

Jeremy Thiesfeldt

STATE REPRESENTATIVE • 52nd ASSEMBLY DISTRICT

Testimony on Assembly Bill 490
The Registry for Babies and Toddlers who are Blind or Visually Impaired Bill
Assembly Committee on Health

Good morning, Chairman Sanfelippo and Honored Members of the Committee. Thank you for holding a hearing today on Assembly Bill 490, a bill which creates a registry for babies and toddlers who are blind or visually impaired.

Assembly Bill 490 was requested by, and we have been working with, Vision Forward Association, a non-profit agency that serves Wisconsin children with visual impairments. Vision Forward specializes in children 0-3 years old who are born blind and visually impaired. Research has shown that up to 90% of what children learn in their first three years of life is acquired visually. Often, parents are so overwhelmed in taking care of a new baby that they don't even know that services exist. There is also amazing work that, if done as soon as possible for infants, can help them immensely for the rest of their lives.

The registry created in AB 490 will connect parents with these life-altering services. This will allow non-profit organizations such as Vision forward to reach out to these parents, who can then have access to these vital resources for their children. The registry is opt-in, so that parents can have the choice to put their children on the registry.

After me, you will be hearing from two non-profit organizations who serve these precious children. You will also hear from parents, and you have some great written testimony from those who couldn't be here in person, including testimony from Dr. Deborah Costakos, Chair of the Ophthalmology Department at Children's Hospital/Medical College of Wisconsin.

This bill is supported by Beyond Vision, Vision Forward, the Wisconsin Academy of Ophthalmology, and the Wisconsin Council of the Blind and Visually Impaired.

In supporting this bill, you really are supporting the littlest among us. Thank you.



DAN FEYEN

STATE SENATOR

18th Senate District
(608) 266-5300
Sen.Feyen@legis.wi.gov

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<http://legis.wisconsin.gov/senate/18/feyen>

To: The Assembly Committee on Health
From: Sen. Dan Feyen
Re: Assembly Bill 490

Hello members of the committee and thank you for taking the time to hold a public hearing on AB 490.

This bipartisan bill requires the Department of Health Services to create a registry for blind or visually impaired children under the age of three.

The moment a child is diagnosed as blind or visually impaired can be very emotional and chaotic. Oftentimes parents are flooded with information and it is easy to either miss or never learn of the wonderful non-profits that exist to help children and their families. The purpose of this registry is to connect parents to non-profit services they might not otherwise know are available.

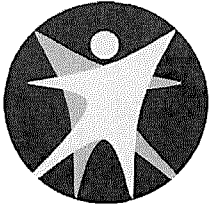
This registry would allow for parents to opt-in, so that they could choose to put their child's name on the list or not. If the parents opt-in, the non-profit organization would reach out to them to inform them on the services and tools provided.

The bill would require physicians, optometrists, or ophthalmologists to notify a parent or guardian of the registry after diagnosing a child with blindness or a visual impairment. Additionally, health care providers or any professional that provides early intervention services would be required to notify a parent or guardian of the existence of the registry.

After opting in, the child's medical provider would submit their information to DHS for inclusion in the registry. The child and their family would then be referred for a functional vision evaluation and also an orientation and mobility assessment if appropriate.

This bill creates a simple, yet, important tool, that will help to connect families with young children who have visual impairments to vital services, ensuring the child receives early intervention services, boosting the child's overall development and future outcomes.

Thank you again for holding a public hearing on this important legislation.



State of Wisconsin
Department of Health Services

Tony Evers, Governor
Karen E. Timberlake, Secretary-Designee

TO: Members of the Senate Committee on Health

FROM: HJ Waukau, Legislative Director Wisconsin Department of Health Services

DATE: January 6, 2022

RE: AB 490, relating to: registry for children with blindness or visual impairment

The Department of Health Services (DHS) would like to submit written testimony for information only on Assembly Bill 490 (AB 490) regarding the creation of a registry for children with blindness or visual impairment. AB 490 would require DHS to establish a registry of children who are under the age of three and are diagnosed with blindness or visual impairment for the purposes of connecting children and their families with visual impairment services provided by nonprofit organizations and reimbursed by DHS. Additionally, DHS would be required to contract with a nonprofit organization that would manage the registry and provide relevant information to parents/guardians about the registry free of charge. Further, participation in the registry would be on an “opt-in” basis. Additional provisions of AB 490 include definitions for visual impairment; requirements for physicians and other health care professionals regarding parental notification and registry information submission; and requirements for referrals to Department of Public Instruction licensed teachers for functional vision evaluations, and their subsequent referrals to services. DHS is continually evaluating how it can improve the coordination of services for the people that we serve and we appreciate feedback we receive from our stakeholders, partners, and members to help us better achieve that goal.

AB 490 would require DHS to create, implement, and contract out the management of a child blindness registry; however, it does not provide any funds or appropriations to do so. At this time DHS is unable to absorb the costs for the creation and management of a new registry under its existing appropriations. Additionally, DHS is unable to append or add child blindness as a reportable condition to an existing registry such as the Birth Defect Prevention and Surveillance System (Wisconsin Birth Defects Registry), without incurring additional costs. The Wisconsin Birth Defects Registry is currently able to carry out its statutory requirements; however, any additional requirements would necessitate additional financial and staffing resources. The Wisconsin Birth Defects Registry is also an “opt-out” registry, which is in conflict with the parameters of AB 490. Further, any additions to the Wisconsin Birth Defects Registry would have to be unanimously approved by the Council on Birth Defect Prevention and Surveillance per Wis. Stat. § 253.12(4)(a).

The parameters and requirements of AB 490 would also interact and overlap with the Wisconsin Birth to 3 Program. The Birth to 3 Program is a federally mandated early intervention special education program that supports the growth and development of children under the age of 3 who have delays or disabilities. Eligibility for the Birth to 3 Program is based on a developmental delay in a specified area such as cognitive development, physical and motor development, speech and language development, social and emotional development, or adaptive development. Evaluation of a child’s developmental capacity is made by parents, health care professionals, professionals trained in child development, and service coordinators. As such, child blindness or visual impairment is an eligible condition to receive services under the Birth to 3 Program.

Once a child's eligibility has been established they can receive services and care coordination from the Birth to 3 Program. The program is managed at the county level by each of Wisconsin's 72 counties. The counties are responsible for coordinating and providing services for eligible children and families, with counties covering 50 percent of the program's costs and DHS covering the other 50 percent. The creation of a child blindness registry under AB 490 for the purposes of referrals and coordination of child blindness services could constitute a duplication of services. Such a relationship is already managed under the Birth to 3 Program which coordinates care and services for children and families with developmental disabilities such as child blindness and visual impairment. On top of creating a potential duplication of services a new registry may also create unnecessary administrative burdens and reporting requirements for the counties who administer the Birth to 3 Program regarding who, where, and how information is being submitted and coordinated. It may also create confusion for the families who utilize the Birth to 3 Program regarding who and where to go to for information and services.

