



Mind the Gap: A Caregiver Support Intervention following a New Developmental Disability Diagnosis

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AIR-B-IV Network

University of California



University of Pennsylvania



UC Davis



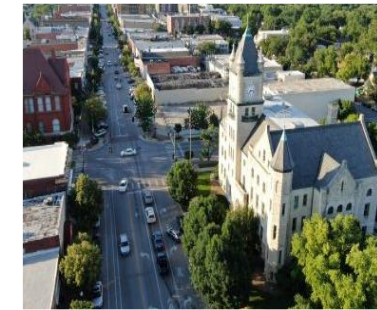
University of Rochester



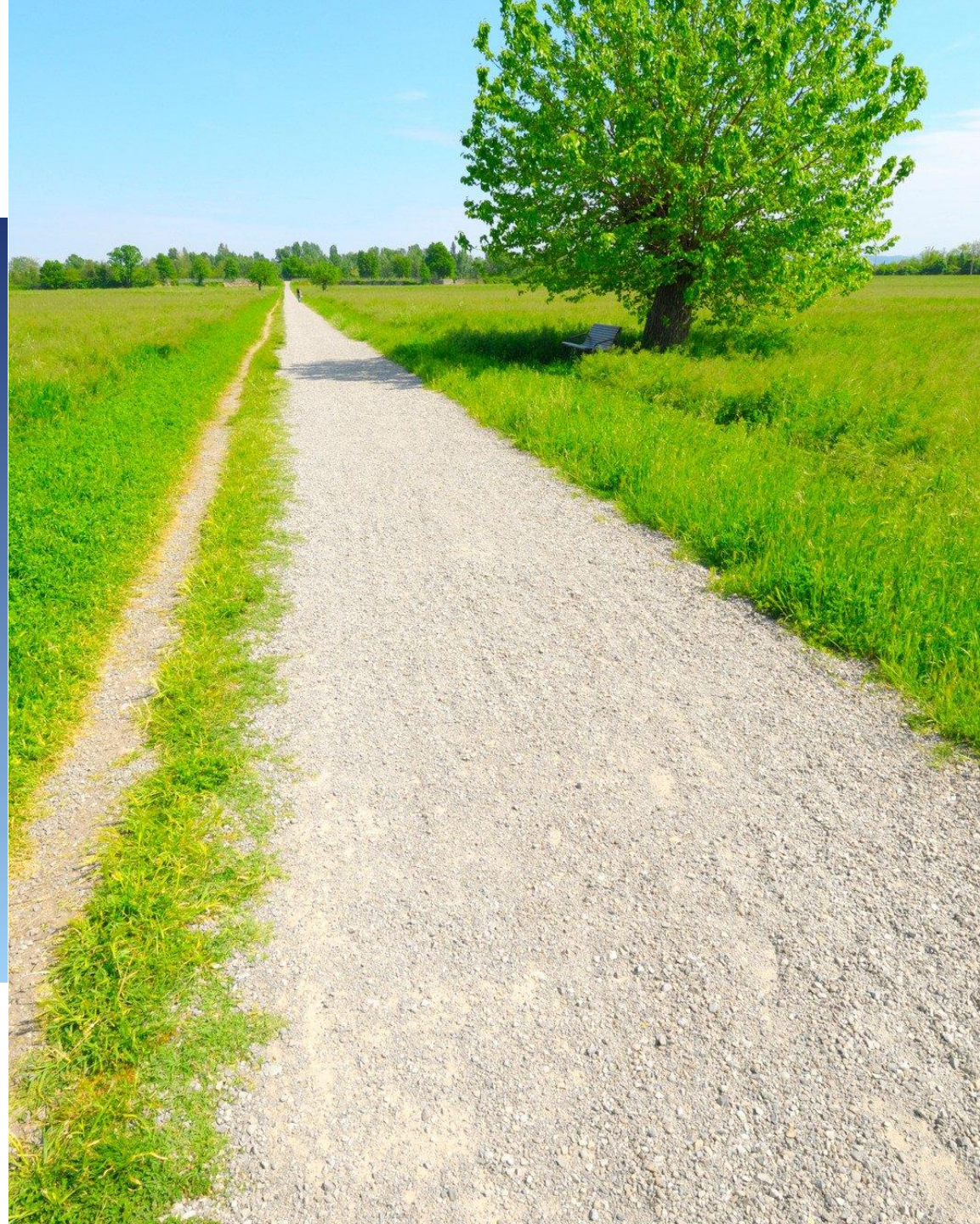
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Caregiver Support Needs



