

Welcome to the 2024 Autism CARES Virtual Series

*Strengthening the MCH Workforce and System of Care: Using Innovative Methods to Measure and
Demonstrate Program Impact*

Monday, July 15th





Jackie Czyzia, MPH

Director, MCH Engagement

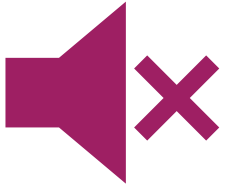
Association of University Centers on
Disabilities (AUCD)



Interdisciplinary Technical Assistance Center (ITAC) on Autism and Developmental Disabilities



Housekeeping Items



- Ensure your name is displayed correctly in the participant list. You may also include program/org and preferred pronouns, if desired
 - Example: Jackie Czyzia (she/her), AUCD
 - Hover over your name in the “Participants” box and select “More” → “Rename”
- Please keep yourself on mute when not speaking
- State your name prior to speaking
- Captioning is available
- If you need tech or accommodation support, please email itac@aucd.org
- Introduce yourself in the chat (name, program, role, & if you had an extra week this Summer, how would you spend it?)





2024 Autism CARES Virtual Series

The Impact of LEND: An MCHB Virtual Feedback Session (LEND Directors only)

- Monday, July 15th at 3:30 PM ET

AIR-P Presents: Leveraging the AIR-P for Collaborative Research Through the LEND Program (all grantees)

- Monday, July 16th at 4:00 PM ET

AIR-P Research Day at Autism CARES Meeting 2024: Translating Research to Community Impact (all grantees)

- Monday, July 22nd at 2:00 PM ET

Westat Presents: Autism CARES Evaluation Update (all grantees)

- Monday, July 29th at 2:00 PM ET



Overview of Today's Event

- 2:00 PM ET Welcome from AUCD and MCHB
- 2:10 PM ET Panel Presentations
- 2:40 PM ET Q&A
- 2:50 PM ET Breakout Discussions
 - ▶ **National Network Impact**
 - ▶ **Program Impact**
 - ▶ **Regional/State/Community Impact**
- 3:10 PM ET Wrap Up and Closing Remarks



Health Resources and Services Administration (HRSA)

Lauren Raskin Ramos, MPH

Director, Division of MCH Workforce
Development

Maternal and Child Health Bureau
(MCHB)





Autism CARES Awardee Meeting

July 15, 2024

Lauren Raskin Ramos
Director, Division of MCH Workforce Development
Maternal and Child Health Bureau (MCHB)

Vision: Healthy Communities, Healthy People



Thank You MCHB Autism Team!

Evva Assing-Murray

Kaitlin Bagley

Karla Brewer

Treeby Brown

Rita Delgado

Jessica DiBari

Donna Johnson

Rui Li

Maura Maloney

Meaghan McHugh

Hae Young Park

Emmie Perchak

Maria Sans

Robyn Schulhof

Debbie Shelef

Deb Wagler



Celebrating CARES Accomplishments!

- Over 20,000 trainees and over 400,000 practicing professionals reached through LEND and DBP in FY22
- Autism Research Networks enrolled 10,191 participants in primary research studies and included over 1.3 million participants in secondary analysis
- Wrap up of State Systems Program setting foundation for new transition work
- Responsive and innovative technical assistance from AUCD
- Supporting Access for Everyone (SAFE) Consensus Statement released (<https://safedbp.org>)
- Refreshed MCHB's Autism Web Page



Looking Ahead

- Implementation of new Transition for Youth with Autism and/or Epilepsy Program
- Increasing capacity of primary care providers through DBP mini fellowship
- Advancing translation of research to practice through a new Coordinating Center for Research to Practice Partnerships
- Ongoing meaningful inclusion of families and people with disabilities across the programs
- Autism CARES Reauthorization



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***Strengthening the MCH Workforce and System
of Care: Using Innovative Methods to Measure
and Demonstrate Program Impact***

Panel Presentations





The LEND Outcomes Study: 10 Years of Impact



Lauren Bishop, PhD

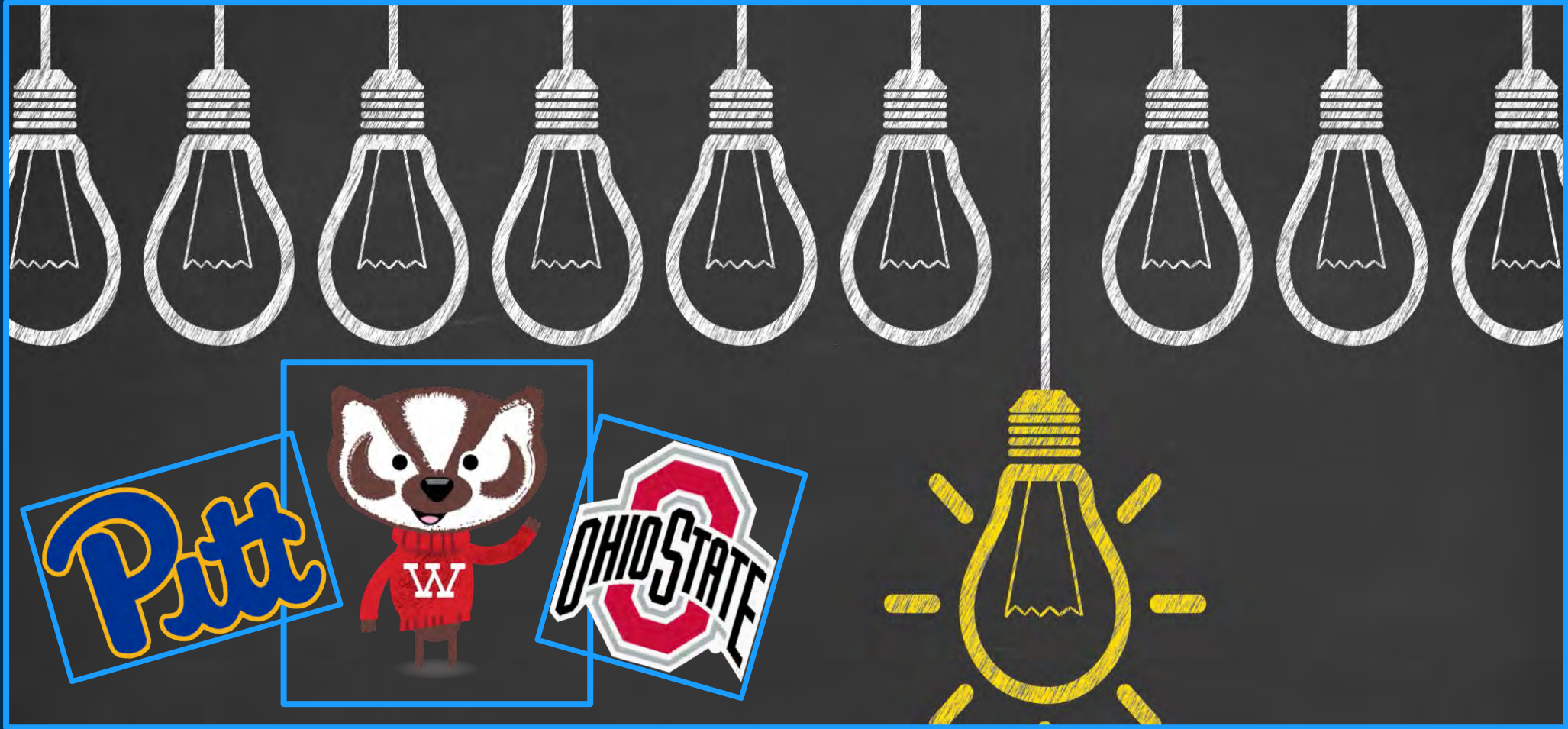
Associate Professor, School of School Work
Waisman Center, University of Wisconsin-
Madison



Sarah Laughlin, PhD

Assistant Professor
Director, Predoctoral Training in Pediatric Neuropsychology
University of Pittsburgh

The LEND Outcomes Study: 10 Years of Impact

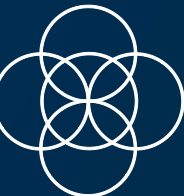


Lauren Bishop,¹ Sarah F. Laughlin,² Paula Rabidoux,³ Anne Bradford Harris,¹ & Robert B. Noll²

¹Waisman Center, University of Wisconsin-Madison; ²Nisonger Center, The Ohio State University; ³University of Pittsburgh

We collectively believe LEND training is effective BUT...

Does LEND add value?



How Are LEND Trainee Outcomes Measured?

