



Family-Led Academic  
Grand Rounds

# FLAG Rounds Session 5

## Key Takeaways

### What is Ableism?

- Discrimination towards people with disabilities—ableism—is extremely common.<sup>1</sup>
- 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'.<sup>2</sup>

### Identified Categories of Disability-Based Discrimination in Pediatric Health Care<sup>3</sup>

#### 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?<sup>4</sup>

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 health care.

### Strategies to Dismantle Ableism through Partnership

#### Family Faculty: Adenike Chon (Story: The First One is a Freebie)

- **Humanizing communication begins with listening, and follows with respect, authenticity, compassion and connection.** Offhanded comments can dehumanize and dismiss, even if that is not the intent.
- **Avoid repeating questions that are based on assumptions.** Repeating the same question can feel like dismissal. Families can feel like they are not being listened to or their response is not respected with each repetition, leaving them feeling dismissed and eroding trust. This is especially true when the question is based on an assumption.
- **Ask questions with curiosity and communicate clearly.** Explain why asking and what you want to know. For example: "You may have already addressed this with someone earlier, but can you tell me so I am clear: has your child had a seizure before?" instead of "When was the last seizure?"

December 4, 2025

**Dismissed: Devaluing the Voices of Families in Health Care**

View session recording:  
[go.wisc.edu/FLAGDecember2025](http://go.wisc.edu/FLAGDecember2025)

### FLAG Rounds Presenters



Adenike Chon  
Minnesota



Ida Winters  
Wisconsin



Ellie Acuna  
Texas

## Family Faculty: Ida Winters (Story: ER Visit Day 9)

- **Actively listen to the concerns of families when they seek care for their children.** Dismissal of families' concerns causes damage. It can make families feel unseen and unheard in the moment and can diminish families' trust in both providers and institutions. Being dismissed can cause families to doubt and question themselves.
- **Use basic communication tools to acknowledge and respect families.** Take time to paraphrase and repeat back what was said by a family, go over test results, and acknowledge symptoms being described.
- **Look for bridges.** If you are having trouble communicating with a family or think they might not understand, reach out to others in the child's care team. For example, the primary care physician may know the child and family better and could help bridge the gap.

## Family Faculty: Ellie Acuna (Story: It is Not the End of the World)

- **Do not minimize families' questions, input, or feelings.** Listening to, acknowledging and acting upon family concerns and input is necessary to create partnerships in care.
- **Do not put families in a box.** While we may share many similar experiences navigating conditions and systems, recognize that we are all different. Listen to understand individual families' needs and priorities.

## Session Q&A

### Is there a specific communication or relational skill that is missing that you think needs to be better taught/fostered in medical education?

Professionalism, as a core competency, is grounded in communication that is respectful and recognizes optimal health and quality of life from the patient and family perspective. Developing the knowledge, skills and attitude to enact professionalism begins first and foremost with listening. Medical education may have a mnemonic for how to deliver bad news, but teaching how to listen, fully, authentically and respectfully to a patient and/or their family (including in a time pressured emergent situation) doesn't fit within the same scheme. Narrative medicine and other practices within the medical humanities offer ways to build narrative competence- the ability to acknowledge, absorb, interpret and act on the stories of others- that involve building the muscles for professionalism.

### 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

**Any questions or want further discussion? [info@flagrounds.org](mailto:info@flagrounds.org)**