

Family-Led Academic Grand Rounds

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Say What? Language Matters



Family-Led Academic
Grand Rounds

Jessica Edgar, Lisa Treleaven, Emma Bouza
March 13, 2025

Conflict of Interest

The planner and speaker of this CE activity has no relevant financial relationships with ineligible companies to disclose.

The speaker does not intend to discuss any unlabeled or unapproved use of drugs or devices.

Please take a moment at the end of the session to complete your evaluation.

Thank you!

Funding Acknowledgement



Lucile Packard
Foundation

Children's Health

FLAG Rounds Flow

- Background
- Learning objectives & competencies
- Story and teaching
 - ▶ Emma
 - ▶ Lisa
 - ▶ Jessica



What is Ableism?

Discrimination towards people with disabilities—ableism—is extremely common.

(Barnes, 1997; Keller & Galgay, 2010; Linton, 1998; Lundberg & Chen, 2024; Nario-Redmond, 2019).

Despite its prevalence, there is no one singularly agreed upon definition of ableism; however, generally, it is, 'stereotyping, prejudice, discrimination, and social oppression toward people with disabilities'

(Bogart & Dunn, 2019, p. 652).

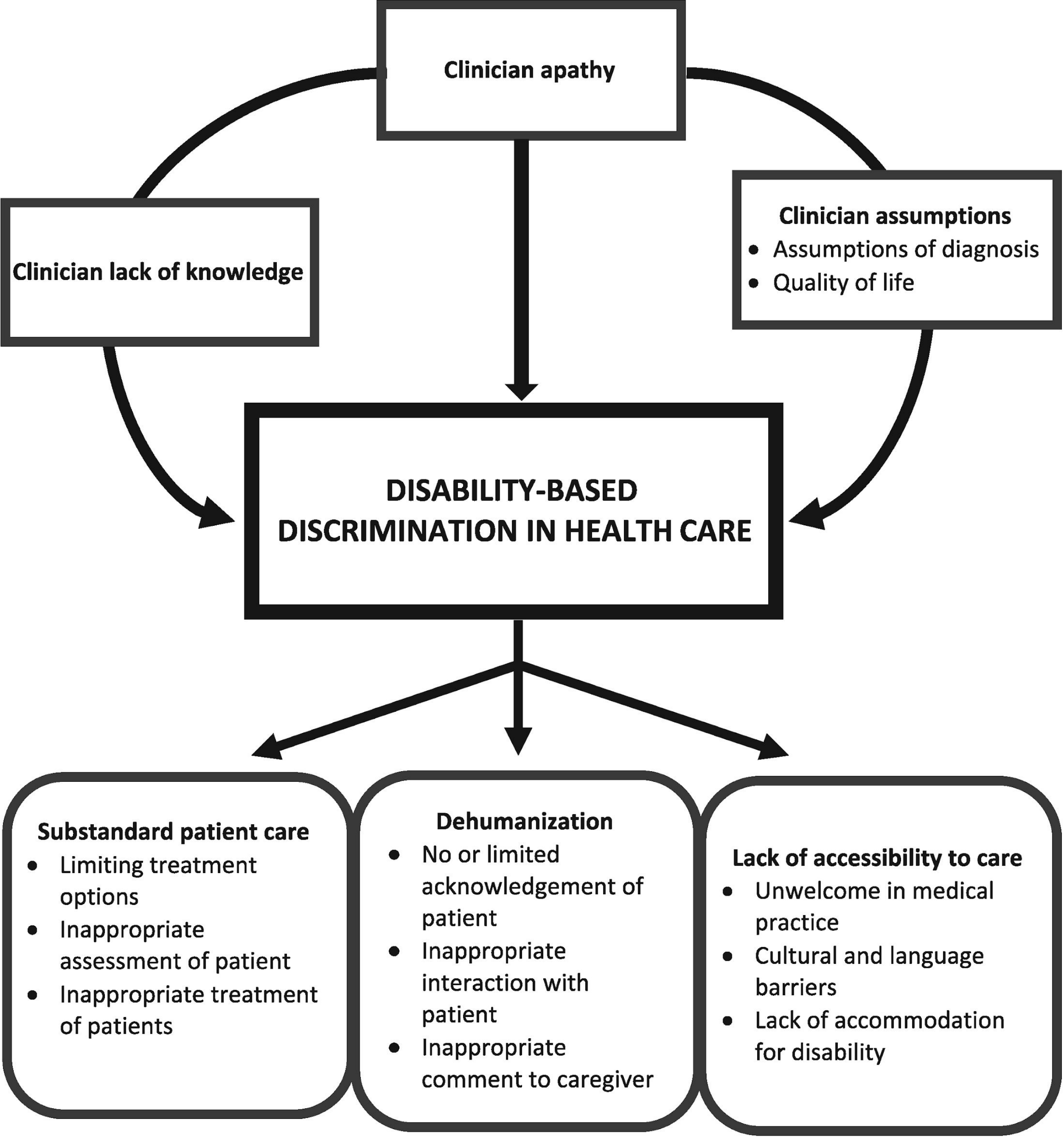
Like other forms of oppression, ableism describes the valuing of some ideals and attributes over others, including compulsory preference for non-disability.

