

Family-Led Academic Grand Rounds

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Family-Led Academic
Grand Rounds

Dismissed: Devaluing the Voices of Families in Health Care



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Grand Rounds

Adenike Chon, Ida Winters, Ellie Acuña
December 4, 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.

Please take a moment at the end of the session to complete your evaluation.

Thank you!

Funding Acknowledgement



Lucile Packard
Foundation

Children's Health



Learning Objectives

1. Identify the difference between humanizing and dehumanizing communication with families of children with disabilities in emergent situations.
2. Describe the importance of listening to families and meeting and caring for each child as an individual.
3. Discuss the effect of dismissing families of children with disabilities and explain how to appropriately respond.

ACGME Core Competency

Professionalism and Patient-Centered Care:

Demonstrate mastery of general principles of professionalism, communication, respect for patients, and recognizes optimal health and quality of life from the patient's perspective.

FLAG Rounds: The Pilot

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;152(1). doi:10.1542/peds.2022-060975

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

Ableism

A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence and fitness.

These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism and capitalism.

This systemic oppression leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave."

You do not have to be disabled to experience ableism.

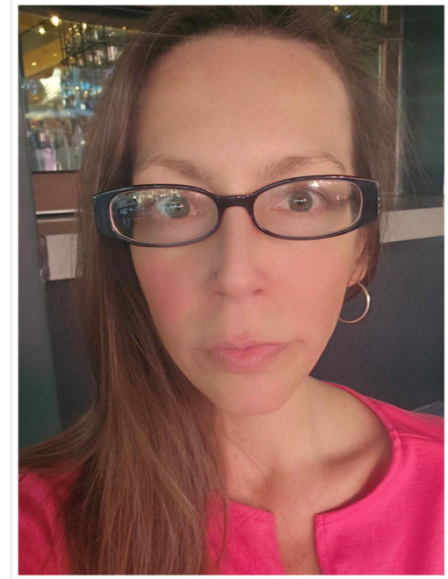
<https://www.ableism.com/origins/origins.html>



ADENIKE CHON
Minnesota



IDA WINTERS
Wisconsin



ELLIE ACUÑA
Texas

Pause and Reflect

- ▶ Take 15 seconds.
- ▶ What did you hear?



