

— What is CVI?

Cortical/Cerebral Visual Impairment (CVI) is the leading cause of childhood blindness and low vision. CVI is a lifelong brain-based visual impairment, caused by damage to the brain's visual pathways or visual processing areas.

People with CVI struggle with visual attention and visual recognition. Because of this, they have trouble learning from their environment and from their instructional materials. Some people see the world as distorted and unrecognizable. Others can focus but might struggle to understand what they see. A crowded setting, a hot day, or fatigue has the potential to make vision use nearly impossible.

People with CVI often display common visual behaviors and traits, but CVI manifests differently in everyone. Some people have trouble with facial recognition, hand- and foot-eye coordination, or integrating vision with other senses. These behaviors may change and improve over time, but they never disappear. As such, people with CVI often develop unique compensatory skills to manage their confusing visual world. Support for CVI needs to be sustained and lifelong.

— Why is CVI so misunderstood?

Often, people associate blindness and low vision with ocular – or eye – impairment. But CVI is a neurological issue, where the brain has trouble processing what the eyes can see. Some people with CVI have perfectly healthy eyes, which can cause diagnostic confusion, though others have refractive errors or misalignment. Many others have coexisting ocular conditions that mask their CVI.

There's no standard diagnostic test for CVI yet, which makes it hard to identify. There is growing research that suggests many people with CVI also have overlapping conditions, such as cerebral palsy, autism, or Down syndrome, which can make diagnosis even more complex.

Significant numbers of children with CVI are being misdiagnosed and mislabeled, which prevents them from accessing effective teaching strategies. Importantly, the National Eye Institute at the National Institutes of Health has now identified CVI as a research priority.

Why is CVI a public health crisis?

With pivotal investments in breakthrough research, diagnosis, treatment, assessment, educational intervention, training of professionals, and parent education, we can empower children with CVI with life-changing access. Consider:

- CVI affects up to 1 in 30 kids in mainstream classrooms, according to one study. These children deserve access to learning, and educators need proper CVI training.
- CVI is common in neuro-developmental conditions. There are significant overlaps with cerebral palsy and prematurity, for instance, but diagnosing CVI remains complex. Currently, there is no International Classification of Diseases (ICD) code for CVI.
- CVI is caused by complications from premature birth, lack of oxygen, pediatric stroke, infections that reach the brain, head injury, and genetic conditions. There is currently no screening tool for CVI for babies with these complications.
- There is a lack of CVI awareness and experience among educators, vision professionals, and medical providers. This puts an entire generation of children with CVI at risk. If we continue to ignore CVI, then we deny already vulnerable children their right to health, education, and full, dignified participation in society. If we invest in equipping professionals with the skills and knowledge to support children with CVI, we can change this paradigm and build a more accessible and equitable world.

— Here are some solutions.

Every person with CVI has a right to early diagnosis, effective vision services, and an accessible education – no matter their zip code and no matter how their CVI manifests.

We believe

- Health care professionals (particularly pediatricians, pediatric ophthalmologists, neurologists, neuro-ophthalmologists, and optometrists) must receive adequate training in CVI diagnosis and treatment.
- Educators (particularly Teachers of the Visually Impaired, or TVIs) and related services personnel (particularly Orientation and Mobility, or O&M, specialists) must be provided with appropriate pre-service and in-service training to address the unique needs of children with CVI.
- Parents must be equipped with robust resources on CVI, advocacy training and support, and the skills and knowledge to be partners in a system that expects parents to play a key role.
- Researchers, neurologists, doctors, optometrists, geneticists, rare disease specialists, educators, policymakers, and families must collaborate and coordinate their efforts.

“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, TVI, M.Ed

We urge provider teams to

- **Adopt a comprehensive whole-child CVI assessment** to evaluate the CVI visual behaviors and how each child uses compensatory skills. The goal is to integrate these findings into the whole picture of the child’s educational needs. Families, educators, and medical professionals must collaborate to provide effective care, services, and opportunities.
- **Center autonomy, agency, and advocacy** by believing the person with CVI, providing choices for access, understanding that behavior is communication, and implementing systems that allow each person with CVI to make their own choices.
- **Make school accessible** with an instructional approach that uses adapted materials, tasks, and environments to meet the unique needs of each child. This will help reduce visual fatigue, a common CVI symptom, and increase access to learning.
- **Use a multisensory approach to learning** that leverages each child’s sensory strengths (auditory, tactile, visual, movement). All sensory inputs support brain development.
- **Implement intentional and systematic instruction** with scenarios that are deliberate, consistent, and predictable. Direct instruction supports concept development and incidental learning (receiving information through observation). People with CVI also require direct instruction in the Expanded Core Curriculum (ECC), which teaches foundational skills needed for daily life, independent living, and the workplace.
- **Create visually simple, quiet environments for learning** by reducing visual clutter, noise, and other sensory information. This kind of overwhelm can make it extremely difficult to visually access objects and environments, and acquire new learning.

“The lesson in CVI is about a much deeper principle: autonomy and choice.”

What we need is respect as the experts of our own brains.”

-Nai, adult with CVI, author of The CVI Perspective



Learn about CVI and join us!
Perkins.org/CVI