SIDNEY KIMMEL MEDICAL COLLEGE

Communication, Common Sense, and Nuance: Care of Patients with IDD

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Disclosures – official and otherwise

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- Dr. Mary Stephens and Karin Roseman from the Jefferson FAB (For Adolescents and Beyond) Center for Complex Care were recipients of a grant from PADDC to fund their project:

Increasing Access to Quality Healthcare for People with Disabilities: A Co-Designed Educational Curriculum for Family Medicine Residents

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We'd like to thank our consultants!

- To help in the planning and design of these didactic sessions, we have hired individuals with lived experience with disabilities, as well as some caretakers, as consultants.

Aronya Waller
Cheryl Trexler
Cristina Grubelic
Corey and Marie Beattie
Dan Lauria
George Lees
Jackie Shapiro Fishbein
Janine Blythe
John and Joan Thomas
John Griffith
Kirah Burgess-Goad
Shannon Taylor Ward
Kristan Scofield
Linda Turner
Mary Griffith
Mia Andrilla
Namiyah and Nicole Ruley-Minus
Rachel Fishbein
Rebecca Bradbeer
Roc and Donna
Stephanie Andrilla
Steven Seibert
Suzy Gladstone
Thomas Butts
Trish Lauria
Victoria Patterson
Victoria Silvestri
Zach Scofield
Zachary Trexler

- **Jefferson FAB Center for Complex Care**
  - Primary care medical home for teens and adults with complex childhood-onset conditions
  - Launched January 2019
  - Jefferson Health at the Navy Yard: 215-503-7136

Our goal:

> "Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs…"

Objectives

- At the conclusion of this lecture, participants should be able to:

1. Discuss barriers and pitfalls for youth with IDD transitioning from pediatric care
2. Apply strategies for involving youth with IDD in achieving their healthcare goals and maximizing their outcomes
3. Discuss decision making in advance of the 18th birthday for all patients with IDD
4. Identify who the decision maker will be for the patient longitudinally and revisit this at each visit

Disability

- One in four non-institutionalized adults in the US has a self reported disability[1]

Hearing	Vision	Cognition	Mobility	Self Care	Instrumental Activities of Daily Living

1. Okoro C, Hollis N, Cyrus A, Griffin-Blake S. MMWR Morb Mortal Wkly Rep. 2018;67(32):882-887

Developmental Disability

- Is attributable to a mental or physical impairment or combination of mental and physical impairments
- Onset before age 22
- Affects 3 or more areas of life activities
  - Self-care, receptive/expressive language, learning, mobility, self-direction, capacity for independent learning, economic self-sufficiency

Intellectual Disability

- Significantly reduced ability to understand new or complex information and to learn and apply new skills
  - Which impairs ability to cope independently

    and begins before adulthood
  - Can be inherited or acquired
    - Fragile X is the most common inherited form of ID and the most common known single-gene cause of autism (Kidd *Pediatrics* 2014)
    - Fetal Alcohol Syndrome is the most common acquired form
  - Considered to range from mild to profound
    - About 85% of those with ID are considered to have mild ID
    - For more on this – see the Vanderbilt tool kit!

Common Causes of IDD

Cerebral Palsy	Autism	Down syndrome
Fragile X	Spina bifida	Fetal alcohol syndrome

Vulnerable Populations

- The WHO and others recognize adults with disabilities as a vulnerable population
  - Risk for secondary conditions/co-morbidities
  - Age-related conditions
  - Higher rates of premature death
- Adults with disabilities AND IDD are at an even greater risk

Vulnerable Populations

- Meet Steve (link to video on website)

Autism Spectrum Disorder (ASD)

- 1/36 eight year olds in the US
  - Rates are higher in minority groups
  - Has been increasing over the last 10 years. Why is that?
- Nearly 4 times as common among boys than girls
- Core deficits in:
  - Social communication/interaction
  - Restrictive, repetitive patterns of behavior
- May or may not have intellectual disability (ID)

Barriers to Identifying ASD

- Milder symptoms
- Average or above-average intelligence
- Gender – girls often underdiagnosed
  - Current ratio 4:1 Boys:Girls
- Co-morbid conditions like ADHD
- Language barrier
- Understanding of cultural differences

Barriers to Care and Outcomes for Patients with ASD

- Survey of autistics and non-autistic adults with and without disabilities (Raymaker 2017)
  - Fear and anxiety
  - Processing time
  - Sensory issues
  - Difficulty communicating with providers

Additional Barriers to Care

- We think there's about 3x the amount of paperwork for patients with IDD and other disabilities
- Social workers are critical to the care process but not everyone is able to have one in their practice
- While no substitute, please review the additional resources on the project website for materials.

