RESOURCES FOR KANSAS PARENTS OF YOUNG CHILDREN WITH SENSORY LOSS

(Birth to Five Years Old)

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Table of Contents

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DISCLAIMER:
The purpose of this document is to provide general information for parents of children with sensory loss. This document is not a comprehensive list of resources. The inclusion or exclusion of any resource in this booklet does not imply endorsement or disapproval of the Kansas deafblind Project or of individuals and organizations that made this resource possible. Parent discretion must be used when determining appropriate programming for their children or in applying principles and guidance from this document.

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IDEAs that Work
Office of Special Education Programs
U.S. Department of Education

Parent to Parent

Dear Kansas family,

Welcome! We are so glad this packet found its way to you. We know personally that sensory loss comes with lots of questions and that answers aren't always easy to find. Lisa and I are both mothers of two children, both with CHARGE syndrome. Juggling all the things that life brings in addition to parenting a child with a disability is hard work. We both found that we had to navigate much of the system on our own and do most of the research ourselves; our goal is to make sure you have a better start. We have compiled a list of resources, therapy options, and locations throughout the state and other information we hope you find helpful.

This road can feel daunting and scary but we are here to help, and we hope to make it a little bit less intimidating as you begin this journey.

Please keep our contact information on hand and reach out if you have any questions or if we can help support you in any other way. Always remember, you are not alone – we are in this together!

Sincerely,

Lisa Collette
Family Engagement Coordinator, Kansas deafblind Project
Lcollette@kssdb.or

Kim Freeman, R.N., Parent

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Hello, Kansas families! I am the CHARGE liaison for the state of Kansas and I am happy to be at your service. I have a child who has CHARGE syndrome and related deafblindness, and I know first-hand how overwhelming and difficult life can get, especially when we don't have access to appropriate resources to help our kiddos.

The Kansas deafblind Project has created this wonderful (birth to five) resource packet specially for families with kiddos that have deafblindness and other sensory issues. Our goal is to make your journey easier and I hope you will find the information within this packet useful.

Please feel free to reach out to me with any questions or concerns. I am *HERE* to help.

Takrima Sadikot - takrima@gmail.com
CHARGE Syndrome Foundation Liaison for Kansas

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.

Parent and Caregiver
Bill of Rights

1. **I have the right to enjoy my life as intensely as possible.**
2. I have the right to play and be silly without feeling guilty.
3. **I have the right to ask for help.**
4. I have the right to grieve.
5. I have the right to laugh or cry, whichever I need at the moment.
6. I have the right to step away and just breathe.
7. **I have the right to have 5 minutes to myself.**
8. **I have the right to just be in the moment.**
9. I have the right to be gentle with myself and know that I don't have to be everything to everyone all the time.
10. I have the right to respectfully disagree.
11. **I have the right to not be judged by myself or others.**
12. I have the right to say "no."
13. I have the right to take time away for myself.
14. **I have the right to feel my feelings and to validate them within myself.**
15. I have the right to share or not share my feelings all the time.
16. I have the right to say that today I did the best I could do.
17. **I have the right to keep things in my life that are special and only for me.**
18. I have the right to take care of myself.

Source: http://www.parentcompanion.org/article/parent-and-caregiver-bill-of-rights

Hearing Loss Factsheet

What is hearing loss?

Hearing loss is a reduced ability to detect sounds. Many people try to describe hearing loss as a percentage. This is not the most accurate way to describe it. It is better to describe it by the type and the degree of hearing loss. Hearing loss can happen when any part of the ear or auditory (hearing) system is not working in the usual way.

What caused my child's hearing loss?

Over 50% of infants born with hearing loss have no known risk factors for hearing loss. Do Not Blame Yourself!

Some of the risk factors for hearing loss are:

- Family history of hearing loss.
- A syndrome that is known to have hearing loss.
- Craniofacial abnormalities, such as a cleft lip, palate, ear pits, or ear tags.
- Certain infections in the mother during pregnancy such as CMV (cytomegalovirus), toxoplasmosis, herpes, and rubella.
- Complications during birth such as prematurity or lack of oxygen.
- Admission to a neonatal intensive care unit for more than 5 days.
- Certain infections such as bacterial meningitis, mumps, measles, or whooping cough.
- Recurrent ear infections.
- Very loud noises such as fireworks, loud music, or gunfire.
- Trauma, such as head injury.

These are some of the most common risk factors of hearing loss. Your audiologist or doctor can give you more information about other risk factors and causes of hearing loss. The cause of your child's hearing loss may never be known.

Types of hearing loss

- **Conductive Hearing Loss-** Hearing loss caused by something that blocks sounds from getting through the outer or middle ear and being "conducted" to the inner ear. Some causes of conductive hearing loss include impacted wax, perforation (hole) in the eardrum, or middle ear fluid and/or infection. This type of hearing loss can sometimes be treated with some medicine or surgery.
- **Conductive Permanent Hearing Loss-** Hearing loss caused by malformation of the outer ear, ear canal, or middle ear structures. This type of hearing loss can sometimes be corrected with surgery at appropriate developmental ages.
- **Sensorineural Hearing Loss-** Hearing loss that occurs when there is a problem in the way the inner ear or hearing nerve works. Some causes of sensorineural hearing loss are hair cell damage or malformation of the cochlea. Sensorineural losses are generally perceived as a loss of clarity of sound, but not necessarily a decrease in loudness, and are more likely to be permanent.
- **Mixed Hearing Loss-** Hearing loss that includes both a conductive and a sensorineural hearing loss. An example of a mixed hearing loss is a child with permanent sensorineural loss and a temporary conductive loss due to middle ear fluid.
- **Auditory Neuropathy Spectrum Disorder** - Hearing loss that occurs when sound travels through the ear normally up to the cochlea but doesn't reach the brain as an understandable input.

Hearing loss can also be described as:

- **Unilateral or Bilateral-** Hearing loss is in one ear (unilateral) or both ears (bilateral).
- **Pre-lingual or Post-lingual-** Hearing loss happened before a person learned to talk (pre-lingual) or after a person learned to talk (post-lingual)
- **Symmetrical or Asymmetrical-** Hearing loss is the same in both ears (symmetrical) or is different in each ear (asymmetrical).
- **Progressive or Sudden**- Hearing loss worsens over time (progressive) or happens quickly (sudden).
- **Fluctuating or Stable**- Hearing loss gets either better or worse over time (fluctuating) or stays the same over time (stable).
- **Congenital or Acquired/Delayed Onset-** Hearing loss is present at birth (congenital) or appears sometime later in life (acquired or delayed onset).

Terms used to describe people with hearing loss:

- **Hearing impaired** is used for a child with any degree of hearing loss. (Many people don't like this term and prefer to use the term *hard of hearing*.)
- **Hard of hearing** is used if a child has a mild to severe degree of hearing loss.
- **deaf,** when spelled with a little or lower case **d**, means "audiologically deaf." This term is used to describe a profound or severe to profound degree of hearing loss.
- **Deaf**, spelled with a capital or uppercase **D**, is used by the Deaf Community to mean "culturally Deaf." A person can have *any* degree of hearing loss to be a member of the Deaf Community. Members of the Deaf Community communicate using sign language and have a culture that they identify as their own.

