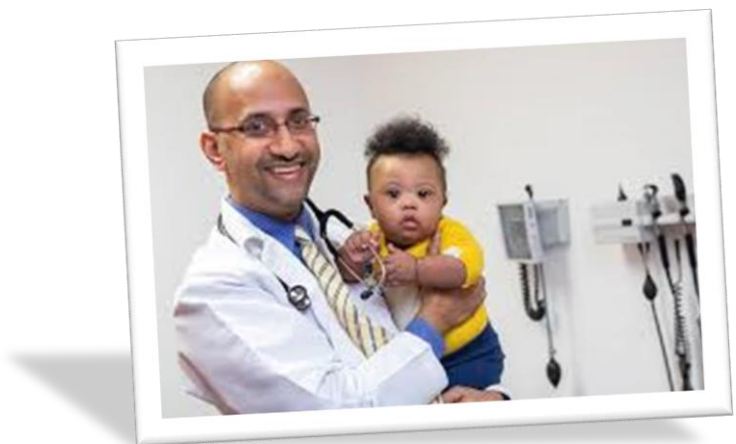


- ***Musculoskeletal*** - Babies with Down syndrome typically have very low muscle tone at birth. Low tone usually continues to be present in the ligaments and joints as these children get older.
- ***General Pediatric Care*** – Immunizations should be given to children with Down syndrome as scheduled for all other children. Additional vaccines may include the respiratory syncytial virus (RSV) vaccine, also called Synagis, if the baby has a cardiac issue that is not repaired or was born significantly premature.

There are several apparent medical benefits of having an extra 21<sup>st</sup> chromosome that are not frequently discussed. People with Down syndrome very rarely develop solid organ cancers. This means that there is a lower rate of lung cancers, liver cancers, and brain cancers in people with Down syndrome. It is unknown why this is so, but it is believed that there is something protective on the 21<sup>st</sup> chromosome that guards against these types of cancers. Though children with Down syndrome do develop leukemia, their response to chemotherapy is much better in certain types of the blood cancer. People with Down syndrome tend to have a lower incidence of cholesterol plaques in the arteries around their heart, which lessens the likelihood of high blood pressure and they do not seem to develop dental cavities at the rate of other children. Their response to treatment for specific childhood seizure conditions also seems to be better than other children.

People with Down syndrome also seem to have benefits in their visual memory skills. Many are able to recall specific life situations much more clearly than others. They may remember specifics from their childhood birthday parties or the names of acquaintances much better than others. These visual memory skills can even help them excel with reading skills if their visual skills are used effectively.

The complete detailed report of Developmental Expectations and Medical Issues, prepared by Dr. Kishore Vellody, former NDSC Board President and Medical Director, Down Syndrome Center of Western PA, can be viewed or download it at <https://www.ndsccenter.org/wp-content/uploads/MilestonesMed-Issues.pdf>.



Photos of Dr. Vellody are graciously provided by UPMC Children's Hospital of Pittsburgh with the consent of Dr. Vellody and the patient's parents.



# "What Parents Wish They'd Known"

**T**hey say hindsight is 20/20. At some point, haven't we all revisited something or someone from the past and seen it in a new and surprising light? Looking over our shoulder, an enemy may emerge as a friend in disguise. A crisis may appear as an opportunity. A burden may look more like a blessing. Sometimes, such perspective leads to regret—if only we'd known then what we know now! But the truth is, we couldn't have known. Only by experience do we enjoy the rich fruits of understanding. And this understanding is of great value to others, as well as to ourselves. This booklet offers glimpses of understanding to individuals



beginning a momentous journey: parenting a child with Down syndrome. The glimpses are given by other parents who have been journeying for some time— months, years, even decades—and who pause here to describe the vistas that have opened to their view. The following pages feature their answers to the question, "What do you know now about parenting a child with Down syndrome that you wish you'd known from the start?" It's my hope that these responses will be encouraging and refreshing to fellow travelers. The insights shared cannot provide a shortcut through the struggle that most new parents face in the early months following their child's diagnosis. But they can offer

support along the steep and rock-strewn path, hope for what awaits around the bend, and light to guide the way."

