

**TRANSITION OF CARE:
WHY? WHEN? HOW?
An AAP-sponsored workshop**

Gregg T. Lueder, MD

Sheryl Menacker, MD

David Epley, MD

Alex Levin, MD

Dan Karr, MD

Mary Louise Collins, MD

None of the panelists have financial interests in the material in this presentation

TRANSITION OF CARE- EXAMPLES FROM PEDIATRICS

- **Complex congenital heart disease**
 - Improved survival
 - Adult cardiologists with no experience

- **Pediatric cancer**
 - Long-term survivors
 - Late effects clinics

A BYPRODUCT OF SUCCESS

- **Complex patients**
 - **Down syndrome**
 - **Congenital heart disease**
 - **Developmental delay**
- **Need for system-wide implementation of programs**

THE ACADEMIC APPROACH: FORMAL CONCEPTS - SIX CORE ELEMENTS

- 1. Transition policy (12-14 years)**
- 2. Transition tracking**
- 3. Transition readiness**
- 4. Transition planning**
- 5. Transfer of care (18-21 years)**
- 6. Transition completion**

WHY IS OPHTHALMOLOGY DIFFERENT?

- **Single organ system**
- **Adult specialists often care for pediatric patients**
- **Many pediatric ophthalmologists care for patients with complex ocular disorders**

DISORDERS THAT PEDIATRIC OPHTHALMOLOGISTS MANAGE

Disorder	% of respondents who manage
Ptosis and anterior orbital lesions	68%
Cataracts	49%
Uveitis	38%
Retinopathy of prematurity	25%
Glaucoma	19%
Retinoblastoma	7%

BVOM (in press)

FOR MOST OF US

- **Doesn't need to be that complicated**
- **Why is ophthalmology different?**
 - **Single organ system**
 - **Adult specialists often familiar with pediatric eye diseases**
 - » **Many care for all ages**

IN A NUTSHELL

- 1. Make patients and families aware of your policy a few years before the transition**
- 2. Identify willing providers**
- 3. Transfer care**
- 4. Provide a lifeline**

ISSUES TO CONSIDER

- **Different types of pediatric ophthalmology practices**
 - Private practice vs academic
 - Competition
- **Availability of providers**
 - Comprehensive vs specialists
 - OD vs MD
- **Children with special needs**

POTENTIAL BARRIER- FINDING A WILLING PROVIDER

- **Sometimes difficult**
 - **Practices too busy**
 - **Don't want to deal with pediatric problems**

POTENTIAL BARRIER- FAMILIES MAY NOT WANT TO LEAVE YOUR PRACTICE

- **Discuss this a few years before**
- **Remind families prior to last visit**
- **Frame it as a good thing**
 - **Sign of maturing**

POTENTIAL BARRIER- HEALTH INSURANCE

- **Currently young adults can be on parents' insurance plan until age 26**
- **Medicaid coverage varies**
 - **Usually more difficult to get coverage when older**

MEDICOLEGAL

OK to limit type of care as long as:

No discrimination or violation of ADA

No contractual obligations

**If patient physician relationship established
must notify when no longer provide care:**

Oral, handout, written letter

MEDICOLEGAL


- **Pediatric patients with complex conditions**
 - **Formal handoff recommended**
 - **Coordinate in advance of transfer**
 - **Send information to new MD**
 - **Few but DIFFICULT**

THINGS YOU MIGHT NOT THINK ABOUT: 18 YEARS OF AGE

- **Patients are considered adults**
 - **Can make their own health decisions**
- **HIPAA rules start to apply at age 18**

Specialized Eye Care for Special Needs Patients:
Why it's Important, Why Everyone Wins, and
What to Do When Your Patients Age Out of Pediatric Care

Sheryl J. Menacker, MD
Emory University
AAPOS/AAP Workshop: Transition of Care - Why? When? How?
AAPOS 48th Annual Meeting - New York, NY
March 31, 2023



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Financial Disclosures/Interests

None – except for an interest in the cost of airfare between Philadelphia and Atlanta



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Objectives

Report the:

- Demographics
- Types and prevalence of visual/ocular pathology

For patients seen in Emory's outpatient eye clinic patients with disabilities

Discuss:

Why dedicated eye care is important for individuals of all ages with disabilities

- Who should do it
- How it can be done in both university-based and private practice settings

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Background

How caring for residents at a residential facility for individuals with disabilities in the Philadelphia suburbs morphed into an eye clinic for patients with disabilities at the Emory Eye Center in Atlanta. . .

