



Family-Led Academic
Grand Rounds

FLAG Rounds Session 4

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 health care.

Strategies to Dismantle Ableism through Family Partnership- Walking the Line between Giving Care and Forgone Care

STRATEGY 1 Adopt Practices to Help Overcome Barriers to Giving Care

- Remember: the moment you are seeing a child or family is only that, just a moment in time.
- Families are often using a well-rounded view of their child's entire life to make decisions, which can make it very difficult to make life or death decisions based on a single moment in time.
 - › Ask questions: What does your child's life look like at home? What are your family values for quality of life and how do you maintain it? What are your family priorities in this moment and how can I help you?
 - › Be compassionate and realistic. Be honest, even when it is hard.

September 25, 2025

**Walking the Line:
Giving Care/Forgone Care
(and everything
in between)**

View session recording:
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FLAG Rounds Presenters



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STRATEGY 2 Create Accessible Care Environments

- Ensure exam rooms and equipment accommodate wheelchairs and medical devices. Notice physical barriers and work with staff to adapt spaces or find better solutions for each family.

STRATEGY 3 Acknowledge and Reduce the Burden on Families

- Recognize that every appointment may require significant time, coordination, and effort from caregivers. Be flexible with scheduling, minimize unnecessary visits, and coordinate care across specialties whenever possible.

STRATEGY 4 Offer Flexible, Family-centered Options

- Offer virtual visits when appropriate. Set clear expectations about when in-person care is necessary and collaborate to find solutions that fit the daily reality of both the child and the family.

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. 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
6. COMMITTEE ON HOSPITAL CARE and INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE. Patient- and family-centered care and the pediatrician's role. *Pediatrics*. 2012 Feb;129(2):394-404. doi: 10.1542/peds.2011-3084. Epub 2012 Jan 30. PMID: 22291118.
7. Ames SG, Houtrow AJ, Gatewood AK, Zigler C, Ware A, Berry JG, Collier RJ. Disability-Based Discrimination and Forgone Health Care in Children With Special Health Care Needs. *Pediatrics*. 2025 Jul 1;156(1):e2024068782. doi: 10.1542/peds.2024-068782. PMID: 40456539.

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