



***Your Guide  
to Raising  
a Child with  
Combined  
Hearing and  
Vision Losses***

# **Parent Road Map**

**—Created for parents by parents**

## Contents:

We're on this road together . . .	1
Photo	
Welcome to Holland	2
Coming to Terms	3
Marja	6
Taking Care	7
Getting Help	11
Services that Help Families	12
Teaching Basics	15
Cues to Help Your Child Learn	16
IDEA	17
Educational Concerns	18
Reaching Out	23
Organizations Serving Special Needs	25
Caring for Family	27
Siblings Need Care	30
Take Care in Difficult Times	32
Florida Faces: Eva-Simone Brooks	33

## Contributors

# We're on this road together...

How did you arrive on this road? Were you in an obstetrician's office the day you learned your baby would be born with a disability? In the delivery room? Or, was your child older, and you were still going to doctors searching for answers?

However you got here, you are not alone. *We* are here—we are parents who have been where you are now. We share a bond that connects us in a way few people will experience. We are linked by our children with combined vision and hearing losses. The road we are on is not well traveled. The truth is, this road, while joyful and fulfilling, also can be filled with bumps, potholes, and even roadblocks. Sometimes the professionals you look to for guidance along this road sound as if they are talking a language you don't speak or understand.

When you are feeling lost on this road, look around. We are traveling the same road and would like to help. This manual has been written by parents like you who are raising children with combined hearing and vision losses. Consider this your "road map," helping you navigate in this new land you've entered. You are not alone—we are here with you.

## Welcome!







# Welcome to *Holland*

By Emily Perl Kingsley

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*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.



# Coming to Terms

## “Is my child really deafblind?”

**A**s a parent, you may have trouble absorbing the term *deafblind*. It may not seem to describe your child’s disability. You may be thinking, my child can’t hear, but she can still see—she is not “blind.”

Very few children are totally deaf and totally blind. Some children who are called deafblind may have mild vision and hearing loss or have an impairment that only effects one eye or one ear. Of course, there are all types and degrees of vision and hearing loss among children who are deafblind. Children who are deafblind also may have additional physical, cognitive or medical needs.

To help us all agree on what *deafblind* means, we use the state and federal definitions. You also may come across terms such as *deaf-blind*, *dual sensory losses*, and, *combined or concomitant vision and hearing losses*.

## Why use the term “deafblind”?

**Y**ou might feel uncomfortable using the term *deafblind*, especially when you first apply that label to your child. It can help to know that by saying “My child is deafblind” you’re giving other people the chance to understand that **your child has some very unique needs**. Educators, service providers, and others need to know that with a little extra effort they can make the world accessible to your child. Just like a child in a wheelchair needs a ramp to enter the school building, your child will need different ways to access information.

In education and rehabilitation settings, the term *deafblind* is used to talk about a specific disability. It describes any combined hearing and vision loss that is significant enough to require special modifications or supports—things that go beyond what would typically be needed if a child had just a hearing loss or just a vision loss.

Children who are deaf rely on their vision to compensate for what they don’t hear. Children who have vision loss use their hearing to make up for what they can’t see. Children with combined hearing and vision losses (deafblind) must find other ways to receive information about the environment. A child who is deafblind requires a unique approach to learning.

*“In the beginning, I didn’t even know my child was considered ‘deafblind.’”*

*“The **label** that your child has been given does not define her. She is a **child** first.”*



*“You **learn** the most  
from other **parents**  
who have been there.”*

*“We parents have great  
dreams for our children,  
and we grieve the loss  
when the dreams don’t  
go as planned. From our  
kids’ viewpoint, though,  
they haven’t ‘lost’ anything  
—they were born with the  
vision/hearing/health they  
have. It’s normal for them.  
It may not be our ‘normal,’  
but it is theirs.”*

## **Deafblindness: Greater than the sum of its parts.**

**D**eafblindness sounds pretty dramatic, but it describes the reality of combined hearing and vision losses. Think of a world where 1+1 does not equal 2, but instead equals 10. Missing a little bit of what can be seen and a little bit of what can be heard often means missing a whole lot of what is going on in the world. Additionally, missing information causes misunderstanding, which causes big problems. It is important for us to realize that without the proper modifications and support, even a mild vision and hearing loss has a dramatic impact on a child’s ability to access information and learn.

## **Your child has a really low-incidence disability.**

**K**ee in mind, deafblindness is not a topic covered in-depth in most teacher training programs. Deafblindness is the LOWEST of “low-incidence disabilities.” In Wisconsin, only 7 students are listed with deafblindness as the primary disability on their IEP (education plan) compared to 1,581 students listed as deaf or hard of hearing. You can see why many teachers don’t understand the unique needs of our kids—there are relatively few children with combined losses.

## **You are your child’s best advocate.**

**Y**ou play an important role in your child’s development. Early interactions with you foster trust and form the foundation for your child’s understanding of the world. Professionals who work with your child will come in and out of your lives. You will be the constant presence. That gives you the opportunity to become the expert on your child — to truly understand her unique abilities as well as disabilities.

You can start right now by watching how your baby reacts as you feed her, change her diapers, hold her and rock her. Look for signs of fear, pain, anger or contentment. Tune into how she reacts to your touch.

When the typical avenues of communication (vision and hearing) don’t work effectively, alternative routes must be used. Touch often is the main avenue for communicating with a child who is deafblind.



Many of our children require frequent hospitalizations, which can mean very unpleasant experiences with touch. We need to show our children that touch can be pleasant; it not only identifies us, the most important people in their lives, but touch also will be their instrument for learning about the world. We want our children to reach out to us and to the world around them, not to turn away.

## **You are not alone.**

**I**t might seem like you've been dropped into this new world without a guidebook. You don't know what to expect from your child or the professionals who will help him. You don't know what questions to ask or where to turn for help. At this point, you might not even know what it is that you should know.

Please be assured that you do not need to make this journey alone. Other families have gone through what you are experiencing. Medical and education professionals can help you along your way. Use these resources to begin your journey.

*Every state has a federally-funded DeafBlind Project*, which provides free assistance and training to families, service providers, Birth to 3 programs, and schools and agencies involved with children from birth through age 21. The Wisconsin Project staff is experienced, compassionate and knowledgeable.

**Florida & Virgin Islands Deaf-Blind Collaborative**  
**University of Florida PO Box 100234**  
**1600 SW Archer Rd, Gainesville, FL 32610**  
**1-800-667-4052**  
**info@deafblind.ufl.edu**  
**www.deafblind.ufl.edu**

**“When Andy was diagnosed 26 years ago, we were overwhelmed with grief. But, we took one day at a time, taught ourselves about deafblindness, advocated on his behalf and, I’m proud to say all these years later, he has exceeded our expectations. He is happy, works full time, lives independently and thinks his vision and hearing losses are no big deal!”**

***“Getting lots of information—from other parents, the Internet, and the DeafBlind Project—helped me feel more confident as a parent.”***

***“It took me about 2 years to realize that Sam was deafblind. We knew his hearing was impaired. We knew that his vision was poor. But, it took a while for us to realize that Sam was in fact DEAFBLIND. I didn’t think he would be classified as that because he still has a little of each sense. I don’t know if I was naive or in denial.”***





**“I knew before Marja left the neonatal intensive care unit that she would have some vision problems. Yet every time we saw the eye doctor over the next three years, and her vision became worse, it felt like a truck ramming into my stomach. I hated taking her to the eye doctor, but, going to the audiologist was no big deal.**

**That all changed when Marja was almost 3. A sedated ABR (hearing test) revealed the depth of her hearing loss. The test confirmed she was deaf. Suddenly, I was the mother of a modern-day Helen Keller. I could hardly take in the information. My insides felt like lead. I managed to walk out to my large truck that barely fit in the hospital parking ramp, carefully strapped Marja in her seat and numbly drove down the ramp. As I pulled up to pay, I crunched the side of the truck on a concrete post. Even though it was bright yellow, I didn't see it. I didn't care about the \$2,000 damage to our new truck. All I could fit in my head was that my daughter was just diagnosed 'deafblind.'**

**The darkest of the days since finding out Marja was deafblind are behind us. It's not that we don't ever feel sad thinking about what her life could have been like if she had perfect vision and perfect hearing. Marja is not sad about it though—this is her life. Honestly, we are aware of her deafblindness and we watch her in continual amazement of how she functions, gets around and does completely normal everyday kid things. Today, we forget more than we remember that she has any losses.”**



# Taking Care

## Medical concerns sometimes take center stage.

**T**his new road you are traveling comes with its own language. You will quickly become an expert on medical terms that describe your child's diagnosis, etiology, therapies, and caregivers. The key to securing the appropriate health care for your child can be found through a [Medical Home](#), which is a partnership between physicians and families. A [Medical Home](#) can help you keep track of your child's care and coordinate referrals to specialists such as an ophthalmologist (for care of the eyes and visual pathways), ENT (ear, nose and throat doctor), or audiologist (for diagnosis and treatment of hearing loss).

