2024 LEND Lived Experience Summit

Monday, March 4 & 5, 2024

3:00 PM-6:00 PM Eastern Time

iTAC

INTERDISCIPLINARY TECHNICAL ASSISTANCE CENTER
ON AUTISM AND DEVELOPMENTAL DISABILITIES

LEND Lived Experience Summit

Day 1

Monday, March 4

LEND Lived Experience Summit
Co-Chairs

Abigail Hann

Oklahama LEND

LEND Self-Advocacy Discipline Network

Jonna Mulvaney

Rhode Island LEND

LEND Family Discipline Network

Thank you!
LEND Lived Experience Summit
Planning Committee

- Planning Committee:
  - Elizabeth Trenkamp, Cincinnati LEND
  - Graciela Sharif, Nebraska LEND
  - Karen Ward, Alaska LEND
  - Kristin Mayleben-Flott, Nebraska LEND
  - Kruti Acharya, Iowa LEND
  - Linda Russo, Alabama LEND
  - Marnie Morneault, Maine LEND
  - Stephanie Coleman, Kansas LEND
  - Vanessa Gonzalez, Rose Kennedy LEND
  - Wanda Felty, Oklahoma LEND

Zoom Housekeeping

- Ensure your name is displayed correctly in the participant list. You may also include the program name and state and preferred pronouns.
  - Example: Jeanette Cordova, AUCD, she/her
  - Hover over your name in the “Participants” box and select “More” → “Rename”
- Feel free to introduce yourself in the chat box!
  - Name, Role, Program
- Please remain muted
- Please type your questions in the chat or use the raise hand icon.
- Captioning is available via the CC icon.

What is ITAC?

- Interdisciplinary Technical Assistance Center (ITAC) on Autism and Developmental Disabilities
- A MCHB-funded project at the Association of University Centers on Disabilities (AUCD) that supports Autism CARES programs
- We provide technical assistance (TA) to interdisciplinary training programs (primarily to LEND and DBP programs). This includes workgroups, such as:
  - LEND Family Discipline Network (LFDN)
  - LEND Self-Advocacy Discipline Network (LSDN)
  - Self-Advocates in LEND (SAIL)

Scan the QR Code to learn more

Brief History

Kruti Acharya

Illinois LEND

LEND Self-Advocacy Discipline Network

Wanda Felty

Oklahoma LEND

LEND Family Discipline Network

Tim Markle

Wisconsin LEND

LEND Family Discipline Network

LEND Self-Advocacy Discipline Network

- Who: **The LEND Self-Advocacy Discipline Network** is open to LEND discipline faculty and staff, including Self-Advocate faculty and staff.
  - Goal: To strengthen the Self-Advocacy discipline across the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) network by supporting self-advocate trainees and faculty, developing best practices, and providing leadership opportunities across the LEND network.
  - Vision: The LSDN sees a future where all advocates are prepared to lead and engage in decision-making toward a fair and inclusive society.

- Self-Advocates in LEND: **Self-Advocates in LEND (SAIL)** is open to current LEND trainees, alums, faculty, and staff who identify as people with disabilities.

LEND Family Discipline History

Wanda Felty (OK) & Tim Markle (WI)

In the Beginning

2004

Informal meeting of LEND faculty who were family members at the AUCD annual conference

2005

Family Discipline Meeting supported by AUCD and MCHB, 50 people attended. Workgroups were created

- Family Trainee competencies
- Family Mentorship

2006

Presentation to LEND Directors

2006

Web-based publications

- Family Discipline Competencies
- Promising Practices in Family Mentorship: A Guidebook to MCH-LEND Training Programs

Keep going

2007-2010

Continued promoting Family Discipline within LEND Programs

2010

Survey developed and conducted to measure character diversity and growth of the Family Discipline in LEND programs.

- Presentation at AUCD Conference LENDs Family Growth Chart

2013

Piloted the Family Involvement in LEND trainee's survey with IRB obtained from Children's Hospital Los Angeles.

- Poster presentation at AUCD Conference

2016-2020

Family Involvement survey continued with more than 1,200 trainee responses

Publication of Fabric Not Fringe White Paper and poster presentation at AUCD conference

Currently

LEND Family Discipline Network Virtual Summit

Hosted a Webinar Series – Fabric Not Fringe

Co-hosting LEND Lived Experience Summit

2021

2023

2024

Family Discipline Leadership Network transition of leaders, Fran Goldfarb retired. New Chair: Stephanie Coleman (Kansas LEND) Co-Vice Chairs: Cristy James (Indiana LEND) and Kristin Mayleben-Flott (Nebraska LEND)

Workshop A

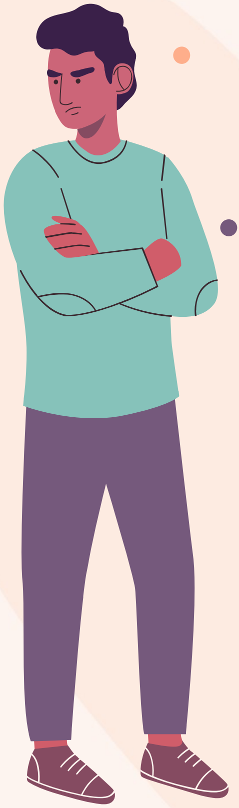
Building Inclusive Spaces for Conversation

Presented by:
Emily Wheeler and Spencer Hunley
Kansas LEND

Lived experience summit

Building inclusive spaces for

CONversation



Emily Wheeler, Kansas LEND Trainee

KANSAS LEND
Leadership Education
in Neurodevelopmental
Disabilities

INTRODUCTION

Emily Wheeler

- ➔ KS LEND Trainee
- ➔ Two months from Master of Arts in Counseling
- ➔ Private and Clinical experience
- ➔ Neuro Atypical
- ➔ Education Advocate in Kansas
- ➔ Have potato tattoo

WHOA!

Let's set some rules and expectations for this presentation.

TABLE OF CONTENTS

KANSAS LEND
Leadership Education in Neurodevelopmental Disabilities

01

Setting Expectations

Build a solid foundation
with a conversation

KANSAS LEND
Leadership Education
in Neurodevelopmental
Disabilities

Why rules

- Sets the tone
- Provides inclusivity
- Explains boundaries
- Gives structure for open discussion
- Creates common foundation

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Leadership Education in Neurodevelopmental Disabilities

Courage & Renewal

Touchstones

CENTER *for* COURAGE & RENEWAL

Give and receive welcome.

