



Family-Led Academic
Grand Rounds

FLAG Rounds Session

Key Takeaways

JANUARY 16, 2025

**Whose Expectation
is it Anyway? Access,
Care and Humanization**

View session recording:
[go.wisc.edu/
FLAGJanuary2025](https://go.wisc.edu/FLAGJanuary2025)

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What is Ableism?

- Discrimination towards people with disabilities—ableism—is extremely common.¹
- 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'.²

Identified Categories of Disability-Based Discrimination in Pediatric Health Care³

Substandard Patient Care

(Limiting treatment options,
inappropriate assessment
and treatment)

Dehumanization

(Inappropriate interactions/communication
with child and/or family, no/limited
acknowledgment of child)

Lack of Accessibility to Care

(Made to feel unwelcome, cultural
and communication barriers,
no accommodations)

What is the heart of Patient and Family Centered Care?⁴

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.

Two core concepts to highlight:

1. Listening to and respecting each child and his/her family.
2. Collaborating with patients and families at all levels of healthcare.

Strategies to Partner to Dismantle Ableism and Reflection Points

Legal Standards Set Expectations

- The Findings and Purpose of the [Americans with Disabilities Act of 1990, As Amended](#) (ADA) are legal tools and also set societal expectations:
"physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society"
- 2024 Final Rule [Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance of Section 504 of the Rehabilitation Act of 1973](#):
 - i. Strengthens to align [Section 504](#) with the ADA.
 - ii. Clarifies NEW non-discrimination obligations with [accessible medical equipment](#), medical treatment, value assessments and others.

STRATEGY 1 Dehumanization to Humanization: Whole Child

- Say Hello to each child with a disability and/or medical complexity.
- SEE the whole child: Move from medical model “fix” to focus on the “F” words of life: fitness, function, friends, family, fun and future.^{5,6}

STRATEGY 2 Making the Inaccessible, Accessible: Full Access

- EXAMINE: Are children with medical complexity and/or disability “welcome?”
LOOK at the “Built” environment- what is built? By who? Why? How?
Physical barriers: where live, play, work, learn... and where get healthcare⁷
Social barriers: assumptions, attitudes and culture of clinic/hospital⁸
- Access requires Communication: Assume everyone requires some sort of accommodation and consider the needs of everyone who will be interacting in clinic visits, inpatient stays, procedures.

STRATEGY 3 Substandard to Excellent Care: Just Ask!

- ASK yourself, your “team” and children and families: How do we partner to provide excellent care?
 - i. Asking questions is the antidote to assumptions
 - ii. Don't just screen, have a conversation
- ASK and plan with children and families: shared plans of care, pain plans, consults (pre-anesthesia, surgical, etc), communication strengths of child/family.

Commitment to Change: Openness, Curiosity, Humility

Whatever your connection to (family or professional) or the type of work you do (clinical, public health, research, etc.), how do you commit to change?

*Regarding the **care** of children with disabilities and/or medical complexity.*

I intend to: _____

*Regarding **partnership** in the care of children with disabilities and/or medical complexity.*

I intend to: _____

Related Resources

1. Barnes, 1997; Keller & Galgay, 2010; Linton, 1998; Lundberg & Chen, 2024; Nario-Redmond, 2019
2. Bogart & Dunn, 2019, p. 652
3. Stefanie G. Ames, Rebecca K. Delaney, Amy J. Houtrow, Claudia Delgado-Corcoran, Justin Alvey, Melissa H. Watt, Nancy Murphy; Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity. *Pediatrics* July 2023; 152 (1): e2022060975. 10.1542/peds.2022-060975
4. COMMITTEE ON HOSPITAL CARE and INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE; Patient- and Family-Centered Care and the Pediatrician's Role. *Pediatrics* February 2012; 129 (2): 394–404. 10.1542/peds.2011-3084
5. World Health Organization. (2001) International Classification of Functioning, Disability and Health (ICF)
6. Rosenbaum P & Gorter JW. (2012). The 'F-words' in childhood disability: I swear this is how we should think! *Child Care Health Dev*; 38
7. Bole A, Bernstein A, White MJ, et al; American Academy of Pediatrics, Council on Environmental Health and Climate Change, Section on Minority Health, Equity, and Inclusion. The Built Environment and Pediatric Health. *Pediatrics*. 2024;153(1):e2023064773
8. Stacey Cook, Sangeeta Mauskar, Jay G. Berry; Discriminating Against Children With Medical Complexity. *Pediatrics* July 2023; 152 (1): e2023061604. 10.1542/peds.2023-061604

Any questions or want further discussion? info@flagrounds.org