Handout for the Therapro webinar
Beyond 20/20: Understanding the Nuances of Vision for Daily Living
presented by Alexis G. Malkin, O.D., F.A.A.O. - May 13, 2025

Beyond 20/20: Understanding the Nuances of Vision for Daily Living

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Learning Objectives

1. Review the most common causes of vision impairment (VI) in individuals with disabilities (IWD)
2. Discuss the differences between routine eye exams and exams to assess functional vision
3. Discuss the role of functional vision throughout a person's daily life

Prevalence

In the USA, 17% have developmental disability, 1.2% have intellectual disability

(Zablotsky B et al, 2019; CDC; Foundation for People with Learning Disabilities)

- It is estimated that 40 - 75% of individuals with ID have vision impairment. (Li, J. et al., 2015)

~860,000 (12.5%) of individuals in Mass are diagnosed with Intellectual and Developmental Disabilities.

(2022 Disability Statistics Compendium)

- 136,000 (15.7%) have a visual impairment

Pediatric Vision Impairment

Babies Count – Birth to 3 years

- 19 States, n= 755
- 2022 Results
  - Cerebral Visual Impairment
  - Optic Nerve Hypoplasia
  - Retinopathy of Prematurity
  - Structural abnormalities

⅔ of children had other disabilities

- Neurological: 64.6%
  - ASD, CP, Seizures
- Global syndrome: 9.8%
  - Chromosomal, Genetic, Birth defect
- Endocrine disorders: 7.2%
- Deaf or hard of hearing: 7.8%
- Feeding problems: 30.6%
- Other: 33.4%
  - Cancer, Respiratory, Born with addiction, etc

Snyder, D., Rife, D., & Lyle, L. (2022). *Babies Count National Registry of Children with Blindness or Visual Impairment, Aged Birth to 36 Months: 2022 Results.* Babies Count. https://babiescount.org

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Developmental Milestones

Age	Normal visual development	Signs of possible visual impairment
Birth-4 months	Focusing on and tracking familiar objects	Decreased sensitivity to bright light, absent or delayed blink reflex to threat or light, slowed development of intentional social smile, nystagmus
5-8 months	Depth perception, facial recognition, color vision	Delayed or absent eye contact, failure to fixate on objects or familiar faces, strabismus
9-24 months	Hand-eye coordination, grasping objects, crawling	Lack of awareness of own hands, absence of goal directed hand and/or arm movements
>24 months	Crawling, walking, exploring the environment	Clumsiness with crawling, difficulty reaching toys, holding objects close to the face, problems navigating curbs or steps
School-age	Reading	Difficulty with reading, complaints of headache

eyewiki.org

Understanding the causes of Vision Changes in IWD

Ocular Causes

- Refractive Error
- Strabismus
- Oculomotor Dysfunction and BV Concerns
- Eye disease/pathology
  - Keratoconus
  - ON Hypoplasia
  - ROP
  - CHARGE

Brain-based Vision Impairment

- Cerebral Vision Impairment

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Refractive Error

- "Needing glasses"
- Myopia, hyperopia, astigmatism, and presbyopia
- Early identification is important to prevent amblyopia ("lazy eye")
- 60% of people with disabilities have refractive error
- Over age 45 it is nearly 100% (presbyopia)

- Determined by the length of the eye, the power of the internal lens, and the curvature of the cornea (clear part at the front of the eye)

What would make you think about refractive error?

- Squinting and eye rubbing
- Getting very close to an object or pushing something further away
- Family history of early eyeglass wear
- Common conditions associated with refractive error: Cerebral Palsy, Down Syndrome, and others

What are the consequences of uncorrected refractive error?

- Impact on learning, depth perception, overall functional development
- Orientation to space
- Communication
- Amblyopia

Addressing Refractive Error and Ambylopia

- Prescribing glasses
- Contact lenses?
- Patching?
- Eye drops?
- Desensitization?

