

# **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

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Since launch in Sept 2020

**CVI NOW**  
Perkins School for the Blind

# 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

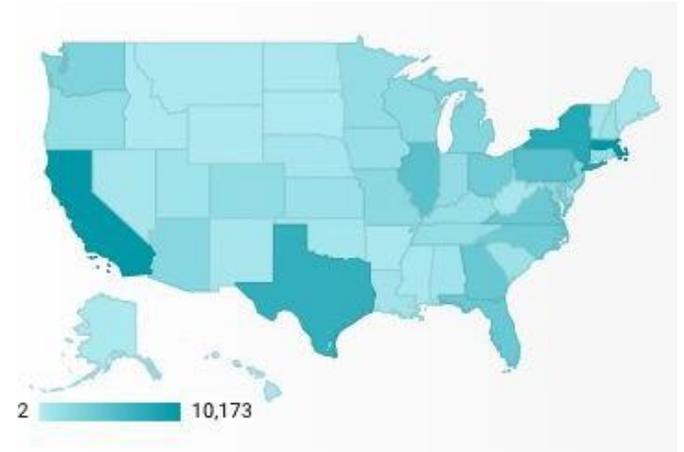
## Empowering the CVI community with knowledge and connection

- 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

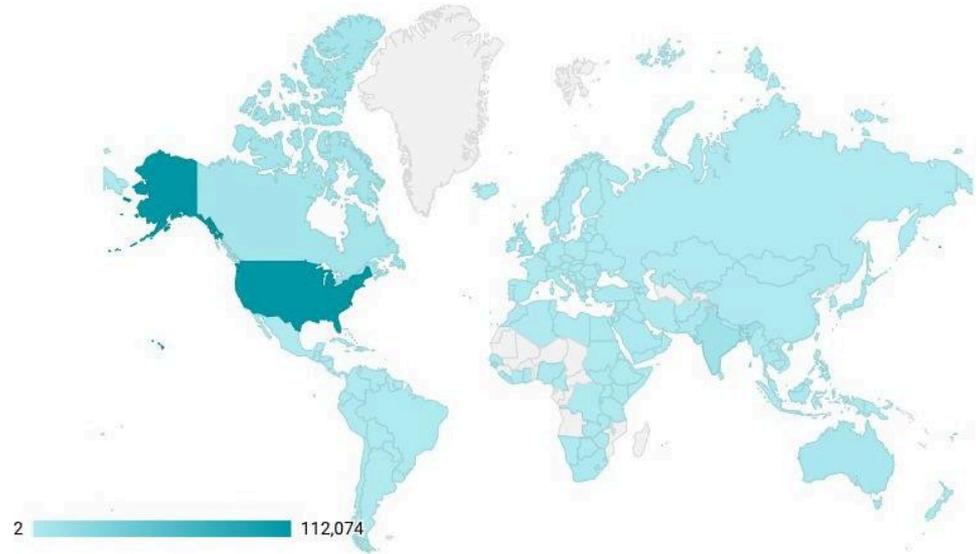


# CVI Now's Global Reach

- 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

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Highlights of resources and topic areas



# CVI Now Sections

## UNDERSTANDING CVI

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

## PROMISING PRACTICES

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

## PARENTING

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

## CVI STORIES

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

# Understanding CVI

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# CVI Intro Resources

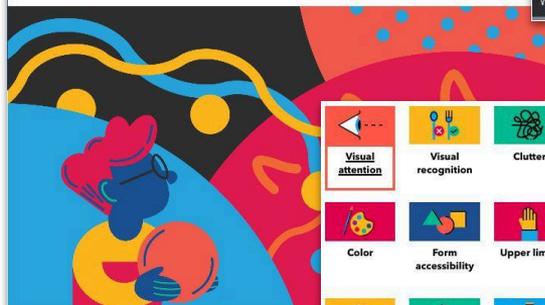
- [What is CVI?](#)
- [CVI Guide](#)

• ARTICLE

## What is CVI?

CVI is a brain-based visual impairment caused by damage to the visual pathways or visual processing areas of the brain.

