



# PARENT TIME

VOLUME 25, ISSUE 1 October 2019

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Hello to all our wonderful MoSPIN families,

Thanks to all the families who returned the Annual Summer MoSPIN Family Survey. Your responses are greatly appreciated, as they help us improve the program. I hope your children are enjoying the Alphabet/Braille Refrigerator Magnets as our gift to you.

Happy Holiday Season to one and all. Enjoy spending special time with family and friends.

I offer some helpful information in this edition. You may not need all this resources now, but you can always hold on to this issue for future reference.



As always, should you have any questions, please do not hesitate to email or call Melissa Moore, Lead Parent Advisor/Family Engagement Coordinator  
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# DELTA GAMMA CENTER

## for Children with Visual Impairments

Delta Gamma Center has been serving children with visual impairments since 1951. Our mission is to help children who are blind or visually impaired reach their full potential through family-centered, specialized services and community support. We provide services to children birth through high school graduation and support to their families.

We serve a 50-mile radius of our Richmond Heights office which includes parts of Missouri and Illinois. Some services are available to families outside of the 50-mile radius if they are willing to travel within our service area. Information and referral services related to a child with a visual impairment are available to anyone upon request.

## WHAT WE DO

**Services for children birth - age 3** are focused on developmental support for children with visual impairments. Services include home-based instruction from a Teacher of Students with Visual Impairment, Orientation & Mobility Specialist, Occupational, Physical, and / or Speech Therapists, and family support. Low vision evaluations are also offered, as needed.

**Services for children 3 - high school graduation** are focused on building friendships and social skills, increasing independence, and actively participating in the community.

Activities include regular meetings, discussion, and a variety of sports, arts, and leisure activities.

**Services for families of children birth - high school graduation** include group services (e.g. training and education for caregivers and/ or recreational family activities with opportunities for networking) as well as individual services (e.g. short-term counseling, support advocating for and accessing resources & services). Individual services are available in person or by phone.

**Services to the community** include free vision screenings for children 6 months to 6 years, ability awareness presentations to groups, and consultation with other professionals.

# INDICATORS OF VISION CONCERNS

If you notice any of the following physical and/or behavioral signs, we recommend that you talk with your child's pediatrician.

## **Some of the physical signs to look for include:**

- Your child's eyes don't move together when they watch you
- Your child's eyes are crossed (both eyes turn in)
- One or both of your child's eyes turn out or in. This may happen all the time, or only sometimes. You may notice it more when they are sick or tired.
- Your child's eyes move quickly and rhythmically – usually up or down or side to side but sometimes around in a circular movement
- Your child's eyes do not seem to focus
- Your child's eyes water frequently
- Your child's eyes appear to bulge
- Your child's pupils are unequal in size or appear white instead of black
- Your child repeatedly shuts or covers one or both eyes
- Your child frequently squints, blinks, or rubs their eyes, even when there's no bright light present

## **Also watch for frequent or regular occurrence of the following behavioral signs:**

- Your child tilts their head when looking towards you
- Your child looks away from an object when reaching for it
- Your child frequently sits close to the TV or holds toys/books very close to their face
- Sometimes it seems like your child can see, other times it seems like they can't
- Your child looks towards people and objects but behaves as though they do not see them
- Your child looks only briefly at people or objects
- Your child seems to have a delay in their visual response – they may be slower to look at and reach for a toy when you hand it to them.
- Your child stares into lights
- Your child avoids looking at lights
- Your child is extremely sensitive to the sunlight and doesn't even want to be outside when it is bright.
- Your child looks above or below objects, but not directly at them
- Your child looks at moving objects, but not objects which are still or stationary
- Your child searches for a dropped item with their hands, but not their eyes
- Your child bumps into things, trips easily, and/or knocks things over frequently
- Your child avoids tasks and activities that require good vision, like reading or catch
- Your child doesn't seem to see steps or drop offs. They may also hesitate at surface changes or stop to feel them with their hand or foot before moving forward.

