

# Family-Led Academic Grand Rounds

**Text: 608-260-7097**

**Code: TUYPAH**

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Need support? Email Kate Dougherty at [catherine.dougherty@wisc.edu](mailto:catherine.dougherty@wisc.edu)



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

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# The Compass We Carry

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Darcel Jackson, Eithne Egan, Lori Ann Dotson  
**May 29, 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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Please take a moment at the end of the session to complete your evaluation.

Thank you!



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# Funding Acknowledgement



Lucile Packard  
Foundation

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Children's Health

# Learning Objectives

1. Describe how diagnostic overshadowing can create barriers to equitable, appropriate and safe healthcare for individuals with neurodevelopmental disabilities.
2. Evaluate risk factors for adverse experiences in healthcare settings and identify strategies for prioritizing safe and effective care for individuals with neurodevelopmental disabilities (NDD)
3. Identify essential and accurate information about the “whole child.”
4. Create and sustain a therapeutic relationship with patients and families by valuing the dignity (merit/worth) of every child through expression and action.

# Core Competencies on Disability for Health Care Education

1. Recognize that people with disabilities experience the same common health conditions as people without disabilities, and that a disability may impact the presenting signs and symptoms.
2. Recognize that children and adults with disabilities are vulnerable to abuse. The nature of abuse may be verbal, financial, physical and/or sexual. Abuse often goes unreported because the person with a disability may depend on the abuser for activities of daily living or social support.

# ACGME Core Competencies

1. Patient Care and Procedural Skills: Gather essential and accurate information about the patient
2. Interpersonal and Communication Skills: Create and sustain a therapeutic relationship with patients and families



# 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



**EITHNE EGAN, PG Cert, CHHC, PMH-C  
Massachusetts**

Eithne is a family partner, parent consultant, advocate and the owner of Sólás Consulting.



**LORI ANN DOTSON, PhD, MBA  
California**

Lori Ann is Chief Knowledge and Learning Officer at the IABA Research & Education Foundation.



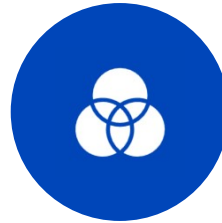
**DARCEL JACKSON, CPXP, LSSGB  
Maryland**

Darcel is Family as Faculty and Manager of Patient and Family Centered Care at Children's National Hospital in DC.

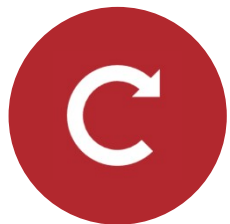
## Using a Compass to Align Care



Move away from  
interference



Remove Obstacles



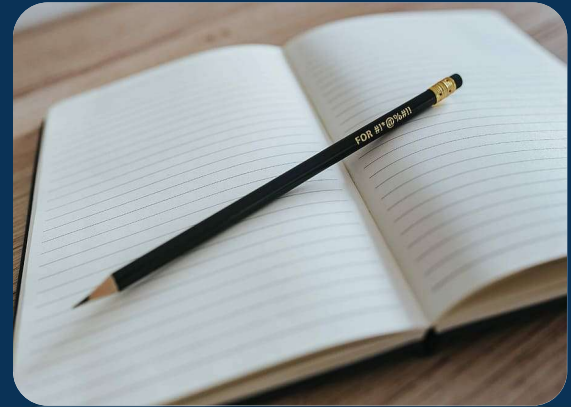
Recalibration is  
constant.



Check your **north**.  
Magnetic north is  
not the same as  
true north.

## Pause and Reflect

- ▶ Take 30 seconds.
- ▶ What did you hear?



# Teaching from stories

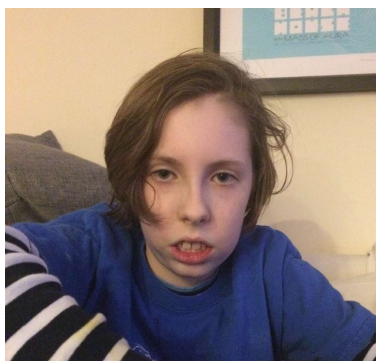
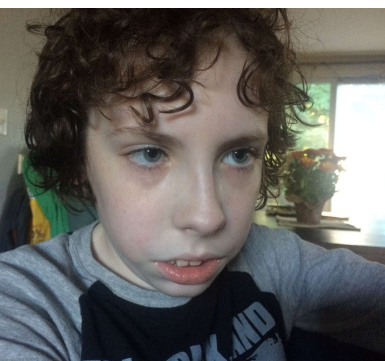
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EITHNE



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# Move Away from Interference: Chronically Misunderstood



- **Diagnostic Overshadowing** – the misattribution of symptoms to a pre-existing or primary condition.
- Autistic children and teens experience higher prevalence of pain

Whitney, D.G. (2019) "National Prevalence of Pain among Children and Adolescents With Autism Spectrum Disorder."