Disparities in Autism Spectrum Disorder



Race & Ethnicity



Language



Income



Create something new



Importance of Partnership



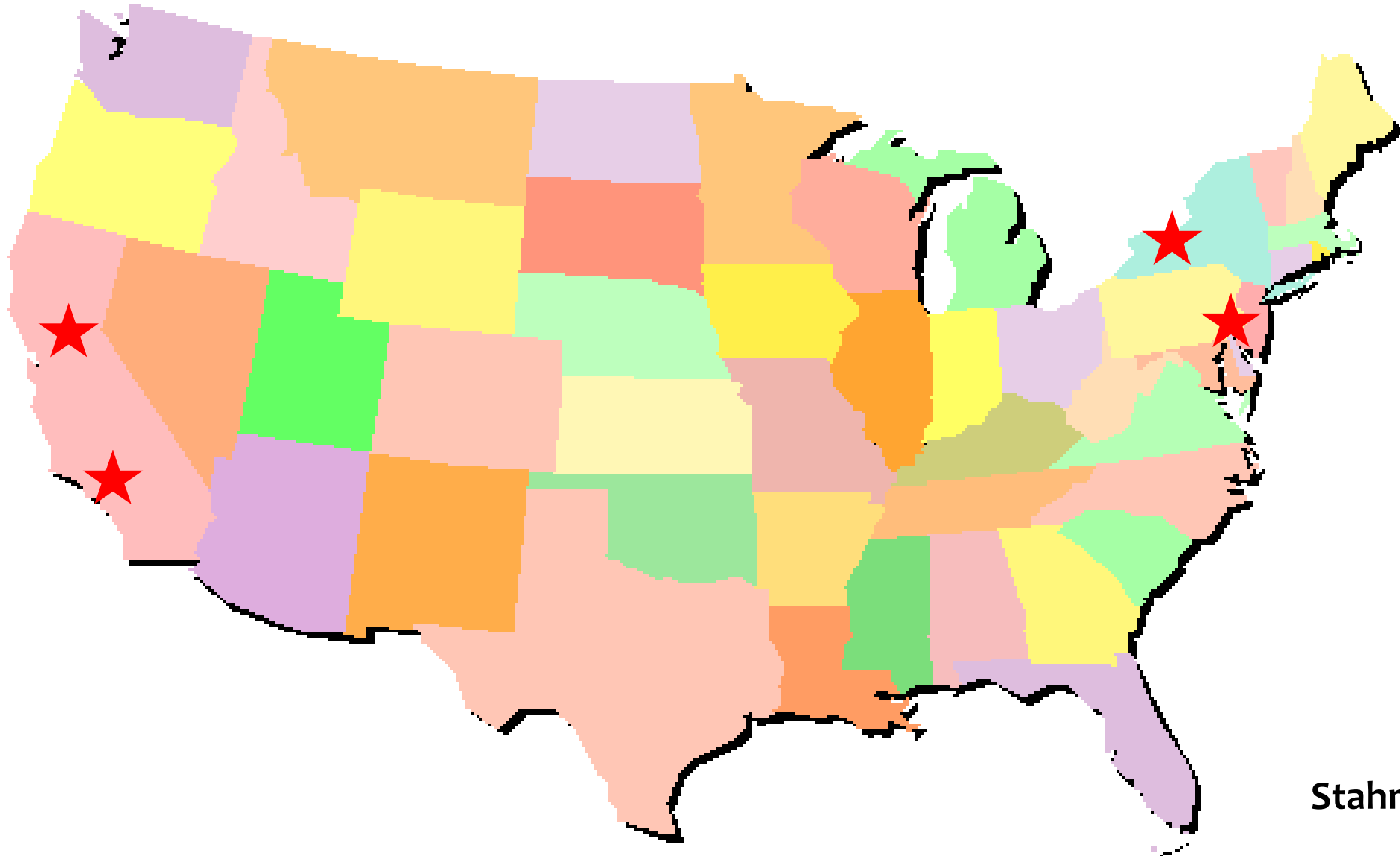
Engaging parents in Tx leads to child improvements (Dowell & Ogles, 2010; Kazantzis, Whittington, & Dattilio, 2010; Haine-Schlagel & Walsh, 2015).

Increasingly true for Tx for children with ASD (Green et al., 2010; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Stadnick, Stahmer, & Brookman-Fraze, 2015; Wetherby et al., 2014).

Identification of Priorities



Focus Groups



Difficulties with **service access** post-diagnosis



Cultural Sensitivity

“But I think that if we're focusing on minorities...I think that [cultural matching] helps because they could understand but [as a professional] she might also be compelled to understand as well.”



Peer Support

“It’s a lot different hearing [information] from somebody who is just like you, than hearing it from a practitioner.”

