An inside look at CVI Now

Resources and key learnings to help inform your work

CVI for the TVI, Jan 2023

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CVI Center’s Core Values

CVI is a lifelong disability and has a big impact no matter how it manifests. Every person with CVI’s lived experience is different. Every person with CVI has a right to access their world in the way that works for them.

As the CVI Center at Perkins:

- We center the person with CVI
- We follow the research
- We partner with the child, family, educational and medical team
- We believe, with access, every child can learn
- We approach CVI with a disability rights lens

Our work is always grounded in both research and practice, and our thinking evolves as our collective understanding of CVI advances.
Overview of CVI
Now’s Impact
Since launch in Sept 2020
CVI Now

Empowering the CVI community with knowledge and connection

- A deep, trusted resource that centers CVI voices and follows the science
- Rooted in current research; vetted; accurate
- Shares the lived experiences of people with CVI and their families
- Disability rights lens of CVI
- Inclusive and values diverse thinking; gathering place of ideas; synthesizes multiple perspectives about CVI
CVI Now - Core Values

Empowering the CVI community with knowledge and connection

- Every child with CVI is teachable. Every child with CVI can learn.
- Every child with CVI has a right to an early diagnosis, effective vision services, and accessible educational programming—no matter how their CVI manifests, no matter their zip code.
- Every person with CVI has a right to joy, purpose, a sense of belonging, and define their own success.
CVI Now’s Reach

Building community + awareness

- 15k+ users per month
- Since launch (Sept. 2020)
  - 205,000 users
  - 377,000 pageviews
- Top 15 states: MA, CA, NY, TX, PA, IL, GA, VA, FL, NC, OH, WA, NJ, MI, AZ
- 1,800 members in CVI Now Parent Facebook Group
CVI Now’s Global Reach

- 184 countries
- Top countries
  - USA
  - India
  - United Kingdom
  - Canada
  - Australia
  - Philippines
  - Japan
  - Ireland
  - New Zealand
  - Pakistan
  - Malaysia
  - Netherlands
  - South
  - Africa Hong Kong
  - Nigeria
  - Indonesia
  - Germany
  - Sweden
  - Sri Lanka
  - South Korea
Explore and tour CVI Now

Highlights of resources and topic areas

CVI NOW
Perkins School for the Blind
CVI Now Sections

UNDERSTANDING CVI
Dive into foundational information about CVI, the CVI Visual Behaviors, CVI Research Library, and CVI and the brain.

PARENTING
Explore the CVI Now IEP Guide, ideas for making daily routines accessible, real talk about raising children with disabilities.

PROMISING PRACTICES
Learn about CVI assessment, a multi-sensory approach to learning, literacy, math, total communication, and more.

CVI STORIES
Find interviews with people with CVI, parent stories, and resources that center the voices of CVI.
Understanding CVI

CVI NOW
Perkins School for the Blind
CVI Intro Resources

- What is CVI?
- CVI Guide
Examples of current topics related to CVI and the visual system

- Clutter / Crowding / Visual Search
- Visual attention and the attention network
- Visual recognition and mental representations
- Global motion processing
- Processing faces, expressions, emotions
- CVI and ocular conditions
- Clinical assessment to support CVI diagnosis and risk factors

https://www.perkins.org/resource/cvi-research-library/
The visual system and the CVI brain

Five-part series about the complex and highly connected visual system

- **Part 1:** How the eyes work
- **Part 2:** Ocular motor conditions and CVI
- **Part 3:** The visual pathway from the eye to the brain
- **Part 4:** Higher-order visual pathways
- **Part 5:** The importance of neuroplasticity

CVI and the brain: Q&A with Dr. Lotfi Merabet
Diagnosing CVI

- **How is CVI diagnosed?**
- **Dr. Nicole Ross presents Diagnosing CVI** [video]
- **No patient is untestable: A CVI Q&A with Dr. Barry Kran** [Q&A]

  “It’s not the patient who’s uncooperative—it’s the doctor’s inability to adjust what they are doing to make it accessible for the patient.”
  —Dr. Kran

- **After the diagnosis**
CVI Visual Behaviors

https://www.perkins.org/understanding-cvi-visual-behaviors/

- Overview video of the CVI behaviors and they are interconnected
- Brief blurbs about each CVI visual behavior
- Links to mini lesson videos and articles for each of the CVI behaviors
- Link to mini-lesson on the role of compensatory skills
Visual Fatigue

A common shared experience among people with CVI

- The science behind visual fatigue
- Parents share how their children with CVI show visual fatigue
- 6 big ideas to help to reduce visual fatigue in children with CVI
CVI Evolving

What we’re learning from the CVI community

- Difficulty with visual-spatial processing
- Difficulty with visualization
- Visual phenomena people with CVI experience
- CVI and chronic migraines
- CVI and the environmental temperature

https://www.perkins.org/resource/cvi-evolving/
Promising Practices

CVI NOW
Perkins School for the Blind
Holistic, comprehensive assessment

- The CVI visual behaviors all overlap at any given time and situation.

