

# Family-Led Academic Grand Rounds

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# Walking the Line: Giving Care/Forgone Care

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(and everything in between)



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Lora Batson, Anastacia Newton  
**September 25, 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.



**Department of Pediatrics**  
UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH

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# Funding Acknowledgement



**Lucile Packard**  
**Foundation**

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Children's Health

# Learning Objectives

1. Analyze how clinical assumptions and dehumanization influence decision-making in pediatric care
2. Summarize two ways assumptions can contribute to forgone or delayed care for children with complex medical needs
3. Identify how ableism can manifest in routine healthcare delivery, particularly in the care of children with medical complexities
4. Explain how virtual care, when used intentionally, can improve access, reduce burden, and enhance care quality for children with medical complexity
5. Describe how communication strategies can improve practice delivery and access for children with medical complexity

# ACGME Core Competencies

- ▶ **Patient Care and Procedural Skills**

  - PC 4: Prescribe and perform essential medical procedures

- ▶ **Professionalism**

  - PROF 2 Demonstrating humanism and cultural proficiency

- ▶ **Interpersonal and Communication Skills**

  - ICS-1 Create and sustain a therapeutic relationship with patients and families

- ▶ **Practice-Based Learning and Improvement**

  - PBLI-3 Improve the Practice of Medicine

# FLAG Rounds: The Pilot

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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.

Patient- and Family-Centered Care and the Pediatrician's Role. Pediatrics 2012.  
Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity. Ames, et al. Pediatrics 2023.

## Lack of accessibility to care

- Unwelcome in medical practice
- Cultural and language barriers
- Lack of accommodation for disability

## Dehumanization

- No or limited acknowledgement of patient
- Inappropriate interaction with patient
- Inappropriate comment to caregiver

## Substandard patient care

- Limiting treatment options
- Inappropriate assessment of patient
- Inappropriate treatment of patients

# Forgone Care

1. ...can be a manifestation of systemic discrimination due to inaccessible healthcare secondary to structural barriers, provider unwillingness to provide care, and lack of trained or accessible providers
2. ...can be the result of increased healthcare avoidance behaviors secondary to discrimination



The screenshot shows the PEDIATRICS journal website. The header includes the journal name 'PEDIATRICS' and navigation links for Content, Authors/Reviewers, Collections, Multimedia, and Blogs. The main content area displays 'Volume 156, Issue 1' for July 2025. The featured article is 'Disability-Based Discrimination and Forgone Health Care in Children With Special Health Care Needs', published in June 2025. The authors listed are Stefanie G. Ames, MD, MS; Amy J. Houtrow, MD, PhD, MPH; Amanda K. Gatewood, PhD; Christy Zigler, PhD; Allysa Ware, PhD, MSW; Jay G. Berry, MD, MPH; and Ryan J. Collier, MD, MPH. A quote from the article is displayed below the article information.

**PEDIATRICS**  
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS  
JULY 2025 • VOLUME 156 • ISSUE 1  
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ARTICLES | JUNE 03 2025

## Disability-Based Discrimination and Forgone Health Care in Children With Special Health Care Needs

Stefanie G. Ames, MD, MS; Amy J. Houtrow, MD, PhD, MPH; Amanda K. Gatewood, PhD; Christy Zigler, PhD; Allysa Ware, PhD, MSW; Jay G. Berry, MD, MPH; Ryan J. Collier, MD, MPH

🗨️ Families and children who experience discrimination may lose trust in the healthcare system and feel forced to choose between forgoing care or exposing themselves and their child to further biased and harmful treatment. 🗨️

# FLAG Rounds: September Family Faculty

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**Anastacia Newton**  
North Carolina



**Lora Batson**  
New York

## Pause and Reflect

- Take 30 seconds.
- What did you hear?



Maya Angelou once said,

“People will forget what you said, people will forget what you did, but people **will never forget** how you made them feel.”

# Dehumanization: What does it mean to be human?

Dehumanization can lead to foregone care.



# This is a SINGLE moment in time



**July 23**



**July 27**



**Aug 1**



**Aug 17**

# Time Changes Everything



**Sept 9**



**Sept 13**



**Oct 13**



**Oct 16**

# Overcoming Barriers to Giving Care

- ▶ Good communication, this includes active listening
- ▶ Respect (two way street)
- ▶ Investment in our child's life and reflecting on ways we can improve upon it
- ▶ Providers who are both compassionate and realistic
- ▶ Providers who share ideas back and forth, both with each other and with us

# FLAG Rounds: September Family Faculty

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**Anastacia Newton**  
North Carolina



**Lora Batson**  
New York

# How is this Ableism?

**“ ...it [ableism] can actively undermine best practices and negatively impact health outcomes without the clinician even realizing it”**

Reynolds JM. Three Things Clinicians Should Know About Disability. *AMA J Ethics*. 2018;20(12):1181-1187. doi:10.1001/amajethics.2018.1181

# Inaccessibility

**“I shift patient chairs... I squeeze him between the table and the wall...  
The door won't close.”**

**- Oscar's Mom**

# Oscar

**Hello there!**



# Inaccessibility- Transportation



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# Healthcare Burden Shifted to Families

**“We have 90 minutes to get uptown... I’m still searching for an outlet... By 5:00 p.m., I’m finally done.”**

**- Oscar’s Mom**

# Inflexible Models of Care

**“No,” she says firmly. “Your child is disabled and medically complex. It’s important that someone has eyes on him frequently.”**

**- Physician A**

# Virtual Visits with Children with Medical Complexities

**Virtual visits aren't appropriate for every health encounter!**

# Virtual Visits with Children with Medical Complexities

**Virtual visits can bridge clinic and home**



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# Virtual Care with Children with Medical Complexities

- ▶ **Start by Asking**
  - ▶ **Plan for Barriers**
  - ▶ **Be Transparent**
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# Walking the Line... in Partnership

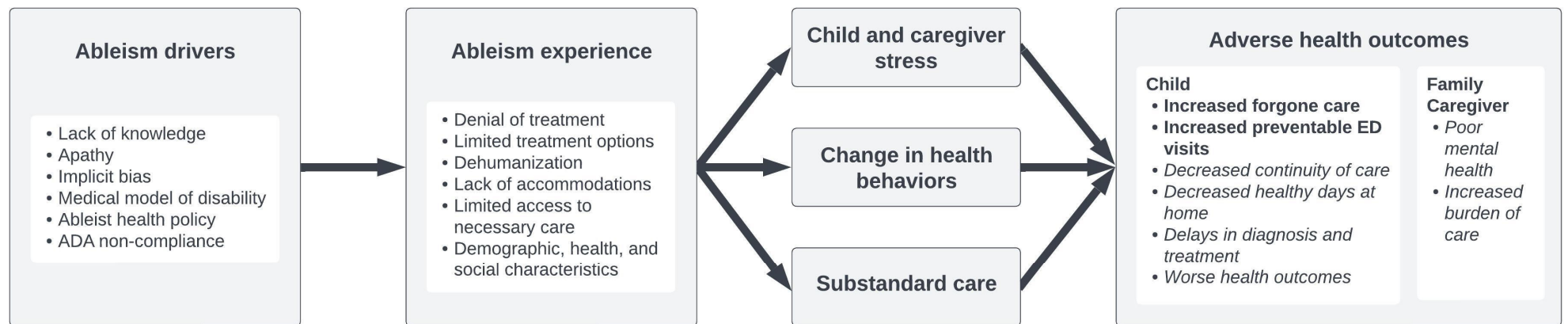


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