At times your child's medical issues might overtake your life. You may not have time to worry about education or other areas. It is okay to put things on the back burner while you are dealing with medical issues. Children with sensory impairments often have multiple therapies to address their challenges. While each therapy is important, remember to pace yourself. Give yourself permission to prioritize the therapies.

Each child is unique, despite the common link of deafblindness. You never know when you may be faced with a medical decision that leads you to choose a path you never thought you would. The choices you make for your child's medical care can be different than other people's choices, and still be the best decision for your child and your entire family.

## Let other parents guide you.

**I**t can be overwhelming to navigate the health care system on your own. There are emotional, physical and even spiritual stresses that result from going to doctors' offices, absorbing what they tell you, and managing your child's health. Hopefully, you'll find guidance as you read the next few pages. We've noted tips from parents—things we have found to be helpful as we have dealt with our children's medical needs.

*“These feelings are normal when you are faced with a new diagnosis for your child: anger, fear, sadness and feeling overwhelmed, inadequate or intimidated by the professionals. We have all been there!”*







***“In the midst of all these doctor appointments, take time to just have fun. This journey is a marathon, not a sprint. Keep in mind that most decisions don’t have to be final. You can try a therapy and change it if it’s not working.”***

**“I seek out medical providers who understand that we are partners in our daughter’s care. We are fortunate to live in a city where we have choices for physicians and hospitals. I look for respect, a willingness to communicate, good follow through and great clinical skills. If I find that a doctor doesn’t meet these criteria, then I look elsewhere. It can be uncomfortable to switch physicians, but it’s worth a bit of discomfort. A good resource for this topic is [www.familycenteredcare.org](http://www.familycenteredcare.org).”**

## **Sound advice from other parents:**

- ◆ Find a great doctor to help with medical issues—do not settle for average!
- ◆ Talk with other families to find the best doctors. Look for doctors, audiologists, and therapists that have experience working with children who are deafblind or children who have severe multiple disabilities.
- ◆ The Internet can provide a wealth of information. But, be sure to check those sources for reliability.
- ◆ Take copies of articles you have found on the Internet, in publications, or other sources to your child’s doctor appointments to discuss. You are the expert on your child and may have information specific to your child’s diagnosis.
- ◆ Take another person with you to appointments to be another set of ears to hear and write down the information the doctor will be giving you.



“Shortly after our daughter came home from the NICU, we quickly became exhausted trying to do each exercise the various therapists had assigned PLUS feeding, diapering, and suctioning her, not to mention trying to devote time to our two older daughters. On one especially trying afternoon, I stopped and added up all the various ‘instructions’ and ‘therapies’ we had been given on discharge from the hospital. They added up to more than 24 hours!

It was at that point we decided to take one day at a time, prioritized our daughter’s needs and adjusted her therapy schedules to a manageable level. Over the course of a year we were able to address each area of need and took comfort in the fact that she had made progress across all areas of her development.”

- ◆ If possible bring a professional (i.e. vision teacher) along to doctor visits to help formulate appropriate questions.
- ◆ Being prepared for doctors appointments is crucial to getting the most out of your time with the doctor. Organization is the key. It is important that you have an organizational system that makes sense to you. There are various medical information forms available. A good place to start is by using “Build Your Own Care Notebook” at <https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx>.
- ◆ When you meet with doctors, ask questions and expect answers. Get over feeling that you are taking up too much of their time.
- ◆ Solutions are often found from a combination of sources.
- ◆ Identifying hearing and vision losses as early as possible will help your child move forward with development.

**“Our son’s medical needs felt overwhelming. Finding the best health care providers helped us so much.”**



“Samuel spent several weeks in the NICU. I owe Sam coming home early to one of our nurses. She was so positive and was determined to help us get him home as soon as possible. Samuel was having difficulties with the bottle and the other nurses would just give up and feed him through a tube. But Nancy worked with him and the bottle. She helped me learn how to feed Sam, too. She often said, ‘Let’s get this baby home.’ Soon, the tube was out. He was eating on his own and bound for home.”



“We have a one-page spreadsheet that we update listing all surgeries and hospitalizations along with the date, facility, and names of the surgeon or attending doctor. We take copies to doctor appointments and to the hospital to share with the anesthesiologist. This reduces the amount of time we spend at various offices filling out forms, and it provides doctors with a snapshot of our daughter’s complex medical history.”

*“To keep track of our son’s medical care, we used a 3-ring binder divided with tabs for each medical specialty. Before going to an appointment, we completed a simple form with the date, who we were to see and questions that we needed answered. It is helpful to have another person with you as secretary to take notes. It is difficult to manage your child, ask questions, listen to the answers, and take notes—not to mention managing all the emotions associated with the situation. Ask for a report at the end of each appointment. One is sent to your primary doctor, so it is not extra work to send one to you, too. Keep the reports in the 3-ring binder to refer to in the future. The binder (or a divided file) maintains all medical records in one spot that you can grab as you walk out the door for your next appointment.”*

# Getting Help

## There's help out there.

As we've said before, you are not alone in this journey. There are many resources available through the state and your county to help you. Some of these social services provide *funds* for medical care and other items for your child. Some provide *help* in the form of a specialist such as a physical therapist who might visit your child in your home to work on improving motor skills. We are fortunate that Florida offers such a range of social services.

There are specific criteria that the state has developed to decide which child is eligible for services. Some of the programs are based on the needs of the child, not on the family's income level. There may be co-pays for some services. But, don't let this stop you from seeking services—you may be surprised at what is available to you.

To learn more about services offered by the state and county, see [www.cms-kids.com](http://www.cms-kids.com) or contact Children's Medical Services (CMS) at 850-245-4200. We know how overwhelming it can be at this stage even to think of completing more paperwork or learning about new programs and systems. But, we also know how much we—and our kids—have benefitted from these services.

## Take the first step with a phone call.

Start by calling CMS for your region (see map next page). They can explain the services available and help you figure out which would work for your child. Don't assume that your child will not qualify or let pride get in the way of obtaining services. Some families never get the help that they need because they are ashamed or afraid to take the first steps. Remember, you are doing this for your child who has extraordinary needs—it may well take a team to provide for those needs. But, if you don't ask for help, you won't get it.

***“Taking care of a child with special needs is a huge job—accept help. You really don't have to do everything.”***

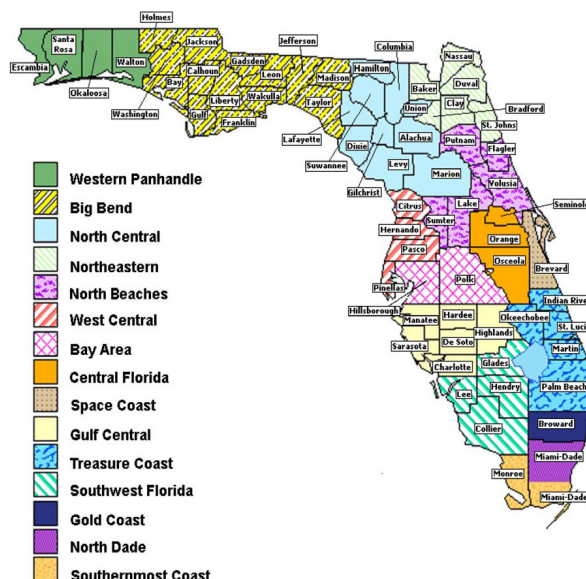
***“I learned so much from watching the therapist work with my child.”***





## Services that help families:

Florida's Early Steps Service Areas



- ◆ Children's Medical Services (CMS) is a collection of special programs for eligible children with special needs. CMS has a variety of services for newborn babies, infants and toddlers, school-aged children, adolescents and young adults. All services are provided by highly qualified physicians, nurses, social workers, and other health care providers throughout the state. Through family-centered programs, CMS helps your child get the care he or she needs.  
[www.cms-kids.com/families/families.html](http://www.cms-kids.com/families/families.html)
- ◆ Early Steps is Florida's early intervention system that offers services to eligible infants and toddlers (birth to thirty-six months) with significant delays or a condition likely to result in a developmental delay. Early intervention is provided to support families and caregivers in developing the competence and confidence to help their child learn and develop.  
[www.cms-kids.com/families/early\\_steps/early\\_steps.html](http://www.cms-kids.com/families/early_steps/early_steps.html)

***“Don’t be afraid to ask if you qualify for services—maybe you won’t, but, most likely you will. And, if there’s a waiting list for a service, make sure your name is on it. You can decide if you still need it when it becomes available.”***

Early Steps services are provided to the family where they live, learn, and play, to enable the family to implement developmentally appropriate learning opportunities during everyday activities and routines. Most services will be early intervention home visits.

## Funding sources:

Medicaid <https://ahca.myflorida.com/Medicaid/index.shtml>

Florida Medicaid is the medical assistance program that provides access to health care for low-income families and individuals. Medicaid also assists the elderly and people with disabilities with the costs of nursing care and other medical and long-term care expenses.

