



# Spiraling:

Visions and Actualization of Family/Provider  
Research Partnership

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FAMILY  VOICES<sup>®</sup>



# Presenter Disclosure

- **Presenter: Cara L. Coleman**
- **Relationships with commercial interests:**
  - Grants/Research Support: LPFCH Home Health Research Grant

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# Accreditation

## Accreditation Statement

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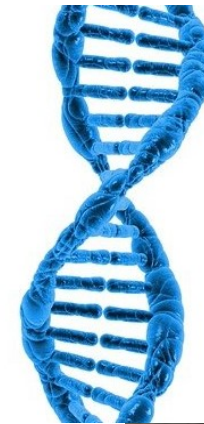
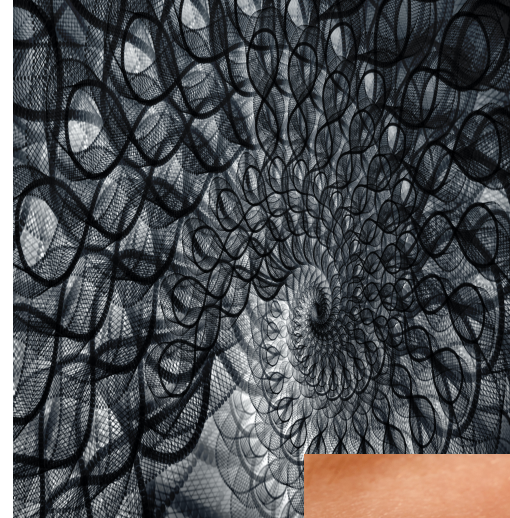
# Objectives

- Partnership in Poetry
- Identify challenges to meaningful and authentic partnership in research with families
- Identify key principles to activate family- provider/professional partnerships in research
- Lessons Learned from Co-Principal Investigators

# Closure by Amanda Gorman

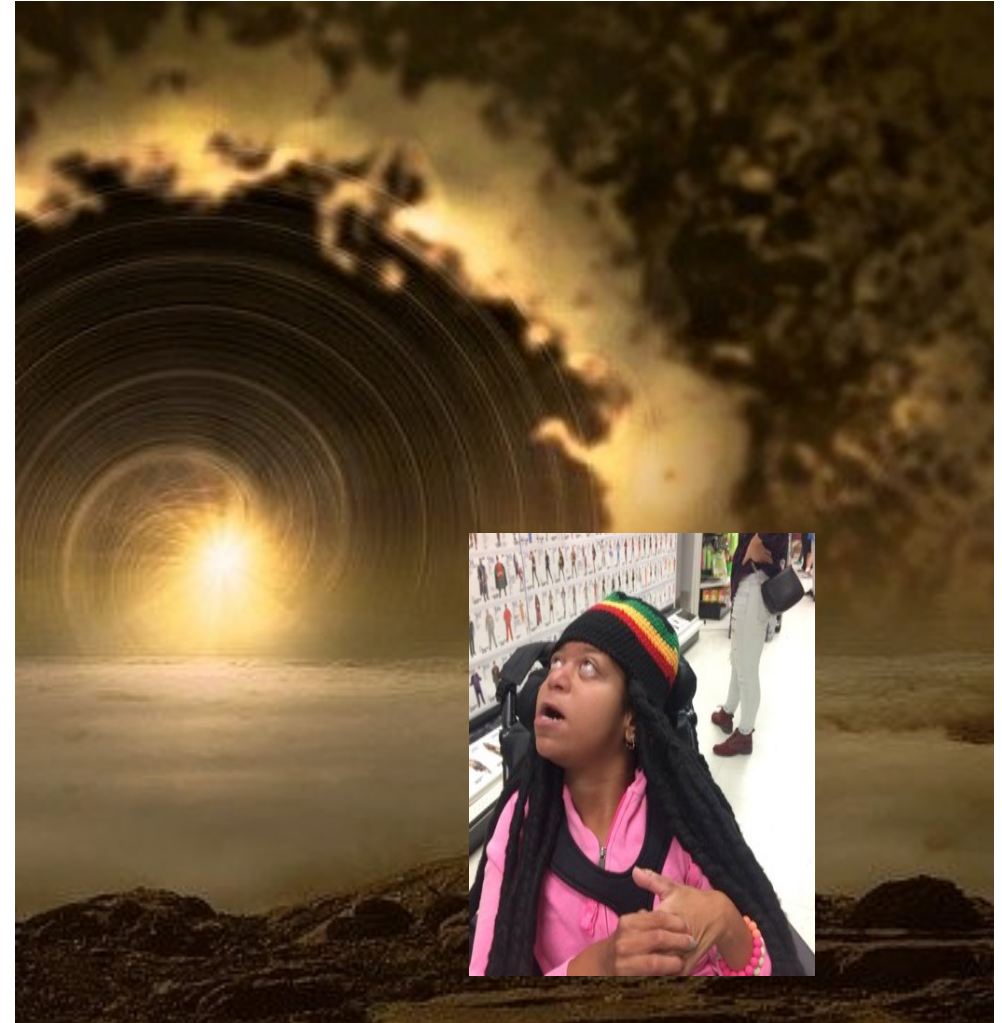
To begin again  
Isn't to go backwards.  
But to decide to go.  
Our story is not a circle carved,  
But a spiral shed/shaped/spinning,  
Shifting inward & outward *ad infinitum*,  
Like a lung on the bank of speech.  
Breathe with us.  
We disembark both beside & beyond  
Who we were, who we are.  
It is a return & a departure  
We spiral on, pushing up & out,  
Like a growing thing  
Making its form out of earth.  
In a poem, there's no end,  
Just a place where the page glows wide  
& waiting,  
Like a lifted hand,  
Poised & paused.