**Hear from experts – why
are these important?**



MiND THE Gap

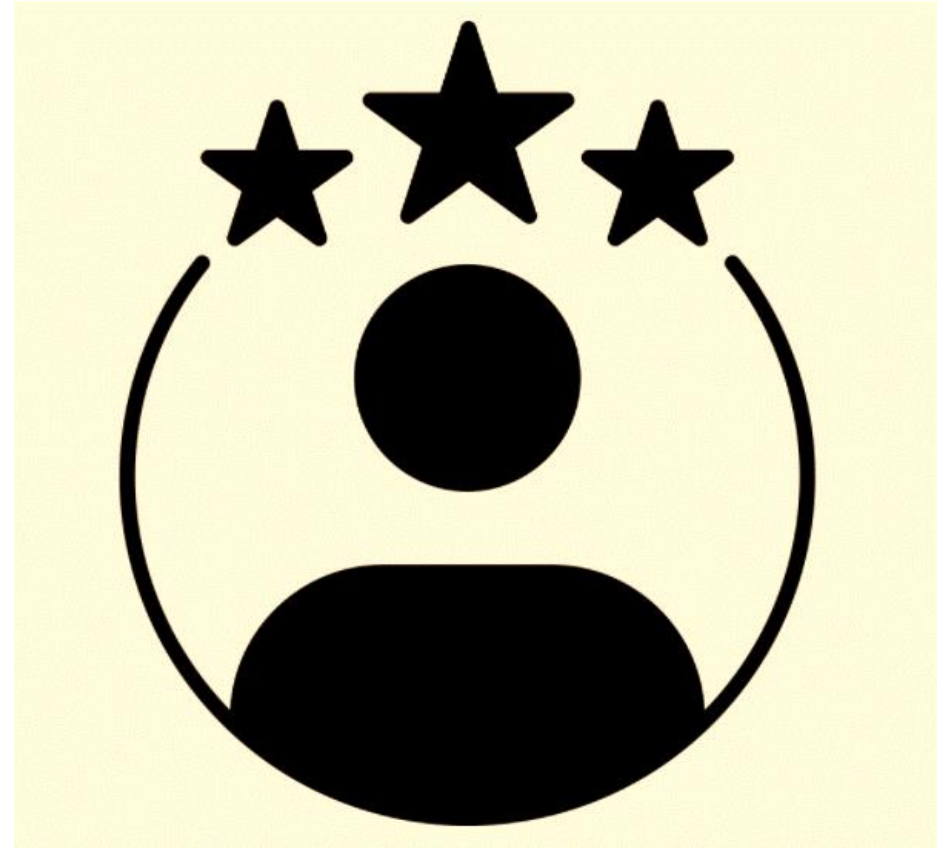
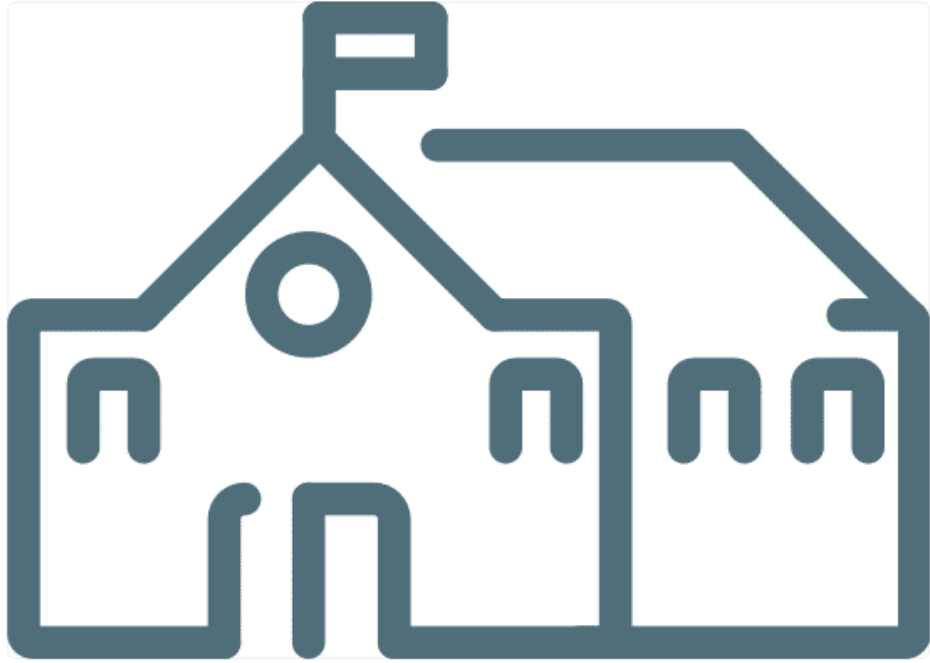


A COMMUNITY PARTNERED INTERVENTION

Co-development of Program



Service Access and Family Power



Foundational Modules



What is
ASD



Navigating
the System



Additional Module(s)



Parent rights and advocacy



Insurance Rights



Coping and Stress Management



Challenging Behavior



Communication



Addressing Stigma

Information Shared via Coaching Model:

12 sessions (i.e., points of contact) over 4 months

- Calls or Zoom once per week
- In-person visits once per month (convenient location)

ALL AS IDENTIFIED BY THE PARENT



Trusted Community Members



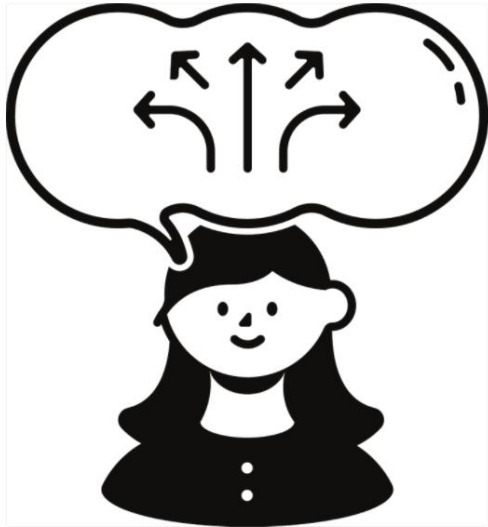
Peer Coaching/ Navigation Model: Other parents of children with ASD/ related disabilities



Increase trust and reduce feelings of isolation (dosReis et al., 2010; Woodgate et al., 2008)

Social support protective against stress (Lovell & Wetherall, 2012)

