

# DISABILITY INCLUSION, INTERSECTIONALITY, AND KNOWLEDGE TRANSLATION

KTDRR's 2024 Virtual KT Conference

October 15, 16, and 18

Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**



# HANDS IN AUTISM®

## AUTISM ENGAGEMENT NETWORK (AEN)

EVOLUTION OF AN EVIDENCE-BASED FACILITATION MODEL TO BEST  
ELEVATE AND LEARN FROM FIRST-PERSON VOICES AND LIVED  
EXPERIENCES

Center on Knowledge Translation for Disability & Rehabilitation Research (KTDRR)  
Center on KTDRR's 2024 Knowledge Translation Conference



HANDS Overview

# HANDS IN AUTISM®

## INTERDISCIPLINARY TRAINING AND RESOURCE CENTER



# Who is HANDS?

## A GLOBAL TEAM WITH COLLECTIVE FOCUS



<https://handsinautism.iu.edu/history-philosophy>

- An interdisciplinary training and resource center founded in 2004 and operating as an IUSM auxiliary since 2013
- Maintains core missions of Indiana University School of Medicine (IUSM) and Indiana University Health



*Outreach, Education and Training*



*Clinical Service*



*Research Innovation*

- Deliver and uphold HANDS' mission and vision as an intermediary-purveyor organization



*Provide unique, interactive learning opportunities*



*Build cross-system bridges of information, resources, and collaboration*

*... to increase local capacity in effective implementation of evidence-based practices and regional community networks*

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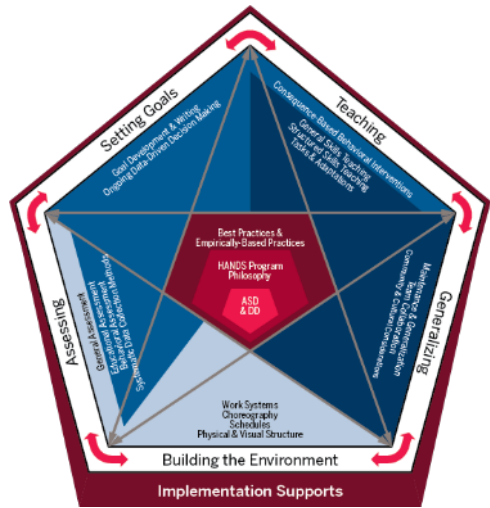


# HANDS STANDARDS

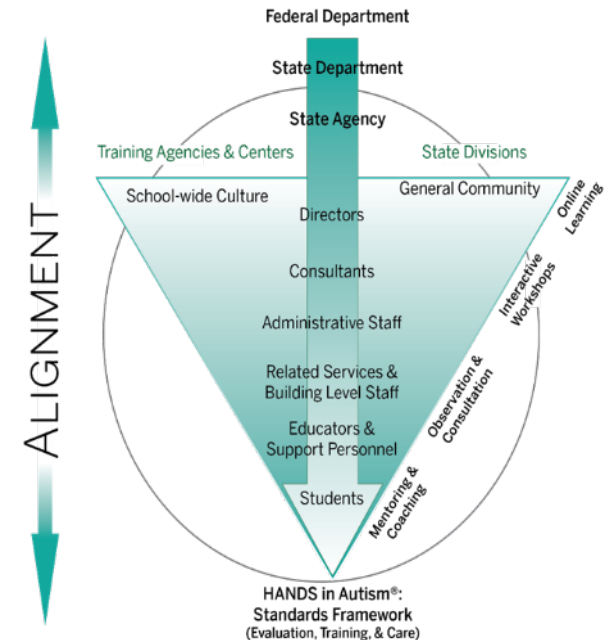
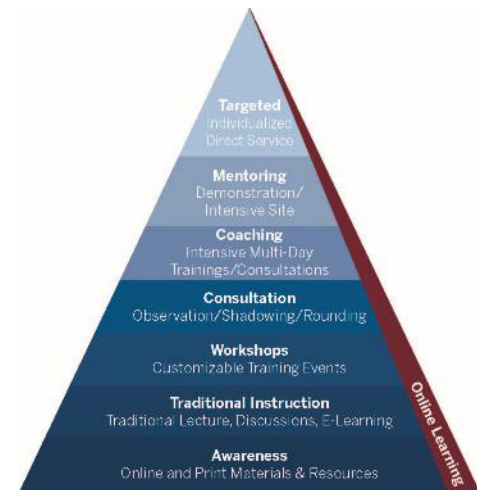
STEEPED IN IMPLEMENTATION SCIENCE, NETWORKS, AND EVIDENCE-BASED MODELS



<https://handsinautism.iu.edu/research/evidence-based/hands-model>



- Modular, comprehensive training curriculum, framework, and process
- Responsive and complementary to initiatives for improved acceptability, integration, and penetration across systems
- Accessibility via increasing options across services and systems
- Meeting people where they are with community-informed focus, sustained outcomes, and agency-sought trainings and consultation



© 2024 The Trustees of Indiana University, HANDS in Autism Interdisciplinary Training and Resource Center.; Fixsen, Blasé, Duda, Naoom, & Van Dyke (2008).



# HANDS Innovation A 20-Year Pipeline

A SYSTEMATIC,  
COMMUNITY-  
INFORMED PATH  
OF SCALIN

“A path is quite  
different from a road.”

• **Foundational funding** thru CDC earmark to establish initial outreach efforts and enable consultation and travel for HANDS Model development

• HANDS service expansion as a **VR and Pre-ETS provider**  
 • **HANDSmade™ partnership** launched between Riley, IUH, and HANDS  
 • HANDS selection as **IIACC facilitator**  
 • **Annual Art Expo** funded thru IAC as annual event  
 • **HANDS CTSI Service Core** approval

• **IDOE IRN funding** as part of TA network  
 • Launch of **HANDS Local Community Cadres**

• **HANDS Model** pilot 5-day training

• Initiation of 2<sup>nd</sup> demonstration site

• IDOE Funding for **pilot demonstration site**  
 • Increased intensive trainings  
 • Foundation funding to expand outreach and training focus

• **HANDS Global site and team** in operation  
 • HANDS partnership with IU auxiliaries (CWT, eDS/IU Expand) for increased innovation and accessibility  
 • **HANDS DD & ASD ECHO Series** launch and expansion  
 • Expanded leadership team with program manager