SHARE    



### Visual attention

|   |   |   |   |
|---|---|---|---|
| <br>Visual attention         | <br>Visual recognition | <br>Clutter        | <br>Fields of view |
| <br>Color                    | <br>Form accessibility | <br>Upper limbs    | <br>Lower limbs    |
| <br>Access to people         | <br>Light              | <br>Response time  | <br>Motion         |
| <br>Multi-sensory situations | <br>Distances          | <br>Visual fatigue | <br>What's ahead   |

Bella works hard to use her vision to focus on school activities, such as flower vase decorating. With CVI, creating opportunities for children to focus is crucial to helping them see more. So, teachers at Perkins School for the Blind use visual and sensory supports like lights, colors, objects, and clutter-free environments to help make focusing and looking at beautiful art projects possible.

[Learn more →](#)

# CVI Research Library

## 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/>

### CVI, the Brain, and Neuroplasticity

- Atkinson, J., & Braddick, O. (2011). [From genes to brain development to phenotypic behavior: "dorsal-stream vulnerability" in relation to spatial cognition, attention, and planning of actions in Williams syndrome \(WS\) and other developmental disorders.](#) *Progress in Brain Research*, 189, 261-283.
- Bennett CR, Bauer CM, Ballin ES, Merabet LB. (2020). Neuroplasticity in cerebral visual impairment (CVI): [Assessing functional vision and the neurophysiological correlates of dorsal](#)

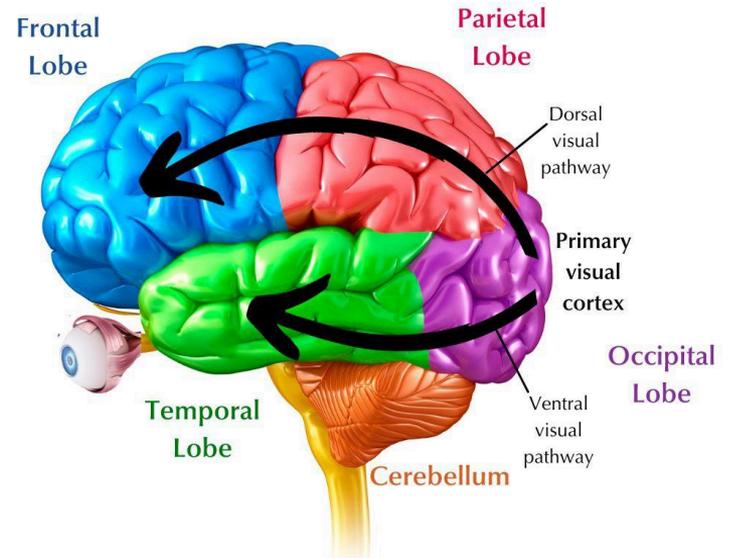
### Prevalence of CVI / Etiology of CVI / Impact of CVI

- Bosch, D., Boonstra, F., Willemsen, M., Cremers, F., & de Vries, B. (2014). [Low vision due to cerebral visual impairment: differentiation between acquired and genetic causes.](#) *BMC Ophthalmology* 14(59), 1-9.
- Bosch, D. G., et al. (2016). [Novel genetic causes for cerebral visual impairment.](#) *European journal of human genetics: EJHG*, 24(5), 660-665.
- Chokron, S., Klara, K., & Gordon D. (2021). [Cortical Visual Impairments and Learning Disabilities.](#) *Frontiers in Human Neuroscience* 15, 573.
- Fazzi, E., Molinaro, A., & Harmann, E. (2015). "The potential impact of visual impairment and CVI on child development." In: A. H. Lueck & G. N. Dutton (eds), *Vision and the Brain: Understanding Cerebral Visual Impairment in Children* (pp. 83-104). New York, New York: American Foundation for the Blind Press.
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- Fazzi, E., Signorini, S., Pina, R., Bertone, C., Missefari, W., Galli, J., Balottin, U., & Bianchi, P. (2012). [Neuro-ophthalmological disorders in cerebral palsy: ophthalmological, oculomotor, and visual aspects.](#) *Developmental Medicine and Child Neurology* 54(8), 730-736.
- Goodenough, T., Pease A., Williams C. (2021). [Bridging the Gap: Parent and Child Perspectives of Living With Cerebral Visual Impairments.](#) *Frontiers in Human Neuroscience*, 15, 373.
- Kran, B. S., Lawrence, L., Mayer, D. L., & Heidary, G. (2019). [Cerebral/cortical visual impairment: a need to reassess current definitions of visual impairment and blindness.](#) *Semin Pediatr Neurol* 00, 1-5.
- Kong, L., Fry, M., Al-Samarraie, M., Gilbert, C. & Steinkuller, P. G. (2012). [An update on progress and the changing epidemiology of causes of childhood blindness worldwide.](#) *Journal of American Association for Pediatric Ophthalmology and Strabismus* 16, 501-507.
- Kozels, N. (2010). [Brain visual impairment in children: mini review.](#) *Hippokratia* 14(4), 249-251.
- Macintyre-Beon, C., Young, D., Dutton, G., Mitchell, K., Simpson, J., Loeffler, G., Bowman, R., & Hamilton, R. (2013). [Cerebral visual dysfunction in prematurely born children attending mainstream school.](#) *Documenta Ophthalmologica* 127(2), 89-102.
- Olson, H., et al. (2021). [Cerebral visual impairment in CPKLS deficiency disorder: vision as an outcome measure.](#) *Developmental Medicine and Child Neurology*, 63(11) 1308-1315.

