Caring for the Eyes of Children with Special Needs

Sandra S. Block, OD, FAAO, FCOVD
Professor Emeritus, Illinois College of Optometry
President-Elect, World Council of Optometry

National Center for Children’s Vision and Eye Health
Prevent Blindness
Goals

• Highlight some of the types of vision problems that children with special needs are known to exhibit.

• Review visual skills that are important in the classroom.

• Discuss the importance of a comprehensive eye exam and why screenings are not appropriate.
Type of Vision and Eye Health Problems

Children with diagnosed syndromes have been studied for years with many specific problems identified:

• Amblyopia or lazy eye – vision is reduced in one or both eyes not due to a disease or known cause
• Strabismus – eyes are not properly aligned
• Uncorrected refractive error – three primary types
Type of Vision and Eye Health Problems

Children with diagnosed syndromes have been studied for years with many specific problems identified:

Amblyopia or lazy eye

Strabismus – eyes are not properly aligned

Uncorrected refractive error
Type of Vision and Eye Health Problems

Children with diagnosed syndromes have been studied for years with many specific problems identified:

Amblyopia or lazy eye

Strabismus – eyes are not properly aligned

Uncorrected refractive error – 3 types:
- Hyperopia or farsightedness
- Myopia or nearsightedness/shortsighted
- Astigmatism
- Combination of myopia or hyperopia with astigmatism
Type of Vision and Eye Health Problems

Eye Health Problems – some causing reduced vision

➢ Cataracts
Type of Vision and Eye Health Problems

Eye Health Problems – some causing reduced vision

- Cataracts
- Retinal problems
Type of Vision and Eye Health Problems

Eye Health Problems – some causing reduced vision

- Cataracts
- Retinal problems
- Lack of full development of structures such as optic nerve hypoplasia or colobomas
- Cortical visual impairment/delayed visual maturation
Type of Vision and Eye Health Problems

Eye Health Problems – some causing reduced vision

- Cataracts
- Retinal problems
- Lack of full development of structures such as optic nerve hypoplasia or colobomas

- Cortical visual impairment/delayed visual maturation – the eye (end organ) is normal. Damage or lack of development between eye and brain.
Type of Vision and Eye Health Problems

Vision Problems interfering with academic performance:

- Poor fixation
- Inaccurate eye movements
- Poor eye-hand coordination
- Inability to maintain focusing up close
Vision Screenings Are Important

A vision screening is typically part of a well child exam in the pediatrician’s office, at schools by the school nurse, or in the community by trained screeners.

It’s a short event that helps indicate if any potential vision problems may be present.

Vision screenings allow a nurse or other trained individual determine if a child is at risk for a vision problem –
Vision Screenings Are Important

What a screening does:

• Identifies subjects at high risk for vision problems or eye disease and are in need of a professional eye examination
• May detect disorders in an early, treatable stage
• Provides the public with valuable information and education about eye care
• May result in a referral to an eye care professional or primary care provider

but..............
### Children Who Should Bypass Vision Screening and Go Directly to Eye Examination - NCCVEH

<table>
<thead>
<tr>
<th>Readably observable ocular abnormalities</th>
<th>Neuro-developmental disorders, such as:</th>
<th>Systemic conditions with ocular abnormalities, such as:</th>
<th>Parents or siblings with history of:</th>
<th>History of prematurity</th>
<th>Parents who believe their child has vision problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strabismus</td>
<td>Hearing impairment</td>
<td>Diabetes</td>
<td>Strabismus</td>
<td>&lt; 32 completed weeks</td>
<td>Message to primary care providers:</td>
</tr>
<tr>
<td>Ptosis</td>
<td>Motor, such as CP</td>
<td>Juvenile Arthritis</td>
<td></td>
<td></td>
<td>Don’t wait and see</td>
</tr>
<tr>
<td></td>
<td>Down Syndrome</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cognitive impairment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Autism Spectrum Disorder</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>ADHD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Vision Screenings Are Important but......

For children with special health care needs, neurodevelopmental problems or communication difficulties there are some challenges:

• Tests are not able to be completed or are invalid due to behavior, attention or willingness to cooperate

• Child cannot respond as needed to complete screening tests requiring verbal or motor responses.

• Children fail in large numbers due to significant vision and eye health problems
Vision Screening for Children 36 to <72 Months: Recommended Practices

Susan A. Cotter*, Lynn A. Cyert†, Joseph M. Miller‡, and Graham E. Quinn§;
for the National Expert Panel to the National Center for Children’s Vision and Eye Healtha

ABSTRACT

Purpose. This article provides recommendations for screening children aged 36 to younger than 72 months for eye and visual system disorders. The recommendations were developed by the National Expert Panel to the National Center for Children’s Vision and Eye Health, sponsored by Prevent Blindness, and funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration, United States Department of Health and Human Services. The recommendations describe both best and acceptable practice standards. Targeted vision disorders for screening are primarily amblyopia, strabismus, significant refractive error, and associated risk factors. The recommended screening tests are intended for use by lay screeners, nurses, and other personnel who screen children in educational, community, public health, or primary health care settings. Characteristics of children who should be examined by an optometrist or ophthalmologist rather than undergo vision screening are also described.