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• Multispecialty ophthalmology practice in suburb of Philadelphia from 1992-2021

Woods Services

- Residential facility for individuals of all ages with disabilities of any type, congenital or acquired
- In suburbs of Philadelphia
- 600-800 residents
- Annual eye exam mandated by PA law
- Clinic there once/month from 1996-2019






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Background

Invited to join the pediatric ophthalmology team at Emory University in Atlanta and happily accepted to set up a clinic for individuals of all ages with disabilities because I loved and had experience working with this patient population and. . .

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... truth be told, a great way to visit my kids and grandkids who lived in Atlanta on a regular basis



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Background

Why have a dedicated clinic for patients with disabilities at all?

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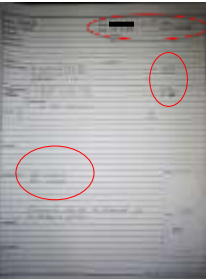
Sarah

- Intellectual disability due to congenital rubella
- Entered residential facility December 1985 at age 22
- Always hungry

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First Eye Exam

- Yearly eye exams from 1/24/86 by same examiner
- No IOP or dilated fundus exam documented for 12 years until...
- Different examiner 4/2/98:
 - Va?LP OD, 20/200 OS
 - +APDOD
 - Tan 4.0 OD, 2.2 OS
 - DfE: total cup OD, increased cupping OS
- Blind OD -glaucoma**



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Sarah – just needed a little food

- Was wearing -5.75 + 1.50 X 175 OS; Va 20/200 Allen chart
- Cycloplegic refraction OS: -11.50 +2.00 X165; Va 20/40+3 Allen chart
- Glaucoma now managed by glaucoma specialist with topical medication: Va NLP OD but no apparent further progression OS
Glaucoma keeps snacks on hand for her – Combos are a favorite. Has never needed an EUA.
- Eventually developed dense cataract OS and had cataract extraction/IOL 8/14/13
- 2019 exam: Va OS 20/40+ without correction, IOP's well controlled

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Lynn

- 52 year old with history of CP due to anoxia at birth
- Cared for by mother until age 50, when Mom died
- Wheelchair bound
- Cannot walk, talk, or care for her needs in any way
- Communicates by moving head toward pictures on lap board on her wheelchair
- Presented January 2015 to Emory Eye Center clinic for individuals with disabilities with aide, who stated she did not think Lynn saw very well until things were close
- Has never worn glasses
- Last eye exam was sometime in early childhood

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Lynn

Cycloplegic Retinoscopy:

OD: -16.50 +1.00 X 80
OS: -15.00 +1.00 X 85

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Lynn

If all you can do is sit in your wheelchair and look at the world around you, imagine how much better your quality of life would be with glasses when you're a -15.00 myope!

Lynn loved her new glasses. . .
Imagine if she had them since childhood.

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So, why have a dedicated clinic for patients with disabilities?

Because:

There is a high prevalence of visual impairment and ocular pathology in a large cohort of patients who, for the most part:

- Cannot verbalize if there is any problem
- Cannot be easily examined
- Cannot be followed by ordinary testing

Examinations are challenging in this patient population, yet services and eye care professionals willing or able to provide them are scarce.

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Emory Eye Clinic for Individuals with Disabilities

Created to fill the void of specialized eye care for this specialized patient population

To my knowledge, this is the first eye clinic in a University setting specifically for patients of all ages with disabilities in the United States.

- Began January 2014
- Patients with non-emergent eye conditions are scheduled when the clinic is held - once/month from 2014-2017, twice/every other month since 2018
- Patients identified with conditions requiring more immediate attention or follow up care are referred to the appropriate subspecialists.

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**Concept at outset for this clinic:
Win – Win – Win situation**

- A win for the *patients* of all ages with disabilities who get an eye care service that anticipates their needs and schedules ample time for examination
- A win for *eye care providers* whose busy clinic schedules are structured around non-challenging patients who can easily converse and follow directions
- A win for *residents* who get specific training for how to examine this demographic.
 - Regardless of ultimate ophthalmic specialty, will need this skill set to examine difficult patients encountered in their careers

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**So, how did we do? Was it worth the effort?
Did we really help anyone?**

Three years after its inception,

- Patients and their families welcomed a clinic that suited their needs,
- Colleagues utilized this resource for difficult cases, and
- Our ophthalmology residents had the resource available to develop the skill set needed for challenging examinations.

What we did not know was how much we were helping our patients.

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So, how did we do? Was it worth the effort? Did we really help anyone?

- Does data support prior reports of a high prevalence of ocular pathology in patients with disabilities? Most reports in literature are old.
- Is the ability to obtain a full eye exam the exception or the rule in this patient population?
- Do our patients have conditions that are mostly treatable or non-treatable?
- Are we diagnosing new problems or confirming those we already know exist?
- Do most patients just need glasses and otherwise have normal exams?