- MEASURES

- **NIRS Survey**

- Common program evaluation technique (Kavanagh et al., 2015)

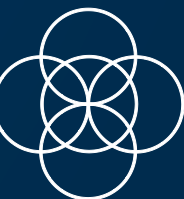
- **I-FOR**

- Faculty observation of family centered and interprofessional care (Brosco et al. 2018; Smith et al., 2022)

- RESEARCH FINDINGS

- Trainee skills improve during LEND training (Brosco et al. 2018)

- Long-term trainees are more likely to work on interdisciplinary teams and with MCH and vulnerable populations (Kavanagh et al., 2015)



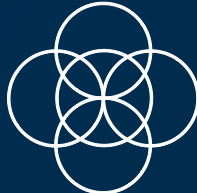
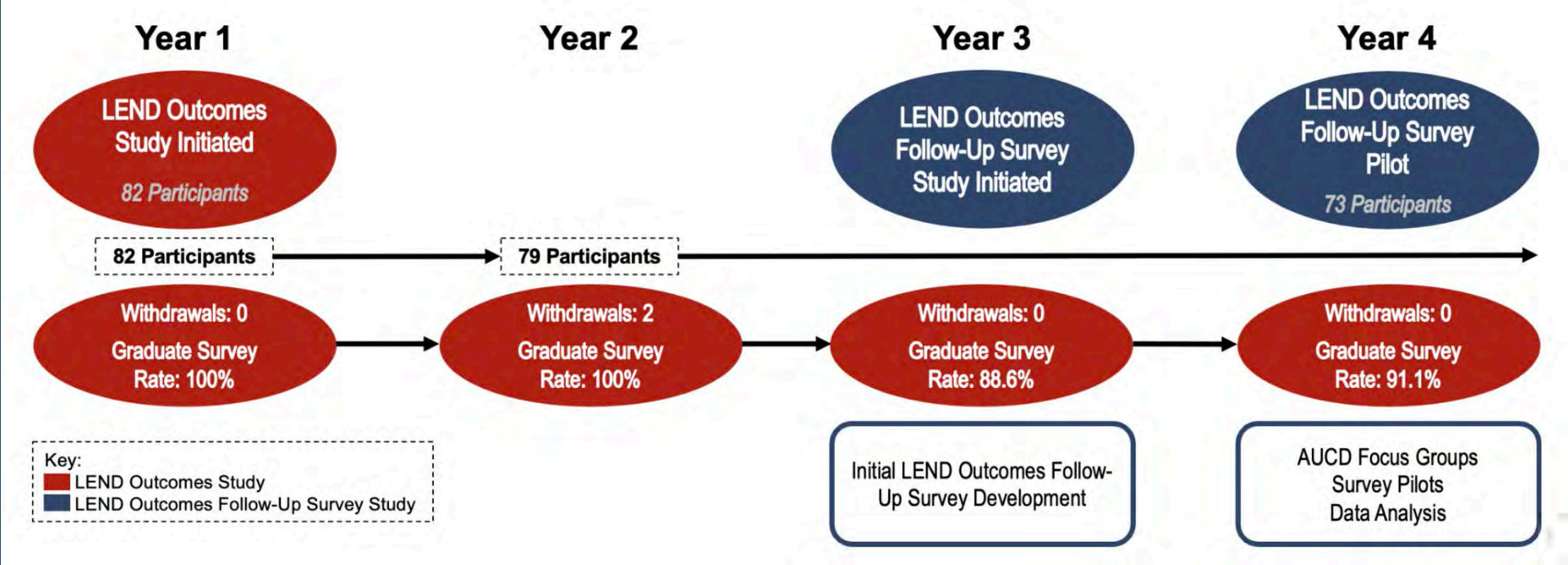


ALL THAT GLITTERS IS NOT GOLD

Could previous positive effects of LEND be caused by something other than LEND training?

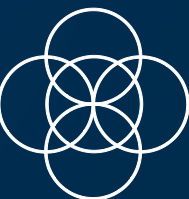
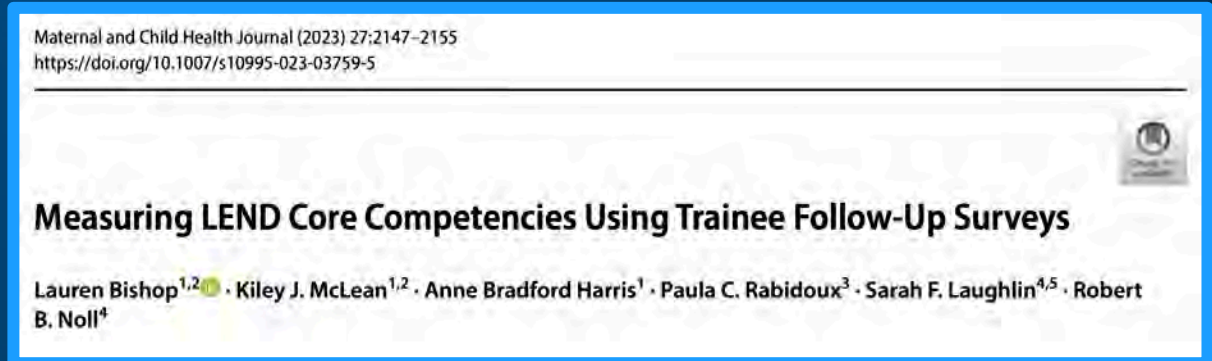


Timeline for Pilot Study & LEND Outcomes Study



Pilot Study: Measuring LEND Outcomes via Novel Survey

- Multi-step, mixed methods process
- Stakeholders identified 8 LEND leadership outcomes in focus groups
 - Interdisciplinary work
 - Advocacy
 - Intersectional approach
 - Systems perspective
 - Life course perspective
 - Leadership
 - Engagement with MCH populations
 - Research experience
- Developed and piloted novel survey: *LEND Outcomes Follow-Up Survey*
- Compared outcomes of LEND trainees & comparison peers



Findings

- Compared to comparison peers, LEND trainees:
 - *Worked with a greater number of disciplines*
 - Were more likely to be engaged in advocacy
 - Were more likely to utilize a systems perspective in their work
 - *Were more likely to work with MCH populations*
 - Were more likely to have experience conducting research
 - No significant differences between groups in terms of utilization of a life course perspective or intersectional approach



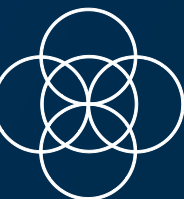
The LEND Outcomes Study

Maternal and Child Health Journal (2022) 26:1622–1631
<https://doi.org/10.1007/s10995-022-03421-6>



A model to evaluate interprofessional training effectiveness: feasibility and five-year outcomes of a multi-site prospective cohort study

Lauren Bishop^{1,2}  · Anne Bradford Harris¹ · Paula C. Rabidou³ · Sarah F. Laughlin^{4,5} · Kiley J. McLean^{1,2} · Robert B. Noll⁴



The LEND Outcomes Study: Feasibility and Preliminary Efficacy

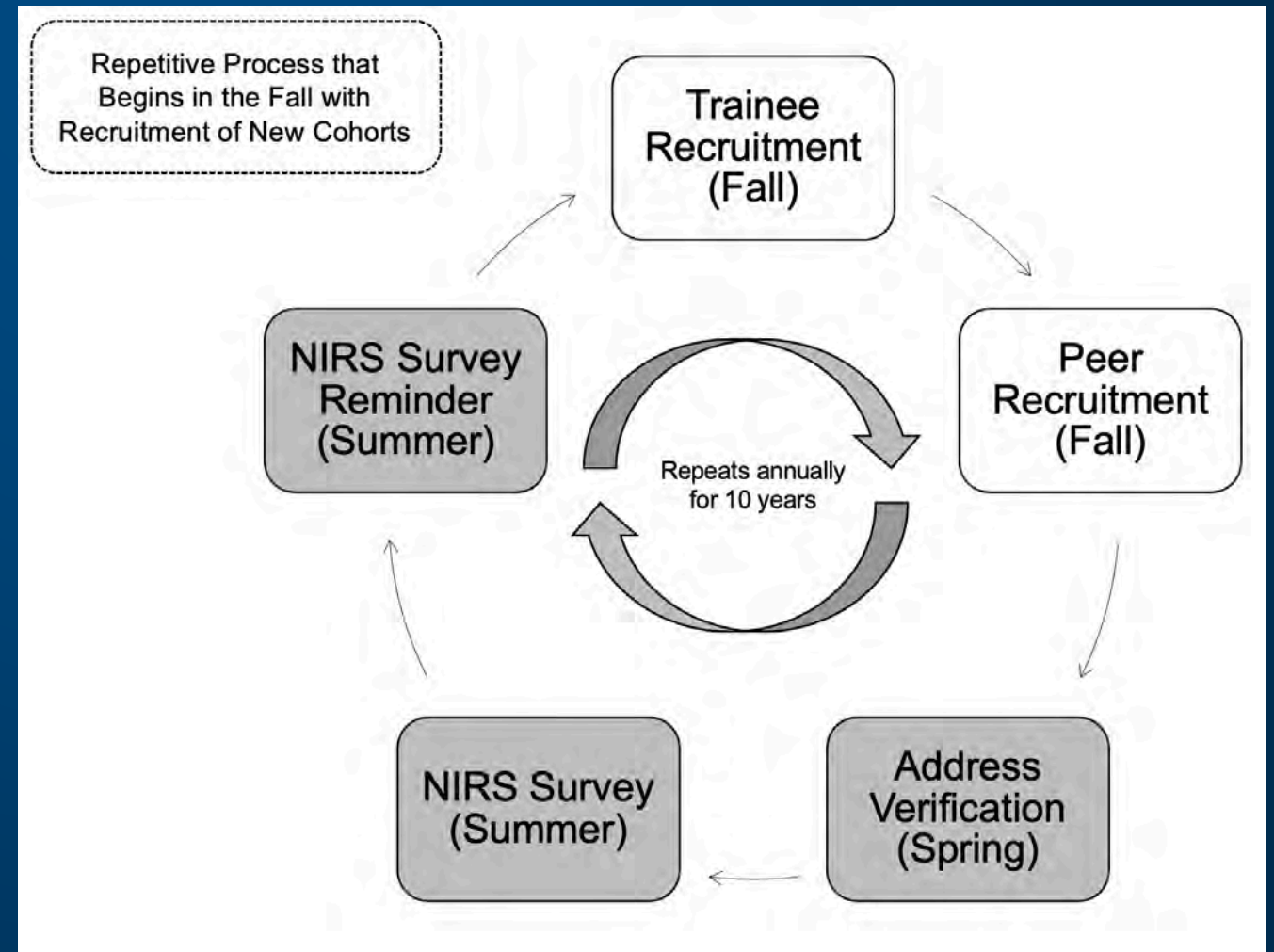
Background:

- Assessing trainee outcomes is difficult, and previous studies have significant design flaws

Our Solution: The LEND Outcomes Study

- Ex post facto, prospective cohort design
- Long-term LEND trainees and matched comparison peers consented to participate in the study
- Completed annual NIRS survey

Figure 1: Annual Recruitment Cycle

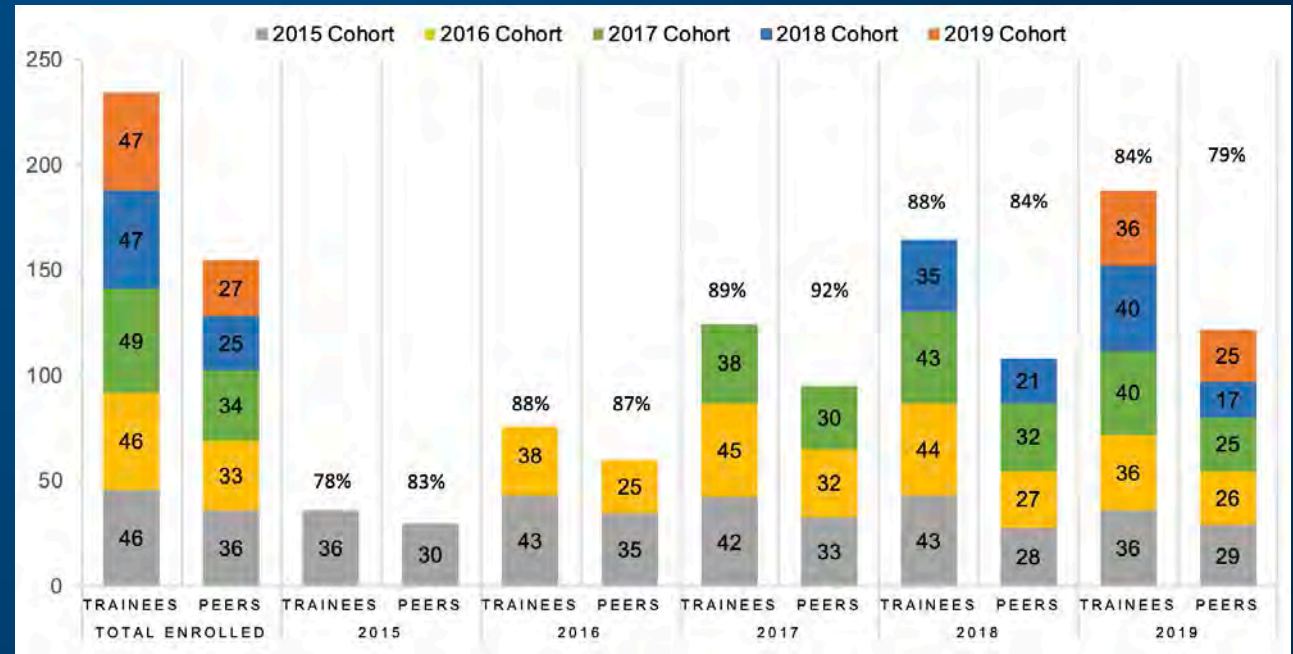


The LEND Outcomes Study: Feasibility

Feasibility:

- Recruited 68.3% of eligible LEND trainees
- 66.0% of LEND trainees were matched to peers
- 5-Year Attrition: 0.9% LEND trainees; 2.6% peers
- On average, 84.4% of LEND trainees and 79.9% of peers completed NIRS annually

Figure 2: Enrollment and Annual Survey Completion



The LEND Outcomes Study: Preliminary Efficacy

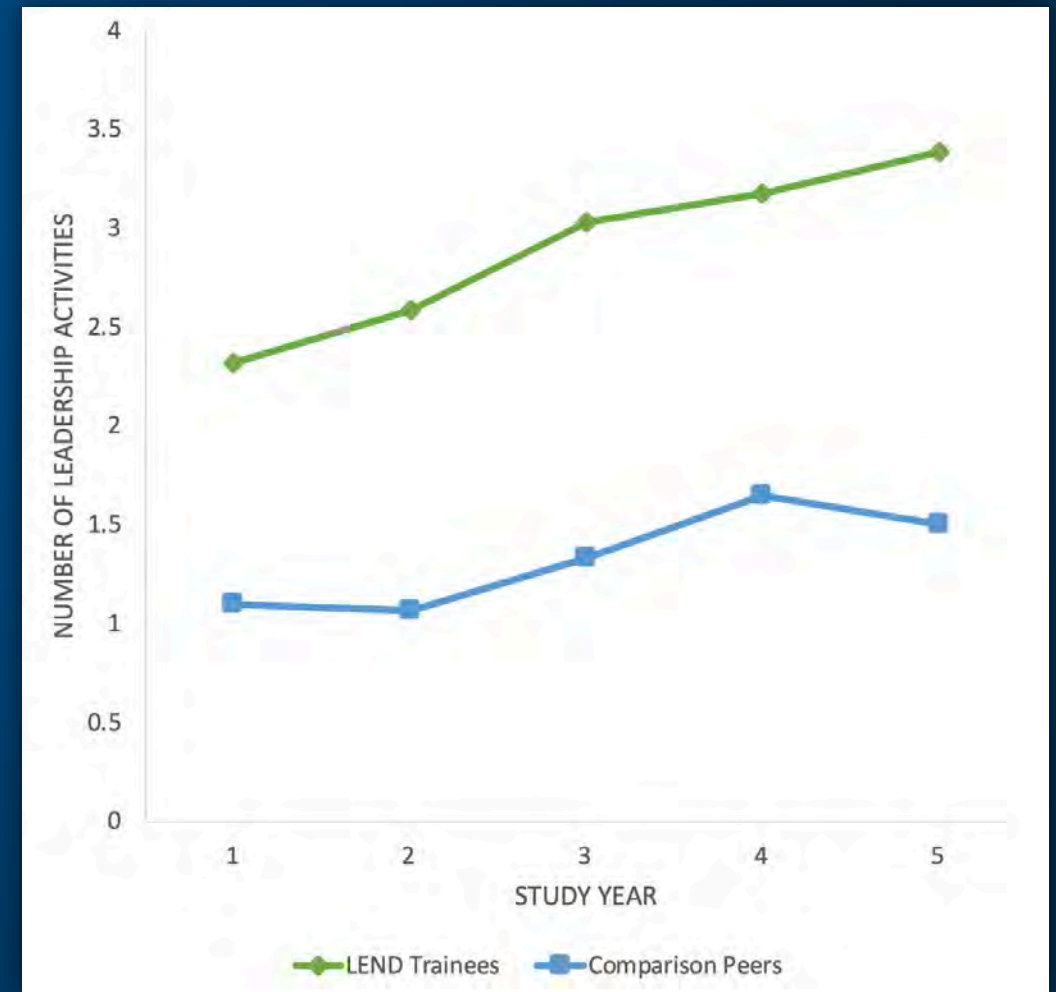
LEND trainees were more likely at 1 and 5 years post-training to work:

- With MCH populations
- With other disciplines
- With underserved and/or vulnerable populations
- In public health agencies


LEND trainees

- began their careers engaged in more leadership activities than comparison peers (Estimate = 0.75, SE = 0.19, $p < 0.001$)
- greater rate of growth in their participation in leadership activities (Estimate = 0.31, SE = 0.08, $p < 0.001$)

Figure 3: Longitudinal Change in Leadership Activities



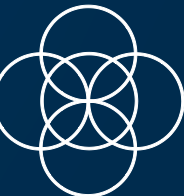
Implications and Future Directions

- Strong methodology  increased confidence in findings
- Identified significant differences: **perspectives** vs. **actual activities**
 - Both LEND trainees and comparison peers **self-report** that they are leaders and utilize MCH and LEND skills and competencies, **but**
 - LEND trainees **actual work activities** included significantly more leadership activities
- LEND training is accomplishing programmatic goals
- Future: Impact of COVID-19 pandemic on trainee outcome trajectories



References

- Bishop, L., Harris, A. B., Rabidou, P. C., Laughlin, S. F., McLean, K. J., & Noll, R. B. (2022). A model to evaluate interprofessional training effectiveness: feasibility and five-year outcomes of a multi-site prospective cohort study. *Maternal and Child Health Journal, 26*(8), 1622-1631.
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- Brosco, J. P., Pulgaron, E., Vanderbilt, D. L., Macias, M., Mathew, M. S., & Blum, N. J. (2018). The interprofessional/family-centered-care observation rubric (I-FOR): Results of a multicenter study of a new measure of educational outcomes. *Maternal and Child Health Journal, 22*(10), 1384-1392.
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- Smith, J. D., Nidey, N., Chödrön, G. S., Czyzia, J., Donahue, M. L., Ford, K., ... & Brosco, J. P. (2022). A quality improvement network for interdisciplinary training in developmental disabilities. *Pediatrics, 150*(6), e2022058236.





