

EDITORIAL

Serving the Needs of the Patient with Autism

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Keywords: Autism, developmental-behavioral-functional optometrist, early intervention, health care barriers, optometric vision therapy, vision information processing

Clear and present need

Vision care provided by all members of the College of Optometrists in Vision Development (COVD) is based upon the principle that vision can be improved, enhanced, developed and changed. COVD, as an organization, supports its members by providing education and information to practitioners and by fostering research and scholarship related to vision development. As an organization, it has a responsibility to address an unmet public health need in providing comprehensive eye and vision care to individuals with autism. Many news stories have focused on the rise in the numbers of individuals who are diagnosed with autism. The Centers for Disease and Prevention in 2007 reported that one out of every 150 8-year-olds in multiple areas of the United States had an Autism Spectrum Disorder.¹ What has not been reported as often is that these individuals frequently have severe, persistent visual signs and symptoms.² Also unacknowledged is the fact that, many of these individuals have not received the same level of optometric vision care that we offer to our other patients. That is, comprehensive care with the goal of providing the patient with single,

clear, comfortable, efficient, binocular and pathology free vision.

Barriers to providing comprehensive care to patients with ASD

Given the pressing need of individuals with autism for comprehensive vision care, what are the barriers that prevent developmental and behavioral optometrists from serving these patients? There are multiple barriers both within, and external to, our profession.^{3,4,5} The first barrier is our own knowledge and understanding of the Autism Spectrum Disorder (ASD), its underlying neurological basis, and its core characteristics and differences in vision information processing. The second barrier is our clinical preparation in evaluating and treating patients with special needs.^{6,7} Patients with autism have major challenges not just associated with vision, but also in their ability to communicate, interact socially, and with appropriate motor planning and sensory integration. Optometrists serving these patients must be prepared to modify assessment and intervention techniques to meaningfully meet the needs of the patient. The third barrier is that many other disciplines do not understand the role of optometry in treating the vision problems of individuals who have autism. Individuals with autism typically seek care from providers from a wide range of disciplines including neurology, psychiatry, psychology, speech and language pathology, as well as, occupational therapy, special educators, early intervention providers and behavioral analysts. Appropriate care requires communication between multiple providers as well as the family and individual with autism. Other providers in contact with the patient may notice visual symptoms or related behaviors, but may not realize what gain may be achieved by referring the patient to a functional optometrist. Additional barriers may include access to a knowledgeable provider, competing needs which take higher priority and limited resources including insurance coverage, money and time. Though we

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Coulter RA. Serving the needs of the patient with autism. *Optom Vis Dev* 2009;40(3):136-140.

cannot eliminate each and every barrier, there is much we can do both individually and as a profession to reduce these barriers.

What do we know about the vision of individuals with autism?

There is a popularized myth among some of the optometric community that there is little literature on vision in individuals who have autism. The truth is quite the opposite. There are hundreds of articles in the scientific literature that investigate and describe vision and vision problems in individuals with autism. Most of these articles, however, have been published in non-optometric journals including journals in psychology, neuroscience, psychiatry, developmental disabilities, autism, occupational therapy and education. As the primary eye and vision care provider, optometrists have an obligation to understand the broader scientific literature regarding vision in individuals with autism. We need to distill and integrate this information with published work by those in our profession who have reported cases, determined the prevalence of vision conditions within clinical and general populations and discussed interventions.

At least as early as 1975, there is been a series of articles and publications by optometrists reporting on diagnostic findings and treatments for individuals with autism. Some of the optometrists who have contributed to our professional understanding include Streff,⁸ Kaplan,⁹ Wachs,¹⁰ Scharre,¹¹ Schulman¹² and Torgerson.¹³ We must continue to report case findings, share information regarding treatments and outcomes and innovations that may help this population.