Lastly, the structure of the registry under AB 490 would be somewhat unique relative to existing registries. Many of the registries administered by DHS such as the Wisconsin Immunization Registry and Wisconsin Birth Defects Registry, are "opt-out" registries. Some significant reasons for the opt-out construction of registries is that it reduces administrative burden, results in better data, and allows for better coordination of services. The child blindness registry under AB 490 would be "opt-in," and as a result may not achieve the desired intent of improving coordination of care for children with blindness or visual impairment. Additionally, AB 490 would require DHS to contract out the management of the child blindness registry after it is created by DHS. It is unclear under AB 490 how such an arrangement would be administered. Typically, DHS would submit a request for proposal and choose the most appropriate vendor to create and administer the registry. Alternately, DHS has also created data use agreements with contracted entities whereby DHS sends specified data to a contracted entity and then the entity would create and administer a database. Conversely, the contractual relationship specified under AB 490 is vague as to how such a unique relationship would function and exist.

DHS is committed to improving the coordination of services for the members that it serves and offers itself as resource and a partner for how that goal can be achieved. DHS thanks the Committee for the opportunity to provide written testimony for information only and is happy to address any questions, comments, or follow up the Committee may have.

Wisconsin Needs a Registry for Children Who are Blind or Visually Impaired

AB 490/SB 467

For over 100 years, Vision Forward has provided comprehensive services to Wisconsinites with visual impairments, from birth through adulthood. We help individuals achieve important developmental milestones as well as educational, personal, and professional goals. Our programs and services are provided regardless of a person's or family's ability to pay.

Visual impairments have a pervasive impact on the development of children, affecting all areas of growth and progression. Reaching babies and toddlers as early as possible in life is critically important. AB 490/SB 467 establishes a registry that will connect the families of children who have been diagnosed with visual impairments or blindness to agencies specially equipped to provide expert services, resources, and support.

Research demonstrates that as much as 90% of what children learn in the first three years of life is acquired visually.

Early Detection Is Critical

Some conditions can be improved if caught early. Without appropriate prompt interventions, visual impairments can have a devastating impact on a child's development. Babies and toddlers who do not get access to early, skilled services experience:

- Difficulty forming concepts of the world-especially people, objects, and the environment
- Dramatic development delays (social, cognitive, motor, communication)
- A wider gap in literacy skills
- Limited ability to function independently
- Less time in the classroom with typically developing peers

“A lot of families get that initial diagnosis and get stuck because they're scared. It's hard to make that first step to move forward and realize this isn't the end of things for my kid. She'll be able to learn and it's going to be okay.”

-Anna, Mother of Eleanna



How the Registry Would Work

The families of children diagnosed with a visual condition, such as albinism, cataracts, cortical visual impairment, optic atrophy, or retinopathy of prematurity during a comprehensive eye exam will have the opportunity to be entered into an electronic registry created by AB 490/SB 467.

Families will then be connected with a non-profit organization, like Vision Forward Association, who has more than a 100-year history of serving individuals who are blind or visually impaired. The agency will educate the family about available resources, support, and interventions, such as the Birth to 3 program and specialized vision services.

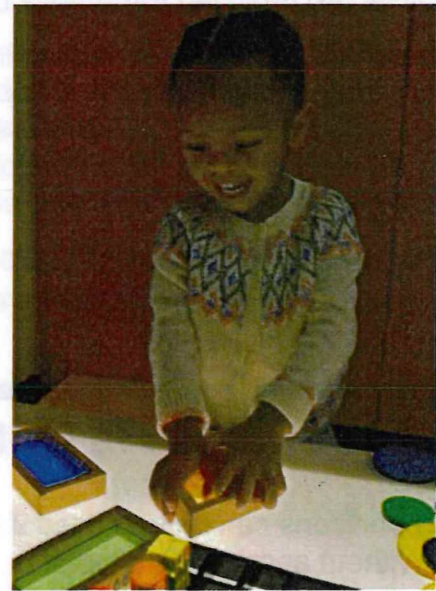
Agencies will also refer families to specialty providers who are trained to provide interventions for children who are blind or visually impaired. This includes teachers of the visually impaired (TVI), orientation and mobility (O&M) specialists, and deaf-blind specialists.

Quality early intervention vision services include:

- Functional vision assessment to fully understand how the child uses his/her vision
- Teaching of concepts typically acquired through vision, including literacy
- Gross and fine motor development, including using a white cane
- Assessment and teaching utilizing all senses
- Adaptation of environments, toys, and learning materials
- Guidance in performing tasks independently like eating and dressing
- Comprehensive family support

The Need for a Registry

- Wisconsin has a registry, Sound Beginnings, for children with hearing impairment, but not one for children with visual impairments
- Blind children deserve to be served by professionals with specialized training
- Thousands of Wisconsin children are blind or visually impaired



“When Naomi started services, we thought she was totally blind. To our surprise she quickly went from not tracking things with her eyes to reaching out for her bottle and turning her head towards the person who was talking to her. A whole new world has opened for her. She’s making such progress and is full of confidence.”

-Jasmine, Mother of Naomi

For more information, contact:

Terri Davis, CEO, Vision Forward
414-615-0102 or tdavis@vision-forward.org



Vision Forward

Association

Jaclyn Borchardt
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Testimony in Support of AB 490

Dear Chairperson Sanfelippo and Members of the Assembly Committee on Health,

Thank you for the opportunity to speak before you this morning. My name is Jaclyn Borchardt and I am the Director of Operations at Vision Forward Association. I am here today to ask for your support of AB 490, to create a registry for babies and toddlers who are blind or visually impaired.

Currently, Wisconsin has a registry program for many other disabilities, including hearing loss. However, children who are blind or who have low vision do not have this same "safety net" and connection point to critical early intervention services. Visual impairments have a pervasive impact on the development of children, affecting all areas of growth and progression. Reaching babies and toddlers as early as possible in life is critically important. Wisconsin is falling behind many other states in our data collection and processes to ensure children get connected to appropriate care. As a result, children who are blind or who have low vision are paying the price and this is increasing disparities in access.

The families of children diagnosed with a visual condition, such as albinism, cataracts, cortical visual impairment, optic atrophy, or retinopathy of prematurity during a comprehensive eye exam will have the opportunity to be entered into an electronic registry created by AB 490. Families will then be connected with a nonprofit organization, like Vision Forward Association, who has more than a 100-year history of serving individuals who are blind or visually impaired. The agency will educate the family about available resources, support, and interventions, such as the Birth to 3 program and specialized vision services. Agencies will also refer families to specialty providers who are trained to provide interventions for children who are blind or visually impaired. This includes Teachers of the Visually Impaired (TVI), orientation and mobility (O&M) specialists, and deaf-blind specialists.

Every day, we hear from families about the difference specialized vision services have made for their child. With skilled and expert services, children who have significant visual impairments can learn about the world, access literacy, and begin to develop critical independent living skills. Unfortunately, almost as often, we hear stories from

families and vision professionals about the devastating effects when children are not connected to these vital services.

Please pass Assembly Bill 490, so that every young child in our state has access to resources, information, and support so that they can get a great start in life.

Thank you for the opportunity to speak before you today. Please do not hesitate to contact me with any questions.

Sincerely,

A handwritten signature in black ink, appearing to read "Jaclyn Borchardt". The signature is fluid and cursive, with the first name "Jaclyn" written in a larger, more prominent script than the last name "Borchardt".

Jaclyn Borchardt



Vision Forward

Association

Testimony in Support of Assembly Bill 490

January 11, 2022

Terri Davis, CEO
Vision Forward Association
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Tdavis@vision-forward.org
414-615-0102

Dear Chairperson Sanfelippo and members of the Assembly Committee on Health,

Thank you for the opportunity to speak before you this morning.