Supplemental Security Income (SSI) [www.ssa.gov/applyfordisability](http://www.ssa.gov/applyfordisability)  
Children from birth up to age 18 may get Supplemental Security Income (SSI) benefits. They must be disabled, and they must have little or no income and resources. In Florida, children who get SSI benefits also get Medicaid.

◆ **Medicaid Waivers** [https://fiddresources.qlarant.com/html/medicaid\\_waivers.htm](https://fiddresources.qlarant.com/html/medicaid_waivers.htm) Medicaid Home and Community Based Services Waivers are Medicaid programs providing community services to individuals specific to their health support needs as an alternative to services provided in an institution. The Developmental Disabilities Home and Community-Based Services Waiver is called the iBudget. This waiver provides specific supports and services that are available to individuals served by the Agency for Persons with Disabilities.

◆ **Agency for Persons with Disabilities (APD)** [www.apd.myflorida.com](http://www.apd.myflorida.com)  
The APD is specifically tasked with serving the needs of Floridians with developmental disabilities. The agency serves more than 50,000 Floridians with the following disabilities:

- \* Autism
- \* Cerebral Palsy
- \* Spina bifida
- \* Intellectual disabilities
- \* Down syndrome
- \* Prader-Willi syndrome
- \* Phelan-McDermid syndrome

The APD also serves children ages 3-5 who are at high risk of a developmental disability.

◆ **Family Care Council** [www.fccflorida.org](http://www.fccflorida.org)  
In 1993, the Florida Legislature created the Family Care Councils in each service area of the APD (Section 393.502, FL Statutes). The Family Care Councils (FCCs) are governor-appointed volunteers who advocate for people with developmental disabilities and their families. Most FCCs are active with other local organizations and partner to provide community forums, events, and conferences to benefit individuals with disabilities and their families.

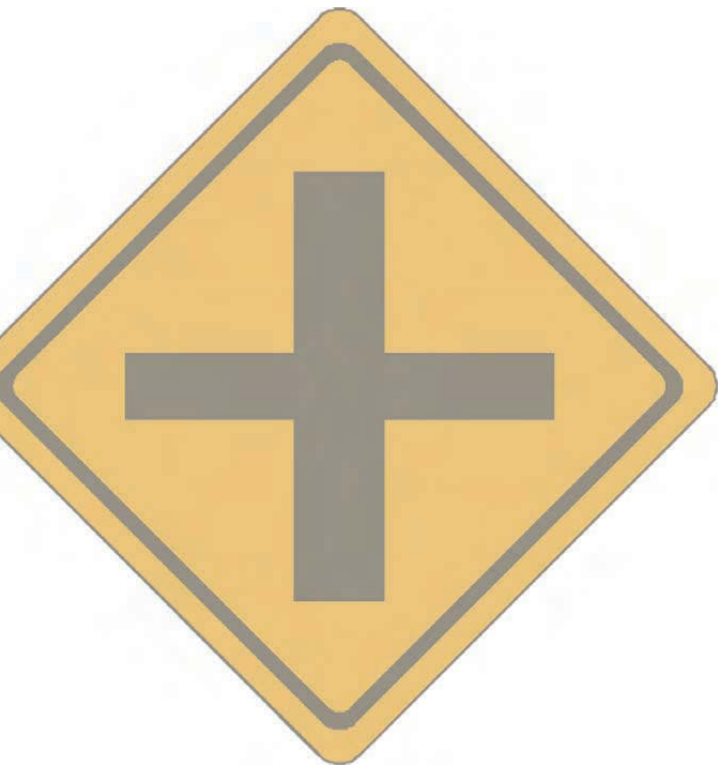
◆ **Resource Directory**  
<http://resourcedirectory.apd.myflorida.com/resourcedirectory>  
The APD Resource Directory includes is a tool for individuals to learn about, and includes direct links to, the resources and organizations available in local areas, programs offered throughout the state, and nationwide resources. The goal is for people to easily and efficiently locate any type of service they need.

*“Getting a Personal Care Attendant and respite care to help do all the things that need to get done for your child is an important piece of keeping your whole family emotionally healthy.”*



*“You are in this for the long haul—pace yourself. Give yourself a break.”*





### Florida Division of Blind Services

(<http://dbs.myflorida.com/information/index.html>)

the Florida Division of Blind Services helps blind and visually impaired individuals achieve their goals and live their lives with as much independence and self-direction as possible.

The Blind Babies Program provides community-based early intervention to children who are visually impaired, from birth through five years of age, and to their families.

The Children's Program serves children who are blind from five years of age through transition to the Vocational Rehabilitation Program. This program supplements services already offered by the school system to foster the child's learning and ability to function independently. Parents, guardians, and family members are an integral part of the program in order to foster independence.

The Transition Program assists young people in transitioning from school to work or to higher education.

### Florida Association of Centers for Independent Living (CILs)

[www.floridacils.org](http://www.floridacils.org)

The Florida network of 17 Centers for Independent Living (CILs) serve persons with all types of disabilities. CILs serve all ages from children to seniors. Every Florida county is served by this network.

The CILs offer services in four core domains: Information & Referral; Independent Living Skills; Peer Mentoring & Networking; and Advocacy.

Each CIL also offers unique services tailored to the needs of its community, including home modifications, equipment loans and repair, computer skills training, recreational activities and community events.

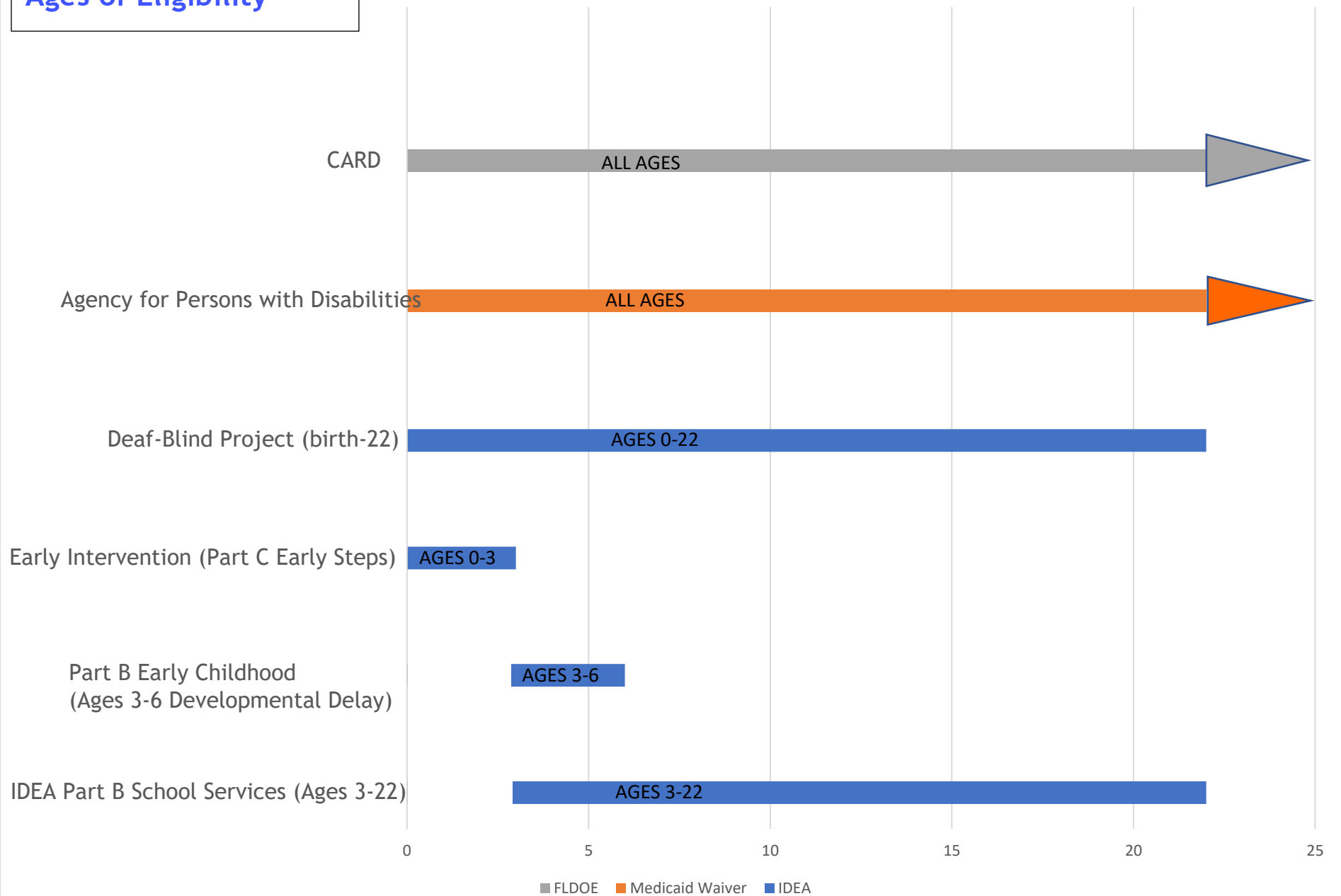
***“Don’t let pride get in the way when your child or your family needs help.”***

**A**s you start navigating around the social services that may be available to your child, remember that once you take the first step, there are people out here to help you find the services that would benefit your child and family. Talk to other parents. They can help you as you walk this road. Don’t give up even if you feel overwhelmed. Remember that there are others out here that have felt the same way. They survived and are thriving—you will too.