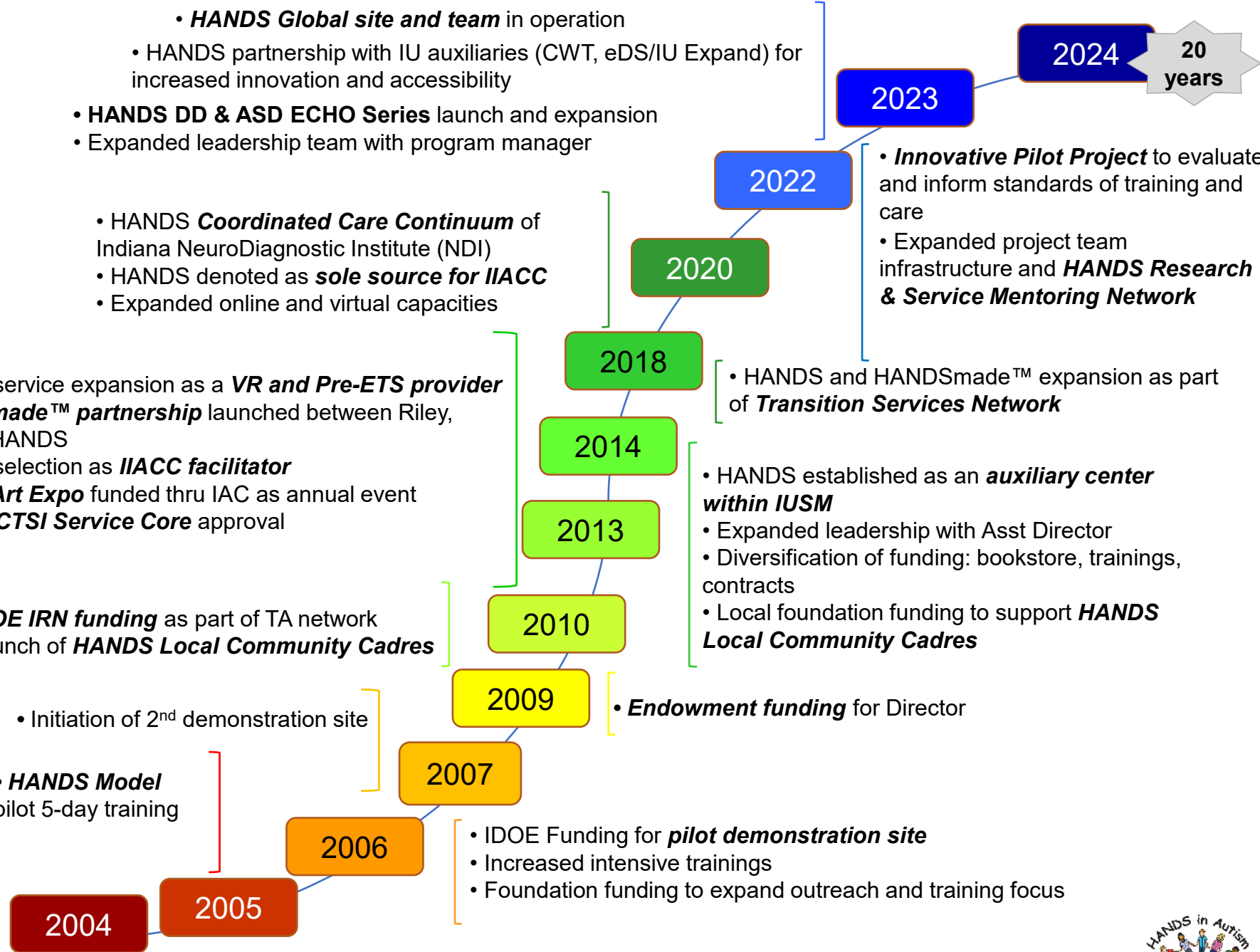
• HANDS **Coordinated Care Continuum** of Indiana NeuroDiagnostic Institute (NDI)  
 • HANDS denoted as **sole source for IIACC**  
 • Expanded online and virtual capacities

• **Innovative Pilot Project** to evaluate and inform standards of training and care  
 • Expanded project team infrastructure and **HANDS Research & Service Mentoring Network**

• HANDS and HANDSmade™ expansion as part of **Transition Services Network**

• HANDS established as an **auxiliary center within IUSM**  
 • Expanded leadership with Asst Director  
 • Diversification of funding: bookstore, trainings, contracts  
 • Local foundation funding to support **HANDS Local Community Cadres**

• **Endowment funding** for Director



HANDS AEN Team

# HANDS AUTISM ENGAGEMENT NETWORK (AEN) REPRESENTATIVES





# HANDS Autism Engagement Network

RESEARCH-COMMUNITY PARTNERSHIP



Naomi Swiezy, PhD, HSPD  
Director



Tiffany Neal, PhD  
Assistant Director



Ryan Steiner  
Autistic Self-Advocate &  
Stay-at-Home "Dad-vocate"