The majority of vision concerns in young children can be corrected, especially when caught early. If your child exhibits any of these physical and/or behavioral signs, or you feel like their vision isn't progressing as it should, we encourage you to talk with your pediatrician; they can answer questions and / or provide information on eye doctors in your area who specialize in young children

## REHABILITATION SERVICES FOR THE BLIND CHILDREN'S SERVICES PROGRAM

### MISSION STATEMENT

It shall be the mission of the Children's Services Program to empower and strengthen families so that they may set the highest expectations for their blind or visually impaired children.

**CORE FUNCTIONS:** The following are the core functions of the Children's Services Program:

1. Early identification and intervention
2. Strengthening a positive sense of self, regardless of vision loss
3. Facilitating access to community services related to the individual needs of the blind/visually impaired child
4. Enabling families to find the answers they need

### SERVICES

RSB may provide the following services, as appropriate, for the needs of each eligible client. An evaluation conducted collaboratively by the Children's Specialist, the parents/caretakers and the client will determine the nature and scope of services needed:

1. Advocacy on behalf of children and families to schools and community service providers
2. Technical assistance to responsible service providers (including families)
3. Evaluation of developmental needs
4. Resource and referral
5. Connecting families
6. Transitional (i.e., to new school/service environment, developmental) services
7. Promoting the Expanded Core Curriculum
8. Educating the community on blindness issues
9. Adjustment counseling for children and families
10. Promoting community integration
11. Securing equipment and services
12. Career Exploration Activities, without cost, that increase the child's vocationally relevant knowledge of themselves and the world of work.
13. Other services in keeping with the mission and core functions of the CS program

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# Field Test of 4to24: App for Youth and Parents to Focus on Employment

The NRTC on Blindness & Low Vision at Mississippi State University is recruiting participants for a field test of our app, “4to24,” developed for youth with blindness or visual impairment and their parents, to help focus on and prepare for employment starting from an early age.

We are seeking:

- Parents of children or youth who are blind or visually impaired, ages 4 to 24
- Youth or young adults who are blind or visually impaired, ages 16 to 24

The field test will entail creating an account in the app and using the app features for a period of 6 months, as well as completing a series of surveys. Surveys will ask questions about preparation for future employment and expectations for the future, as well as seek feedback about how the app fits your needs.

The app will provide information and resources to **support families in fostering independence and building skills toward employment**. It will send modules of information about different topic areas such as academics, technology, and social skills, based on the youth’s age and skill levels. Modules will include a list of suggested activities that parents and youth can do to build skills related to each topic.

We will ask you to use the app as you normally would, and to complete surveys related to our study before, during, and after the 6-month trial period. The surveys should take between 10 and 35 minutes each, for a total of about 1.5 hours of time on surveys. Participants who complete the final survey of the study will receive a thank-you gift card for \$35.

If you’re interested in becoming a field tester for the app and participating in our study, please fill out the information form at this link:

[www.research.net/r/MSUAppRegistry](http://www.research.net/r/MSUAppRegistry).

For assistance or further information, contact Anne Steverson ([acc155@msstate.edu](mailto:acc155@msstate.edu)) or Karla Antonelli ([kantonelli@colled.msstate.edu](mailto:kantonelli@colled.msstate.edu)).



# Cortical Visual Impairment (CVI)

## A Fact Sheet for Families & Professionals

**What is CVI?** Cortical visual impairment (CVI) is a neurological form of visual impairment caused by “damage or atypical structures in the visual pathways and/or visual processing centers of the brain” (Roman, 2018). CVI is the leading cause of visual impairment in children in countries or regions with access to quality neonatal health care.

### ***How is it different from other visual impairments?***

Individuals with CVI often have healthy eyes and obtain normal results on an eye exam, because it is the processing of vision in the brain that is atypical. CVI does not have an impact on visual acuity, contrast sensitivity, or many of the other symptoms of ocular visual impairments. CVI cannot be corrected with glasses.

Children and youth with CVI can be **expected** to make progress in their visual functioning over time if provided with appropriate assessment and intervention. CVI requires a very different approach to instructional supports and environmental/material adaptations as compared with ocular visual impairments.