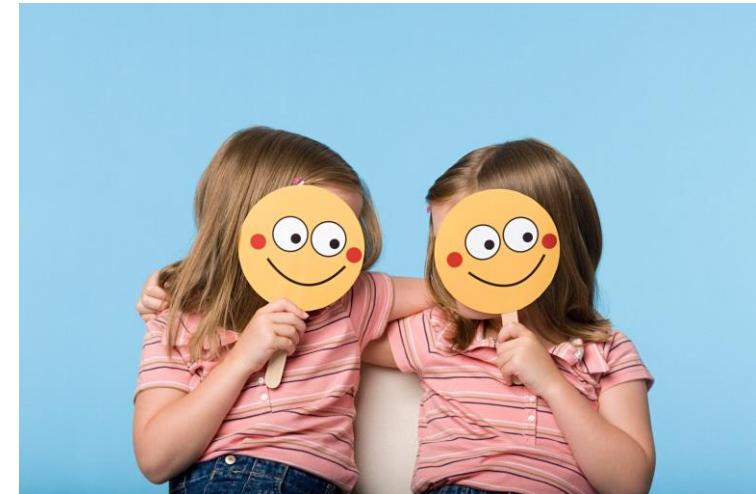
Flexibility: Scheduling, Communication, Parent- Led



Translation: English, Spanish, Korean



Coach Matching



What was it like to be a peer navigator?



Does it work? Testing and refinement



Feasibility Study—Can we do it?

Recruitment/Retention

Coaches' use of the model to fidelity

Satisfaction



Iadarola et al., 2020





Retention: 78% completion rate

Fidelity: 83% adherence to the Mind the Gap procedures

Satisfaction: Good satisfaction (3.9 on a 4.5 scale)

Sessions Attendance

	# Sessions Attended	% Sessions Attended
Family 1	11	92
Family 2	12	100
Family 3	4	33
Family 4	12	100
Family 5	12	100
Family 6	12	100
Family 7	8	67
Family 8	1*	8
Mean (SD)**	10.1 (3.1)	84.5 (25.7)



Refinements for larger study based upon feedback:

Increase flexibility of sessions

Improve coach/family match

Simplify data collection

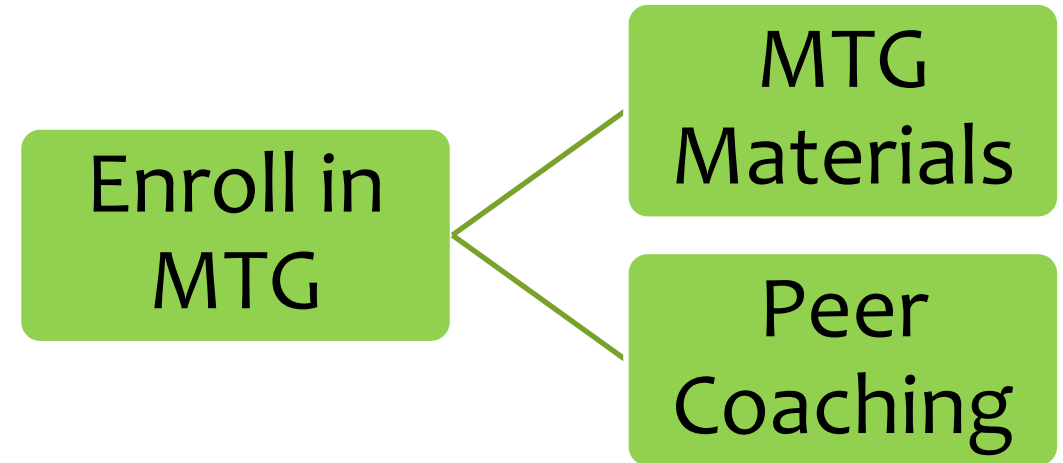


Large Scale Study



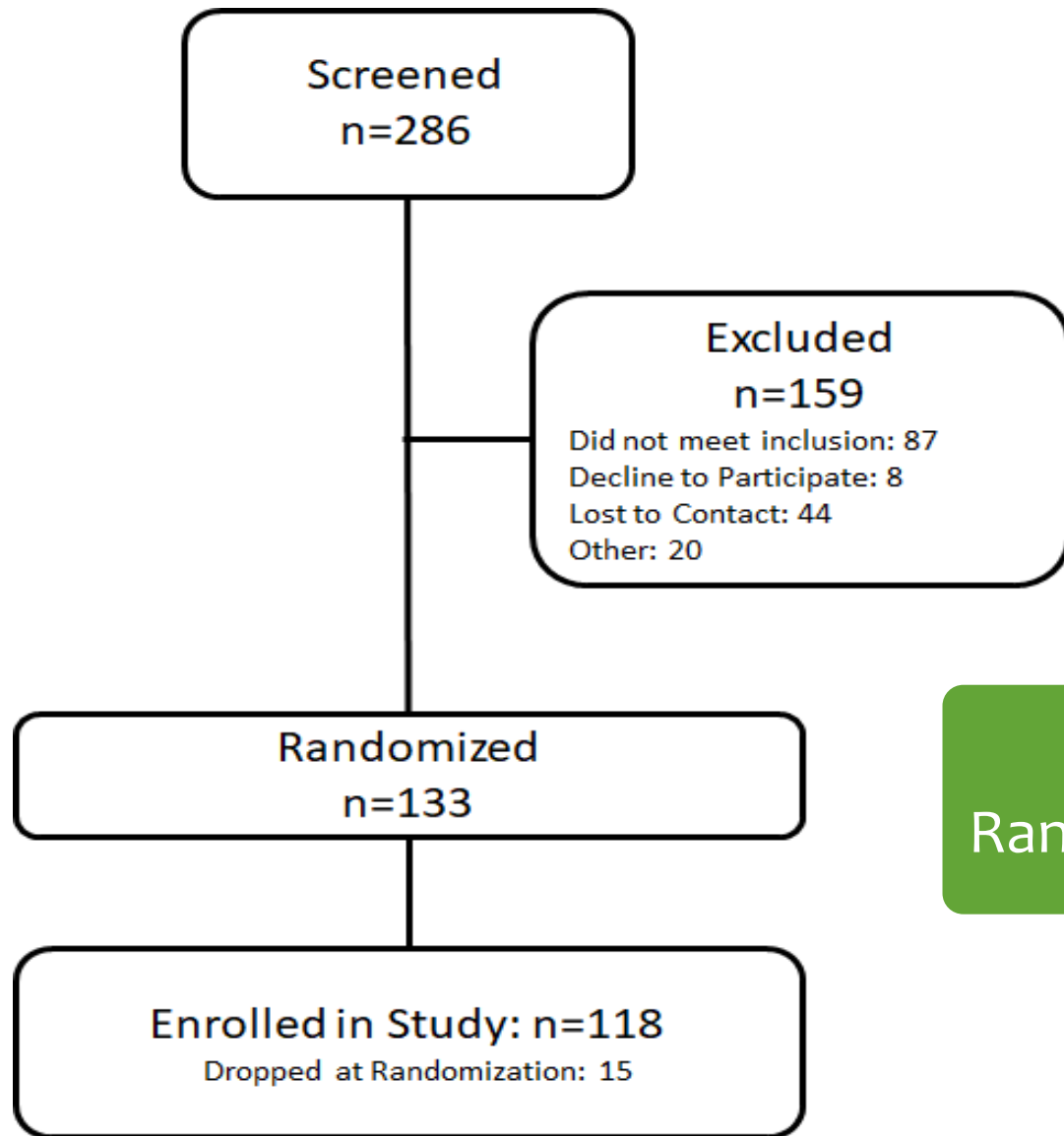
Enroll families

- **With child (<9 years) with new ASD diagnosis**
- **At or below 250% of federal poverty line (based on household)**
- **English, Spanish, Korean speaking**



**Randomize to *MTG Materials only*
OR *MTG with Peer Coaching***

Primary reason for not meeting eligibility:
Income too high



Measure	Construct
Caregiver Agency Scale	How often caregiver engaged in activities promoting child's development
Autism Knowledge Scale	Knowledge of autism re: diagnosis, characteristics, interventions
Social Dynamics of Intervention (SoDI)	Interview with caregiver about social network supporting their child
Service Access	Interview with caregiver regarding new services/ waitlists accessed

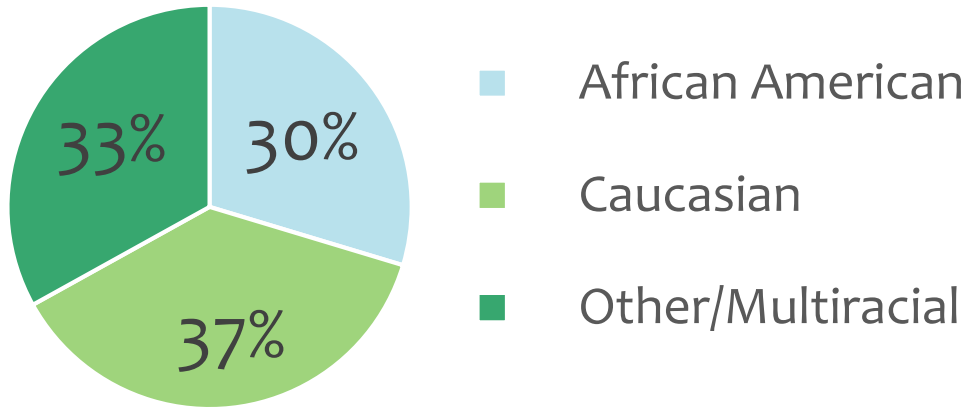
Data and Characteristics *before* getting MTG (entry)

What do we know about caregivers just following a new diagnosis?

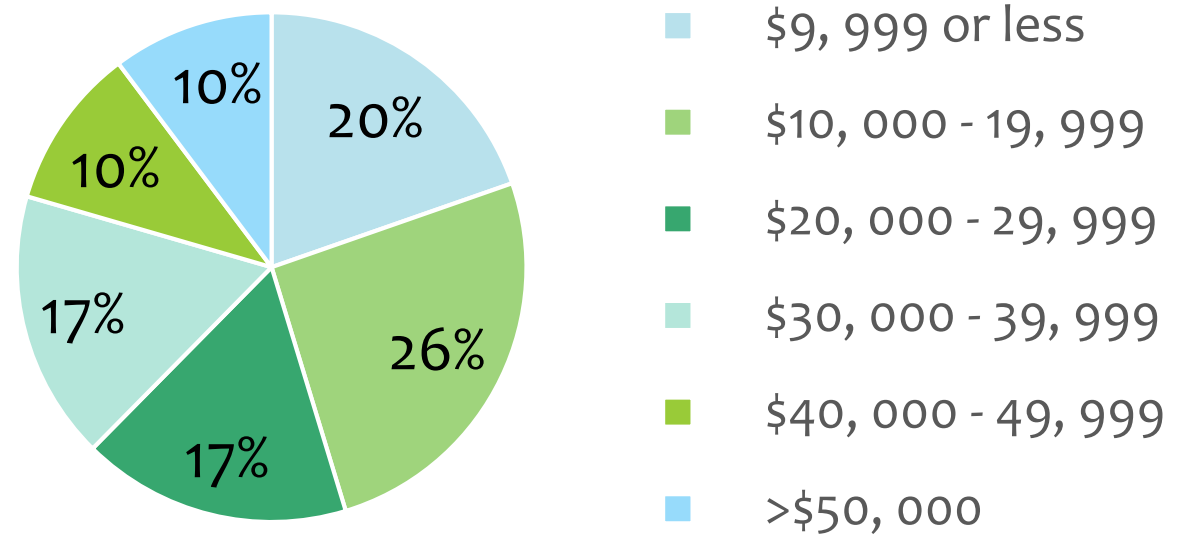
What do we know about how different factors affect service access?

