



Governor's Committee on People with Disabilities (GCPD)

Policy Development Proposal

Describe the proposed policy or legislative solution:

Proposal for an Early Screening and Referral Bill for Infants and Toddlers with Developmental Histories at Risk for Cerebral/Cortical Visual Impairment (CVI)

Executive Summary

Cerebral/Cortical Visual Impairment (CVI) is now recognized as the leading cause of visual impairment in children in developed countries, as highlighted in recent landmark publications in *Ophthalmology* and *Pediatrics*. Despite its prevalence and significant impact on a child's development, CVI often goes undiagnosed or is misdiagnosed due to a lack of systematic early screening processes and referral pathways. The National Eye Institute (NEI), a part of the National Institutes of Health (NIH), has identified CVI as a **national emergency**, emphasizing the urgent need for action to address this escalating public health crisis.

Vision is the primary modality for learning during early childhood. Failing to identify and intervene early in children with CVI deprives them of critical opportunities to develop visual skills and foundational abilities for learning, resulting in cascading developmental delays that are difficult, if not impossible, to remediate later in life. This proposal seeks to establish a state-mandated early screening and referral program for infants and toddlers at risk for CVI. By identifying CVI during critical early developmental windows, we can connect families with interventions that maximize outcomes, reduce educational and societal costs, and foster long-term independence and quality of life for affected children.

The Case for Action

Cerebral/Cortical Visual Impairment arises from damage or dysfunction in the brain's visual pathways rather than the eyes themselves, distinguishing it from traditional ocular visual impairments. According to the recently published *Special Commentary: Cerebral/Cortical Visual Impairment Working Definition* in *Ophthalmology*, CVI requires a nuanced understanding that integrates neurodevelopmental, ophthalmological, and functional perspectives.

A recent study in *Pediatrics* (*Diagnosis and Care of Children with Cerebral/Cortical Visual Impairment*) and other leading research emphasize that **early identification and**

intervention are imperative to mitigating CVI's impact. Vision serves as the primary sensory modality for learning in young children. Delayed diagnosis and intervention for CVI result in cascading developmental delays that are extremely difficult, if not impossible, to remediate later in life. These findings underscore the urgent need for systemic change to prioritize CVI screening and referrals during critical developmental windows.

The NEI has declared CVI a **national emergency** due to its status as the most common cause of visual impairment in children, with rates continuing to climb. NEI researchers stress that failure to address this crisis will result in lifelong developmental, educational, and societal consequences for affected children and their families.

Proposed Legislation

This bill proposes the following:

1. Universal Early Screening:

- Incorporate CVI screening into existing developmental and vision screening protocols for all children under age three, focusing on those with known risk factors such as, but not limited to:
 - Premature birth
 - Neonatal intensive care unit (NICU) stays
 - Neurological injury or infection
 - Low Apgar scores or significant perinatal events
 - Diagnosed genetic or neurological conditions.
 - Seizures
 - Pediatric Stroke

2. Referral and Diagnostic Pathways:

- Require automatic referral to a neuro-ophthalmologist, ophthalmologist, optometrist, neurologist, or developmental pediatrician when CVI risk indicators or functional visual concerns are identified.
- Establish a multidisciplinary CVI diagnostic team consisting of the above specialists along with Teachers of the Visually Impaired (TVIs).

3. Education and Awareness:

- Provide mandatory training for healthcare providers, educators, and early intervention professionals on the updated CVI definitions and screening protocols, as outlined in the *What Is Cerebral/Cortical Visual Impairment and Why Do We Need a New Definition?* article.

4. Data Monitoring and Research:

- Develop a state registry to track diagnosed cases of CVI, outcomes of early interventions, and access to services.
- Fund longitudinal research to assess the efficacy of early screening programs and intervention strategies.

Benefits of Early Screening and Intervention

- 1. Optimized Developmental Outcomes:** Early identification and intervention allow children with CVI to access specialized educational and therapeutic resources tailored to their unique needs.

