



Family-Led Academic
Grand Rounds

FLAG Rounds Session 2

Key Takeaways

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.

Core concepts:

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

Strategies to Dismantle Ableism through Family Partnership

STRATEGY 1 Recognize and Challenge Disability Bias in Clinical Decisions⁵

- Treat all with dignity and respect; see the person first, not their diagnosis.
- Avoid assumptions based on diagnosis. Example: Don't assume a diagnosis of Down Syndrome excludes a person from a recommended course of treatment.

March 13, 2025

Say What? Language Matters

View session recording:
go.wisc.edu/FLAGMarch2025

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STRATEGY 2 Build Trust through Communication

- **Say it plain.** Use clear, everyday language. It's not about "patient or family friendly language", it's about making sure children and families understand what is happening in their care.
- **Ask for and use names.** This creates connection and, if the child is unborn, signals that the baby is already seen as a person.⁶
- **Invite curiosity** and genuinely encourage questions; "What questions do you have for me?"
- **Presume competence.** Assume patients and families can understand and participate in their care.
- **Create a space where patients and families feel heard** and involved; "I want to make sure you are comfortable with this plan of care."

STRATEGY 3 Stay Family-Centered in Systems-Based Practice

- **LISTEN** to families' experiences with systems and look for clues in verbal and nonverbal communication.
- **UNDERSTAND** that "dehumanizing systems of care reduce quality of life and wellbeing⁷".
- **ACT** on communication with families by incorporating their input into treatment planning, using shared decision making tools and interdisciplinary case staffings.

Commitment to Change: Openness, Curiosity and Humility

Whatever your role (family, clinician, researcher, public health professional, etc.) or the type of work you do (clinical and otherwise), how will 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. VanPuymbrouck, Laura, et al. "Explicit and Implicit Disability Attitudes of Healthcare Providers." *Rehabilitation Psychology*, U.S. National Library of Medicine, May 2020, pmc.ncbi.nlm.nih.gov/articles/PMC9534792/.
6. Anolak H, Thornton C, Davis D. What's wrong with using the F word? A systematic integrative review of how the fetus is talked about in situations of fetal demise or high risk of fetal loss. *Midwifery*. 2019 Dec;79:102537. doi: 10.1016/j.midw.2019.102537.
7. Houlihan BV, Coleman C, Kuo DZ, Plant B, Comeau M. What Families of Children With Medical Complexity Say They Need: Humanism in Care Delivery Change. *Pediatrics*. 2024 Jan 1;153(Suppl 1):e2023063424F. doi: 10.1542/peds.2023-063424F.

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