

BRIGHT FUTURES: FAMILY MATTERS

FAMILY VOICES®
...keeping families at the center
of children's health care

AUGUST 2014

Promote Eye Health for Children!

August is National Children's Eye Health and Safety Month, and gives us an opportunity to think about how we can promote eye health and protect those precious eyes.

Much like promoting good health in general, promoting eye health is a balance between doing the day-to-day things that help protect our eyes and by being alert to any signs that something might be wrong.

This goes hand in hand with routine eye care by professionals who can spot potential problems and provide treatment options should they occur.



Vision and Children with Special Health Care Needs

Children with special needs, particularly those with Cerebral Palsy and Down Syndrome, have a greater risk of visual and eye health problems than their peers. In many cases, these children may be unable to participate in typical eye exam methods. For example, children on the Autism Spectrum may show sensitivity to light, or discomfort in new surroundings, making a traditional eye exam a challenge. And that increases the likelihood that a vision problem might be missed.

Children with special needs typically receive help through their Individualized Education Plan (IEP) or Individualized Family Service Program (IFSP), such as occupational, physical, and/or speech therapy. However, in many cases, they do not receive a comprehensive eye and vision examination.

Frequently, those with special needs who have vision or eye health problems may not show obvious symptoms or may be unable to describe their symptoms. It is important for families to be aware of potential vision issues and have their children receive annual eye exams. Often, those involved with a child's care may be the first to suspect a problem.

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Among preschool-aged children, there is a vision problem in one out of every twenty children.

Undiagnosed vision problems may lead to permanent loss of sight if not detected or treated in a timely manner.

PLEASE HELP SPREAD THE WORD

Children's vision is important. Family Voices' National Center for Family/Professional Partnerships has developed resources to help you spread the word. For sample newsletter articles, Twitter messages, Facebook postings, posters, web buttons, and more, visit: www.fv-ncfpp.org/activities/vision-screening/vision-media-toolkit/

RESOURCES FOR FAMILIES

National Center for Children's Vision and Eye Health/ Prevent Blindness:

<http://nationalcenter.preventblindness.org>

Find information on vision screening, eye safety, signs of vision problems, etc.

Who's Who in Eye Care Providers: <http://www.preventblindness.org/whos-who-eye-care>

Help for Finding an Ophthalmologist or Optometrist:

Parents or guardians may ask for recommendations from their child's primary care physician, school nurse, or health manager. In addition, the following directories are available to identify eye care providers in your area.

Eye Care Provider Directories:

American Association for Pediatric Ophthalmology and Strabismus

<https://aaosso.aapos.org/ebusaapos/FindanEyeMD/tabid/1192/Default.aspx>

American Optometric Association

www.aoa.org/doctor-locator-search

American Academy of Ophthalmology

www.geteyesmart.org/eyesmart/find/index.cfm

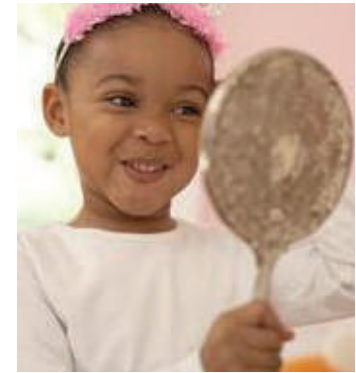
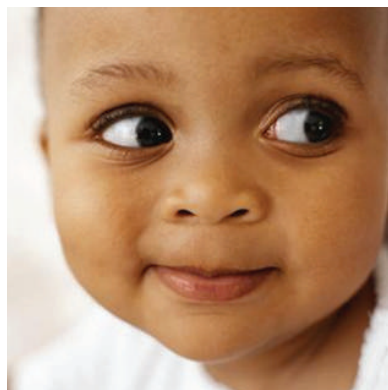
Vision Health for Children on the Autism Spectrum

by Lisa DiBonaventura, M.A.,COMS, the Statewide Director for Vision and Vision Loss Services at the Massachusetts Department of Developmental Services (Reprinted with permission.)

Why is it important to regularly assess a child's vision?

Regularly assessing a child's vision is critical starting within the first year of life because it is the only way to ensure that eyes are healthy and that the visual perception system is developing and functioning properly. Vision impacts development, safety and health, and affects how a child learns, plays, and feels. Some children, especially those with neurodevelopmental delays including Autism Spectrum Disorders, and/or who have a family history of eye problems, are at a greater risk for vision concerns. Unfortunately some vision problems, such as having an eye turn, if left undetected and untreated in childhood can lead to lifelong and permanent vision loss.