Tips and Strategies for a Child With Hearing Loss

What Do We Do Today?
Love Your Baby and Enjoy Them!!!!
The first few weeks and months after you have learned about your child's hearing loss can be a busy and overwhelming time.

Here are some ideas to help you:

Interact and communicate with your child.
Some parents find that talking to their child feels "different" because they aren't sure how much their child is hearing. You don't have to wait to start working on communication. Communicate with your baby as you normally would.

Use a natural voice. Babies do respond to the special intonation patterns and facial expressions we reserve just for them. Lots of eye contact, touch, hugs, and kisses help babies learn how to interact. Face-to-face conversations are good for all babies, but especially for babies with hearing loss.

Your child needs to watch your mouth move, and watch your facial expressions.
Be sure to stay close and face-to-face when communicating with your child. Babies learn from routines you have and the things you do and say in everyday life. Your child will benefit from your communication as you do tasks such as change a diaper, give a bath, and play games like peek-a-boo.

Seek support from family and friends.

People who are close to you can be a great support. Your friends and family may share your feelings and opinions about what is best for your child. They may also have differences. Invite the support people in your child's life to participate in visits to the audiologist, early intervention visits, and parent group meetings.

Keep a journal.
A journal is a place where you can write down important things about your child.
Write down sounds that your child responds to or new vocalizations your child makes. As your child changes and grows, you will be able to see how far she has come!
Write down questions to ask professionals when you meet them.
Write down the feelings and experiences you are having.
A notebook such as one that holds this guide is a great place for keeping copies of clinical reports and important forms for your child. When you go to appointments, it will be easy to show others results or have them make copies if needed.

PEOPLE YOU WILL MEET ALONG YOUR JOURNEY

You will meet many new people as a result of your child's hearing loss.
These people could be audiologists, early intervention specialists, medical professionals, and parents and caregivers of children with hearing loss. Here is a brief description of ways in which each of these groups may be of help to you.

Audiologist

The audiologist may help by:

- Having the skills and equipment for infant hearing testing. ▮ Recommending amplification (hearing aids, FM systems), or cochlear implants to meet the needs of your child.
- Providing audiological follow-up, monitoring, and maintaining your child's amplification system including well-fitting earmolds.
- Testing your child with and without amplification and discussing your child's responses to sounds.
- Providing information about early intervention program options and working with you and early intervention specialists.

Early Intervention Specialist (Maybe a Speech-Language Pathologist, Teacher of the Deaf, Audiologist, Early Childhood Special Educator, Occupational Therapist, Physical Therapist, etc.). The Early Intervention Specialist may help by:

- Describing the support and available services through early intervention programs and your family's participation.
- Discussing your observations and concerns about your child.
- Answering your questions about the effects of your child's hearing loss on communication, and participating in family activities and learning.
- Helping to assess both your child's and family's strengths and needs.
- Providing a comprehensive family-centered early intervention program that will help your child with listening and communication skills.

- Working with you and the audiologist to help your child learn to use amplification and make sure it functions properly.
- Documenting records of your child's progress in communication and developmental areas.
- Working with you to plan your child's educational needs when at age 3, your child is ready to transition from the early intervention program.
- Providing opportunities for networking with adults and children with hearing loss.

Pediatrician/Family Practitioner

Your child's primary care physician may help by:

- Coordinating care as well as addressing other medical conditions that may be associated with hearing problems.
- Working with an audiologist experienced in infant hearing testing.
- Providing information about medical and/or surgical treatment for the various types of hearing loss.
- Referring promptly for amplification and early intervention upon confirmation of a hearing loss.
- Referring to early intervention programs and specialist counseling (*i.e.* ENTs, Geneticists).
- Treating your child – or referring to an ear specialist – when your child has a middle ear infection that may increase the degree of hearing loss.
- Referring to specialist counseling (i.e., ENTs, Geneticists).

Otolaryngologist or Ear, Nose, Throat (ENT) Physician

The ENT may help by:

- Confirming the nature of the hearing loss.
- Answering your questions about medical or surgical treatment for different types of hearing loss.
- Authorizing the use of hearing aids for your child.
- Evaluating your child's need for ventilation tubes.

Genetics Team Consists of a clinical geneticist and a genetic counselor The Geneticist may help by:

- Performing a test or examination to find out the cause of your baby's hearing loss.
- Determining if the hearing loss is genetic or inherited.
- Informing you of the chance of having another child with hearing loss.
- Working together to offer the best advice and care for you and your child.

Cochlear Implant Team/Surgeon

The cochlear implant team may help by:

- Determining if your baby is a candidate for an implant.

Parent of children who are deaf or hard of hearing (D/HH)

Parents (hearing/deaf) may help by:

- Sharing experiences they have had with professionals and early intervention programs.
- Telling you about the people and resources they have found useful.
- Listening to you.
- Sharing their initial feelings related to parenting a child with hearing loss and how

  feelings change over time.
- Telling you about their child's achievements.
- Getting your children together for playtimes.

Adults who are deaf or hard of hearing

Adults who are Deaf or Hard of Hearing may help by:

- Sharing life experiences.
- Serving as a role model.
- Serving as a language model.

Sound START
Birth to Three Services for Children Who are Deaf/Hard of Hearing

A Program of the Kansas School for the Deaf

Sound START Mission:

To ensure that families of infants and toddlers who are deaf/hard of hearing receive comprehensive, unbiased information and support.

Services we provide:

- Visits with primary service providers and families in the natural environment
- Consultations with service providers and families
- In-services and workshops on issues relating to servicing the deaf/hard of hearing Population

Who we serve:

- Sound START works directly with service providers servicing children who are deaf/hard of hearing, regardless of level or type of hearing loss. This includes children who have mild hearing loss or unilateral hearing loss.
- We service children regardless of communication mode
- Communication opportunities
- Early language development
- ASL development
- Auditory skill and speech sound development
- Information about a child's hearing loss
- Technology available for children with hearing loss
- Deaf culture
- Transition to Part B

Contact Information:

Erin Schuweiler, MS Ed
Sound START Coordinator
Phone: 913-210-8149
Email: eschuweiler@kssdb.org

Kansas School for the Deaf
450 E. Park, Olathe, KS 66061
Fax: 913-324-0601

Deaf/Hard of Hearing Resource List

- SoundBeginnings (Kansas' Newborn Hearing Screening Program): http://www.soundbeginnings.org/
- Kansas Hearing Aid Bank: Supports families in acquiring hearing aids for their children who are deaf/hard of hearing ages birth-three. Please talk to your audiologist or email Liz Schardine, Elizabeth.Schardine@ks.gov.
- Kansas School for the Deaf (statewide supports for children who are deaf/hard of hearing): www.ksdeaf.org
- PATHS: Kansas support group for families with children who are deaf/hard of hearing. Contact Loralee Plummer, lplummer@kssdb.org
- My Baby's Hearing: https://www.babyhearing.org/
- National Deaf Education Center: https://www3.gallaudet.edu/clerc-center.html

Parent to Parent Support:

- Hands & Voices: http://www.handsandvoices.org/
- American Society for Deaf Children: https://deafchildren.org/

Visual Impairment
Factsheet

What is visual impairment?
Not all visual impairments are the same, although the umbrella term "visual impairment" may be used to describe generally the consequence of an eye condition or disorder. The eye has different parts that work together to create our ability to see. When a part of the eye doesn't work right or communicate well with the brain, vision is impaired.