2. **Reduced Healthcare and Educational Costs:** Addressing CVI early reduces the need for costly remediation, additional supports in schools, and lifelong dependency services.
3. **Equitable Access to Care:** The legislation ensures all children, particularly those in underserved communities, receive equitable opportunities for early diagnosis and intervention.
4. **More Effective Use of Resources:** Currently, many children with CVI are misidentified as having autism or intellectual and developmental disabilities (IDD). As a result, the educational and therapeutic interventions they receive often fail to address their fundamental challenges, including visual access and the lack of concept development stemming from that visual impairment. Without accounting for these critical factors, interventions provide little value, resulting in wasted resources and poor outcomes. Early identification ensures that interventions are targeted at the root cause, making them more effective and cost-efficient.

Alignment with Current Research

The proposed legislation aligns with the most recent and comprehensive guidance on CVI:

- *Ophthalmology*: The call for a standardized working definition and updated diagnostic frameworks underscores the necessity of earlier and broader screening initiatives.
- *Pediatrics*: The recognition of CVI as a distinct and pressing pediatric concern reinforces the urgency of establishing state-level legislation to address gaps in early detection and care.
- **National Eye Institute**: The NEI's declaration of CVI as a national emergency further validates the importance of systemic and immediate intervention to combat this escalating crisis.

Call to Action

Cerebral/Cortical Visual Impairment is not just a medical condition; it is a public health issue requiring immediate attention. Vision is the cornerstone of early learning, and the imperative for **early identification and intervention** is supported by the latest research in *Ophthalmology* and *Pediatrics*, as well as the *National Eye Institute*. These publications emphasize that timely diagnosis allows children to access crucial therapeutic and educational resources when their brains are most capable of adapting and developing. Failure to act results in profound developmental delays, unnecessary mischaracterizations of abilities, and lifelong challenges for children and families alike.

Early screening is a cost-effective, evidence-based intervention that will transform lives and reduce the burden on our education and healthcare systems. Inaction is no longer an option.

We urge policymakers to adopt this proposal and ensure that no child with CVI goes undiagnosed or unsupported during their most critical developmental years.

Issue Description:

Explain how this is a common/frequent issue:

Cerebral/Cortical Visual Impairment (CVI) is increasingly recognized as a leading cause of vision impairment in children, particularly those with complex developmental or neurological conditions. Recent studies in the U.S. and Europe estimate that approximately **1 in 30 children** is affected by CVI, underscoring its prevalence and making it far more common than previously understood. Alarming, the **Child Neurology Foundation** reports that **40% of children in self-contained special education classrooms** have CVI, yet the majority remain undiagnosed. This significant underdiagnosis stems from a lack of routine screening protocols and limited awareness among both medical and educational professionals.

CVI is not only common but also profoundly impactful. Both the **National Center on Deaf-Blindness (NCDB)** and the **American Speech-Language-Hearing Association (ASHA)** identify CVI as the most severe form of visual impairment, critically affecting a child's ability to process and interpret visual information. Children with CVI are at heightened risk for developmental delays that impact learning, communication, socialization, and independence, particularly when left undiagnosed and unsupported. https://www.nationaldb.org/media/doc/Range_of_Combined_Vision_and_Hearing_Loss_in_Deafblindness_a.pdf

This urgent issue demands a systematic approach to early screening and identification. Children with high-risk developmental histories—such as those born prematurely, with neurological conditions, or who have experienced significant perinatal events—should be routinely evaluated for CVI to ensure timely intervention. Without this, educational and therapeutic interventions often miss the root cause, resulting in suboptimal outcomes.

Recognizing this growing need, at least three **Regional Service Centers** have begun bringing in outside experts to provide specific training on CVI, reflecting an emerging but still insufficient effort to address the gap in professional knowledge and intervention strategies. A concerted push for early screening and professional training is essential to reduce underdiagnosis and improve developmental outcomes for children with CVI.