Here is our bond, unbordered by bone.  
Perhaps love is how it feels  
To breathe the same air.  
All we have is time, is now.  
Time takes us on.  
How we are moved says everything  
About what we are to each other  
& what are we to each other  
If not everything.



# From “Closure:” Meaningful and Authentic Partnership in Research

- To go
- Return and departure
- Shedding
- Growing
- Change is the only constant- *ad infinitum*
- Opportunity
- Our bond
- Now
- EVERYTHING



# The grey areas that cloud

- Fear, uncertainty
- Power dynamics, culture
  - What is an expert? Is there place on a TEAM for them?
- Valuing
  - Academic expertise (and agendas/ ladders)
  - Lived experience/expertise
- Muddy the waters and more difficult/work
  - who needs prep/training?
- Trust/ mistrust, history
- Boundaries
- Honesty, communication
- Funding, leadership

Equity will remain out of reach unless we work in the grey together





# It's all in the approach: From adjectives/nouns to verbs

## Patient and Family Centered Care

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all health care settings.

This approach is based on the recognition that patients and families are essential allies for quality and safety—not only in direct care interactions, but also in quality improvement, safety initiatives, education of health professionals, research, facility design, and policy development.

## Core Concepts of Patient- and Family-Centered Care

- Dignity and Respect.
- Information Sharing.
- Participation.
- Collaboration.

Johnson, B. H. & Abraham, M. R. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

## PCORI Principles of Engaging Diverse Partners in Research

- Trust
- Reciprocal Relationship
- Honesty
- Transparency
- Cultural Competence
- Co-Learning
- Partnerships

Coleman, C. L., Abraham, M. R., & Johnson, B. H. (2019). Strengthening diversity in research partnerships: Knowledge to action guide. Bethesda, MD: Institute for Patient- and Family-Centered Care. Available from <http://ipfcc.org/bestpractices/strengthening-diversity/index.html>



# Being “Co’s” & Doing “Co’s”

- “In the beginning...”
  - passion
- Non-traditional plan: time, resources, \$
- Mutually beneficial relationship
  - valuing each piece/person
  - science and flexibility, what is “evidence?” (quant v. qual)
- Authenticity & vulnerability
- Learning- together and from each other
- Language, intentional communication- not silence or omission
- Trust