Teaching from stories

ADENIKE

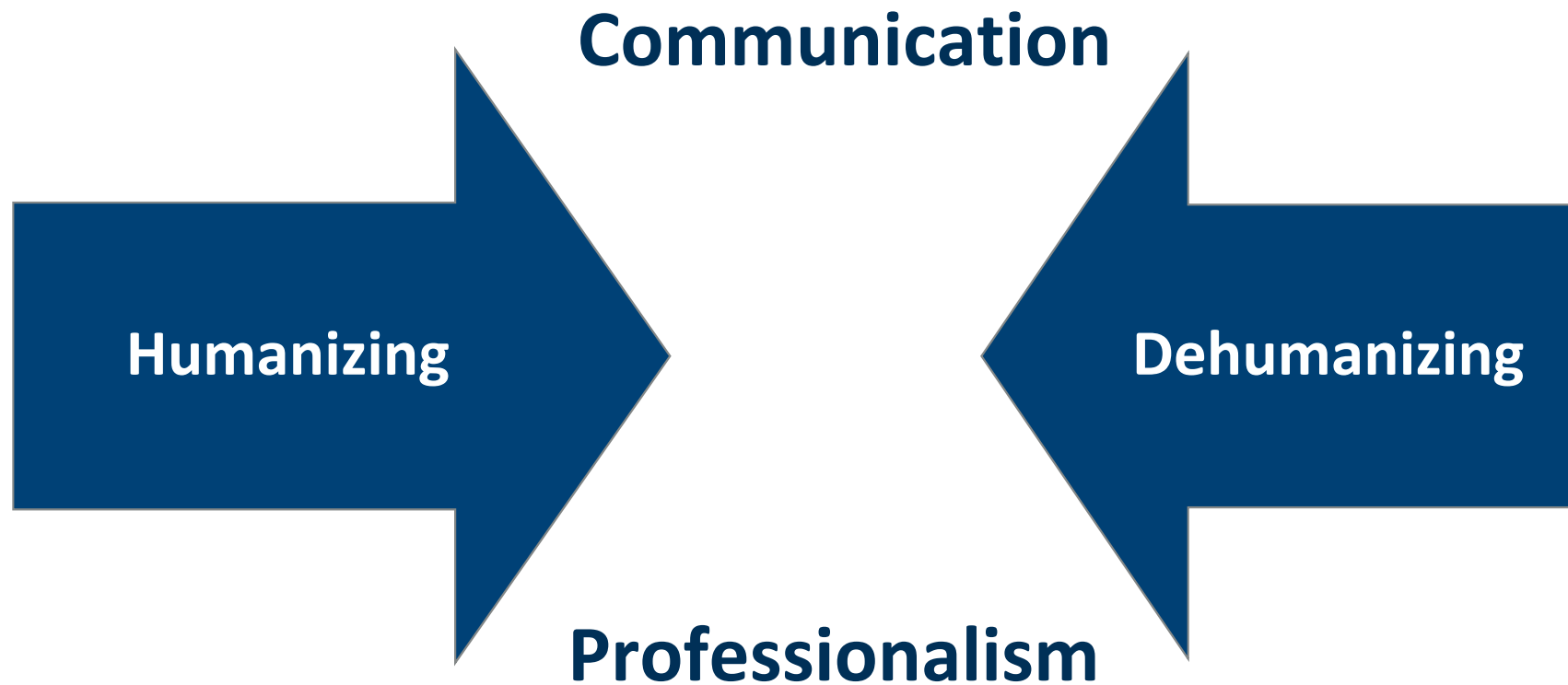


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“...The first one's a freebie”



“...The first one’s a freebie”



How do you communicate with dignity and respect?

How do you:

- ▶ Listen?
- ▶ Be present?
- ▶ Respond?
- ▶ Act?



Assumptions

- ▶ **Repetition of questions**
 - Issue lies with “*how*”, not “*that*”
 - Try following with a “*why*” explanation
- ▶ **Dismissing with assumptions:** “When was his last one?”
- ▶ **Direct question:** “Has he had a seizure before?”



Pause and Reflect

- ▶ Take 15 seconds.
- ▶ What did you learn?



Pause and Reflect

- ▶ Take 15 seconds.
- ▶ What did you hear?



Teaching from stories

IDA



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The nurse walks us to the exit and tells me,

“The next time you have a concern, don’t come here, go to his pediatrician!”

“The hospital is where they treat people who are sick, right?”

He says, “Yes, but people who are really sick!”



What Being Dismissed Did to Me

- ▶ Made me feel unseen and unheard.
- ▶ Instead of dismissing me, try to:
 - Listen and ask questions.
 - **Use communication tools** to let me know you hear and see me (and my son):
 - ▶ paraphrasing what we said,
 - ▶ going over test results and what they mean, or
 - ▶ simply acknowledge the symptoms we presented as concerning.

Further Impact of Dismissal

- ▶ Caused me to doubt and question myself.
 - “Angry Black woman”
- ▶ Instead of dismissing me, try:
 - Talking to me and if you think I may not understand or you have more questions, reach out to the pediatrician.
 - ▶ Look for a bridge, call in your teammates!

Dismissal and Distrust



Pre-event



ER: Day 1



ER: Day 9

Pause and Reflect

- ▶ Take 15 seconds.
- ▶ What did you learn?



Pause and Reflect

- ▶ Take 15 seconds.
- ▶ What did you hear?



Teaching from stories

ELLIE



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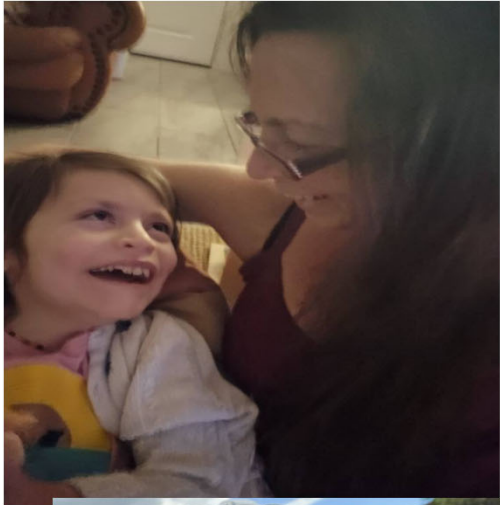
"This isn't the end of
the world you know..."

“This isn’t the end of the world, you know...”

- ▶ **Do not minimize me, my input or my feelings.**
 - Pause; imagine yourself in my shoes.
 - Ask yourself, why is this a big moment in my life? In the life of my newborn?
 - For me, this was devastating.
 - ▶ **DO listen to HEAR.**

“This isn’t the end of the world, you know...”