Legislative History:

As of November 2024, there have been no specific legislative mandates in Texas or other U.S. states requiring universal screening for Cerebral/Cortical Visual Impairment (CVI) in infants and toddlers. However, broader legislative efforts have been made to address children's vision health. For instance, in May 2024, the U.S. House of Representatives introduced the Early Detection of Vision Impairment in Children (EDVI) Act, aiming to

establish grants for states and communities to improve children's vision and eye health through coordinated systems of care. I have been in touch with Texas U.S. Rep. Veasey's office about the inclusion of CVI in the bill and the sponsors of the bill have agreed to do so.

[Ophthalmology Times](#)

While this federal initiative underscores the importance of early vision screening, it does not specifically mandate CVI screening.

In Texas, the education code mandates that school districts provide special education services to children with visual impairments, including those with CVI. The Texas School for the Blind and Visually Impaired (TSBVI) has also initiated programs to increase awareness and support for students with CVI.

[Texas Public Law](#)

[Texas School for the Blind](#)

Despite these efforts, there remains a significant gap in early identification and intervention for CVI, highlighting the need for targeted legislation to mandate screening for this specific condition.

As of November 2024, Louisiana has not enacted specific legislation mandating universal screening for Cerebral/Cortical Visual Impairment (CVI) in infants and toddlers. However, the state has taken steps to address CVI through regulatory changes to its educational and health services. The Louisiana Department of Education recognizes CVI as a significant visual impairment and includes it in the eligibility criteria for special education services under the category of visual impairment. Anyone can refer a child for a functional vision assessment based on suspicion of CVI. This inclusion ensures that children diagnosed with CVI have access to appropriate educational support and resources. Additionally, the Louisiana Department of Health provides resources and guidance for healthcare providers to identify and manage CVI in children, aiming to improve early detection and intervention. While these measures address CVI within existing frameworks, there is currently no specific state regulation mandating universal CVI screening for all infants and toddlers. Louisiana also no longer requires a medical diagnosis and permits screenings and evaluations for eligibility under the Individuals with Disabilities Education Act to Teachers for the Visually Impaired.

<https://www.perkins.org/in-louisiana-cvi-activism-ignites-policy-change/>

Explain the feasibility of this recommendation:

In proposing mandatory CVI screening, several successes and challenges are anticipated. The fact that many children with CVI are already receiving special education services—albeit often under the wrong eligibility classification and significantly delayed access to the Expanded Core Curriculum, the state-mandated curriculum for blind and visually impaired students—presents both advantages and potential obstacles.

Anticipated Successes

1. **Optimizing Educational Resources by Addressing Misaligned Strategies:** Many children with undiagnosed CVI are currently served in Early Childhood Intervention or special education under classifications that don't accurately reflect their visual needs. This misclassification leads to therapeutic and educational resources being spent on interventions that may not align with the child's challenges, possibly exacerbating the manifestations of the disability, thus limiting their progress. By identifying CVI accurately and realigning eligibility, therapeutic and educational teams can employ targeted, CVI-specific strategies, such as tailored visual supports and appropriate communication aids. This can optimize existing resources and improve outcomes without necessarily adding new costs. Instead of increasing budgets, it would mean reallocating resources to more effective approaches, providing a compelling argument for cost-neutral benefits.
2. **Broad Support from Stakeholders:** Given the prevalence of CVI and its underdiagnosis, many stakeholders—such as healthcare providers, educational organizations, advocacy groups, and parents—are likely to support early screening. Advocates for children's rights, special education, and vision health may unite to champion the proposal, creating a solid foundation of support.
3. **Alignment with Research and Improved Outcomes:** Growing awareness and data on CVI's impact strengthen the case for early intervention, making the proposal compelling. Data-driven advocacy can help illustrate how early identification and intervention lead to better developmental, social, and educational outcomes, which appeals to evidence-focused legislators.
4. **Potential for State and Federal Collaboration:** With recent federal attention to early vision screening through initiatives like the EDVI Act, Texas could serve as a model for state-level CVI screening. Demonstrating success in Texas could encourage broader adoption nationwide and pave the way for future federal policies.