Health Disparities and IDD

Social Determinants of Health

- Think about a “cascade effect”
  - Starting with co-morbidities/underlying condition and key social determinants
    - Access to care
    - Access to quality care
    - Challenges with screening and detection of disease
    - Communication barriers
    - Lack of validated scales – depression or anxiety

Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health care access for people with intellectual disabilities. Ment Retard Dev Disabil Res Rev. 2006;12(1):70-82. doi: 10.1002/mrdd.20098. PMID: 16435327.


Equality
Equity

Racial and Ethnic Differences

Adults with Intellectual and Developmental Disabilities from Racial and Ethnic Minority Groups May Perceive Different Barriers to Healthcare than Their White Peers

A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). 2021

- While some factors lead to delayed care in the White group, the same factors led many Black and Latinx individuals to forego care altogether.
  - The authors suggested this may lead to additional preventable health problems in those two groups.

- The authors suggested that future interventions aim to address institutional racism and develop trust between the racially and ethnically diverse disability community and health professions in an effort to reduce barriers to healthcare access for Black and Latinx individuals with IDD.

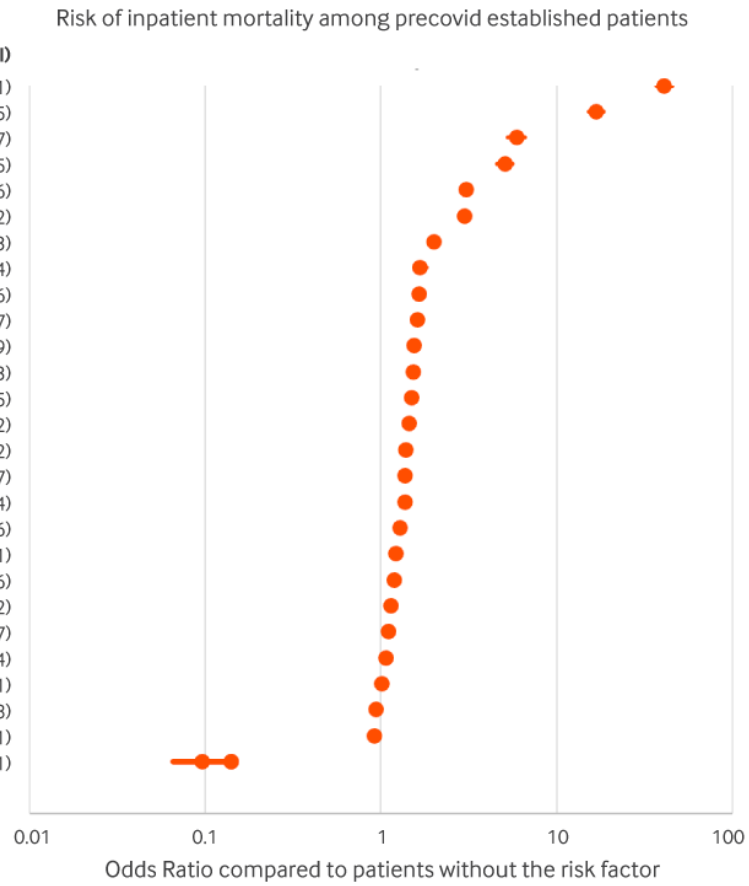
Patients with IDD face health disparities

- More likely to:
  - report being in poor health
  - have poorly managed chronic health conditions
- Less likely to:
  - receive preventative screenings and vaccinations
- Higher rates of:
  - undiagnosed hearing and vision impairments
  - obesity
  - poor dental health
  - diabetes, arthritis, cardiovascular diseases, and asthma
  - prescribed psychotropic medications
- Shorter average life expectancy than the general population
- Most common causes of death differ from the general population and show higher rates of mortality due to illnesses/conditions less likely to lead to death in the general population