Amy Shamanov  
Autistic Individual & Graduate  
Services Professional



Kristan Sievers-Coffer, MSED  
Comm Transition Specialist



Mounika Gottipati, MSHI  
Data Specialist



Julie Burk-Smith  
Family & Community Liaison



Lexi Westerfield  
Advocacy Leader & Self-Advocates  
of Indiana Board Member



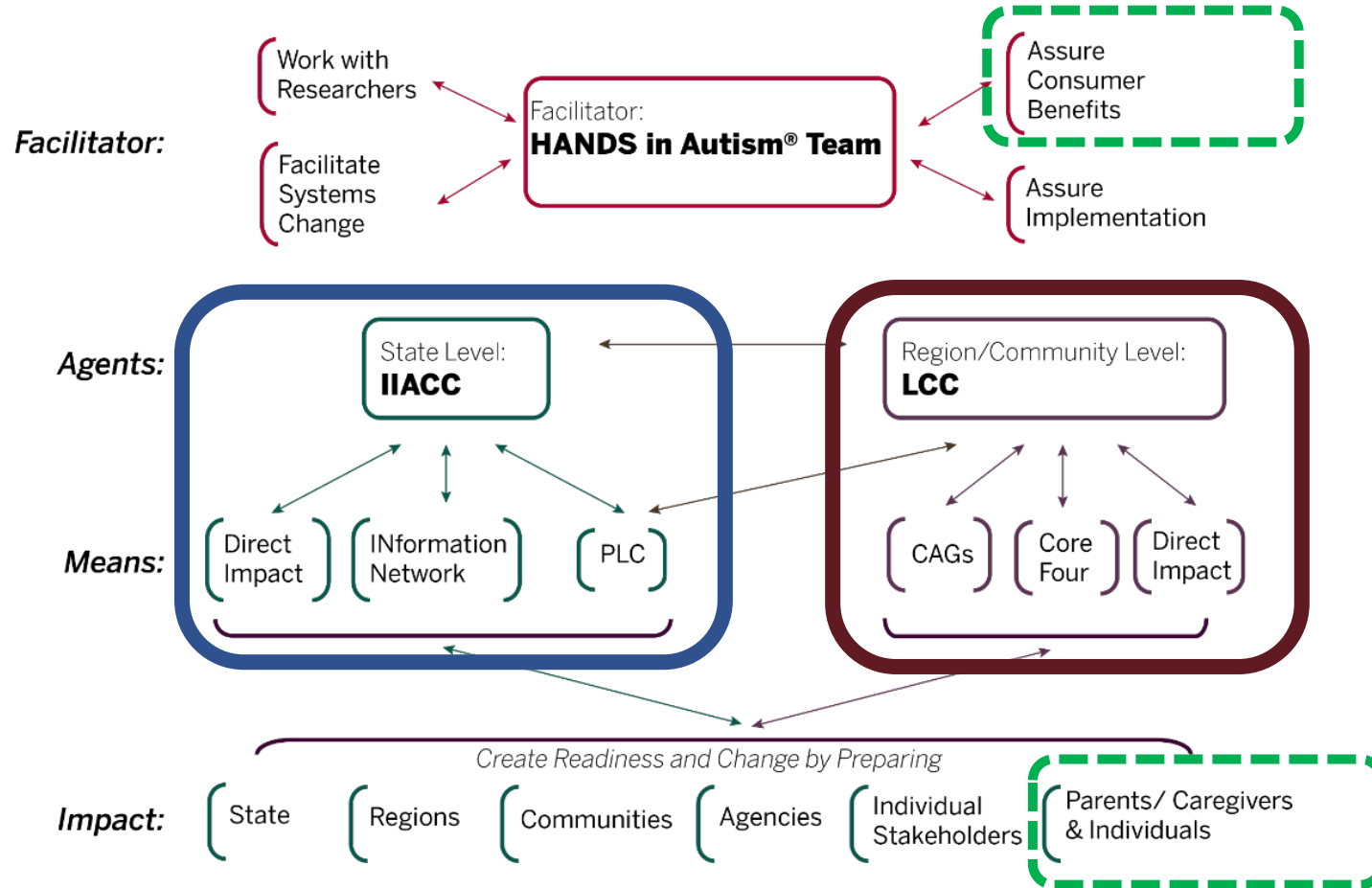
HANDS AEN Overview

# HANDS AUTISM ENGAGEMENT NETWORK (AEN) OVERVIEW



# HANDS Autism Engagement Network

## MECHANISM OF CHANGE FOR DISABILITY INCLUSION, INTERSECTIONALITY, AND KNOWLEDGE TRANSLATION



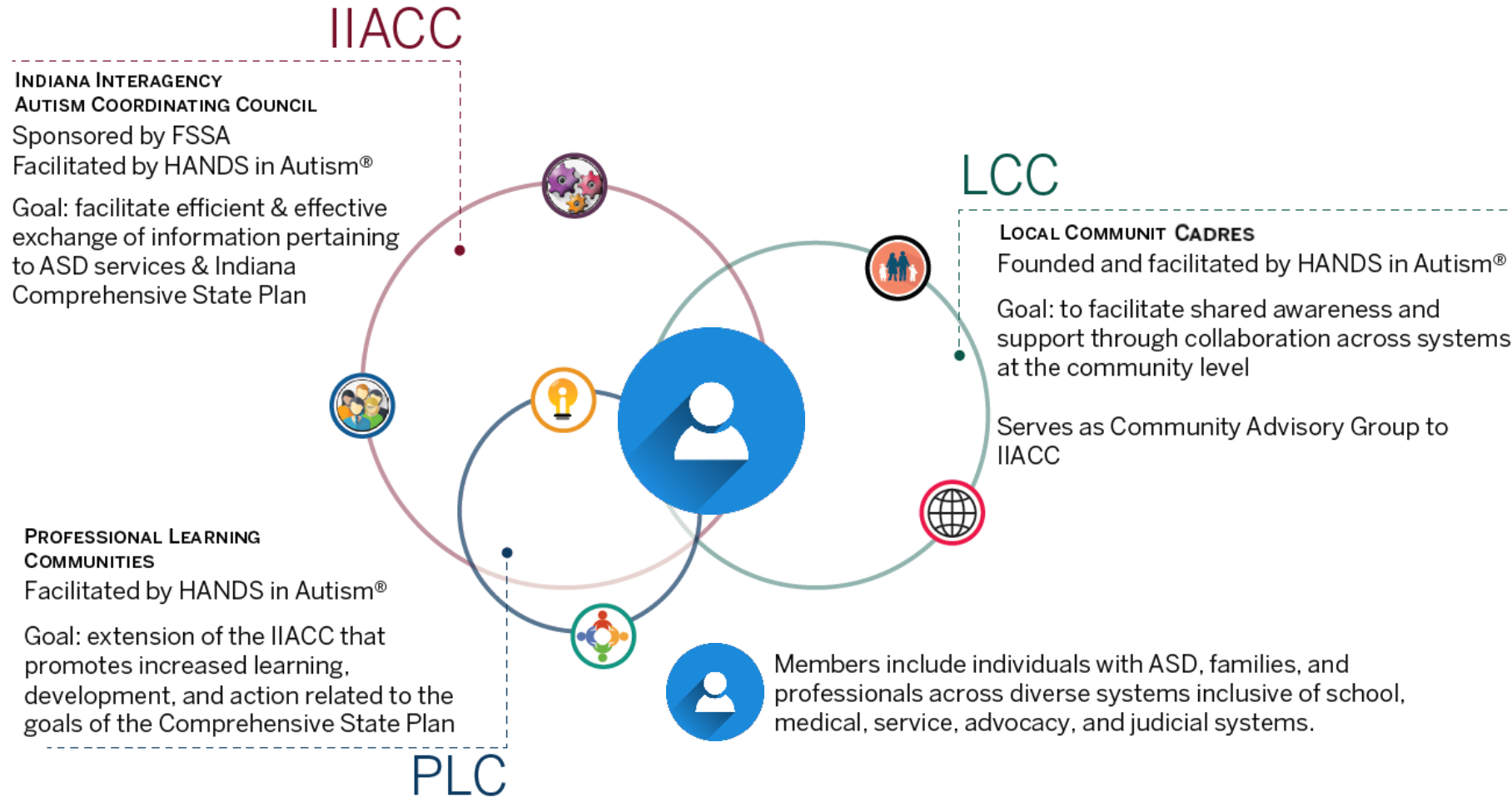
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# Autism Engagement Network

PERSON-CENTERED, STRENGTH-BASED FOCUS

## NETWORK OF STAKEHOLDER GROUPS



<https://indiananetwork.org/about/the-indiana-interagency-autism-coordinating-council/>



# Autism Engagement Network

EFFORTS TO INFORM POLICY THROUGH MEANINGFUL, FIRST-PERSON METHODS

## Active, first-person methods foster:

- A community with informed policymaking (Perry-Hazan, 2016; Shier et al., 2014)
- Empowerment and participatory citizenship with feelings of increased self-esteem, self-efficacy, ownership, and belonging to a community (Andersen & Dolva, 2015; Bailey et al., 2015; Graham & Fitzgerald, 2010)
- Expressed value in having their voices heard (Andersen & Dolva, 2015; Cavet & Sloper, 2004; Stafford et al., 2003)

### Tailor the Approach:

- Provide appropriate and comprehensible information.
- Find the "hook": work to understand and capture intrinsic interests and motivations.
- Provide incentives.
- Give parents options to make decisions among methods and communication styles.
- Emphasize questions and the constructs in thinking about how to gain input on the methods.
- Create a comfortable and safe space.
- Keep it short.
- Use social narratives to prepare for conversation.
- Use visual supports and materials, such as photos, to decrease anxiety.
- Restrict conversation to concrete experiences (here and now).

*Do these look familiar to you?  
Are they methods you have used?*

		Communication Output			
		Oral Language	Sign Language and Gestures	Written Text	Image-Based
Primary Method	Questionnaire/Summary	●		●	●
	Interview	●	●	●	●
	Group Discussion	●		●	●
	Narrative	●		●	
	Diaries	●		●	●
	Art				●

Tesfaye, R., Courchesne, V., Yusuf, A., Savion-Lemieux, T., Singh, I., Shikako-Thomas, K., ... & Szatmari, P. (2019). Assuming ability of youth with autism: Synthesis of methods capturing the first-person perspectives of children and youth with disabilities. *Autism*, 1362361319831487.

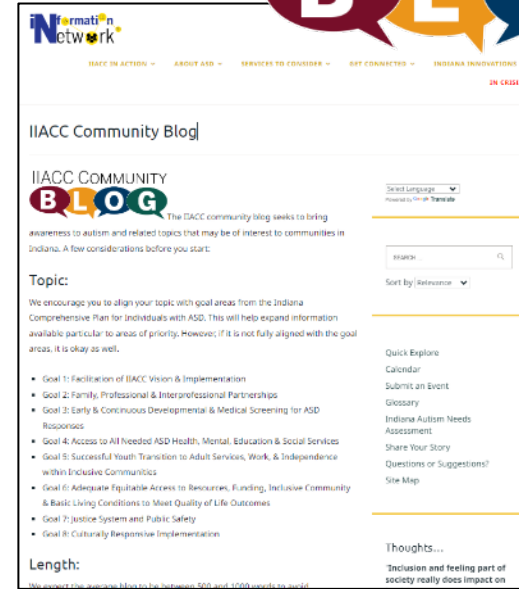


# ANNUAL IIACC Focus AREAS

## 2024 AREAS IN FOCUS SAMPLE



<https://indiananetwork.org/iacc-guidelines-reporting/>



**@IndianaIACC**



**Blog spotlight:**  
Podcasts & resources



HANDS IIACC and LCC Impact

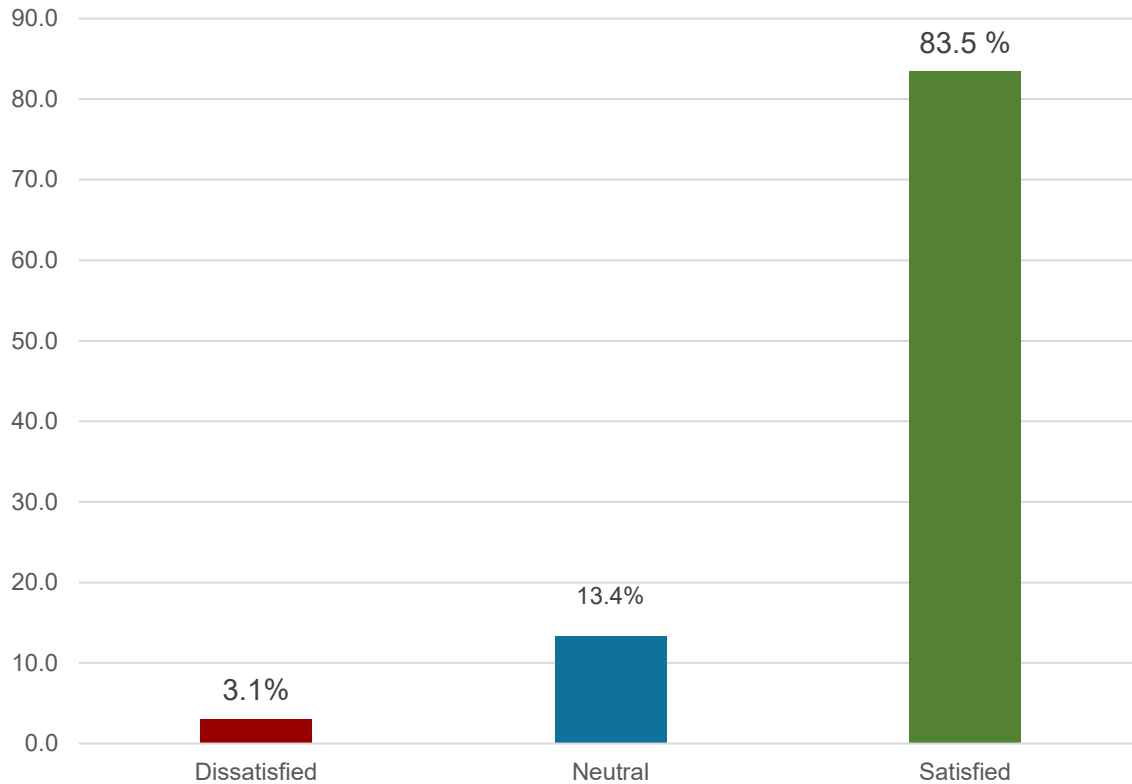
# INDIANA INTERAGENCY AUTISM COORDINATING COUNCIL (IIACC) & LOCAL COMMUNITY CADRES (LCCs)