What are the different types of visual impairments?
Most of us are familiar with visual impairments such as near-sightedness and far-sightedness. Less familiar visual impairments include:

- strabismus, where the eyes look in different directions and do not focus simultaneously on a single point;
- congenital cataracts, where the lens of the eye is cloudy;
- retinopathy of prematurity, which may occur in premature babies when the light-sensitive retina hasn't developed sufficiently before birth;
- retinitis pigmentosa, a rare inherited disease that slowly destroys the retina;
- coloboma, where a portion of the structure of the eye is missing;
- optic nerve hypoplasia, which is caused by underdeveloped fibers in the optic nerve and which affects depth perception, sensitivity to light, and acuity of vision;
- cortical visual impairment (CVI), which is caused by damage to the part of the brain related to vision, not to the eyes themselves.
- There are also numerous other eye conditions that can cause visual impairment.

Because there are many different causes of visual impairment, the degree of impairment a child experiences can range from mild to severe (up to, and including, blindness). The degree of impairment will depend on:

- the particular eye condition a child has;
- what aspect of the visual system is affected (e.g., ability to detect light, shape, or color; ability to see things at a distance, up close, or peripherally); and
- how much correction is possible through glasses, contacts, medicine, or surgery.

The term "blindness" does not necessarily mean that a child cannot see anything at all. A child who is considered legally blind may very well be able to see light, shapes, colors, and objects (albeit indistinctly). Having such residual vision can be a valuable asset for the child in learning, movement, and life.

Where to go next:

If you have a child with a visual impairment, there are special services available through the Individuals with Disabilities Education Act (IDEA). Depending on the age of your child, the following may be available:

- Family Infant-Toddler Program - Kansas State School for the Blind. See resources.
- Kansas Tiny K services | A system of services to support infants and toddlers with disabilities (before their 3rd birthday) and their families. A list of contacts for Tiny K services is included in this packet under resources.
- Special education and related services | Services available through the public school system for school-aged children, including preschoolers (ages 3-21).

Center for Parent Information and Resources. (2017, March 31). *Visual Impairment, Including Blindness.* http://www.parentcenterhub.org/wp-content/uploads/repo_items/fs13.pdf

Tips and Strategies for a Child Who is Blind or Visually Impaired

Tips and general strategies for a child who is blind or visually impaired

- **Learn** as much as you can about your child's *specific* visual impairment. The more you know, the more you can help yourself and your child.

- Understand that your child is **receiving small bits of information at a time**, not all at once through vision. Help your child explore new things with his or her senses and build up a concept of the "whole." For example, your child might need to be shown a banana, help you peel it, feel the banana without its skin, have a bite of it, and then help you mash it in her bowl to understand the qualities of bananas and that bananas can be eaten in different ways. (2)

- **Encourage curiosity and explore** new things and places often with your child. Give lots of opportunities to touch and investigate objects, ask questions, and hear explanations of what something is, where it comes from, and so on.

- Learn how to **adapt your home**, given the range and degree of your child's visual impairment. Help your son or daughter explore the house and learn to navigate it safely.

- Encourage your child's **independence** by letting him or her do things, rather than you doing them. Teach how to do a chore by using hands-on guidance, give lots of practice opportunities with feedback. Now, your child knows the skill, too.

- **Work with the early interventionists or school staff** (depending on your child's age) to build a solid individualized plan of services and supports that address your child's unique developmental and educational needs.

- **Talk to other parents** of children who have visual impairments similar to your child's. They can be a great source of support and insight into the challenges and joys of raising a child with vision problems.

- **Keep in touch with the professionals** working with your child. Offer support. Demonstrate any assistive technology your child uses and provide any information teachers will need.

Find out how you can augment your child's learning at home.

1. Center for Parent Information and Resources. (2017, March 31). *Visual Impairment, Including Blindness.* https://www.parentcenterhub.org/visualimpairment/#parents
2. American Foundation for the Blind. (2011). *What's different about the way visually impaired children learn?* Retrieved April 4, 2017, from the Family Connect website:

http://www.familyconnect.org/info/browse-by-age/infants-and-toddlers/education-iandt/whats-different-about-the-way-visually-impaired-children-learn/1235

Blind/Visual Impairment Resource List

Organizations that will help or assist with getting eyeglasses.

Kansas Lions Sight Foundation and Lions Clubs
Local clubs offer help for vision services such as eye exams, glasses, vision screenings, and eyeglass recycling. Clubs also provide health programs to control and prevent diabetes and diabetic retinopathy, the leading cause of vision loss among working adults. For more information, visit: https://kansaslions.org/

Sight for Students-VSP Global
Have providers throughout the state who can provide free vision exams and eyeglasses to children in need.
https://vspglobal.com/cms/vspglobal-outreach/gift-certificates.html

New Eyes for the Needy

Provides glasses for people in need. An application must be applied for by a social service agency.

https://new-eyes.org/

Kansas City Free Eye Clinic

Helps low-income and homeless people in the metro area with access to preventive eye exams and glasses.

https://www.kcfreeeyeclinic.org/

Local Catholic Charities:

Sometimes local Catholic Charities organizations will pay for eyeglasses. Contact your local Catholic Charities organization.

Kansas City's Medicine Cabinet

Provides help (including eyeglasses) to low income, underinsured, and uninsured metro-area residents.

https://kcmedicinecabinet.org/get-help/

One Sight:

Provides assistance in getting eyeglasses to eligible patients who demonstrate a visual and financial need.

https://onesight.org/faqs

Success Vision-Topeka:

Provides one free pair to a student in Topeka "low income" schools. They need a letter confirming enrollment of the student in that school on school letterhead with the federal tax id number.

https://successvision.com/

All About Vision

Provides free eye exams and glasses for individuals including infants, students, and adults as well as discussing eye services available through Medicaid, the Child Health Insurance Program, and Medicare.

For more information, visit:

https://www.allaboutvision.com/eye-exam/free-exam.htm

Vision USA

A program provided by doctors of optometry that provides basic eye health and vision care services free of charge to uninsured, low-income people and to families that do not qualify for government aid or private health care assistance.

For more information, visit:

http://www.aoafoundation.org/vision-usa/whoiseligible

Deafblindness (Combined Hearing & Vision Loss) Factsheet

What is deafblindness?
A child doesn't have to be completely deaf and/or blind to be considered deafblind. deafblindness is a combination of hearing and vision loss to some degree. The degree of vision and hearing loss varies from one child to another. Deafblindness impacts the way an individual accesses information.