# 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/>

ARTICLE

## Understanding the CVI visual behaviors

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An overview of the CVI visual behaviors and how they interconnect  Play the video

Individuals with CVI tend to display key visual behaviors, and might display some or all of these behaviors. At Perkins, we synthesize current research and build on the work of leading theorists to ensure all individuals with CVI are fully understood. This is why we follow the science and center voices of individuals with CVI. The CVI visual behaviors are an ongoing need, they can change and they can improve for some, but the need never goes away.

- 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

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# 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.



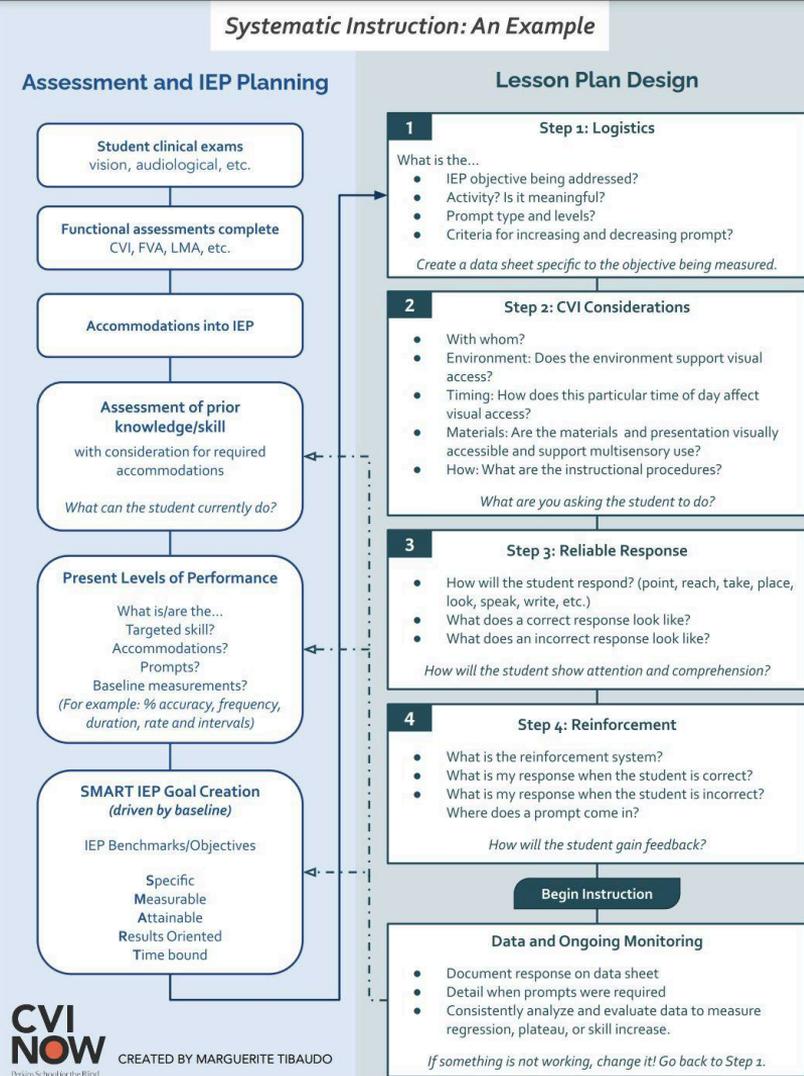
## Getting Started with CVI Assessments

# Systematic Instruction

## Building accessible and meaningful learning experiences

"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 Tibaldo, 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](#)