People learn best in hospitable spaces. In this circle we support each other's learning by giving and receiving hospitality.

Be present as fully as possible.

Be here with your doubts, fears and failings as well as your convictions, joys and successes, your listening as well as your speaking.

What is offered in the circle is by invitation, not demand.

This is not a "share or die" event! Do whatever your soul calls for, and know that you do it with support. Your soul knows your needs better than we do.

Speak your truth in ways that respect other people's truth.

Our views of reality may differ, but speaking one's truth in a Circle of Trust does not mean interpreting, correcting or debating what others say. Speak from your center to the center of the circle, using "I" statements, trusting people to do their own sifting and winnowing.

No fixing, saving, advising or correcting.

This is one of the hardest guidelines for those of us who like to "help". But it is vital to welcoming the soul, to making space for the inner teacher.

Learn to respond to others with honest, open questions...

instead of counsel or corrections. With such questions, we help "hear each other into deeper speech.

Learn more at **www.couragerenewal.org**

Courage & Renewal

Touchstones

CENTER *for* COURAGE & RENEWAL

When the going gets rough, turn to wonder.

If you feel judgmental, or defensive, ask yourself:

- I wonder what brought them to this belief?
- I wonder what they are feeling right now?
- I wonder what my reaction teaches me about myself?

Set aside judgment to listen to others – and to yourself – more deeply.

Attend to your own inner teacher

We learn from others, of course. But as we explore poems, stories, questions and silence in a Circle of Trust, we have a special opportunity to learn from within. So pay close attention to your own reactions and responses, to your most important teacher.

Trust and learn from silence

Silence is a gift in our noisy world, and a way of knowing in itself. Treat silences as a member of the group. After someone has spoken, take time to reflect without immediately filling the space with words.

Observe deep confidentiality

A Circle of Trust depends on knowing that whatever we say will remain with the people whom we chose to say it – whether in small groups or in the large circle – and will never be passed on to others without our explicit permission.

Know that it's possible...

to leave the circle with whatever it was that you needed when you arrived, and that the seeds planted here can keep growing in the days ahead.

Learn more at **www.couragerenewal.org**

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Disabilities

02

Who’s in the room?

Unknown trauma and
losses in others.

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“Never underestimate the pain of a person, because everyone is struggling. Some people are just better at hiding it than others.”

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People Have Trauma

Give space	Give respect	Give grace
People make mistakes.	Apologize and validate feelings.	You don’t know what you don’t know.

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03

Sitting in “the suck”

Holding space for
big emotions.

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Life is hard

04

Conflict resolution

How to handle conflicts
when they occur

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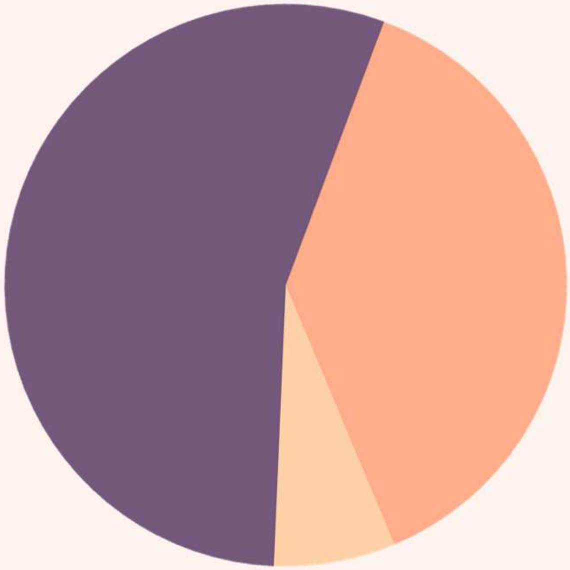
Disabilities

Communication

Nonverbal

55%



Vocal

38%

Words

7%

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Disabilities

Assume positive intent

THE PEACE PROCESS

Step 1

BREATH

Put time and space between an action and a reaction.

Step 2

Clarify

Ask clarifying questions and stop accusations or generalizations.

Step 3

FIX

Compromise, apologize, work through or agree to disagree.

Step 4

FUTURE

Check back in later to continue relationship.