Results. There are two current best practice vision screening methods for children aged 36 to younger than 72 months: (1) monocular visual acuity testing using single HOTV letters or LEA Symbols surrounded by crowding bars at a 5-ft (1.5 m) test distance, with the child responding by either matching or naming, or (2) instrument-based testing using the Retinomax autorefractor or the SureSight Vision Screener with the Vision in Preschoolers Study data software installed (version 2.24 or 2.25 set to minus cylinder form). Using the Plusoptix Photoscreener is acceptable practice, as is adding stereoaucity testing using the PASS (Preschool Assessment of Stereopsis with a Smile) stereotest as a supplemental procedure to visual acuity testing or autorefract.

Conclusions. The National Expert Panel recommends that children aged 36 to younger than 72 months be screened annually (best practice) or at least once (accepted minimum standard) using one of the best practice approaches. Technological updates will be maintained at http://nationalcenter.preventblindness.org.

(Optom Vis Sci 2015;92:6–16)
Children Requiring Automatic Referral for Examination

- Children at high risk for vision disorders and those with readily recognized eye abnormalities such as strabismus or ptosis should be referred directly.

- Children with known neurodevelopmental disorders (e.g., hearing impairment, motor abnormalities such as cerebral palsy, Down syndrome, cognitive impairment, autism spectrum disorders, or speech delay) have a higher rate of vision problems than those without neurodevelopmental abnormalities.

- Children with special needs should be referred directly to an optometrist or ophthalmologist for a comprehensive eye examination.
Children Requiring Automatic Referral for Examination

- Children with systemic diseases... and children born prematurely at less than 32 completed weeks of gestation also should receive a comprehensive eye examination rather than be screened.
- Additionally, when a parent or guardian believes his or her child may have a vision-related problem, an eye care professional should examine that child.
- Because the purpose of vision screening is to identify children in need of further care, those who have received a comprehensive eye examination from an eye doctor within the previous 12 months do not need to be screened but should be referred back to their eye doctor for follow-up.
Exams Versus Screening

• The primary purpose of screening tests is to detect early disease or risk factors for disease in large numbers of apparently healthy individuals.

• The purpose of a diagnostic test is to establish the presence (or absence) of disease as a basis for treatment decisions in symptomatic or screen positive individuals (confirmatory test).

<table>
<thead>
<tr>
<th></th>
<th>Screening tests</th>
<th>Diagnostic tests</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Purpose</strong></td>
<td>To detect potential disease indicators</td>
<td>To establish presence/absence of disease</td>
</tr>
<tr>
<td><strong>Target population</strong></td>
<td>Large numbers of asymptomatic, but potentially at risk individuals</td>
<td>Symptomatic individuals to establish diagnosis, or asymptomatic individuals with a positive screening test</td>
</tr>
<tr>
<td><strong>Test method</strong></td>
<td>Simple, acceptable to patients and staff</td>
<td>maybe invasive, expensive but justifiable as necessary to establish diagnosis</td>
</tr>
<tr>
<td><strong>Positive result threshold</strong></td>
<td>Generally chosen towards high sensitivity not to miss potential disease</td>
<td>Chosen towards high specificity (true negatives). More weight given to accuracy and precision than to patient acceptability</td>
</tr>
<tr>
<td><strong>Positive result</strong></td>
<td>Essentially indicates suspicion of disease (often used in combination with other risk factors) that warrants confirmation</td>
<td>Result provides a definite diagnosis</td>
</tr>
<tr>
<td><strong>Cost</strong></td>
<td>Cheap, benefits should justify the costs since large numbers of people will need to be screened to identify a small number of potential cases</td>
<td>Higher costs associated with diagnostic test maybe justified to establish diagnosis.</td>
</tr>
</tbody>
</table>
Are all screening tests created equal?

The answer is “NO”

Typically, a vision screening should be at a minimum, a valid and reliable visual acuity test. Ex: LEA, HOTV

NCCVEH also recommended a stereo test. PASS

In the absence of the ability of the child to respond to the above, the NCCVEH recommends technology that has been scientifically proven to be accurate.

Unfortunately, many photoscreeners/autorefractors that are used for screening do not uncover the presence of farsightedness/hyperopia well.
Barriers to Follow-Up of Screening

These are many barriers that families face with any child failing a vision screening.

Prevent Blindness does have resources that can help!
How often should children with special needs receive exams?