Gail Chödrön, PhD

Director, WI LEND

Director, WiCII

Waisman Center, University of
Wisconsin-Madison



Measuring and Demonstrating Impact: Wisconsin Care Integration Initiative (WiCII)

Measuring and Demonstrating Impact: Wisconsin Care Integration Initiative (WiCII)

Gail Chödrön, Project Director

Waisman Center, University of Wisconsin-Madison



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Meredith Vitaloli
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Aracely Portillo
Bilingual Family Navigator



Ida Winters
Family Leader



Rose Cutting
Family Leader



Heidi Lehman
Family Leader



Hector Portillo
Family Leader

WiCII Levels of Family Navigation (FN)

1 – Information & Referral

- All families
 - No barriers → provide info
 - Some barriers → warm hand-off to service providers

2 – Targeted, Time Limited

- Families needing additional short-term support
 - Assess short-term goals/needs
 - Make additional community service provider referrals

3 - Ongoing

- Families with complex barriers needing longer term support
 - Assess short- and long-term goals/needs
 - Assess barriers
 - Develop plan to meet goals/needs

Measuring Impact of Level-3 FN services

Methods: Parents of children that have received WiCII family navigation (FN) services receive a call to assess self-efficacy and satisfaction with FN services using a 7-question survey. Calls are made after the child no longer receives FN services or after 6 or 12 months of enrolled service.

99% of families **felt more confident** getting the support their child needs

“I don't think there's any way possible that I'd be able to find the resources that she found for my son and he wouldn't have been evaluated. Her support has enabled my son to stay in school and have an IEP that meets his needs.”

“She went through a lot of things that I already knew from my first child but also helped me with some things I didn't know about like the Katie Beckett program. I wish I'd had this service available when I was navigating services for my first child. It was very clear that she knew what she was doing. She was amazing and I was am very appreciative,”

96% of families were **very or mostly satisfied** working with the family navigator

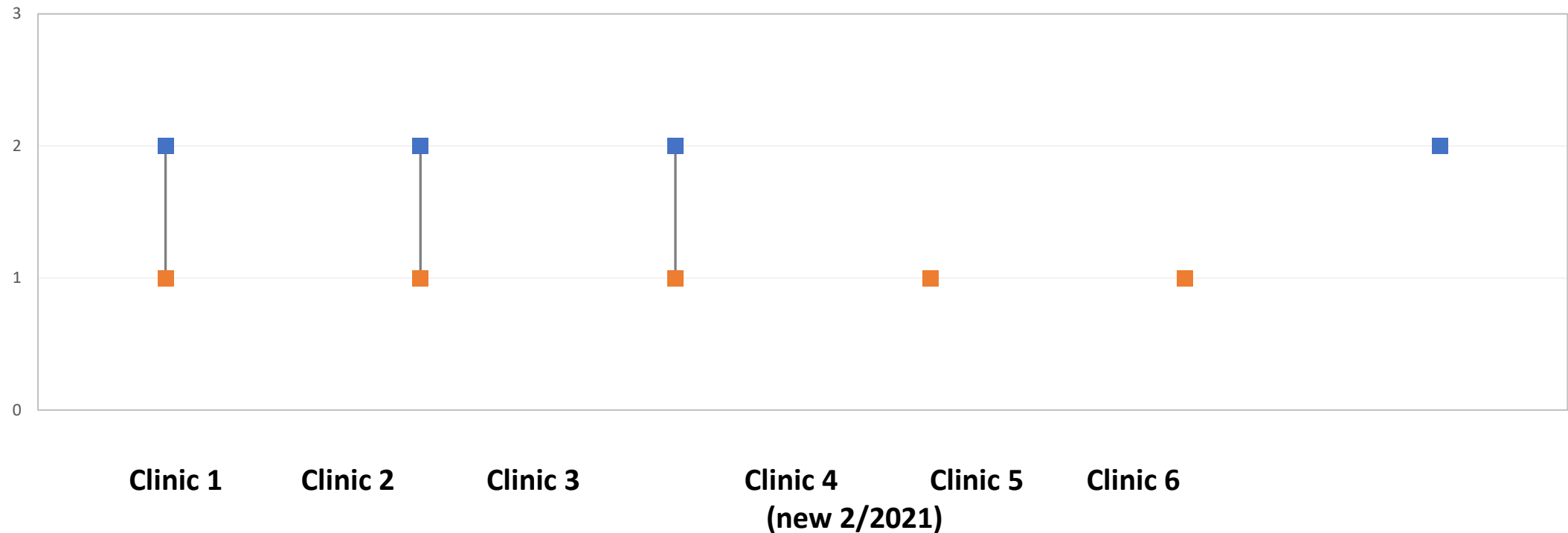
“She was really helpful and I really appreciated her calling and helping my case worker. They put a great plan together and I'm really grateful.”

“I just love talking with her because she always has an answer for me or if not she finds it.”

“[She] was wonderful, knowledgeable, compassionate, respectful, non-judgmental, thorough, followed through really well.”

Measuring Change in Level of Clinic-Based FN

Baseline (Sept 2019) and April 2022



Measuring Self-Efficacy in Family Leaders

- Initial assessment once onboarded
- Ongoing assessment every 6 months
- Online survey assesses self-efficacy, satisfaction, and impact
- First assessment completed Jan/Feb 2021

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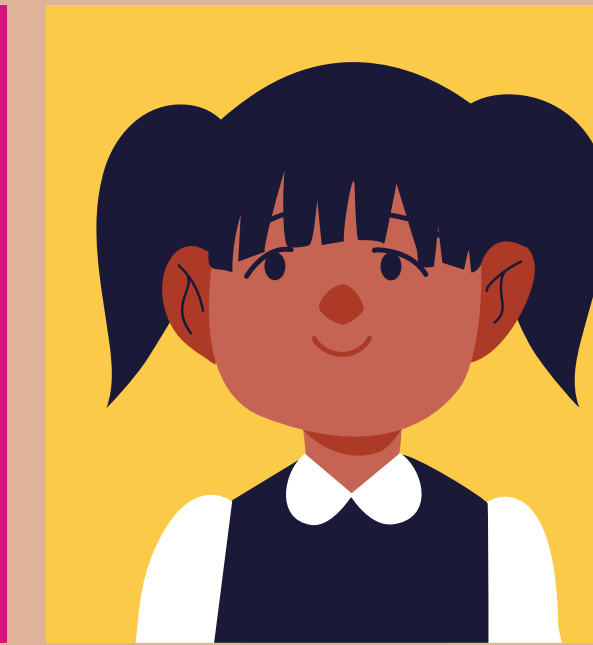
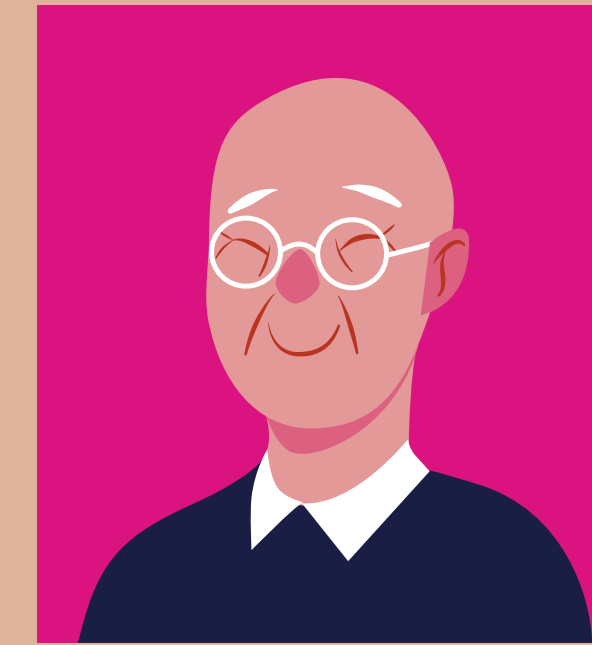
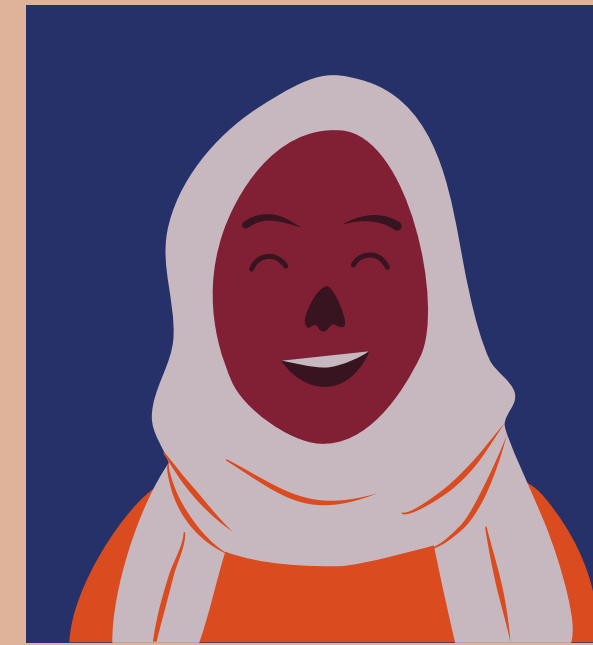
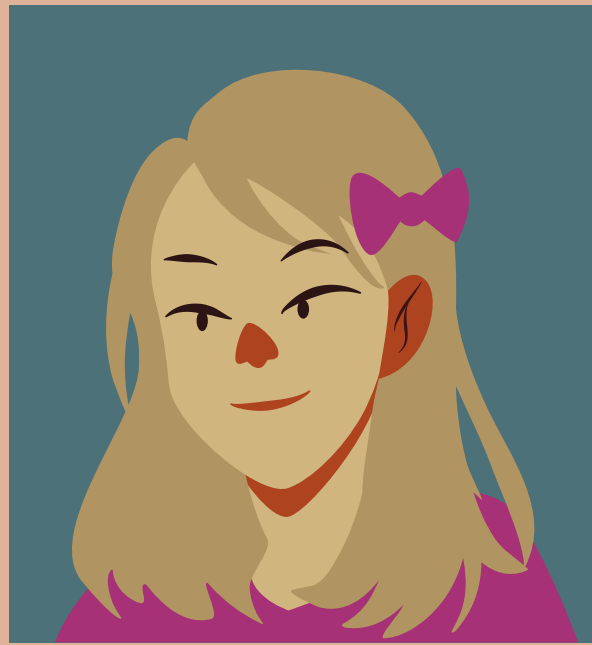
Using an Ecological, Network Approach to Measure Project Impact

