

# Family-Led Academic Grand Rounds

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Family-Led Academic  
Grand Rounds

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

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Family-Led Academic  
Grand Rounds

Danielle Gerber & Cara Coleman  
January 16, 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.

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# Funding Acknowledgement



Lucile Packard  
Foundation

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Children's Health



# FLAG Rounds Flow

- Background
- Learning objectives & Competencies
- Definitions
- Story
- Legal standards
- Story
- Teaching points





# Why Family-Led Academic Grand Rounds?



# Grand Rounds, FLIPPED

Each FLAG Rounds will involve:

- ▶ Family faculty presenting their “case” as a story
  - a specific moment or experience with ableism in pediatrics
- ▶ Strategies to develop the knowledge, skills and attitudes to:
  - dismantle ableism *and*
  - partner with families in the care of CWD/MC

CWD/MC = children with disabilities and/or medical complexity

## Core Components of Family Faculty Development:

*Writing*

*Empathy Building: Journey  
of Pediatric Training*

*Competency-Based  
Medical Education (CBME)*

*Faculty Development*



# Session Learning Objectives

1. Examine instances of inaccessibility to care for children with disabilities and/or medical complexity.
2. Describe the effect of substandard care of children with disabilities and/or medical complexity.
3. Identify strategies and opportunities to partner to humanize healthcare interactions for children with disabilities and/or medical complexity, their families and all providers.

# ACGME Core Competencies

**Patient Care:** *highlights the necessity of physicians maintaining a patient-centered approach to health care. This entails forming a bond of trust between patient and provider.*

A physician will meet all the requirements for this competency when they are able to demonstrate an ability to listen and absorb medical histories, diagnose, properly inform and educate, and prescribe and perform necessary procedures in a way that maximizes patient comfort.

**Interpersonal and Communication Skills:** *to demonstrate the ability to effectively exchange information with patients, their families, and professional associates. Effective communication is a two-way street. It requires the resident to be both an active listener as well as a clear, articulate speaker. The ability to receive information is as important as the ability to transmit it to others.*

To do this, physicians must develop meaningful relationships with not only their patient but the patient's family and the other medical professionals and health care team members they interact with on a daily basis.

**Professionalism:** *standard speaks directly to the attitude and behavior of the resident physician.*

The expectation for all medical professionals is that each and every one will treat all people with respect, compassion, and dignity.

# Core Competencies on Disability for Health Care Education

## **Professionalism and Patient Centered Care:**

- 2.1 Explore and mitigate one's own implicit biases and avoid making assumptions about a person's abilities or lack of abilities;*
- 2.2 Treat all patients, regardless of disability and functional status, with respect and humility;*
- 2.3 Demonstrate communication strategies to best meet the needs/abilities of the patient.*

## **Legal Obligations and Responsibilities for Caring for People with Disabilities:**

- 3.2 Identify the physical access requirements of the ADA, Rehabilitation Act, and related that apply to health and the provision of health care;*
- 3.3 Plan for accessible communication in all aspects of the healthcare encounter; and*
- 3.5 Discuss strategies for meeting access requirements of the ADA, Rehabilitation Act, and related laws and policies.*

## **Teams and Systems-Based Practice:**

- 4.2 Describe impact of teams and the unique and the discipline-specific responsibilities of team members in addressing health needs of patients with disabilities and in partnering with the patient as a central member of the team; and*
- 4.3 Describe challenges in creating a person-centered or family-centered system of care.*

## **Clinical Assessment:**

- 5.2 Discuss situations where the caregiver(s) can be helpful to inform or enhance assessments and interventions and the importance of securing patient permission before engaging caregivers.*

# What is Ableism?

Discrimination towards people with disabilities—ableism—is extremely common.

(Barnes, 1997; Keller & Galgay, 2010; Linton, 1998; Lundberg & Chen, 2024; Nario-Redmond, 2019).

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’


(Bogart & Dunn, 2019, p. 652).

Like other forms of oppression, ableism describes the valuing of some ideals and attributes over others, including compulsory preference for non-disability.