Differences in vision information processing are linked to the core aspects of autism and are probably a factor in problems in face processing and social interaction. Toe walking and tactile handling of surfaces in an unfamiliar environment are examples of behaviors that individuals may use when vision is not adequate to guide motor movement. Hand flapping and finger flicking are attempts by these individuals to regulate themselves in a world where sensory information is difficult to process. Even types of repetitive play, such as repetitively putting objects and toys in line, are attempts to organize a chaotic visual environment. Integration of vision and vestibular, proprioceptive, tactile, motor, language, and auditory processing often will result in changes in posture, movement, cognitive processing.

What can the individual optometrist do?

To increase our ability and comfort level in caring for individuals with autism, we need to first deepen our knowledge of Autism Spectrum Disorder. Steps toward this goal may include reading the literature including recent articles and books, familiarizing ourselves with activities of the local chapter of the Autism Society of America, reviewing the websites of national organizations such as the Centers for Disease Control and Prevention, Autism Speaks, the Autism Society and attending continuing education courses focusing on care of patients with autism. We can also learn about the impact of autism on vision. By reading articles, attending continuing education courses, and seeking mentoring; we can broaden our understanding of vision differences in autism and methods and techniques for assessment and intervention.

Each of us must determine where and how therapeutic, education and support services are provided within our own communities to the local community of individuals who have autism and their families. How are individuals who are suspected of the condition referred for evaluation and to who are they referred? Early intervention programs are organized at the state and local level. Are services provided at home or at a separate center or school? How do children progress through these services until they reach school age? How are children referred for specific services such as speech and language therapy or occupational therapy? What other services, such as applied behavior analysis, developmental therapies, biomedical interventions, and parent-training programs, are available? How are these services supported fiscally? Payment for services for autism may be provided through state Medicaid programs, private insurance, private-pay and in a few cases, through public school districts. Some states now require that private insurance companies cover therapeutic interventions while others do not. Therefore, each optometrist will have to investigate to determine how his or her local area services are administered.

Once we have enhanced our own knowledge base and clinical techniques, we will need to review our own practice. Have we considered the sensory impact of our reception area, examination rooms and optometric vision therapy areas? Have we identified potential irritants, such as fluorescent lighting, highly trafficked areas, and strong smells (cleaning products, perfumes)? Are there small changes that

can make our practices more user-friendly to patients with autism and their families?

We should survey the tools in our toolbox. Knowledge of objective techniques⁶ and specific observation of behaviors may allow gathering critical information when subjective testing is not productive. Incorporating specific checklists to elicit information from caregivers and to capitalize on clinical observation may be helpful. Remember to request information from parents, caregivers, teachers, and therapists regarding the patients' developmental, medical, educational, and social history, as well as other treatments used previously. Consider modifications to optometric vision therapy techniques to adapt them to patients who face communication, sensory and motor challenges.

Remember to prepare your staff as well. Have you discussed autism and its general characteristics with your staff? Have they been prepared for behaviors patients with autism may display as they cope with sensory challenges? Do they understand what your practice can do to help these patients? Have you brainstormed about potential solutions to unanticipated challenges? For example, if a patient with autism seems distressed about the noise in your reception area, is there a quiet place with less stimulation where he or she can wait?

For some optometrists, this list may seem overwhelming. Don't be afraid to start small or to start with simpler cases and interventions. Different optometrists may need to work at different levels that are consistent with their knowledge and preparation. As in the case of strabismus, that varies widely in complexity and clinical difficulty, vision problems in individuals with autism vary greatly in the knowledge and clinical expertise required. Practitioners who treat strabismus do not start with the most complex presentation (such as a patient with long-standing unharmonious, noncomitant, esotropia with deep suppression and a large angle of magnitude), but may feel very comfortable in treating a patient with accommodative esotropia with minimal suppression and three months duration. It is acceptable to start with simpler cases at your professional comfort level and work to take on more complex cases over time.