Recommendations for eye care for children, which include guidelines for vision screening and comprehensive eye exams, differ slightly among professional organizations and states (state law). Vision screenings, designed to detect vision problems, are typically



recommended annually or once every two years, and are provided at the primary care provider or pediatrician's office, at school, and/or in collaboration with a Department of Public Health. Comprehensive eye exams by an eye care provider including an optometrist, an ophthalmologist, or a pediatric ophthalmologist or optometrist typically occur as a follow up to a vision screening, as recommended by a primary care provider, pediatrician; and lead to diagnosis and treatment.

Although startling to consider, vision concerns in children can indeed be difficult to detect both from a child and caregiver perspective:

- Each child sees the world only through his/her own eyes. If the images a child views are blurry, doubled, or otherwise impaired, he/she may (or may not) experience these unclear images as normal. Also, depending upon age, the child may lack the language or ability to explain how he/she is seeing or attribute how he/she is feeling to a vision problem.
- Parents and teachers, likewise, cannot always easily detect that a child has a vision concern. Even if a child's eyes look perfectly healthy and beautiful to others, the visual experience for the child may be distorted.

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Thus, vision problems can go undetected, especially if regular eye exams and/or vision screenings are missed, resulting in significant impact on growth during this critical time of brain development.

A helpful list of common signs and symptoms associated with vision problems typically experienced by children

can be found on the Prevent Blindness website for its National Center for Children's Vision and Eye Health (<http://nationalcenter.preventblindness.org/links-additional-resources-childrens-vision>). If your child presents with any vision concerns, be sure to document your observations, and report these to your child's primary care provider, pediatrician, or an eye care provider. Even if no vision problems are apparent, having regular eye exams and/or vision screenings, with follow up as recommended, is an important part of health care for every child.

Why is it particularly important to focus on the vision of kids with Autism Spectrum Disorders?

Focusing on the vision of children with an Autism Spectrum Disorder (ASD) is critical for two reasons: Studies suggest that children with ASD have an increased rate of vision problems (compared to children who do not have ASD), and children with ASD may have specific vision perception sensitivities and/or traits which impact their daily lives. A concern is that a visual behavior believed

related to an ASD, may in fact be a sign of an undiagnosed vision problem, making eye exams vitally important for children with ASD.

Two small scale studies published in 2013 point to higher rates of refractive error, eye turn, and amblyopia among children with an ASD^{1,2}:

- **Refractive Error**, including nearsightedness, farsightedness, and/or astigmatism, and which affect how clearly a child sees, was found in 27-29% of children with ASD.
- **Eye Turn**, or strabismus, can affect a child's depth perception and ability to see one clear image instead of double vision, and was found in 21-41% of children with ASD.
- **Amblyopia**, a decrease in vision from an eye which can impair a child's depth perception and may result in visual field loss, was found in 10-11% of children with ASD.

Many of these causes of vision problems can be treated, and amblyopia prevented, if diagnosed early in life. The "eyeSmart" website hosted by the American Academy of Ophthalmology (www.geteyesmart.org/eyesmart/diseases/index.cfm) and the American Optometric Association's website (www.aoa.org/patients-and-public/eye-and-vision-problems/glossary-of-eye-and-vision-conditions) are two sources for information regarding these and other conditions affecting vision throughout a child's life.

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RESOURCES FOR FAMILIES WITH CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Families of Children with Vision Impairment: Working with Medical Professionals:

- **English:** www.familyconnect.org/PDFs/Eye_Care_Professionals_English.pdf
- **Español:** www.familyconnect.org/PDFs/Eye_Care_Professionals_Spanish.pdf

Safety Tips for Children with Vision Loss: <http://cshcn.org/sites/default/files/webfm/file/SafetyTips-VisionLoss-English.pdf>

Perkins Webcasts: Assistive Technology, Curriculum, Independent Living Skills, etc. www.perkins.org/resources/webcasts/

Adapting Your Home for a Child who is Blind or Has Low Vision: www.familyconnect.org/info/after-the-diagnosis/adapting-your-home/13

NICHCY: Visual Impairments including Blindness: <http://nichcy.org/wp-content/uploads/docs/fs13.pdf>