- https://dhhs.ne.gov/Documents/Henrichs.pdf

Risk of Covid-19 Mortality — All Established Patients

Risk factor:	Odds ration (CI)
80 and Over vs Age 20-39	41.07 (37.06 - 45.51)
Age 60-79 vs Age 20-39	16.88 (15.28 - 18.65)
Intellectual Disability	5.909 (5.277 - 6.617)
Age 40-59 vs Age 20-39	5.088 (4.594 - 5.635)
Hispanic vs NH White	3.056 (2.930 - 3.186)
SNF Admit	3.008 (2.879 - 3.142)
Black vs NH White	2.002 (1.934 - 2.073)
Asian vs NH White	1.678 (1.552 - 1.814)
Male	1.649 (1.604 - 1.696)
Chronic Kidney Disease	1.619 (1.563 - 1.677)
Fluid/Electrolyte Disorders	1.544 (1.490 - 1.599)
Diabetes	1.535 (1.488 - 1.583)
Other Race/Ethnicity vs NH White	1.494 (1.409 - 1.585)
Hypertension	1.458 (1.405 - 1.512)
Deficiency Anemia	1.392 (1.343 - 1.442)
Lung Disease	1.381 (1.337 - 1.427)
Congestive Heart Failure	1.372 (1.322 - 1.424)
Obesity	1.290 (1.245 - 1.336)
Neurological Disorders	1.223 (1.187 - 1.261)
Coagulopathy	1.190 (1.137 - 1.246)
Low SES (by payer)	1.143 (1.097 - 1.192)
Pulmonary Circulatory Disease	1.106 (1.057 - 1.157)
Liver Disease	1.068 (1.024 - 1.114)
Thyroid Disease	1.013 (0.977 - 1.051)
Oncology	0.936 (0.905 - 0.968)
Malnutrition	0.915 (0.881 - 0.951)
Under 20 vs Age 20-39	0.096 (0.066 - 0.141)



Source: The authors

Jonathan Gleason, Wendy Ross, Alexander Fossi, Heather Blonsky, Jane Tobias, Mary Stephens. **The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States**. *New England Journal of Medicine (NEJM) Catalyst*, March 5, 2021; DOI: 10.1056/CAT.21.0051

Unpublished work on DNR and DS

Code status disparity in patients with Down syndrome during the COVID era

- Findings:
  - Respiratory infection is a known leading cause of mortality in patients with DS, and thus, perhaps a higher mortality rate from COVID-19 pneumonia is to be expected.
  - However, the data presented demonstrates that the odds of being made DNR on admission are out of proportion to the risk of mortality and that the diagnosis of Down syndrome is the greatest driver of DNR status after controlling for other risk factors.

Caring for Patients with IDD

What About US?

Survey of physicians who care for people with disability (excluding PM&R) 2019-2020[1]

- Only 18.1% strongly agree that PwD are unfairly treated in health system
- 82.4% rate quality of life for PwD as worse

Survey of family and internal medicine residents 2019-2020[2]

- 34.6% of residents remembered any disability training in medical school

1. Iezzoni LI, Rao SR, Ressalam J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, Lagu T, Campbell EG. Health Aff (Millwood). 2021 Feb;40(2):297-306. doi: 10.1377/hlthaff.2020.01452. PMID: 33523739.
2. Stillman MD, Ankam N, Mallow M, Capron M, Williams S. Disabil Health J. 2020 Oct 7:101011. doi: 10.1016/j.dhjo.2020.101011. Epub ahead of print. PMID: 33041247.

"Without explicit disability training, health care providers are likely to view disability as a negative health outcome and to hold low expectations for the function and quality of life of individuals with disabilities. "

Bowen CN, Havercamp SM, Karpiak Bowen S, Nye G. A call to action: Preparing a disability-competent health care workforce. Disabil Health J. 2020 Oct;13(4):100941. doi: 10.1016/j.dhjo.2020.100941. Epub 2020 May 14. PMID: 32467076.

Ableism

Ableism is a form of discrimination against individuals with disabilities, built on assumptions that life without a disability is superior to life with one.

Disparities in Healthcare- partly related to *Diagnostic Overshadowing*

Physicians attribute non-specific symptoms to the disability, halting further diagnostic investigation.