Individuals with deafblindness cannot rely on vision or hearing to effectively compensate for the lack of the other sense. It requires special modifications and support that go beyond what is typically necessary with a vision or hearing loss or alone.

Four primary causes of vision and hearing loss:

- Hereditary/chromosomal disorders
- Prenatal viruses, diseases or harmful chemicals
- Complications at birth
- Postnatal injuries or illnesses

How deafblindness impacts and individual depends on three main factors:

- Type and degree of the vision and hearing loss
- The age of onset of the vision and hearing loss
- The presence of additional disabilities

Children who are deafblind share similar characteristics related to learning and interaction:

- They may be withdrawn, inwardly focused, or preoccupied with their bodies.
- They need to feel secure
- They have difficulty development concepts
- They have difficulty communicating and interacting with others
- They require specific modifications and supports to learn and interact with the world
- They can benefit from routine and systematic instruction

Source: http://www.sparkle.usu.edu/Topics/deafblindness/index.php

Tips and Strategies for a Child Who is deafblind (Combined Hearing & Vision Loss)

The senses of vision and hearing are often referred to as the “distance senses” – that is, they connect a child with the world that extends beyond his or her personal body space. Children who are sighted and hearing learn language and many important concepts without any specifically planned structure. They learn simply by being surrounded by language and by having ready access to environments that are safe, interesting, and invite exploration. The senses of vision and hearing help the child organize information from the environment. The young child who is deafblind, however, does not have access to opportunities for this “incidental learning” and the information the child does obtain from contact with people and the environment is often fragmented or distorted.

A sighted and hearing infant comes to anticipate daily routines because of the sights and sounds associated with them and can prepare himself or herself for the activity in advance. A young child who is deafblind misses these cues because of limited vision or hearing and may find the world unpredictable and confusing, possibly even scary.

The amount of information children are able to gather depends not only on the amount and type of vision and hearing they have, but also on how they learn to use that vision and hearing. Each child learns to make use of available sensory information in his or her own way. Some children interact with their world primarily through touch, while others may rely more on vision or hearing. For many children, a combination will be most useful.

“Hello. It’s me. Let’s play”
Always greet your child with a special "hello" (touching her chest or shoulder, for example) to let her know someone is there. Then let her know who it is with your own special "name sign" (by helping her feel Daddy's scratchy chin or beard, or Mom's hair, or a watch or ring you always wear). Tell her what you will do together (touch her diaper to indicate diaper changing, for example, or introduce a favorite toy or movement game). Remember to say “goodbye” before you leave, perhaps by waving “bye” with your hand under her hand.

Establish predictable routines with clear beginnings and ends
What routine activities happen during the day for you and your child? Consider activities such as eating, dressing, bathing, and playing and think about how you can let your child know what will happen when it will start, and when it will end. Perhaps you have a special blanket on which you play on the floor together. Getting this out together and sitting down on it will signal the beginning of play. Putting it away together signals the end.

Involve your child in the whole activity
Your child will learn the sequence of the activity and develop many concepts through his active participation in the whole activity. Remember that a young child who is deafblind must physically participate in the entire sequence of an activity in order to gather the same information that another child gathers just by watching.

For example, at mealtime, you and your child go to the kitchen together, open the cabinet, take out a bowl, take out the jar of food, open the drawer to get a spoon, and put the food into the bowl. Perhaps you heat it up in a microwave oven and when the bell rings, you both bring the warm food to the table. At the beginning of a meal, your child may touch his bib before you help him put it on, and when he is finished eating he can help take off his bib. You bring the dirty dishes to the sink together and turn on the warm water to rinse them. Throughout the activity, you offer your child simple signs (hungry, eat, drink, all done, wash).

Provide opportunities to make choices
Throughout the day, give your child choices: bounce or rock? cracker or juice? bells or slinky? pat your hands or kick your feet? You could show her two toys (perhaps the giggle ball and a mylar balloon) from which to choose. If she has some vision, you may hold the toys where she is best able to see them, alternately moving each one to help get her visual attention and watching to see which one she looks at longer or reaches toward. If she is not able to see the toys, you can help her touch each toy by gently bringing the toys to her hands (rather than taking her hands and putting them on the toys) and watching to see which one she touches longer, keeps her hand on, or tries to grasp. (Sometimes you may have to guess her choice.)

Remember to offer pauses
Some children take a little longer to process the information that they are receiving. It is important that they are given enough time to respond. If we don't allow the child this time, she may give up trying. Respect your child's pace and follow his or her lead. If she has chosen the giggle ball, you turn it on for her, then after brief playtime, turn it off and pause, waiting expectantly, leaving both your hand and the giggle ball very close to her hand. She can have some control over the game by telling you she wants "more. " She may do this by vocalizing, or making movements such as kicking her feet, waving her arms, touching the ball, or touching your hand. When you slow down and offer plenty of pauses, you allow your child time to anticipate and respond. You also give yourself time to recognize your child's responses.

Watch for cues
Stay alert for signals your child may give you that he or she is "ready" to communicate and participate in turn-taking games. Your child may signal that she wants to continue the game or, perhaps, she is "all done" or needs a break from the communication/interaction. She may kick her feet, wave her arms, make sounds, reach to touch your hand or the giggle ball or use another signal.

Explore the world together ("hand under hand")
Helping your child understand that others are sharing the same experiences with him is an important factor in building relationships and self-esteem. The hands of a child who is deafblind become his ears, eyes, and voice. If he is exploring a toy, join him by gently placing one of your fingers under part of his hands. Likewise, if you want to show something to a child, encourage him to place his hands over your hands as you move toward the object. This way you can explore together. Then you may gently remove your hand so he can play on his own.

Encourage use of all sensory information
Help your child who is deafblind learn to use vision and hearing for functional activities and to interpret the limited sights and sounds that are available. Approach your child gently to let him know you're available for interaction; do not "surprise" him with unexpected or abrupt touches or sounds. Attend to and imitate any actions and sounds; invite him to take another turn; let him know you share his interests. Offer consistent touch and object cues to signal the beginning of an activity and use movement and body contact during your interactions.

Use appropriate cues

Use simple, consistent, and respectful cues that will be understandable to your child. Cues should be clearly related to the activity from your child's perspective and presented just before the activity starts. To let your child know it is bath time, for example, you might dip his foot in the water, sign "bath," pause to observe his response, then lower him into the tub. In this way your child will learn to anticipate familiar activities; his world will be predictable and interesting, and he will develop a trusting relationship with the people who care for him.

Expose your child to language

Children hear a great deal of verbal language long before they learn to talk by themselves. Likewise, a young child with deafblindness needs to be involved in an environment that is rich in all forms of communication. This may include words, signs, gestures, touch cues, object cues, movement cues, contextual cues, visual and/or auditory cues. Provide your child with language in any form he can understand. When you use object cues, pair them with simple signs. As you respond to your child's communications, offer him simple signs. As a parent, you instinctively can discriminate between a cry of hunger and a cry of pain. Just as a mother would respond to a baby's cry by saying, "Oh, you're hungry", we must provide the same response using signs so the child will gradually learn that "every time I'm hungry and I cry, mom does this; maybe if I do the same thing I won't need to cry."

