Early Detection of Vision Impairments in Children Act (EDVI) Partner and Advocate Toolkit







The **Early Detection of Vision Impairments in Children Act (EDVI)** will establish state based EDVI programs across the United States that foster coordinated systems of care for children's vision and eye health. This legislation would create the first federal program that specifically addresses children's vision and eye health in the United States.

Prevent Blindness thanks our partners and advocates for their dedicated efforts in support of advancing children's vision and eye health in the United States and has put together this toolkit for use in organizational and individual grassroots advocacy to advance the EDVI Act. Please also visit the EDVI Act website for additional information, including downloadable fact sheets and resources.

Note: For the most recent version and legislative text of the EDVI Act, please visit congress.gov.

TABLE OF CONTENTS

| Background and Key Points | Page 2 |
|---|---------|
| Problem Statement | Page 2 |
| Summary of the Legislation | Page 3 |
| Section-by-Section Legislative Summary | Page 3 |
| Advocate Talking Points | Page 6 |
| Social Media Messaging, Tools, and Graphics | Page 7 |
| Advocacy Resources for Organizations: Call to Action Template for Newsletters and Letter of Support Template | Page 10 |
| Additional Resources on Children's Vision and Eye Health | Page 12 |



Background and Key Points

On May 14, 2024, Congressional Vision Caucus Co-Chairs Representatives Gus Bilirakis (R-FL-12) and Marc Veasey (D-TX-33) introduced the Early Detection of Vision Impairments in Children (EDVI) Act of 2024. This legislation seeks to create the first federal public health program dedicated to addressing children's vision and eye health through grant-based funding to states and establishing a national technical assistance center.

The goal of the EDVI Act is to ensure that every child with a possible vision problem is identified and connected to appropriate eye care, to support early childhood professionals, health care providers, public health professionals, and families with updated and evidence-based vision screening methods and established referrals to care, and advance follow-up protocols to ensure that children who need eye care treatment receive it before a vision problem leads to potential vision loss.

The EDVI Act is endorsed by the following organizations: American Academy of Ophthalmology, American Academy of Optometry, American Association of Pediatric Ophthalmology and Strabismus, American Optometric Association, American Society of Ophthalmic Registered Nurses, Association of Clinicians for the Underserved, Association of Maternal and Child Health Programs, Children's Vision Equity Alliance, Family Voices, Healthy Schools Campaign, National Alliance for Eye and Vision Research, National Association of School Nurses, and the School-Based Health Alliance, among others.

If your organization would like to endorse the EDVI Act, please contact Sara Brown, Director of Government Affairs, at sbrown@preventblindness.org.

Problem Statement

Vision and eye health are essential to physiological and psychological aspects of childhood development, including motor skill development, hand-eye coordination, cognition, and socialemotional well-being. Students with unaddressed vision disorders may fall behind in school, exhibit behavioral disorders in the classroom, and fall behind in reaching developmental milestones. A child's vision is not fully developed at birth and changes throughout the childhood years. Thus, consistent evaluation, referral to care, diagnosis, treatment, and follow-up after care are necessary to ensure possible vision problems are caught and treated before progressing to permanent vision loss.

However, there is currently no national-level children's vision and eye health program in place that supports these interventions. Unlike many aspects of children's health, our nation lacks a concerted public health approach to children's vision and eye health. Thus, many children are not receiving timely and needed eye care for vision problems. Failure to treat vision problems can, in the short term, impede academic progress and development and, in the long term, lead to permanent vision impairment or blindness that follows them into adulthood.

Complicating the matter, professional guidelines and state laws can vary widely in approaches and protocols and be outdated. Activities to improve surveillance, vision screening and referral practices, access to professional eye care, and coordination with the child's medical home are critical steps for improving children's vision and eye health. However, many states and communities lack the

resources to carry out these activities or conduct surveillance needed to identify and address disparities in eye care access.