# IIACC Impact

IIACC Quarterly meeting Satisfaction (2018-2024)



IIACC Vision & Implementation  
**Goal 1**

Family and Professional Partnerships  
**Goal 2**

Early & Continuous Screening  
**Goal 3**

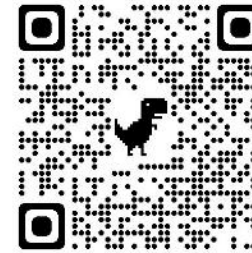
Access to Diverse Services  
**Goal 4**

Transition to Adulthood  
**Goal 5**

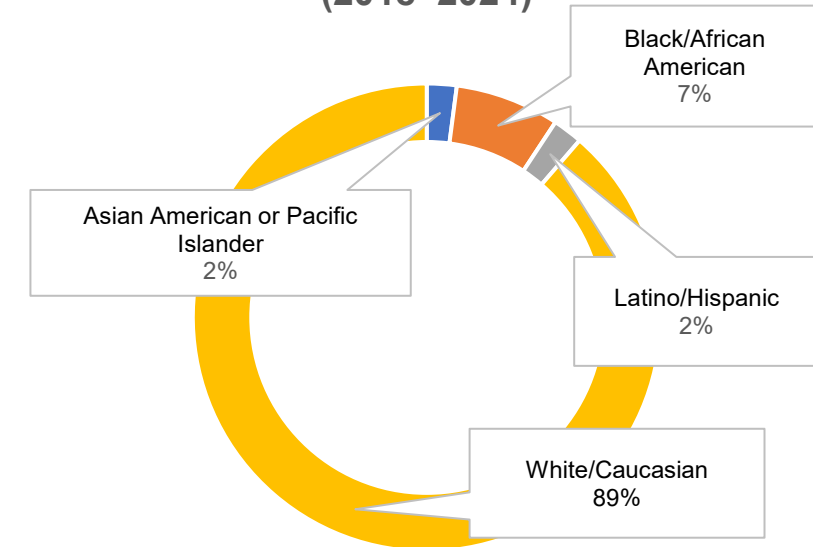
Equitable Access & Quality of Life  
**Goal 6**

Justice & Public Safety  
**Goal 7**

Cultural Responsivity  
**Goal 8**

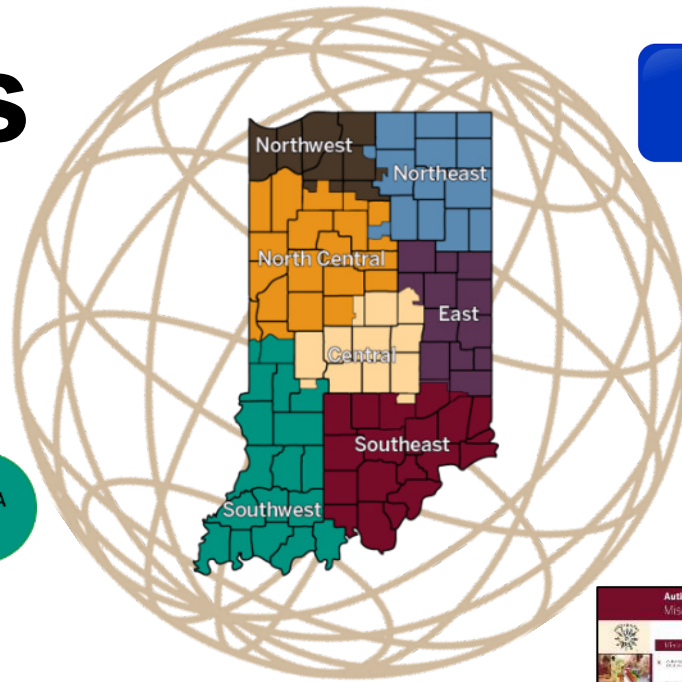
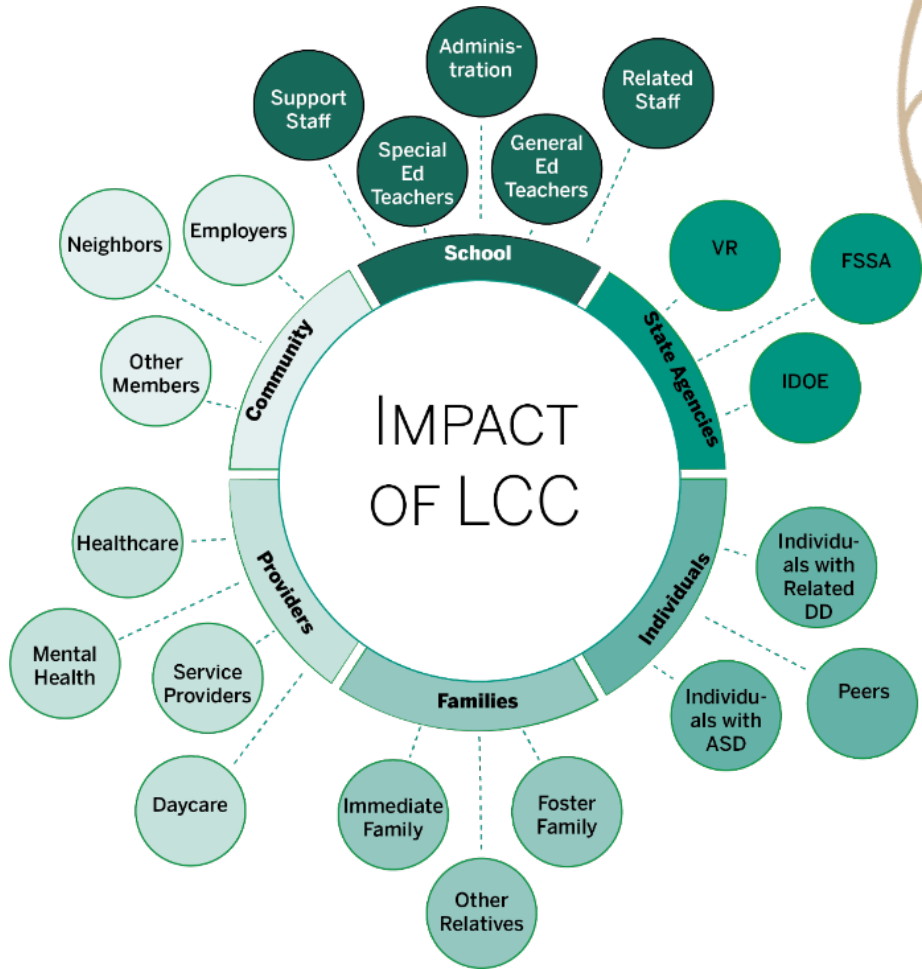


IIACC participation-Race distribution percentages (2018-2024)