- Primary language spoken in the home
- Caregiver social network size
- Caregiver knowledge
- Caregiver agency

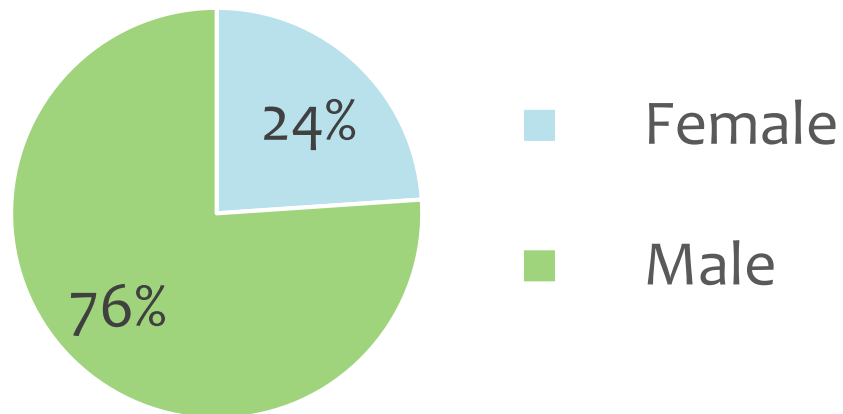
Family Race



Family Income



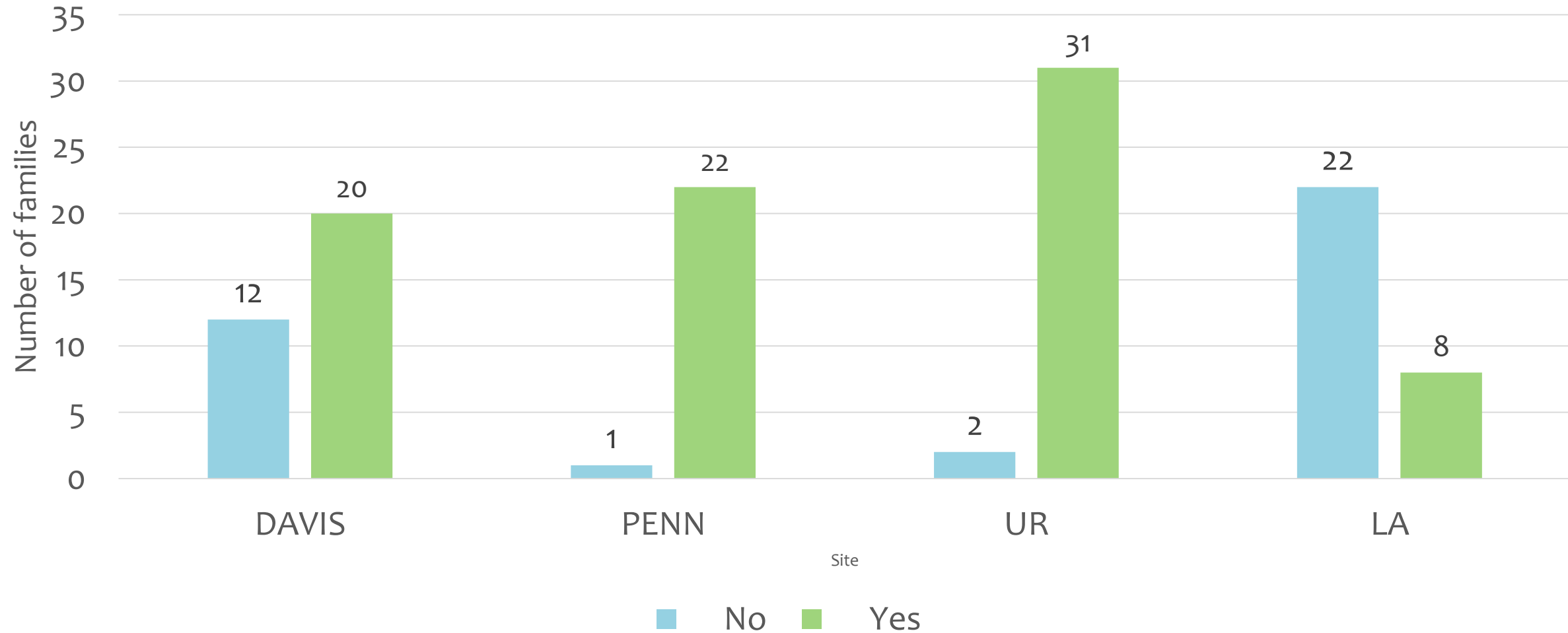
Child's Gender



Who did we reach?