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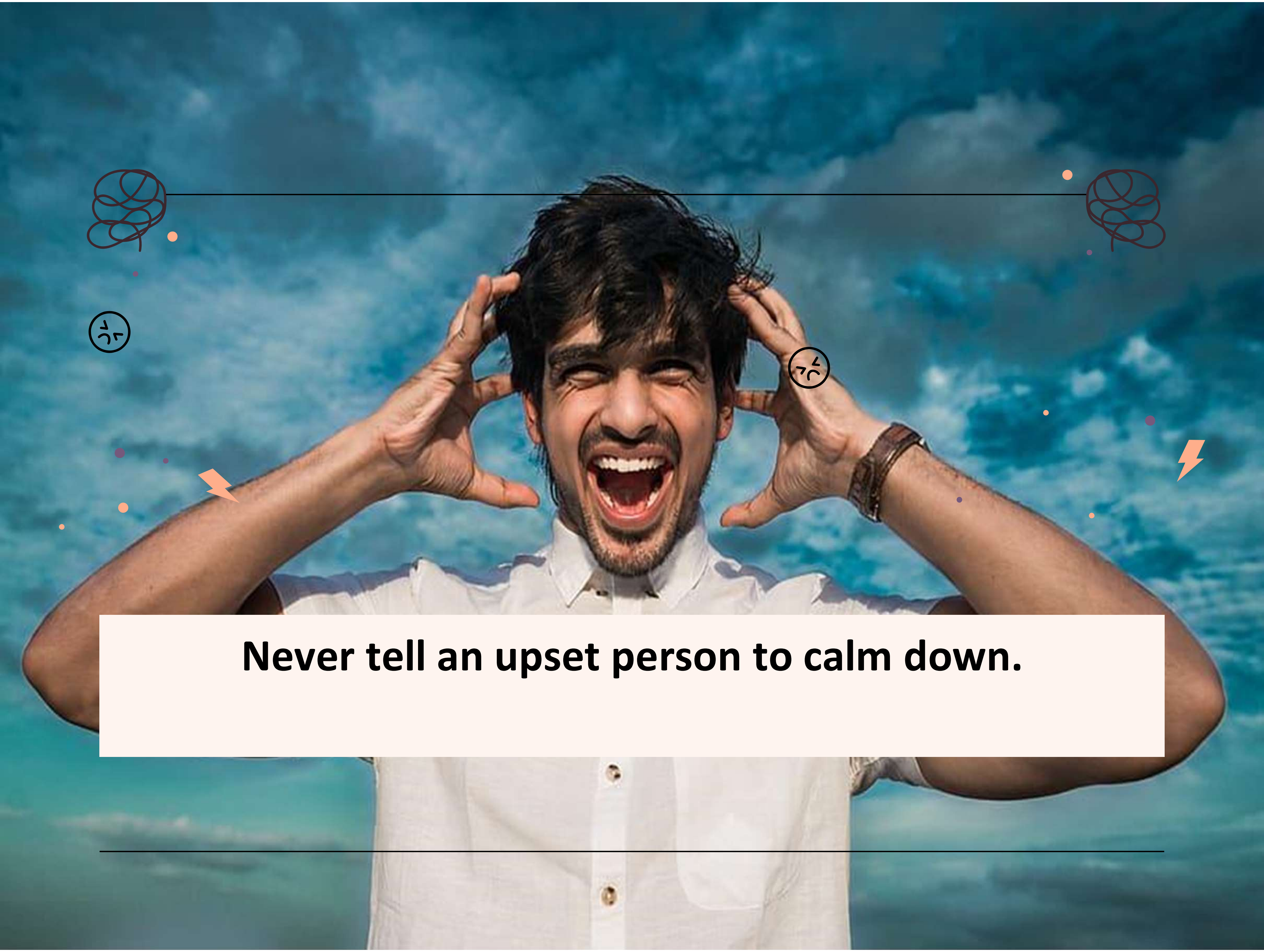
Leadership Education in Neurodevelopmental Disabilities



Never tell an upset person to calm down.

FINAL thoughts

Stay collected. Take breaks. Drink Water. You got this!

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Leadership Education in Neurodevelopmental Disabilities

ThANKS!

Any questions, comments, concerns?

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Leadership Education in Neurodevelopmental Disabilities

Poster Session 1

Developing a Self-Advocacy Core Faculty Position for Oklahoma LEND: Challenges, Successes, and Lessons Learned over 20+ Years

Presented by:
Chuck Roberts and Megan Roberts
Oklahoma LEND

Oklahoma LEND Self-advocacy Core Faculty Position: Successes, Challenges, and Lessons Learned over 20+ Years

OK LEND at Child Study Center

Developing leaders across fields of service to work with people with disabilities and families

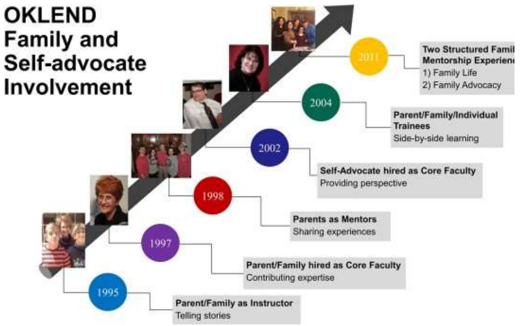
Chuck Roberts, BS; Megan Roberts, PT, DSc

University of Oklahoma Health Sciences Center

Background

- Established relationship in 1998
- Staff member at the OUHSC University Affiliated Program (Oklahoma's UCEDD)
- Attended some LEND classes as guest
- OKLEND Requested permission from MCHB
- Champions
  - Program Director
  - Training Director
- Core Faculty role in 2002

Lived Experience in OKLEND



OKLEND Family and Self-advocate Involvement

1995 — **Parent/Family as Instructor**
Telling stories

1997 — **Parent/Family hired as Core Faculty**
Contributing expertise

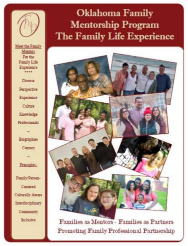
1998 — **Parents as Mentors**
Sharing experiences

2002 — **Self-Advocate hired as Core Faculty**
Providing perspective

2004 — **Parent/Family/Individual Trainees**
Side-by-side learning

2011 — **Two Structured Famil Mentorship Experien**
1) Family Life
2) Family Advocacy

- Faculty and learners
- Family mentors
- Panelists
- Policy, and advocacy



Oklahoma Family Mentorship Program
The Family Life Experience

Meet the Family Mentors
For the Family Life Experience
****
Diverse
Perspective
Experience
Culture
Knowledge
Professionals
~
Biographies
Contact
~
Principles:
Family/Person-Centered
Culturally Aware
Interdisciplinary
Community
Inclusive

Families as Mentors - Families as Partners
Promoting Family Professional Partnership

Successes

- Relationships with trainees
- Core Faculty peer network
- Connection to National Leaders and Advocates
- Participation in the AUCD conferences and network

Trainees say:
We can't imagine Oklahoma LEND without a Self-advocate Core Faculty

Challenges and Opportunities

Transportation	Campus bus
Office and building accessibility	Door openers, universal designs, modified restroom
Computer and phone access	Assistive technology
Communication	Co-faculty support
Assistance needed for travel to events and conferences	Colleague support and program supported assistance
Inaccessible design of required university annual online trainings	Still an issue, suggested alternative training formats

Highlighted Activities

- Home visits
- In-class discussions
- Guest lecturer in courses campus wide
- Stories on video

Chuck's Career Trajectory

- Graduated with Bachelors Degree
- Became acquainted with the UAP (Oklahoma's UCEDD) through a presentation
- Connection led to employment with the UAP
- Guest presenter
- Staff position
- Core Faculty
- Currently seen as expert
  - Helps to develop training activities

Coffee break...