Help your child interact with others

As she begins to interact with other children, you can be a facilitator. Help other children learn effective ways to understand and respond. Help them learn how to use their hands to provide cues and how to use their hands to play together in a respectful way that encourages active participation and exploration by both children.

Through play, your child can learn a great deal:

- Trust and anticipation that certain things will always occur
- How to make things happen
- Ways to ask for help, ask for more, ask to be done
- The power of making choices
- Better understanding of the world
- Communication in its many different forms

Source: Early Interactions With Children Who Are deafblind by Debora Gleason
https://www.nationaldb.org/info-center/early-interactions-factsheet

Tips and Strategies for a Child Who is deafblind (Combined Hearing & Vision Loss)

Concept Development :

For children with deafblindness, one of the most critical areas related to learning is concept development. Concept development is sometimes confused with skill development.

- A concept is a mental representation, image, or idea of tangible and concrete objects (e.g., a chair, a dog) and intangible ideas and feelings (e.g., colors, emotions).
- A skill is the ability to do something (e.g., tying a shoe, using vision to find an object).

Concepts can be divided into three groups:

- Concrete concepts: relate to objects or things that are tangible (e.g., a car, a chair).
- Semi-concrete concepts: relate to an action, color, position, or something that can be demonstrated but not held in one's hand (e.g., jumping, behind, red).
- Abstract concepts: include feelings (e.g., love, nervousness).

Sighted and hearing children receive a constant flow of visual and auditory information which facilitates the development of concepts. For children with combined hearing and vision loss, the flow of information is incomplete. Concepts don't develop naturally or easily. Alternate strategies must be useful to teach these children concept development.

The six areas of concept development are affected by deafblindness:

- Objects exist: children with deafblindness have difficulty learning about the existence of objects because they can not see or hear objects clearly.
- Objects have permanence: children with combined vision and hearing loss can't observe objects and people at a distance and know that things exist beyond their fingertips.
- Objects differ: children with deafblindness won't know that one object is different from another unless they can touch and explore them.
- Objects have names or labels: children with both hearing and vision loss need to use touch to support language learning.
- Objects have characteristics: children with deafblindness will have difficulty identifying the different characteristics of objects because of the lack of access to information about those objects.
- Objects have functions or use: children with combined vision and hearing loss can't observe how objects are used or hear the sounds associated with the functions of objects.

General Strategies that can be helpful in assisting children who are deafblind to develop concepts:

- Use activities that are meaningful to the child
- Use activities that the child enjoys
- Attach language to all experiences
- Build on language that is already known to the child
- Use a total communication approach that is appropriate for the child
- Remove variables that may cause confusion for the child
- Generalize the concepts to a variety of situations.

Source: http://www.sparkle.usu.edu/Topics/concept_development/index.php

The KS deafblind Project offers free SPARKLE training and materials from the Ski-Hi Institute for parents to help support young children with deafblindness (combined hearing and vision loss).

Please contact: ksdeafblind@kssdb.org

Project SPARKLE is a program of individualized learning that enhances the ability of parents of children who are deafblind to fulfill their roles in the development and education of their children. The training program focuses on deafblindness, vision, hearing, touch, concept development, intervention and communication.

Deafblindness
Resource List: Programs & Services

Students who are identified as deafblind in Kansas are eligible for different services through a variety of groups and programs. Here is a brief look at some of the services available.

The Kansas State School for the Blind
The Kansas State School for the Blind's vision is "The right help, at the right time, in the right location". KSSB is the home of the Kansas deafblind Project, a key component of our Field Services Department that provides statewide outreach to students in Kansas aged 0-21 who are Blind, Visually Impaired, or deafblind. Website: www.kssb.net.
Phone: 913-305-3015 (voice)

Kansas School for the Deaf
Every student who is Deaf or Hard of Hearing in Kansas will achieve personal success and become a responsible citizen—this is KSD's vision. Individuals throughout the state of Kansas, aged birth to 21, who are Deaf or Hard of Hearing deserve quality outreach services, resources, and support. For information, go to www.ksdeaf.org.
Phone: 913-210-8111 (voice)

Kansas Deaf-Blind Project

Provides free consultation and distance mentorship, professional development training, person-centered planning, transition support and resources, limited scholarships for workshops/conferences, scholarships for certified paraprofessionals (interveners), family engagement, and parent networking opportunities.

Serves families and educators with a student, birth to 21 years of age, and on the Kansas deafblind Project registry and census.

To register a student, obtain the application from our website, www.kansasdeafblind.org

For more information, email: ksdeafblind@kssdb.org.

KSDE/Kansas Deaf-Blind Fund

Kansas is the only state that has a special fund appropriated by the legislature to support students (birth through 21) who are deafblind in their educational programs. This fund is administered by the Kansas State Department of Education and provides up to $4,500 per student. The funds are used to offset costs associated with educating students who are deafblind and who have current certification on the Kansas deafblind Census. Funds can be used in the following areas:

Assistive technology (including adaptive equipment), Consultation

Evaluation as described in the deafblind Fund application

For information on the Kansas DeafBlind Fund, visit https://www.ksde.org/Programs-Services/Special-Education/Sensory-Losses

Or Contat Lisa Karney at lkarney@ksde.org

Deaf-Blind:
Programs and Services for Kansas Students

Helen Keller National Center, Great Plains Regional Office

Advocates for individuals with combined vision and hearing loss

Serves students age 14—senior citizens. Serves as a life-long point of contact to services and resources. Connects individuals, families, and agencies to resources

Identifies individuals for the National Registry of Persons Who are deafblind (https://www.helenkeller.org/hknc/national-registry)

Offers access to an array of training programs for youth and adults at our training center on Long Island, New York (https://www.helenkeller.org/hknc/youth-programs)

Provides consultation, technical assistance, and learning opportunities. (professional/consumer) to support successful outcomes for consumers to work and thrive in the community of their choice.

For more information, call 913-677-4562 (voice) / 913-227-4282 (videophone)

iCanConnect in Kansas
Free technology and training for people of all ages with combined vision and hearing loss. Applicants must be able to perform a "distance communication" function including sending texts, making phone calls, receiving email messages, using social media, and making video calls.
Technology assessments can determine what equipment is provided including smartphones, computers, tablets, keyboards/skins, screen reader and magnification software, braille displays and notetakers, alerting devices, neck loops, and amplifiers.
Eligibility includes verification of vision and hearing loss and household income
The program is administered through Assistive Technology for Kansans: 620-421-8367 (voice).
Application and contact information are available at
http://www.icanconnect.org/how-to-apply/kansas

Kansas Instructional Resource Center
The purpose of the Kansas Instructional Resource Center (KIRC) is to work with local, state, and federal entities to identify and acquire educational resources needed for the success of all Kansas learners with vision impairments, including deafblindness, birth to 21 years of age.