(Campbell, 2009; Kafer, 2013; Wolbring, 2008).

This system of marking some bodies/minds as deviant not only impacts attitudes of individual people, but also embeds within environments, systems, and structures.


(Keller & Galgay, 2010; Linton, 1998; Lundberg & Chen, 2024; Nario-Redmond, 2019). (<https://doi.org/10.1111/jar.13218>)

Figure Legend:
Conceptual framework of
interpersonal disability-based
discrimination in health care.



Core of FLAG Rounds

Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a **mutually beneficial partnership** among patients, families, and providers that recognizes the importance of the family in the patient's life.



*mutually
beneficial
partnership*

Session Learning Objectives

1. Identify implicit bias and understand potential harm to individuals with disabilities
2. Illustrate how stories are a means to understand how a system is functioning
3. Discuss the phrase "nothing about us without us" as it relates to systems
4. Describe the importance of language in how a diagnosis is introduced, communicated and understood

ACGME Core Competencies

▶ Patient Care and Procedural Skills

- Gather essential and accurate information about the patient
- Make informed diagnostic and therapeutic decisions

▶ Systems based practice

- "It is safe to say that if good systems can make a medical practice, then bad systems can certainly break one."

▶ Interpersonal and Communication Skills

- Demonstrate the ability to effectively exchange information with patients, their families, and professional associates.

Core Competencies on Disability for Health Care Education

- ▶ Teams and Systems-Based Practice:
 - (4.5) List systems of community-based services and supports that may be useful for patients with disabilities outside of the clinical care system. Be prepared to consider cultural factors and interact with these systems.

Emma Bouza



Ruby







Teaching from stories

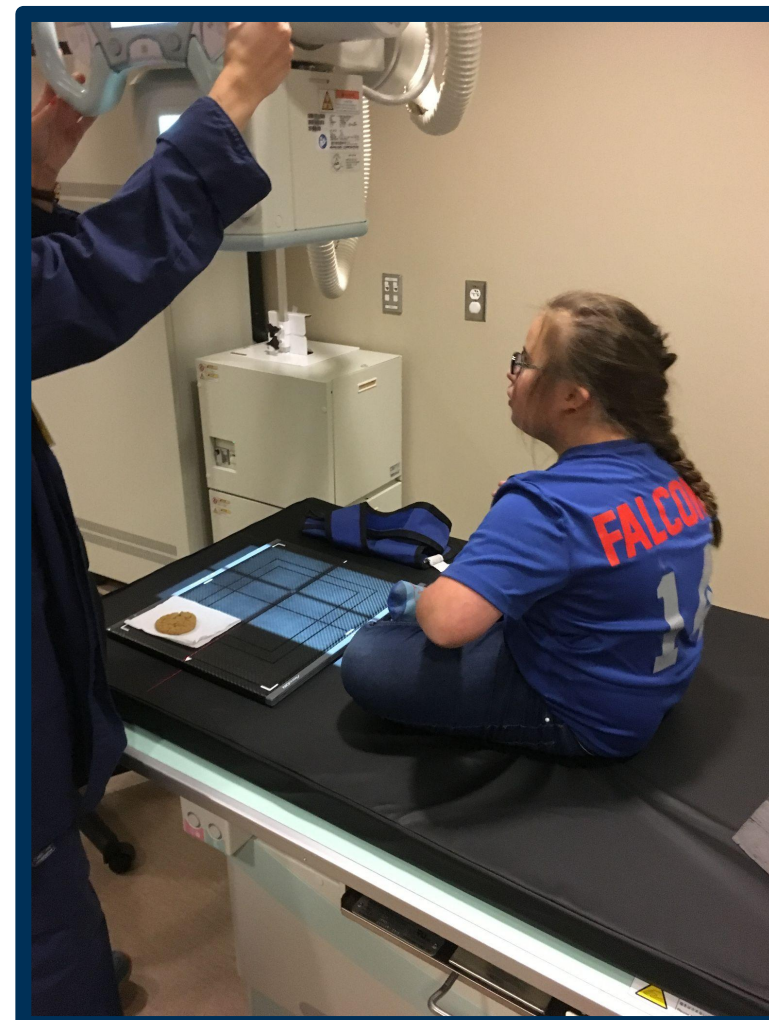
Emma
and Ruby

Say What? ~~Demented~~

Say What? Say Hi.

