

Meeting the Optometric Needs for Patients with Autism

KOA Fall Conference
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FINANCIAL DISCLOSURE

*I do not have any relevant financial relationships to disclose.



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Lecture Objectives

- History of Autism
- Overview of Autism Spectrum Disorder (ASD)
- Epidemiology of ASD
- Signs of ASD
- Diagnosis and treatment for patients with ASD
- Ocular associations with ASD
- Ocular examination techniques for patients with ASD
- Academic support for patients with ASD

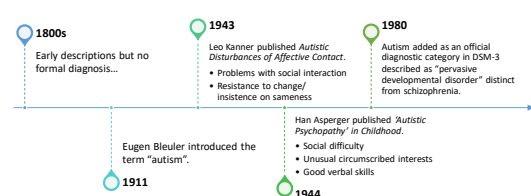
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“When you have seen one person with autism, you have seen one person with autism.”

– Arshya Vahabzadeh, Child And Adolescent Psychiatrist

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History of Autism Spectrum Disorder



1800s
Early descriptions but no formal diagnosis...

1911
Eugen Bleuler introduced the term "autism".

1943
Leo Kanner published *Autistic Disturbances of Affective Contact*.
• Problems with social interaction
• Resistance to change/insistence on sameness

1944
Han Asperger published *Autistic Psychopathy in Childhood*.
• Social difficulty
• Unusual circumscribed interests
• Good verbal skills

1980
Autism added as an official diagnostic category in DSM-3 described as "pervasive developmental disorder" distinct from schizophrenia.

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Autism Spectrum Disorder

- Defined by the DSM-V in 2013
- Previously defined as separate subcategories on the autism spectrum:
 - Asperger Syndrome, PDD-NOS, Childhood Disintegrative Disorder, and Autistic Disorder
- NOW defined as **"Autism Spectrum Disorder" (ASD)** by the DSM-V
 - Improved clarity
 - Defined by a common set of behaviors and should be characterized by a single name according to severity

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Autism Spectrum Disorder - Prevalence

1 in 36 children identified with ASD according to 2024 CDC Data

5.4 million adults with ASD in US (2017 survey)

4:1 males vs females

No differences in racial groups

- Higher percentage of intellectual disability in black children with ASD

About 1 in 6 (17%) children aged 3-17 years were diagnosed with a developmental disability.

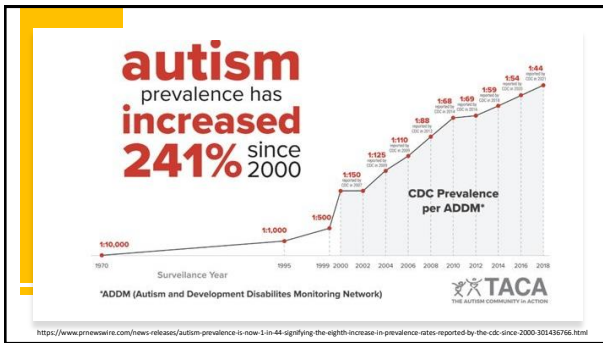
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Increasing Prevalence of ASD

Surveillance Year (Birth Year)	Number of ADDM Sites Reporting	Prevalence Per 1,000 Children	Prevalence (1/X)
2000 (Born 1992)	6	6.7	1 in 150
2002 (Born 1994)	14	6.6	1 in 150
2004 (Born 1996)	8	8.0	1 in 125
2006 (Born 1998)	11	9.0	1 in 110
2008 (Born 2000)	14	11.3	1 in 88
2010 (Born 2002)	11	14.7	1 in 68
2012 (Born 2004)	11	14.5	1 in 69
2014 (Born 2006)	11	16.8	1 in 59
2016 (Born 2008)	11	18.5	1 in 54
2018 (Born 2010)	11	23.0	1 in 44
2020 (Born 2012)	11	27.6	1 in 36