- We need a holistic and comprehensive assessment that looks at every possible angle to create a baseline of understanding of how CVI and other factors uniquely impact the individual. What strategies are they using to make sense of their world (compensatory skills).

- Ongoing assessment is critical to better understand the impact of CVI visual behaviors and the interventions that are supporting access to learning.

Getting Started with CVI Assessments
"If the child with CVI is less engaged, there's a reason for it. It's on us, the educators and providers, to optimize every opportunity for accessible learning to move that child as close to their learning goal as possible. We cannot predict what a child with CVI can or cannot do, but we can thoughtfully design instruction that is accessible and meaningful, so they have every opportunity to show us their skills and abilities."

—Marguerite Tibaudo, Asst. Dir. CVI Center
CVI and Communication

● 5 essential steps to finding the best AAC system for a learner with CVI:
  ○ Assessment
  ○ Define the purpose
  ○ Evaluate the learner’s unique profile
  ○ Thoughtfully consider CVI visual behaviors
  ○ Monitor progress

● Expert Q&A: CVI and AAC

● Childhood Apraxia of Speech (CAS) in children with CVI

● Navigating my son’s CVI and complex communication needs

● A total communication approach for my son with CVI

● Making strides: Aiden’s communication journey
CVI and literacy

- Impact of CVI: Building a foundation for literacy
- 6 ways CVI impacts the reading process
- 8 literacy resources for children with CVI
- Everyday literacy tips from CVI parents
- Adapting worksheets for CVI
- “Literacy is a human right”: Exploring CVI and dual media literacy
- In celebration of reading (and its many forms) for my child with CVI
CVI and math

- Adapting worksheets for CVI
- **Visualizing Math**: Considerations for students with CVI
- Matt Tietjen presents **CVI and the math mind**
- Math and CVI: **Ideas for a multisensory approach**
CVI and social access

- How to rethink four social and environmental norms to fully include individuals with CVI
- CVI and Social Skills [video]
- CVI and the ECC: Focus on Social Interaction Skills
CVI and Central Auditory Processing Disorder (CAPD)

CVI and O&M

CVI in the OT Setting

Empowering access in daily life: CVI, sensory processing, and independent living

CVI and APE

CVI and Assistive Tech

CVI and the Expanded Core Curriculum (ECC)
Parenting
CVI Now IEP Guide

https://www.perkins.org/cvi-now/cvi-now-iep-guide/

- A productive, solutions oriented resource
- Walks through the IEP process from beginning to end
- Covers how IEPs are built and implemented, questions to ask and what to expect at each stage
- Incorporates CVI considerations throughout!
CVI and the everyday

- Why it’s challenging for some kids with CVI to eat
- 9 CVI adaptations for mealtime
- How to declutter your home for your child with CVI
- Party time! Helping kids with CVI make the most of celebrations
- CVI and Halloween
- The CVI parent’s guide to the holidays
All that comes with disability parenting

- Balancing emotions with IEP advocacy
- Permission to talk about the hard stuff, with Amanda Griffith-Atkins
- CVI parenting with self-compassion
- The essential self-care guide for CVI parents
- We can do hard things: Insights into the CVI parent journey
- Speaking of the brain

Explore CVI stories from people with CVI and families raising children with CVI.
CVI Stories
People with CVI tell their stories

- Centering CVI Voices
- Adults with CVI share how “CVI leaves no stone unturned”
- Tina’s CVI Perspective: “Your eyes see, but your brain doesn’t”
- Albie’s CVI Perspective: “I want people to be more open to CVI”
- Why music is my vision: Dagbjört talks about living with CVI as an adult
- Nai’s CVI Perspective: “You’re seeing but you’re not” (3-part series)
3 big takeaways
Some big takeaways from CVI Now

1. CVI is a public health crisis
Prevalence of CVI

- **1 in 30 kids**: The CVI Project (www.thecviproject.co.uk) found that at least 3% of children in mainstream school—equating to **one child in every classroom**—had CVI-related visual difficulties (Williams, et al., 2021)

- CVI is **common in neurodevelopmental conditions**: prematurity, cerebral palsy (60-70%), hypoxic ischaemic encephalopathy (HIE), hydrocephalus, meningitis, Autism, Down syndrome (38%) (Pilling, et al., 2022)

- A wide range of **genetic syndromes** (Williams, Rett, CDKL5, Trisomy 21, West, Pitt Hopkins, etc.) and genetic variants are associated with CVI (Phillip & Dutton, 2014; Bosch, et al., 2014; Olson, 2021; Wilton, et al, 2021)

- Children receiving special education services are **28 times** more likely to encounter vision problems than typically developed children. (Pilling, et al., 2022)

- ~**50%** of children in with visual impairments have CVI in the UK (Teoh, 2021; Pilling, et al., 2022)
Some big takeaways from CVI Now

1. CVI is a growing public health crisis
2. Families are doing the impossible and need support and resources
Our kids matter, they are worthy

- Parents of kids with disabilities and complex medical need are navigating a tremendous amount of trauma, grief, stress, and anxiety.