Children's vision and eye health <u>must</u> become a national priority to ensure that children grow up with the healthiest vision possible and realize their full potential across their lifetime. The EDVI Act will establish the first federal program to *specifically* address children's vision and eye health; thus, signifying a national commitment to improving vision and eye health access and outcomes in children and youth.

Summary of the Legislation

The EDVI Act authorizes the <u>Health Resources and Services Administration (HRSA)</u> at the U.S. Department of Health and Human Services (HHS) to award grants and cooperative agreements for states, communities, and tribes issued through a competitive grant process for purposes of:

- Implementing early detection practices (such as vision screenings) and intervention initiatives for the purpose of identifying vision concerns in children, to promote referrals for eye care, and establish follow-up mechanisms to ensure care was received,
- Raising awareness to the public of the importance of vision and eye heath in children,
- Reducing disparities in eye health, and/or
- Developing state-based data collection, surveillance, and performance improvement systems.

The EDVI Act also makes resources available through the <u>Centers for Disease Control and Prevention</u> (CDC) to establish a national level technical assistance center to provide guidance to any state or community implementing, updating, or improving children's vision programs, to promote surveillance, and to advance population health research priorities in children's vision. The EDVI Act also encourages collaboration across various agencies under HHS and with the U.S. Department of Education—a key step to ensure that children's vision and eye health resources are broadly addressed to improve academic outcomes.

Section by Section Legislative Summary

The following is meant to provide an overview of each section. For the most recent text of the legislation and other official legislative documents, please refer to <u>congress.gov</u>. For a downloadable section-by-section summary and other bill materials, please visit the <u>EDVI Act website</u>.

| EARLY DETECTION OF VISION IMPAIRMENTS IN CHILDREN ACT (EDVI Act) | |
|--|---|
| IN GENERAL. | Amends the Public Health Service Act to improve children's vision and eye health through grants to states, territories, and Tribal organizations and the provision of technical assistance. |
| SECTION 1. Short Title | Names the legislation as the "Early Detection of Vision Impairments for Children Act of 2024." |

| SECTION 2. Statewide early vision detection and intervention programs and systems related to children's vision and eye health | Amends Part Q of Title III of the Public Health Service Act (42 U.S.C. 280 et seq.) with addition of: "Sec. 399Z-3. Statewide early vision detection and intervention programs and systems related to children's vision and eye health." |
|---|---|
| SECTION 2 (a)(1). Grants or Cooperative Agreements | Authorizes the Secretary of Health and Human Services, acting through the Administrator of the Health Resources and Services Administration, to make available awards of grants or cooperative agreements to eligible entities to develop and implement statewide early detection and intervention programs and systems related to children's vision and eye health. |
| SECTION 2 (a)(2). Eligibility | Establishes that, to receive a grant or cooperative agreement as authorized under Section 2(a)(1), an entity shall be a state, territory, Indian tribe or Tribal organization, or Urban Indian organization including a state or community department of children and families, health or public health, or a state educational agency and shall apply. |
| SECTION 2 (a)(3). Use of Awards | Outlines that amount provided through grants or cooperative agreements shall be used for three or more of the following activities: Implementing early detection practices (such as vision screening) and intervention initiatives for the purpose of identifying vision concerns in children as they engage in the medical, home, public educational, or early learning setting, promoting referrals to eye care, and promoting the use of evidence-based and age-appropriate standards guided by nationally recognized and uniform guidelines. Developing an integrated approach to state-level data collection and management to advance state-based performance improvement systems and uniform children's vision and eye health guidelines across relevant and appropriate state-level jurisdictions. Identifying strategies to improve eye health outcomes, expand access to care, and reduce health disparities for the detection, diagnosis, and treatment of ocular disease and eye conditions in children who experience barriers to eye care from rural and underserved populations. Raising awareness by providing the public, including families, guardians (permanent, legal, or temporary), family or community caregivers, and early learning settings with children's vision and eye health information that is accurate, accessible, culturally and |