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Retrospective Chart Review

Emory University IRB00092327
Co-investigators: Sheryl Menacker, MD, Alcides Fernandes, MD, Laura Ward, MSPH
Emory University, Atlanta, GA

- Medical records for all patients examined from January 2014 through December 2016 were reviewed.
- Descriptive statistics were calculated for demographics, visual acuity, visual/ocular diagnoses, non-ocular diagnoses, refractive error, and achievable examination data.
- All exams were performed in their entirety by the same pediatric ophthalmologist (SUM)

Menacker SJ, Fernandes A, Ward L. Prevalence of visual impairment, ocular pathology, and a ability to achieve a thorough examination in an eye clinic for patients with disabilities. JAAPOS 2019. doi: https://doi.org/10.1016/j.jaapos.2019.06.001.

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Methods

Full details of the methods are in the handout for how data was obtained, including:

- Definition of "treatable" vs. "non-treatable" conditions
- Visual acuity
- Intraocular pressure
- Alignment
- Slit lamp exam
- Cycloplegia
- Refraction
- Dilated fundus exam

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Results: Study Population

- Total of 188 patients seen at 293 visits
 - 10 patients erroneously scheduled who did not have any disability
- Total number of patients with disabilities included in this study: 178 patients seen at 281 visits
 - 119/178 (66.9%) patients were nonverbal
 - 11 could communicate through pointing or gestures
 - 108/178 (60.7%) patients could not communicate verbally or nonverbally

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DEMOGRAPHICS	Overall (n=178)
Sex	
Male	121/178 (68.5%)
Female	57/178 (31.5%)
Age at first visit	16.7 (mean; SD=18.8)
Range	0.4 - 99 years
Age group	
0-9yrs	99/178 (55.6%)
10-19yrs	24/178 (13.5%)
20-29yrs	35/178 (19.7%)
30-39yrs	22/178 (12.4%)
40-49yrs	8/178 (4.5%)
50-59yrs	59/178 (33.3%)
Verbal ability	
Verbal	119/178 (66.9%)
Non-verbal	59/178 (33.1%)
Non-verbal, can point/communicate	12/178 (6.7%)
Non-verbal, cannot point/communicate	47/178 (26.4%)
Insurance status	
Medicaid	108/178 (60.7%)
Private insurance	47/178 (26.4%)
Medicare	26/178 (14.6%)
None	3/178 (1.7%)
No insurance/self-pay	2/178 (1.1%)
New patient	122/178 (68.5%)

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Non-Ocular Diagnoses (n=178)

Autism	34 (19.1%)
Down Syndrome	36 (20.2%)
Cerebral Palsy	31 (17.4%)
Intellectual disability (no other specified diagnosis)	20 (11.2%)
Other	169/178 (95%)
Neuropathology	16 (9.0%)
Chromosomal/genetic disorder (non-Down)	12 (6.7%)
Stroke	9 (5.1%)
Hydrocephalus	8 (4.5%)
Diabetes	5 (2.8%)
Metabolic disease	5 (2.8%)
Traumatic brain injury	5 (2.8%)
Mitochondrial disorder	4 (2.2%)
Duchenne	4 (2.2%)
Psychiatric disorder	3 (1.7%)
Encephalopathy	2 (1.1%)
Low-copper syndrome	1 (0.6%)
Parinson's	1 (0.6%)
Craniofacial syndrome	1 (0.6%)
Hemangioma/vascular	1 (0.6%)
Neurofibromatosis	1 (0.6%)

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Ability to Obtain Examination Data, n=178 patients

A complete exam was possible in the vast majority of 178 patients

Slit lamp exam: Achieved in 177/178 (99.4%)
Could not achieve in 1 patient due to cooperation

Cycloplegic refraction: Achieved in 168/178 (94.4%)
Could not achieve in 3 patients due to cooperation
Could not achieve in the remainder due to pathology (corneal, cataract, retinal detachment, phthisis)

Dilated fundus exam: Achieved in 171/178 (96.1%)
Could not achieve in 4 patients due to cooperation
Could not achieve in the remainder due to pathology

IOP: Care/Goldmann achieved in 150/178 (84.3%)

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Overview of Results for Visual/Ocular Diagnoses: n=178 Patients

The meat and potatoes of our study results...