<https://www.cdc.gov/ncbddd/autism/data.html>

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Signs of ASD

Onset usually occurs before the age of 3

Meet developmental milestones until 18-24 months

Long-term but symptoms can improve with time

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Autism Spectrum Disorder

Deficits in social communication and social interaction

- Social reciprocity – how actions of one affect others
- Joint attention – wanting to share an interest
- Nonverbal communication – using or interpreting
- Social relationships – developing and maintaining friends

Restricted repetitive patterns of behavior, interests, and activities

- Lining up toys, flapping hands
- Fixed on routine
- Restrictive thinking

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Sensory Issues

- Over or under reaction to common environmental stimuli
- Stimuli may relate to sense such as auditory, tactile, visual, etc
- Stereotyped body movements (ie. flaps hands, rocks, bounces repetitively)
- Unusual behaviors (ie. looks from angles, sniff/licks objects, toe walks, etc)

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Social Difficulties

- Difficulty relating to or expressing emotions
- Limited eye contact
- Limited use or understanding of non-verbal gestures
- Flat or limited facial expressions
- Minimal initiation or response to joint attention
- Lack of social/emotional reciprocity (difficulty taking perspective of another person)
- Difficulty making friends
- Trouble understanding abstract words or concepts (analogies, sarcasm, love)
- Inappropriate behaviors may occur due to anxiety and discomfort

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Repetitive Interests and Activities

- Limited range of interests
- Finds comfort in predictability of structure and repetition
- Often rigid and excessive interest in unusual objects/activities
- Exhibits atypical play behaviors
- These actions may cause the individual to appear distracted/inattentive and viewed as inflexible and disobedient.

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Most Common Special Interests of Children with ASD

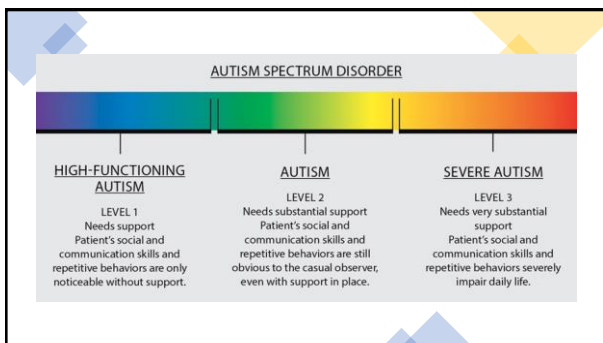
- **Sensory-related interests (44%)** – bright or vividly colored objects, spinning objects, soft or textured objects, etc.
- **Vehicles/transportation (19%)** – cars and trucks, trains, planes and rockets, etc.
- **Characters from movies, books or cartoons (15%)** – Thomas the Tank Engine, Marvel Universe characters, Dora the Explorer, etc.
- **TV/DVDs/movies (13%)** – The Wiggles, Dr. Who, Star Wars, etc.
- **Individual interests (12%)** – cleaning-related interests, rocks, keys, toilets, etc.

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Communication

- Very limited verbal communication
- Communicates primarily to have needs met and not for social reasons
- Language often develops late
- Prior to language development
 - Poor understanding of language
 - Gestural deficits (lack of understanding)
 - Jargon/unusual noises

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Autism Spectrum Disorder

Early Indicators

- No babbling or pointing by age 1
- No single words by 16 months or 2-word phrases by 2
- No response to name
- Loss of language or social skills
- Poor eye contact
- Excessive lining up of toys or objects
- No smiling or social responsiveness

Later Indicators

- Impaired ability to make friends
- Impaired ability to initiate or sustain a conversation with others
- Absence or impairment of imaginative and social play
- Restricted patterns of interest that are abnormal in intensity or focus
- Preoccupation with certain objects or subjects
- Inflexible adherence to specific routines or rituals

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Diagnosis of ASD

- Doctors assess the child's behavior and development to make a diagnosis.
- Development: meeting developmental milestones and observe playing, learning, speaking, behaving, and moving
- Often performed by developmental pediatrician, child psychologist, speech-language pathologist, occupational therapist, or other physicians

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MCHAT®

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior at least once, but not often, you should tick the "I see or suspect the behavior" column. Please print the name for every question. Thank you very much.