—Kathryn Lynard Soper, mother of Thomas (4 years old)

*"I wish I'd known* that my daughter would be so able. To clean her own room. To charm grown men. To plant the garden with me. To play dress-up with other little girls. To read and write. To be a friend that cares and shares. She is so able."

—Jeni, mom to Joy Daisy (6 years)

*"I wish I'd known . . .* That it was OK to feel broken-hearted when we first heard the news. That having a child with Down syndrome is NOT a life sentence. That my son would have his own agenda for doing things and that it's a privilege to be his mom."

— Sara, mom to Nathaniel (9 years)

Check out other people's stories and the rest of this article at [https://www.ndsccenter.org/wp-content/uploads/Soper\\_booklet.pdf](https://www.ndsccenter.org/wp-content/uploads/Soper_booklet.pdf)





# The *important* role of *siblings*

**K**ris Faith was born in June 1978, along with his twin sister, Katie. Growing up, Katie, their younger sister Carrie, and older brothers, Tom and John, were always helpful and positively influenced Kris. At the same time, Kris, who has Down syndrome, taught them about the important contribution people with disabilities make to the world around them. Kris's parents, Cliff and Rosalie, saw to it that Kris participated in all family activities and had regular chores like his siblings. "Kris went to our neighborhood school and was active in Special Olympics," they shared. "Kris and his sisters started Shasta Buddies, a club for disabled and non-disabled students at their high school. Katie even went to Kris's High School IEP meetings to advocate for him." Now in his 30s, Kris works for the California State Department of Developmental Services as an Office Aide. Before this, he volunteered for the Sacramento Police Department and worked at Starbucks. In his

free-time, Kris loves to go to concerts, movies, gamble at casinos, road trips, and restaurants. "Kris has taught his family that people with disabilities have value. Our family is enlightened because of Kris. He has an awesome and active life."

Adult siblings are a key part of their brothers' and sisters' lives, and we recognize how meaningful those relationships are. In addition to our Adult Sibling Toolkit, we offer many workshops at our annual convention, perfect for adult siblings and caregivers. Created with the adult sibling role

and needs in mind, this toolkit is designed to jump-start conversations with parents about becoming more involved in their siblings' lives. The toolkit helps organize all information assisting the adult sibling to be an effective advocate and perhaps, caregiver after their parents are no longer able.

You can access our adult sibling toolkit at [www.ndsccenter.org/programs-resources/adult-siblings/](http://www.ndsccenter.org/programs-resources/adult-siblings/)



**Adult Sibling Toolkit™**





# "Welcome to Holland"

*By Emily Perl Kingsley*

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this..... When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.



The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills.... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very, very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.



# Early *intervention* and *services*

**E**arly intervention refers to a range of specialized programs and resources that professionals provide to very young children with Down syndrome and their families. These professionals may include educators, speech therapists, occupational therapists, physical therapists, and social workers. The most common early intervention services for babies with Down syndrome are physical therapy, speech and language therapy, and occupational therapy.

Research indicates that early intervention improves outcomes for children with Down syndrome. This assistance can begin shortly after birth and often continues until a child reaches age 3. On a child's fourth birthday, most children receive interventions and treatment through their local school district.

A physical therapist also can help a child with Down syndrome compensate for physical challenges, such as low muscle tone, in ways that avoid long-term problems. For example, a physical therapist might help a child establish an efficient walking pattern, rather than one that might lead to foot pain.

Children with Down syndrome often learn to speak later than their peers. Speech-language therapy can help children with Down syndrome improve their communication skills and use language more effectively. A speech-language therapist can help them develop the early skills necessary for communication, such as imitating sounds. The therapist also may help an infant breastfeed because breastfeeding can strengthen muscles that are used for speech.

A speech-language therapist can help a child use alternative means of communication, such as sign language and pictures until they learn to talk. Building communication skills is an ongoing process, and many benefit from speech and language therapy through school and beyond. The therapist may help with conversation skills, pronunciation skills, understanding what is read (called comprehension), and learning and remembering words.



Physical therapy includes activities and exercises that help build motor skills, increase muscle strength, and improve posture and balance. Physical therapy is important, especially early in a child's life, because physical abilities lay the foundation for other skills. The ability to turn over, crawl, and reach helps infants learn about the world around them and how to interact with it.