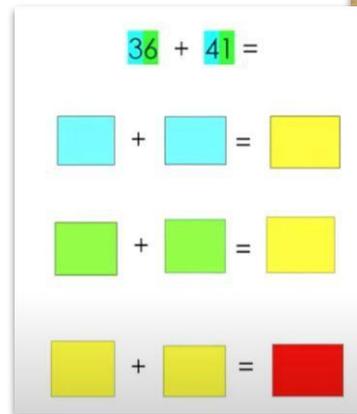
# CVI and literacy

- 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](#)



Sue Sullivan

Matt Tietjen



Matt Tietjen

# 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](#)

**We need to rethink what we say to individuals with CVI.**

*"Look at me while I'm talking."*

"To listen well, I need to tune out my vision."

*"Pay attention."*

"There's too much on the walls, it's really noisy, and it's too hot. I'm stressed, anxious, and can't use my vision."

*"Sit still."*

"I need to move to help process the world."

*"Work with others in your group."*

"I need help recognizing people and knowing where they are."

*"Follow along."*

"I need someone to describe what's happening around me."



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# CVI and CAPD, O&M, OT, APE, AT, the ECC

[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

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# 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!



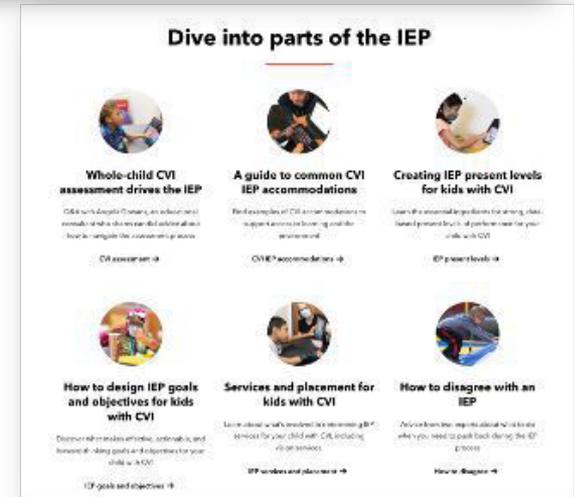
**Get started**

**Starting the IEP process: A guide for CVI families**  
An introduction to IDEA and the IEP and some initial steps to begin the IEP process.  
[Let's get started →](#)

**Anatomy of an IEP for kids with CVI**  
An overview of the purpose of the various sections of an IEP document with CVI considerations.  
[Learn about the IEP →](#)

**What makes a well-written IEP?**  
An educational case that shares what to look for in your child's draft IEP.  
[A well-written IEP →](#)

**How to maximize your IEP meeting**  
Tips for a more productive and effective IEP meeting for your child with CVI.  
[IEP meetings →](#)



**Dive into parts of the IEP**

**Whole-child CVI assessment drives the IEP**  
CVI is a complex condition, an educational needs assessment should be conducted that addresses how to integrate the assessment process.  
[CVI assessment →](#)

**A guide to common CVI IEP accommodations**  
Real examples of CVI accommodations to support access to learning and the general curriculum.  
[CVI accommodations →](#)

**Creating IEP present levels for kids with CVI**  
Learn what is essential to gather the information that is present in all of your child's life for your child with CVI.  
[IEP present levels →](#)