**“We are a middle-class family. It was difficult to complete an application for Medical Assistance. But, it is what we needed to do to ensure that our daughter would be eligible for other services that we felt she would need as the result of her disabilities. When we heard that she could get a pair of prescription glasses each year through MA, we thought, ‘We certainly won’t need to do that.’ But the reality of plunking down another \$300 for a pair of back-up glasses each time a lens popped out of the first pair or a bow was broken, changed our minds. So yes, we do often, but not always get a pair of MA glasses. They have saved our daughter’s day more than once.”**

## Ages of Eligibility

## Ages and Eligibility





# Teaching Basics

## **You are your child's first teacher.**

**M**any people associate the term “education” with “school,” but your child’s education really begins at birth—at home with you. You are the expert on your child, and will be his or her first teacher. Forming an attachment to you and developing communication lay the foundation for your child’s learning. Because of your child’s dual sensory impairments, this foundation will require unique strategies to fully develop. This section is intended to serve as a guide in identifying strategies that are specific to deafblindness and explain the basics of the special education process.

*“Know that your child will learn—perhaps just at a different pace and with more supports.”*

## **Give your child the gift of communication.**

**T**he degree of hearing and vision losses, as well as additional disabilities, will impact the way your child communicates. The first step in developing communication is to provide your child with a feeling of security. For children with combined vision and hearing losses, it’s important that their environment be governed by routines and repetitive activities so that they can anticipate what is about to happen. The ability to anticipate and predict what is coming next, combined with feeling safe and secure, will lead to a positive learning environment.

Because of your child’s vision and hearing losses, his communication may look different than other children’s. You can build up his ability to communicate by supplementing your normal communication with cues to let him know what is about to happen. For example, flash the lights in your child’s bedroom to let him know you have entered the room, then gently shake the crib to let him know you are there. Finally, put your hands under his back, lifting him a bit off the mattress, pause, and then lift him completely off the bed. All these steps allow your child to anticipate being picked up. After many repetitions, he will learn that this means it is time to get out of bed.



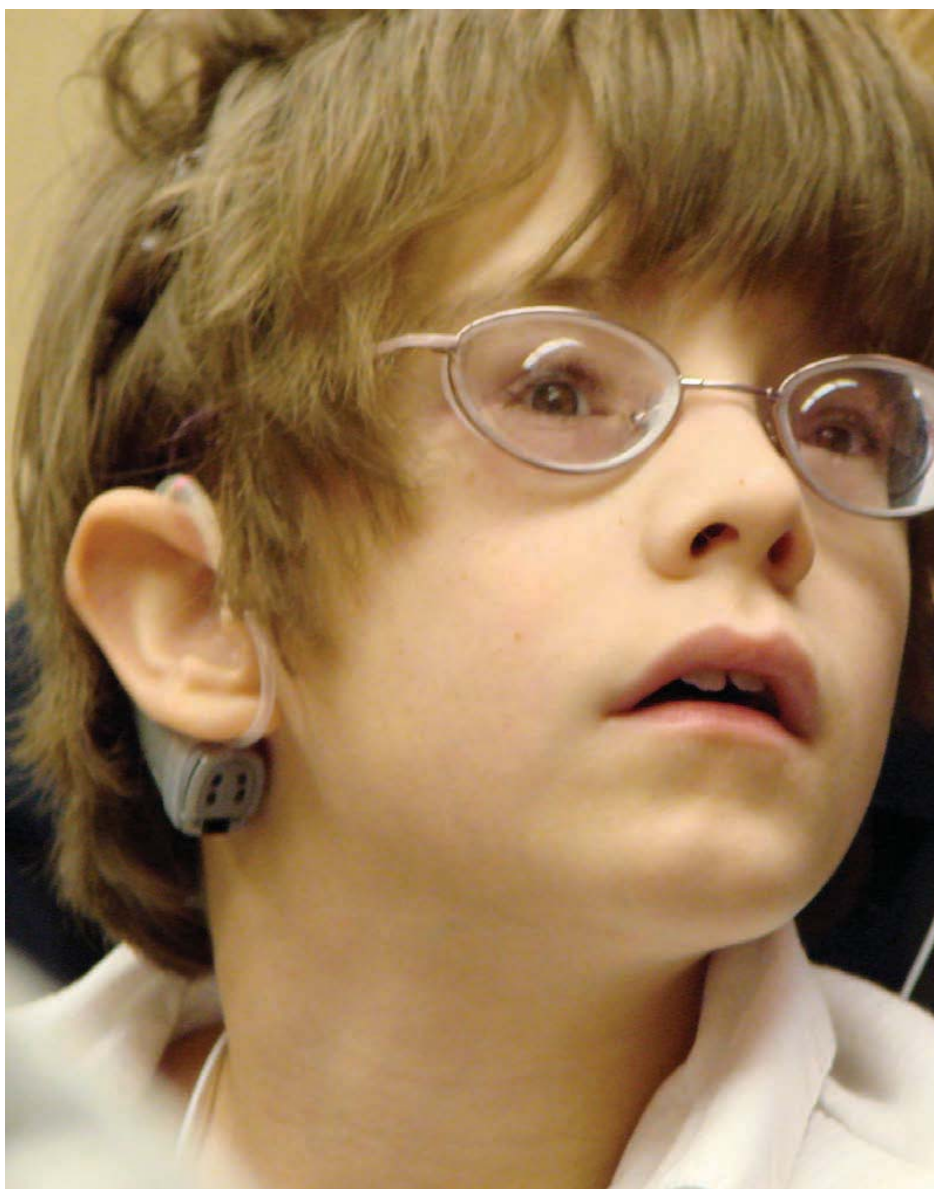
## Cues help your child learn.

**Y**ou can create many cues so your child can begin to understand the world and to anticipate what will happen next:

- ◆ **Touch Cues:** A gentle pat on the bottom may signal time to sit or a tap on the arm may signal putting an arm inside a shirt sleeve.
- ◆ **Sensory Cues:** The smell of soap or sound and feel of water signals it is time for a bath.
- ◆ **Object Cues:** A bottle means it's time to eat. A diaper means it's time to change diapers.

You can also encourage your child's efforts to communicate by letting him know that you appreciate even the small things he does. This can be as simple as breathing along with him when you are holding him or imitating sounds he makes, your cheek against his. This will build his confidence as a communicator.

Depending on your child's use of hearing, you may consider using sign language to communicate. You don't have to learn it all at once. There are books that show signs for words. But, since signing involves movement, it is easier to learn by watching someone sign.



As your child begins to understand basic communications, you might want to try other communication systems described in the National Center on Deaf-Blindness (NCDB) Library. [www.nationaldb.org](http://www.nationaldb.org) Explore other communication choices at the Hands & Voices website [www.flhv.org/resources/communications-choices](http://www.flhv.org/resources/communications-choices)



## **IDEA is the foundation for educational services.**

**T**he Individuals with Disabilities Education Act (IDEA) is a federal law providing guidance in educating children with disabilities.

In Florida, Early Steps is the agency that provides early intervention services. Infants and toddlers (birth to 3) are provided early intervention services within natural environment settings (home, child care, etc.). Services also may be provided in special settings or settings that do not fall into the “natural” setting definition, if the child’s Individual Family Service Plan (IFSP) team determines this setting is needed for a child to meet their IFSP outcomes. The IFSP acts as a contract between a family and the Early Steps Program, in which family priorities for their child and family are addressed in the form of “outcomes.” Participation is voluntary for families.

***“It really helped me understand the services my child was getting when I spent some time in the classroom. It also helped me see some things that weren’t working. I felt better prepared for the next IEP meeting.”***

Referral to the Early Steps Program can be made by anyone, not just by a medical or social service provider. After a referral, children are determined eligible for services through a process of evaluation. Once a child is determined eligible, assessment information is gathered to determine the need for services, which will assist in guiding identified outcomes for both the child and family. For a child with combined vision and hearing loss, best practices recommends that a vision teacher and a teacher of the deaf and hard of hearing are involved in the evaluation and assessment process.

Services from the Early Steps Program can continue until a child’s third birthday. On or after a child turns 3 years old, services are then provided through the local school districts and are called Early Childhood Services. Children are first deemed eligible for services, then a determination for the need for services is decided, which then guides the educational goals for the child. This process is referred to as the Individual Education Plan (IEP) process. Types of services, accommodations, and educational environments in which a child participates are based upon goals written in the IEP.