1. Does your child avoid eye contact? (I see or suspect the behavior) Yes No
2. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
3. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
4. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
5. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
6. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
7. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
8. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
9. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
10. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
11. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
12. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
13. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
14. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
15. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
16. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
17. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
18. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
19. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No
20. Does your child avoid eye contact when you are talking to him or her? (I see or suspect the behavior) Yes No

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AAP Developmental Screening Recommendations

- The American Academy of Pediatrics (AAP) recommends developmental and behavioral screening for all children during regular well-child visits at these ages:
 - 9 months
 - 18 months
 - 30 months
- In addition, AAP recommends that all children be screened specifically for ASD during regular well-child visits at these ages:
 - 18 months
 - 24 months

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Your child at 18 months*

Child's Name _____ **Child's Age** _____ **Today's Date** _____

Milestones matter! How your child plays, learns, speaks, acts, and moves offers important clues about his or her development. Check the milestones your child has reached by 18 months. Take this with you and talk with your child's doctor at every well-child visit about the milestones your child has reached and what to expect next.

What most children do by this age:

<p>Social/Emotional Milestones</p> <ul style="list-style-type: none"> <input type="checkbox"/> Moves away from you, but looks to make sure you are close by <input type="checkbox"/> Points to show you something interesting <input type="checkbox"/> Puts hands out for you to wash them <input type="checkbox"/> Looks at a few pages in a book with you <input type="checkbox"/> Helps you dress him by pushing arm through sleeve or lifting up foot <p>Language/Communication Milestones</p> <ul style="list-style-type: none"> <input type="checkbox"/> Tries to say three or more words besides "mama" or "dada" <input type="checkbox"/> Follows one-step directions without any gestures, like giving you the toy when you say, "Give it to me." <p>Cognitive Milestones (learning, thinking, problem-solving)</p> <ul style="list-style-type: none"> <input type="checkbox"/> Copies you doing chores, like sweeping with a broom <input type="checkbox"/> Plays with toys in a simple way, like pushing a toy car 	<p>Movement/Physical Development Milestones</p> <ul style="list-style-type: none"> <input type="checkbox"/> Walks without holding on to anyone or anything <input type="checkbox"/> Scribbles <input type="checkbox"/> Drinks from a cup without a lid and may spill sometimes <input type="checkbox"/> Tries to use a spoon <input type="checkbox"/> Climbs on and off a couch or chair without help <p><small>* It's time for developmental screening! At 18 months, your child is due for general developmental screening and an autism screening, as recommended for all children by the American Academy of Pediatrics. Ask the doctor about your child's developmental screening.</small></p> <p style="text-align: right;">https://www.cdc.gov/ncbddd/actearly/pdf/FULL-LIST-CDC_LTSAE-Checklists2021_Eng_FNL2_508.pdf</p>
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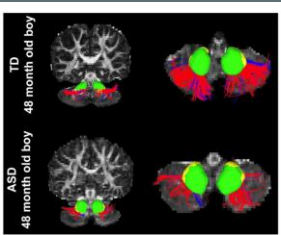
Etiology

Pathogenesis is not completely understood.

Genetics

- May alters brain development and connectivity.
- Multiple genes are responsible for ASD with genetic and environmental factors that contribute to variable expression.
- MRIs indicate that ASD individuals use different patterns of connectivity, cognitive strategy, and brain areas to process information.