Elizabeth McGhee Hassrick, PhD

Associate Professor

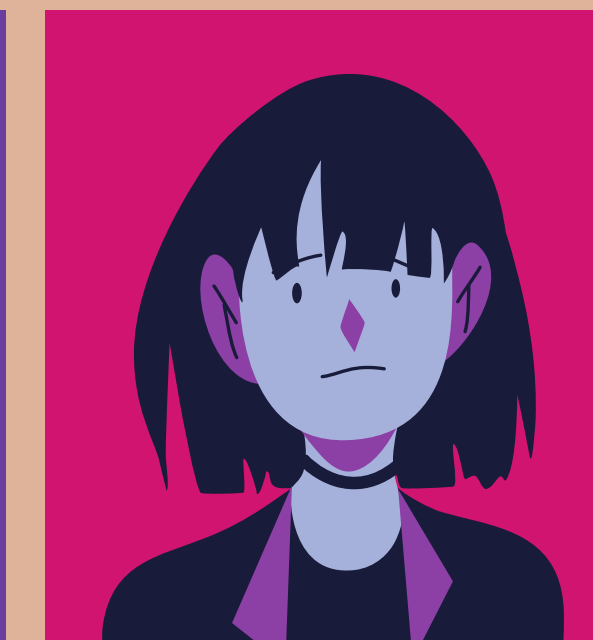
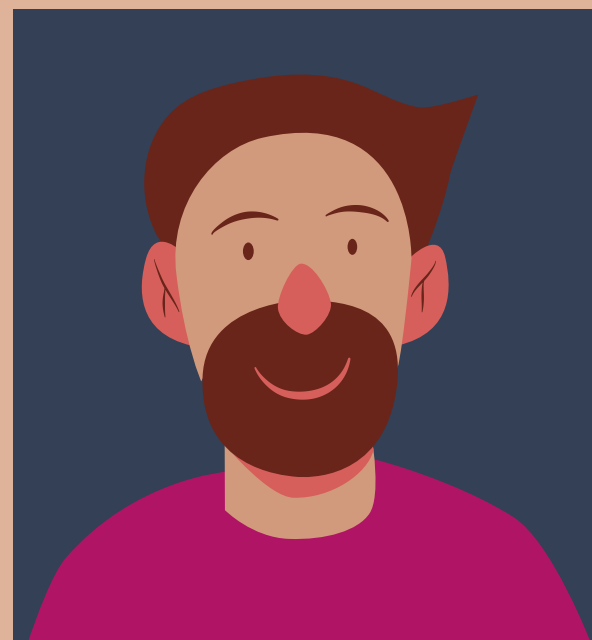
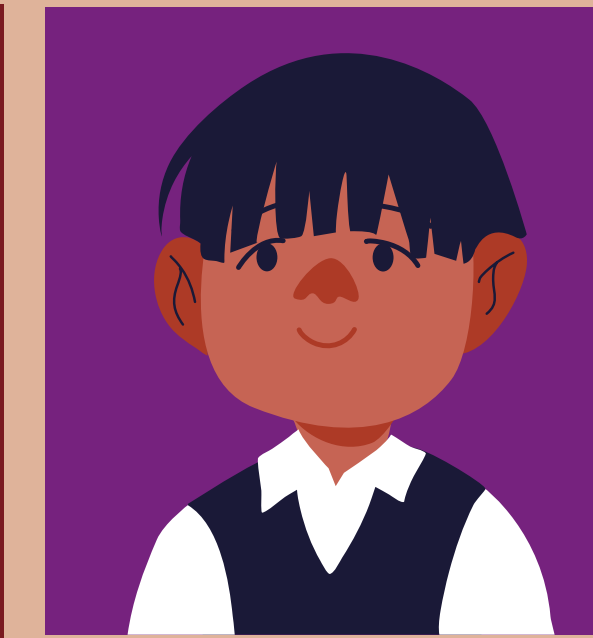
A.J. Drexel Autism Institute, Drexel
University

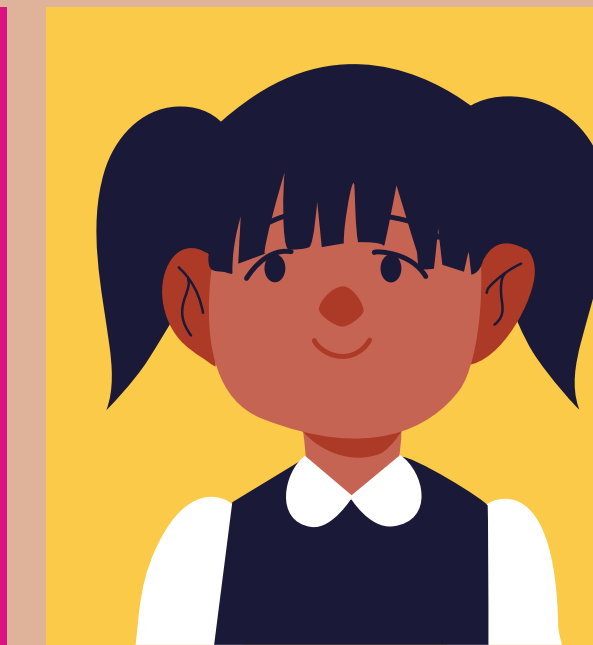
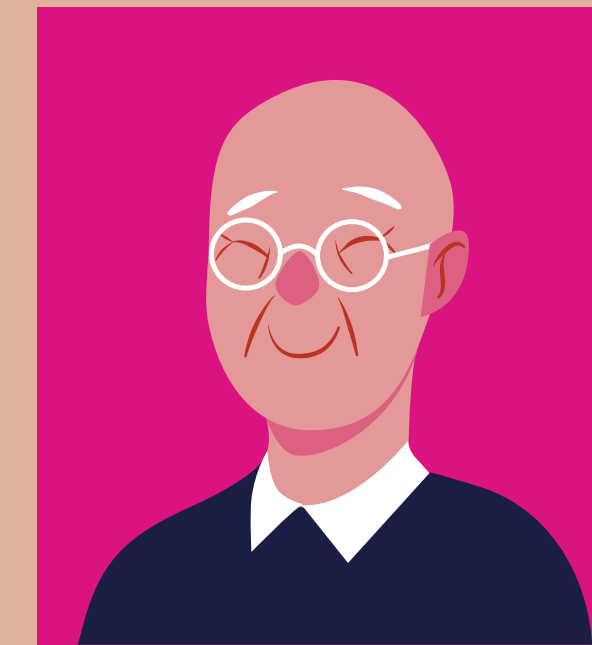
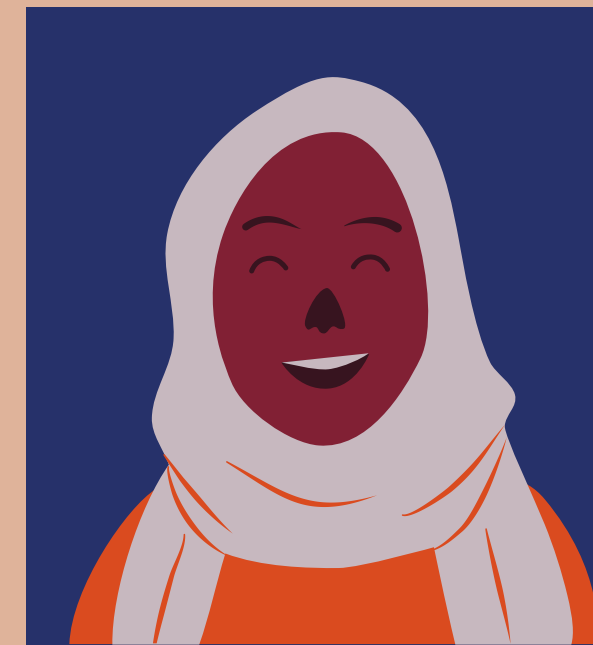
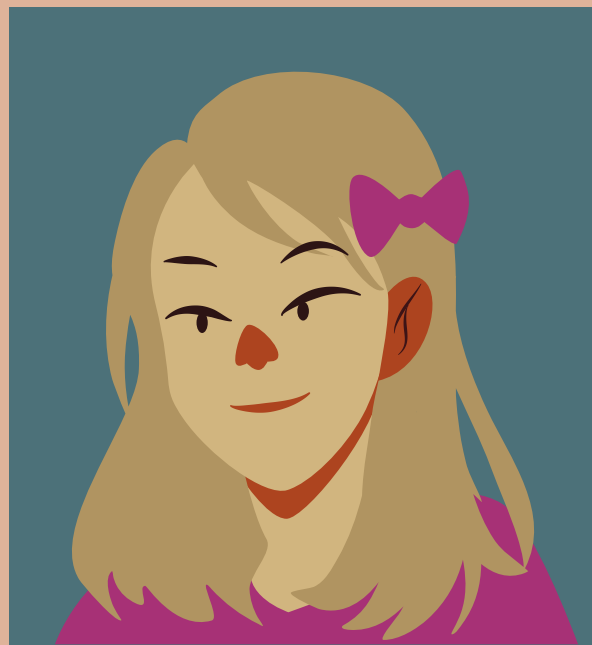