Northeast Regional Center for Vision Education: www.nercve.org/

ADDITIONAL RESOURCES FOR CHILDREN WITH VISUAL IMPAIRMENTS

National Association for Parents of Children with Visual Impairments (NAPVI):

www.spedex.com/napvi/ and www.spedex.com/nap-vi/index_sp.htm (Spanish)

National Organization of Parents of Blind Children:

<https://nfb.org/parents-and-teachers>

Family Connect Online Community (Program of American Foundation for the Blind and NAPVI):

www.familyconnect.org/parentsitehome.aspx

National Association for Deaf-Blind:

<http://nfdab.org/>

Hadley School for the Blind Family Education Program:

Free distance learning programs.
www.hadley.edu/fe.asp

HELP FOR EXAMS AND GLASSES

Charitable Vision Clinics: <http://onesight.org/how/charitable-vision-clinics/>

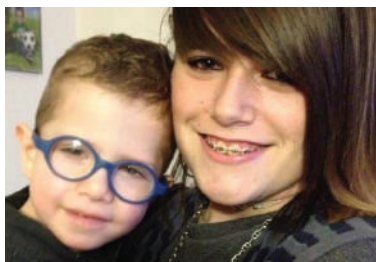
New Eyes for the Needy: www.new-eyes.org/us-voucher-program/

Vision USA: www.aoafoundation.org/vision-usa/how-to-apply/

In addition to increased prevalence for some vision problems, a child with an ASD may also present with specific vision perception sensitivities and/or traits^{3,4,5} which can impact daily function, and also affect how an eye exam should be performed. Some of these traits are similar to symptoms of various eye conditions, including Cortical Vision Impairment (CVI), and are why eye exams for children are so important. Vision sensitivities and/or traits of children with an ASD may include but are not limited to:

- Intense focus on light, people, objects, brightly colored objects.
- Focus on visual details rather than the whole.
- Focus on very small items/pieces
- Increased ability on tasks of visual search.
- Movement of hands, fingers, or objects in front of eyes.
- Avoidance of eye contact.
- Dislike/Avoidance of dark lights, bright lights, and/or flashes of light.

Information regarding all visual behavior is important for an eye care provider to know and consider when preparing for and during a child's eye exam. The keys for healthy eyes and the healthy development of the visual perception system for children with an ASD include early detection of vision problems, early treatment, regular care throughout childhood by an ophthalmologist or an optometrist who understands the child's needs, and consistent communication and follow up with eye care providers by parents or guardians.



It can be challenging to find providers for kids with special concerns. What do you recommend?

Even in states with adequate resources for eye care, finding providers for children with special concerns can be challenging. Communication is critical to find the right provider, to make sure that the ophthalmologist or optometrist understands your child's needs prior to the eye exam, and so that your child is prepared as can be for the exam. Here are some tips and resources:

Insurance Coverage for Eye Exams and Eye Glasses:

Insurance plans vary regarding benefits for eye care. Depending upon your child's insurance provider, you may need a referral from your child's primary care provider or pediatrician prior to scheduling a visit with an eye care provider. If your child does not have insurance for eye exams or for prescription eyeglasses, assistance programs such as EyeCare America (www.eyecareamerica.org/), InfantSEE (www.aoa.org/optometrists/education-and-training/public-health/infantsee), and Prevent Blindness (<http://nationalcenter.preventblindness.org/vision-care-financial-assistance-information>) are available to help.

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Considerations for Scheduling and Preparing for Eye Exams:

Take care when scheduling and planning your child's eye care provider appointment to help create the most successful atmosphere for the exam:

- Share specific vision-related information. Some providers will send you a packet of information, along with a questionnaire to help prepare for your child's eye exam. Regardless, share all questions, concerns, and observations, and provide information regarding any vision perception sensitivities or traits that your child has.
- If waiting is difficult, schedule the appointment to be the first of the day, the first after the provider's lunch break, or the last of the day to reduce waiting time as much as possible.
- Prepare your child based on his/her needs. It may be helpful to talk about the appointment, visit the office, or watch a video about going to the eye doctor. (Many videos are available on YouTube: search for "eye exams for children." It is important that you first watch videos without your child, as you'll know best which videos, if any, will be helpful.) Whatever approach you use, planning with your child is an important step to drawing attention to his/her eyes, and for a successful exam.

Is there anything else you recommend for families?