Each child grows at an individual pace, but research shows that a child’s first three years are the most important time for learning. Getting help early puts your child on the right path to learn and develop at their full potential. Early Steps services are based on Early Steps evaluations and your family’s concerns, resources, and goals. Early Steps uses a Team Based Primary Service Provider approach which aims to empower each eligible family by providing a comprehensive team of professionals from the beginning of services through transition. The goal is for the family to receive strong support from one person, provide a comprehensive team of professionals from beginning to end, and for the family to have fewer appointments and more time to be a “family.” Services are provided to the family and child where they live, learn and play, to enable the family to implement developmentally appropriate learning opportunities during everyday activities and routines. Most services will be early intervention home visits.

[www.CMS-Kids/families/early\\_steps/early\\_steps.html](http://www.CMS-Kids/families/early_steps/early_steps.html)

***“If you have high expectations for your child, others will, too.”***



## **Deafblindness raises extra educational concerns.**

**D**eafblindness is a disability of access—access to information. It is commonly estimated that 85% of what a child learns comes to him via his vision and hearing, which are the most important avenues for receiving information about the world around him. If there is a loss in either of these senses, the impact on learning can be huge. A child who is deafblind has losses in *both* of these senses. He can misunderstand, misinterpret or totally miss what’s being presented.

Because deafblindness is a disability of access to information, our children receive only pieces of the total information presented. Many of us have found it helpful to describe our children as deafblind to educators to highlight their unique educational needs. And, in the case of a child who has multiple disabilities, the impact of a combined vision and hearing loss might be overlooked in the mix.

Some children who are deafblind may need to use sign language. When these kids are in school, they may need an educational sign language interpreter. An interpreter is fluent in sign language and interprets what is spoken for someone who utilizes sign language to communicate. This could include both expressive language and/or receptive language.

Sometimes a child who is deafblind may need someone else to be his eyes and ears. That person is an intervener, a paraprofessional who has training in specialized skills related to deafblindness and who works consistently with one child or student. Other children with combined vision and hearing losses may benefit from working with a combination interpreter/intervener.

<http://intervener.org/>

**“During our daughter’s transition meeting for kindergarten, the teacher of the deaf objected to adding OT and PT services to her IEP, stating that she ‘is already receiving more services than our other deaf students.’ Team members pointed out our daughter’s documented needs and the uniqueness of a child with combined hearing and vision losses, as well as additional challenges. The needed services were included in the final IEP thanks to true team collaboration.”**



***“Develop a positive relationship with the people who work with your child at school.***

***You are on the same team.”***

The information provided in this Education section is just the tip of the iceberg.

*You know your child best!*

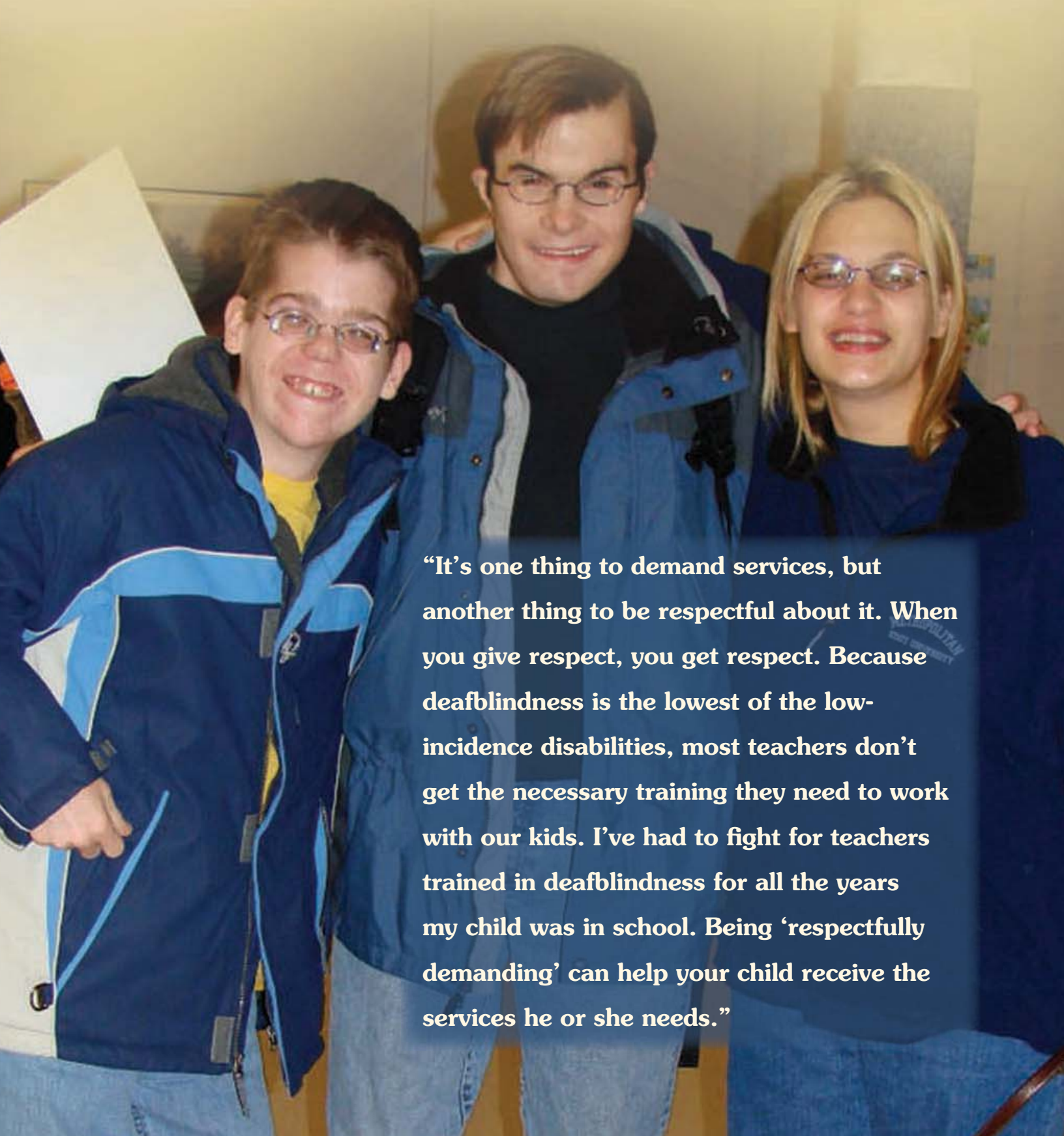
So, if you feel that your child’s education is not progressing as smoothly as you had hoped, you can get help.

Your child’s education begins the day of his birth. With your guidance, your child will travel along the path of lifelong learning.

***“My biggest realization when Andy was young was that I didn’t know what I didn’t know! I used to wonder, why don’t ‘they’ just tell me and provide what he needs educationally? He was diagnosed deafblind as an infant. I slowly discovered, most teachers don’t know.... They may think they know, but deafblindness is unique.”***



*“Success may have different definitions for each child. For some of our kids, success may mean going to college. Others may find success in being able to assist with their own self care.”*



**“It’s one thing to demand services, but another thing to be respectful about it. When you give respect, you get respect. Because deafblindness is the lowest of the low-incidence disabilities, most teachers don’t get the necessary training they need to work with our kids. I’ve had to fight for teachers trained in deafblindness for all the years my child was in school. Being ‘respectfully demanding’ can help your child receive the services he or she needs.”**



*“Our daughter’s third birthday brought the transition from home-based services to early childhood school-based services. Since she was non-verbal, she was not able to share with us anything about her school day. Wanting to reinforce the skills the classroom teacher was working on, as well as simply know how her school day had gone, we sent a spiral notebook with her to school each day for everyone who worked with her to jot down a few lines about the day’s activities. My husband and I also used the communication book to share any news from home with the staff. This flow of information also helped us track the services our daughter was receiving, as well as helped the team members be on the same page while implementing her IEP goals.”*

*“There may be times you need to fight for what your child needs. Pick your battles so that you will be more effective when you need to fight the big fights.”*

*“The intervener our son has had this year has made a huge impact on his growth in school. For example, on Friday after a field trip to the Horse Expo, our child’s experience book had hay, grain and many descriptions of the horses so we could discuss this outing with our son even though he has limited communication. His intervener does all this extra work to benefit Matthew, because her salary does not start to compensate her for all her efforts with him!”*

*“What I have found that helps most in these settings is to be prepared, respectful and to look everyone in the eye.”*

“Be firm in ensuring that any services or adaptations the IEP team agrees on are written into your child’s IEP document. Remind the team that team members may change during the year, and having the necessary services or adaptations in writing will provide continuity for your child, as well as a roadmap for any new service providers.”