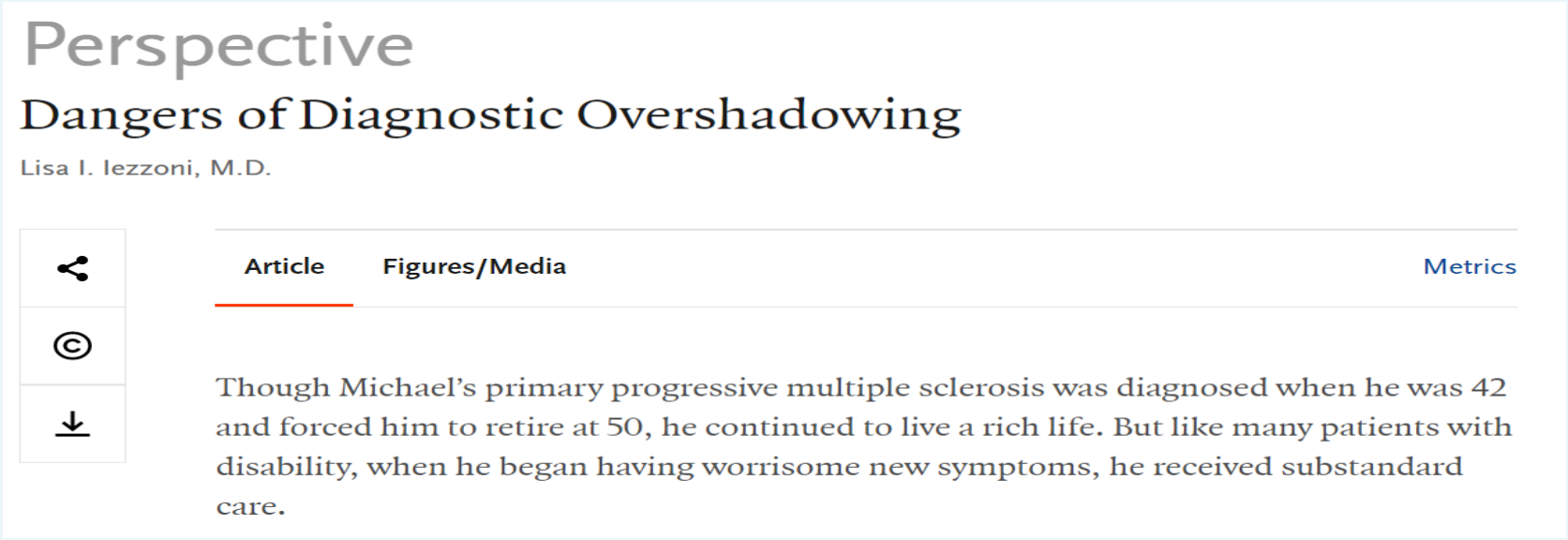
Health disparities & diagnostic delays

- Higher rates of colorectal cancer, non-Hodgkin's lymphoma, prostate cancer, ovarian cancer AND diagnosed at later stages of the disease process in those with movement difficulty and complex activity limitation[1]
- Increases in agitation in IDD attributed to IDD rather than investigation of physical symptoms - case reports of missed GERD, aspiration, cholecystitis[2,3]

1. Iezzoni LI, Rao SR, Agaronnik ND, El-Jawahri A. 2020 Aug;18(8):1031-1044. doi: 10.6004/jnccn.2020.7551. PMID: 32755976.
2. Javaid, A., Nakata, V. and Michael, D. (2019), Diagnostic overshadowing in learning disability: think beyond the disability. Prog. Neurol. Psychiatry, 23: 8-10. https://doi.org/10.1002/pnp.531
3. Grier E, Abells D, Casson I, Gemmill M, Ladouceur J, Lepp A, Niel U, Sacks S, Sue K. Can Fam Physician. 2018 Apr;64(Suppl 2):S15-S22. PMID: 29650740; PMCID: PMC5906780.

Prevention of Diagnostic Overshadowing

- Need to design curricula such that graduates do not attribute everything to the disability, but also understand that the disability may have unique secondary complication considerations.



Perspective

Dangers of Diagnostic Overshadowing

Lisa I. Iezzoni, M.D.