| | linguistically competent, comprehensive, up-to-date, and evidence-based or evidence-informed. Establishing a coordinated public health system for vision care and eye health, including early detection, referral to eye care, diagnosis and intervention, and follow-up for children. Providing referrals to wrap-around vision services, as necessary, for a future of independent living. |
|---|--|
| SECTION 2 (a)(4). Collaboration with Necessary Community and State Partners | Provides that an eligible entity that receives amounts shall, for the purpose of program and policy development, collaboration, and improvement, consult necessary community and state partners, including state agencies responsible for the administration of title V of Social Security Act (the Maternal and Child Health Block Grant Program), title XIX of such Act (the Medicaid Early Periodic Screening, Diagnosis, and Treatment Program), title XXI of such Act (the State Children's Health Insurance Program), and parts B and C of the Individuals with Disabilities Education Act, the Indian Health Service, and consumer groups. |
| SECTION 2 (a)(5). Evaluation and Report | Instructs that the eligible entity having received an award or grant shall submit an annual report to the Secretary describing activities carried out with award during the period of performance including outcomes of such activities, and a demonstration of whether funding recipients have met project goals. These reports shall be publicly available. |
| SECTION 2 (b)(1) Technical Assistance | Technical assistance shall be provided to states, territories, and Tribal organizations. |
| SECTION 2 (b)(2) Grants | The Secretary, acting through the Centers for Disease Control and Prevention, shall award grants or cooperative agreements to provide technical assistance to eligible entities to: Develop, maintain, and improve data collection systems related to children's vision screening, evaluation, diagnosis, and intervention services, Disseminate information for stakeholders, including states and local governments, Indian Tribes, Tribal organizations, Urban Indian organizations, public health departments, and nonprofit organizations, to launch effective strategies and interventions in preventing and treating childhood vision disorders, Conduct applied research related to early vision screening and intervention programs and outcomes, Ensure quality monitoring of vision screening, evaluation, and intervention programs and systems; and |

| | Assist eligible entities in coordinating on best practices and maintaining national goals related to vision and eye health. |
|---|---|
| SECTION 2 (b)(3) Evaluation | An entity, having received an award or contract, shall within 4 years after enactment of the Act evaluate activities conducted and submit a report to the Secretary on outcomes, costs, and program effectiveness and other information as requested by the Secretary. This report will also be submitted to Congress. |
| SECTION 2 (b)(4) Eligibility | Establishes the eligibility criteria for an entity to receive a grant or cooperative agreement to carry out technical assistance activities to be a public or nonprofit private organization or institution with expertise, or demonstrated proficiency, in developing systems-based approaches to children's vision and eye health. |
| SECTION 2 (c) Coordination and Consultation | Establishes that the Secretary of HHS shall coordinate with the Health Resources and Services Administration, the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services, the Administration for Communities and Families, the Indian Health Service, and the Department of Education and including stakeholder engagement at federal, state, and tribal levels, the private sector including consumer groups, medical, and other health or education or child-serving nonprofit organizations. |
| SECTION 2 (d) Definitions | Provides definitions for purposes of the Act for Indian Tribe, state educational agency, tribal organization, and urban Indian organization. |
| SECTION 2 (e) Authorization of Appropriations | Authorizes \$5,000,000 for each fiscal years 2025 – 2029 related to grants and cooperative agreements and \$5,000,000 for each fiscal years 2025 – 2029 for activities related to technical assistance. |

Advocate Talking Points

Please use these general talking points in your conversations and meetings with legislators about the EDVI Act.

- The EDVI Act is important bipartisan legislation sponsored by Reps. Gus Bilirakis (R-FL-12) and Marc Veasey (D-TX-33) that would create the first federally funded program to address children's vision and eye health in the United States.
- Despite the presence of numerous public health programs that support early childhood development, including children's hearing and oral health, there is currently no federally funded program in the United States that specifically addresses children's vision or that fosters a cohesive and equitable system of eye health for children.