### **How is CVI diagnosed?** *There are 3 criteria for diagnosing cortical visual impairment:*

- **History of neurological impact**, abnormal development, damage or trauma (the most common causes are anoxic brain injury associated with premature birth or other TBI [hypoxic ischemic encephalopathy, periventricular leukomalacia, stroke or seizure]). CVI can also be associated with genetic syndromes such as AGS, CDKL5, etc.)
- **Abnormal visual behaviors that cannot be explained by the clinical eye exam**
- **The presence of unique visual Characteristics associated with CVI:**

**10 Characteristics** are associated with CVI, and each will look different depending on where the individual’s visual processing falls on a range of visual functioning (**The CVI Range** [Roman, 2007]). The 10 CVI Characteristics are:

- |  |   |
|--|---|
| ○ Color preferences (often red, yellow, saturated)                                 | ○ Difficulty with distance viewing  |
| ○ Need for movement (to elicit/sustain attention)                                  | ○ Atypical visual reflexes<br>(blink to touch, blink to threat)                             |
| ○ Visual latency (processing time)   | ○ Difficulty with visual novelty<br>(easier with familiar objects, people, settings)        |
| ○ Visual field preferences   | ○ Difficulty with visually guided reach<br>(looking and reaching/touching at the same time) |
| ○ Difficulty with visual complexity<br>(array, target/object, multisensory, faces) |   |
| ○ Need for/attraction to light   |   |

Visual functioning in CVI is measured across the CVI Range (0-10), with three major phases describing level of impact of the CVI Characteristics on the individual’s ability to use her vision functionally:

- |        |           |  |
|--------|-----------|--|
| • 0-3  | Phase I   | Most severe impact on visual functioning |
| • 3-7  | Phase II  | Moderate impact on visual functioning    |
| • 7-10 | Phase III | Closest to typical visual functioning    |

It is important to identify a child’s specific visual functioning on the CVI Range with regard to each characteristic, as **the intervention approaches needed to support progress in visual functioning are unique to each Phase.**

## Frequently Asked Questions:

### ***Who can diagnose CVI?***

An ophthalmologist, neuro-ophthalmologist, optometrist, neurologist, or other clinical specialist.

### ***The eye exam said “normal” or “unable to test” but I know that my child/student has atypical visual behaviors.***

Make sure that the clinical specialist has knowledge of and ability to diagnose CVI before making the appointment. Clinical vision specialists who have expertise in the structure of the eyes may not necessarily be familiar with or able to diagnose CVI.

### ***The functional vision assessment (FVA) did not address the unique characteristics of CVI.***

You are entitled to educational assessment that is relevant to your child’s specific visual condition(s). You can ask for an assessment that addresses the unique visual implications of CVI, which is very different from other ocular forms of visual impairment.

### ***I have heard other terms for CVI that are confusing, such as “cerebral visual impairment” or “cortical blindness.”***

“Cerebral visual impairment” is not the same as cortical visual impairment (Jan, 2010). Cerebral visual impairment refers to a larger “umbrella” category of neurological visual conditions, including dyslexia and synesthesia.

“Cortical blindness” is an incorrect term, because individuals with CVI are never totally blind, in the absence of an additional ocular visual impairment. They always have *some* vision.

## **ADDITIONAL RESOURCES:**

- [Perkins School for the Blind’s E-Learning website](#) resources for professionals and families development
- [“Statement on Cortical Visual Impairment”](#) (Roman, Baker-Nobles, Dutton, Evans Luiselli, Flener, Jan, Lantzy, Matsuba, Mayer, Newcomb, & Nielsen, 2008)
- [Pediatric Cortical Visual Impairment Society](#) family advocacy group with extensive resources on CVI
- General resources for ideas on CVI:
  - [Little Bear Sees](#) family-oriented website and resources
  - [West Virginia Dept. of Education](#) training resources and videos
  - [Georgia Sensory Assistance Project](#) training resources and videos
  - [Texas School for the Blind & Visually Impaired](#) training resources and videos
  - [Paths to Literacy](#) resources and intervention ideas on CVI
  - [Salient Features Collaborative](#) – a website collaboration by professionals to support children with CVI
- National family teleconference group for families of children/youth with CVI (hosted by [Lighthouse Guild International](#)). If you are interested in joining the CVI teleconference call, email [judithmillman@aol.com](mailto:judithmillman@aol.com)
- Professional development opportunities:
  - [Perkins E-Learning](#) online classes on a variety of topics related to CVI
  - For experienced professionals, an [Endorsement](#) in CVI assessment and intervention is offered by Perkins