My name is Terri Davis, and I'm the Chief Executive Officer of Vision Forward Association. I'm here today to ask that you pass Assembly Bill 490 for the establishment of a registry for children who are blind or visually impaired.

My organization, Vision Forward, has been providing services for individuals who are blind or visually impaired for 102 years. Our mission is to empower, educate and enhance the lives of individuals impacted by vision loss through all of life's transitions.

Although we serve people of all ages, our programs for infants and toddlers, birth to three years of age, are some of the most important services we provide because as much as 90% of what a child learns in the first three years of life is acquired visually. Our Children's Program offers expert, individualized services to help children at a critical time in their development, providing opportunities for them to maximize their progress and potential.

I would like to ask you to now think about the infants and toddlers you know. This may be your child, grandchild, a neighbor, or friend's baby. If they could not see, how would you teach them to play, interact with their siblings and friends, read a story, eat, or dress themselves?

This bill is very important because it addresses two significant issues:

1) infants and toddlers with vision loss have limited access to critical specialized sensory services and families may not even know what services, support and resources are available; and 2) medical and educational professionals who serve children under age three have very limited access to providers with expertise in vision.

Yet, the reality is that early detection and intervention is vitally important for these children. A lack of skilled early intervention services or a generalist (non-specialized)

approach to serving infants and toddlers with vision loss has serious lifelong ramifications that include developmental delays in speech and language, motor skills, concept development and independence. In addition, some specific disorders have a window of opportunity to help improve visual functioning—if the appropriate services are not provided as early in life as possible, that window of opportunity closes, and improvement in vision and overall development may not occur.

Further, we know that vision impairment can affect all areas of development, and that a well-coordinated and highly skilled interdisciplinary team can prevent a child with vision loss from experiencing additional delays. Hence, the importance of early diagnosis and treatment.

Early intervention vision loss services should be easily accessible to all families with infants and toddlers. Research shows that early identification and appropriate intervention accelerate a child's overall development and lead to better long-term functional outcomes.

Conversely, if vision loss is not treated early and adequately, children will most likely miss out on key elements of motor, language and cognitive development, significantly impacting their ability to learn, be school ready, and develop strong, positive social relationships.

Please pass Assembly Bill 490 so that our youngest and most vulnerable citizens receive access to the vital, high quality, skilled services to which they are entitled.

Thank you for the opportunity to speak before you today. I would be happy to answer any questions.



Terri Davis
CEO Vision Forward



Vision Forward

Association

Colleen Kickbush
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Teacher of the Visually Impaired
Vision Forward Association
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Testimony in Support of AB 490

Dear Chairman Sanfelippo and Members of the Assembly Committee on Health,

Thank you for the opportunity to speak before you this morning. My name is Colleen Kickbush, and I am a Teacher of the Visually Impaired at Vision Forward Association in Milwaukee. My primary responsibilities are conducting Functional Vision Evaluations and providing specialized, educational vision services to infants and toddlers with visual impairments. I am here today to ask for your support of AB 490, to create a registry for children under 3 who are blind or visually impaired.

Imagine yourself as a parent being told by the doctor that your newborn is blind. Life as you know it changes in an instant. What should you do? Where should you even start? These questions and hundreds more invade your mind all at once. And then comes the flood of emotions, including grief and uncertainty.

For some parents these thoughts and emotions go on like this for what seems like an eternity. Beginning the journey but never really moving forward. Stuck in uncertainty without guidance. Through regular pediatrician and ophthalmologist appointments you may eventually hear about providers that can help your child learn to walk or talk. The critical questions are: Do these therapists have experience working with a child who is blind? Who knows how to teach your child essential skills like how to read braille or use a white cane?

These skills, which are unique to children who are blind, need to be taught before a child starts school in order to increase the chances of success for learning alongside sighted peers. Teachers of the Visually Impaired, like me, along with Orientation & Mobility Specialists, are the only professionals specially trained and credentialed to work with children who are blind. There is a learning window for many early skills, and if a child doesn't acquire those skills, the window closes making it very difficult and sometimes impossible for the child to ever gain competency in that area.

It's incomprehensible, but reality, that vision professionals and tools to help babies who are blind exist but may not be accessed until a child who is blind enters school. In my time as a Teacher of the Visually Impaired in the Milwaukee Public Schools, only about

one in five children had received early intervention vision services before starting school.

Now, I want you to imagine a day as a Teacher of the Visually Impaired, walking into the home of 2 ½ -year-old James for an initial evaluation. James is just like most 2-year-olds—spirited and happy. One thing that sets him apart from other children his age, besides his blindness, is that James has almost no access to books or understanding of literacy. His parents are excited to show you the one textured book they own. However, they don't know how to get braille books, much less how to teach James to use his hands to read. You try not to show it, but you are saddened because you know James' peers have dozens of books with bright colorful pictures and letters and words. They know how to hold a book upright and understand that pictures and words have meaning beyond the page. James only enjoys touching the soft textures and pulls his hands back and throws himself into his parents if they try to place his hands. You wish you had met James as a baby instead of at almost 3 because of the negative impact it has had on his development. As the Teacher of the Visually Impaired, you know that James' friends will begin school with a broad understanding of literacy and may even be able to read some words or recognize their name. So, when James and his friends set foot into their first classroom, they are much different. James, a once happy-go-lucky child, is years behind his peers in reading and other literacy skills. Instead of working on sounds and letters, James needs to focus on learning pre-braille, such as touching all textures, book orientation, concept development, and following lines with his fingers, before learning braille letters and finally, years later, learning to read.

Fortunately, with passing AB 490, you, our elected officials, can not only change James' story, but also change the life of every baby who is born blind in the state of Wisconsin. Through this registry, you can immediately connect families with resources and individualized services from a Teacher of the Visually Impaired, positively impacting their journey with vision loss. All you must do is establish this registry to introduce us.

Thank you for the opportunity to speak before you today. Please do not hesitate to contact me with any questions.

Sincerely,

A handwritten signature in black ink that reads "Colleen Kickbush". The signature is fluid and cursive, with a long, sweeping tail on the final letter.

Colleen Kickbush

Braille Copy of Colleen Kickbush's written testimony:

Imagine you are the parent of a baby who is blind. Can you read this? How can you tell if it is upside down or not? How do you teach this to your child? A Teacher of the Visually Impaired can help guide you, and AB 490 starts that journey.

Population Data for Students with Visual Impairments in the United States

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Rachel Anne Schles¹

Abstract

Introduction: The purpose of this study was to determine how many young children and students (birth to 22 years old) were identified with visual impairments and receiving special education services in the United States. Professionals estimate at least 50% of students with visual impairments have additional disabilities and are not identified as having a visual impairments for the purposes of the federal Child Count census; therefore, the differences between Child Count and states' total population counts were explored. **Methods:** A mixed-methods survey was sent to each U.S. state to determine the total population of students with visual impairments (birth to 22 years old) during the 2016–2017 school year. **Results:** The 49 responding states reported an average total population four times greater than the number of students with visual impairments than were documented in Child Count data. Many states had limited or no data on their total population of students with visual impairments. **Discussion:** The findings demonstrate many states are making policy and administrative decisions based on Child Count data not their total population data of students with visual impairments (e.g., planning for 100 students with a primary disability of visual impairments rather than a total population of 405 students with visual impairments). Misuse of Child Count data contributes to underfunding and under-hiring of teachers of students with visual impairments and orientation and mobility instructors. How to address these issues at a systemic level so all students with visual impairments receive appropriate access to resources and quality instruction is also discussed. **Implications for practitioners:** Practitioners can use available population data across states to educate decision makers at local and state levels regarding the differences between Child Count and total population data for students with visual impairments. Statewide vision programs can also circumvent limited data collection programs at the state level by developing their own systems for total population counts of students with visual impairments.