# Your child's *education*

The NDSC, together with the larger disabilities community, has made great strides toward securing quality education for all people with cognitive disabilities. Public Law 105-17 (2004): The Individuals with Disabilities Education Act (IDEA) makes it possible for children with disabilities to receive free, appropriate public education as well as services and devices to assist them. Under IDEA, children are entitled to these services from birth through the end of high school, or until age 21, whichever comes first. Most early intervention programs also fall under this legislation.

If it is determined that a child has specific cognitive or learning deficits, they will be eligible for free special education programs. Parents can contact a local school principal or special education coordinator to inquire about having their child examined to determine if they qualify for services under the IDEA.

If a child qualifies for special services, a team including parents or caregivers, teachers, a school psychologist, and other child development specialists or education specialists will design an Individualized Educational Plan (IEP) for the child. The IEP contains specific learning goals based on the child's needs and capabilities. The team will also determine how best to carry out the IEP.



IDEA also states that each child must be taught in the least restrictive environment that is appropriate. Educators work to provide an environment that best fits the child's needs and skills. For some, this may be in a general education classroom. Others may require a special education classroom, and some may find a hybrid of the two classrooms the most appropriate setting. Educators and health care providers can help families determine what environment is best for the student. Integration into general classrooms has become much more common in

recent decades as IDEA requires that public schools maximize a child's access to typical learning experiences and interactions.

The U.S. Department of Education funds the Parent Center Network, which provides resources, contacts, and assistance for parents and families navigating special education programs. To learn more about the Parent Center Network, visit their website at <http://www.parentcenterhub.org/>.



# Waiver *information*

If your child with a disability is uninsured, needs additional services, or needs wrap-around Medicaid coverage to help with finances and uncovered services, your child probably needs a Medicaid waiver or program. These programs "waive" one or more Medicaid rules in order to extend eligibility and/or services to children. For children, the most common rule to be waived is the way income is calculated, meaning the waiver is based on the child's income instead of the family's income.

Medicaid began as a program for low-income families. Over time, Medicaid transitioned to serving primarily children, the elderly, and people with disabilities. Before the 1980s, most children with disabilities were institutionalized because most families and communities did not have the resources to keep them in their homes. Ironically, it costs more to keep people in institutions than at home, but traditionally, Medicaid only paid for people's care while in an institution.



To overcome this institutional bias, two types of Medicaid programs began in the early 1980s. These included a provision of the TEFRA Act of 1982, often called the Katie Beckett or TEFRA option, which gives states the option to extend Medicaid to children with severe disabilities by only counting the income of the child with a disability, and not the income of his/her parents.

Around the same time, 1915(c) Home and Community Based Services (HCBS) waivers were introduced for people with intellectual and other disabilities. These waivers allowed states to waive three possible Medicaid rules to provide better services for people with disabilities. The 1915(c) waivers waive comparability, which means states can offer people with disabilities extra benefits that other Medicaid recipients do not receive. Some waivers also allow states to use institutional deeming rules, meaning they only count the income of the individual with a disability rather than the entire family income. This type of waiver typically allows children who do not fall in a low-income bracket to access Medicaid. In rare cases, states may also waive geographic requirements, meaning that they only serve people in certain counties or areas.

These programs are important for children because Medicaid typically counts the entire family's income when determining eligibility until a child turns 18. Because private insurance may not cover many services that children with disabilities require, or children with disabilities cannot obtain insurance, Medicaid waivers and programs allow another pathway to access Medicaid services such as private duty nursing and specialized therapies. Additional services, such as respite, home/vehicle modifications, or training programs may also be included. Visit <https://www.kidswaivers.org> for state by state information.





# Additional *resources*

## FOR NEW PARENTS

***Babies with Down Syndrome: A New Parent's Guide*** by Susan J. Skallerup (Ed.) Woodbine House. 2008 (3rd Edition). A comprehensive guide for new parents, covering all aspects of care for babies and young children.

***Parent's Guide to Down Syndrome: Toward a Brighter Future.*** By Siegfried M. Pueschel (Ed.). Brookes Publishing. 2001. - A comprehensive reference book especially for new parents, but useful and informative for "seasoned" parents as well. Topics include: history of Down syndrome; developmental expectations; early intervention; the school years; recreation; adolescence and adulthood; vocational training and employment.