Eye Safety & Sun Protection:

Caring for children's vision includes focusing on eye safety and sun protection for eyes. The Prevent Blindness website (<http://preventblindness.org/preventing-eye-injuries>) provides information to protect your child from eye injuries, including at home, at play, during sports, and from the sun. Prevent Blindness also offers resources on first aid for eye emergencies.



Teacher of the Visually Impaired & Orientation & Mobility Specialist:

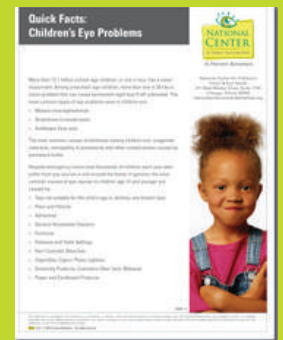
Teachers of the Visually Impaired (TVI) (www.familyconnect.org/parentsite.asp?SectionID=72&TopicID=345&DocumentID=3947) and Certified Orientation & Mobility Specialists (COMS) (www.visionaware.org/section.aspx?FolderID=8&SectionID=115&TopicID=515) are professionals who work in the school system with children who have vision impairment, including challenges with visual perception, legal blindness, or deaf-blindness. For additional information, please contact your state department for education or disability services.

References:

1. J Autism Dev Disord. 2013 Jun;43(6):1447-51.
2. Strabismus. 2013 Jun;21(2):98-102.
3. J Abnormal Psychology 2012 Vol. 121, No. 2, 544-551
4. NeuroImage: Clinical 2 (2013) 303-312
5. J of Neuroscience 2013 April 33(16):6776-6781

MORE FROM PREVENT BLINDNESS

Children's Eye Problems: <http://tinyurl.com/ChildrensEyeProblems>



Selecting Sunglasses for Children:

<http://tinyurl.com/sunglassesforchildren>



Most Hazardous Products to Children's Eyes:

<http://tinyurl.com/eyehazards>



Family Story: In My Daughter's Eyes

By Peggy Curran,
Family Voices Consultant



I knew something was wrong with my daughter's eyes when I first met her as an infant during her adoption process. Anna did not seem to be able to track her eyes to locate a sound or pick up a movement. Little did I know that the eyes are a window to the brain. We would find out that Anna's problems were much more global. Unfortunately after many years of medical, neuropsych, and educational testing and more doctors than I ever want to see again, we never did arrive at a diagnosis.

Anna presented with several vision issues—nystagmus, strabismus, pale optic nerve—and exhibited no depth perception, confusing foreground/background, restricted peripheral vision, and poor tracking. I remember the day we were in the car and I excitedly pointed out the Easter Bunny waving from the sidewalk. She couldn't locate him ... couldn't find the moon in the sky ... couldn't walk down a trail without tripping ... couldn't cross a street safely. But Anna adapted. She learned to reach for someone's hand when walking on unfamiliar terrain. She learned to tap forward with her foot to feel the ground. She learned that swimming was much more enjoyable than hiking.

Along the way we found doctors who were very helpful and some not so much. One doctor, after reviewing my daughter's records and examining her eyes, said her acuity was great—good enough to drive a car. Wow! I would have loved to see him in the passenger seat on that trip! We quickly learned that a pediatric ophthalmologist was more knowledgeable and understanding than an adult doctor. Perhaps the best help we received was from a Vision Teacher, whose services were provided through an IEP. She taught Anna strategies for reading, demonstrated how working on a computer was easier for her than using a paper and pencil, showed us that cluttered backgrounds confused her, explained why it was easier for Anna to walk uphill than downhill, and so much more.

Today, in my daughter's eyes, I no longer see those problems that once loomed so large but see a young, happy, eager-to-please young woman who finds a hero in everyone she meets.

The National Center for Children's Vision and Eye Health at Prevent Blindness is teaming up with Family Voices National Center for Family Professional Partnership to offer free information on a variety of children's eye health topics, from UV safety, the Affordable Care Act and children's vision services, to general eye health. Read more about our partnership here: www.fv-ncfpp.org/files/2414/0553/4479/NCCVEH-NCFPP_Partnership_Announcement.pdf

For more health and wellness information:

www.fv-impact.org

FAMILY VOICES MISSION

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

Through our national grassroots network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

www.familyvoices.org

IMPACT

on HEALTH & WELLNESS for FAMILIES

Family Voices IMPACT works to develop ways to improve health and wellness for all children and families, and to encourage partnerships between families and professionals for children's good health. Share Bright Futures: Family Matters with your networks.

Visit www.fv-impact.org

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