Autism Inclusion Networks

Using an Ecological, Network Approach to Measure Project Impact



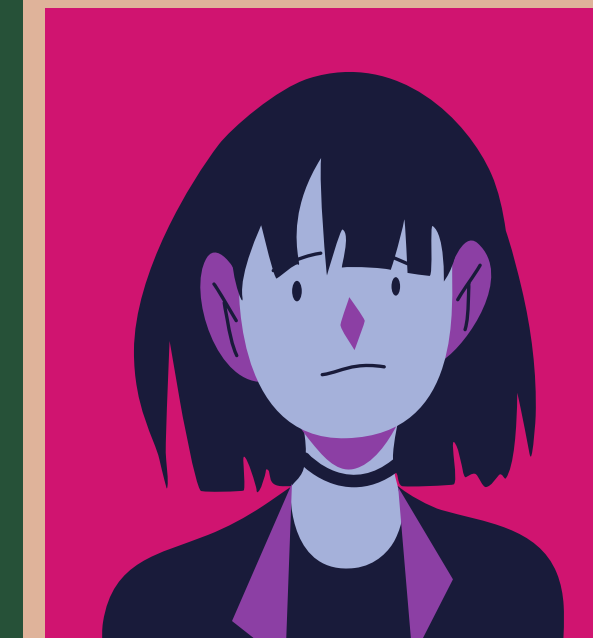


Elizabeth McGhee Hassrick
(She, Her)

Faculty Lead - SoDI Lab
 (Social Dynamics of Intervention)

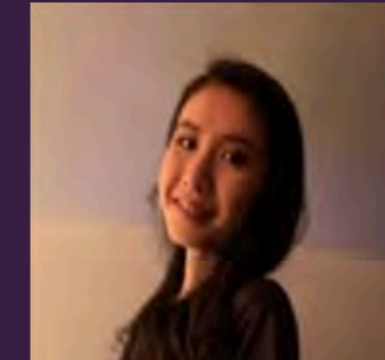
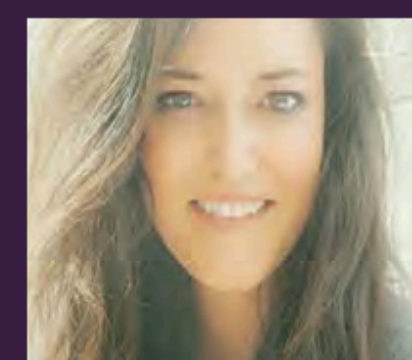
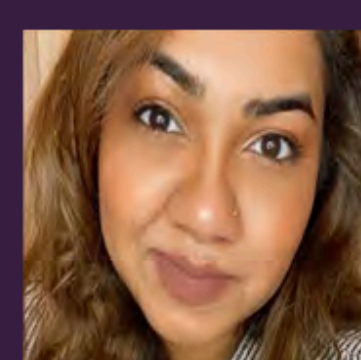
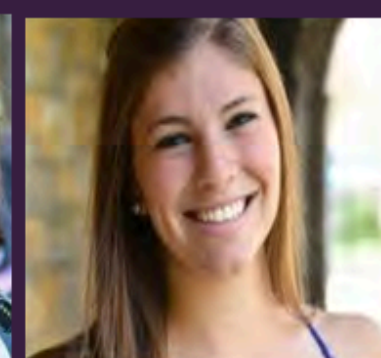
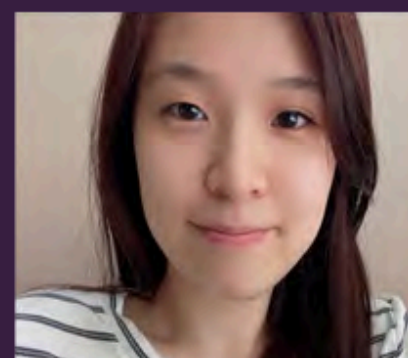
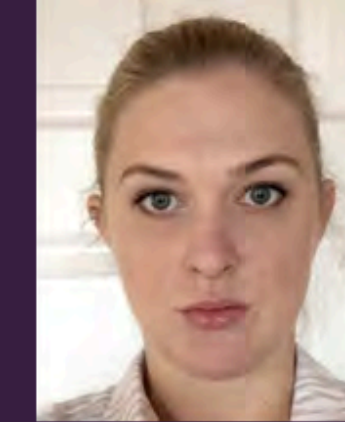
Positionality: Sociologist, Teacher, White, Woman, Parent of neurodivergent young adults, Sister of an autistic person

AJ Drexel Autism Institute Life Course Outcomes
 emh347@drexel.edu



SoDI Lab Collaborators - Faculty, Staff, Students

Current and Alumni



SoDI Lab Funders



The Individual is the Problem

The Medical Model of Disability



Traditional View

- disability is caused by the impairment
- the individual is impaired
- Focus is on cure or lessening the effect



We learn about autistic people (often from a deficit perspective)

Intervention is primarily focused on changing autistic people to fit in society, not how society can be changed to support them. Research is conducted by professionals and does not intergate or co-produce research with community partners



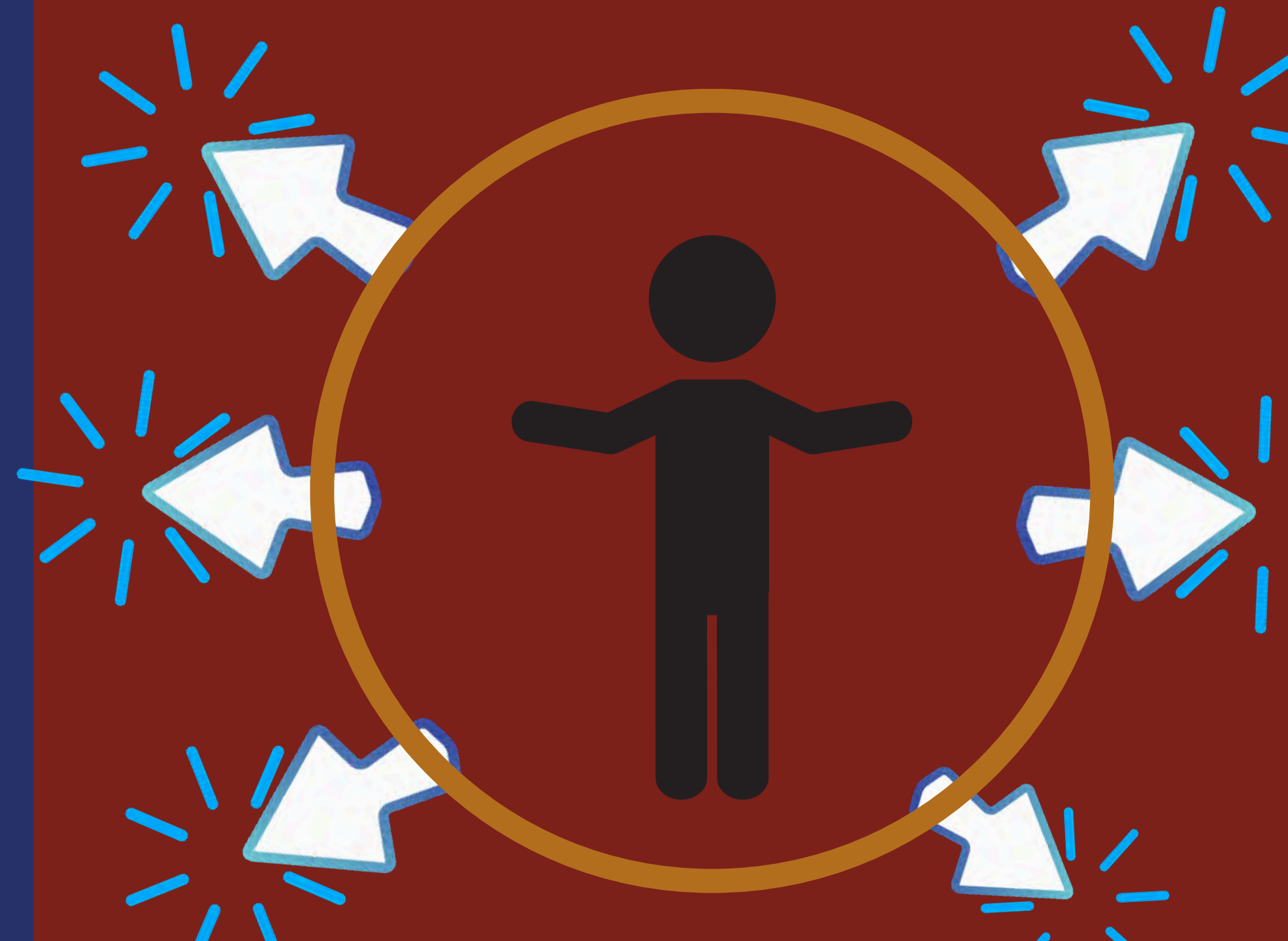
Society is the problem

The Social Model of Disability



Social Barriers

- Inaccessible environment
- Discrimination, stigma and Stereotyping
- Organizations with inflexible procedures and practices