- Failure to treat childhood vision problems can, in the short term, impede academic progress and development and, in the long term, lead to permanent vision impairment or blindness that follows them into adulthood.
- A child's vision develops and changes from birth through childhood. Because of these changes, a child should be screened regularly, referred to eye care, and receive any needed treatment and follow-up to care to ensure vision problems are caught early and permanent vision loss is avoided.
- The goal of the EDVI Act is to ensure that every child with a potential vision problem is identified and connected to appropriate eye care as early as possible to receive a diagnosis and necessary treatment.
- The EDVI Act will provide grants for states and communities to establish, modernize, or improve state-based programs that foster coordinated systems of care for children's vision and eye health. The EDVI Act also creates a technical assistance center to support states and communities in their efforts to develop systems of care.
- Without early detection and treatment, uncorrected vision disorders in childhood, such as amblyopia (lazy eye), strabismus (crossed eyes), myopia (nearsightedness), or hyperopia (farsightedness), may continue to affect health and well-being throughout a person's life.
- According to the <u>Centers for Disease Control and Prevention</u> (CDC), more than 1 in every 4
 American children (approximately 19.6 million) have a vision problem requiring treatment.
- The EDVI Act models the bipartisan success of the Early Hearing Detection and Intervention (EHDI) program that has drastically increased the rates of screening and referral to care for infants with hearing loss since 1999.
- Passing this important legislation would signify Congress's commitment to preventing
 avoidable blindness and preserving the sight of our nation's children. Children deserve to have
 the best start in life, which begins with ensuring that this important aspect of health is
 adequately addressed.

Social Media Messaging, Tools, and Graphics

Prevent Blindness has prepared the below hashtags, tools, and graphics for personal advocate and organizational partner use. Use the suggested posts in your captions, and please be sure to tag Prevent Blindness in your posts so we can amplify your voices!

Prevent Blindness Websites:

Main Website: PreventBlindness.org

Advocacy Action Center: Advocacy.PreventBlindness.org

o EDVI Act Website: PreventBlindness.org/edvi-act

Prevent Blindness Social Media Accounts:

- X (formerly known as Twitter):
 - o @PBA SavingSight General
 - o <u>@EyesOnCapHill</u> Advocacy and Government Affairs
- Instagram
- Threads
- Facebook
- LinkedIn
- YouTube

Suggested Hashtags: #EDVIAct #SupportTheEDVIAct

Call to Action Link: Advocacy. Prevent Blindness.org/prevent-blindness-legislative-action-center

Find Your Member of Congress or Senator's Social Media Accounts

Advocacy.PreventBlindness.org/prevent-blindness-legislative-action-center/#/legislators

- **Step One:** Click on interested state.
- **Step Two:** Click on the legislator's profile box.
- Step Three: Click on the desired social media account icon.

Note: Not every legislator uses every social media channel available.

Suggested Social Media Posts and Captions

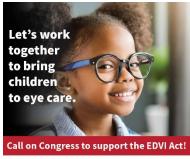
The following suggested posts are a guide for use in posting with social media graphics. Please feel free to customize your own post (such as by adding a vision story) if you prefer. Remember to add the hashtag and include the "Call to Action" link in your post!

- Prevent Blindness is proud to support the introduction of the #EDVIAct. This landmark, bipartisan legislation will establish the first federal program to specifically address children's vision. We call on Congress to #SupportTheEDVIAct and invite advocates to do the same: Advocacy.PreventBlindness.org/prevent-blindness-legislative-action-center
- Prevent Blindness applauds @RepGusBilirakis and @RepVeasey for their bipartisan leadership in introducing the #EDVIAct. Contact your Member of Congress and ask them to support children's vision and eye health: <u>Advocacy.PreventBlindness.org/prevent-blindness-legislative-action-center</u> #SupportTheEDVIAct
- Early detection and intervention of vision problems can help a child avoid preventable vision loss and blindness. The #EDVIAct is an important step in providing children with the services and eye health care they need and deserve. PreventBlindness.org/edvi-act #SupportTheEDVIAct
- Did you know that there is no specific federal program that addresses children's vision and eye health? The #EDVIAct is bipartisan legislation that seeks to change that. Learn more and act today to help pass this important bill! <u>Advocacy.PreventBlindness.org/prevent-blindnesslegislative-action-center</u>