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Overview of Results for Visual/Ocular Diagnoses: n=178 Patients

- 38 (21.3%) had a normal eye exam
- 140 (78.7%) had pathology or refractive error requiring glasses
 - 129 (70.8%) had pathology
 - 14 (7.9%) needed glasses but had no pathology
- Of the patients with pathology,
 - 113/178 (63.5%) had treatable ocular diagnoses
 - 56/113 (49.6%) were newly diagnosed
 - 71/113 (62.8%) were nonverbal
 - 13/178 (7.3%) had only non-treatable diagnoses
 - 6/13 (46.2%) were newly diagnosed
- Together, the 113 patients with treatable ocular diagnoses and 14 patients who needed glasses comprised 127 (71.3%) study patients with a treatable ocular condition.

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What responsibility do we have for our patients with disabilities once they become adults?

As pediatric ophthalmologists, don't we have a responsibility to assure the special needs patients we have followed through childhood have the resource of adequate eye care when they become adults?

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Recommendations: University-based setting

We suggest that in a university-based setting, a dedicated eye clinic for individuals with disabilities staffed by experienced eye care physicians provides a desirable environment for examination because

- The needs of this patient population are anticipated,
- Adequate time is factored into the schedule, and
- It provides the opportunity to teach ophthalmology residents the skills necessary to perform challenging examinations they undoubtedly will encounter in their careers.

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Recommendations: Private Practice

In private practice, setting aside dedicated clinic time for individuals with disabilities is advantageous—even just one session/month

- Smart scheduling: more time allotted per patient than in a regular clinic setting
- Physician and staff anticipate special needs
- Helps prevent running behind when a difficult patient is scheduled in the middle of a busy everyday clinic

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How this works in a university setting

Patients are referred from within the university by:

- Ophthalmologists – comprehensive and subspecialty
- Optometrists
- Neurologists and neuro-ophthalmologists
- Primary care/pediatric physicians
- Genetics
- Other specialties

Patients are referred from outside the university by:

- Primary care/pediatric practices
- Schools
- Specialty centers: Autism, brain injury, other facilities/homes for individuals with disabilities
- Word-of-mouth

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How this works in a university setting

Call center and schedulers must be aware that ONLY patients with disabilities can be scheduled in this clinic

IMPORTANT: For all new patients, schedulers must write comment of some sort in the appointment list regarding the type of disability (Down syndrome, autism, etc.)

Depending on schedulers' turnover rate or knowledge of your clinic, mistakes can be made, so be sure you or a designated person checks the schedule ahead of time for these comments to assure patients are correctly scheduled. Those without a disability will need to be rescheduled to a different clinic. (ROP, strabismus, sickle cell disease/trait, cataract are not disabilities in and of themselves.)

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How this works in a university setting

Patients are scheduled every 30 minutes. Yes, you really need all that time.

At every 30 minutes, you want to minimize your no-show rate, so appointments should be confirmed in advance.

Keep a waiting list, if possible, to fill cancellation spots.

Review appointments beforehand (I usually do this 1-2 weeks in advance)

- To assure each patient scheduled does have a disability and
- You are aware of any diagnosis with which you may be unfamiliar so you can be prepared. (It's sometimes hard to keep up with the newer identified genetic mutations and any possible associated eye findings.)

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How this works in private practice

Patients are referred from within your practice:

- Solo practitioner: schedule your patients with disabilities. *It is also an opportunity to schedule those who have challenging or time-consuming exams.*
- Multi-specialty practice:
 - Patients referred from your associates
 - Your own your patients with disabilities and others who have challenging or time-consuming exams

Patients are referred from outside your practice:

- Primary care/pediatric practices
- Schools
- Specialty centers: Autism, brain injury, other facilities/homes for individuals with disabilities
- Word-of-mouth

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How this works in private practice

Just like in a university setting:

Patients are scheduled every 30 minutes. Yes, you really need all that time.

At every 30 minutes, you want to minimize your no-show rate, so appointments should be confirmed in advance.

Keep a waiting list, if possible, to fill cancellation spots.

Review appointments beforehand (I usually do this 1-2 weeks in advance)

- To assure each patient scheduled does have a disability or is someone you have identified as challenging or needing a time-consuming exam and
- You are aware of any diagnosis with which you may be unfamiliar so you can be prepared. (It's sometimes hard to keep up with the newer identified genetic mutations and any possible associated eye findings.)

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How this works in both university-based and private practice settings

Patients are seen for non-emergency eye care

Those who need routine/regularly scheduled/annual eye care are followed in your regularly scheduled hours for patients with disabilities, at whatever interval works for you (weekly, monthly, every other month).

Those with emergencies, need more immediate follow up, or who need subspecialty evaluation/treatment (Retina, Glaucoma, Cornea, etc.) are referred to an appropriate physician for treatment.

FIND YOUR PEOPLE and cherish them!
Not every eye care professional has the demeanor and/or skill set to treat patients with disabilities. Identify who is good with this patient demographic in your area and refer accordingly. I have one or two glaucoma specialists, retina specialists, comprehensive colleagues, etc. who I know and trust with these patients.