Desensitization

Goal: Increase patient comfort and participation by acclimating them to tasks/activities over time to increase their sensory tolerance

- Glasses wear
- Accepting eye drops
- Allowing eyes/ lids to be touched

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Strabismus

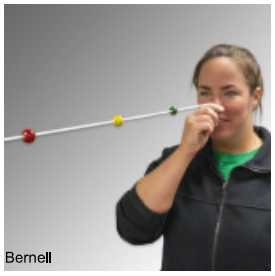
- An eye turn (in/out/up/down)
- Sometimes called a “lazy eye”
- Variable prevalence: 26.5%-44.1% (Karadag et al., 2007; van Splunder et al., 2004)
- Signs:
  - Squinting
  - Closing/covering an eye
  - Seeing the eye drift (can be especially notable when someone is tired or ill)
- Symptoms:
  - Depth perception issues
  - Double vision
  - Eye fatigue

- Consider in:
  - Autism
  - Cerebral Palsy
  - Down Syndrome
  - Prader Willi Syndrome
  - Others

- Treatment:
  - Glasses
  - Patching
  - Vision Therapy
  - Surgery

Binocular Vision Concerns

- Can have issues focusing with both eyes even without an eye turn
- Multiple visual systems involved
  - Accommodation
  - Vergence
  - Oculomotor dysfunction (OMD)
- Not a lot of data on prevalence but anecdotally common especially OMD

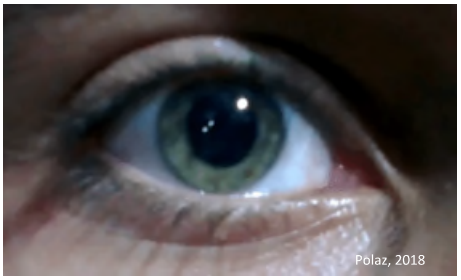


- Signs and Symptoms
  - Difficulty keeping one’s place/using a finger to guide when reading
  - Difficulty tracking and shifting focus from distance to near or vice versa
  - Blurry vision
  - Double vision
  - Increased strain/fatigue with extended near tasks
- Consider in:
  - Autism
  - ADHD
  - Cerebral Palsy
  - Down Syndrome
  - TBI

Nystagmus

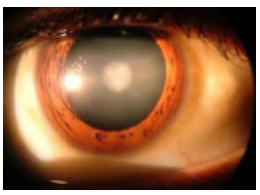
- Regular, involuntary rhythmic eye movements
- Occurs in many types of congenital eye diseases (e.g. albinism)
- Also consider in Down Syndrome, Cerebral Palsy

- Signs/Symptoms:
  - Noticeable eye movements
  - Adjusted head postures/eye positioning
  - More obvious with fatigue/illness
  - If acquired: sensation of the world moving



Eye diseases: front of the eye

- 35% of IWD may have significant findings in their anterior segment/front of the eye
- Eyelids~ 18%
  - Blepharitis
  - Congenital ptosis
- Lens opacities/cataracts ~17%
- Dry eye



Karadag et al., 2007

- Signs/Symptoms
  - Blurry vision
  - Cloud appearance
  - Excessive tearing
  - Discharge
  - Light sensitivity
  - Variable vision especially with lighting changes
  - Worse function in low lighting or in highly glaring environments (facing a window, in grocery stores, in school gyms)

Eye diseases: front of the eye

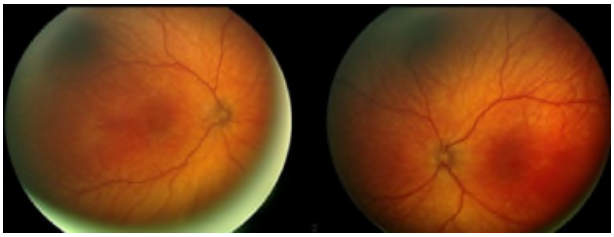
- More common in:
  - Autism
  - Down Syndrome
  - Individuals with frequent eye rubbing, eye poking, and other similar behaviors
- Treatment Strategies:
  - Ensure that the eyes are comfortable (i.e. treat the dryness, allergies, etc)
    - Can use OTC eye drops to help manage
  - Good lid hygiene
  - Frequent hand washing
  - Trimmed nails
  - Possible Rx medications if there is significant redness, discharge, or other signs