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Keywords

students with visual impairments, Child Count, population data

The Individuals with Disabilities Education Act (IDEA, 2004) outlines how students with disabilities may be categorized to receive special education services. IDEA requires an annual Child Count to document how many students received special education services in each state. Child Count only reports students by their primary disability. For example, if a student is identified with autism and a visual impairment and autism is their primary disability, they are reported as having autism in Child Count. Alternatively, a student with an intellectual disability and visual impairment may be labeled as having multiple disabilities. That student would be reported with multiple disabilities in Child Count. For both students, their visual impairments are not reflected in the data. The accuracy of Child Count data is further confounded by the fact that very small values (<10) are suppressed to protect student confidentiality (Office of Special Education Programs [OSEP], 2016). It is understood that more than 50% of students with visual impairments have multiple disabilities (Erin, 2007; Kapperman & Love, 1999) and that visual impairment is a low-incidence disability that is underreported in Child Count data (Kirchner & Diamant, 1999; Muller, 2006). Therefore, Child Count data are not a reliable source of prevalence data regarding the total number of students with visual impairments in the United States, yet Child Count data are often used as such.

Why labels matter

IDEA recommends students with two or more disabilities be categorized with the multiple disabilities label (except for students who are deafblind; IDEA, 2004). However, some states identify students in

multiple special education categories and students' primary disability label are at the discretion of the Individualized Education Program (IEP) team (e.g., Delaware Administrative Code, 2018). At the national level, Child Count data are primarily collected to gain a general sense of the number of students with disabilities within and across states. At the state and local levels, however, Child Count data are used for several purposes. As a result, there are large-scale implications for state and local planning for services for students with visual impairments based on students' primary disability label. For example, teacher hiring and resource allocation decisions are dependent on Child Count data in many state education agencies (SEAs) and local education agencies (LEAs). It is hypothesized the use of Child Count data exacerbates understaffing of teachers of students with visual impairments across the country. Notably, there is an estimated shortage of 10,000 teachers of students with visual impairments in the United States (Mason & Davidson, 2000; U.S. Department of Education, 2016). However, there may be an even greater identified need if SEAs and LEAs hired or created job opportunities for teachers of students with visual impairments based on the SEAs' and LEAs' total population of students with visual impairments.

Existing population data on students with visual impairments

For the National Agenda in 1995, Kapperman and Love (1999) surveyed states to determine potential discrepancies between Child Count and the total number of students with visual impairments. Although the survey was

technically flawed in its assumption that Child Count and total number of students with visual impairments should be the same number, the data provide some insights. The difference between 1995 (contemporary) Child Count data and survey responses documented a discrepancy of approximately 10,000 students or 40% (24,252 students compared to 34,250 students). Project FORUM also documented substantial differences between states' Child Count and total number of students with visual impairments (e.g., 323 versus 900 students in Colorado and 475 versus 2,000 students in Maryland; Muller, 2006). To date, Project FORUM and Kapperman and Love (1999) are the only available data on the total number of students with visual impairments in the United States. Given the considerable difference in population estimates, updated research is needed to understand students with visual impairments and the needs of the field of visual impairment.

Research questions

Given the limited information on the discrepancies between students with a primary disability of visual impairments and total population of students with visual impairments, the following research questions were asked: (1) Are there differences in the Child Count data and the total number of students being served in each state in the area of visual impairments (i.e., blindness and low vision)? If so, (2) How do the differences between Child Count and the total population of students with visual impairments (regardless of their primary disability) affect states?

METHOD

The survey sample consisted of the 50 United States and Washington, DC (referred to as "51 states" in this report). Targeted statewide information related to the total number of children and youths (birth through 22 years

old) who were eligible for special education services as students with visual impairments at a single point in time during the 2016–2017 school year. The survey asked respondents for the total number of students with visual impairments in their state, regardless of primary disability status.

Data collection occurred from February through June 2018. Survey respondents were solicited from the Council of Schools for the Blind and the National Leadership Consortium on Sensory Disabilities. Additional respondents were identified through the American Printing House (APH) for the Blind's Directory of Ex Officio Trustees and the National Center on Accessible Educational Materials' State Contacts. In approximately five states, potential respondents were not permitted to reply, directing the author to submit a data request to their state department of education. Fourteen states submitted the survey without a follow-up reminder. The remaining 37 states averaged 3.3 follow-up e-mails (range = 1–8). After four e-mails without response, a formal data request was sent to the state's department of education.

Survey instrument. The survey instrument included four main questions. Question 1 asked respondents to confirm their state's Child Count numbers for the 2016–2017 school year. All Child Count data were drawn from the U.S. Department of Education's (2018) website. If respondents believed the Child Count data to be inaccurate, they were asked to provide the correct number of students with visual impairments in their state.

Survey Question 2 consisted of three parts. Question 2A inquired, "During the 2016–2017 school year, how many students in your state were eligible as a student with a visual impairment including blindness as a primary, secondary, or tertiary disability?" Respondents could indicate if their data

represented an exact, estimate, or partial count of students with visual impairments. Question 2B asked respondents to report how many infants and toddlers with visual impairments were in their state. Question 2C asked respondents to share how the data provided were collected and verified.

Survey Questions 3 and 4 were open-ended questions. Question 3 asked whether the difference between Child Count and the total population of students affected planning for or serving students in their state. An optional Question 4 provided an open-ended space to share additional information.

Prior to the survey's release, two experts with a combined 80 years of experience in the field of visual impairment, including experience as state-level administrators, reviewed the survey for clarity and validity. Their feedback was incorporated into the survey prior to release. The survey letter is available from the author upon request.

Data analysis. Descriptive statistics were calculated for the numeric results of survey Questions 1, 2A, and 2B. The open-ended responses for Questions 2C, 3, and 4 were analyzed using *Nvivo* Qualitative Research Software (QSR International, 2014). Qualitative concept coding procedures (Saldaña, 2015) were used to identify common themes across survey questions. When possible, first-round in vivo codes were developed based on survey responses (i.e., using respondents' own words to name each code or theme; Saldaña, 2015). Ultimately, 12 concept codes were developed. The concept codes with definitions are summarized in Table 1 and prioritized by the number of times the code was identified, as this might be an indicator of how universal the topic was throughout the country.

Results

Respondents from 49 states completed surveys; respondents from Montana and Hawaii did not return surveys. Twenty returned surveys required follow-up to clarify responses. Fifteen of the 20 surveys were clarified via follow-up e-mail correspondence, five requests for clarification went without response. Although one survey response was solicited from each state, 43 surveys were completed by a single respondent and six surveys were completed by two respondents. Surveys completed by two respondents did not report overlapping data, since one person reported data for school-aged students and one reported early childhood services or a general special education administrator reported Child Count data while a vision-specific administrator reported total population data.

STUDENT POPULATION DATA

Child Count data. Thirty-nine respondents answered Question 1, with 28 confirming the Child Count data and 11 reporting small differences (range = 1–63 students). Six respondents reported no access to their states' Child Count data. Four respondents reported their states' total number of students with visual impairments rather than confirming the Child Count data, even after being contacted to clarify their response.