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How this works in both university-based and private practice settings

Be familiar with resources available for those with disabilities in your community:

- Who handles vision services for preschool and school age children?
- Early intervention services for children with developmental delays
 - Children with special needs are usually entitled to receive additional services or accommodations through the public schools. Different states use different criteria for eligibility, so researchers, and providers for the federal laws that mandate a free and appropriate education in the least restrictive environment possible. Familiarize yourself with the criteria in your state.
- Services available for visually impaired adults
- Vision requirements for a driver's license in your state
- Your local facilities/centers for children and adults with autism
- Your local facilities/centers for those with traumatic brain injuries

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Importance for this patient population

Results of our study highlights the importance of eye examinations in individuals with disabilities. While the underlying non-ocular conditions of these patients may not be curable,

- We can prevent additional disability through diagnosis and treatment of vision-threatening disorders and
- We can eliminate the disability of diminished eyesight by providing glasses when significant refractive errors are detected.

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Why have a clinic for individuals with disabilities?

- We owe it to the Sarahs out there so they don't go blind because they were difficult to examine.
- We owe it to the Lynns out there so they don't have the additional disability of poor vision because nobody realized they simply needed glasses.

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Acknowledgements

Many thanks to this study's co-investigators:
Alcides Fernandes, MD
Laura Ward, MSPH



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Supplementary slides with data and results from study

Menacker SJ, Fernandes A, Ward L. Prevalence of visual impairment, ocular pathology, and ability to achieve a thorough examination in an eye clinic for patients with disabilities. J AAPOS (2019). doi: <https://doi.org/10.1016/j.jaapos.2019.06.001>.

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Methods – Data Collection

What Constituted "Treatable" vs. "Non-Treatable" Conditions?


- Conditions for which treatment by an eye care physician is customarily available to provide resolution or improvement were designated as "treatable."
- Ocular conditions that were unable to be rehabilitated and non-ocular visual problems were designated as "non-treatable."
- In an effort to delineate amblyopia in children from long-standing amblyopia in older individuals, an age criteria of ≤17 years was chosen to divide this diagnosis into "treatable" vs. "non-treatable" groups based on previously published results from the Pediatric Eye Disease Investigator Group (PEDIG).*

*Pediatric Eye Disease Investigator Group. Randomized trial of treatment of amblyopia in children aged 7 to 17 years. Arch Ophthalmol. 2004;122:579-87.

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Methods – Visual Acuity

- Visual acuity measured using Lea, HOTV, or Snellen charts in patients who could cooperate verbally.
- If non-verbal but could cooperate, matched distance Lea or HOTV characters to a lap card.
- For patients unable to cooperate for such measurement, fixation and following were assessed by response to visual stimuli. The presence of a fixation preference was determined by preferred eye in those with strabismus and by base down prism testing when strabismus was not present.



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Methods – Intraocular Pressure

- IOP first attempted by iCare, with multiple measurements taken if necessary to document repeatability.
- If unsuccessful or results questionable, Goldmann tonometry was then utilized.
- Finger tension estimate of IOP was documented if unable to be measured by iCare or Goldmann tonometry.

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Methods – Alignment


- Alignment assessed with cover-uncover and alternate cover testing.
- If refraction or cooperation precluded such assessment, alignment was evaluated by corneal light reflexes, measuring with prism when possible when strabismus was present.



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Methods – Slit Lamp Exam


- Slit lamp examination was achieved using portable or standard equipment



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Methods – Cycloplegia/Dilation

- Adults: phenylephrine 2.5% and tropicamide 1%
- Children without history of seizures: combination phenylephrine 2.5%/tropicamide 1%/cyclopentolate 1% drop or tropicamide 1% and cyclopentolate 1%
- Children with history of seizures: phenylephrine 2.5% and tropicamide 1%, repeated once in 10 minutes



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Methods – Refraction

- Refractive error was ascertained by cycloplegic streak retinoscopy, recorded in plus cylindrical notation, and classified as "significant" if it met the age-related criteria defined in previously published guidelines.¹

Age, months	Astigmatism	Hyperopia	Anisometropia	Myopia
12-30	>2.0 D	>4.5 D	>2.5 D	>-3.5 D
31-48	>2.0 D	>4.0 D	>2.0 D	>-3.0 D
>48	>1.5 D	>3.5 D	>1.5 D	>-1.5 D

1. Donahue ST, Arthur B, Newly DE, et al. Guidelines for automated preschool vision screening: a 10-year, evidence-based update. J AAPOS. 2013;17:14-6.

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Controversy


Point of controversy: What is a "significant" refractive error?