- ▶ **Do not put me, or my daughter, in a box.** We won’t fit!
 - A mom with questions does not equal a mom who needs a psych evaluation.
- ▶ **DO say hello.**
 - Let’s talk about it.
 - How can you as her doctor and me as her mother share information and create a plan we’re both comfortable with?
 - I want to partner with you!



Pause and Reflect

- ▶ Take 15 seconds.
- ▶ What did you learn?



So maybe someone else's
walk down this path may
be easier...

To make “team” a reality
for us all in healthcare

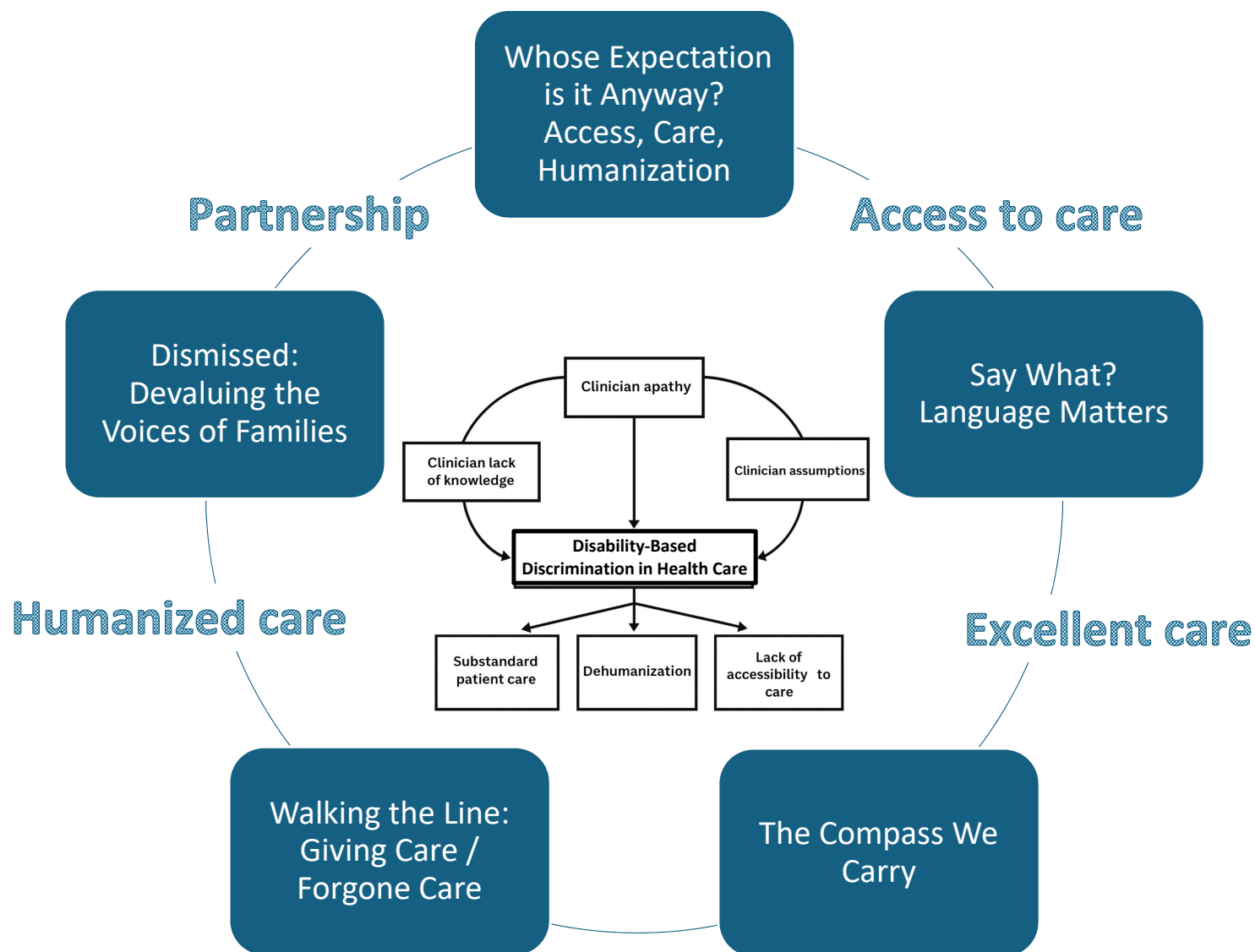
WHAT IS YOUR “WHY”?

... Because I can't live
without her (my child)

To make the system
better for everyone

We all possess different
powers – together as a team,
we all win. Time to put care
back into healthcare!





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to access it.

Thank you!



go.wisc.edu/decflageval



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