10:00

Workshop B

Empowering Accessibility: Innovative AI Applications for Enhanced Inclusion in LEND

Presented by:

Kara Ayers, Stephanie Weber, and Sarah Phillips

Cincinnati LEND

To AI and Beyond: Using Artificial Intelligence to Benefit All in LEND

LEND Lived Experience Summit

Sarah Phillips, BS, Kara Ayers, PhD, & Steph Weber, PsyD, MPH

Cincinnati Children's
changing the outcome together

University of CINCINNATI

LEND
Leadership Education in Neurodevelopmental and related Disabilities

Introductions

Learning Objectives

- Describe artificial intelligence (AI) uses in one LEND program
- Identify benefits of using AI to support individuals with lived experience to learn about healthcare topics

Cincinnati LEND

- Program and Cohort

- Cincinnati Children’s and University of Cincinnati

- Curriculum
  - Journal article plain language summaries
  - Evidence-Based Case Discussions

Demonstration

AI From a Self-Advocate’s View

Sarah Phillips, Cincinnati LEND Self-Advocate

A Little Background…

- In recent years, AI (Artificial Intelligence) technology has advanced dramatically
- We are beginning to explore how this effects day-to-day life
- There are several benefits to AI, specifically within the context of neurodevelopmental disabilities

Pros and Cons

- Potentially alleviates communication barriers
- plain language summaries
- Auditory inputs
- Enhances/equalizes productivity challenges

- Doesn’t always learn diverse speech patterns
- Vulnerable to outside influences
- Can potentially hinder personal motivation and creativity

Workshop C

Teaching LEND Students the Value of Communities with Lived Experience in Disability Health Equity Research

Presented by:

Stephanie Meredith, Kentucky LEND

Disability Health Equity Research

Teaching LEND Students the Value of Communities With Lived Experience

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HDI’s Vision

Our vision is the full participation and contribution of *all* people with disabilities in *all* aspects of society.

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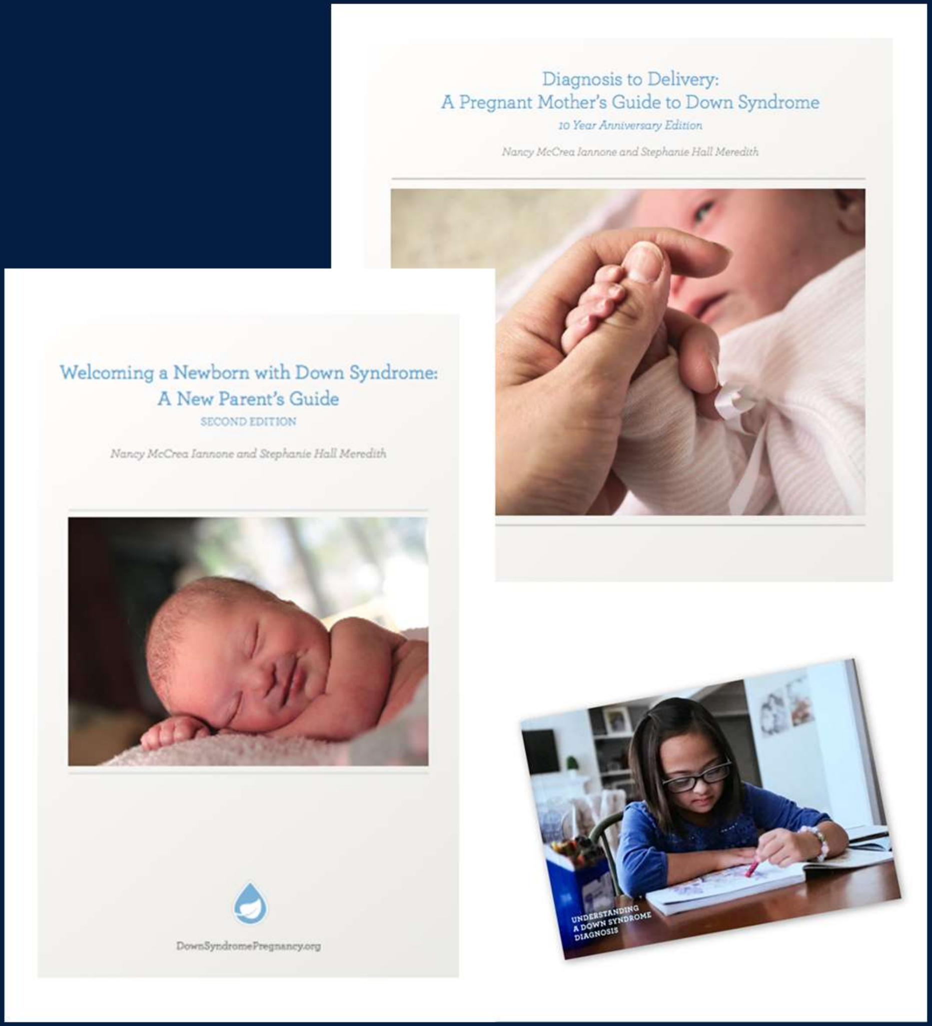
Stephanie Meredith

Director of the National Center for Prenatal and Postnatal Resources

HDI LEND Family Faculty

Human Development Institute

Introduction



Diagnosis to Delivery:
A Pregnant Mother's Guide to Down Syndrome
10 Year Anniversary Edition
Nancy McCrea Iannone and Stephanie Hall Meredith

Welcoming a Newborn with Down Syndrome:
A New Parent's Guide
SECOND EDITION
Nancy McCrea Iannone and Stephanie Hall Meredith

DownSyndromePregnancy.org

UNDERSTANDING A DOWN SYNDROME DIAGNOSIS

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Disability Bias in Healthcare and Health Disparities Designation

Overwhelming implicit bias against people with disabilities (VanPuymbrouck et al., 2020)

82.4% reported that people with significant disability have worse quality of life than nondisabled people (Iezzoni et al., 2021)

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Disability Health Equity Research Possibilities

- NIH Minority Underserved Population designation
- Recent NIH Funding Opportunities
- Patient-Centered Outcomes Research Institute

People with Disabilities Designated a Health Disparity Population

NEWS RELEASES

Tuesday, September 26, 2023

NIH designates people with disabilities as a population with health disparities

Designation, new research program and update to NIH mission are actions to ensure inclusion of people with disabilities.