- It’s not okay that it’s this hard to fight for our kids’ right to fully access their education and post-secondary opportunities.

- Our kids need for support and accommodations to access their world does not take away from their worth in our society, nor does it take away from their gifts, competencies, and skills. Their needs are, in fact, human needs. With the right support, our kids can express themselves, participate in our communities, and define their success.
Some big takeaways from CVI Now

1. CVI is a growing public health crisis
2. Families are doing the impossible and need support and resources
3. Believe people with CVI, fight for their right to access, and deeply listen to their stories and experiences
Believe people with CVI

- “We are the experts of our own brains.” (Nai)
- “CVI leaves no stone unturned.” (Dijana)
- People with CVI get to choose how they want to access the world. Many people with CVI develop incredible compensatory skills and workarounds to exist in a society that is not accessible. Some use vision, some non-visual skills, and some use both.
- Every person with CVI has a right to access life-changing healthcare, education, and services.

“Children with CVI will grow into adults with CVI. If these children are not diagnosed on time, and help and intervention is not offered shortly after their diagnosis, these children will have much difficulty navigating their way through life as children, as teenagers, and adults. Please do not dismiss them due to a lack of misunderstanding or training, but be patient and actively listen and hear these big or little people. Your judgment may have a profound effect on these people, and this is the last presumption they need.”

-Dijana, adult with CVI
4 foundational ideas about how to approach access

Hint: It’s about access to learning and using a whole-child approach

CVI NOW
Perkins School for the Blind
1. Know how the person with CVI is making sense of their world

- People with CVI have a strategy and workaround for nearly everything, everyday
  - What are the skills and sensory channels they are innately using during their everyday routines?
  - What is meaningful, motivating, and interesting for them?
  - What are their reliable responses?
- Access is individual and strength-based
- Curiosity about how people with CVI make sense of their world will drive meaningful and empowering supports and accommodations.
- Develop an accessible educational program by centering the student with CVI, rather than “doing CVI.”
2. Create a strong sensory foundation for new concepts and skills

- All development matters. Neuroplasticity is about brain growth and development. Our sensory systems are highly interconnected.
  - Just get out there; experiential learning
  - Balance repetition with new experiences
  - The more experiences kids have, the better they understand, predict, and become familiar with concepts and environments.
- Use of all sensory modalities builds a bridge to perception and understanding.
- Recognition is foundational to learning, and we use all of our senses to recognize our world. Compensatory skills enhance and support visual recognition abilities.
3. Use a wide array of design tools to remove barriers to access

- People with CVI are on the blindness spectrum. Build their toolbox with various skills and tools they need for long-term success.
- Multisensory approach to process information, apply their skills, and show what they know. Be mindful, that many with CVI use one sensory channel at a time.
- Explicit and direct instruction to develop rich concepts in all areas of learning
- Direct instruction in all Expanded Core Curriculum domains (AT, O&M, social inclusion, literacy, sensory efficiency, independent living, compensatory skills, career ed)
Our design tools

**Autonomy, agency, advocacy:** Choices for access, model permission/consent, ongoing data collection, self-advocacy skills, calendar systems, total communication systems

**Auditory:** Audiobooks, screen readers, text-to-speech, speech-to-text, images descriptions, verbal descriptions of items, people, and the environment

**Kinesthetic:** Movement as part of learning, movement breaks, pro tactile sign language, drawing on own body

**Tactile:** Tangibles (manipulatives, objects, models), braille, tactile diagrams, white cane

**Visual:** Color, spacing, reduce clutter, environmental supports, movement, light, visual instructional supports, and visual breaks.
4. Create a system to foster agency, autonomy, and self-advocacy

- Calendar systems, predictable routines, learning sequences
- Scaffolds to support self-advocacy skills
- Inclusive classroom practices and policies
- Behavior is communication: “Behaviors are symptoms of an internal reality.” (Nai)
- Create space for students to express their needs and choose how they want to access their learning
- Collaborate with families and build trusting relationships
Thank you!

Questions?

Comments?