Total population data. Thirty-nine respondents provided exact, estimate, or partial counts of the total population of students with visual impairments (see Tables 2 and 3). Seventeen respondents provided an exact count, 14 reported close estimates, and eight provided partial counts due to lack of total population data. Nine respondents indicated they did not have data or left the question

Table 1. Survey response concept codes.

Concept code	Description	Number of surveys referencing code
BIG IMPACT	Difference between Child Count and actual count of students with VI greatly impacts services or planning (including general limitations of Child Count)	11 states
MONEY SOURCE	Sources of funding to support efforts of population counts or services for students	9 states
MISUNDERSTOOD	Misunderstood question based on response or stated that they do not understand Question #3	8 states
DoE versus VI	Disconnect between the department of education and vision services or providers	7 states
MD versus VI (categories)	Issues or concerns about the use of multiple disability versus VI labels and how it impacts planning, services, and identification—also any reference to issues with special education categories or labels	7 states
EI REF	Referral to early intervention (EI) department or specialist to gather EI population counts or estimates	6 states
TVI SHORT	Reference to the TVI shortage and/or personnel planning issues	3 states
DATABASE	Reference to plans of creating a new (or updating current) database system for documenting statewide student population	2 states
LACK MONEY	References to lack of funding or money and impact to population count or services for students	2 states
PRIVACY	Privacy or student confidentiality issues are a barrier to collecting a total population count in the state	2 states
TRANSITION	Importance of total population data (or lack of data) and the impact on or planning for transitioning students (any transition)	2 states
CMA	Cogswell Macy Act reference	1 state

Note. TVI = teachers of students with visual impairments; VI = visual impairments.

blank, and one respondent declined to answer the question due to confidentiality concerns. Table 2 documents states' population data by age-group, with school-age students ranging from 3 to 22 years old. States vary in reporting students eligible for special education services until 21 or 22 years old, so the more inclusive 22 years old was written in the table. In Table 2, Child Count data from OSEP were documented, with the reported total population counts in parentheses when available. The far-right column of Table 2

indicates the magnitude to which the total population of students with visual impairments exceeded Child Count data (calculated by dividing the total population by the Child Count statistic). Table 3 documents reported partial population counts, sources of data, and any additional population data provided by respondents.

Thirty-one states provided an exact, estimate, or partial count of the number of young children with visual impairments (birth to 2 or 3 years old) receiving Part C early

Table 2. 2016–2017 Child Count and total population data for students with visual impairments by state.

State	Early intervention	3–5 years	6–22 years	3–22 years	Comparison of VI Child Count to total population of students with VI
	Total population	Child Count (total population)			
Alabama ^a	96	47 (116)	469 (783)	516 (899)	1.7
Alaska	?	8 (?)	37 (?)	45 (?)	
Arizona ^a	?	107 (256)	494 (1,745)	601 (2,001)	3.3
Arkansas	?	21 (?)	227 (?)	248 (?)	
California ^a	220	227 (?)	3,062 (?)	3,289 (?)	
Colorado ^b	110	46 (110)	271 (970)	317 (1,080)	3.4
Connecticut ^a	55	22 (?)	128 (?)	150 (926)	6.2
Delaware ^a	17	13 (34)	59 (187)	72 (221)	3.1
District of Columbia ^a	11	2 (?)	23 (?)	25 (?)	
Florida ^a	375	106 (301)	1,258 (2,759)	1,364 (3,060)	2.2
Georgia	?	61 (?)	716 (?)	777 (?)	
Hawaii	(NR)	10 (NR)	42 (NR)	52 (NR)	
Idaho ^a	74	7 (?)	82 (?)	89 (413)	4.6
Illinois ^b	?	95 (308)	991 (2,108)	1,086 (2,455)	2.3
Indiana ^a	47	79 (97)	907 (1,176)	986 (1,276)	1.3
Iowa ^b	?	7 (?)	79 (?)	86 (609)	7.1
Kansas ^b	?	15 (24)	197 (392)	212 (416)	2
Kentucky ^a	?	84 (?)	495 (?)	579 (1,609*)	
Louisiana ^a	41	44 (?)	488 (?)	532 (1,072)	2
Maine ^b	24	6 (62)	42 (248)	48 (310)	6.5
Maryland ^b	24	40 (300)	272 (1,480)	312 (1,780)	5.7
Massachusetts ^b	?	52 (?)	565 (?)	617 (4,879)	7.9
Michigan ^a	41	67 (?)	694 (?)	761 (?)	
Minnesota ^b	20	59 (165)	408 (1,284)	467 (1,401)	3
Mississippi ^a	?	27 (42)	329 (514)	356 (556)	1.6
Missouri ^a	29	42 (?)	432 (?)	474 (?)	
Montana	(NR)	10 (NR)	51 (NR)	61 (NR)	
Nebraska ^b	25	Suppressed (77)	214 (718)	Suppressed (795)	3.5 ⁺
Nevada	?	16 (?)	126 (?)	142 (?)	
New Hampshire	?	22 (?)	113 (?)	135 (?)	
New Jersey	?	15 (?)	365 (?)	380 (?)	
New Mexico ^a	59	25 (53)	184 (548)	209 (602)	2.9
New York	?	68 (?)	1,243 (?)	1,311 (?)	

(continued)

Table 2. (continued)

State	Early intervention	3–5 years	6–22 years	3–22 years	Comparison of VI Child Count to total population of students with VI
	Total population	Child Count (total population)			
North Carolina ^a	279	84 (305)	553 (?)	637 (?)	3.6 ⁺
North Dakota	?	2 (?)	48 (?)	50 (?)	
Ohio	?	76 (?)	890 (?)	966 (?)	
Oklahoma	?	61 (?)	579 (?)	640 (?)	
Oregon ^a	70	79 (?)	306 (?)	385 (?)	
Pennsylvania ^a	?	150 (?)	1,109 (1,959)	1,259 (?)	1.6 ⁺
Rhode Island ^b	20	3 (?)	59 (?)	62 (300)	4.8
South Carolina	?	49 (?)	403 (?)	452 (?)	
South Dakota ^b	27	4 (50)	42 (225)	46 (275)	6
Tennessee ^b	25	32 (?)	560 (?)	592 (1,050)	1.8
Texas ^a	411	440 (1,011)	3,028 (7,273)	3,468 (8,284)	2.4
Utah	?	43 (?)	196 (?)	239 (?)	
Vermont ^a	26	2 (50)	18 (224)	20 (274)	13.7
Virginia ^a	?	50 (176)	596 (1,281)	646 (1,457)	2.3
Washington ^b	237	47 (?)	386 (?)	433 (1,686)	3.9
West Virginia	(declined)	42 (declined)	248 (declined)	290 (declined)	
Wisconsin	?	Suppressed (?)	Suppressed (?)	Suppressed (?)	
Wyoming ^b	14	8 (12)	41 (174)	49 (186)	3.8

Note. ? = The total population is unknown; * = Kentucky reported an exact population count of students' birth to 22 years old; + = comparison of Child Count and total population was made with available data (not all students, 3–22 years old). *Suppressed*: OSEP did not report Child Count statistics due to concerns with data. *Declined*: State respondent(s) declined to provide total population data. NR = no response was received from the state; VI = visually impaired.

^aTotal population data represent an exact count. ^bTotal population data represent an estimated count.

Table 3. Partial counts of students with visual impairments and additional information.