KIRC maintains an up-to-date collection of braille and large print textbooks, specialized equipment, and professional resources in support of parents, Teachers of Students with Visual Impairments (TSVIs), and education facilities working with qualified students in obtaining educational goals. Through annual APH Quota funds, and a repository textbook and equipment library, available items are loaned at no cost to those working with eligible learners. Materials are loaned on a "school year" basis but may be renewed as needed. When items are no longer needed, those materials and locally purchased textbooks are returned to KIRC and made available to others. Material requests may be submitted by phone to 913-305-3071.

APH Registration and Quota Funds
Each January, in cooperation with The American Printing House (APH), under the Act to Promote the Education of the blind, notification regarding the registration of eligible students is sent to directors of infant toddler services and superintendents of public and private pre-kindergarten through 12 programs throughout Kansas. The number of registered students is used to determine the Annual QPH Quota allocation for each state. Annual Quota funds may then be applied toward the acquisition of qualified APH products
https://www.aph.org/federal-quota/

Nationwide Resources

National Family Association for Deaf-Blind
The National Family Association for Deaf- Blind (NFADB) is a nonprofit, 501(c)(3) organization that has served families with individuals who are deafblind since 1994. Originally started by and for families, NFADB has expanded to include any interested individuals, professionals, organizations, and agencies that wish to empower the voices of families with individuals who are deafblind. The term "deafblind" means any combination of hearing and vision loss, occurring at any age, for any number of reasons.

Website: https://nfadb.org/

National Center on Deaf-Blindness
There are approximately 10,000 children and youth in the United States who have been identified as deafblind. deafblindness is a low-incidence disability and within this population there is great variability in terms of age, race/ethnicity, cause of deafblindness, and severity and type of hearing and vision loss. Ninety percent have additional physical, medical, or cognitive disabilities.
As a national technical assistance center, NCDB works with state deafblind projects and other partners to improve educational results and quality of life for children who are deafblind and their families.

Website: https://www.nationaldb.org/

CHARGE SYNDROME
Factsheet

CHARGE syndrome refers to a specific set of birth defects, medical problems, and developmental issues. The most distinctive birth defects are coloboma, choanal atresia, and characteristic ears (external ears and small/absent semicircular canals).

Diagnosis should be made by a medical geneticist. Diagnosis is based on key features, ideally with DNA testing for CHD7 mutations.

Key features:

- Coloboma
- Cranial nerve abnormalities
- Choanal atresia
- Heart defects
- Characteristic external ears
- Esophageal defects
- Small/absent semicircular canals
- Genitourinary abnormalities
- CHD7 gene mutations

Incidence: One in every 8,000-10,000 births. Every person with CHARGE has a unique set of features. There is a wide variation in physical features and cognitive ability.

Cause: Mutations in the CHD7 gene on chromosome 8 are found in 80-90% of cases. There is no relationship to sex, race, nationality, religion, socio-economic status, or prenatal exposure. Recurrence: It does not usually run in families. Recurrence risk to unaffected parents is 1-2%. If a parent has CHARGE Syndrome, the risk to a baby is 50/50. Sensory deficits: Most individuals with CHARGE have difficulty with hearing, vision, and balance. This results in delayed motor development and communication. The educational term for combined vision and hearing deficits is "deafblind."

Cognitive ability & testing: Many have decreased cognitive abilities, but 30-50% have normal intelligence. The intelligence of children with CHARGE is often underestimated due to the effects of combined hearing, vision, and balance issues. Testing, therapies, and educational intervention MUST take into account hearing, vision, and balance status.

Lifespan: There is increased mortality, especially in the first two years. Although individuals with CHARGE remain medically fragile, lifespan can be normal.

Outcome: Individuals with CHARGE need medical care appropriate to their particular features. In addition, early intervention and appropriate and challenging educational and vocational programs specific to their sensory needs are imperative. Although there are many problems, children with CHARGE can survive and become healthy, happy citizens.

CHARGE SYNDROME
Frequently Asked Questions

Why do they think my child has CHARGE?
Your child likely has several birth defects and may already have had some genetic testing, such as chromosomes or a microarray. If those tests have not provided the answer and the baby has coloboma, choanal atresia, or distinctive ear findings, CHARGE syndrome should be considered. Most babies with CHARGE also have other problems (heart, trachea, esophagus, etc.). Your medical geneticist should be able to tell you why the diagnosis of CHARGE is being considered.

What is CHARGE syndrome?
CHARGE is a recognizable genetic syndrome most often caused by mutations in the CHD7 gene. It occurs in about 1 in every 10,000 births. Most individuals with CHARGE have distinctive features, including coloboma, choanal atresia, and/or ear abnormalities, along with other birth defects.

Why is a diagnosis important?
A diagnosis provides an explanation for why your child has multiple issues. It tells the doctors what other potential problems to look for in your baby and gives you information about what caused your baby's problems and whether it could happen again.

How do they make a diagnosis?
Confirming a diagnosis of CHARGE requires exams by various specialists (genetics, ophthalmology, cardiology, ENT, audiology), imaging (kidney ultrasound, brain & inner ear MRI), and tests (CHD7 DNA testing). A medical geneticist should put together all of the information to determine if CHARGE is the best diagnosis for your child.

Is there a test to confirm CHARGE?
Yes and no. CHARGE is still diagnosed by a medical geneticist primarily based on clinical features. CHD7 gene testing is very helpful and should be ordered if CHARGE is being considered. This test takes several weeks to be completed and does not always provide answers. If a mutation in CHD7 is identified in a child with CHARGE features, the diagnosis is confirmed. But negative CHD7 testing does not rule out CHARGE. A significant number (~20%) of individuals with CHARGE do not have identifiable mutations in CHD7. Testing may become better in the future.

Why are so many different specialists seeing my child?

Who is in charge? Most children with CHARGE have complex medical issues. Many different specialists will be following your child. Communication between all these specialists and with the parents is often less than ideal. If you can identify one specialist who is in charge of coordinating your child's overall care, that may help. It may be a cardiologist, a geneticist, or someone else. Some hospitals have care coordinators to help. Sometimes it is possible to have a "team meeting" to bring together all of the specialists to explain (to you and one another) the plan of care for your child. The Management Manual for Parents can help you understand the role of each specialist. Don't forget your pediatrician. Children with CHARGE are children first. A pediatrician is important for all of the regular things like immunizations, weight checks, ear infections, and so on. Your pediatrician may also be an advocate for you and your child in the complex medical system.

How does CHARGE syndrome happen?

Most cases of CHARGE are caused by a mutation, or change, in the gene CHD7. This mutation usually happens for the first time in the person with CHARGE – it is usually not inherited from either parent. Not all people with CHARGE have a change in the CHD7 gene – other genes for CHARGE may be discovered in the future. CHARGE is NOT caused by any known exposures during pregnancy nor is it related to sex, race, nationality, religion, or socioeconomic status.