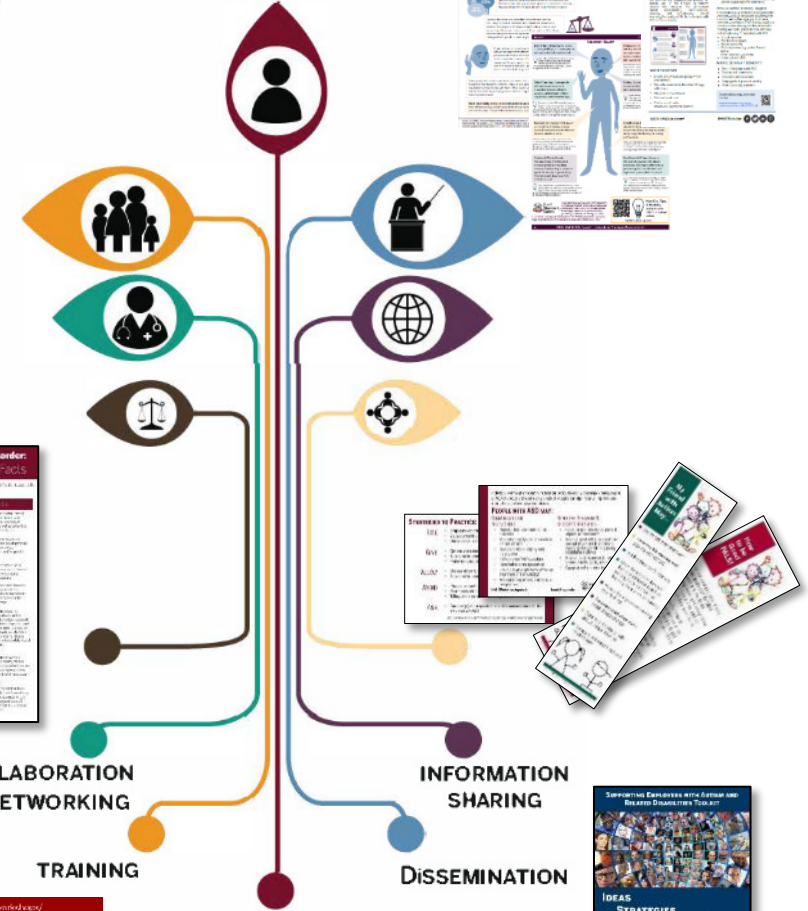
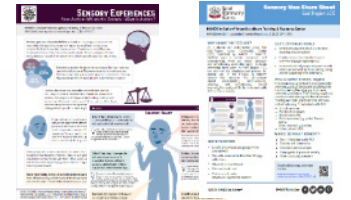




# Impact of LCCs



Tell us about Tuesday Friends & Networking Friday



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IIACC and LCC Panel Discussion

# VOICES OF THE IIACC AND LCC: FOSTERING INCLUSION, INTERSECTIONALITY, & KNOWLEDGE TRANSLATION



# HANDS Local Community Cadre

## VOICES SHARED OVER TIME AND FINDING A PLACE

1

### Questions and themes among panelists:

- Why do you engage in these efforts?
  - Vision for a better future
    - “...want it to be different for others than it was for him”
    - “...can’t imaging a better future than one where he is able to influence that”
  - Education and awareness
    - “The more we can educate with [our] lived experiences the more can fit in though not fitting in a box or tiny box but in a spectrum of boxes/spaces...”
  - Connection and communication
    - “...brings about consistency and recognize faces and allows to relax in friend mode and friendship with that activity. Even if not want to go, it pops up in email and know can talk about topics of interest and will see other neurodiverse individuals.”

# HANDS Local Community Cadre

## VOICES SHARED OVER TIME AND FINDING A PLACE

2

### Questions and themes among panelists:

- How do you feel your voice being heard and elevated?
  - Active participation
    - “...knowing what have to say will have an impact. Others on the call are taking things said to heart and taking notes and going to apply to their practice and who they are going to serve...”
  - Welcoming environment
    - “...situation where people aren’t expecting or demanding social normity. It is a more welcoming environment and I don’t have to try so hard - say this, say that, not do those things.”
    - “...feel humanized and that [joining is] worth the labor at that stage and supported.”
- Bridging vs dividing among participants
  - “...bridges instead of divisions. Discourse online comes from an understandable space.”

# IIACC and Let's Talk Registration



**LCCs**

Local Community Cadres (LCCs) are regional community networks of families and professionals invested in serving individuals affected by autism spectrum disorder (ASD) and related developmental disabilities.

**Mission**

To facilitate the sharing of information, training and resources that improve understanding and support of ASD and other disabilities through collaboration across community systems including, but not limited to:

- Family Members
- Service Members
- Individuals
- Advocacy
- School
- Judicial
- Medical

*Want to know more?*



[Local Community Cadre](#)

**Let's Talk LCCs**

**Local Community Cadres**

Calling all LCC members, whether you are returning, new or looking to learn more!

**SAVE THE DATES**

- July 11th, 12-1 pm EST
- August 8th, 12-1 pm EST
- September 12th, 12-1 pm EST

[HANDSinAutism.iu.edu/partnerships/community/community-cadres](https://HANDSinAutism.iu.edu/partnerships/community/community-cadres)



**QUARTERLY IIACC MEETING**

IIACC functions as a platform to enhance shared dialogue, understanding, planning, and goal-setting for autism services in Indiana.

In this session, we will be addressing GOALS 5 and 6!

- Transition to Adulthood **Goal 5**
- Equitable Access & Quality of Life **Goal 6**

**THURSDAY, SEP 5<sup>TH</sup>**  
**9-11:30 AM ET**  
 VIRTUAL-ZOOM  
 &  
 HANDS IN AUTISM CENTER  
 3002 WESTFIELD BLVD.  
 WESTFIELD, IN 46081

HANDS ECHO Overview

# HANDS DEVELOPMENTAL DISABILITIES AND AUTISM EXTENSION FOR COMMUNITY HEALTHCARE OUTCOMES (ECHO)

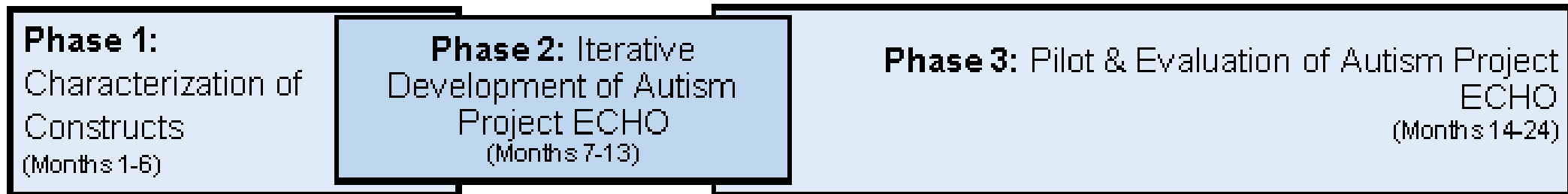


# HANDS DD & Autism ECHO

COMMUNITY-INFORMED, EVIDENCE-BASED TELE-MENTORING

**Intentional, community-based participatory research design:**

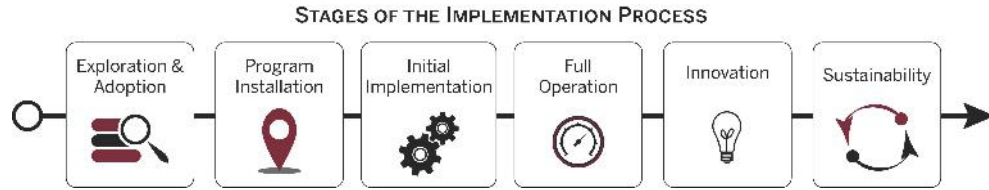
- Measures
  - *Exploring ASD through Lived Experiences (ASDLE; HANDS, 2020)*
  - *Exploring DD through Lived Experiences (DDLE; HANDS, 2022)*
- Multi-Modal Formats
  - Survey
  - Interview
  - Focus Group
  - Pilot Findings (see below visual for phased timelines in development and evaluation)