*“I had heard about families who had done it — moved to get their kids better services or education. I NEVER thought it would be us. Never say ‘never.’ We decided it wasn’t worth the fight where we were living, and another community next door impressed us greatly with their schools. So we took a deep breath, made the decision and didn’t look back. It was daunting at the time and tiring. But, it has brought benefits to everyone in our family.”*





# Reaching Out

## Build friendships with other families.

**B**y the time you read this, you probably have experienced the gamut of emotions surrounding your child's diagnosis of deafblindness. You can find support as you ride this emotional roller coaster by connecting with other families that have children with similar needs. Becoming involved in this community of families can help your child—and you—make life-long friends. Sharing your joys as well as your challenges with families on a similar path can build strong bonds, providing your child and family with a sense of belonging and acceptance.

You might find that having this supportive community can cushion you and your family from some of the bumps on this journey. As we all know, the road isn't always smooth. Sometimes when you and your child are out in public, people might stare. They might ask unkind questions. They might not make you feel welcome. We have all had these experiences. It helps to realize these people probably don't mean to be hurtful. They might just be curious or simply have no experience interacting with a child who is deafblind. When you belong to a supportive community, you can share these "bump" stories and laugh or learn from each other.

## Find support in a wider community.

**I**n this section, we have highlighted some organizations that serve families that have children with special needs. These groups often organize activities that give families the chance to get to know each other. The community where you live might have its own resources. Your county social services staff will know what's available in your area.

As you look for ways to build a community for your family, you don't have to be limited to groups that include children with special needs. There will be times when you want your child to be involved in an activity in your area, and he or she is the only child who is deafblind.

***"Joining in activities for families with kids who have vision and hearing losses has helped everyone in our family find support and make friends."***

***"Be encouraged—you are **not** on this road alone!"***



***“One way I encourage friendships is to invite kids to our house. That way I can keep an eye on them and explain things like why Sam needs to bring things close to his eyes to see.”***



### **Join in at school, church, community centers.**

**W**hile you might think of school only as the place where your child is educated, school also can be a place for community gatherings. Your child can experience local culture by attending or participating in choir and band concerts, plays, demonstrations, and school carnivals.

Church groups can provide spiritual support as well as peer activities such as Vacation Bible School. Many churches offer Youth Group programs for teens that provide opportunities for service and volunteer activities where your child can help others in the community. Many families have found that their church communities gladly provide the supports their children might require, such as an interpreter or a one-on-one support person, to enable the children to be full participants in activities. Work with the youth ministry in your church to help them understand your child's needs.

Many families have had good experiences with local community centers such as a YMCA. Talk with member services about programs that would be appropriate for your child and any accommodations (such as an interpreter) that your child requires to participate.

Having strong community ties will make it easier for you when the time comes to let your little one spread his or her wings and go out into the community without Mom or Dad. You will know that others care about your son or daughter and will look out for his or her safety. Your child is never too young to begin this community integration. There is a place for every individual!

**“Therapeutic horseback riding has been such a blessing for our daughter. Having begun walking independently at age four, she was still wobbly on her feet at age six when she began her first lesson. Within weeks we noticed her improved balance and posture. With each passing year she has gained skills, the most important being her ability to converse with her side walkers and leader as she confidently rides and guides her horse around the ring. Horseback riding is a favorite topic of many of her classmates and her knowledge and skills on this topic enable her to relate to her peers.”**

*To find a riding stable near you, see [www.pathintl.org](http://www.pathintl.org).*





## Organizations serving special needs:

### The Florida & Virgin Islands (FAVI) Deaf-Blind Collaborative

[www.deafblind.ufl.edu](http://www.deafblind.ufl.edu)

serves the entire state of Florida providing training and consultation services to the families and educational teams of Florida's children and young adults (ages birth through 21) with combined hearing and vision losses. These services are free. Call FAVI at 800-667-4052 for information about the services offered and how to access them.

- ◆ Parent to Parent of Miami ([www.ptopmiami.org](http://www.ptopmiami.org)) is a community parent resource center serving parents of children with disabilities in Miami-Dade and Monroe counties.
- ◆ The Family Network on Disabilities (FND <http://fndusa.org>) is a network of individuals of all ages, who may be at-risk, have disabilities, or have special needs, as well as their families, professionals, and concerned citizens. Parents of the Panhandle Information Network (POPIN) <http://fndusa.org/contact-us/programs/popin> POPIN provides parent training and information services to the panhandle of Florida from Escambia to Volusia County. Parent Support Network (PSN) <http://fndusa.org/contact-us/programs/psn> The Parent Support Network is the parent training information center for Florida's most southern counties.



***“This isn’t an easy road. It helps to have the support of friends, especially other families that have children who are deafblind. We share common experiences.”***

**“Despite ongoing physical therapy, our son’s physical development was slow. Rolling and sitting late, he finally walked independently when he was 4. He wanted to participate in sports like his older brother, so we enrolled him in a karate class at our community center. The center provided an interpreter who happened to have karate skills herself. Those three years of karate turned out to be the best physical therapy for him!”**



- ◆ The Florida Instructional Materials Center for the Visually Impaired ([FIMC-VI www.fimcvi.org](http://www.fimcvi.org)) is a statewide resource center designed to assist schools with specialized materials for students with visual impairments. FIMC-VI provides services to students with visual impairments enrolled in Florida’s public and private schools, as well as those students who are home schooled. There is no charge for any services offered by FIMC-VI. Materials are produced by the Center staff, produced by certified volunteer transcribers, and/or purchased by the Center. Outreach, consultation, workshops, webinars, independent modules, student events, and other learning opportunities are offered to families, teachers, and agency personnel throughout the state at no charge.
- ◆ Florida Hands & Voices ([www.flhv.org](http://www.flhv.org)) is a non-profit organization dedicated to supporting families and their children who are deaf or hard of hearing, as well as the professionals who serve them. This parent-driven, parent/professional collaborative group is unbiased towards communication modes and methods. Their diverse membership includes individuals and families who communicate with American Sign Language, cued speech, oral language, or with a combination of communication methods.
- ◆ Disability Rights Florida ([www.disabilityrightsflorida.org](http://www.disabilityrightsflorida.org)) is the designated protection and advocacy system for individuals with disabilities throughout the state of Florida. Services are free and confidential.

**“One of the most heartbreaking aspects of raising a child who is deafblind is seeing her not have the friends that her ‘typical’ sister has. It hurts to see the birthday party invitations stop coming as she is getting older and the differences between her and her ‘typical’ peers are so much more apparent. Many times, my daughter who is deafblind seems very content to play on her own. She rarely expresses any signs of sadness or envy that her sister has so many invitations from friends. When she refers to her classmates, she always calls them her friends. Do they come over to play? Rarely, but she says they are her friends. I guess that should be good enough for me, too.”**



# Caring for Family

## **You can manage life on this new road.**

**Y**our baby or child has received a diagnosis of deafblindness. You are learning more about this new reality every day. It's true there is a lot to learn about your child's condition and the services available to help with it. But, you don't need to learn everything at once. Looking too far down the road at this point can be overwhelming. It can leave you feeling "out of gas" to deal with everyday life at home.

Throughout this Road Map we've given you insights from parents and families who have traveled this road before you. We hope to do the same here. We all have seen and felt the stress on family life when there is a child with special needs involved. We also have found ways to manage that stress.

Just as your child's situation is unique within the deafblind world, the ways you manage stress will be unique to you and your family. This is a situation where one size does not fit all. As you read this advice from experienced families, you may find ideas that fit your current needs and glean ideas to support you as you move forward on your journey.

***"When your child is first diagnosed deafblind, give yourself time to grieve.***

***You are grieving the loss of dreams. One day, life will seem manageable and okay again."***



***“It is important to take time out to go on dates with your spouse if you are married. Taking care of a child with special needs can strain a marriage. It’s also important to give yourself time, even just five to ten minutes a day—you need to take a breather.”***

***“I sometimes look back wistfully at the time in my life when I was inconspicuous—before we used sign language, before there was a guide dog in the family. It was nice to just blend in. This is not an option any longer when we go places as a family. There are times when I just want to stare right back at those who stare at us. Thankfully, I usually am able to either ignore them or look back with a smile.”***

## **Don’t travel alone.**

**A**s we’ve traveled this road, we’ve come to recognize the importance of taking care of ourselves—the primary caregivers—even while we take care of those we love. We must take time to care for our own physical and emotional needs in order to be able to care for others’ needs.

One of the most important ways you can take care of yourself is to seek others’ support. This support can come in many forms, including support groups that focus on your child’s specific etiology, professional counseling, and support from families that also have a child who is deafblind.

Many parents find that their friends who have typically developing children cannot relate to the unique development of a child who has combined vision and hearing losses. Connecting with parents who are on this same path provides an outlet for celebrating successes as well as frustrations. Plus, you can pick up knowledge from other parents that reduces your learning curve on many deafblind issues.

There may be points along this road where you or another family member could benefit from professional counseling. A trained professional can help with personal, sibling, or marriage issues. Your physician or your child’s doctor can refer you to appropriate service providers.