*The New York Deaf-Blind Collaborative is a federally funded grant program (U.S. Department of Education, Office of Special Education Programs) providing FREE resources, training and support services to families of and professionals working with children and youth (age 0-21) who have combined vision and hearing loss in New York State.*

Contact [nydbc@qc.cuny.edu](mailto:nydbc@qc.cuny.edu) for additional information or visit [www.nydbc.org](http://www.nydbc.org)

## **Suggested APH Products for Children with CVI**

*The following are APH products that may be appropriate for use with children who have Cerebral/Cortical Visual Impairment. Comprehensive assessment should determine which products are best matched to your learner's needs.*

All-in-One Boards: 1-08833-00, 1-08836-00  
APH Sound Balls: yellow 1-07510-00 or Red 1-07516-00  
Bright Shapes Knob Puzzles 1-03722-00  
Colored Shape Cards 1-08667-00  
CVI Complexity Sequencing Kit 1-08156-00 and eBook D-03610-ED  
CVI Book Builder 1-08825-00  
Digital Light Box Artwork 1-08691-00  
Expandable Calendar Boxes: Black 1-08652-00  
Flip-Over Concept Books Textures 1-08829-00  
Geometric Textured Shapes 1-08838-01  
Giant Textured Beads 1-03780-00  
Giant Textured Beads with Pattern Matching Cards 1-03778-00  
Increasing Complexity Pegboard 1-08160-00  
Invisiboard 1-08541-00  
Joy Player 1-07089-00  
Jumbo Work/Play Tray 1-03764-00  
Light Box (Standard yellow or LED Mini Lite Box) to be released in near future with LED lights  
Light Box Materials Level I: 1-08680-00  
Light Box Materials Level II: full kit 1-08680-00  
    Pegs/Pegboard 1-08665-00  
    Familiar Object Picture Cards 1-08666-00  
Match-it-Up Frames: small set 1-08828-00; large set 1-08827-00  
Match Sticks 1-08157-00  
Mini Lite Box LED to be released in near future  
Mini Lite Box Overlays 1-08659-00  
Picture Maker: Wheatley Tactile Diagramming Kit 1-08838-00  
Picture Maker Storage Panel 1-08838-03  
Rib-It- Balls: 14-inch 1-07513-00; 18-inch 1-07514-00; 30-inch 1-07515-00  
Sensory Learning Kit 1-08611 1-08838-00  
Shape Board 1-03710-01  
Spangle Tangle 1-08755-00  
Spinner Overlays for the Light Box 1-08692-00  
Swirly Mats CVI 1-08153-00  
Swirly Mats II CVI 1-08158-00  
Tactile Connections: Symbols for Communication 1-08837-00  
Tadpole Kit (selected items) 1-08155-00  
Talking GlowDice 1-07500-00  
ToAD Kit (selected items) 1-08152-00  
Textured Sorting Circles & Shapes 1-08834-00  
Tri-fold Board 1-08859-00  
Work/Play Trays (small & large in yellow or black)

Revised 10/2019



## CONNECTING YOUR STUDENTS TO PERSONALIZED EDUCATION, TRAINING AND SUPPORT



### The CVi Connect PRO iPad App

- Cutting edge technology with Look Detection
- Provides learning Activities
- Access to Activity data
- Supports multiple students
- Supports all Phases of the CVI Range

### CVi Connect is a...

community of CVI professionals, utilizing cutting-edge technology, that offer hope and confidence in the form of personalized education, training and support for children with Cortical Visual Impairment.