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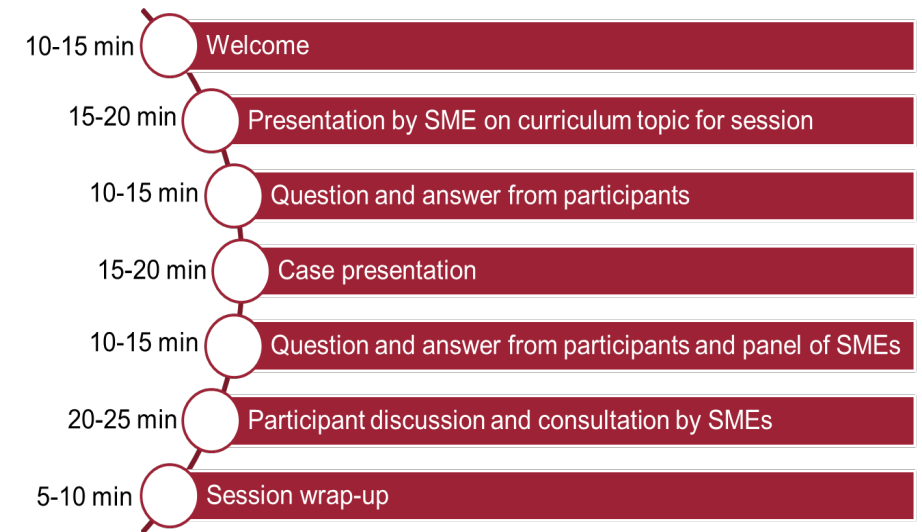


# The ECHO Model AND Session Overview



**From initial implementation to full implementation, innovation, and sustainability across series:**

- Healthcare
- Education
- Justice & Access
- Behavioral Foundations
- Community Provider
- Individuals & Caregivers



Arora (2008); Fixsen, Blasé, Duda, Naoom, & Van Dyke (2008).

HANDS ECHO Impact

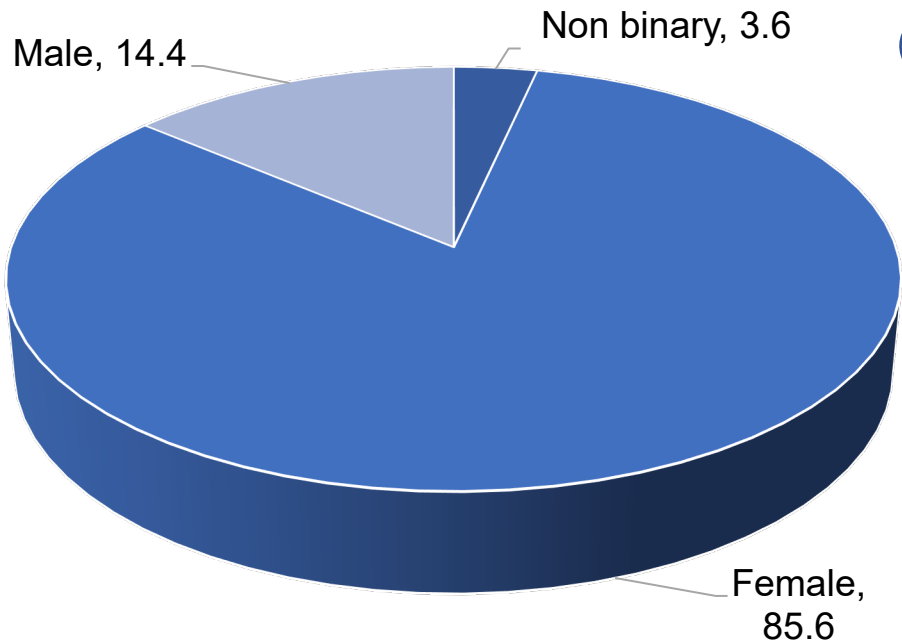
# HANDS ECHO IMPACT



# ECHO Impact

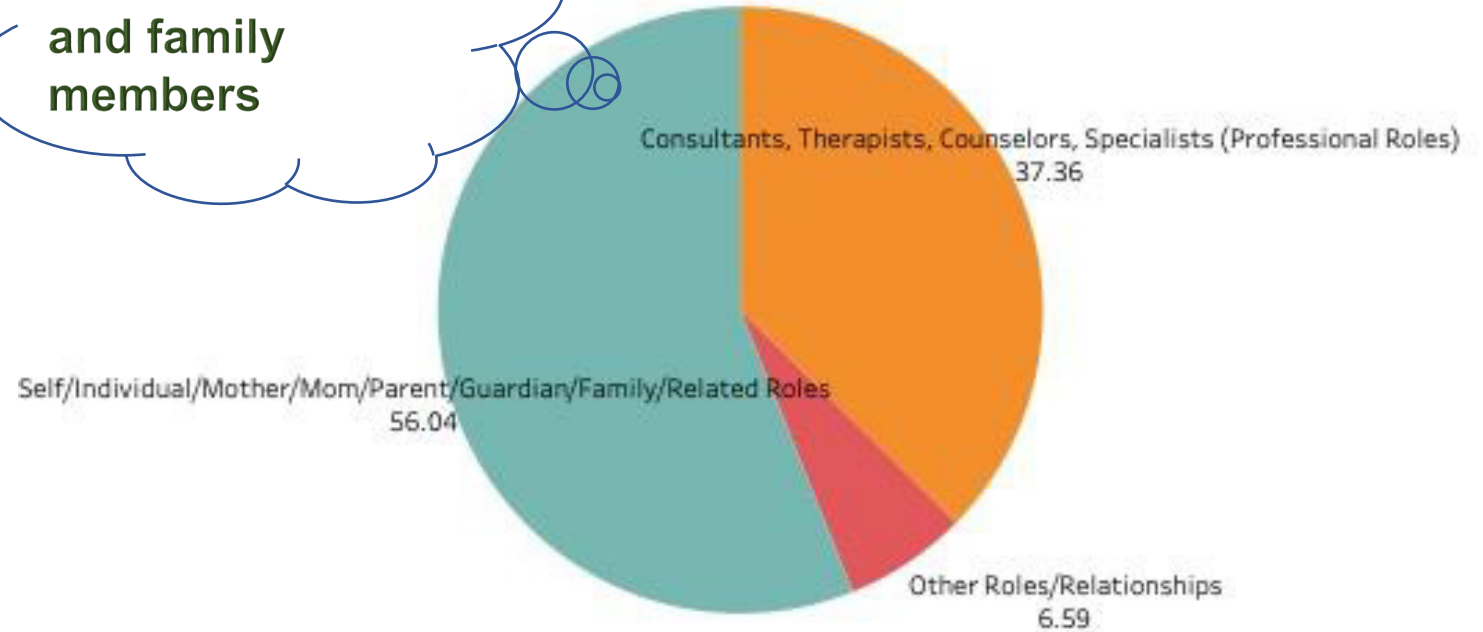
## GENDER AND ROLE DISTRIBUTION

Gender distribution-ECHO participants (2023-2024)