- The #EDVIAct would establish the first federal program to address children's vision and eye health. Without it, children face numerous challenges accessing the vision and eve health services they need to thrive. Contact your Member of Congress and ask them to #SupportTheEDVIAct: Advocacy.PreventBlindness.org/prevent-blindness-legislative-actioncenter
- The path to eye care for children is not always clear. The #EDVIAct promotes a system of care—including early detection (such as vision screening), referral to eye care, diagnosis, treatment, and follow-up to care—that ensures that childhood vision problems are caught and treated before progressing to unnecessary permanent vision loss. Learn more here: PreventBlindness.org/edvi-act
- The #EDVIAct creates resources for states and communities to use to improve children's vision and eye health. Congress can pass the #EDVIAct to help ensure children have access to sight-saving eye care. Here's how you can help: Advocacy. PreventBlindness.org/preventblindness-legislative-action-center

Downloadable and Shareable Graphics

Graphics are available for use in social media posts, newsletters, or adding to your website to help drive support for the EDVI Act. Use the suggested posts and captions and tag Prevent Blindness with the appropriate hashtags and Call to Action link! Download at: Advocacy. Prevent Blindness.org/edviact-social-media-toolkit/





PreventBlindness.org/edvi-act





PreventBlindness.org/edvi-act



PreventBlindness.org/edvi-act

Web Sticker

Add this web sticker to your personal website or to your organization's website, which will direct those interested in learning more about the EDVI Act or taking action to the Prevent Blindness Legislative Action Center. Simply copy the code below **AS IS** and embed it on your website.

• Note: Do not modify the code below or it may not function properly on your site!

<script type="text/javascript" src="//www.congressweb.com/webstickers/js/jquery.min.js"></script>
<script type="text/javascript"</pre>

src="//www.congressweb.com/webstickers/js/iframeResizer.min.js"></script>

<iframe id="congressweb_websticker_Custom_710A8679-A051-F7B5-4D14F3258E1D9A7A"
src="//www.congressweb.com/webstickers/index.cfm?action=getStickerHTML&publicAccountId=BDD
FBC37-D53A-4C9B-A38FE1300EB37FA0&webstickerId=710A8679-A051-F7B5-</pre>

4D14F3258E1D9A7A&siteId=preventblindness" frameborder="0" width="100%" scrolling="no"></iframe>

<script type="text/javascript">\$cwebwebstickers('#congressweb_websticker_Custom_710A8679-A051-F7B5-4D14F3258E1D9A7A').iFrameResize();/script>

Advocacy Resources for Organizations

Organizational Letter of Support Templates

These letter templates can be customized to reflect your organization's and/or its membership's priorities and support for the EDVI Act. Please cut+copy+paste the below text onto your organization's letterhead and replace the HIGHLIGHTED items with the pertinent information.

• Note: There are active web-based links in the text below that are used for references. Be sure they carry over into your letter.

DATE

The Honorable Gus Bilirakis U.S. House of Representatives 2227 Rayburn House Office Building Washington, DC 20515 The Honorable Marc Veasey U.S. House of Representatives 2348 Rayburn House Office Building Washington, DC 20515

Dear Representatives Bilirakis and Veasey:

On behalf of ORGANIZATION NAME, I write to express strong support for H.R. xxxx, the Early Detection of Vision Impairments in Children (EDVI) Act of 2024. ORGANIZATION thanks you for your leadership on this important legislation to establish a first-of-its-kind federal program that will specifically address children's vision and eye health, and we encourage you to work with your colleagues to swiftly pass this important bill.