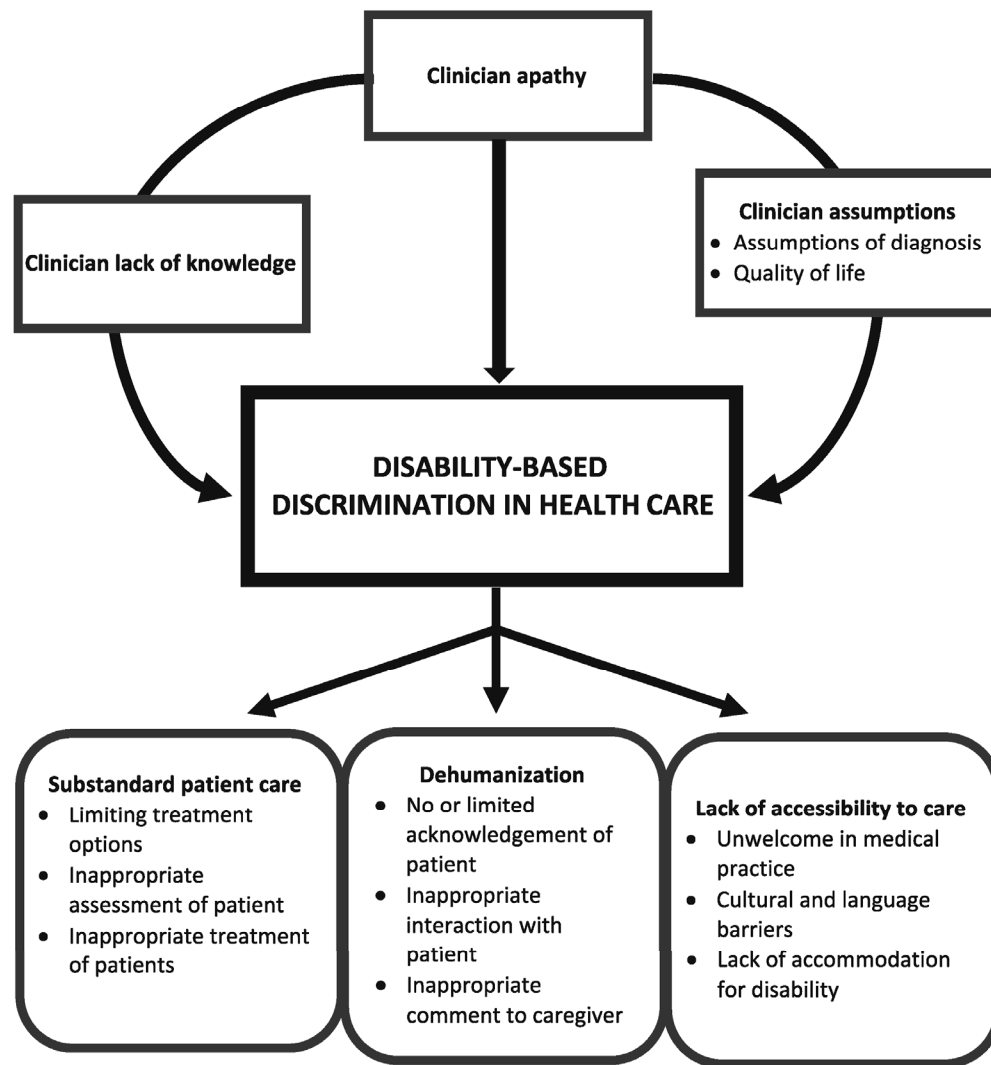
(Campbell, 2009; Kafer, 2013; Wolbring, 2008).

This system of marking some bodies/minds as deviant not only impacts attitudes of individual people, but also embeds within environments, systems, and structures.

(Keller & Galgay, 2010; Linton, 1998; Lundberg & Chen, 2024; Nario-Redmond, 2019). (<https://doi.org/10.1111/jar.13218>)



**Figure Legend:**  
Conceptual framework of  
interpersonal disability-based  
discrimination in health care.



# What is Patient and Family-Centered Care?

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.

1. Listening to and respecting each child and his or her family.
2. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family and facilitating choice for the child and family about approaches to care.
3. Sharing complete, honest, and unbiased information with patients and their families on an ongoing basis and in ways they find useful and affirming, so that they may effectively participate in care and decision-making to the level they choose.
4. Providing and/or ensuring formal and informal support (eg, peer-to-peer support) for the child and family during each phase of the child's life.
5. Collaborating with patients and families at all levels of health care.
6. Recognizing and building on the strengths of individual children and families.



**Justice Hope**





# Expectation

**Americans with Disabilities  
Act of 1990, As Amended**

**Title 42 - The Public Health  
and Welfare Chapter 126**



# Equal Opportunity for Individuals with Disabilities Sec. 1210: Findings

The Congress finds that—

- (1) physical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination; others who have a record of a disability or are regarded as having a disability also have been subjected to discrimination;
- (2) historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;
- (3) discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;
- (4) unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination;
- (5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities;
- (6) census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally;
- (7) the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and
- (8) the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.