We learn how we can change the way society is organized to remove barriers for autistic people



We consider the neurodiversity of autistic people and focus on the self determination of autistic people. Research is conducted in partnerships between community people and professionals, intergating and/or co-producing research with community partners

Big Question #1

**How does our society shape our
everyday lives?**

Larger Social Structures



Our Everyday Lives

LARGER SOCIAL STRUCTURES

CREATE BENEFITS



DEVELOPMENTAL DISABILITIES

OUR MISSION
MAKING CONNECTIONS TO PROMOTE ABILITIES AND ENRICH LIVES

OUR VISION
COMMUNITY WITHOUT BARRIERS


OUR VALUES
LISTENING
WORKING TOGETHER
PUTTING PEOPLE FIRST
GROWING AND LEARNING
PROMOTING CREATIVITY
MAKING THINGS EASIER



SOCIAL NORMS ON DISABILITY

The Role of Social Norms in Decisions to Provide Schooling to Children with Disabilities in East and Southern Africa

Dr Symen Brouwers, UNICEF Eastern and Southern Africa Regional Office (ESARO)

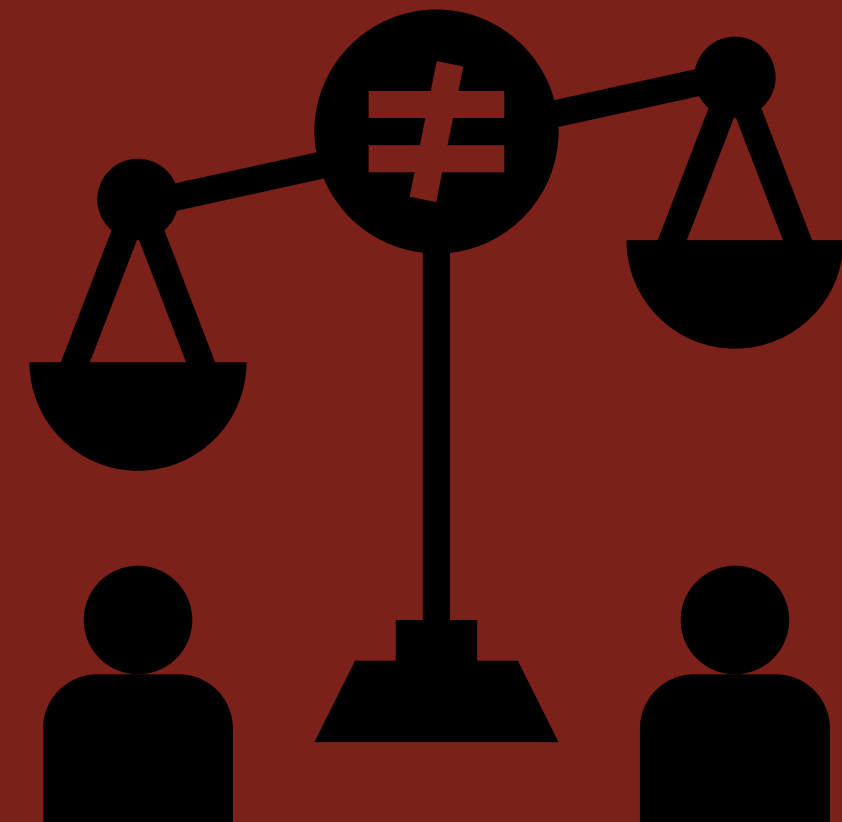


ADA
Americans with Disabilities Act



LARGER SOCIAL STRUCTURES CREATE INEQUALITY

one's laughter
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shame or dis
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LARGER SOCIAL STRUCTURES

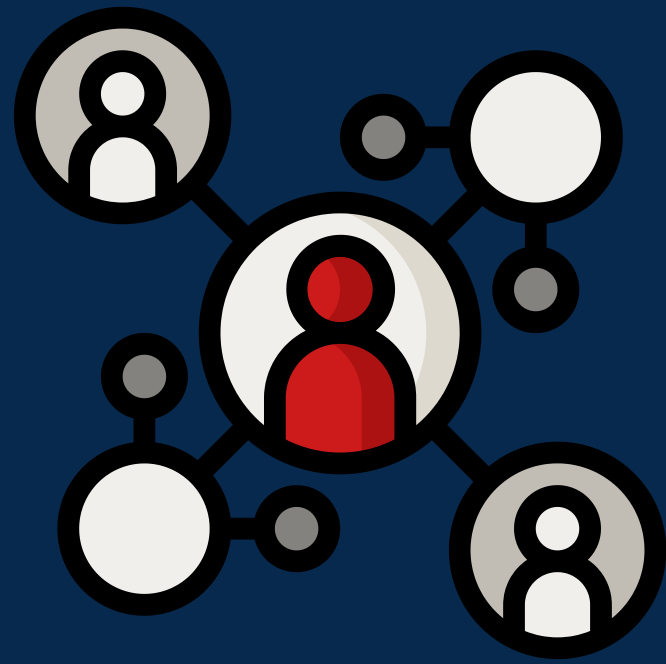


Individual People

Big Question #2

How do our everyday social interactions shape society?

Our Society



**The Networked Ecological Systems of
Interactions of Our Everyday Lives**

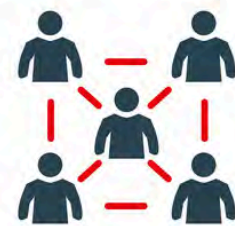
NETWORKED ECOSYSTEMS

CREATE BENEFITS

SOCIAL CAPITAL



PARTICIPATION



NETWORK



TRUST



BELONGING



RECIPROCITY



ENGAGEMENT

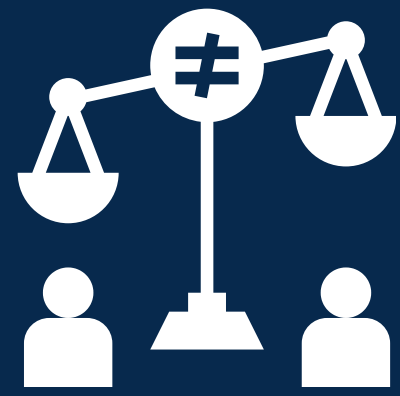


VALUES + NORMS

NETWORKED ECOSYSTEMS

CREATE BENEFITS





NETWORKED ECOSYSTEMS CREATE INEQUALITY



Systemic Exclusion



Social Network Approach

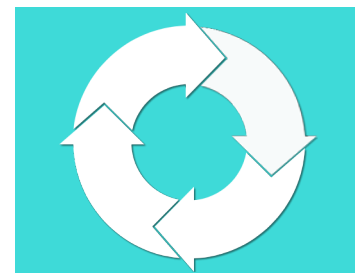
In partnership with autistic researchers and community members, we developed a social network survey to measure, visualize and modify networked ecological systems that emerge in Autism Research Networks to create greater inclusion of people on the autism spectrum, their families and community supporters

CREATE NEW KNOWLEDGE AND NEW OPPORTUNITIES FOR COMMUNITY ACTION

Co-create together the future of autism research and community action



**CHANGE WHO
DOES SCIENCE**



**CHANGE HOW
SCIENCE GETS
DONE**



**CHANGE WHO
DOES COMMUNITY
ACTION**



**CHANGE HOW
COMMUNITY
ACTION IS DONE**

Community-Partnered Participatory Research (CPPR)



CPPR was pioneered by the late Dr. Loretta Jones, the founder of the Healthy African American Families (HAAF) nonprofit.

Dr. Jones dedicated her life to the hope and healing of community.

AASPIRE Guidelines for Participatory Research with Autistic Adults

Cristina Nicolaidis and Dora Raymaker developed the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) through collaboration with autistic and non-autistic researchers and stakeholders.

AASPIRE developed tools and guidelines to include diverse autistic people in all stages of research.



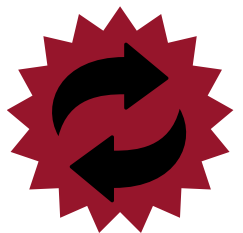
The CPPR Model Focuses on Building High Quality Collaboration



Increased trust among diverse stakeholders



Shared goals and norms



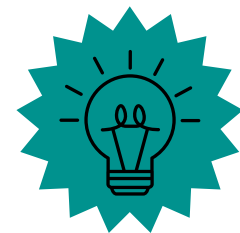
Reciprocal exchanges



Better Information



Diverse Resources



New Knowledge

"It's not just who you know but what you share with each other"

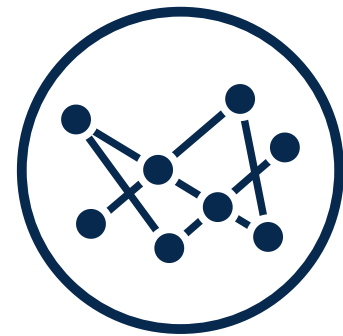
CPPR Annual Surveys and Reports for Projects

1. Quantity Measures



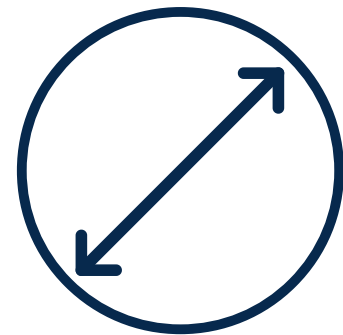
1 Growth

New collaborations
Increase in collaboration frequency



2 Connectivity

The interconnectedness of every person's network



3 Size

The amount of collaborators in an individual's network.
We present the min, max, and mean values across the node.

