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Supporting Caregiver Engagement in Autism Early Interventions: A Mobile Health Approach

Yue Yu, PhD

UCLA Tarjan Center Lecture Series

May 11, 2026



Agenda



Importance of caregiver involvement



Barriers to caregiver engagement



Strategies in supporting caregiver engagement



FANS-EI

Caregiver-Mediated Early Intervention for Autism



- Children under 3 with autism eligible for EIs (IDEA Part C)
- EIs target social engagement, communication, imitation, and play skills
- Best practice



Importance of Caregiver Involvement



**Provider–Caregiver
Partnership**



**Practice in
Naturalistic Settings**



**Family-Centered
Care**



Positive Outcomes

Barriers to Caregiver Engagement



What is Caregiver Engagement



Attitudinal Engagement

Expectations and perceptions of the intervention.



Behavioral Engagement

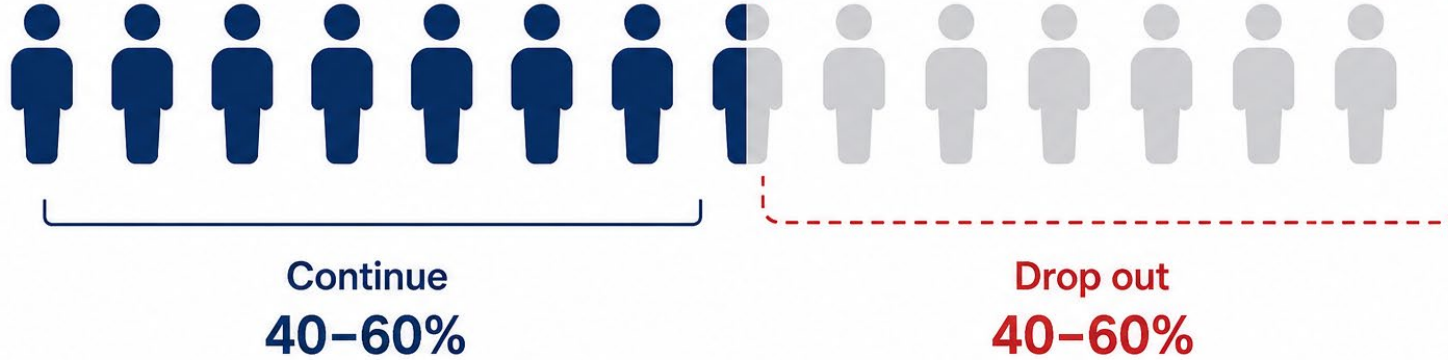
Attendance, participation, and home practice.



Barriers to Consistent Caregiver Engagement



Drop-out rate is high: **40–60%**



A large proportion of participants discontinue treatment before completion.

Barriers to Consistent Caregiver Engagement



Clinical Child and Family Psychology Review, Vol. 8, No. 2, June 2005 (© 2005)
DOI: 10.1007/s10567-005-4753-0

Parent Management of Attendance and Adherence in Child and Adolescent Therapy: A Conceptual and Empirical Review

Matthew K. Nock^{1,2} and Caitlin Ferriter¹

Clin Child Fam Psychol Rev (2015) 18:133–150
DOI 10.1007/s10567-015-0182-x



A Review of Parent Participation Engagement in Child and Family Mental Health Treatment

Rachel Haine-Schlagel · Natalia Escobar Walsh



Strategies Used to Support Caregiver Engagement



Clin Child Fam Psychol Rev
DOI 10.1007/s10567-013-0163-x

Identifying the Common Elements of Treatment Engagement Interventions in Children's Mental Health Services

Michael A. Lindsey · Nicole E. Brandt · Kimberly D. Becker · Bethany R. Lee · Richard P. Barth · Eric L. Daleiden · Bruce F. Chorpita

Studies (2018) 27:3141–3154
26-018-1144-y

REVIEW PAPER



Published in final edited form as:

Res Autism Spectr Disord. 2016 May 1; 2: 87–96. doi:10.1016/j.rasd.2016.02.003.