Implicit Bias and Potential Harm

- ▶ The most common type of bias in healthcare = implicit bias
- ▶ A 2020 study found that 86% of healthcare providers have an implicit preference for people without disabilities. They found little explicit prejudice, but prominent bias in attitudes and interactions, including providers making clinical decisions that help them avoid treating people with disabilities.

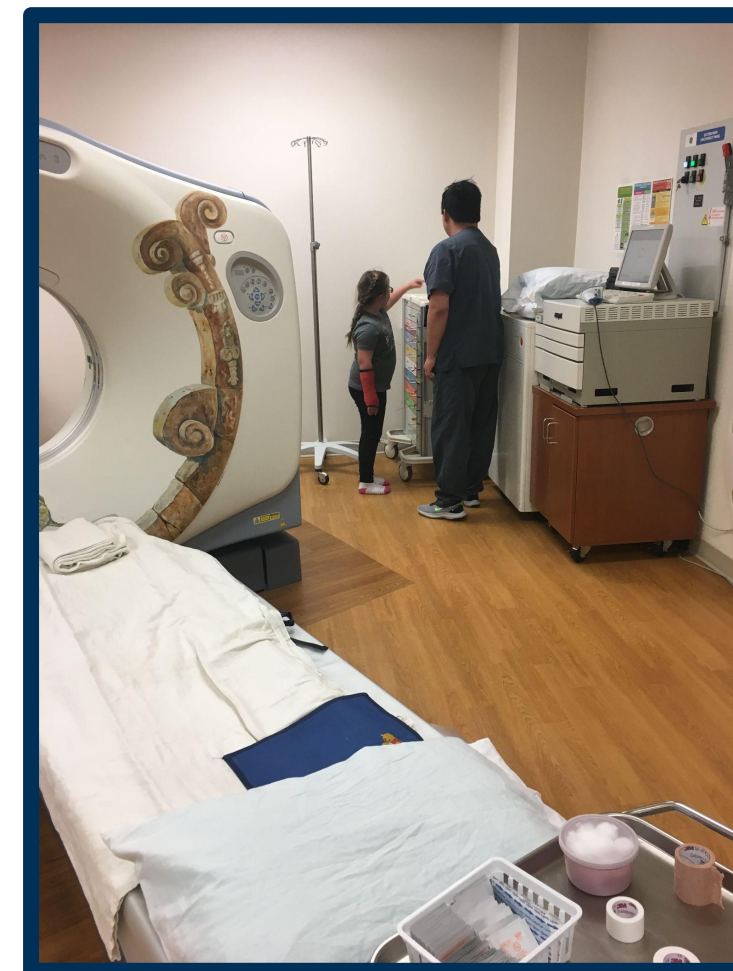
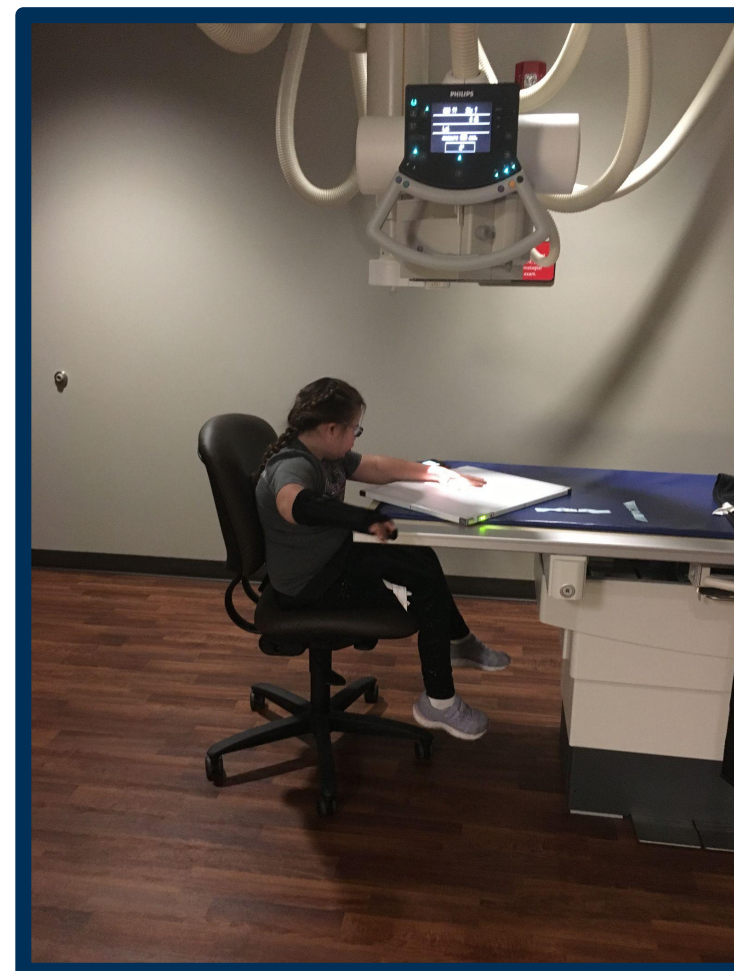