Anticipated Difficulties

1. **Resource and Funding Concerns:** While reclassifying eligibility may optimize resources, some legislators may view initial costs related to retraining, specialized tools, and IEP updates as a budget strain rather than a reallocation. Securing sustainable funding and demonstrating the cost-effectiveness of this shift will be key to addressing concerns about additional expenditures.
2. **Resistance from Educational and Medical Institutions:** Although many professionals may support CVI screening, some schools and healthcare providers may see it as an added burden. Shifting approaches and training staff to implement new strategies may require time and effort, although screening is not arduous and is being successfully piloted in Pittsburgh, PA and New Mexico. This initial hesitancy can be overcome through educating providers that screening and diagnosis is, in fact, a fairly simple process once awareness of CVI is known.
3. **Public Awareness and Misunderstanding of CVI:** CVI is still not widely recognized outside specialized fields. Clear, accessible information on CVI and its developmental impact will be essential to garnering support from legislators, educators, and the public, who may be unfamiliar with its specific challenges.

4. **Privacy and Data Management:** Implementing systematic screening requires secure and efficient tracking of results, raising potential concerns around data privacy. Ensuring robust data management practices will be necessary to maintain trust and compliance with privacy standards.

Strategy for Success

To maximize support, this proposal should:

- **Emphasize Cost-neutral Benefits:** Highlight how reclassification and targeted strategies can make better use of existing resources, potentially offsetting costs by improving educational alignment.
- **Engage Stakeholders Early:** Involve educators, healthcare providers, and advocacy groups from the outset to gather feedback, build buy-in, and identify practical solutions for implementation.
- **Offer Training and Resources:** Provide a clear plan for training and resources to empower staff to implement screen and identify CVI and CVI strategies effectively without overwhelming existing systems.

List any known cost factors (fiscal note). Show calculations.

☐ Training and Recruitment of Specialists:

- **Teachers of the Visually Impaired (TVIs):** Recruiting and training additional TVIs who are skilled in CVI-specific strategies will be essential. CVI often requires unique teaching methods, so specialized training programs will be necessary.
- **Orientation and Mobility Specialists (O&M Specialists):** Many children with CVI need support in navigating their environments. Recruiting and training more O&M specialists skilled in CVI support would help meet this need.

☐ Development and Implementation of Training Programs:

- **Initial and Ongoing Training for Existing Staff:** Current TVIs, O&M specialists, and general educators would need comprehensive training in recognizing CVI signs and implementing effective strategies.
- **Professional Development for Healthcare Providers:** Training pediatricians, neurologists, ophthalmologists, and optometrists in CVI identification can improve early detection, which may require dedicated workshops, certification programs, or online modules.

□ **Screening Tools and Equipment:**

- **Acquisition of Screening Tools and Training:** Some screening tools may need to be procured for healthcare providers or early childhood programs, potentially incurring costs for initial setup and training, but this is minimal.

□ **Data Management and Tracking Systems:**

- **Development of a Tracking Database:** A secure database to manage screening results, monitor follow-ups, and track CVI diagnoses and interventions would likely be required.
- **Data Privacy and Compliance:** Ensuring compliance with data privacy regulations, particularly for sensitive child health information, may involve additional software and administrative oversight.

□ **Educational Materials and Resources:**

- **CVI-specific Learning Materials:** Costs for CVI-adapted educational materials, such as tactile or high-contrast learning aids, would be necessary for effective intervention.
- **Adaptations for Visual Environment Modifications:** Adjustments to classroom environments to make them CVI-friendly, including lighting modifications, contrast enhancement, and simplified visuals, may require some investment.

□ **Administrative Costs for Policy Implementation:**

- **Oversight and Coordination:** Hiring or assigning coordinators to oversee the rollout of the screening program, manage stakeholder communication, and ensure consistent implementation across districts.
- **Evaluation and Reporting:** Regular program assessments to monitor effectiveness, identify improvements, and report on progress may require additional administrative resources.

