FLAG Family-Led Academic Grand Rounds

# FLAG Rounds Session 3
# Key Takeaways

**May 29, 2025**

**The Compass We Carry**

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## 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 Care[3]

| Substandard Patient Care | Dehumanization | Lack of Accessibility to Care |
|---|---|---|
| (Limiting treatment options, inappropriate assessment and treatment) | (Inappropriate interactions/communication with child and/or family, no/limited acknowledgment of child) | (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 healthcare.

## Strategies to Dismantle Ableism through Family Partnership - Using a Compass to Align Care

### STRATEGY 1 Adopt Trauma-informed Practices through Co-regulation, Compassion, and Collaboration

- Treat all with dignity and respect; see the person first, not their diagnosis.
- Recognize that children with disabilities may experience and express pain and discomfort differently.[5,6]
- Collaborate with parents and knowledgeable caregivers to develop a holistic understanding of the child's needs and experience of healthcare settings.[7]
- Prioritize the safety and well-being of disabled children who may be at risk for maltreatment.[8,9]
- Become aware of the power of mutual collaboration with patients and families by modeling trauma-informed co-regulation and relationship-based care.[10]

**The Compass We Carry**

**C**ompassion over compliance
**O**ffer and extend grace
**M**indful presence
**P**romote dignity
**A**lign to "true north"
**S**hare vision
**S**hift perspective and culture

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## STRATEGY 2 **Quality of Life**[11,12]

- Care must reflect what families define as meaningful — not just survival, but joy, comfort, and connection.
- Challenge the assumption that disability equals suffering by seeing the full child and responding to evolving signs of distress.
- Normalize proactive, values-based conversations.
- Proactively engage families in care planning conversations before crisis moments.

## STRATEGY 3 **Gather Essential and Accurate Information**

- See the child as a whole- not a case or collection of symptoms.[13]
- Be fully present. Spend time at the bedside with intention. Take note of the physical and interpersonal ecologies. What do they tell you about dignity and comfort?[14]
- Imagine the child in community. Ask "What does thriving look like for this child at home, at school, or in their community?"[15,16]
- Make joy visible. Ask "What is something you wish every doctor could know or see?"[17]

### 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. Calabrese, M.E., Sideridis, G. and Weitzman, C. (2024) 'Physical and Pharmacologic Restraint in Hospitalized Children With Autism Spectrum Disorder', Pediatrics, 153(1), p. e2023062172. Available at: https://doi.org/10.1542/peds.2023-062172.
6. Whitney, D.G. and Shapiro, D.N. (2019) 'National Prevalence of Pain Among Children and Adolescents With Autism Spectrum Disorders', JAMA Pediatrics, 173(12), p. 1203. Available at: https://doi.org/10.1001/jamapediatrics.2019.3826.
7. Horton, C., Evans, N., Charkowski, R., D'Amico, P., Gomez, M., R., Henderson Bethel, T., Kraps, J., Vogel, J., and Youde, J. (2021) Children with intellectual and developmental disabilities can experience traumatic stress: A fact sheet for parents and caregivers. Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.
8. McDonnell, C.G., Boan, A.D., Bradley, C.C., Seay, K.D., Charles, J.M. and Carpenter, L.A. (2019) 'Child maltreatment in autism spectrum disorder and intellectual disability: results from a population-based sample', Journal of Child Psychology and Psychiatry, 60(5), pp. 576–584. Available at: https://doi.org/10.1111/jcpp.12993
9. Muskett, C. (2014) 'Trauma-informed care in inpatient mental health settings: A review of the literature', International Journal of Mental Health Nursing, 23(1), pp. 51–59. Available at: https://doi.org/10.1111/inm.12012.
10. Weitzman, C., Nadler, C., Blum, N.J., Augustyn, M., and Supporting Access for Everyone Consensus Panel (2024) 'Health Care for Youth With Neurodevelopmental Disabilities: A Consensus Statement', Pediatrics, 153(5), p. e2023063809. Available at: https://doi.org/10.1542/peds.2023-063809.
11. Back, A. L., Arnold, R. M., & Tulsky, J. A. (2009). Mastering Communication with Seriously Ill Patients: Balancing Honesty with Empathy and Hope. Cambridge University Press. https://www.cambridge.org/core/books/mastering-communication-with-seriously-ill-patients/0AA9843246D48D47636DAA53DB36A2F5
12. Bernacki, R. E., & Block, S. D. (2014). Communication about serious illness care goals: A review and synthesis of best practices. JAMA Internal Medicine, 174(12), 1994–2003. https://doi.org/10.1001/jamainternmed.2014.5271
13. Houlihan, B. V., Coleman, C., Kuo, D. Z., Plant, B., & Comeau, M. (2024). What families of children with medical complexity say they need: humanism in care delivery change. Pediatrics, 153(Supplement 1).
14. Julião, M., & Buonaccorso, L. (2025). Building dignity at the bedside: A reflective clinical model for clinical encounters. Palliative & Supportive Care, 23, e94.
15. Hobbs, J. E., Tschudy, M. M., Hussey-Gardner, B., Jennings, J. M., and Boss, R. D. (2007). "I don't know what I was expecting": Home visits by neonatology fellows for infants discharged from the NICU. Birth. 44:331–336.
16. Steinkuller, J. S. (1992). Home visits by pediatric residents: a valuable educational tool. American Journal of Diseases of Children, 146(9), 1064-1067.
17. Kluger, B.M., Garvan, C.W., Holloway, R.G. (2001). Joy, Suffering, and the Goals of Medicine. JAMA Neurology;78(3) 265-266.


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


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