# Equal Opportunity for Individuals with Disabilities Sec. 1210: Purpose

## (b) Purpose

It is the purpose of this chapter—

- (1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;
- (2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;
- (3) to ensure that the Federal Government plays a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities; and
- (4) to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.

# Section 504 of the Rehabilitation Act of 1973

- ▶ **1973 Act: Nondiscrimination Under Federal Grants Sec. 504.**

*No otherwise qualified handicapped individual in the United States, as defined in section 7 (6), shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.*

- ▶ 1977 Sit-in forced regulations
- ▶ 2024: *Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance*- updates, modernizes, clarifies, and strengthens the implementing regulation for Sec. 504 of the Rehabilitation Act of 1973.

Not just a 504 plan in special education...

*Section 504 prohibits discrimination on the basis of disability in programs and activities that receive Federal financial assistance*

# 504 Revisions Made for Consistency with the Americans with Disabilities Act (ADA)

- ▶ **Reasonable modifications, § 84.68(b)(7):** Recipients must make reasonable modifications to policies, practices, and procedures unless the recipient can demonstrate modification would fundamentally alter the nature of the program or activity.
- ▶ **Maintenance of accessible features, § 84.70:** Recipients must maintain in operable working condition those features of facilities and equipment that are required to be readily accessible, but isolated or temporary interruptions due to maintenance or repairs are permitted.
- ▶ **Accessibility standards, §§ 84.21-84.23:** Regarding existing facilities, recipients must operate each of their programs and activities so that the program or activity, when viewed in its entirety, is readily accessible to and usable by individuals with disabilities.
- ▶ **Communications, §§ 84.77-84.81:** Recipients must take appropriate steps to ensure that communications with individuals with speech, hearing, and vision disabilities are as effective as communications with others.

# New 504 Sections Clarifying Non-Discrimination Obligations

- ▶ **Accessible Medical Equipment (MDE), § 84.90-84.94:** Prohibits discrimination against people with disabilities because the medical diagnostic equipment (MDE) used by a recipient in its programs or activities is not accessible to or usable by people with disabilities.
- ▶ **Medical Treatment, § 84.56:** Recipients cannot deny or limit clinically appropriate treatment to a qualified individual with a disability when the denial is based on bias or stereotypes, a belief that the individual will be a burden on others, or a belief that the life of an individual with a disability has a lesser value than the life of a person without a disability.

The rule also prohibits the denial of treatment to a person with a disability when the same treatment would be offered to a similarly situated person without a disability, provided that the disability does not impact the effectiveness, ease of administration, or have a medical effect on the condition to which the treatment is administered.
- ▶ **Value Assessment, § 84.57:** Recipients are prohibited from using any measure that discounts the value of life extension based on disability to deny or afford an unequal opportunity to qualified individuals with disabilities. This applies to the eligibility or referral for, or provision or withdrawal of any aid, benefit, or service, including the terms or conditions under which they are made available.



# Jack

Inpatient, working with CASC team  
(Communication aids and systems clinic)







# Teaching from stories

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# But first, back to our core

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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.

## Dehumanization

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

## Lack of accessibility to care

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

## Substandard patient care

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

# Humanization > Dehumanization: Whole Child

- ▶ Assumptions
- ▶ Attitudes
- ▶ “F” words
  - From “fix” to:
  - Fitness, function, friends, family, fun and future

1) World Health Organization. (2001) International Classification of Functioning, Disability and Health (ICF) ) Rosenbaum P & Gorter JW. (2012).  
2) The 'F-words' in childhood disability: I swear this is how we should think! Child Care Health Dev; 38.

# Humanization > Dehumanization: Whole Child



# Making the inaccessible, accessible: Full Access

Are we “welcome?”

- ▶ “Built” environment
  - Community & healthcare settings
  - Social
- ▶ Perceptions/assumptions, attitudes, culture and communication

# Making the inaccessible, accessible: Full Access

- ▶ Communication
  - Planning
  - Asking
  - Accommodations

# Substandard to Excellent Care: Just Ask!

- ▶ Ask Yourself
- ▶ Ask your “team”
- ▶ Ask us!!!

Not just screening questions on iPad or by reception...a conversation

# Substandard to Excellent Care: Just Ask!

- ▶ Opportunities to plan ahead
  - Shared plan of care
  - Pain plan
  - Consults - pre-surgery, pre-anesthesia
- ▶ ...But what about time?!



# Final thoughts

## ► Stories + Strategies

- Whole Child (Humanize)
- Full Access
- Ask

## ► Questions?



[info@flagrounds.org](mailto:info@flagrounds.org)



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evaluation using the QR code below.

Reminder that you need to text in to claim  
attendance to access it.

Thank you!