The goal of the EDVI Act is to ensure that every child with a possible vision problem is identified and connected to appropriate eye care, to support early childhood professionals, health care providers, and families with updated and evidence-based vision screening methods and established referrals to

care, and advance follow-up protocols to ensure that children who need eye care treatment receive it before a vision problem leads to potential vision loss.

According to the National Center for Children's Vision and Eye Health, children across the United States face disparate levels of access to eye care due to the significant variety of state- and community-based approaches to children's vision and eye health. Several long-standing, federal-level public health programs address various aspects of a child's health, development, and well-beingincluding oral and hearing care—through funding for states, technical assistance, professional development and training, stakeholder collaboration, and public engagement. However, no such federal program exists for children's vision and eye health, even as early detection and intervention for vision disorders in children are part of national goals and health care standards. Without the EDVI Act, states and communities—and ultimately children and families—will continue to lack the resources to maintain eye health in children.

OPTIONAL - INSERT A FEW SENTENCES ABOUT HOW THE EDVI ACT WILL BENEFIT YOUR **ORGANIZATION AND/OR YOUR MEMBERS.1**

The EDVI Act models the bipartisan success of the Early Hearing Detection and Intervention (EHDI) program that has drastically increased the rates of screening and referral to care for infants with hearing loss since 1999. Like the EHDI program, the EDVI Act will provide states and communities with the necessary resources to integrate vision and eye health into ongoing programs and systems of care that already address other aspects of children's physical, behavioral, and sensory health in places such as early learning, school-based, public health, and community-based health settings. ORGANIZATION believes that this is the right approach to model for children's vision and eye health, and we look forward to working with you to advance this critical legislation.

If you or a member of your staff have any questions, please don't hesitate to contact ORGANIZATION'S CONTACT NAME/ TITLE/ EMAIL ADDRESS AND/OR PHONE NUMBER.

Sincerely,

NAME OF ORGANIZATION CONTACT

Call to Action Template for Newsletters, Blog Posts, and Member Updates

The following text can be customized and used to input into your organization's newsletters, blog posts, or member updates to inform about your organization's support of the EDVI Act and to direct those interested to more information about the legislation.

ORGANIZATION has proudly endorsed the Early Detection of Vision Impairments in Children (EDVI) Act of 2024. This bipartisan legislation, introduced in the U.S. House of Representatives on May 14, 2024, is led by Congressional Vision Caucus Co-Chairs Rep. Gus Bilirakis (R-FL-12) and Rep. Marc Veasey (D-TX-33). This legislation seeks to create the first federal public health program dedicated to addressing children's vision and eye health through grant-based funding and technical assistance for states and communities.

The goal of the EDVI Act is to ensure that every child with a possible vision problem is identified and connected to appropriate eye care, to support early childhood professionals, health care providers, and families with updated and evidence-based vision screening methods and established referrals to care, and advance follow-up protocols to ensure that children who need eye care treatment receive it before a vision problem leads to potential vision loss.

ORGANIZATION and Prevent Blindness are asking the public to show support for the EDVI Act and its goal of supporting children's vision and eye health by contacting their members of Congress and asking for their support of the EDVI Act. Individuals can contact their Representative in support of the bill by visiting the Prevent Blindness Legislative Action Center.

For more information on the EDVI Act, please visit the Prevent Blindness EDVI website.

Additional Resources on Children's Vision and Eye Health

- National Center for Children's Vision and Eye Health
- Prevent Blindness Eye and Vision Fact Sheets
- **EDVI Act Website and Resources** www.PreventBlindness.org/edvi-act
 - o EDVI Act Frequently Asked Questions, Summary, and Issue Briefs
 - Children's Vision and Eye Health State-Based Fact Sheets
 - 50 fact sheets containing the most up-to-date information on children's vision and eye health in your state.
 - Prevent Blindness Legislative Action Center