State	Partial counts of students with visual impairments			
	Early intervention	3–5 years	6–22 years	3–22 years
Alaska ^a	15	17	114	131
California ^a				5,768
District of Columbia ^b		11	54	65
New Hampshire ^a				397
New Jersey ^b	140	166	1,876	2,042
North Dakota ^b	62	49	125	174
Oklahoma ^c		28	662	690
Texas ^d	5	16	1,363	
Utah ^{b,e}	555	68	351	419
Virginia ^f	164			
Wisconsin ^g		31	447	478

^a American Printing House Census, number of children with legal or functional blindness. New Hampshire reported all children, birth to 22 years old.

^b Number of students directly served by the responding agency.

^c Total number of students with visual impairments since only some local education agencies voluntarily report secondary disabilities.

^d Number of students with 504 plans for vision-related needs in Texas.

^e Total number of children served or consulted with through early intervention vision services during 2016–2017 school year, not all children received ongoing services or identified with a visual impairment.

^f Virginia only reported children receiving early intervention services with visual impairments as a primary disability.

^g State-reported number of students with a primary disability of visual impairments (suppressed in federal reports).

intervention services in their state. Most reported serving children birth to 2-year-old, while Alaska, Louisiana, Rhode Island, Utah, and Washington reported serving children birth to 3-year-old. These data are reported in Tables 2 and 3.

OPEN-ENDED SURVEY QUESTIONS

Data collection for total population counts. Across 37 respondents, six methods were described for collecting total population counts of students with visual

impairments (note: the following is greater than 37 because respondents listed multiple methods). Data collection approaches included: state-maintained (nonvision personnel) IEP system or database (15 states), state-level vision program database (14 states), pairing APH annual census with a total population count (five states), and/or early-intervention specific databases for young children with visual impairments (eight states). The APH annual census accounted for some partial counts (three states). Finally, one respondent noted their

exact total population count was a result of twice annual statewide data collection for full-time-equivalent of the teacher and student populations.

Child Count and total population count differences. Across surveys, the most prevalent response (11 respondents) indicated that the differences between Child Count and the total population significantly affected their ability to support students with visual impairments. All acknowledged the “huge discrepancy” (direct quote, three respondents) between the two values. One respondent called Child Count a “gross underrepresentation of the students served throughout the state with visual impairments.” Three respondents noted that the difference furthered the shortage of teachers of students with visual impairments. One explained, “The Child Count number is significantly smaller, so those that look at teacher shortages and need areas from a state level do not always see that we are running into big issues with filling vacancies.” Survey responses unequivocally indicated Child Count data were treated as a total population count in most states, much to the frustration of those serving students with visual impairments.

The multiple disabilities category was a concern (seven respondents) since many students with visual impairments do not have a primary disability of visual impairment. One respondent observed school districts operated under the assumption that labeling students as having multiple disabilities would result in higher funding than a “visual impairment” label, thus, they labeled the student as having multiple disabilities to receive higher funding.

Disconnect between vision programs and departments of education. A significant disconnect between departments of education and vision services programs or providers was an unanticipated theme across

surveys. One respondent reported that it had been 1.5 years since the state department of education had reached out for data on statewide vision services. Another respondent noted, “Up to this date the state department hasn’t really been involved.” A third respondent expressed concern that students without a primary disability of visual impairment received minimal vision-related services. As a result, addressing the needs of students and LEAs “in a systematic way (with all special education directors) does not happen in meaningful way.”

Additional information. Nine respondents described funding supporting their total population counts or additional funding for students with visual impairments beyond money tied to Child Count or both. Two respondents noted concerns for the lack of funding they receive since their funding is based on Child Count data. Two respondents were in the process of improving statewide vision data collection. Confidentiality concerns regarding the development or release of deidentified, state-level aggregate data on the entire population of students with visual impairments were brought up by two respondents.

STATISTICAL ANALYSIS

States reporting a total population of students with visual impairments were supporting between 1.2 and 13.7 times greater than their number of students reported in Child Count (see Table 2). On average, states were supporting 4.05 times more students with visual impairments than were reported through Child Count during the 2016–2017 school year. Comparison of Child Count data to total population ranged from discrepancies as small as 137 students (Wyoming; 49 versus 186 students) to discrepancies as large as 4,816 students (Texas; 3,468 versus 8,284 students).

A paired *t*-test was conducted to determine whether the differences between Child Count and total population data were statistically significant. Twenty-six states supplied sufficient data for analysis. There was a statistically significant difference ($t = -8.62$, $p < .001$) between Child Count data compared to the total population of students with visual impairments.

Discussion

This study was developed to update available data regarding students with visual impairments and identify how data informs educational decisions and supports for these students. Survey results indicated a statistically significant difference between Child Count and total population reports of students with visual impairments during the 2016–2017 school year. Furthermore, the differences between these numbers affected the ability of practitioners to plan for and support students with visual impairments. Understanding the available population data for students with visual impairments is key for practitioners, administrators, and policy makers to make informed decisions to support students with visual impairments.

DIFFERENCES BETWEEN CHILD COUNT AND TOTAL POPULATION DATA

Across states, the total number of students with visual impairments exceeded Child Count data by 1.2–13 times Child Count reporting. Since Child Count data are the most commonly used population data for students with disabilities, this finding should be a wake-up call to policy makers and administrators that, on average, states were supporting 4.1 times higher the number of students with visual impairments than were reported through Child Count in the 2016–2017 school year. Within a state, this discrepancy could mean the difference between

planning for 50 students versus 205 students or 200 students versus 820 students with visual impairments. These differences are substantive and cannot be overlooked. Overreliance on Child Count data, as reported by survey respondents, particularly around teacher hiring, may contribute to the understaffing of teachers of students with visual impairments. For example, survey respondents and prior research (Parrish & Esra, 2006) noted that students whose primary disability was identified as “multiple disabilities” averaged the highest funding allocation. As a result, students with visual impairments who are primarily categorized as having multiple disabilities may be allocated the highest amount of special education funding. Decision makers at the school, district, and state levels, however, may be unaware of how those funds need to be spent to achieve the most benefits for students and economic benefits for the school, including truly understanding the need for additional teachers of students with visual impairments and orientation and mobility (O&M) specialists. When analyzing the Child Count and state-reported population data, practitioners and policy makers need to consider the most accurate population data to make informed decisions.

Data for young children with visual impairments. Twenty-six of 49 returned surveys included exact or estimated total population data on infants and toddlers with visual impairments who were receiving early intervention services. Some respondents reported numbers in proportion with the number of school-aged students with visual impairments in their state (e.g., Colorado, North Carolina, and Texas). Curiously, 12 of the 26 respondents reported serving fewer than 30 infants or toddlers with visual impairments (see Table 2). Some states reported that they were supporting fewer

than 30 infants or toddlers with visual impairments, a number that was lower than the proportion of students with visual impairments in the school-age population (e.g., Maine and South Dakota). Other states (e.g., Maryland and Tennessee) reported having fewer than 30 young children with visual impairments in receipt of services, a number that was significantly lower than and disproportionate to their school-aged population of students with visual impairments. These discrepancies may partially result from the general “developmental delay” label that is commonly applied to young children. In addition, early intervention services tend to be overseen by general early intervention specialists, who are not trained in the unique needs of children with visual impairments. Therefore, an important question to ask is: What level and quality of services are young children with visual impairments receiving, and who are actively identifying young children with visual impairments? Another factor may be the under-identification of young children with visual impairments. Babies Count research established that, among very young children, only those with the most visible and severe visual impairments are identified in a timely manner (Hatton et al., 2013). No standards exist for childhood or young adult vision screenings (Prevent Blindness, 2015), and children may not be identified as having visual impairment until they reach school and need access to fine visual details (e.g., when reading, font sizes decrease, or visual tasks increase). Prior to the current study, no data were available regarding young children with visual impairments (birth to 2 years old). Additional research is needed to better understand possible trends in identifying and supporting young children with visual impairments.