Today, Eliseo J. Pérez-Stable, M.D., director of the National Institute on Minority Health and Health Disparities (NIMHD), designated people with disabilities as a population with health disparities for research supported by the National Institutes of Health. The decision was made in consultation with Robert Otto Valdez, Ph.D., the director of the Agency for Healthcare Research and Quality, after careful consideration of a report pdf delivered by an NIMHD advisory council, input from the disability community and a review of the science and evidence. A report pdf issued in December 2022 by the Advisory Committee to the (NIH) Director (ACD), informed by the work of the Subgroup on Individuals with Disabilities, explored similar issues faced by people with disabilities. The designation is one of several steps NIH is taking to address health disparities faced by people with disabilities and ensure their representation in NIH research.

"This designation recognizes the importance and need for research advances to improve our understanding of the complexities leading to disparate health outcomes and multilevel interventions," said Dr. Pérez-Stable. "Toward this effort, NIMHD and other NIH institutes launched a new research program to better understand the health disparities faced by people with disabilities who are also part of other

Institute/Center

NIH Office of the Director (OD)

National Institute on Minority Health and Health Disparities (NIMHD)

Contact

NIH News Media Branch
301-496-5787

NIMHD Press Team
301-402-1366

Connect with Us

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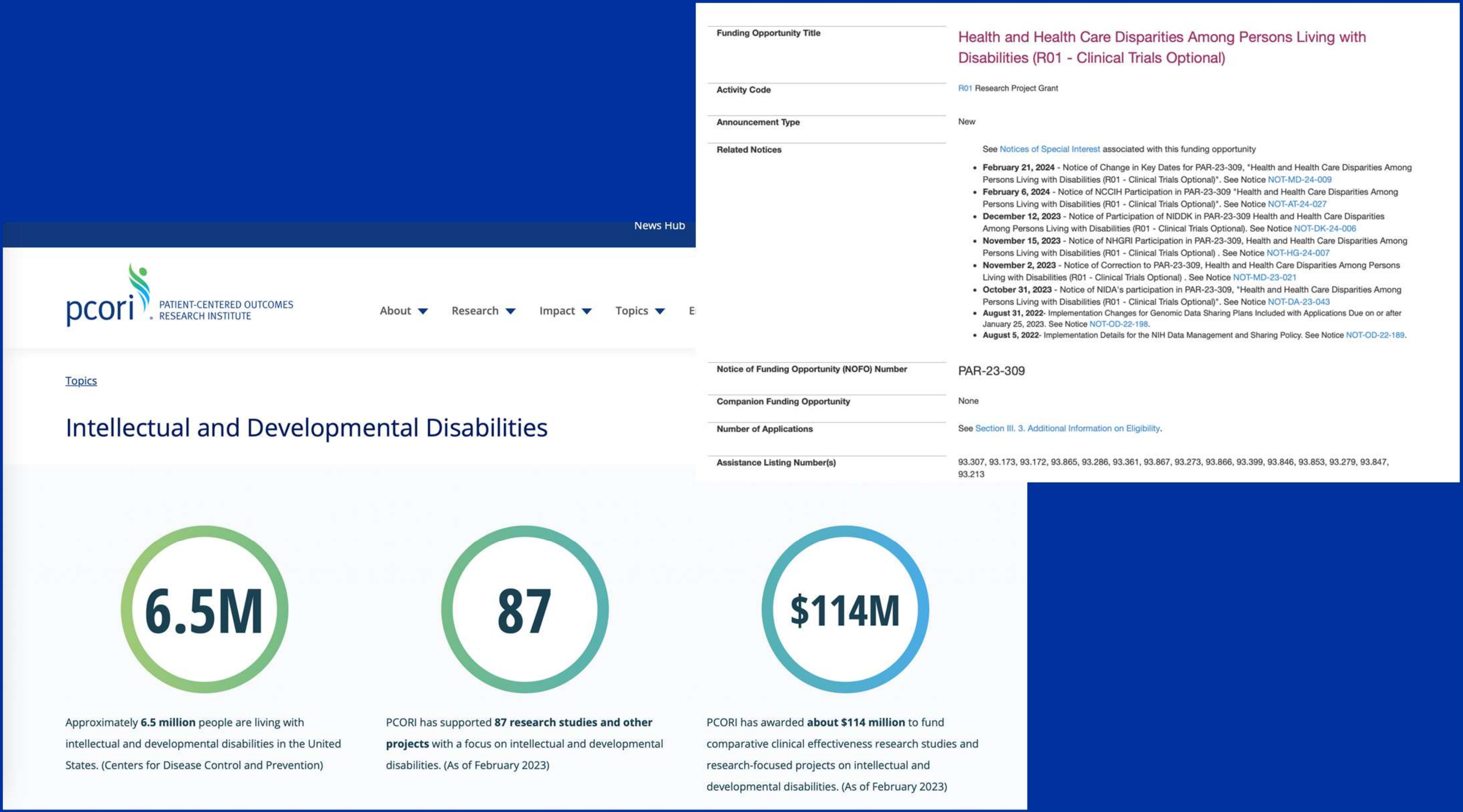
NIH and PCORI



Funding Opportunity Title	Health and Health Care Disparities Among Persons Living with Disabilities (R01 - Clinical Trials Optional)
Activity Code	R01 Research Project Grant
Announcement Type	New
Related Notices	See Notices of Special Interest associated with this funding opportunity • **February 21, 2024** - Notice of Change in Key Dates for PAR-23-309, "Health and Health Care Disparities Among Persons Living with Disabilities (R01 - Clinical Trials Optional)". See Notice NOT-MD-24-009 • **February 6, 2024** - Notice of NCCIH Participation in PAR-23-309 "Health and Health Care Disparities Among Persons Living with Disabilities (R01 - Clinical Trials Optional)". See Notice NOT-AT-24-027 • **December 12, 2023** - Notice of Participation of NIDDK in PAR-23-309 Health and Health Care Disparities Among Persons Living with Disabilities (R01 - Clinical Trials Optional). See Notice NOT-DK-24-006 • **November 15, 2023** - Notice of NHGRI Participation in PAR-23-309, Health and Health Care Disparities Among Persons Living with Disabilities (R01 - Clinical Trials Optional) . See Notice NOT-HG-24-007 • **November 2, 2023** - Notice of Correction to PAR-23-309, Health and Health Care Disparities Among Persons Living with Disabilities (R01 - Clinical Trials Optional) . See Notice NOT-MD-23-021 • **October 31, 2023** - Notice of NIDA's participation in PAR-23-309, "Health and Health Care Disparities Among Persons Living with Disabilities (R01 - Clinical Trials Optional)". See Notice NOT-DA-23-043 • **August 31, 2022**- Implementation Changes for Genomic Data Sharing Plans Included with Applications Due on or after January 25, 2023. See Notice NOT-OD-22-198. • **August 5, 2022**- Implementation Details for the NIH Data Management and Sharing Policy. See Notice NOT-OD-22-189.
Notice of Funding Opportunity (NOFO) Number	PAR-23-309
Companion Funding Opportunity	None
Number of Applications	See Section III. 3. Additional Information on Eligibility.
Assistance Listing Number(s)	93.307, 93.173, 93.172, 93.865, 93.286, 93.361, 93.867, 93.273, 93.866, 93.399, 93.846, 93.853, 93.279, 93.847, 93.213