Will it happen again? Probably not. Most of the time, the CHD7 mutation happened only in the sperm or egg that formed your child with CHARGE. In rare cases, the mutation happened in the gonads – the organs that make sperm or eggs. In those rare cases of gonadal mosaicism, there is a recurrence risk. Overall, if we look at all couples who have one child with CHARGE and look at what happens in the next pregnancy, 98% of the time, the next baby is fine. About 1-2% of the time (1/50-1/100), there is another baby with the same CHD7 mutation as the first child with CHARGE.

What about my child's children? A person with CHARGE has one gene for CHARGE and one normal gene. The chance of passing on the CHARGE gene is 50-50 for an individual with CHARGE. People in the family with the same CHD7 mutation may or may not have similar features.

Can it be diagnosed before birth?

If a CHD7 mutation is identified in a person with CHARGE, it is possible to test other people (or pregnancies or pre-implantation embryos) for that same gene. One reason to do CHD7 testing in a child with CHARGE is to make it possible to look for it in other family members.

Will my child see and hear? Most children with CHARGE have limited vision and/or hearing. Many parents are told their child will be "blind" or "deaf." Legal blindness does not mean the inability to see anything. Even significant hearing loss can often be helped with aids of various sorts. In the early stages of a newborn's life, it is difficult to predict eventual vision and hearing abilities. The early predictions you are given may not turn out to be accurate. Routine visits to pediatric ophthalmology, ENT, and audiology will help uncover your child's abilities.

You as parents or caregivers know your child best. Doctors see your child for short periods outside of the home. Keep doctors and therapists informed of the progress you see at home. Take comfort in knowing that these kids learn to naturally compensate by using whatever vision or hearing they have. For them it is not a loss – it is all they know.

How does CHARGE affect cognitive abilities?

The sensory losses (hearing, vision, balance), time lost to surgeries, and frequent illness have a huge effect on the child's exposure to the stimulation that shapes cognitive abilities and other skills. We expect children with complex medical issues to be delayed. But catch-up often happens. Because of the sensory deficits, especially vision and hearing, communication is a big concern. A communication system must be established before the cognitive ability can be determined. Intelligence is routinely underestimated due to vision, hearing, learning, motor, and/or speech disabilities. Take advantage of all services available to help your child reach full potential, whatever that may be.

What does the future look like for my child?

Although children with CHARGE have many challenges, they can survive and become healthy, happy citizens. Doctor visits and medical problems taper off and/or change as your child grows. Accept that you can't predict what will happen and enjoy today while doing what you can to prepare for the future. NEVER underestimate your child's abilities. Be involved, interact, and enjoy. As hard as it may be at times, they grow up fast, overcome many obstacles, and will make you proud.

What services are available? Most states have Early Intervention (EI) programs for children from birth to three and school-based programs starting at age three. Most EI programs include services such as physical therapy (gross motor skills such as crawling and walking), occupational therapy (fine motor skills such as pinching and grasping), speech therapy, education, and possibly vision and hearing services.

In the US, every state has a DeafBlind program. Your child does not have to be deaf or blind to qualify. Most children with some vision loss and some hearing loss qualify for services through the DeafBlind program starting in the newborn period.

If you have not heard of these programs yet, ask to speak with a hospital social worker and ask her to help you find out more about what is available in your area.

Source: © The CHARGE Syndrome Foundation 318 Half Day Road #305, Buffalo Grove, IL 60089 • www.chargesyndrome.org • info@chargesyndrome.org

Tips and Strategies for a Child with CHARGE Syndrome

Educational Needs of Children with CHARGE Syndrome

By Martha M. Majors and Sharon Stelzer

Educating a child with CHARGE is very complex. When developing an educational program many components should be considered. These include the following topics:

COMMUNICATION

Most children with CHARGE have both vision loss and hearing loss (dual sensory impairment: deafblindness). Most benefit from a *total communication* approach. Total communication means incorporating anything and everything: gestures, simple signs, print/Braille, facial expression, symbols, and PECS (Picture Exchange Communication System) in addition to speech and sign language. The modes for each child are highly individualized and the entire team (including the family) needs to participate in developing and consistently instituting the plans.

SENSORY LOSSES AND THE IMPACT OF VISION AND HEARING LOSS

It is important for the team to take careful notice of the functional vision of the child as well as the hearing loss, the impact of hearing loss on communication, and the total effects on day-to- day functioning. Determine the communication bubble! [The communication bubble includes how far out and how well a child sees and how far out and how well a child hears. It also needs to take into account things like lighting, ambient noise and other factors.] Many types of accommodations will likely be necessary in the educational setting and these should be written into the child's IEP. Consultation with vision and hearing specialists can be helpful in determining appropriate accommodations.

CURRICULUM

Curriculum should be challenging and both age and content appropriate. Children with CHARGE are very capable. Due to communication challenges and delays in using expressive language, their overall cognitive ability is often, if not usually, underestimated. In fact, many children with CHARGE are very clever, have an impressive capacity to learn information, to retain ideas and to do well in academic subjects. They have specific learning needs, can benefit from specific teaching strategies and must be challenged through access to a highly motivating and flexible curriculum. They benefit from a curriculum that incorporates a variety of skills across a variety of settings. As goals are achieved other skills can be added to enhance knowledge and growth.

ENVIRONMENTS

Children with CHARGE often require frequent sensory "breaks." Some types of break examples might include: bean bag chair, soft cushion on the floor, magazines and books in a comfortable space, a quieter room with low lighting; small space with three walls and comfortable seating swings of different types, weighted blanket or vest.

There should be adequate space within classrooms or nearby to ensure access for the child who needs time to relax, to do something that calms and allows time to be quiet (see article by David Brown). Fatigue can quickly overcome a child. The ability to take a quick "break" is critical for the child to be able to maintain a calm demeanor. A flexible schedule that allows for "breaks" is important; staff should be aware of "signals of behavior" and how to respond to the child; anticipation of the need for a break is a key to minimizing the behavioral outbursts and creating a successful educational environment for a child with CHARGE.

Physical environments can be arranged to motivate and intrigue the child with CHARGE. By having a flexible environment that can change and grow, optimal learning can take place. For example

- Having a space that reflects the likes of the student, such as hanging pictures of their favorite people including characters can make the work or relaxing space inviting.
- Having some environments or spaces created with intriguing materials that peak the interest of the student can make learning fun. Rotate materials to keep the child interested and motivated.
- Using creative imaginative ideas can change an ordinary space into anywhere in the world. For example, the science area can become a spaceship to our solar system.