Article Figures/Media Metrics

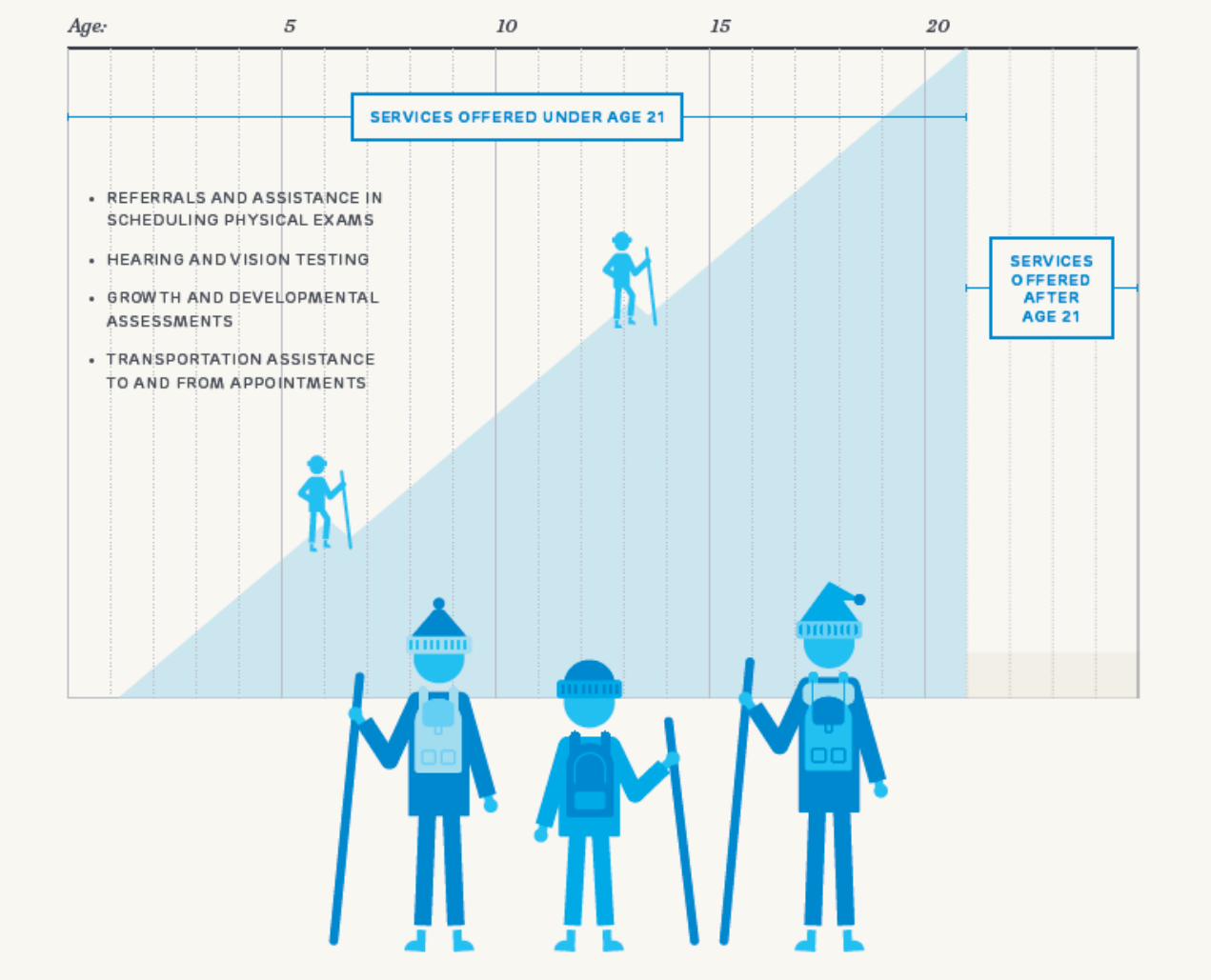
Though Michael's primary progressive multiple sclerosis was diagnosed when he was 42 and forced him to retire at 50, he continued to live a rich life. But like many patients with disability, when he began having worrisome new symptoms, he received substandard care.

Think about this from the very beginning!
"Great joys and great expectations!!"