Topics

Intellectual and Developmental Disabilities

6.5M

Approximately **6.5 million** people are living with intellectual and developmental disabilities in the United States. (Centers for Disease Control and Prevention)

87

PCORI has supported **87 research studies and other projects** with a focus on intellectual and developmental disabilities. (As of February 2023)

$114M

PCORI has awarded **about $114 million** to fund comparative clinical effectiveness research studies and research-focused projects on intellectual and developmental disabilities. (As of February 2023)

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Disability Health Equity Research: Including lived experience at every phase

- PI and COIs with lived experience
    - Consider intersectional identities (GSU Mentor)
- Research populations with lived experience
- Quantitative and qualitative data about lived experience

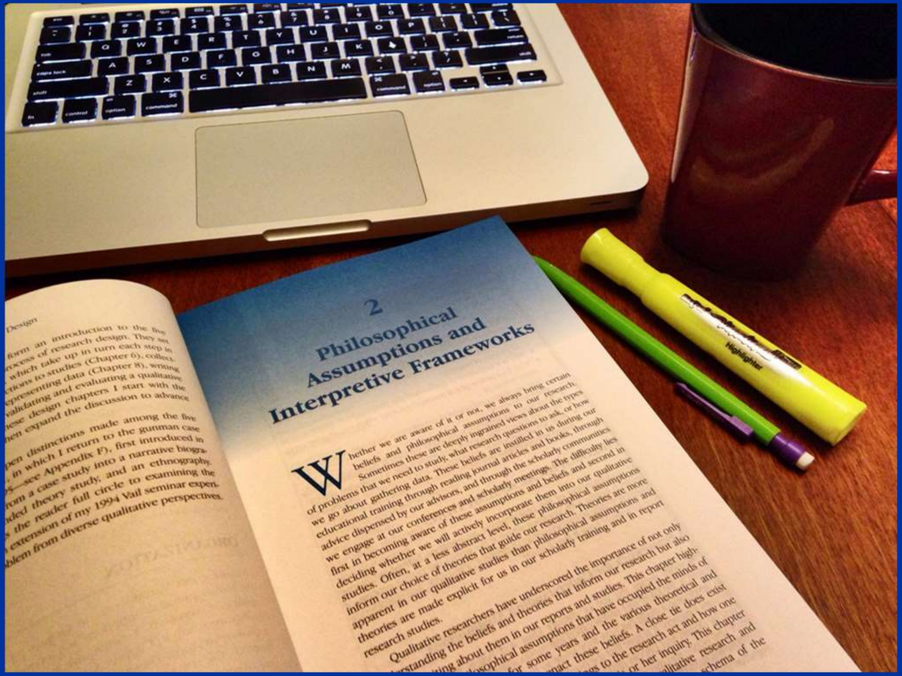
LEND Family Rotation Projects: Health Equity Focus

- PCORI project
- Research publications on family experiences
- Translating research

Patient Centered Outcomes Research Institute

PCORI Presentation

https://www.pcori.org/engagement/research-fundamentals/pcori-approach-pcor



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Problem to address

- Moment of diagnosis as the first point on the life course
  - Sets the stage for the rest of your life in making health care decisions.
  - Need strategies to share research specifically with Black and Hispanic families at the moment of diagnosis

Aims of the Project

- Bring together parents of children with DS, support group leaders, public health experts, and medical professionals to get recommendations about the best ways to share PCOR with Black and Hispanic new and expectant parents learning about a diagnosis.

- Work together to find strategies, platforms, and formats for medical professionals and support group leaders to share the latest research with new and expectant Black and Hispanic parents of children with DS.

Year 1: Summary of project activities

1. Online community conversations with 20 parents and support group leaders about strategies to share research with Black and Hispanic new and expectant parents.

2. Online meeting with 5 public health equity experts to review recommendations from parent meeting and get their input.

Year 1: Summary of project activities

3. Online meeting with 5 national health care experts to share findings from the parent and health equity meeting and construct a plan for medical professionals to better share PCOR with Black and Hispanic families learning about a prenatal or postnatal diagnosis.

Year 2: Summary of project activities

1. **White paper** for medical professionals and advocacy groups leaders

2. **Online training course**

3. Work with medical and advocacy organization to use those resources in their current organizational practices.

Project Partners

1. Down Syndrome Association of Atlanta (Sheryl Arno)
2. Down Syndrome Association of Minnesota (Sarah Curfman)
3. Massachusetts Down Syndrome Congress (Maureen Gallagher)
4. Club 21 (Pasadena, CA; Nancy Litteken)
5. National Association for Down Syndrome (Chicago, IL-based; Linda Smarto)
6. Rio Grande Valley Down Syndrome Association (McCallan,. TX; Deborah Tomai)
7. Down Syndrome Association of Maryland (Baltimore, MD; Terria Brown)