Eye diseases: front of the eye

- Keratoconus
  - Significant astigmatism with changes to the cornea (front surface of the eye)
  - Associated with eye rubbing
  - Also associated with Down Syndrome
- Symptoms:
  - Blurred vision especially that can't be corrected with glasses
  - Glare sensitivity
  - Pain?
- Treatment:
  - Corneal Cross-Linking
  - Specialized Contact Lenses
  - Reduced eye rubbing

Eye Diseases: Optic Nerve

- Optic Nerve Hypoplasia (ONH) and Septo-Optic Dysplasia
  - ONH can occur in isolation (1:10,000) but can also occur with SOD and CP



- Septo-Optic Dysplasia (DeMorsier Syndrome) are less commonly used terms
- Associated with variable brain abnormalities especially hypothalamus and pituitary
- Signs:
  - Nystagmus
  - Variable vision (NLP to near normal vision)

https://rarediseases.org/rare-diseases/optic-nerve-hypoplasia/

Eye disease: back of the eye (retina and optic nerve)

- **13.8%** have posterior segment findings (Karadag et al., 2007)

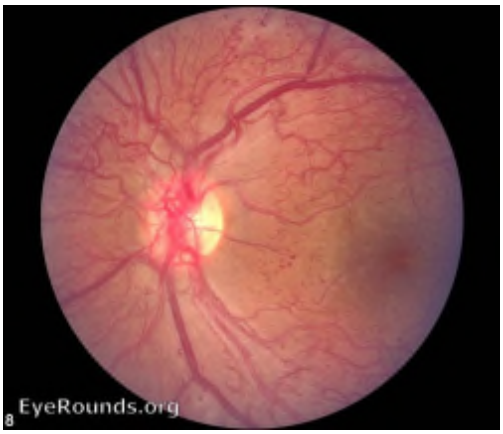
- Tilted disc 4.8%
- Myelinated nerve fiber 1.8
- Optic atrophy 1.2%
- Large C/D ratio 1.2%
- Tortuous blood vessels 1.2%

Glaucoma

- Prevalence values vary
  - **0.8% to 1.19%** of individuals with intellectual disability (Aslan, L. et al., 2013; Li, J., et al., 2015; Warburg, M., 2001)
- 11.5% of individuals with Down Syndrome (Yokoyama et al., 2006)
- 11.8% glaucoma suspects in high school students with ID in Taiwan Chang et al., 2005)

Eye disease: back of the eye

- **Diabetes Mellitus**
- **1.5x** more likely to develop diabetes
- It is estimated that up to 16.3% of adults with IDDs have diabetes, compared with only 7.2% of their counterparts without IDDs (Oyetoro et al., 2023)



Eye disease: back of the eye
Retinitis Pigmentosa

- Progressive photoreceptor degeneration
  leading to peripheral visual field loss, vessel tortuosity, and increased risk of cataracts

- Bardet-Biedl Syndrome (Tatour et al., 2017)
- 50% of individuals with B-B have IDD
- IDDRP: Intellectual developmental disorder and retinitis pigmentosa
  - Co-occurring ADHD

Eye disease: back of the eye

- Symptoms:
  - Flashes and floaters
  - Blurred vision
  - Loss of color vision (especially with optic nerve conditions and macular conditions)
  - Night blindness
  - Loss of peripheral vision
- Impact on Daily Living
  - Increased social isolation
    - Especially with worsening vision in dim and dark conditions
    - With reduced facial recognition
  - Worsening mobility
  - Increased glare complaints

Brain-Based Vision Impairment (CVI)

Cerebral Visual Impairment (CVI): Neurological visual impairment relating to visual perception and processing; often related to early brain injury

- **Consider for:**
  - Autism
  - Cerebral palsy
  - Down Syndrome
  - Epilepsy
  - Fetal alcohol syndrome
  - Premature birth
  - HIE
  - Other genetic syndromes

Impact of CVI

Types?