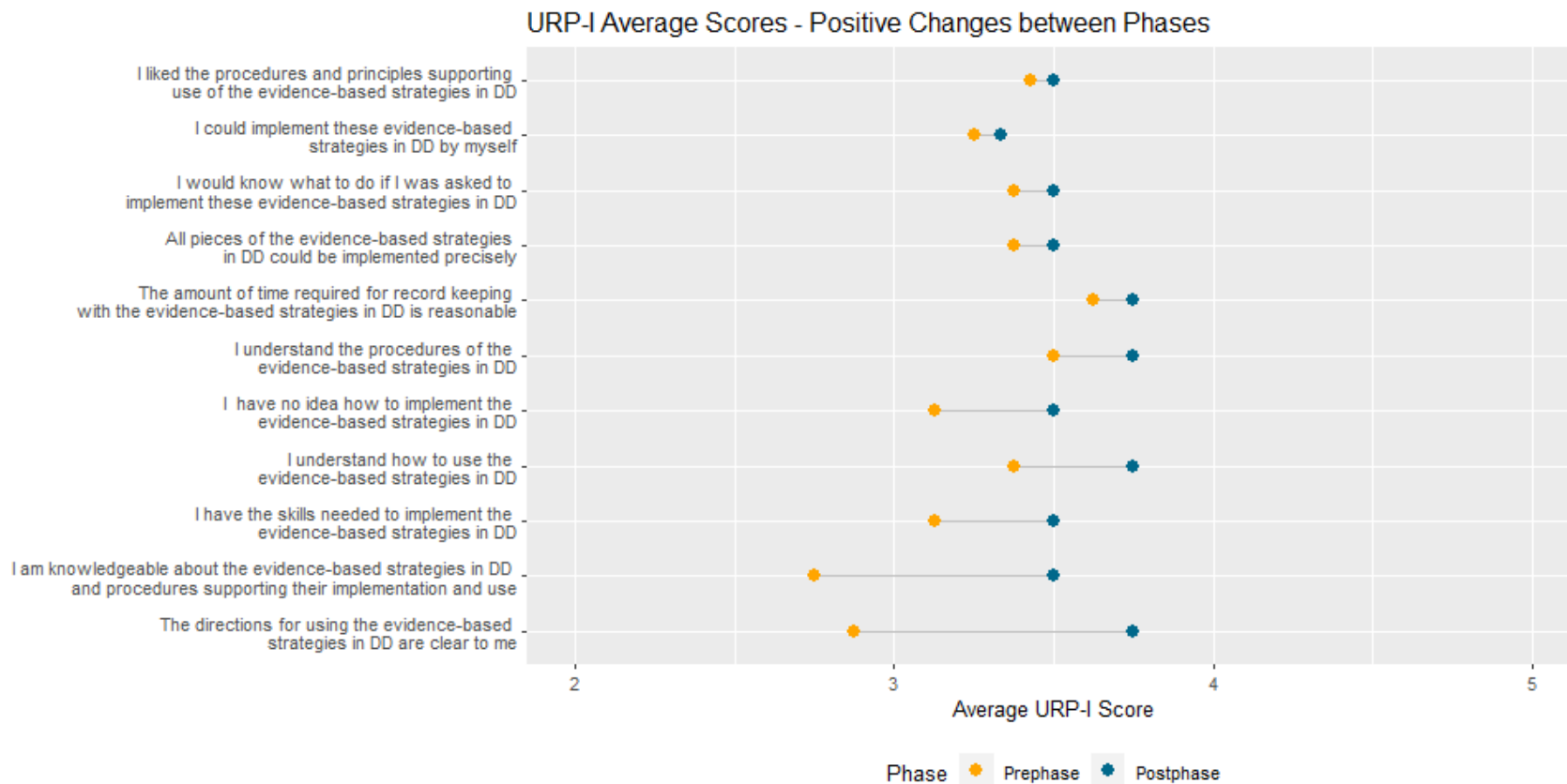


The majority of ECHO attendees are individuals and family members

Role distribution-ECHO participants (2023-2024)



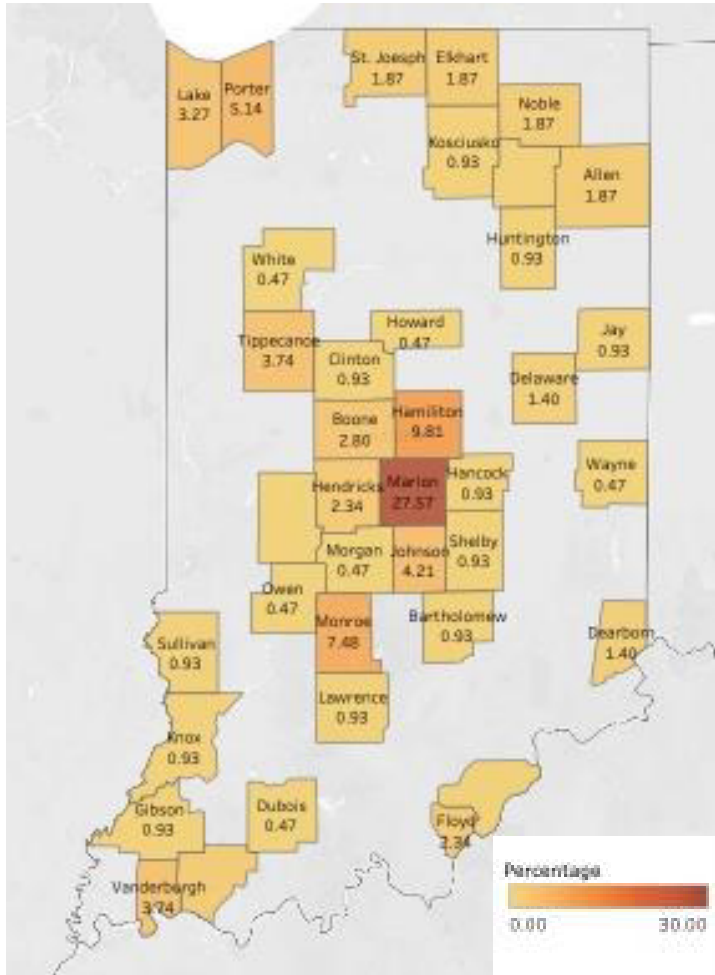
# ECHO IMPACT



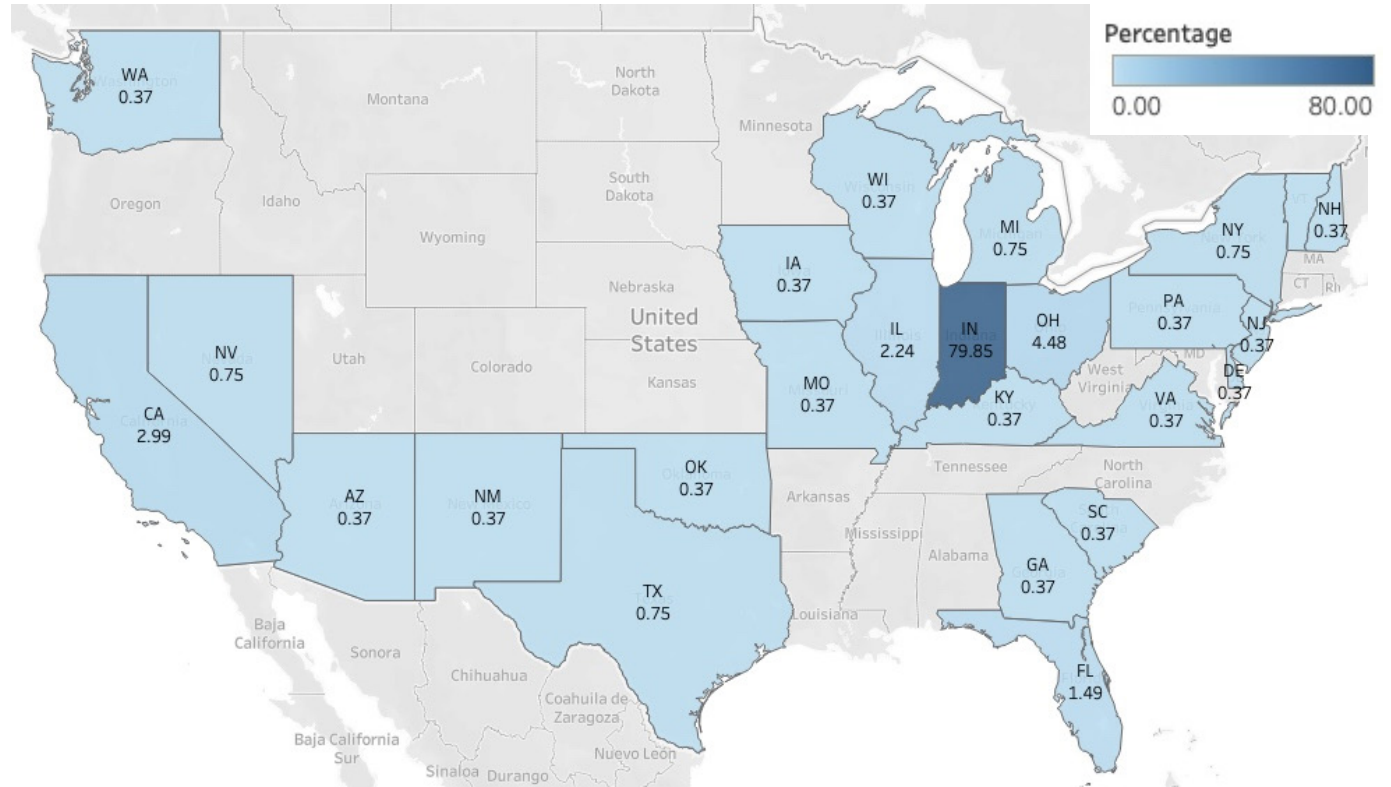
**Aggregate Changes to URP-I Scores Between Phases.** Average URP-I scores, ranging from one (disagree) to six (agree) were calculated for each question before and after participation in the ECHO program. Several scores increased, most significantly regarding knowledge and clarity about implementing evidence-based strategies.