- Other studies have reported a high prevalence of significant refractive errors in patients with disabilities, but there is no clear definition of what, exactly, this means.
- Before calculating descriptive statistics for refractive error, we felt it was important to define what "significant" meant for the purposes of this study.
- Since there is no standardized designation for both children and adults, as needed for our patient population, the thresholds for "significant" refractive error were selected from previously published guidelines set for automated preschool screenings, since they were delineated by type of refractive error and could be applied to various ages.
- Adhering to a clearly defined standard for classifying refractive errors is a strength of this study, but one weakness is that it likely underestimates the number of patients with significant refractive error since, for example, the threshold set for hyperopia as >3.0D is probably too high for adults.

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Methods – Dilated Fundus Exam

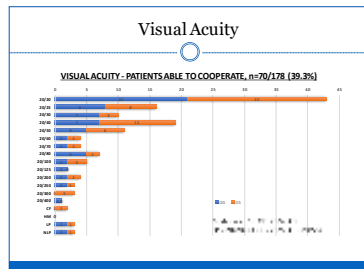
- Indirect ophthalmoscopy performed using 20D lens
- Direct ophthalmoscopy performed if further assessment needed
- If no fundus view was possible and cooperation permitted, B-scan ultrasonography was obtained



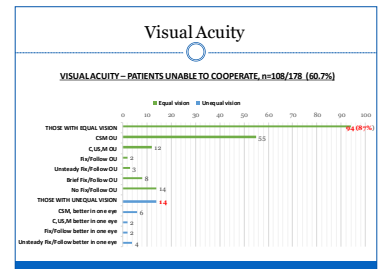
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How well could our patients see?
and
How often did they need glasses?

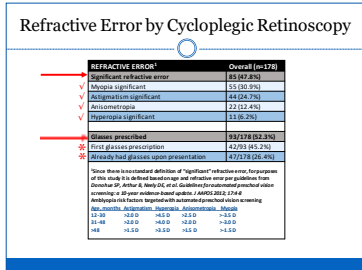
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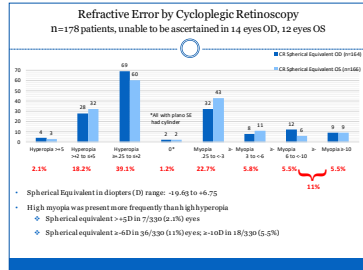
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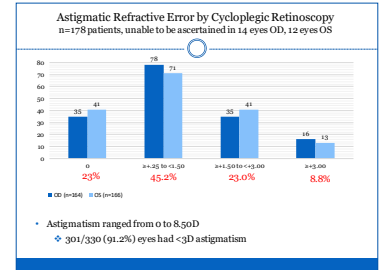
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OPHTHALMIC DIAGNOSIS	Overall (n=178)	New Diagnosis
Strabismus	86 (48.3%)	24/78 (30.8%)
Exotropia	46 (25.9%)	14/38 (36.8%)
Esotropia	28 (15.6%)	10/28 (35.7%)
Intermittent Exotropia	12 (6.7%)	1/12 (8.3%)
Hyperopia	55 (30.9%)	4/55 (7.3%)
Myopia	44 (24.7%)	5/44 (11.4%)
Convergence Insufficiency	21 (11.8%)	0/21 (0%)
Convergence Excess	21 (11.8%)	1/21 (4.8%)
Other Ocular Pathology	12 (6.7%)	1/12 (8.3%)
Other	11 (6.2%)	1/11 (9.1%)

Of the 86 patients with strabismus, there were only 4 who did not have ET, XT, or HT. 2 with only CI, 1 Duane's, 1 with only HT.

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Highlights of what we learned about strabismus in patients with disabilities in our study:

- 50% of our patients had strabismus, our most common ocular diagnosis
- 2/3 of patients with strabismus had other visual/ocular pathology, 41% with treatable problems
- 95% of patients with strabismus had esotropia or exotropia, evenly divided
- There was a high prevalence of strabismus in the 6 disabilities that comprised 95% of our patients
(Autism, Down syndrome, Cerebral Palsy, Intellectual Disability, Neuropathology, Genetic disorder)

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What did we learn?

- Patients with disabilities have a high prevalence of ocular pathology, often treatable and previously unrecognized.
- Strabismus is the most common ophthalmic diagnosis
- Refractive errors are common, frequently accompanied by other treatable conditions.
- Trained providers such as pediatric ophthalmologists can achieve a complete ophthalmic examination in the vast majority of these patients.