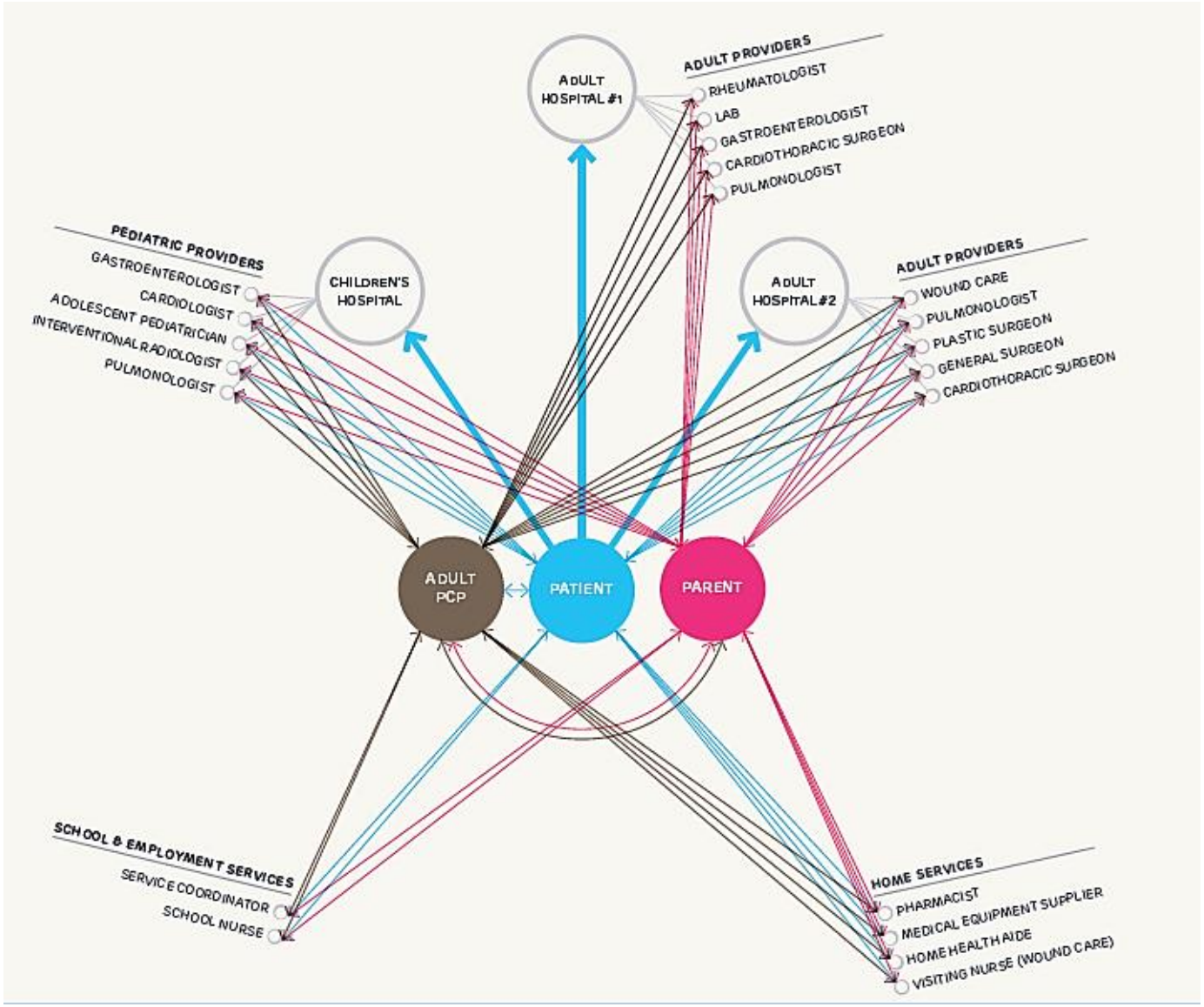
Barriers and pitfalls for youth with IDD transitioning from pediatric care…

There are many!

“The Cliff”



Steinway et al, CHOP PolicyLab 2017



Steinway et al, CHOP PolicyLab 2017

The patient as an expert in their own care!

- How to involve patients with IDD
  - https://iddtoolkit.vkcsites.org/

Let’s start with the basics to make a difference!