- Complexity
- Motion processing
- Visual attention
- Variable visual field
- Visually guided movement

CVI in Daily Life:

- Not looking at objects they are working with/looking away when reaching
- Difficulty in crowded/complex and/or new environments
- Difficulty finding or running into otherwise obvious objects

How do we examine individuals with disabilities?

- Same way we examine all individuals!
  - With some modifications
- Goals:
  - Collect clinical data
    - Visual acuity
    - Visual fields
    - Refraction/Glasses Rx
    - Contrast sensitivity
  - Assess the ocular health
    - Pupils
    - EOMs
    - Eye Pressure
    - Dilation
- Collect Functional Data
  - Use of vision for working, navigating, learning
  - Puzzles and games (and lots of doctor observation)
  - Surveys/Extended histories
  - Functional fields

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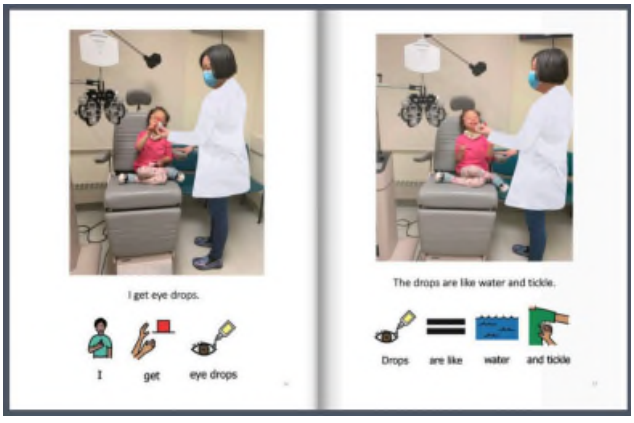
Criticality of History/Review of Medical Conditions

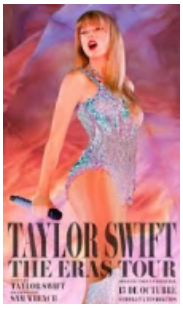
- When possible, the provider will review past eye exams and other medical records
- Providing the IEP can help address specific concerns in the exam
- Rarediseases.org can help identify specific ocular findings to be addressing

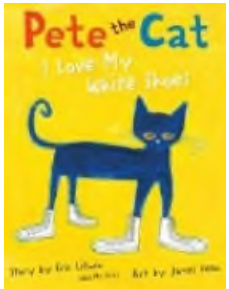
NORD®
National Organization for Rare Disorders

Prepping the patient

- Social stories with pictures of the space
- Extra time to allow for acclimatizing
- Use favorite music/videos/toys to get comfortable







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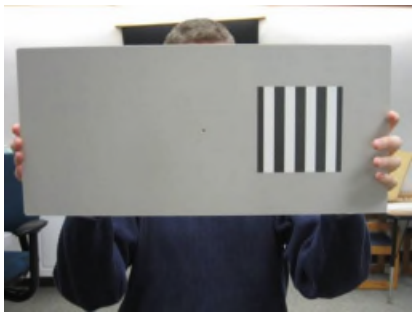
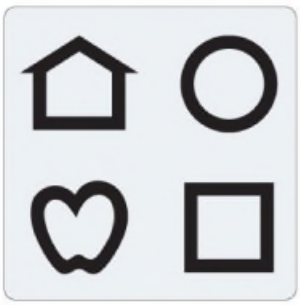
Performing the Exam

- Observation is key!
  - How do they navigate the space?
  - Head tilts or turns?
  - Independent navigation or relying on someone else
  - Any mobility aids?
- Communication
  - Verbal or non-verbal
  - Lots of narration of the steps of the exam

Measuring vision

- Lots of strategies:
  - Preferential looking
  - Matching
  - Naming (numbers, letters, shapes)
  - Can be done in free space/outside the exam room