However, since most children with CVI already receive early intervention and special education services, reallocating resources to focus on CVI-specific needs is a pragmatic approach that can improve outcomes without significantly increasing costs. The prevalence of CVI justifies a shift toward specialized training for Teachers of the Visually Impaired (TVIs) and Orientation and Mobility (O&M) specialists, aligning existing services with the real needs of this population. By identifying and supporting CVI early, schools can maximize the effectiveness of their special education resources, improve developmental outcomes, and potentially reduce the need for more intensive interventions down the road.

1. **Reallocation of Existing Resources:** Since children with CVI are already receiving special education services, redirecting these resources to target CVI-specific needs may not require significant new funding. These children often have educational or therapeutic interventions in place, but they may be ineffective if not adapted to address CVI directly. By investing in specialized training for TVIs and O&M

specialists, schools can enhance the effectiveness of existing services without substantially increasing overall costs.

2. **Prevalence and Justified Demand:** The high prevalence of CVI, coupled with conservative estimates that 1 in 30 children is affected, underscores the need for more specialized services. The prevalence rate suggests that CVI is a substantial portion of the visually impaired student population, justifying the training of more specialists to meet this demand effectively. In other words, given the number of children who need CVI-specific support, the additional training represents a necessary adjustment rather than an entirely new expenditure.
3. **Long-term Cost-effectiveness:** Addressing CVI accurately from the outset can be more cost-effective over time. When children receive appropriate support early on, they are more likely to make developmental gains, engage better in the classroom, and achieve independence in daily tasks. This reduces the need for costly interventions later, when delays or developmental gaps may have widened due to inadequate support.
4. **Increased Efficiency through Targeted Approaches:** Correctly identifying and supporting children with CVI can improve the allocation of special education resources across the board. Instead of applying generalized or less-effective strategies, teachers and specialists can focus on proven CVI-specific approaches, increasing the efficiency and impact of their work with each child.

Link to additional information:

The National Institutes of Health and the National Eye Institute has identified CVI as a national health crisis resulting in CVI being prominently included in their strategic plans. The Child Neurology Foundation as well as the Journal of the American Academy of Pediatric Ophthalmology and Strabismus has published many research-based articles on CVI as well as other reputable medical journals. The EDVI Act is including CVI specifically in its early detection and identification efforts at the federal level. There have also been numerous news articles on the rise in CVI:

Recent articles in major ophthalmology journal: Special Commentary: Cerebral/Cortical Visual Impairment Working Definition [https://www.aaojournal.org/article/S0161-6420\(24\)00565-7/fulltext](https://www.aaojournal.org/article/S0161-6420(24)00565-7/fulltext)

Recent Article: What Is Cerebral/Cortical Visual Impairment and Why Do We Need a New Definition? [https://www.aaojournal.org/article/S0161-6420\(24\)00559-1/fulltext](https://www.aaojournal.org/article/S0161-6420(24)00559-1/fulltext)

Recent Report about CVI in a major pediatrics journal: <https://publications.aap.org/pediatrics/article/doi/10.1542/peds.2024-068465/199942/Diagnosis-and-Care-of-Children-With-Cerebral>

<https://www.opthalmologytimes.com/view/advancing-cvi-research-nei-initiative-and-multidisciplinary-collaboration>

<https://www.opthalmologytimes.com/view/cvi-moving-past-the-eyes-and-into-the-brain>

<https://cviscotland.org/news/newsletter-30-cvi-prevalence-cvi-project-findings--31-03-2021>

<https://www.perkins.org/in-louisiana-cvi-activism-ignites-policy-change/>

<https://focus.masseyeandear.org/blindness-brain-explaining-cvi/>

<https://www.nei.nih.gov/sites/default/files/2021-10/NEI-StrategicPlan-ExecutiveSummary-508c.pdf>

<https://merabetlab.meei.harvard.edu/national-eye-institute-releases-new-strategic-plan-cvi-identified-as-a-top-priority/>

State agency(ies) affected by proposal:

- Texas Education Agency
- Local Education Agencies
- Texas Health and Human Services
- The Blind Children's Program

Stakeholder groups likely to support this proposal:

- Families of Children with developmental histories of pre-term or neurological insults
- Teachers
- Medical professionals

Stakeholder groups likely to oppose this proposal:

- Honestly, I do not know as these children are here and I would imagine that LEAs want the help and support
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Describe how affected groups will be impacted by proposed solution(s) (i.e., cities, counties, businesses, employers, etc.):

The proposed solutions for systematic early screening, referral, and intervention for Cerebral/Cortical Visual Impairment (CVI) will have far-reaching benefits for a wide range of affected groups, including cities, counties, businesses, employers, and educational systems:

Cities and Counties

- **Improved Public Health Outcomes:** Early identification and intervention will lead to better developmental outcomes for children with CVI, reducing the long-term burden on local health systems and public assistance programs.
- **Enhanced Education Systems:** Schools will receive better-prepared students whose needs have been accurately identified, reducing the strain on special education programs. Counties will see cost savings through more effective allocation of resources to appropriately tailored educational and therapeutic interventions.
- **Reduced Community Costs:** By addressing CVI early, families and communities will experience less demand for emergency interventions and crisis management in

educational and social service settings, leading to more stable and productive community environments.

Educational Institutions

- **Accurate Identification of Needs:** Schools will be able to identify students with CVI earlier, leading to the development of individualized education programs (IEPs) and 504 plans that are more closely aligned with students' actual needs.
- **Cost-Effective Interventions:** Early intervention reduces the need for more intensive and costly supports later, as students with CVI who receive appropriate therapies are better equipped to access and succeed in their education.
- **Specialized Training for Educators:** Professional development and CVI-specific training will empower educators to effectively teach students with visual processing challenges, fostering more inclusive classrooms.

Businesses and Employers

- **Workforce Development:** Long-term, the proposal will contribute to a workforce that includes individuals with CVI who have received adequate support to reach their potential, reducing dependency on disability-related benefits and increasing employment opportunities.
- **Decreased Caregiver Burden:** Parents and caregivers of children with CVI who receive appropriate interventions are less likely to experience the financial and emotional strain associated with managing undiagnosed or misdiagnosed conditions. This allows them to maintain stable employment and contribute to the economy.

Healthcare Providers

- **Streamlined Referrals and Diagnoses:** Providers will benefit from clear screening protocols and pathways to specialists, such as neuro-ophthalmologists and developmental pediatricians. This will enhance care coordination and reduce diagnostic confusion.
- **Professional Development Opportunities:** Increased training on CVI for medical professionals will ensure accurate diagnoses and early referrals, improving the quality of patient care and outcomes.

Families and Communities

- **Empowered Families:** Parents of children with CVI will gain access to timely diagnoses and tailored resources, improving their ability to advocate for and support their children effectively.
- **Stronger Communities:** As children with CVI achieve better developmental outcomes, communities will benefit from their increased ability to participate in social, educational, and eventually professional settings, creating more inclusive and equitable environments.

Overall Economic Impact

Investing in early screening and intervention reduces long-term costs for public health systems, special education programs, and social services. It shifts resources toward preventative measures, yielding significant savings for taxpayers and contributing to a healthier, more productive society. This proactive approach will lead to measurable improvements in quality of life for affected individuals and their families while creating a more inclusive, equitable system that benefits all stakeholders.

The policy proposal will require a change in:

Administrative Policy ☒ **Agency Rule** ☒ **State Law** ☒

New Law ☒ **Other (e.g. public awareness campaign, etc.)** ☒

Link: If it requires a change in agency rule or state law, link to the rule or law.

Identify GCPD Issue Area(s) affected:

Access☒ **Communications**☒ **Criminal Justice**☐ **Education**☒ **Emergency**

Management☒ **Employment**☐ **Health**☒ **Housing**☐ **Transportation**☒ **Veterans**

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Contact:

Mara LaViola, Parent and Board Member of Texas Parent to Parent

If GCPD adopts this policy, do you commit to directly supporting this proposal through the legislative session? Yes

Recommended for GCPD policy recommendations: Yes ☐ No ☐

MOTION: GCPD staff use only