#### The Team

The team includes teachers of the visually impaired (TVIs), technical staff, and Christine Roman-Lantzy. Dr. Roman-Lantzy is a world leader in the understanding, assesment and intervention strategies for CVI.



#### The Technology

The CVi Connect application uses the camera inside of the iPad to detect whether the child is looking at or away from the activity, has their eyes open or shut, and is smiling. The software leverages the data to suggest more advanced exercises.



#### The Education

The CVi Connect community includes parents, TVIs, technology experts and medical professionals, all providing content via our blog, social media outlets and webinars, to create a robust learning environment





## **2019-2020 Webinar Wednesday Series**

### **Nov 13 – Interpreter or Intervener: Which Will Meet the Educational Support Needs of Your Child? 8:00 p.m. – 9:30 p.m. EST**

**Presented by: Susanne Morgan Morrow** – Director  
New York Deaf-Blind Collaborative

**Beth Kennedy** – Director

DeafBlind Central: Michigan's Training & Resource Project and the DeafBlind Intervener Training Program at Central Michigan University

An educational interpreter and intervener have overlapping roles in the classroom, which may cause confusion for parents of children with CHARGE syndrome, thus leading to challenges when advocating for the supports for school. This presentation will explore the differences and the similarities in the roles and assist families in identifying which one is the best fit for their child's needs. An overview of each role will be provided, including examples of how interpreters and interveners work with students who are deafblind in K-12 settings.

#### **Participants will:**

1. Identify the differences and similarities between an educational interpreter and an intervener.
2. Identify the principles behind the roles of an educational interpreter and intervener.
3. Apply these concepts to the support needs of their child.

### **December 4 – Using Photos to Tell your Child's Story – 8:00 p.m.- 9:30 p.m. EST**

**Presented by: Donna Carpenter** – Kentucky DeafBlind Project

Come learn how using 20 photos to tell your child's story to his/her educational team can provide valuable perspective of your child as part of a family. Your short digital video will provide the educational team information about strengths, preferences, who your child's favorite person is, what pets are at home and family vacations. Change your child's educational team's perspective from a "can't do" to a "can do" mindset.

**Jan 22 – The Power of the Deaf-Blind Network: What's in it for you? – 8:00 p.m. – 9:30 p.m. EST**

**Presented by: Sam Morgan**, Co-Director of the National Center on Deaf-Blindness (NCDB)

Join us to learn about the various levels of support available for your family and how you can get involved at the local, state and national levels. You will learn about how the Deaf-Blind Network partners together to provide families high-quality services and support to families.

**Feb 19 – Lessons Learned: A Parent Panel – 8:00 p.m. – 9:30 p.m. EST**

Raising a child with CHARGE syndrome can sometimes feel overwhelming. Please join us to hear the perspective of mothers as they share their lessons learned and what they know for sure. There will be time for Q&A at the end.

**March 25 – The Role of the Family in the IEP Process – 8:00 p.m. – 9:30 p.m. EST**

**Presented by: Kristi Probst** – Initiative Lead for Interveners and Qualified Personnel and Assessment, Planning and Instruction at the National Association on Deaf-Blindness

Navigating the IEP process can be very daunting, to say the least. Join Kristi as she shares practical tips and strategies on how to ensure that the needs of your child and family are at the forefront of the educational programming for your child. She'll be joined by a few families of children with CHARGE syndrome who plan to share their real-life experiences and tips for effective partnership with their child's educational team.

**April 22- Let them Play: Getting Involved in your Community – 8:00 p.m. – 9:30 p.m. EST**

**Presented by: Matt LaCortiglia M.Ed. and Maebh Barry MS Ed.**

Adapted Physical Education Teachers in the Deafblind program at the Perkins School for the Blind

During this webinar we will discuss considerations for assessing, selecting, and identifying potential recreational physical activities for individuals of all ages with CHARGE syndrome in community settings. Strategies for successful community experiences, planning considerations, and possible activity modifications will also be included.

*Watch for registration information in your email inbox or sign up for [eNews](#) now.*

# Meet the Outreach Staff



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