If a child has a known vision or eye health problem, the eye care provider should guide the parent as to how often the child should be seen.

If it is a refractive problem, i.e. simply needs glasses, then children with special needs should be seen on an annual basis.

If a child was prescribed glasses but is not wearing them, inquire with the parent as to the reason – broken or lost glasses are a common occurrence. There are resources to get them replaced.
Sandy Block
sblock@ico.edu
+1 (847) 280-6410
Vision Health of Children with Special Needs
The Facts, The Law, and Best Practices

Rachel A. “Stacey” Coulter, OD, MS

National Center for Children’s Vision and Eye Health
Prevent Blindness
Webinar Series
Vision in Special Needs Children

• Webinar 1 - Why Vision Matters
• The connection of vision and neurodevelopmental disorders
• Best practices for addressing vision as part of the IEP evaluation process (early detection, referring for eye care, coordination with eye care and primary care providers)
• The role of primary care providers in offering guidance about vision follow-up
• Webinar 3 – The Role of the Family in Navigating the System to Obtain Vision Care
  May 12, 2022, 4PM Eastern
Focus of this Webinar

- Special needs children
- 3-8 year olds
- Not visually impaired
- Heterogeneous population
Children with Special Health Needs

- Children with physical, intellectual, or developmental disabilities or long-standing medical conditions
Webinar Objectives

- Learn best practices for a comprehensive system of care for children with special health or learning needs,
- Gain an understanding of the vision-related components of the federal Individuals with Disabilities Education Act (IDEA),
- Increase skills to address barriers to eye care for children with special needs, and
- Acquire strategies for working with families, eye care providers, special education staff, and healthcare providers.
Teamwork

• Coordination of medical and educational networks
• Interdisciplinary communication
• Today’s webinar includes school nurses, National Department of Education, and eye care providers
Know your state

- Federal law guides IEP evaluations
- States may have different guidelines and regulations
- Importance of knowing YOUR state’s law
• Personal Perspective
• Eye Care Provider
• Real-world challenges
• Complexity of problem-solving
Acknowledgements

- Recognize the role that you play
- Importance of early intervention, special education, school nurses, Head Start professionals and staff in reaching children with special needs and supporting their families in obtaining vision care
Special Education & Vision Assessment
Special Education Process

1. Refer
2. Evaluate
3. Eligible?
4. Develop IEP
5. Implement IEP
Initial Special Education Eligibility Determination for School-Age Children

• **Evaluations** are to determine whether a child is a child with a disability as defined in the Individuals with Disabilities Education Act (IDEA) and to determine the educational needs of the child.
  
  20 USC § 1414; 34 CFR § 300.301

• Eligibility categories include:
  
  o Autism
  o Deaf-blindness
  o Deafness
  o Developmental delay
  o Emotional disturbance
  o Hearing impairment
  o Intellectual disability
  o Multiple disabilities
  o Orthopedic impairment
  o Other health impairment
  o Specific learning disability
  o Speech or language impairment
  o Traumatic brain injury
  o Visual impairment, including blindness

  20 USC § 1401; 34 CFR § 300.8
Special Education Eligibility Evaluation Requirements

(generally, with a few exceptions)

• Parent consent and notice

• “A variety of assessment tools and strategies to gather relevant functional, developmental, and academic information, including information provided by the parent…”

• “Not use any single measure or assessment as the sole criterion…”

• “In all areas of suspected disability”

20 USC § 1414; 34 CFR § 300.301
“Assessments are selected and administered so as best to ensure that if an assessment is administered to a child with impaired sensory, manual, or speaking skills, the assessment results accurately reflect the child’s aptitude or achievement level or whatever other factors the test purports to measure, rather than reflecting the child’s impaired sensory, manual, or speaking skills (unless those skills are the factors that the test purports to measure).”
Vision & Test Validity
State Differences in Assessment/Eligibility Requirements: Example 1

Southeastern State:

• “Vision and hearing screenings (traditional or functional, as appropriate) must be the first evaluations conducted for all children suspected of having a disability, unless otherwise indicated.”

• For all eligibility categories, vision screening is one of the minimum evaluation components and for most categories, evaluation criteria include “Evidence that vision/hearing screening results are satisfactory prior to proceeding with evaluations.”
State Differences in Assessment/Eligibility Requirements: Example 2

Mountain/Western State:

• Evaluation requirements in the category of **Deafblindness** include “Ophthalmological testing. (A) Clinical assessment of visual acuity, visual field, fixation and movement, refractive errors, and health of the eye structure. (B) Additional diagnostic tests...”

• Evaluation requirements in the category of **Multiple Disabilities** include “vision and hearing must be assessed.”