Say What? ~~Can't~~

Say What? Say Ruby.

Open, Empathetic Communication

- Engage in meaningful conversations
- Actively listen
- Presume competence -assume that there is understanding with what's happening even if they have trouble expressing themselves

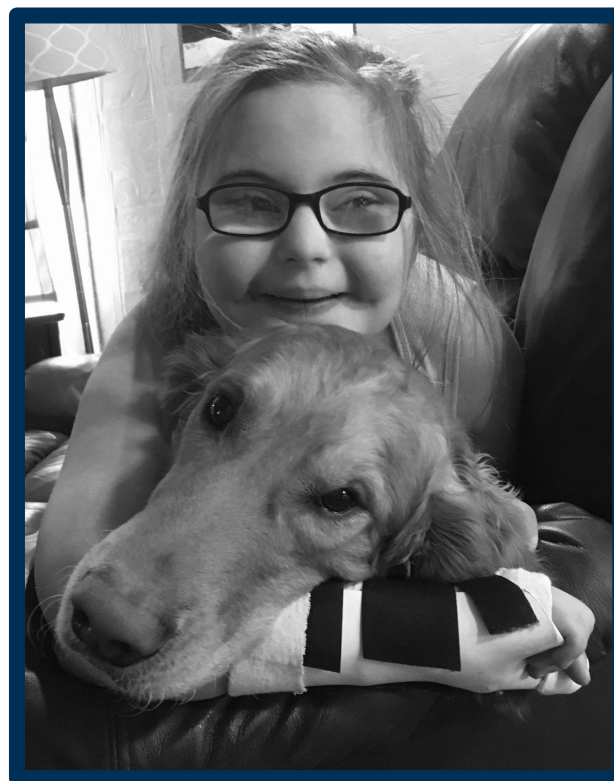


Say What? ~~Deformity~~

Say What? Ruby.