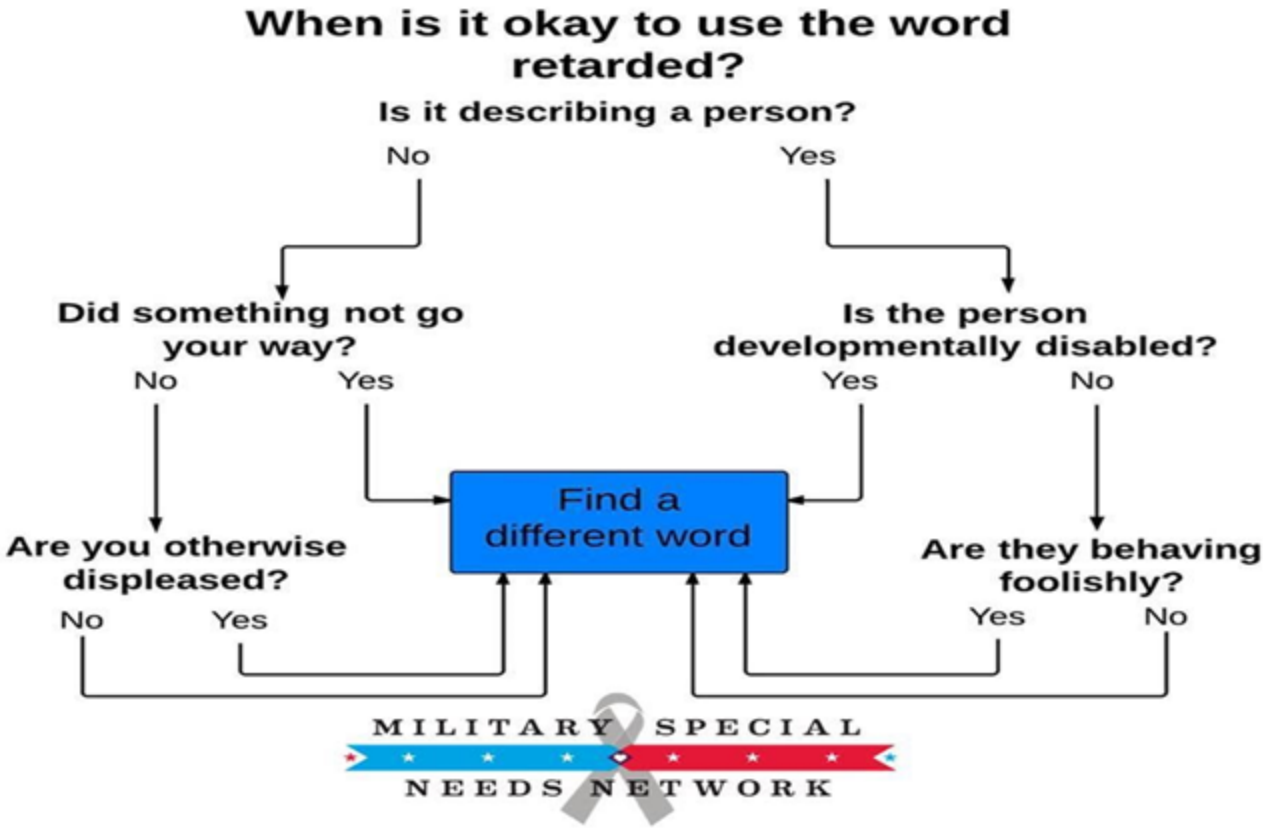
Communication!!

Language Guidelines

- Person first language or identity first language
  - An adult with Down syndrome vs. “He has Down’s” or Down syndrome adult
  - Autistics or Deaf may prefer identify first language
- Cognitive or intellectual disability, not mental retardation

It doesn’t always flow smoothly off the tip of the tongue. . . that’s ok, keep trying. . . And ask an individual for their preference or follow their lead!

Never okay!!