## PARENTING SUPPORT AND INSPIRATION

***The Shape of the Eye: A Memoir*** by George Estreich. Penguin Group USA. 2013. A touching story of a father's love for his daughter, his struggle to understand her disability, and his journey toward embracing her power and depth.

***Road Map to Holland*** by Jennifer Graf Groneberg. New American Library. 2008. A beautifully written story by a mom getting to know "the child she didn't know she wanted, the child she always needed", her son with Down syndrome.

***Bloom – Finding Beauty in the Unexpected – a memoir*** by Kelle Hampton. HarperCollins Publishers. 2012. A memoir by an award winning writer and photographer, takes the reader on a wondrous journey of her daughter's first year of life and encourages accepting and embracing unexpected circumstances.

***Married with Special Needs Children*** by Laura E. Marshak and Fran Pollack Prezant. Woodbine House. 2008. Professional expertise and personal experiences from hundreds of parents help you realize you are not alone in facing relationship challenges, and provides guidance in keeping a marriage strong and healthy.

***Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives*** and ***Gifts 2: How People with Down Syndrome Enrich the World*** by Kathryn Lynard Soper. Woodbine House. 2007 and 2009. Includes essays from a

## FOR PARENTS OF ADOLESCENTS & ADULTS

***Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality*** by Terri Couwenhoven. Woodbine House. 2007. Factual information and practical ideas for teaching children with Down syndrome about body awareness, puberty, sexuality, appropriate behavior and relationships.

***The Guide to Good Health for Teens & Adults with Down Syndrome*** by Brian Chicoine and Dennis McGuire. Woodbine House. 2010. Provides invaluable insight into what health problems are more common in their patients, and how medical issues can "present" differently in people with Down syndrome. In a clear, empathetic style, they discuss how to promote a healthy lifestyle to prevent problems, and how to recognize health problems early on to ensure appropriate care and the best outcome.

***Mental Wellness in Adults with Down Syndrome: a Guide to Emotional and Behavioral Strengths and Challenges*** by Dennis McGuire and Brian Chicoine. Woodbine House. 2006 (2<sup>nd</sup> edition releases in Feb 2021). Readers will learn about the common behavioral characteristics of Down syndrome, how some can be mistaken for mental illness, and the bona fide mental health problems that occur more commonly in people with Down syndrome.

***The Down Syndrome Transition Handbook: Charting Your Child's Course to Adulthood*** by Jo Ann Simons. Woodbine House. 2010. Simons writes from a professional perspective as someone who worked with many families as they went through Transition.

## SPECIFIC AREAS OF DEVELOPMENT

***Fine Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals, Third Edition*** by Maryanne Bruni. Woodbine House. 2016. A practical and accessible guide to understanding and developing fine motor skills in children with Down syndrome, with a thorough overview of the building blocks of fine motor development, from infancy through to adulthood.

***Off to a Good Start: a Behaviorally Based Model for Teaching Children with Down Syndrome*** (a two book set). Emily A. Jones and Kathleen M. Feeley. Woodbine House, 2019. With these





variety of perspectives — family, friends, teachers, medical professionals and more.

***Choosing Naia: A Family's Journey*** by Mitchell Zuckoff. Beacon Press. 2002. A routine ultrasound reveals that the baby Tierney carries has a major heart defect, leading doctors to suspect Down syndrome. This book follows the Fairchild family and the decisions they must make regarding their unborn baby.

## NUTRITION

***The Down Syndrome Nutrition Handbook: A Guide to Promoting Healthy Lifestyles*** by Joan Guthrie Medlen. Woodbine House. 2002. A comprehensive guide teaching nutrition and healthy living for children with Down syndrome from birth through young adulthood.

***Broccoli Boot Camp: Basic Training for Parents of Selective Eaters*** by Keith E. Williams and Laura J. Seiverling. Woodbine House. 2018. A comprehensive guide for parents of children who are selective or "picky" eaters, and can be used with children with or without special needs (e.g. autism or Down syndrome). It presents commonsense behavioral interventions to successfully expand children's diet variety and preferences for healthy foods.