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TD 48 month old boy
ASD 48 month old boy

Figure 1. Reduced connectivity between the posterior-lateral cerebellar cortex with the dorsal striatum nucleus (red) and the ventral striatum nucleus (blue) in a boy with autism spectrum disorder (bottom) compared with a typical developing boy (top). (Reproduced with permission from the author, Joong et al.¹⁶)

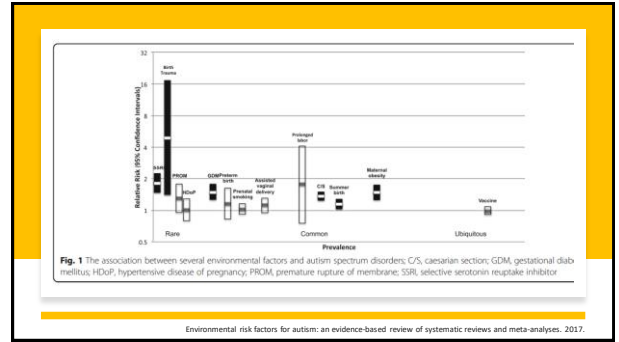
Visual function in autism spectrum disorders Bakroon and Lakshminarayanan

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Risk Factors

- Having a Sibling with ASD
- Genetic or Chromosomal Conditions
- Perinatal Complications
- Parental Characteristics
- Male

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Increasing exposure to antibody-stimulating proteins and polysaccharides in vaccines is not associated with risk of autism

Frank DeStefano¹, Catherine S. Poole, Eric S. Weitzsaecker

Affiliations: ¹ required
PMID: 22945498 DOI: 10.1016/j.jaac.2013.02.001

Abstract

Objective: To evaluate the association between autism and the level of immunologic stimulation received from vaccines administered during the first 2 years of life.

Study design: We analyzed data from a case-control study conducted in 3 managed care organizations (MCOs) of 276 children with autism spectrum disorder (ASD) and 722 control children matched on birth year, sex, and MCO. In addition to the broader category of ASD, we also evaluated autistic disorder and ASD with regression. ASD diagnoses were validated through standardized in-person evaluations. Exposure to total antibody-stimulating proteins and polysaccharides from vaccines was determined by summing the antigen content of each vaccine received, as obtained from immunization registries and medical records. Potential confounding factors were ascertained from parent interviews and medical charts. Conditional logistic regression was used to assess associations between ASD outcomes and exposure to antigens in selected time periods.

Results: The odds ratio (OR) of ASD associated with each 25-unit increase in total antigen exposure was 0.998 (95% CI: 0.996-1.002) for cumulative exposure to age 1 month, 0.998 (95% CI: 0.997-1.002) for cumulative exposure to age 1 month and 0.998 (95% CI: 0.996-1.002) for cumulative exposure to age 2 years. Similarly, no increased risk was found for autistic disorder or ASD with regression.

Conclusions: In this study of MCO members, increasing exposure to antibody-stimulating proteins and polysaccharides in vaccines during the first 2 years of life was not related to the risk of developing an ASD.

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Demographic Data

- Race and Ethnicity**
 - Prevalence does not differ across racial and ethnic groups.
 - Delay in diagnosis noted in ethnic minorities in numerous countries
 - Negative effect on developmental and educational support
- Socioeconomic Status**
 - Differs by country and region
 - May relate to poverty rates
 - Concerns with access to services and education

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ASD Comorbidities

- Intellectual Disabilities
- Seizures
- Fragile X Syndrome
- Tuberous Sclerosis
- Down Syndrome
- Cerebral Palsy
- Neurofibromatosis

20% with ASD are diagnosed with a psychiatric disorder by adulthood

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Study to Explore Early Development (SEED)

- Compare physical and behavioral characteristics of children with ASD, developmental disabilities, and without a developmental delay or disability
- Health conditions among children with and without ASD
- Factors associated with a child's risk for developing ASD
- 2021-2026 SEED Follow-Up Study: Aims to learn more about the health, functioning, and needs of children with ASD as they mature and how to better support families

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SEED Findings: Factors Associated with ASD