***“In the beginning, we were overwhelmed by information, especially while caring for our baby. We asked my sister to sort through the volumes of information and share the condensed version with us. We filed away the ‘volumes’ for reference when we need specific information.”***

***“When Andy was young, I wished for a crystal ball so I could look into his future. Now that he’s older, I realize how rewarding it has been having him in our lives. He has helped us realize what is really important in life: a loving family. We have learned not to impose our concept of success on him. Andy is happy with his independent life. We know he will face challenges and frustrations in the future. But, we hope the foundation of love, self-confidence, and support he has will help him continue to experience a productive, rewarding life.”***

## Pace yourself for the long haul.

This is a marathon, not a sprint; a journey, not a destination. In other words, don't wear yourself out. Learn to say "yes" when help is offered. A ready-made meal or an offer to take a sibling on a play date can provide the break you need to make it through the day.

Keep a list where you jot down things you run across in your day that you could use help with. That way you will have specific jobs ready when someone offers to help with "whatever you need." Remember that most people who offer to help truly want to make your life easier. They know they cannot change your child's disability, but they can help relieve some of the demands on your time. When you accept their help, you are giving them a chance to feel valued. Your acceptance is a gift to them, just as their offer is a gift to you.

If you don't have family and friends offering to help (or even if you do), consider respite care. It can be a lifeboat to keep your family afloat. Children who are deafblind require an enormous amount of hands-on instruction since they miss incidental learning due to their sensory deficits. For caregivers, this constant state of being "on" is both emotionally and physically draining. Respite care for a few hours or an entire weekend can recharge your batteries.

You can also feel energized when you take time every day to do something for yourself. A walk outdoors, a few minutes of quiet time with a cup of tea and a good book, or a few extra minutes in bed can do wonders to clear your head and help you find joy in each day. Also, schedule regular check-ups for yourself, just as you do for your child. Prolonged stress is a threat to your well-being. Addressing it with your physician is the first step in learning to relieve or minimize the stress in your busy life.

### **A note about holidays:**

Holidays and family get-togethers can be challenging for a family with a deafblind child. Since many of our children require daily routines to allow them to anticipate what is to happen next, anything out of the ordinary can set off fears and unwanted behaviors. Besides the change in scenery, the child may be surrounded by others who cannot communicate with him or her. We have had to adjust our expectations for these times. That might mean going to events for just a short time, hosting events at our homes so that our kids feel comfortable, or having a sitter stay with the child while the rest of the family attends an event.

*"For me, the key to achieving balance in life is to break things down into manageable pieces—and then have someone else take care of some of those pieces!"*





***“It is an eye-opener to realize that, as much of an impact as we parents believe we have on our children who are deafblind, the reality is that in most cases their brothers and sisters will live longer with them than we will. We cannot control what will happen to these relationships after we are gone. But, we can do our best now to foster strong relationships between everyone in the family.”***

## **Siblings need special care, too.**

**Y**our other children might feel their world has turned on end with the arrival of a sibling who is deafblind. They might feel that the disability is their fault and/or simply miss time spent with you. Some families set up a regularly scheduled “date” with each sibling, providing individual attention for each child. Dates can range from an afternoon or evening out somewhere, or simply ten or fifteen minutes of story or game time. If your deafblind child’s medical needs prevent you from leaving home, “date time” can be arranged when your medically involved child is napping.

Siblings of children who have special needs bear their own type of “battle scars.” It can help them understand what they are living through if they have the chance to connect with other children who are traveling the same road. Sibling support groups can provide these connections.

Visit the Sibling Support Project online [www.siblingsupport.org](http://www.siblingsupport.org) to find a nearby sibling support group.

**“We have always wondered about the effects our special needs child has on his siblings and will it drive them to therapy or make them more accepting of society.**

**Last year there was another boy in our son’s school who had Down Syndrome and vision**

**problems. One of my daughters pointed out how our son looked so much like the boy. I launched into what I thought was a very detailed explanation of the characteristics of Down Syndrome. At the end of my ‘speech’ my daughter looked at me bewildered and said, ‘I meant they both have blond hair and glasses.’”**



“As we all know, having a child who is deafblind changes life for everyone in the family, especially for sisters and brothers. I have worried about how our ‘typical’ daughter is impacted. Will she need years of therapy to deal with these issues? Will she go running from our home as soon as she has her high school diploma in hand?

Now that our daughter is old enough, I signed her up for a sib shop—a support group for siblings of kids who have special needs. I wasn’t sure how she would like it. After the first meeting, I peppered her with questions about what it was like. I received mostly monosyllabic responses. I felt a little frustrated and not sure if it was going to be a worthwhile effort. Later, I saw that my daughter had written in big letters ‘SIBSHOP’ on the calendar for all the upcoming meetings. That was all I needed to know.”

*“My son gets more attention because he has more needs than my daughter. She was so patient and good, but I could tell that her spirit was deflating. Now, I make it a point to do something just with her. This one-on-one time recharges her.”*

### **One sibling’s view:**

*“Having a sister who is deafblind has been an eye-opening experience for me. I was just nine years old when she was born, so I didn’t fully understand the implications of her disabilities at the time, but as I grew older I was able to see how my life changed when Emily entered it. For me, having a deafblind sister meant taking sign language classes, attending deafblind family retreats, and being exposed to many other people with disabilities. It was overwhelming, but I’m thankful for these experiences because they changed the way I look at the world.*

*Many big sisters might excitedly relate tales of their sibling’s first word; I, however, will always remember my sister’s first sign: ‘more.’ Because of her, I now have rudimentary signing skills, I know how to use a TTY, and I’ve even become acclimated to having captions on the television. One thing I love about having a sister who is deafblind—it’s never a boring day at our house!”*





*“When our son was 5, he got glasses to see better and tubes to facilitate better hearing—hopefully speech would follow. Neither happened, and we had to accept that quick fixes would not be a part of our lives. But after six years of trying our little guy can finally put on his own socks, which shows sometimes success comes to those who take the hard road and just keep trying.”*



“I think my breaking point was when Samuel was in his first week in the NICU (neonatal intensive care unit) and undergoing his first major surgery. I was nervous and trying to heal from surgery myself. When I saw Samuel being rolled down the hall by his doctor, my heart felt like it was going to come out of my chest. As I watched him roll by, I knew that I could not look at him, not this way. My sweet baby had bars on his face called a jaw distraction. My friend noticed the expression on my face as I made my husband go see Sam first. She said the most profound words, ‘It’s okay to not be okay.’ I let go and began to weep. I had been trying with all my might to hold it together and be the strong one. With her help, I realized I don’t have to—it’s okay to not be okay.”

### **Take care in difficult times.**

Sometimes it seems as though the road you’re traveling is off the map. How can you know where to turn when the road becomes really rough? At difficult times, such as when caring for a medically fragile child, seeking the support of families that share this deafblind connection can be invaluable. In sharing time with these families, you will find a safe haven to talk about your child’s diagnosis, work through the loss of abilities as your child’s health declines, or find support for your other children. The people you choose to surround yourself with should be those who acknowledge and accept your feelings as valid—even those mixed feelings of grief and relief for both your child and you if your child’s life comes to an end. We’re on this road together. We can help each other along the way.

“When your child has a terminal condition, there may come a time when you must come to the realization that there is nothing more that you can do. You need to keep in mind quality of life issues for your child—not for yourself, but for your child. This could mean letting the inevitable happen. There may be some medical procedures that could extend your child’s life, but at what cost? If the side effects of the procedure would decrease your child’s quality of life, you, as the parent, may need to make the decision that the procedure may not be in your child’s best interest. This is hard to write, but that is the place we are at now.”

## My Story: EVA-SIMONE BROOKS

Full Trisomy 13, 7 ½ years old, Parents: Sean and Daisy Brooks



Eva-Simone is our fourth child. We did not know she had Trisomy 13 until she was born. Eva was born in Virginia the day before Thanksgiving in 2008. We knew she had complications due to abnormal ultrasounds but we did not have tests done while we were pregnant to figure out exactly what condition she had. For our family, the end result would be the same so there seemed no need to

pay extra for these tests. We would love her and care for her as we did our older 3. I believe it was a blessing in disguise that we did not know early on. Additional stress during an already stressful pregnancy was unnecessary for our family.

The moment after I gave birth to Eva I waited, for what seemed like forever, before I heard her cry. Once I did hear her cry I had this feeling rush over me that everything would be ok. Apparently, I was the only one having that feeling. The doctors were in emergency mode...they saw her low set/malformed ears, cleft palate, small right eye and extra digit. The craziness that would become our new "normal" began. I gave Eva a quick kiss and she was rushed out of our room to the NICU.

We stayed in the NICU with her for 7 days exactly. On the 7<sup>th</sup> day we had confirmation of what the doctors dreaded, a Trisomy 13 diagnosis. We were told that "we would be lucky to have 2 weeks with her". My husband, Sean and I decided that if we would only have 2 weeks with Eva we would like to enjoy these moments at home with her rather than in the NICU. The NICU staff taught us how to care for her. They taught us CPR, how to feed her through her NG tube and how to measure and place her NG tube. We were sent home with a few contact numbers- Genetics in DC, SSI and a DME company.