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Transition of Care Workshop
 AAPOS 2023 Annual Meeting
 NYC
 K. David Epley, MD

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Disclosures
 Advisory Board – Vyluma
 Employee - Pediatrix

2



Transitions of care can be difficult

3

I'll be covering two types of care transition:

1. Transition of care due to changing/moving/leaving practice
2. Transition of care from pediatric age to adult age



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Transition of practice

- * In 2008, Krista Heidar, MD and I made the difficult decision to leave our practice and venture out on our own.
- * At the time, there were less than 10 pediatric ophthalmologists in Washington State.
- * We chose to move to a suburb of Seattle about 12 miles from the Seattle office at which we practiced. This was partly our decision and partly because of restrictive covenants, which are enforceable in WA.
- * Now, 15 years later, Dr. Heidar is transitioning again, moving to New Mexico.

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ARS Slide #1

6

What are your obligations when changing practices?

- * Both the individual ophthalmologist and the practice have obligations:
- * Steps need to be taken to ensure continuity of care, to prevent allegations of abandonment, and to make sure all involved ophthalmologists have access to records in the event that care is called into question.
- * You must also abide by your contract, state and federal laws.

<https://www.omic.com/leaving-practice-toolkit/>

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Things to consider in transition

- * Decide when to stop performing surgery
- * Notify patients about the physician's departure
- * Take over care from the departing physician
- * Protect the medical records
- * Review your professional liability insurance policy
- * Notify third parties

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Decide when to stop performing surgery

- * What is best for the patient should drive this decision, not what is best for the practice or you financially.
- * Complex patients need more complex care following surgery: will there be someone available to do this care?
- * Is there someone in the practice who can take over care of the departing physician's patients?
- * Does the practice have a shared post-operative care protocol?
 - * Be sure to inform the patient if post-operative care is to be shared!

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ARS Slide #2

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Notify patients about the physician's departure

- * Depending on your situation, this could be amicable or could be a point of contention: a joint letter from the practice and the departing physician is ideal.
- * Patient abandonment occurs when a physician fails to provide necessary medical care to a current patient without adequate justification.
- * High risk, active and inactive patients may require different types of notification: use the OMIC toolkit for examples.
- * There may be state laws that require certain types of notifications: check with your state medical board.

<https://www.omic.com/leaving-practice-toolkit/>

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Key points in your letter to patients

- * Explain options when the departing physician will not be locally available for ongoing care.
- * Explain options when the departing physician will be locally available for ongoing care.
- * Explain how to get a copy of the medical record.
- * Inform the patient of any fees for copying and sending the record.

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Take over care from the departing physician

- Make sure you have someone in your practice to take over care, or a community physician where you can refer these patients
 - Especially for those with high-risk diagnoses
- Review charts of patients you are taking over before seeing the patient or treat each of these patients as new patients and workup thoroughly
- Exercise caution when discussing previous care or diagnoses
 - "I was not involved with your care at the time, so I don't have all the information"
 - "There are several ways to treat your condition."
 - "I would like to try a different treatment now."

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Protect the medial records

- Practices need to work in good faith with the departing ophthalmologist to provide access to his/her former patients' medical records as allowed by law
- There are many federal and state laws to pay attention to with regard to patient records
- If possible, have a written agreement on medical records
- Make sure your patients have access to a records release and understand there may be a cost for this
- Prioritize patient care and safety over all else

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Review your professional liability insurance policy

- You need to make sure you have coverage for any claims that arise from your old practice: "tail" coverage.
- You will also need to set up coverage for your new practice location and situation.

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Notify third parties

- Reach out to referring doctors and practices with your new information
- Contact insurance and managed care companies, CMS, Medicaid, etc. to initiate new contracts and terminate old ones
 - This takes 6 or more months—do this as soon as you know!
- Notify your state medical board, local county or city organizations, DEA, etc.
- Change your information with local hospitals and emergency departments
 - Resist the urge to badmouth your former practice and colleagues!

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Transitioning from Pediatrics to Adult

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Why is this change so hard?

In a word: trust

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Concerns about transition: colleagues

- Will our colleagues take as much care with them as you have?
- Will they pay attention to all the details and understand the subtleties?
- Will they just use the autorefractor for your patient's refraction?

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Concerns about transition: retinoscopy



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Never fear: you've done your job!

- You've spent years making sure this patient can see as best as possible for his or her situation.
- You've done your job.
- You can be proud of your work, your relationship with the patient and family, and it's time for them to move to the next step in their lives.
- Pick good colleagues and make specific recommendations based on your knowledge of the family.

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What age to make the change?

- If you are part of a large system (hospital, university, etc.) you may have no choice.
- If you can make the decision, consider what's best for your patients:
 - Having a set age (e.g. 18 years) doesn't fit well with life at that age.
 - Consider using a life change point in time: graduation from high school, college, transition program, etc.