- Mother and child autoimmune conditions, such as eczema/psoriasis
- Pregnancy factors, such as infection with fever in the second trimester of pregnancy
- Environmental factors, such as the interaction between air pollution and neighborhoods with high poverty

Children with ASD are also more likely to have:

- developmental delays
- gastrointestinal issues
- sleep problems
- engage in self-harming behaviors

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Treatment

Treatment Goals: reduce symptoms that interfere with daily functioning and quality of life

Treatment Options

- Behavioral
- Developmental
- Educational
- Social-Relational
- Pharmacological
- Psychological
- Complementary and Alternative

Treatment typically involves multiple professionals and is catered to each individual ASD patient.

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Cognitive Abilities

- Intelligent Quotient Testing
- Intellectual Disability vs. High-Functioning

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IEP Vs. 504 Plan

Individualized Education Plan

- Federal special education law
- A child with delayed skills or other disabilities may be eligible for special education services in school.
- Qualify with one or more of the 13 specified disorders listed in IDEA that affects the child's performance in the classroom
- Often includes goals, services provided and their frequency, assessment modifications, and personnel

504 Plan

- Federal civil rights law to stop discrimination against children with disabilities.
- A plan that addresses how a child will have access to learning at school.
- The child has a disability that is hindering his performance in the general classroom but does not need specialized instruction.
- More often changes are made to the learning environment (accommodations)

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Autism Spectrum Disorder – Ocular Associations

- Refractive Error
- Binocular Testing
- Accommodative Testing
- Oculomotor Testing

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Refractive Error with ASD

Study	Year	Number and gender with ASD	Astigmatism (%)	Hypermetropia (%)	Myopia (%)	Other findings (%)	Study type
Scharne and Oredson ⁷¹	1992	32 M 2 F	17.6	17.6	8.8	5.8% anisometropia	Prospective
Dennis et al. ⁷²	1997	4 M 6 F	60	70	-	60% strabismus	Prospective
Hedda et al. ⁷³	2013	122 M 32 F	3.89	16.88	5.8	1.95% anisometropia	Retrospective
Black et al. ⁷⁴	2013	44 3:1 M:F	18.2	9.09	11.36	6.81% anisometropia	Retrospective
Exequeri et al. ⁷⁵	2014	13 M 5 F	22.2	11.1	-	-	Retrospective

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Binocularity Findings with ASD

- Eye alignment – more exophoric at near
- Receded NPC
- No differences in vergence amplitudes
- Subtle reduction in stereoacuity

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Strabismus with ASD

Higher incidence of strabismus compared to typical population

- Anketell et al (2018) – 11% with greater exo deviations
- Wang et al (2018) - 16.1% with greater eso deviations
- Black et al (2013) – 41% with greater exo deviations
- Denis et al (1997) – 60% with greater exo deviations

Concern for amblyogenic risk factor

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Accommodative Findings with ASD

- Significant lag of accommodation for patients with ASD (17.4%) relative to control group (4.9%)
- Association with accommodative disorders and near work complaints



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Oculomotor Findings with ASD

- Studies show deficits in saccades, pursuits, and fixations in patients with ASD.
 - Lack of maturation of cortical networks in ASD?
 - Inconsistent findings
- Lack of appropriate eye gaze and joint attention could be used as a biomarker for ASD diagnosis.

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Before Starting an Exam

- A successful visit often begins before you ever see the patient.
- Staff training for awareness of ASD and appropriate interactions during office visits.
- Consider the best time to see these children given your schedule – Limit wait time!
- Consider a quieter location to wait.
- It may be beneficial to have the caregiver complete the forms prior to the exam.

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Pre-Examination Questions

Patient's mode of communication?

Any sensory triggers?

Any motivations?

Proactive behavioral strategies used before?

Negative behaviors?

Echolalic?

Follow directions?

Able to answer questions?

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History Questions

Any developmental delays including motor, speech, language, social, and cognitive?

Any other therapies such as occupational, physical, speech, etc?