A Pilot Study Promoting Participation of Families with Limited Resources in Early Autism Intervention

Themba Carr^{a,*} and Catherine Lord^{a,*}

^aUniversity of Michigan, Department of Psychology, University of Michigan Autism and Communication Disorders Center, Ann Arbor, Michigan

Strategies to Engage Underrepresented Parents in Child Intervention Services: A Review of Effectiveness and Co-occurring Use

Melanie Pellecchia¹ · Heather J. Nuske¹ · Diondra Straiton¹ · Elizabeth McGhee Hassrick² · Amanda Gulsrud³ · Suzannah Iadarola⁴ · Sarah Fulton Vejnosa⁵ · Beth Bullen⁴ · Rachel Haine-Schlagel⁶ · Connie Kasari³ · David S. Mandell¹ · Tristram Smith⁴ · Aubyn C. Stahmer⁵

Published online: 19 June 2018
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Strategies Used to Support Caregiver Engagement



KEY BARRIERS TO CAREGIVER ENGAGEMENT



**Structural
Barriers**



**Other
Stressors**



**Relationship
with Provider**



**Perception
of Treatment**

TARGETED STRATEGIES TO SUPPORT ENGAGEMENT



Promote accessibility

- Childcare, flexible scheduling, transportation, appointment reminders



Assessment



Shared goal setting



Problem Solving

Strategies Used to Support Caregiver Engagement




KEY BARRIERS



"So, after he got the diagnosis, I just shut down. I did not say anything, I did not tell anybody...I just – I could not do it. So, one of the moms calls me...She called me at work and I just started bawling and I told her that this is what happened."

Caregiver Voice to Autism Services

Aubyn C. Stahmer¹  • Sarah Vejnosa¹ • Suzannah Iadarola² • Diondra Straiton^{3,4} • Francisco Reinos Segovia⁵ • Paul Luelmo^{5,6} • Elizabeth H Morgan¹ • Hyon Soo Lee⁵ • Asim Javed² • Briana Bronstein³ • Samantha Hochheimer² • EunMi Cho⁷ • Aritz Aranbarri^{1,8} • David Mandell³ • Elizabeth McGhee Hassrick⁹ • Tristram Smith² • Connie Kasari⁵

Received: 7 August 2018 / Revised: 17 January 2019 / Accepted: 12 February 2019 / Published online: 11 March 2019
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Peer Pairing

Mind the Gap



AIR-B AUTISM INTERVENTION RESEARCH NETWORK ON BEHAVIORAL HEALTH



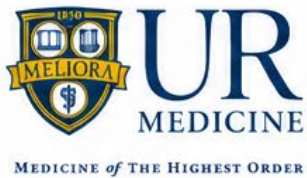
PI: Dr. Connie Kasari



PI: Dr. Aubyn Stahmer



PI: Dr. David Mandell



PI: Dr. Suzannah Iadarola



PI: Dr. Jill Locke



PI: Dr. Brian Boyd



A program to help families with recent autism diagnoses:

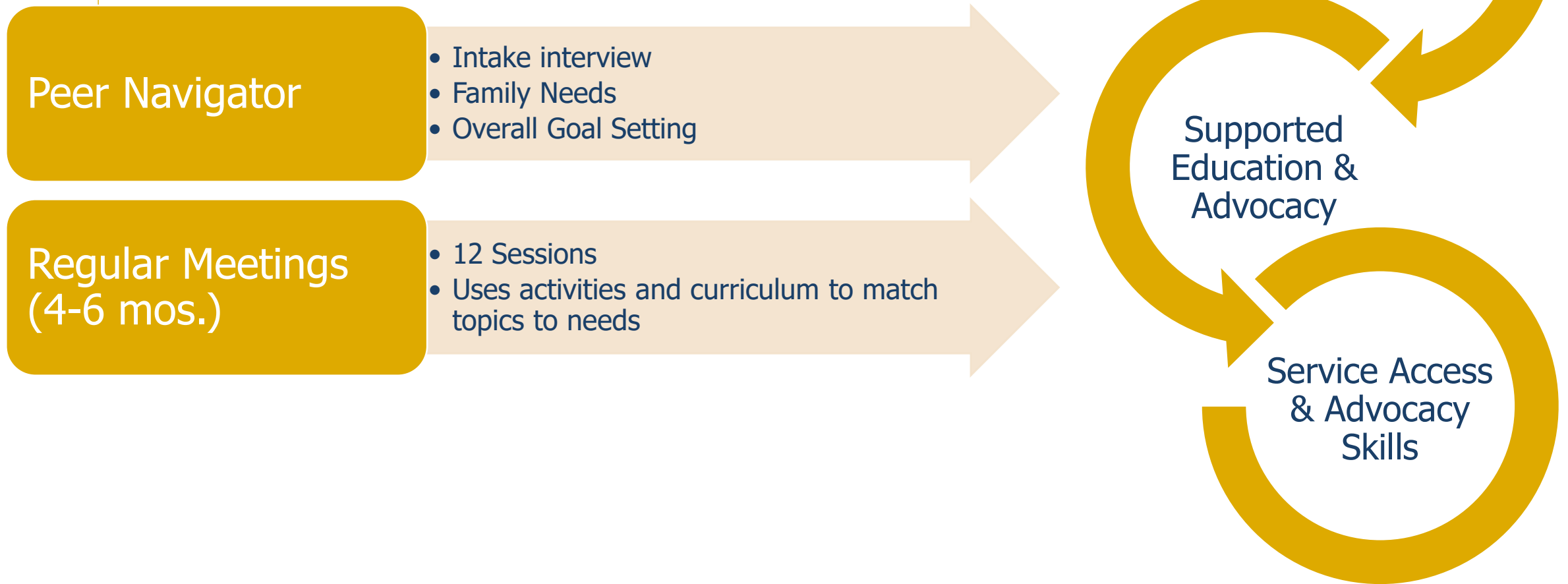
-  Understand the diagnosis
-  Learn next steps
-  Access services