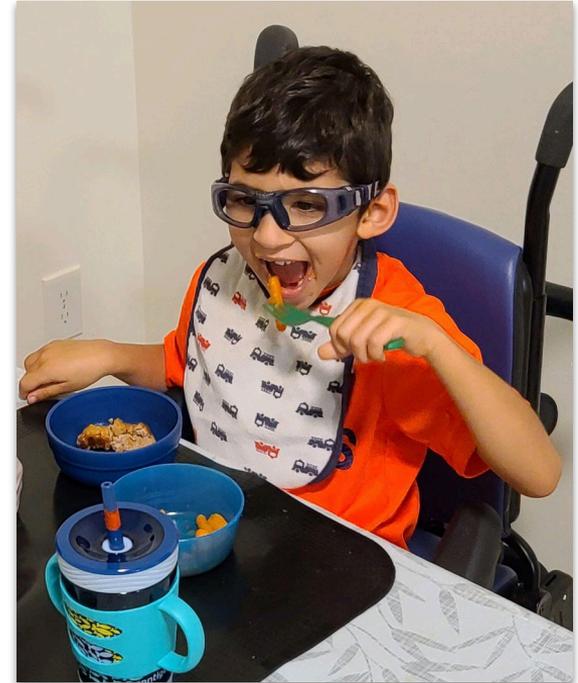
**How to design IEP goals and objectives for kids with CVI**  
Determining the end state, starting point, and forward-looking goals and objectives for your child with CVI.  
[IEP goals and objectives →](#)

**Services and placement for kids with CVI**  
Learn about what is involved in determining IEP services for your child with CVI, including out-of-school services.  
[IEP services and placement →](#)

**How to disagree with an IEP**  
Dive on from the beginning about how to do it when you need to push back during the IEP process.  
[How to disagree →](#)

# 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

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# 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

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# 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](http://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

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

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# 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

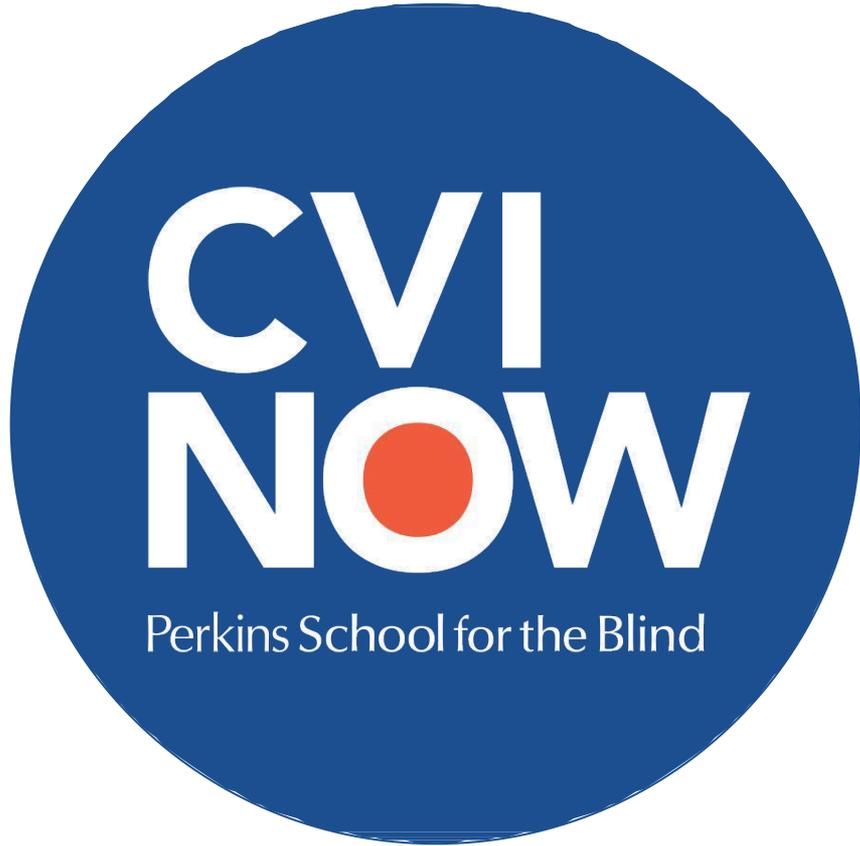
**Tactile:** Tangibles (manipulatives, objects, models), braille, tactile diagrams, white cane

**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

Behavioral 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
- Observe. Ongoing assessment. Collect Data. Consistent check-ins with the student. Self reflection. Evolve. Adapt.



**Thank you!**

Questions?  
Comments?