3. Success Ratings



1 Overall Project Success

2. Quality Measures



1 Perceived Collaborator Diversity

Autism spectrum
Gender
Ethnicities



2 Collaborator Expertise

Autism-related expertise
Expertise in community/stakeholder engagement
Expertise in research
Expertise in underserved/vulnerable populations



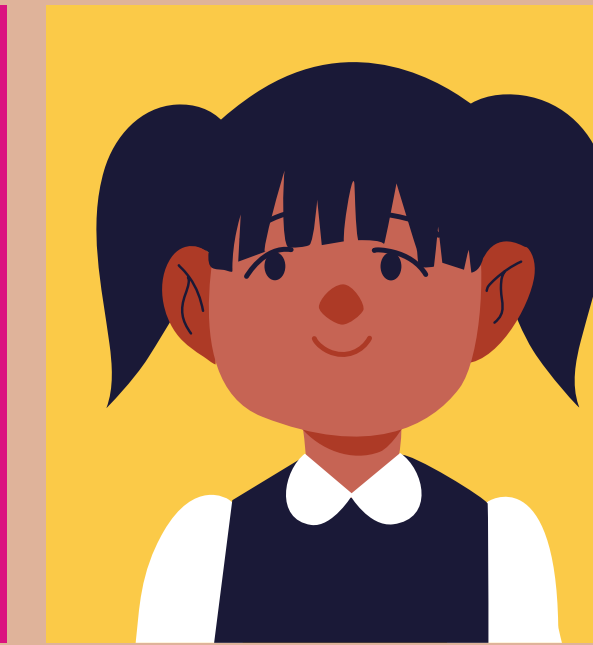
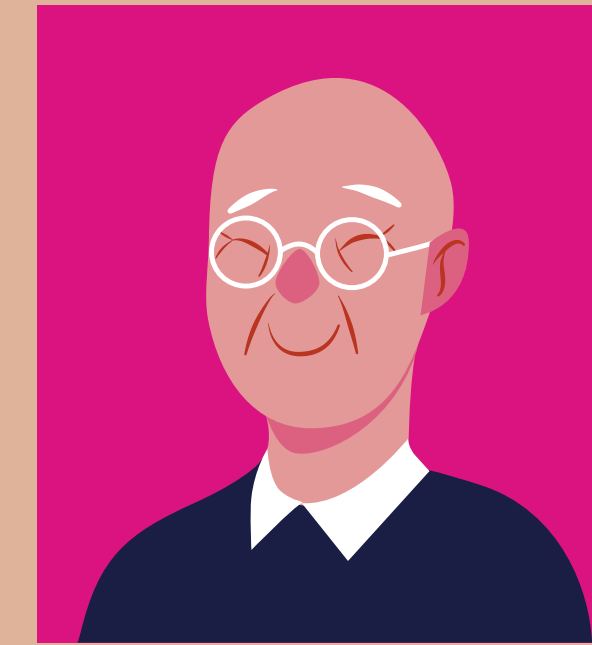
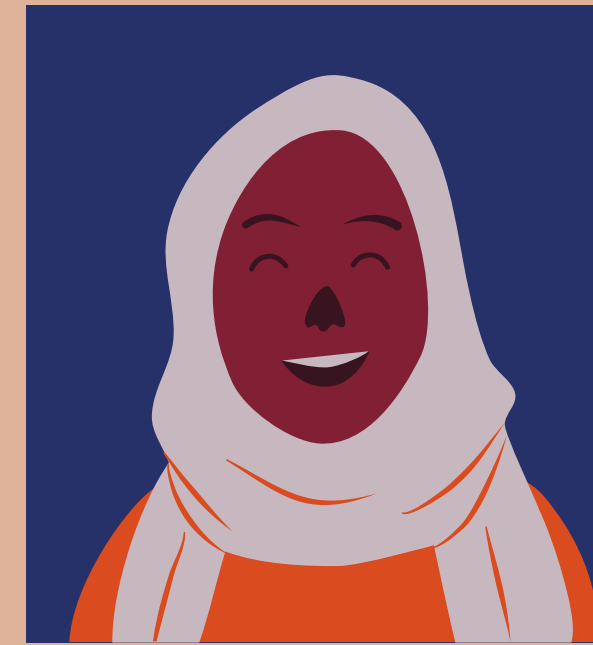
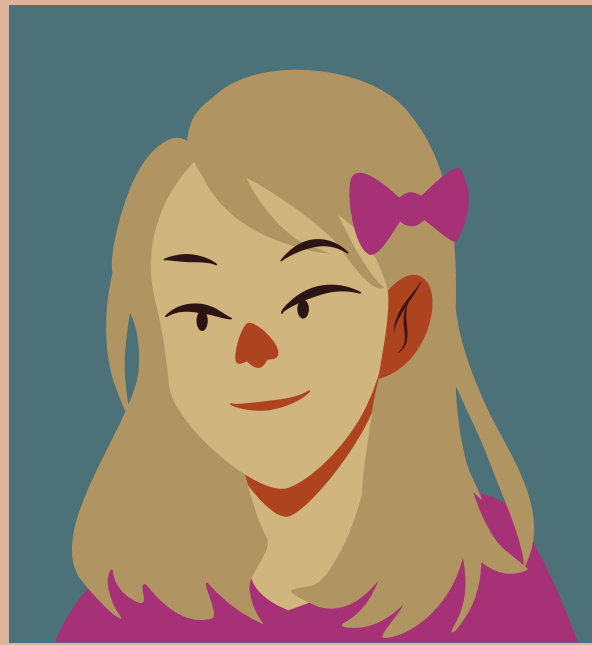
3 Collaborator Types of Engagement

Stakeholder/community engagement
Research engagement
Research mentorship engagement

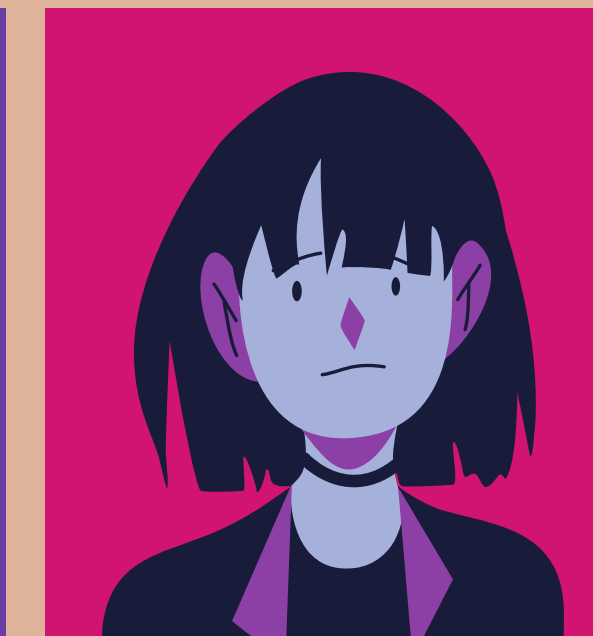
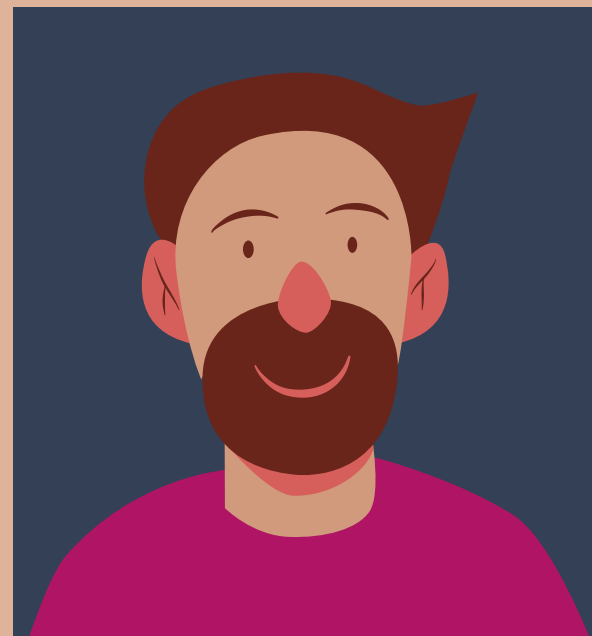


2 Project specific goals





Thank you!





1. National Network Impact

- *How can the Autism CARES Network come together to measure and demonstrate impact?*

2. Program Impact

- *How are programs defining impact? Innovative strategies? Challenges?*

3. Community, State, Regional Impact

- *How are programs defining impact at the community, state, or regional level? Innovative strategies? Challenges?*

Closing Remarks





Thank You!

- The recording, resources, and slides will be available within one week of today's meeting.
- We will see you in-person next Summer! If interested in joining the 2025 Autism CARES planning committee, email jczyzia@aucd.org.
- Please take 2 minutes to provide feedback on today's meeting: <https://www.surveymonkey.com/r/2024AutismCARES>

or scan the
QR Code