• Evaluation requirements in the category of **Visual Impairment (Including Blindness)** include “A description of the student’s visual impairment and visual capabilities must be on record from a qualified eye care professional.”
Importance of Identifying Visual Impairment

• “It is not unusual for students with low vision who also have severe developmental or multiple disabilities to be unidentified as students with visual impairments. Although these students may be receiving educational services… needs related to their visual impairment may not be addressed” (p. 282).

• “The assessment of the abilities, strengths, and needs of students with visual impairments is extremely complex… The teacher of students with visual impairments [TVI] frequently serves as the coordinator of the assessment team, helps the other team members to understand the impact of visual impairments on learning, and facilitates appropriate accommodations and interpretation of the tests” (p. 283)

(Lewis & Allman, 2017)
“While States are permitted to establish standards for eligibility for special education and related services and are not required to use the precise definition of a disability term in the IDEA, these State-established standards must not narrow the definitions in the IDEA.”

“There is nothing in the IDEA or the Part B regulations that would prohibit a State from requiring that a medical diagnosis be obtained for purposes of determining whether a child has a particular disability, provided the medical diagnosis is obtained at public expense and at no cost to the parents, and is not used as the sole criterion for determining an appropriate educational program for the child.”
Challenges

• Students need to be identified and evaluated in a timely manner! IDEA regulations (34 CFR § 300.301(c)(1)) require that an evaluation must be conducted **within 60 days** of receiving parental consent or within the timeframe established by the state.

• When a child is referred for a comprehensive eye exam...
  o Time and resources are required to find an eye care provider, schedule and attend an appointment, and (if needed) acquire corrective lenses
  o Eye care providers should provide more information than “unable to assess”
  o Information in the eye report should be reviewed and used to inform special education evaluation
Solutions?

• School-based vision programs (e.g., “Vision for Baltimore” [Neitzel et al., 2021])
• School/community-based clinics
• Financial and logistical supports to help kids and families get to eye exams and purchase glasses
Vision and Special Health Needs

MaryAnn T. Strawhacker MPH, BSN, RN SEN
Special Education Nurse Consultant
Heartland AEA in Central Iowa
mstrawhacker@heartlandaea.org

Disclosure Statement

I disclose the absence of personal financial relationships with commercial interests relevant to this educational activity within the past 12 months. I am a volunteer presenter and did not receive compensation for this presentation.

National Association of School Nurses

• School Nurse Special Needs Special Interest Group
  - Co-chairs Linda Kimmel and MaryAnn Strawhacker
  - Moderator Denise Buffin
  - SIG is a free benefit to members

• https://www.nasn.org/nasn/nasn-resources/practice-topics/vision-health

• VSP Global® for Sight for Students®, an Eyes of Hope® gift certificate program. This program provides gift certificates for a no-cost eye exam and, if prescribed, new glasses that NASN members can distribute to students 19 or younger who qualify.
The Future of Nursing 2020-2030

School nurses are essential to expanding access to quality health care for students, especially in light of the increasing number of students with complex health and social needs (p.108).

Through a team based approach, nurses can partner with professionals and community members to lead and manage teams and connect clinical care, public health, and social services while building trust with communities and individuals (p. 120).

When not to screen but refer

• Visible eye anomalies
• Medical conditions that can cause eye disorders
• Congenital infections
• Neurodevelopmental disorders
• Prematurity (prior to 32 weeks)
• S/P TBI
• HX of prenatal drug or alcohol exposure
• Family history
• Unable to screen

Eye Exams and Strategies
1. Lack of follow through to schedule exam and receive results

• Provide a list of local eye care professionals accepting new clients. Note Medicaid Status, usual wait time, and schedule.

• Contact guardian/parent to provide list, release, and set a F/U date.

• Obtain a release of information to provider records/results.

• Obtain (voucher) gift certificate if no Medicaid or eye insurance

• Partner with teacher to review education progress, need for exam, and follow-up
Eye Exams and Strategies

2. Transportation
   • Connect with case manager to obtain a Medicaid travel voucher
   • PTO/PTA gas cards or bus tokens
   • Check with public health for mobile eye clinics.
   • Call local charities for volunteer drivers

3. IEP or Section 504 has a 60 day timeline for initial evaluation
   • Comprehensive evaluation is required.
   • Assist family to find pediatric eye care specialists and neuroophthalmologists.
   • Can wrap up evaluation in other areas and sign for another 60 days if unable to get results.
   • Enlist other members of the IEP team to assist.

Provide Education to Parents and Staff

• Educate regarding the implications of the child’s visual impairment such as:
  • Prescribed glasses
  • No depth perception
  • Visual field cuts
  • Visual fatigue
  • Visual complexity of graphics
  • Contrast between print and background
  • Lighting requirements...
Reduce Language Barriers
• ELL only: use LEA symbols or HOTV
• Use an interpreter to provide parent education

https://talkingpts.org/

Thank you for your time and attention!