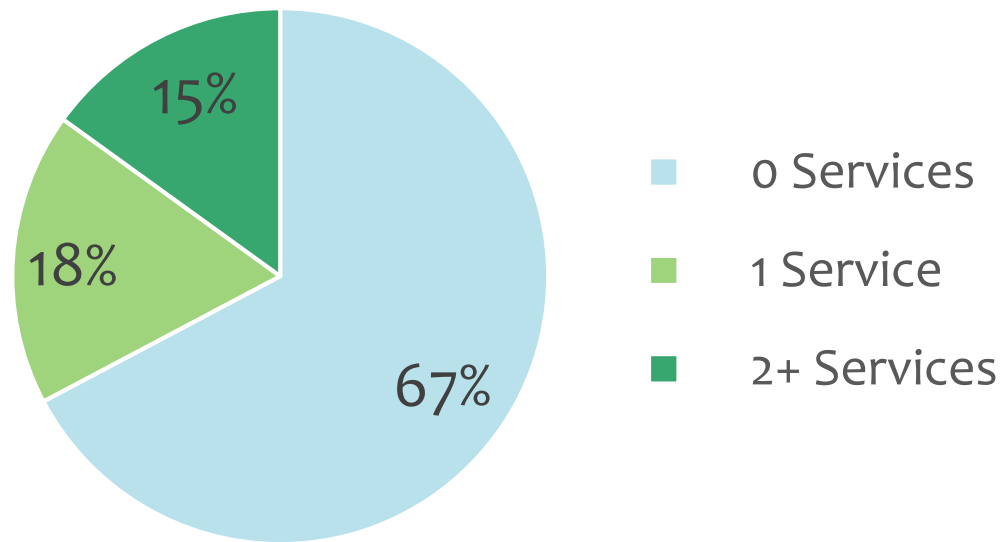
Who did we reach?

English as Primary Language



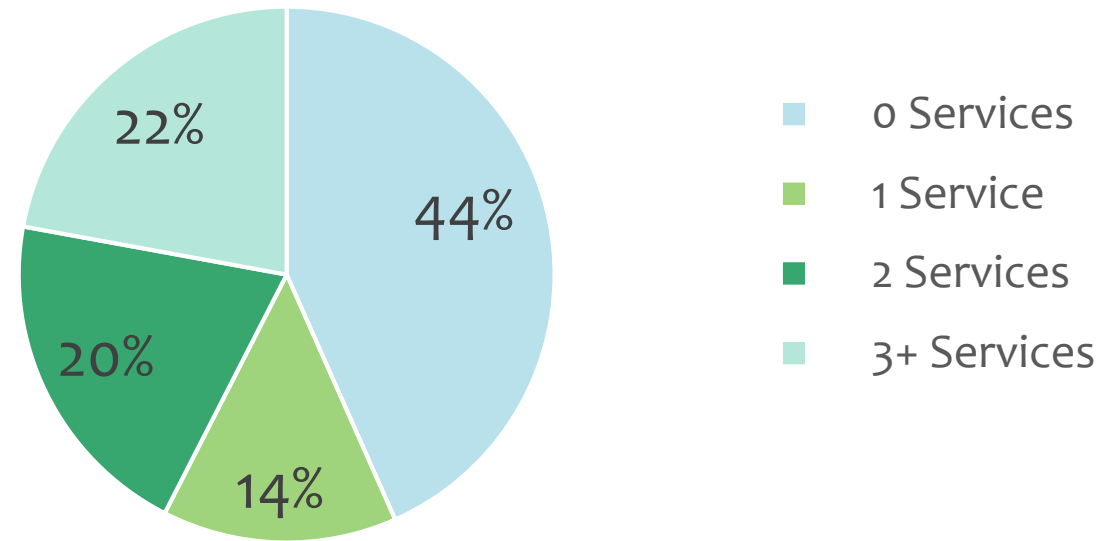
Mean number of services received = 1.95 (SD = 1.54)
87% receiving at least 1 service

Community Services Recieved



M = .67 (SD = 1.11)

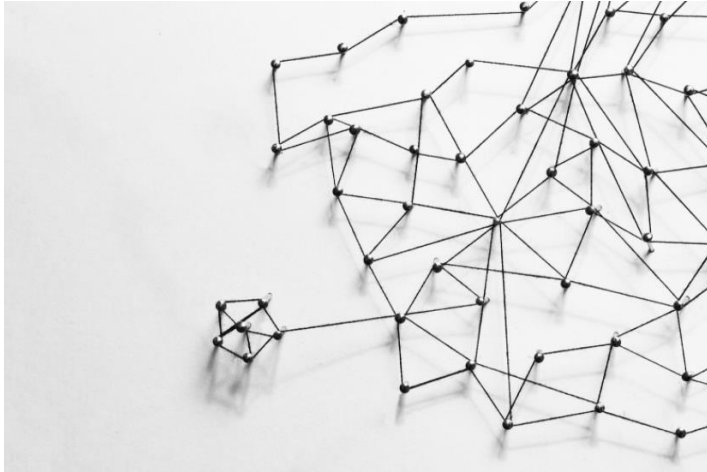
School Services Recieved



M = 1.34 (SD = 1.46)