1. **Leah Smith**, **MPP**, Project Coordinator of the Center for Dignity in Healthcare for People with Disabilities with lived experience as a person with skeletal dysplasia
2. **Jessica Franks, MPH,** a DrPH student at Georgia State University with a focus on health and disability and CDC Health Communications Specialist at the CDC Office of Minority Health and Health Equity (OMHHE).
3. **Dena Cherry-Brown, MPH**, a DrPH student at Georgia State University with lived experience as a Black mother and a CDC Senior Scientific Data analyst working on the Pregnancy and Infant Linked Outcomes Team
4. **Jennie de la Cruz, MMSc, PA-C**, a Physician's Assistant, Clinical Assistant Professor at Mercer University in the Physician Assistant Studies Program, and a PhD Public Health Policy student at Georgia State University with lived experience as the Hispanic mother of a child with a disability
5. **Albert Pless**, **MS**, a DEI consultant on the DSC2U PCORI-funded project

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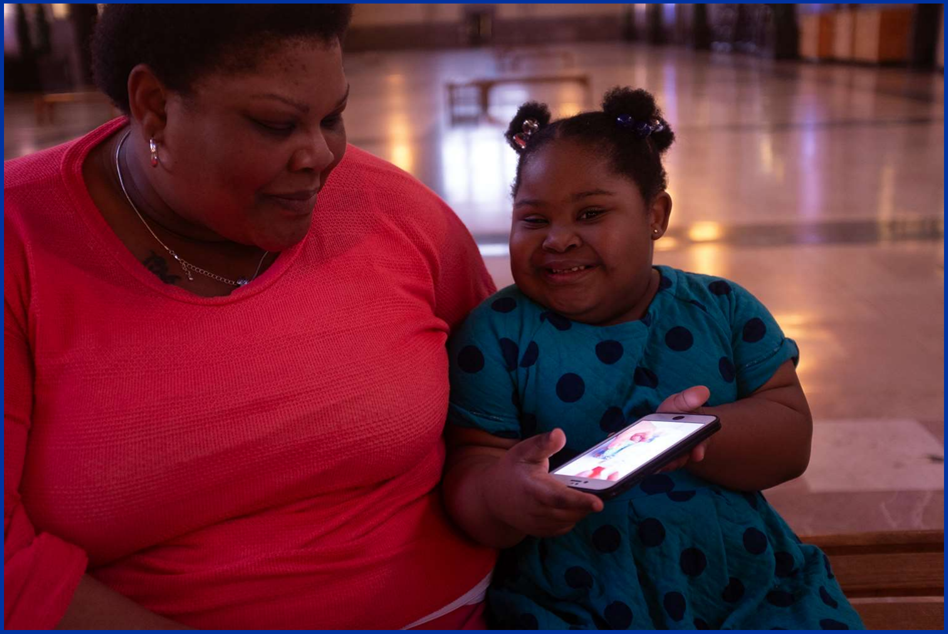
Medical Professionals

Medical Team

1. **Angela Trepanier, MS, CGC**, Director of the Wayne State Genetic Counseling Program, Past President of the National Society of Genetic Counselors and the Association of Genetic Counseling Program Directors, and representative of the National Society of Genetic Counselors on our Genetic Conditions Consensus Group
2. **Brian Skotko, MD, MPP**, Director of the Down Syndrome Program at Massachusetts General Hospital and PCORI Principal Investigator of “Does a Web-Based Platform for Caregivers Help People with Down Syndrome Get Recommended Health Services?” and “Engaging Underserved Families in the United States with Down Syndrome Clinic to You (DSC2U);”
3. **Kandamurugu Manickam, MD, MPH**, FACMG, Clinical Geneticist at Nationwide Children’s Hospital and certified Implicit Bias Trainer with expertise in genetic conditions;
4. **Beth Pletcher**, **MD, Associate Professor of Pediatrics and Medicine at Rutgers New Jersey Medical School and** representative of the American Academy of Pediatrics on our Genetic Conditions Consensus Group
5. **Asha Talati MD, MSCR** is a Clinical instructor in Maternal Fetal Medicine and fellow in Medical Genetics and Genomics at University of North Carolina, Chapel Hill.

Other Project Priorities



- Equitable compensation for participants
- Diverse racial and disability representation in every stage of the project.

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LEND Student Family Rotation Projects: PCORI

- Helping with notetaking and facilitating community conversations with parents and providers
- Collecting feedback, identifying themes, and hosting reviews
- Gathering data for white papers and online modules