## Check for Deviation: What are the Obstacles?

### The Wrong Lens - Compliance

- ▶ Children with disabilities are at higher risk for maltreatment in all settings
- ▶ Hospitalized children with ASD are at significantly higher risk of restraint than neurotypical children
- ▶ A crisis mentality creates the crisis

McDonnell, C.G. (2019) "Child maltreatment in autism spectrum disorder and intellectual disability: results from a population-based sample"

Calabrese, M.E. ( 2024) 'Physical and Pharmacologic Restraint in Hospitalized Children With Autism Spectrum Disorder'

## Adjust for Declination: Stay the Course

### A Different Lens: Thinking about Safety Differently

- Children with neurodevelopmental disabilities have specific and unique needs in healthcare settings
- Appropriate, meaningful, and trauma-informed care is essential to ensure safety
- We must be able to take the perspective of the child in order to create a true sense of safety



# Check your North: Recalibration is Constant

## Turning the temperature down: Trauma-Informed Care

- Trauma is both common and complex in this population
- Trauma-informed care is patient-centered, simple in practice, and benefits everyone
- Safety is created through connection and co-regulation:
  - ▶ Supporting sensory and communication needs
  - ▶ Modeling co-regulation and positive rapport
  - ▶ Reinforcing and recognizing the child's attempts to self-regulate

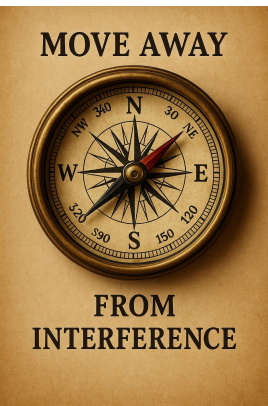
# Teaching from stories

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DARCEL



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# Quality of Life is Not a Medical Algorithm

- ▶ Define quality of life **with** families early – and revisit often
- ▶ True North varies - ask what matters most
- ▶ Listen for family-defined dignity, joy and connection
- ▶ See the whole child – not just the diagnosis

## Finding True North

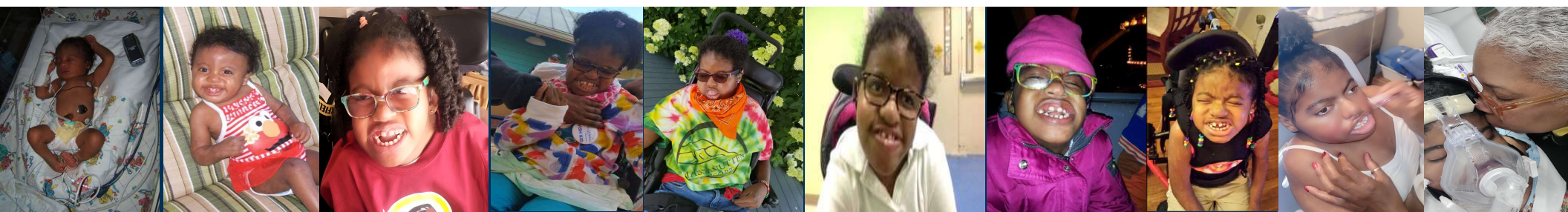


## From Doing *Everything* to Doing What *Matters*

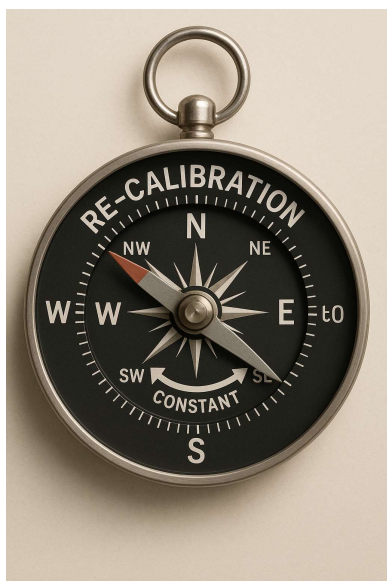


- ▶ Honor when families shift from cure to comfort
- ▶ Recognize when systems lag behind decline
- ▶ Don't treat numbers and miss the child
- ▶ Honor when goals evolve – past choices may no longer apply