Like snowflakes, no two patients with autism are the same

As the teacher of a class of preschool students with autism once told me, *"once you've seen one child with autism, you've seen one child with autism."*

Not only do the type and severity of vision problems present vary greatly from individual to individual, but optometrists will have to consider the individual's cognitive and communication abilities as well as sensory sensitivities in choosing appropriate interventions. The clinical art of practice constantly demands that we adjust treatment regimens to our patients' needs, preferences, and environment.

Managing vision problems in individuals with autism will particularly require individually tailored interventions.

Goals for the profession

As a profession, we need more and better information regarding autism and its associated visual anomalies. ODs must continue their efforts to publish journal articles, books and other resources as well as providing up-to-date continuing education courses. The College of Optometry in Vision Development's (COVD) journal, *Optometry & Vision Development* (OVD) has taken a leadership role in its willingness to dedicate an issue on autism toward this goal. Included in this issue are numerous open access articles focusing on understanding the basic science aspects of autism,¹⁴ the etiology of autism,¹⁵ clinical intervention for patients with autism¹³ and the multidisciplinary role of optometrists in early identification of those with ASD.¹⁶ COVD, OEP (Optometric Extension Program Foundation) and SECO (Southern Educational Congress of Optometry) have offered continuing education courses on autism this year.

As practitioners within a multi-disciplinary system, developmental and behavioral optometrists should converse using the latest knowledge of the larger scientific community. This must include broadening our information of vision and autism beyond what has been disseminated within the optometric community and when possible communicating our diagnosis and treatment plans in terminology that is understood by other professions including neurologists, psychiatrists, psychologists and occupational therapists. For example, concepts such as "focal" and "ambient" are deeply meaningful to developmental optometrists. These terms, however, are not meaningful to practitioners in other disciplines such as occupational therapy, neurology or psychology. When we can converse in a manner that is consistent with the broader scientific literature, it enables us to be understood by others and extends our credibility. This is not only important on writing

reports for individual patients, but also when we describe what we do to other professionals as well as when billing third parties/insurance for our services.

There is a need for additional research to investigate aspects of treatment of vision problems in individuals with autism. There are reports of a wide range of treatment programs that have been used for individuals with autism that include various lens applications, yoked prisms, colored filters, vision therapy, syntonics and more. Which treatments work and for which individuals? Which signs and symptoms are improved, by how much and for how long? How do we document outcomes and progress, particularly for patients who may not reach expected values for age? Given that we know that patients with autism have biological differences created by neuronal under-connectivity, what is the expected course of treatment? What is the appropriate length of treatment? Expected treatment lengths that are based on typically developing patients may not serve these patients. In a world of competing needs for limited resources, how do we determine when we should continue treatment and/or when we have reached the maximum benefit to be gained from therapy?

Given the heterogeneity of this population, it will be difficult to design and carry out clinical trial research studies. Finding enough individuals with autism who are similar in cognitive level, motor and communication abilities to create a control and experimental group will often not be possible. Single subject study design research studies will be more appropriate in most cases.

Since little research is available investigating optometric interventions for visual problems in individuals with autism, some in the profession have stated we should leave the work entirely to occupational therapists and special educators. Though occupational therapists and special educators play a critical role in providing intervention; their knowledge of vision will not be sufficient to reach our goal of providing single, clear, comfortable, efficient binocular vision that is free of disease. We have the professional responsibility to pursue and support research. In the interim period, professional judgment with a judicious eye to maximizing benefit with limited resources must be applied. It would be professionally irresponsible to deny treatment to such a large and deserving population.

Looking to the future

Nancy Minshew, MD, a well-respected neurologist and researcher of autism and brain functioning stated,

"Autism really impacts behavioral function in the brain very broadly. It affects sensory, motor, memory, and postural control -- anything that requires a high degree of integration of information.

I think treatments are coming.... In autistic brains, circuitry is developing into adulthood -- but it's not developing in the right way, and it stops developing too soon. With the right treatment, though, it can be pushed."⁷

Functional optometrists have unique and important abilities and opportunities to develop vision within ASD populations and to support its integration with other sensory/motor functions.

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