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Eye Examinations with Autism

- Test reliability was high for patients with ASD (88-100%)
 - Ability to perform visual acuity at distance/near, stereoacuity
- Difference noted in testability with IOP (71 vs 89%)
 - IOP testability varied greatly with verbal communication level (37% in non-verbal and 44% in short word skills)

Clinical measure	Communication level, n (%)		
	Verbal (n = 17)	Uses short words (n = 9)	Nonverbal (n = 8)
Visual acuity test—distance			
Snellen	16 (94)	4 (44)	4 (50)
Lea crossed symbol	1 (6)	5 (56)	4 (50)
Could not complete	0	0	0
Visual acuity test—near			
ETDRS	13 (76)	2 (22)	2 (25)
Lea	4 (24)	7 (78)	4 (50)
Could not complete	0	0	2 (25)
Stereoacuity			
Random Stereotest	11 (65)	9 (100)	3 (38)
Random Dot E	6 (35)	0	1 (12)
Lang I	0	0	3 (38)
Could not complete	0	0	1 (12)

Eye Testing of Children with Autism. Coulter et al 2021.

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Examination

- **Visual Acuity:** Consider non-verbal techniques including matching (Lea or HOTV)
- **Ocular Motility:** Saccades and pursuits
 - Hypometric saccades with compensatory head/body movement
 - May experience difficulty with holding fixation
- **Ocular Alignment:** difficult with poor fixation, consider your target
 - Hirschberg if necessary
- **Accommodation:** Objective testing (MEM) may be most accurate, lag of accommodation is common.
- **Refractive Testing:** Objective testing, videos, and loose lenses may be helpful to most accurately determine refractive error.
- **Ocular Health:** Many are light sensitive, consider hand-held slit lamp, BIO, or MIO

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Communication Supports

- Be Clear and Concise
- Set Clear Expectations
- Respectful, Neutral Tone
- Use Visuals (Pictures, Pointing, Gestures, etc)
- Praise Often

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Other Examination Considerations

- Consider Talk-Pause technique and Show-Tell-Do
- Reinforce items throughout
- Consider a shortened visit or taking a break
- End on a positive note

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Important Keys for Examining Patients with ASD

- ✗ ASD should not automatically limit your exam – Be flexible.
- 🧘 Remain calm.
- 👤 Demonstrate techniques before performing or on another person.
- ⚠ Be cautious of "look at me".
- ⚠ Some tests may need to be modified if fixation is an issue – often will not look at clinician.
- ⚠ Know when to throw in the towel BUT ALWAYS END ON A POSITIVE NOTE.
- 👤 Know when to refer to another doctor.

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Communication Tools



Use of visual supports such as a social story or visual schedule



Video to view before exam encounter

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After this, we played a matching game, and I had to point to what I saw on the TV. While I know some of my letters, it was hard to see those for this game.

Then I got on special glasses to look at this book to check my depth perception. Some of the pictures looked like they were 2D.

The doctor then looked at my eyes while he covered them with this paddle. He said it was to check for stray eye turn.

Next, I pointed to some shapes in a book and even got to trace them. This was used to look at my color vision.

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Optometric Treatment and Education

Treatment

- Do not avoid giving glasses just because you do not think the patient will respond.
- Talk about adaptation to the frames and lenses.
- Consider the type of frame – sensory issues, frame adjustment, period of adjustment to glasses

Education

- Don't say "For an autistic child..."
- Instead "Everything is normal for your child"
- Do NOT identify the child by the condition!

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Lecture Summary

- At least 1 in 36 children in the United States have been diagnosed with Autism Spectrum Disorder (ASD).
- Patients with ASD can vary, but ASD often affects how a patient behaves, communicates, interacts, and learns.
- Patients with ASD are known to have a higher incidence of ocular conditions such as strabismus and accommodative dysfunction.
- It is important to be aware of techniques to help your patient feel most comfortable and maximize your exam's effectiveness.

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