IMPLICATIONS OF CHILD COUNT DATA

Although Child Count provides data on students’ primary disability status, the results of the current survey indicate that Child Count data are often misunderstood or misused in practice. Of the returned surveys, nine respondents mistakenly reported Child Count as the total population count of students. Five respondents corrected their survey response after being contacted. However, three respondents remained insistent Child Count data represented the total number of students with visual impairments (and one respondent did not reply to clarification requests). Another example of misinterpreting Child Count data was shared by a survey respondent. Reporting over the telephone rather than in writing, the respondent explained that their vision program maintained a total count of students with visual impairments; however, their state department of education repeatedly denied the accuracy of the vision program’s population count. Rather than consider the validity of the vision program’s methods, the state’s department of education insisted Child Count data represented the total state population of students with visual impairments. This misapplication of Child Count data was echoed throughout several respondents and is documented in Table 1.

Misunderstandings regarding Child Count data are pervasive throughout education, although some administrators may simply be unaware of the limitations of Child Count data. Misinterpretation of Child Count data as representing the total population of students with visual impairments has happened for a long time. In some states, administrators may be choosing to ignore or not seek out total population data for students with visual impairments. Since Child Count only represents a fraction of students with visual

impairments, administrators can unintentionally or intentionally hire fewer teachers of students with visual impairments and O&M specialists and allocate less funding for classroom supplies and assistive technology for students with visual impairments. Students with visual impairments represent a small, low-incidence group of students with disabilities. In several states, however, administrators' reliance and misuse of Child Count data are perpetuating underrepresentation and likely under-serving students with visual impairments. Decisions related to budgeting and the hiring of teachers of students with visual impairments and O&M specialist need to be made with the most accurate data on students with visual impairments.

STATEWIDE INITIATIVES

Some statewide vision programs are taking the initiative to gather accurate data on their states' population of students with visual impairments. Across survey respondents, total population counts were typically overseen by state vision consultants or programs or instructional materials centers (21 states). A variety of strategies were reported for collecting total population data. For example, Colorado reported in-depth, multiagency collaboration to collect data about the needs of students, parents, and teachers of students with visual impairments. Kentucky's Instructional Materials Resource Center simply paired data collection with the APH Annual Census. They collected data on the number of students who are legally blind, visually impaired (i.e., not meeting legal blindness criteria) or receiving vision services without an eye report on file. Students without an eye report accounted for 15% of the state's total population and were in their own category, since, without medical documentation, they cannot be appropriately characterized as being visually impaired or legally blind.

Some states have electronic IEP systems, easily reporting the number of students eligible for or receiving special education services in any disability category at any point in time. However, many states do not utilize such technology and, according to survey respondents, most statewide IEP systems only report students by primary disability.

LIMITATIONS

There were limitations affecting the current study. Although the preferred survey respondents were vision professionals, many respondents did not have backgrounds in visual impairment. In a few states, respondents were not permitted to complete surveys but instead were required to send the survey to their Department of Education data specialists. Consequently, more responses were gathered for Questions 1 and 2 than for Questions 3 and 4 of the survey. In both e-mail correspondence and survey responses, a small number of respondents indicated a misunderstanding that releasing state-level aggregate data on students with visual impairments would violate student confidentiality, preventing a few states from answering the survey in its entirety. Finally, because this study was the first systematic attempt to collect total population data for students with visual impairments, the results should be interpreted with caution and considered preliminary. Multiple years of data are needed to understand if the student population numbers in this report are reliable.

IMPLICATIONS AND FUTURE DIRECTIONS

The current study holds several implications for students, practitioners, families of children with visual impairments, and policy makers in education. First, understanding the total population of students with visual impairments in a state is essential for informed decision making. The systematic

misuse of Child Count data as data representing states' total population of students with visual impairments needs to end. When funding, hiring decisions, and resource allocation are made based on the entire population of students with visual impairments, regardless of their primary disability, the overall quality of and access to vision-specific services may improve. Additional research is needed on how the differences between Child Count and total population reports affect students, practitioners, and policy makers at all levels. By educating stakeholders on the differences between population data, more effective systems to understand and support students with visual impairments can be collaboratively built.

Declaration of conflicting interests

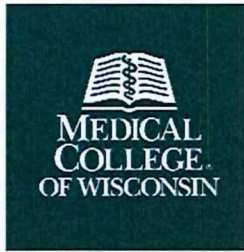
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knowledge changing life

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January 7, 2022

Written Testimony in Support of AB 490

Dear Chairperson Sanfelippo and Members of the Assembly Committee on Health:

Thank you for the opportunity to provide this written testimony to the Committee. My name is Dr. Deborah Costakos, and I am a pediatric ophthalmologist, professor, and the Chair of the Department of Ophthalmology at the Medical College of Wisconsin. I specialize in treating ocular and neurological visual impairments, which include Retinopathy of Prematurity, Cortical Visual Impairment, and Optic Nerve Hypoplasia, which are the 3 most prevalent eye conditions in children under three. I am writing today to ask for your support of AB 490, to create a statewide registry for babies and toddlers who are blind or visually impaired.

The Department of Ophthalmology at Children's Wisconsin is the primary provider of pediatric ophthalmology services for Wisconsin. Our department serves children and families from every county in the state.

Our team of optometrists and ophthalmologists regularly diagnose babies and toddlers with visual conditions that will result in lifelong visual impairment or blindness. We have many innovative and exciting medical treatment options to offer, but unfortunately, we cannot always restore or improve vision. We recognize the critical importance of connecting children and families with the training, education and support services that will help families understand how to best assist their child with vision loss to grow and thrive. We greatly value expert early intervention vision providers like Teachers of the Visually Impaired and Orientation and Mobility Specialists, and we want all eligible children to receive these important services.

A registry program would help to ensure that there is a consistent and streamlined process for connecting all young children with visual conditions to these vital services. Availability and systems for access to services can vary in different areas of the state and this can

complicate the process of linking families to the most appropriate early intervention and support services. In addition, a registry would help to create a "safety net" to assist with follow-up with families and reduce barriers to access.

Thank you for the opportunity to provide this testimony, and I hope you will vote to pass Assembly Bill 490. Please contact me with any questions.