When is it okay to use the word retarded?
Is it describing a person?
No
Yes
Did something not go your way?
No
Yes
Is the person developmentally disabled?
Yes
No
Find a different word
Are you otherwise displeased?
No
Yes
Are they behaving foolishly?
Yes
No
MILITARY SPECIAL NEEDS NETWORK

Communication strategies

- **ESTABLISHING RAPPORT**
  - Speak directly with the patient
    - Parents have to get used to this to!
  - Avoid talking to an adult as if he/she were a child

  - From The Toolkit for Primary Care Providers
    - Vanderbilt Kennedy Center

John and Joan’s Video (link to video)

CHOOSING APPROPRIATE LANGUAGE

- Use concrete language

  Example – Please put your coat on vs. get ready

- Avoid shouting

Listening

- Listen to what the patient says
- Behavior is a form of communication!
- Allow enough time
  - **Processing takes time!**

Aronya’s video (link to video)

Communicating Without Words

- Use visual aids
- Act or demonstrate

Explaining Clearly

- Explain what will happen before you begin
- Tell and show what you are going to do and why

Modifications to consider. . . In addition to time!

Office Policy Adaptations

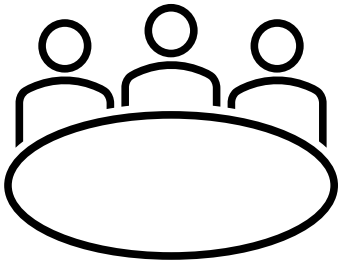
- Scheduling more time
- Avoid fees for lateness
- Educate staff in disability etiquette

Takeaways and Final Points

Pearls from AADMD Panelists

Listen and be willing to learn!

To medical educators: we need to teach it!



Goal: co-creation of health/healthc are goals

Don't interrupt - listen with intent and don't assume

We just need to remember to treat patients with disabilities like anyone else. . . it's not an unattainable goal

Decision Making

- Start the discussion early!
  - Teens are invincible
    - And disappear from care!!
- 18 is the age of majority in most states
  - POA
  - Guardianship
  - Supported decision making

It’s a team sport

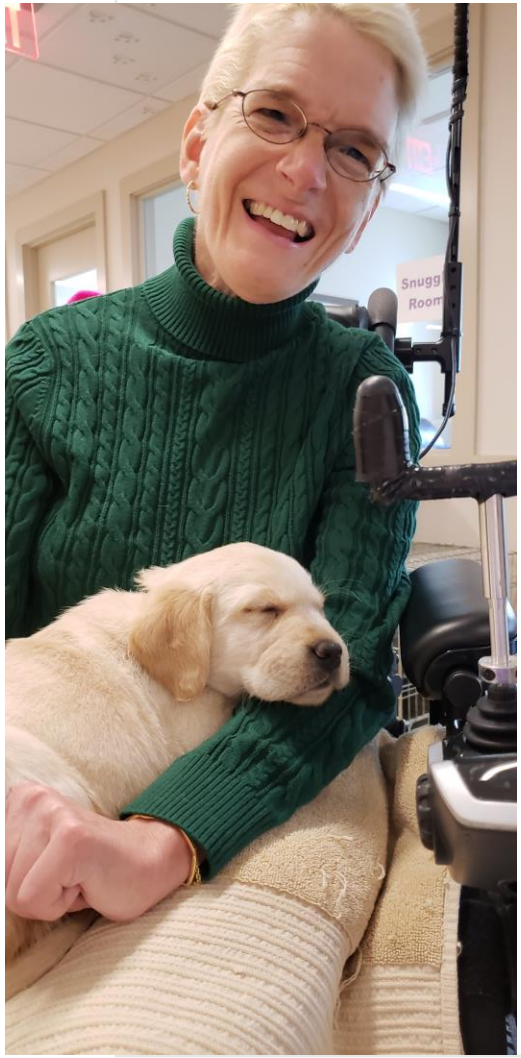
- Take advantage of pre-season
  - Don’t assume someone else has covered it!
  - Or that the patient will be in for their annual visit!
  - Maybe it’s the specialist and not the primary that’s closest to the patient!
- A tool for your toolkit!
  - https://iddtoolkit.vkcsites.org/general-issues/informed-consent/
  - https://iddtoolkit.vkcsites.org/supported-decision-making-for-adults-with-intellectual-or-developmental-disabilities/

Final Thoughts

Underlying assumptions/biases when working with a person with a disability ex. People may associate a physical disability w/cognitive impairment.

Bias that all disability must need the same accommodations

Remember, our patients are more than just patients…



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We are ALWAYS looking for collaborators in care!!!

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