Treat All With Dignity and Respect

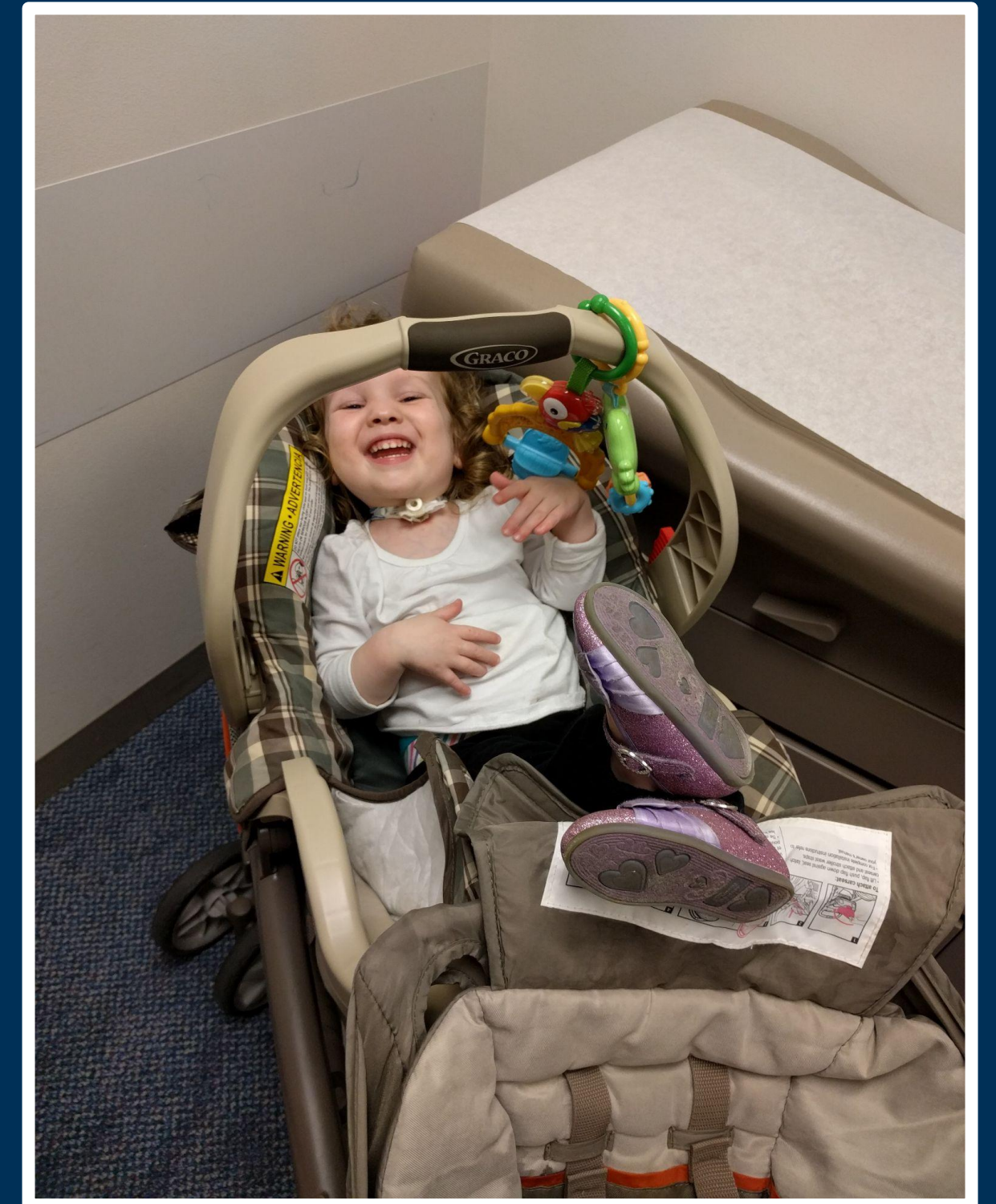
- Everyone, regardless of abilities, deserves respect & dignity



Lisa Treleaven



June







Teaching from stories

Lisa
and June

Say what?

~~"Kids like your daughter."~~

Say what?

"Juniper."

- We care for our kids within broken systems
 - ▶ "...The highly untenable cost of navigating dehumanizing systems of care reduces quality of life and wellbeing and must be transformed."

Say what?

~~"Kids like your daughter."~~

Say what?

"I see you."

- Listen to families about their experience of systems



Short on time? Stop, look and listen for clues in the child and family's communication



Broken systems influence all interactions

Say what?

~~"Kids like your daughter."~~

Say what?

"I hear you."

- Act on communication from families
 - ▶ Be responsive
 - ▶ Work "with" children and families rather than doing "to" and "for" them
 - Specific tools:
 - ▶ Shared decision making
 - ▶ Family meetings
 - ▶ Care coordination
 - ▶ Interdisciplinary case staffings
- (....also subject to system limitations)

Say what?

~~“Kids like your daughter.”~~

Say what?

“Let’s work together.”

- Keys to system change

- Nothing about us without us

“Families authentically involved at every level of health care systems are critical partners in designing policies and systems that will improve care for children with medical complexity...”

Jessica Edgar



Finley







Teaching from stories

Jessica
and Finley

Say what?

~~R-----.~~

Say what? Finley.

- “Have you chosen a name?”
- “Speak with us, not at us”
 - Invite questions
 - Create space for open dialogue
 - Anticipate concerns before they are voiced
- Say it plain
 - The “black butterfly”



Say what?

~~R-----.~~

Say what?

Finley.

- Compassion in action
 - Slow down
 - Make eye contact
 - Space for processing



3 stories; 1 message: Language Matters



Emma & Ruby



Lisa & June



Jessica & Finley

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to access it.

Thank you!