Modified content from B. Kran 2022

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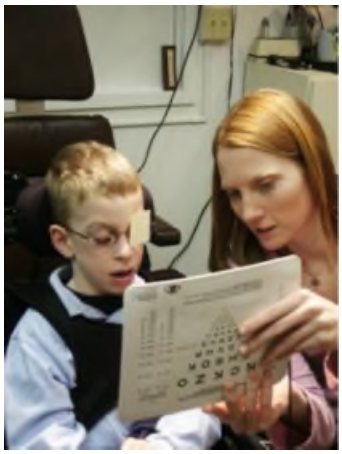
Measuring Vision

- Start with both eyes and then work towards each eye
  - Both eyes is a more functional measure but still need each eye when obtainable
  - Sticky note, sticky patch, tissue, hand, occlude to cover an eye
- Often done in full lighting but can be done in dim lighting to direct the attention to the chart



Modified content from B. Kran 2022

Measuring Contrast

- Contrast is often thought of as the most “real world” measure of vision
- Helps with object detection and with changing thresholds
- Most eye exams use only high contrast materials
- Contrast varies in variable lighting
- Critical for facial identification

Singapore Eye Institute

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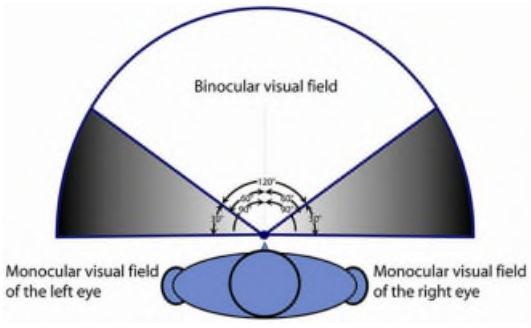
Measuring Contrast

Dr. Luisa Mayer
NECO Center for Eye Care at Perkins

Bernell

Assessing Visual Fields



- Ask about bumps/trips/stumbles
- Ability to use full screen of an AAC
- Comfortable in gym classes, crowded environments
- Ask about visual search skills

Assessing Visual Fields

- Static or kinetic
- Often done with both eyes open (best functional assessment)
    - Standard exam is usually each eye individually
- Try to incorporate motivating targets or at least something motivating to maintain attention
- Often done as a team

Use of puzzles/games

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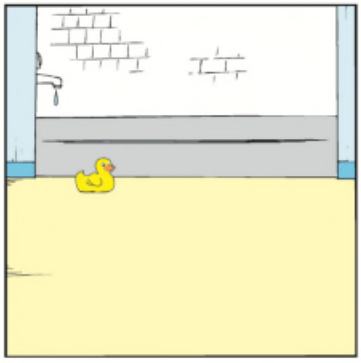
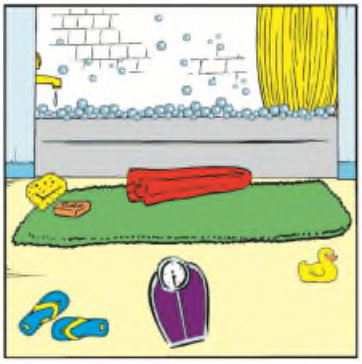
Measuring Ability to Process Complexity





Assessing Binocular Vision and Eye Movements

- Interesting targets:
  - Following a favorite toy, phone with a video, etc
  - Follow flickering toys (make sure it isn't a seizure trigger)

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Color Vision

Eye Health Evaluation

- Free space - use of hand held equipment
- Portability
- “Out of chair” capability
- Less intimidating
- Allows for optimal position for patient

- Drop prep

Use of Vision in Daily Life

- Remember that ALL of the testing is designed to help the person use their vision in the many aspects of daily life
- Will come up with a plan for school, work, home, mobility, and for ADLs/IADLS
- Be sure to check in on mental health, coping, and support systems
- Visits must be patient-centered
- For some people, multiple visits are needed to get a complete picture of the person and their use of vision

Questions?

Special thanks to Dr. Jem Martin for their assistance with slide preparation