Life at home was more comfortable than the NICU but it was exhausting. Sean and I took turns caring for Eva and watching her sleep. We were told Trisomy 13 babies have apnea and will eventually stop breathing. The first 4 months of Eva's life were the most difficult. She was in pain



because she had a very sensitive GI tract. After 2 months, due to stress, I didn't produce enough breast milk for Eva. We began formula but she was not reacting well to the change.

Our families lived out of state, so we did not have a local support system. We, also, did not qualify for Medicaid through SSI. Finally, we learned about the Medicaid Waiver. At 4 months we were able to have nursing help for 8 hours a day and 8 hours at night through the Med Waiver Program. At 6 months old Eva had Nissen surgery to help with GERD, hernia corrected and a g-tube placed. After surgery she had a few really bad seizures. They performed an EEG to formally diagnose her with seizures. We'd witnessed seizure activity since birth but were not able to confirm it with the 4 hour EEG given previously.

Physically life became easier for Eva as she grew. Our older 3 children loved having Eva home. Dayzha quickly took to wanting to love on Eva but also understand scientifically what was going on with her. Savon and Alani enjoyed having a little one to cuddle with. She quickly became the heart of our family. We had to learn Eva's medical needs to give her a better quality of life. Much of the first year of her life was full of finding the best combination of supportive doctors, nursing help, medicines, therapies and diet for her sensitive and unique body.

Much of Eva's care early on depended on the help of Dr. Bloom. She was our Complex Care Doctor-she played the same role Dr. Komatz now plays for Eva's care. Dr. Bloom and Dr. Komatz both helped set our family up with doctors who were willing to look past the Trisomy 13 diagnosis. It's very important to our family that we have doctors and other professionals in Eva's life that understand we make decisions together as a team. The best appointments for us are when we are able to ask many questions and are given full information about what options are available for Eva. At times we may need to get creative with treatments for her because her body reacts differently than most and/or she has limitations (such as surgery being only a last resort). Professionals that take the time to learn about Eva and our family as a whole have made the biggest impact on Eva's overall health and wellbeing.

Eva is complex medically and otherwise. She takes complex to another level that many didn't know existed. She challenges those who feel they have seen it all. She expects patience, greatness and respect. We no longer need to advocate as much for doctors to see past her Trisomy diagnosis. Our current challenges in advocating for Eva tend to be in the school system. There is a very fine line between medically necessary and educationally relevant. We have a great team of educators that have worked with Eva since she was 3 years old and now are happy to advocate for us to ensure Eva has what she needs to learn and grow. Finding a team we trust was the most important thing we

have done for Eva. The professionals that work with Eva understand and support our goals for her. When we need to add a new professional to our team Eva's current team members will usually recommend someone who will well with Eva and our family. This leads to a smooth transition to tackle the next challenge in Eva's life.

Eva has many challenges daily. She has her own timeline of when she will do things... everything from getting over a cold to learning how to sit up. We have quickly learned we are all on Eva's schedule. She is a princess and we just live in her world. We are happy to live in her world and follow her lead.

It's difficult to condense 8 years of life into a 10 to 15 minute presentation. We have learned so much along the way. Most importantly we have learned to slow down. Eva has taught us our every moment is a gift. We wake up in the morning; see the sun shine through the windows which cause shadows that are fun to look at. She enjoys small things like that. When she is happy, we are ALL happy. We could be having a stressful day but if Eva smiles... we stop, look at her, smile with her and enjoy the moment.

Eva gives love and shares life's beauty by being present in it. She sees the contrast between the sky and the trees. She smiles. She listens to our voice and acknowledges our presence by pausing. Her subtleties are important and meaningful. She has fulfilled the type of life we all strive to have... a happy life full of love, appreciation and beauty.

We have also learned our capacity to learn new things is endless. I never in a million years would have thought I would be able to understand so many medical terms, conditions and how they can affect someone. I never would have thought I would have to preform CPR correctly and have it save Eva's life. I would never have expected that our experiences would give us the opportunity to help families locally and globally. Eva has made all these things happen. She has showed me how to be a better version of myself and continue to better myself through education, patience and allowing this new passion for life to guide me.

Our journey with Eva has led our family to create Eva's Gift Non-Profit Organization which we have named in her honor. Eva has taught our family as a whole to be more giving and compassionate. Eva's Gift consists of our immediate family, Eva's nurse Ms Robin and some amazing Trisomy mom's I've met online.

Online support is also key to our journey. I have met some wonderful parents who have taught our family a lot through the years. We support each other's journey through sharing our experiences,



educating each other and celebrating milestones that only another parent of a complex special needs child can appreciate.

Every child deserves a chance at life. Eva has a purpose in life that may not seem obvious but has indirectly make amazing positive changes in our family and our community. We become better people when we learn to humble ourselves and become the student to a child like Eva. They have the ability to see life through an innocent lens, non-biased and full of appreciation.

*Daisy Brooks*

Mom of 4 Amazing Children

Advocate for [Children with Trisomy](#) and other Special Needs

Director of Eva's Gift Non-Profit Organization

[www.facebook.com/evasgift](http://www.facebook.com/evasgift)

## More Family Stories:

The **National Center on Deaf-Blindness (NCDB)** offers a wonderful collection of *Families Matter* stories. Told mostly through video, these stories will introduce you to children and young adults who are deaf-blind and their families. “As you get to know them, you will discover how individuals who are deaf-blind learn, develop, and live their lives.” <https://nationaldb.org/families/familiesmatterstories>  
Also join **NCDB on Facebook**, where they share weekly posts highlighting families.

[#DBFamilyFunFact](#) <https://www.facebook.com/nationaldb> [https://twitter.com/nationaldb\\_ncdb](https://twitter.com/nationaldb_ncdb)

The **National Family Association for Deaf-Blind (NFADB)** offer a collection of Family Spotlights. These brief stories profile NFADB families. Meet individuals who are deaf-blind of different ages and with different etiologies and learn how their families support them. <http://nfadb.org/family-stories/>

A collection of longer stories is **NFADB Family Journeys**. Parents write in their own words about the experiences and emotions that come with raising a child who has multiple disabilities and how their families’ lives have changed.

<http://nfadb.org/stories/family-journeys/>

From other sites, NFADB has collected links to **More Stories**, as well as links to blogs, from family members and individuals affected by deaf-blindness.

<http://nfadb.org/stories/more-stories/>

The **American Foundation for the Blind’s “Family Connect”** for parents of children with visual impairments offers Personal Reflections which include stories from families affected by deaf-blindness.

<https://www.familyconnect.org/blog/familyconnect-a-parents-voice/personal-reflections/topic/135>

<http://www.familyconnect.org/info/after-the-diagnosis/browse-by-condition/deafblindness/123>

The **CHARGE Syndrome Foundation** offers a variety of stories and profiles of individuals and families with CHARGE syndrome.

<https://www.chargesyndrome.org/our-role-impact/our-stories/>

<https://www.chargesyndrome.org/our-role-impact/profiles-archive/>

## Our Contributors

Many people shared their expertise/experiences to create this Road Map. Thank you to:

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Berdans (cytomegalovirus, CMV)  
Bibbees (partial trisomy 3 & 6)  
Blanchard/Hennessys (CHARGE Syndrome)  
Boelters (CHARGE Syndrome)  
Cassidys (prematurity)  
Coninxs (Goldenhar Syndrome)  
Eggerts (Usher Syndrome)  
Erdmans (oxygen deprivation at birth)  
Fosselmans (Stickler Syndrome)  
Kadries (CHARGE Syndrome)  
Kimlingers (Lenz-Majewski hyperostosis)  
Korns (Marshall/Stickler Syndrome)  
Manleys (Stickler Syndrome)  
Martindales (prematurity + meningitis)  
McDevitts (prematurity)  
Merciers (unknown)  
O'Kanes (brain tumor)  
Pedersens (Down Syndrome)  
Proutys (CHARGE Syndrome)  
Robinson-McLaughlins (Chromosome translocation 11;22)  
Rothbauers (CHARGE Syndrome)  
Sadowskys (unknown)  
Schmidts (Beckwith-Wiedeman Syndrome)  
Seelyes (Marshall Syndrome)  
Soukups (CHARGE Syndrome)  
Stidmons (CHARGE syndrome)  
Stevermers (CHARGE Syndrome)  
Thompsons (CHARGE Syndrome)  
Totenhagens (Wolf-Hirschhorn Syndrome; Trisomy 4p)  
Volkers (prematurity)  
Werners (Down Syndrome)  
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**[www.deafblind.ufl.edu](http://www.deafblind.ufl.edu)**



# Parent Road Map

**—Created for parents by parents**

***Your Guide  
to Raising  
a Child with  
Combined  
Hearing and  
Vision Losses***



**U.S. Office of Special  
Education Programs**