Sincerely,

A handwritten signature in black ink, appearing to read "D Costakos". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Deborah M. Costakos, MD, MS
Professor and Chair
R.D. and Linda Peters Professorship in Ophthalmology
Department of Ophthalmology and Visual Sciences
Medical College of Wisconsin

Dear Wisconsin State Assembly Committee,

My name is Shandell Wedl. I live in Fort Atkinson, WI, with my husband and four children. This past summer, on June 21st, We welcomed our fourth child Edison into the world. My pregnancy wasn't any different than the others, except I had been given more ultrasounds due to my BMI. All the ultrasounds came back normal, and he was looking healthy. On June 21st, 2021, Edison was born at St. Mary's in Madison. He received all tests as normal. There was a concern about his hearing in one ear. He didn't pass his hearing test, Which he later retested and passed. We were discharged and sent home like usual. No concerns. Once we got home, I started noticing his eyes seemed different. Different in the way of the movement and size. We had Edison's first appointment scheduled for that Friday, so I thought I'd mention it when we went in. That is when our life flipped and took a turn. When we went for his check-up they sent us to Children's Hospital in Madison. For over the next eight hours we spent there, it seemed like an eternity. Edison was diagnosed with Bilateral Microphthalmia. For the following months, he had multiple appointments to see many specialists. Edison's diagnosis is rare, and it seemed to leave us feeling defeated and lost. I joined a couple of Facebook groups but didn't see anyone with the same diagnosis as Edison's. I was able to connect with one family who recommended a specialist out in Pittsburgh, PA, who has seen this condition all over the world. If it weren't for this family, We wouldn't know of Edison's other diagnosis of Microcornea, which a specialist in Pittsburgh discovered. We had no time to prepare for this. We have to rely on what each specialist says. We had to dive right in, and finding such limited resources is disheartening and scary. We are currently in the works with him to have a sedated exam to get a better look to see if any potential vision is there, but the back parts of his eyes are significantly underdeveloped. Battling with insurance to go back out to Pittsburgh has been a battle in its self as no local specialist even recommended this exam.

Parents/guardians of blind/VI need the resources to connect with other individuals and other blind/VI community services. Not everyone has social media. Not everyone knows of even the current resources out there. There are a wide variety of eye diseases/conditions out there. To have as many resources as possible would be life-changing to many families. I kindly ask you to think about if you were in my shoes as a parent and want the absolute best and want to know as much as possible what would you hope is out there? When there are limited resources for such a large community, it's disheartening, frustrating, and downright cruel. Let's get these resources for the blind/VI community. We are all looking up to you to make a life-altering movement to support Assembly Bill 490.

Thank you for your time,

Shandell Wedl

Mother to a Blind/VI 6-month-old

307 Memorial Dr.

Fort Atkinson, WI 53538

1/10/2022

Written Testimony in Support of AB 490

Dear Chairperson Sanfelippo and Members of the Assembly Committee on Health,

My name is Kathy Bonesho, I live in Menomonee Falls, and I am a Registered Occupational Therapist. I am writing to ask for your consideration in supporting the Assembly Bill 490/Senate Bill 467, which would create a registry for children who are blind or visually impaired. I have been a pediatric occupational therapist for 30 years. Most of my career has been devoted to serving infants and children who are blind or have visual impairments. I have worked at the Center for Blind and Visually Impaired Children /Vision Forward for 20 years, and currently work in the NICU at Ascension St. Joseph Hospital. Throughout the years, I have been blessed to celebrate with families and experience the joy and triumphs watching their child progress in their development. Unfortunately, I have witnessed many children who, and I hate to use this cliché but “have fallen through the cracks”. If my experience working with children who are blind or have a visual impairment has taught me anything, it is that they do not have time, nor do they deserve to fall through the cracks. Assembly Bill 490/Senate Bill 467 is critical to ensure that children and families are connected early to organizations that employ a team of licensed professionals that specialize in visual diagnoses and impairments.

When thinking about typical development and sharing success of reaching particular milestones, people often think of the obvious such as walking or talking. It is rare if anyone ever triumphs when a child obtains visual regard of an object, or celebrates when visual convergence is obtained. However, without the integration of these critical visual components that make up the foundation of motor, social and emotional development, concept development, language and learning, many of these milestones become obsolete or certainly delayed.

The one-month-old begins to fixate on objects, shows interest in faces, vision is monocular but they start to develop slow jerky tracking. At two months the infant begins to inconsistently use binocular vision. The baby turns towards movement. They pair vision with items such as a rattle placed in their hands. At three months the baby has proximal stability for improved eye convergence, midline visual regard and binocular fixation. Tracking 180 degrees and shifts visual glances between 2 objects. Vision is drawing the infant upward (vertical posture against gravity) and outward (reaching and moving toward targets) they explore their environment. Four months is the magic age of rolling. The baby now visually directs reach. Their eyes move separate from the body and can shift gaze between three objects and have added the diagonal plane of vision needed to roll. Skipping ahead to 12 months, they can shift gaze of vision from near to far to explore their environment and move through space to a visual target. At 14 months, they show visual interest in books pointing to familiar objects. At 2 years of age, toddler's visual skills and concepts are so sophisticated they can inspect an object without touching it.

Now imagine, the parents who try desperately to bond with their baby that does not look at their face. Parents carrying through with directed “tummy time”, however *their* baby does not lift up their head because there is no visual reward. A baby that will not roll over because they lack spatial and body awareness, and may not feel safe in their non visual world. A child that has difficulty sitting because optical reflexes that establishes vertical alignment and development of graded movements and balance

is strongly reduced if not eliminated. Imagine trying to teach your child what a star is, a tree, or a monkey, these concepts cannot be taught by simply looking through a novel picture book. Toys that might have been used with a sibling may have no meaning to their visually impaired child.

The importance of connecting infants and their families to places such as Vision Forward who have the skills, expertise, technology, staff, and most importantly the passion to provide specialized functional vision evaluations, education, therapy services, and family support can literally make a world of difference.

Fortunately, and unfortunately, I have seen the outcome of children and families who have been supported by licensed professionals including teachers of the visually impaired, orientation and mobility specialists, occupational, physical, and speech therapists, adaptive technology specialists, and social workers who have advanced training working as part of an agency that specializes in working with children with blindness or visual impairments in every capacity. I have also witnessed the outcomes of children who, did not received services they have needed, were connected at a late age, or have been part of birth to three agencies, and private agencies that lacked the specialized skills and because of this, despite best intentions have provided services in such a way that has caused more harm than good.

I urge you to empower the families and children who are impacted with blindness and visual impairments and support the Assembly Bill 490/Senate Bill 467 which will connect families to agencies filled with good people, professionals who have dedicated their careers to help so many.

Sincerely,

Kathy Bonesho
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Menomonee Falls, WI 53051

Tiffany Meridith
6646 N. 55th St
Milwaukee, WI 53223

Written Testimony in Support of AB 490

Dear Chairperson Sanfelippo and members of the Assembly Committee on Health,

I live in Milwaukee, and I am a parent of a child who is visually impaired. I am submitting written testimony today to ask for your support of Assembly Bill 490, which would create a registry for children who are blind or visually impaired. The registry will help connect families to agencies and providers that are specifically trained to meet the unique needs of these children. Participation in the registry is voluntary and would be up to the child's parents.

As much as 90% of what children learn in the first three years of life is acquired visually. Without proper support, children who are blind or visually impaired can experience dramatic developmental delays.

As a former childcare teacher, working with children is my specialty. However, rearing a child of my own with several developmental delays, including visual impairments, has presented me with quite a challenge. I have Vision Forward to thank for presenting solutions to my many concerns in regards to my child's vision. Their skills and expertise have helped to provide many resources for other delays that my child has in relation to his lack of vision. With their determination and dedication, my child has made tremendous progress in his abilities. While Vision Forward is a resource that I was once not very familiar with, I am extremely fortunate for the referral leading me to their remarkable program.

I would appreciate your vote to pass Assembly Bill 490.

Sincerely,

Tiffany Meridith