# ECHO State and Local Impact

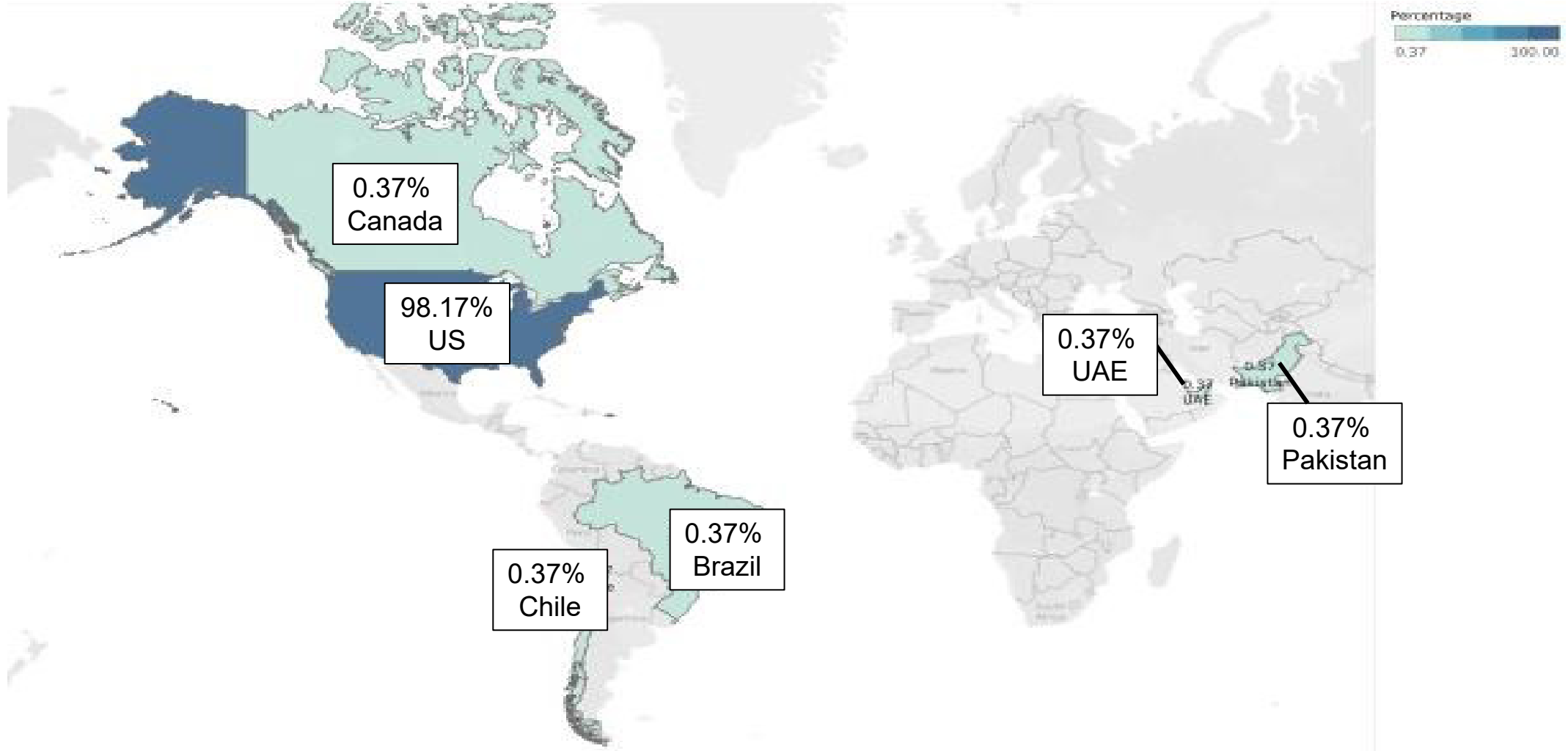


County-wide distribution of ECHO participants(2023-2024)



State-wide distribution of ECHO participants (2023-2024)

# ECHO Global Impact



Country-wide distribution of ECHO participants (2023–2024)

ECHO Panel Discussion

# HANDS DD & AUTISM ECHO PANEL





# HANDS DD and Autism ECHO

ALL TEACH, ALL LEARN MISSIONS ELEVATED BY VOICES OF THOSE WITH LIVED EXPERIENCE

3

## Questions and themes among panelists:

- What would further enhance these experiences?
  - Discussion and dialogue time
    - “...love format that always a discussion. Within the ethos that there is an opportunity to have discussion. Most times, people give a talk and then there is only 5 minutes of discussion. Not only allowed to say “I actually disagree with that” and there is time built in to disagree or agree and come back around. Recommend that the lesson part is shorter and discussion time is longer.”
    - “...how soak up is thru interactive dialogue; Basically ,soak up from others. “
    - “...talked to and supporting and hearing and learning from each other makes information just soak up and becomes engrained and learn from many voices and much more enriching.”
  - Planning for sustainability
    - “...seeing new faces and fresh people. Continuing to see it grow! Good programs tend to run out of funding before they can make a full difference. Longevity helps with new voices. Not have a lot of patience but have patience with new voices.”

# HANDS DD and Autism ECHO

ALL TEACH, ALL LEARN MISSIONS ELEVATED BY VOICES OF THOSE WITH LIVED EXPERIENCE

4

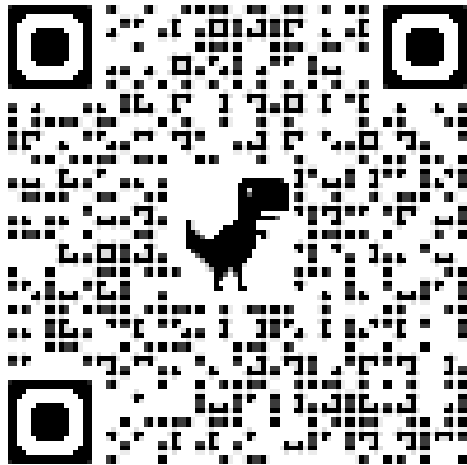
## Questions and themes among panelists:

- What recommendations do you have for others who have had a similar offerings or are working to be more inclusive?
  - Accessibility
    - Virtual and in person options – “more statewide expansion for both virtual and in person.”
    - Urban but also local – “not get a lot of connection with local community.”
    - Size – “like to do all virtually and have a bit of agoraphobia. I like idea of a small educational luncheon to get together.”
    - Timing – “...have some groups available but they meet during the day.”
  - Lifespan considerations
    - Adults – “...find myself envious of children now as working to setup kids for lifelong friends.”
  - Representativeness and connections
    - Level of support – “...the more severe the disability the more severe the isolation.”
    - Neurodiversity – “...often have no connection with non-disabled peers in school and you’re lucky if you have any such friends.”

# ECHO Registration and Supports

Register here to join our ECHO sessions:

[https://iu.co1.qualtrics.com/jfe/form/SV\\_b2uslWtbcHiDuR0](https://iu.co1.qualtrics.com/jfe/form/SV_b2uslWtbcHiDuR0)



and Autism Project ECHO:

[asdecho@iupui.edu](mailto:asdecho@iupui.edu)

A blue rectangular graphic with a black border. At the top center is a glowing yellow lightbulb with four question marks around it. Below the lightbulb, the text 'DID YOU KNOW?' is written in large, bold, black letters. Underneath, a paragraph of text describes the ECHO series.

**DID YOU KNOW?**

The HANDS in Autism Extension for Community Healthcare Outcomes (ECHO) series aims to educate community providers, healthcare providers, educators, families, consumers, and other participants on developmental disabilities, such as autism spectrum disorder, through virtual sessions.

## Conclusion and Impact

# CONCLUSION AND IMPACT



*“This is the first service we’ve had that immediately provides materials needed to implement, make needed materials onsite, and works shoulder to shoulder with my staff! Excellent service!!!”*

*“The insight and knowledge of staff was invaluable in observing and learning/learning to practice new skills.”*



**Request an informational packet!**



**Questions?  
Interested in learning more  
or partnering?**

# Thank you!

## We look forward to staying in touch!



HANDS in Autism



handsinautism



HANDS in Autism®



@HANDSinAutism



# Q&A



 [www.ktdrr.org](http://www.ktdrr.org)

 [ktdrr@air.org](mailto:ktdrr@air.org)

 800.266.1832

Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**