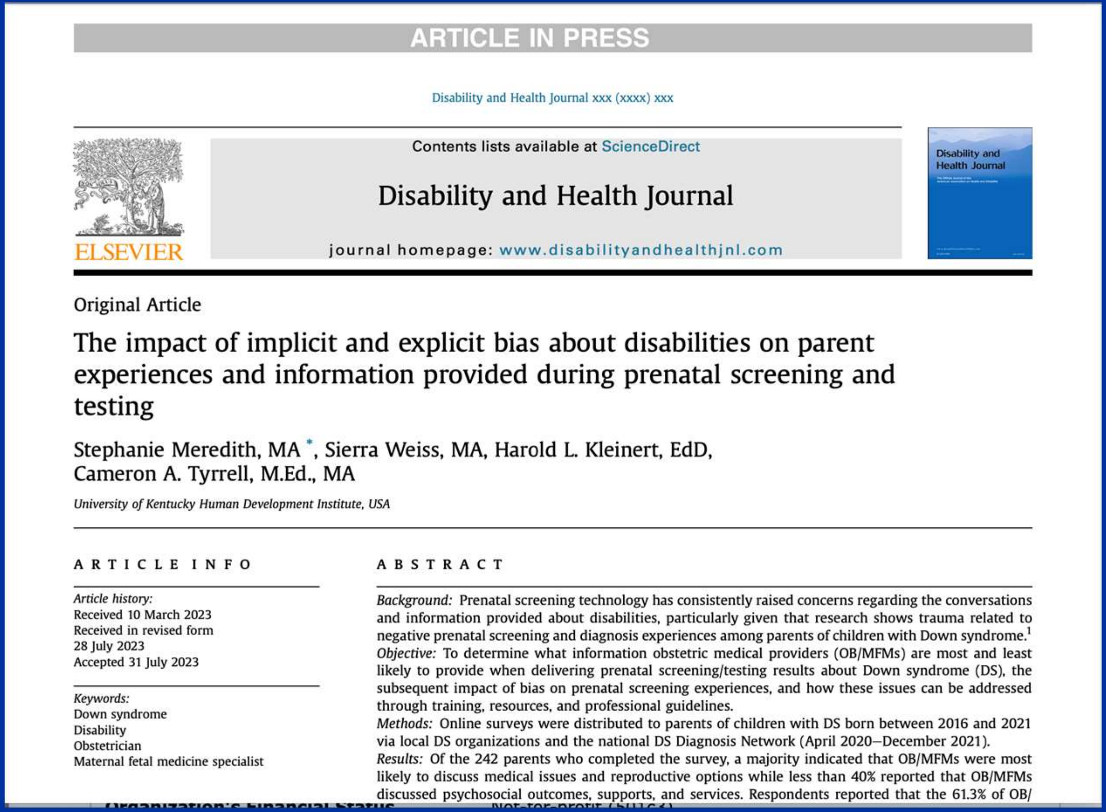
Prenatal Diagnosis Experience Study

- 12 local Down syndrome organizations and one national Down syndrome organization
- Mixed Methods Framework:
    - Yes/No Questions about whether obstetricians and genetic counselors followed guidelines/best practices
    - Qualitative questions about diagnosis experiences, what was done well, and what could have been done better
- Prenatal Diagnosis of Down syndrome (DS) Between January 1, 2016-December 31, 2021
- 242 respondents

Diagnosis Experiences: Disability and Health Journal: 242 Responses (2016-2021)

- OBs most likely to discuss medical issues (64%) & reproductive options (76%)
- Less than 40% of OBs discussed supports and services and life outcomes.
- 61% of OBs delivered the diagnosis as bad news or said “I’m sorry.” Measure for implicit bias.
- OBs with implicit bias significantly less likely to provide more comprehensive prenatal care, information about DS, life outcomes, advocacy organizations & available supports and services
- 51% of unbiased OBs gave patients accurate, up-to-date, and balanced resources about DS while only 17% of biased OBs did so.
- Almost 1/10 described explicit bias.

LEND Student Family Rotation Projects: Bias Study



ARTICLE IN PRESS

Disability and Health Journal xxx (xxxx) xxx

Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

Original Article

The impact of implicit and explicit bias about disabilities on parent experiences and information provided during prenatal screening and testing

Stephanie Meredith, MA *, Sierra Weiss, MA, Harold L. Kleinert, EdD, Cameron A. Tyrrell, M.Ed., MA

University of Kentucky Human Development Institute, USA

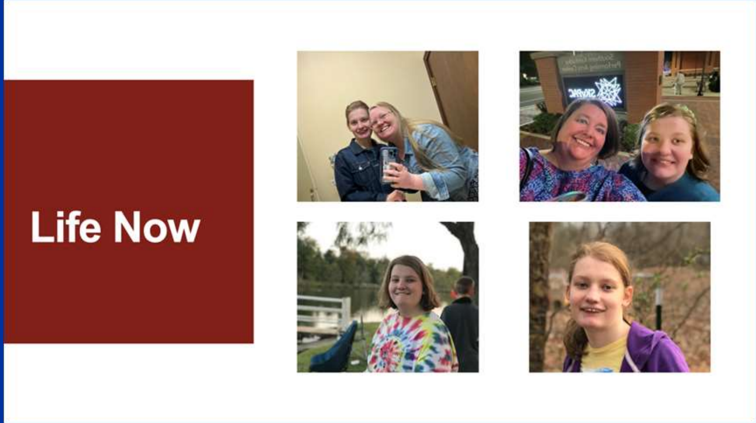
ARTICLE INFO

Article history:
Received 10 March 2023
Received in revised form
28 July 2023
Accepted 31 July 2023

Keywords:
Down syndrome
Disability
Obstetrician
Maternal fetal medicine specialist

ABSTRACT

Background: Prenatal screening technology has consistently raised concerns regarding the conversations and information provided about disabilities, particularly given that research shows trauma related to negative prenatal screening and diagnosis experiences among parents of children with Down syndrome.[1]
Objective: To determine what information obstetric medical providers (OB/MFMs) are most and least likely to provide when delivering prenatal screening/testing results about Down syndrome (DS), the subsequent impact of bias on prenatal screening experiences, and how these issues can be addressed through training, resources, and professional guidelines.
Methods: Online surveys were distributed to parents of children with DS born between 2016 and 2021 via local DS organizations and the national DS Diagnosis Network (April 2020–December 2021).
Results: Of the 242 parents who completed the survey, a majority indicated that OB/MFMs were most likely to discuss medical issues and reproductive options while less than 40% reported that OB/MFMs discussed psychosocial outcomes, supports, and services. Respondents reported that the 61.3% of OB/



Human Development Institute

LEND Student Family Rotation Projects: Translate Research

Down Syndrome Bias Study by Grace Kozal

DOWN SYNDROME BIAS STUDY

Purpose

The purpose of this study was to find out what recommendations clinicians are following when delivering prenatal screening results and what factors influenced the information provided.

This is the largest study to date of parents who received a prenatal diagnosis of Down Syndrome with 242 respondents, and all received their diagnosis between 2016-2021.

What evidence was found?

Bias significantly impacted the provision of information following screening results.

Implicit Bias

61%

61% of obstetric providers delivered the diagnosis as bad news, or said "I'm sorry."

Only **17% of biased clinicians provided accurate, up-to-date, and balanced resources about Down Syndrome at the moment of diagnoses**, opposed to 51% of unbiased obstetric providers.

Obstetric Providers Were Most Likely to Discuss

- **< 30%** Advocacy Organizations
- **< 40%** Supports, services, and life outcomes
- **64%** Medical Issues

Clinicians with implicit bias were significantly less likely to provide the following: comprehensive prenatal care, information about life outcomes, information about Down syndrome advocacy organizations, available supports and services, condition-specific resources.

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Stephanie, M., Sierra, W., Harold, L. K., & Cameron, A. T. (2024). The impact of implicit and explicit bias about disabilities on parent experiences and information provided during prenatal screening and testing. Disability and Health Journal, 17(1), 101514.

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Many thanks to the Down Syndrome Diagnosis Network and the local Down syndrome organizations who helped in sharing this study.

Infographic by Grace Kozal

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End of Day 1!

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