## BOOKS FOR SIBLINGS

***The Sibling Slam Book: What it's REALLY Like to Have a Brother or Sister with Special Needs*** by Don Meyer (Ed) Woodbine House. 2005. The thoughts and feelings of eighty teen siblings from around the world, in the answers to 54 posed questions.

***Thicker Than Water: Essays by Adult Siblings of People with Disabilities*** by Don Meyer (Ed). Bethesda, MD: Woodbine House. 2009. Thirty-nine adult siblings wrote essays about their experiences growing up with their now adult siblings with disabilities. They write of relationships that are complex and simple, joyful and hard, accepting and resentful, ordinary and extraordinary.

***Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*** by Brian Skotko and Susan P. Levine. Woodbine House. 2009. Nearly 100 questions and answers on a broad range of issues considered by siblings of individuals with Down syndrome, this is a terrific guide for teenagers, and lets them know they are not alone in trying to figure out how to manage their feelings about their sibling.

books, readers will learn ABA practices for teaching children the all-important foundational skills in motor, social-communication, cognitive, and self-care development.

***Supporting Positive Behavior in Children and Teens with Down Syndrome*** by David Stein. Woodbine House. 2016. The Respond but Don't React method examines how the brain of a person with Down syndrome works, how those differences impact behavior, and why bad behavior should not be viewed as a willful act. Governed by this new awareness, parents are in a better position to change and manage their child's behavior.

***Potty Time for Kids with Down Syndrome: Lose the Diapers, Not Your Patience*** by Terry Katz and Lina Patel. Woodbine House. 2020. Drawing on their years of experience working with and toilet training children with Down syndrome, the authors have created a customizable developmental-behavioral model based on a thorough understanding of how the behaviors of children with Down syndrome are affected by their neurodevelopment.

***Early Communication Skills for Children with Down Syndrome*** by Libby Kumin. Woodbine House. 2012 (Third Edition). Features expanded information on the needs of children with apraxia, dual diagnosis of autism and Down syndrome, and updated terminology and information on special education law.

***Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals, Second Edition*** by Patricia C. Winders. Woodbine House. 2014. Provides parents and professionals with essential information about motor development associated with Down syndrome.

## EDUCATION

***From Emotions to Advocacy—The Special Education Survival Guide, 2nd Edition*** by Peter W. D. Wright and Pamela Darr Wright. 2006. Includes hundreds of strategies, tips, references, and internet resources to help parents understand the special education system. Reflects most recent changes to IDEA 2004 and NCLB Act.

***The Paraprofessional's Handbook for Effective Support in Inclusive Classrooms*** by Julie Causton-Theoharis. Brookes Publishing Co., 2009. This book explains what special education is; what inclusive education looks like; how to collaborate with other team members and presume competence in students rather than making assumptions about their abilities. Three chapters offer numerous suggestions on how to provide social support by standing back, and ideas for academic and behavioral supports.



# Bibliography

---

"About." *Kids' Waivers*, September 16, 2019, [www.kidswaivers.org/](http://www.kidswaivers.org/).

"Data and Statistics on Down Syndrome." Centers for Disease Control and Prevention, Centers for Disease Control and Prevention, December 5, 2019, [www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html](http://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html).

"Down Syndrome." *Eunice Kennedy Shriver National Institute of Child Health and Human Development*, U.S. Department of Health and Human Services, [www.nichd.nih.gov/health/topics/downsyndrome](http://www.nichd.nih.gov/health/topics/downsyndrome).

"Facts about Down Syndrome." *Centers for Disease Control and Prevention*, Centers for Disease Control and Prevention, December 5, 2019, [www.cdc.gov/ncbddd/birthdefects/downsyndrome.html](http://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html).

"Welcome to Holland." Emily Perl Kingsley, Copyright 1987.

"What Are Common Treatments for Down Syndrome?" Eunice Kennedy Shriver National Institute of Child Health and Human Development, U.S. Department of Health and Human Services, [www.nichd.nih.gov/health/topics/down/conditioninfo/treatments#therapy](http://www.nichd.nih.gov/health/topics/down/conditioninfo/treatments#therapy).

---

Copyright Jan. 14, 2021