TEACHING STRATEGIES FOR CHILDREN WITH CHARGE SYNDROME

As much as possible, these ideas should be integrated into all educational settings and across all environments:

- Strategies for structuring activities
  - Organizational skills – work in an organized manner (left to right, top to bottom) using Checklist
  - Negotiation – allow the child to feel as if he/she is in control. Give a variety of choices as well as use first, then, strategies.
  - Sharing – foster peer-to-peer interactions. Encourage turn taking as a precursor for conversational communication.
  - Motivation – select activities that are interesting to the student. Use materials that are interesting and rewarding.
  - People preferences – give choices of WHO should do tasks/lessons with the student whenever possible.
  - Partial vs. Full Participation – have the child do as much of a task or activity as possible to feel successful. Avoid setting up for failure by having an activity that has too many steps or is too long.
  - Functional Activity – in all activities, ask yourself “will this skill or activity be useful in the future?”
  - Modeling – engage the child by modeling the steps in an activity
  - Choice making – allow for choices across settings. Let the child feel in control. Choices may be limited or guided, but must be offered.
  - Age appropriate content/curriculum – all content and curriculum should be based on age and cognitive abilities. Don’t underestimate the cognitive abilities of these children! Both factors should be considered when planning.
  - Active vs. Passive learning – alternating activities between quiet (sitting-desk work) and movement oriented (delivery jobs, getting things, physical education class, recess, etc.)

    - Clear expectations/Limit setting – set clear, firm limits that remain consistent. Give the child time and opportunities to learn these expectations.
    - Follow Student's Lead – allow students to be leaders, watch and see what interests them. Incorporate these ideas into lessons.
    - Natural routines environment – teach in environments in which activities naturally occur.
    - Variety of exciting content – although routines and structure are important, keeping the content dynamic is critical for the student with CHARGE.
    - Task analysis – break tasks into smaller steps that allow the child to feel successful.
- Sensory Techniques
    - Awareness of hands/touch – allowing others to touch for signaling, (tapping) tactile signing, etc.
    - Signals: Verbal/Auditory/Visual – gesturing to gain attention, using voice or sound cue to gain attention
    - Prompt levels hand-under-hand – use an adults' hand as guides under the child's as a less invasive technique.
    - Sensory breaks – allow pause time during activities and in between activities.
- Timing
    - Beginning-middle-end – make sure all activities have a clear beginning, middle, and end that are at the student's level of understanding.
    - Structure and routine – having predictable schedules and routines play to the strength of the child with CHARGE.
    - Pause time for response – WAIT, WAIT, WAIT, allow the child with CHARGE to respond in a manner they are most comfortable.

- Curriculum
    - Child centered curriculum – the child should drive the curriculum, the curriculum should not drive the child.
    - Expanding environments – some children with CHARGE need to start activities in "smaller" environments (less physical space or less cluttered). As they mature and grow, environments can become bigger (physically) and more challenging.

What Every Student with CHARGE Needs to Know:

- Social Skills (how to be an effective communicator)
    - How to be a part of a group – as member that is accepted by the group
    - How to Negotiate – how to get their point across and know when to surrender
    - How to take turns & share – to take the appropriate amount of turns in conversations. BE a listener as well as a speaker/signer.
    - How to help out – be part of a family by doing chores. In school, they can have school jobs.

- Cognitive Skills
    - How to be organized – work, think & execute in an organized manner
    - How to anticipate activities (calendar system) – know exactly when the order things will happen
    - How to cope with behaviors – know when & what to do when on "sensory" overload or stressed.
    - How to make choices – know that there are choices & the choices may be from a "set" group. Know that all choices are not possible at all times.

CHARGE Syndrome Resource List

CHARGE Syndrome Foundation Parent to Parent Resources

If you are interested in finding someone in your area please contact the foundation at 800-442-7604 or by sending an email to info@chargesyndrome.org for a list of families.

https://www.chargesyndrome.org/

CHARGE Family Support Groups

CHARGE Syndrome Foundation Facebook Group

http://www.facebook.com/groups/chargesyndrome

CHARGE Syndrome Foundation Facebook Page

https://www.facebook.com/chargesyndromefoundation/

CHARGE Syndrome Checklist

https://www.chargesyndrome.org/wp-content/uploads/2016/03/CHARGE-Syndrome-Checklist.pdf

Kansas Organizations, Agencies and Parent Groups

B.E. Smith Family Center – Britain Development
Providing therapy and education for children with special needs
913-676-2253
7415 Grandview St
Shawnee Mission, KS 66204
https://besmithfamily.org/

Children's Mercy Hospital
*Please note: *Children's Mercy has multiple locations and clinics to help meet your needs**
816-234-3000
Adele Hall Campus
2401 Gillham Rd,
Kansas City, MO 64108
https://www.childrensmercy.org/

Deaf Mentor Program
The Deaf Mentor Program provides weekly home visits by a deaf adult who is trained in using the Deaf Mentor Program curriculum. The goals of the program are to support families in learning American Sign Language (ASL) and to help them learn about Deaf Culture. The three areas of focus are ASL for Families, Early Visual Communication, and Deaf Culture.
https://www.ksdeaf.org/deafmentor

Discover CVI Parent Group
Kansas DeafBlind Project/Kansas State School for the Blind
Discover CVI is a parent-led support group for parents of children with Cortical Visual Impairment (CVI).
To join, register at https://form.jotform.com/81925819584168

Jessica Cartwright,	Angela Degnan
Discover CVI Parent Lead	Discover CVI Parent Lead
every.tribe78@gmail.com	ardegnan@hotmail.com

Envision Child Development Center
610 N Main St, Wichita, KS 67203
Provides programs and services to Kansans across the lifespan: The Early Childhood Development Center (ECDC) is a daycare center for children who are blind or visually impaired from two weeks to age 5 years. ECDC also provides home-based services to children who have a vision impairment and other health issues that prevent them from attending daycare. Envision also offers services to school-aged children and adults.
https://www.envisionus.com

Families Together, Inc.
Assisting Kansas parents and their sons and daughters who have disabilities and/or special health care needs.
https://familiestogetherinc.org/

Family Infant-Toddler Services
Kansas State School for the Blind
Email: fit@kssdb.org
The KSSB Family Infant Toddler (FIT) program, in partnership with the Kansas Early Childhood Developmental Services, offers high-quality vision services for Kansas families and their children who are blind or visually impaired **ages birth to three, at no cost.**
https://kssb.net/

Preschool Enrichment Program for
Children who are Blind/Visually Impaired
Kansas State School for the Blind
1100 State Ave., Kansas City, KS 66102
https://kssb.net/

KDPOK, Disability Planning Organization of Kansas
https://dpok.com/dpok/

Infant Toddler Network:
http://www.ksits.org/download/network_brochure.pdf

The Kansas Special Health Care Needs (SHCN) Program promotes the functional skills of persons, who have or are at risk for a disability or chronic disease. The program is responsible for the planning, development, and promotion of the parameters and quality of specialty health care in Kansas in accordance with state and federal funding and direction. SHCN provides specialized medical services to infants, children and youth up to age 21 who have eligible medical conditions. Additionally, the program provides services to persons of all ages with metabolic or genetic conditions screened through the Newborn Screening. Services may include diagnostic evaluations, treatment services or care coordination and must be prior authorized.
https://www.kdheks.gov/shcn/

1-800-Children provides 24/7 support for parents. No question is too big or too small when it comes to parenting. Find helpful resources and supports near you through this site or connect with a real person by calling 1-800-CHILDREN. We offer free and confidential support in English and Spanish as well as multiple other languages.
https://1800childrenks.org/