Total Number of Services

PREDICTIVE



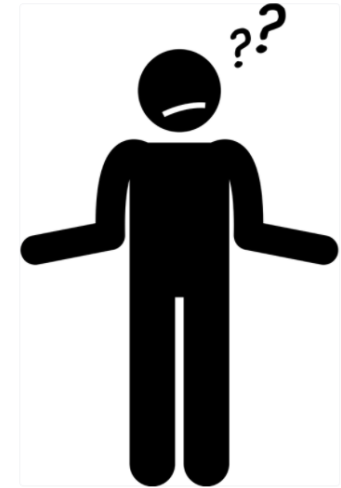
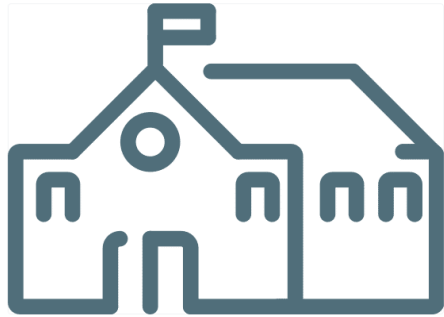
Peer support networks (p=.011)
Mean network size = 5.15 (2.41)
agency

NOT PREDICTIVE



Language, race,
ethnicity, knowledge,

Split the Sample



Families with at least one service....

At one site (UCLA), *non-English speaking* families had more services

At all other sites, *English speaking* families had more services (p=.06)

Successful in recruiting a
very diverse sample
Social networks matter!
Language disparities upheld
at 3 of 4 sites
Partnership and
consideration of
implementation yielded
high engagement and set
us up for a next phase



A low-angle, upward-looking photograph of a forest. The image shows several tall, slender tree trunks that converge towards the top center of the frame. The foliage is dense and green, with some sunlight filtering through, creating a dappled light effect. The sky is a clear, bright blue, visible through the canopy. The overall composition emphasizes the height and verticality of the trees.

Time to scale up!

Implementation Science Study



MTG Refinements

- **Expanded beyond ASD**
- **Languages**
 - Spanish, Korean, Chinese, Punjabi
- **Virtual model, including PN training**

Must compare two approaches to MTG. Agencies get *either*:

Mind the Gap as usual

OR

“UNITED”

Using Novel Implementation Tools for Evidence-Based Delivery



MiND THE Gap

Everyone gets.....

To identify a team that will help with Mind the Gap

Mind the Gap materials (in multiple languages)

Virtual training for peer navigators

Coaching for peer navigators and monthly peer supervision

Assistance with needed materials and resources



“UNITED” ALSO GETS

Additional sessions with the agency’s leadership team

Two initial team sessions to create an action plan for Mind the Gap

Monthly sessions with the agency’s leadership team to do things like...

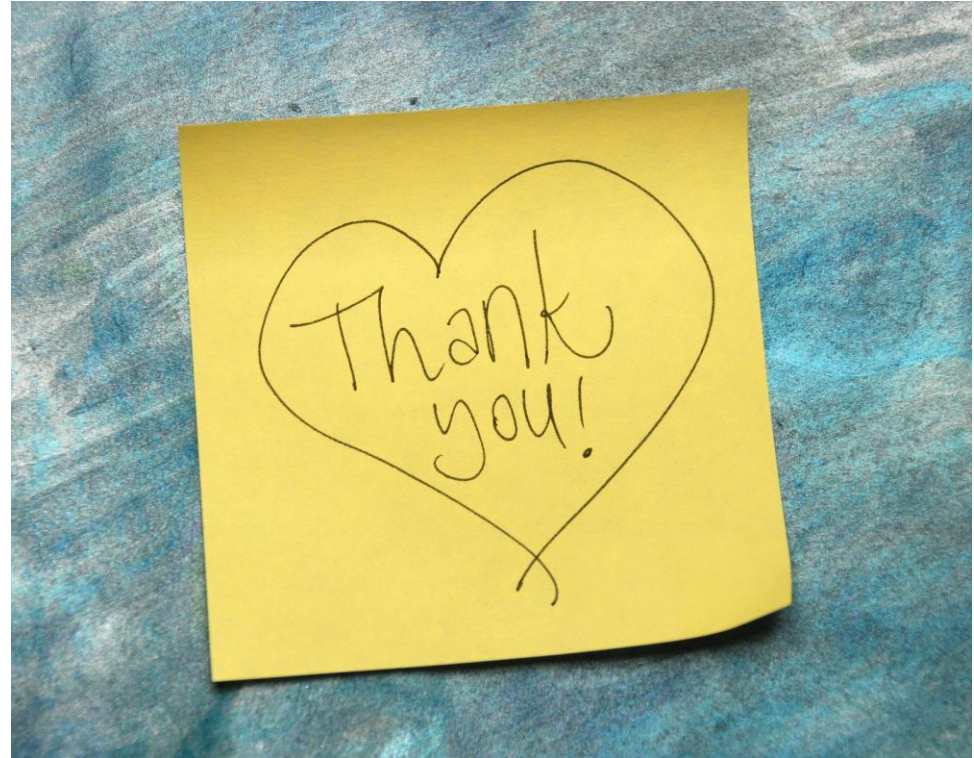
Problem-solve around any issues with Mind the Gap

Change the action plan as needed

In progress...



AIR-B AUTISM INTERVENTION RESEARCH NETWORK ON BEHAVIORAL HEALTH



FAMILIES, PROVIDERS, RESEARCH TEAMS, AGENCY PARTNERS

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Photos obtained via Canva