## True North Requires Regular Reassessment and Emotional Courage

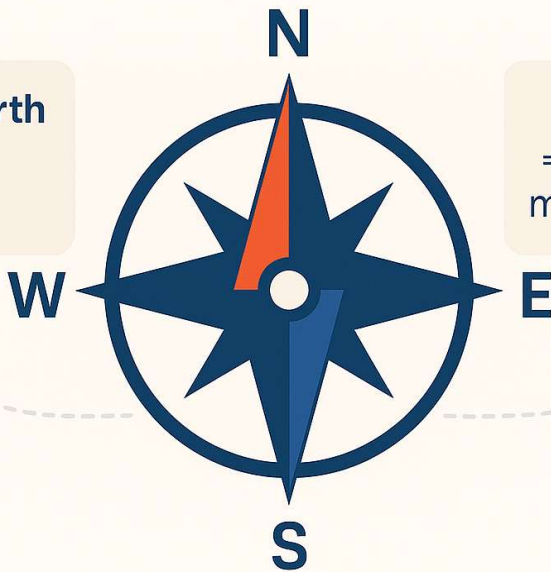


- ▶ Healing isn't always found in more treatment
- ▶ Re-calibrate with families – don't leave them alone
- ▶ True North evolves
- ▶ Prepare to sit with grief, not solve it

# Check your North – Magnetic North is Not the Same as True North

## Magnetic North vs. True North

**Magnetic North**  
= System  
priorities



**True North**  
= What matters  
most to the family



# What Matters



- ▶ Ask early and often
- ▶ Name the shift with honesty and heart
- ▶ Revisit goals – alignment is an ongoing practice

# Teaching from stories

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Lori Ann



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## Frequent Flyer. Terminal.

- ▶ Non-verbal. Trach/Vent. Tube Fed. Port. Shunt. Syringomyelia. Dysautonomia. Epileptic. Growth Restricted. Obese. Quadriplegic. Visually Impaired. Hearing Impaired. Anemic. Renal Disease. Spasticity. Profound Cognitive Delays. Iron, Pancreatic, Adrenal Insufficiency. Coagulation defect. Hypogammaglobulinemia. Contracted. Kyphotic...
- ▶ Life Limited.

**Whole Child.**

Joyous.

Comfortable.

Curious.

Wanted.

Valued.

Loved.

See My Joy Campaign

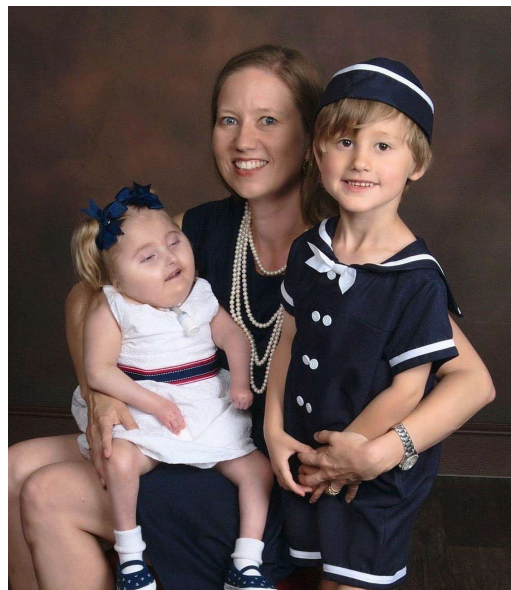




What Does Dignity Mean?

The word "**dignity**" comes from the Latin word ***dignitas***, which means "**worthiness**" or "**merit.**" This, in turn, comes from the Latin adjective ***dignus***, meaning "**worthy**" or "**deserving.**"





**Equestrian. Fashionista. Thespian.  
Student. Teacher.  
Daughter. Sister. Cousin. Friend.**

- Research has found that few medical programs have home visits to patient homes as part of their training for pediatric residents, despite the benefits to both the patient and the doctors in training (Hobbs, et al., 2007; Steinkuller, 1992).
- **How can you “see” what you’ve never seen?**

## Things you can do

- Get to know the “whole” child.
- Be willing to ask for and extend grace.
- Be brave in the face of uncertainty.

**Providers and caregivers are more alike than we are different.**





# The Compass We Carry

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- **Compassion over Compliance**
- **Offer and Extend Grace**
- **Mindful Presence**
- **Promote Dignity**
- **Align to “True North”**
- **Share Vision**
- **Shift Perspective & Culture**



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to access it.

Thank you!



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