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Prepare the family

- Start talking about the transition a few years prior
- The year before, remind the family about the transition
- The year of transition, hold their hand through the process
 - Give the family the name of an adult colleague near where they live
 - Review how to get records transferred to the new provider
- Remember that the family is going through more than just this transition:
 - Kid off to college, trade school, etc.
 - Changing pediatrician

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Prepare your office

- * Have a written policy the staff can follow.
- * Allow some flexibility with the policy.
 - * Emergencies
 - * Insurance issues
- * Empower the staff to make decisions with regard to whether the patient is seen again or not.
- * Make sure that staff know that emergencies or other visits are okay until they have established care with the adult colleague to whom you've referred them.

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Prepare yourself

- * It's bittersweet to have to say goodbye after following a patient for so long.
- * You may see them back in the future with their children!
- * Each situation is different; try to read the social dynamics and match how the patient is feeling.

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ARS Slide #3

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Summary

- * Transitions of care are hard and some attention to detail is needed.
- * It's important to remember that what is best for the patient should drive each decision.
- * Use OMIC's free resource to help you and your practice in the transition: <https://www.omic.com/leaving-practice-toolkit/>.
- * Help prepare your patient and family for the bittersweet "graduation" from your office by talking about it early.

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Transition of Care: Ethics Challenges

Alex V. Levin, MD, MHSc, FRCSC

Adeline Lutz - Steven S.T. Ching, M.D. Distinguished Professorship in Ophthalmology
Chief, Pediatric Ophthalmology and Ocular Genetics, Flaum Eye Institute
Chief, Clinical Genetics, Golisano Children's Hospital and
University of Rochester Medical Center

I. Duty to Care

A. Moral Foundations

Non maleficence (do no harm)

Beneficence (do the best for the patient)

B. What are our obligations? The spectrum...

Good Samaritan

Contracted care

Choice to care

We choose...

Our specialty

Our subspecialty

Our sub sub specialty...

C. Can we ever say no? Absolutely!

As long as...

Nondiscriminatory (e.g., Morgentaler case)

No abandonment

Not malicious

Especially if...

Non maleficence (do no harm)

Beneficence

II. Transition of care

A. Uphold...

Ethics

Non maleficence

Beneficence

Policy (e.g. no one over a certain age)

Law (e.g. HIPAA)

B. What if options are sub optimal?

Special policy (e.g. extending age limits for certain disorders)

Create resources thru training and advocacy

Systemic response (e.g. adult cystic fibrosis service)

Personal response (e.g. continued consultation/availability)

III. International Care

A. Many considerations

Financial incentives and medical tourism

Other conflicts of interests (e.g. personal, academic)

Ongoing care at home (non-maleficence)

Consent (language AND understanding)

Cultural sensitivity ("When in Rome...")

Unrealistic expectations



Transition of Care

In the Context of International Service



Daniel J Karr MD FAAO FAAP
Oregon Health and Science University
Casey Eye Institute



International Service Experience

- Extremely popular altruistic “Mission” for ophthalmologists
- Ophthalmology resident and fellow applicants-essential part of CV
- Ophthalmology skill sets are highly productive in international setting
- Services provided limited local availability and life-changing for patients



International Service Concerns



- Short-term one-time vacation project
- Procedures performed which would not be performed in home country
- Training experience, often unsupervised, for medical students residents etc.
- No regulation by host country or interaction with local medical community
- Unregulated research projects
- No documentation of services provided

Medical Tourism

- Major benefit may be for the doctor rather than the patient
- May undermine or compete with local caregivers-risk of long-term service
- May not adequately consider long-term care and complications



International Service Requirements

- Current license and active practice
- May need to meet with medical board
- Malpractice coverage
- Declaration of proposed scope of service
- Identification of local sponsor



International Service Considerations

- What is in the purpose-goal of the trip?
- Partnership with established organization HCP, SEVA
- In country organizations to consider: Rotary Lions
- What services will be provided. Infrastructure available?
- What happens to your patients after you leave?
- Long-term care for Glasses, PCO, Glaucoma, RD, Infection?



Transition of Care

- Integration with local doctors and clinics from pre trip to completion
- Careful selection of patients
- Education of local providers for both performing procedures and handling potential complications
- Providing infrastructure with equipment and medications
- Providing post trip support through video conferencing photos and ongoing training
- Consider training of host country doctors in your facility
- Consider established organizations which have transition of care built into their program



So You Want to Work Overseas?

AAO CME course

Johns Hopkins University Bloomberg School of Public Health

David S. Friedman, MD, PhD, MPH

Alfred Sommer, MD, MHS

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