Literature Review

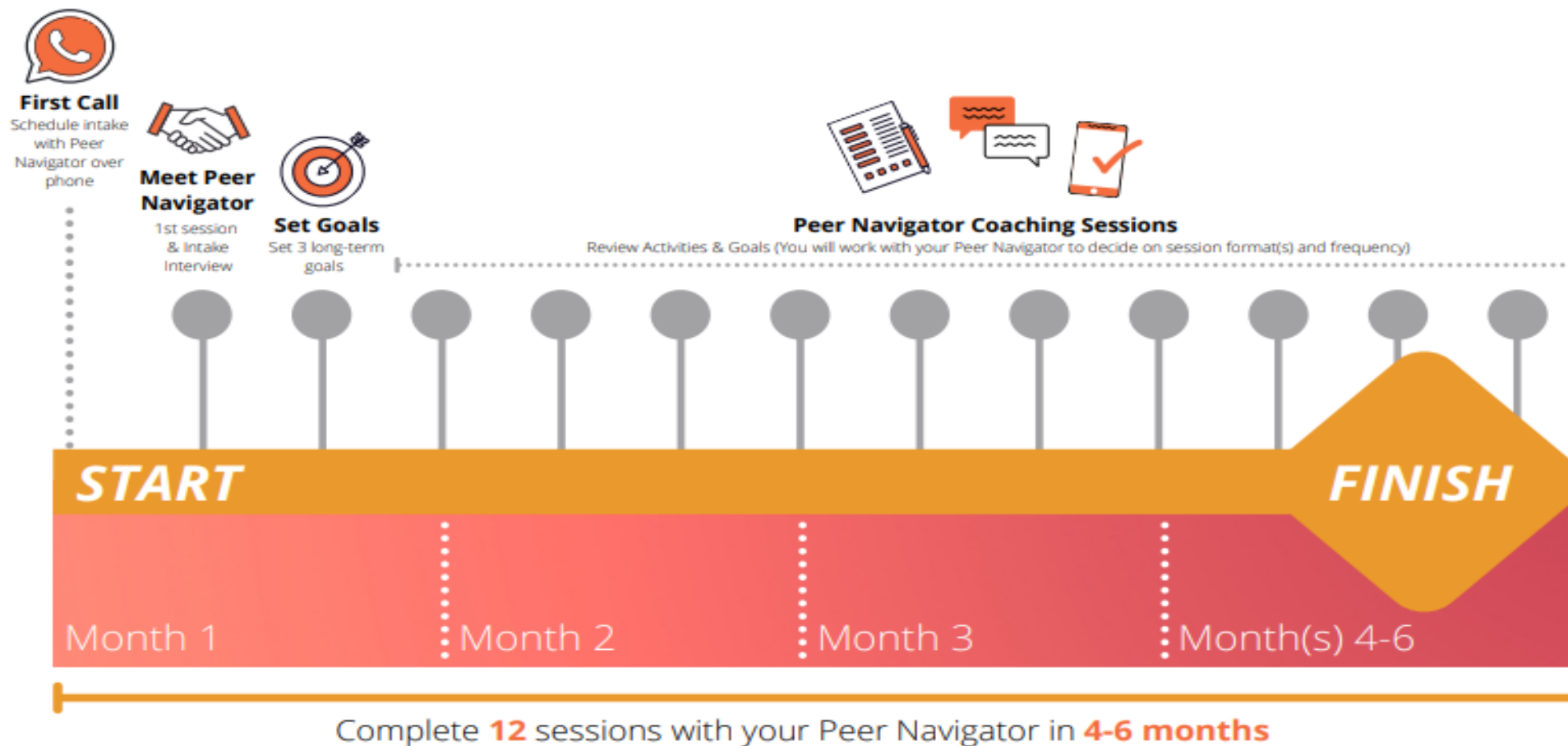
Focus groups
(families & /providers)

Community
Collaborative Groups

MiND THE Gap Process

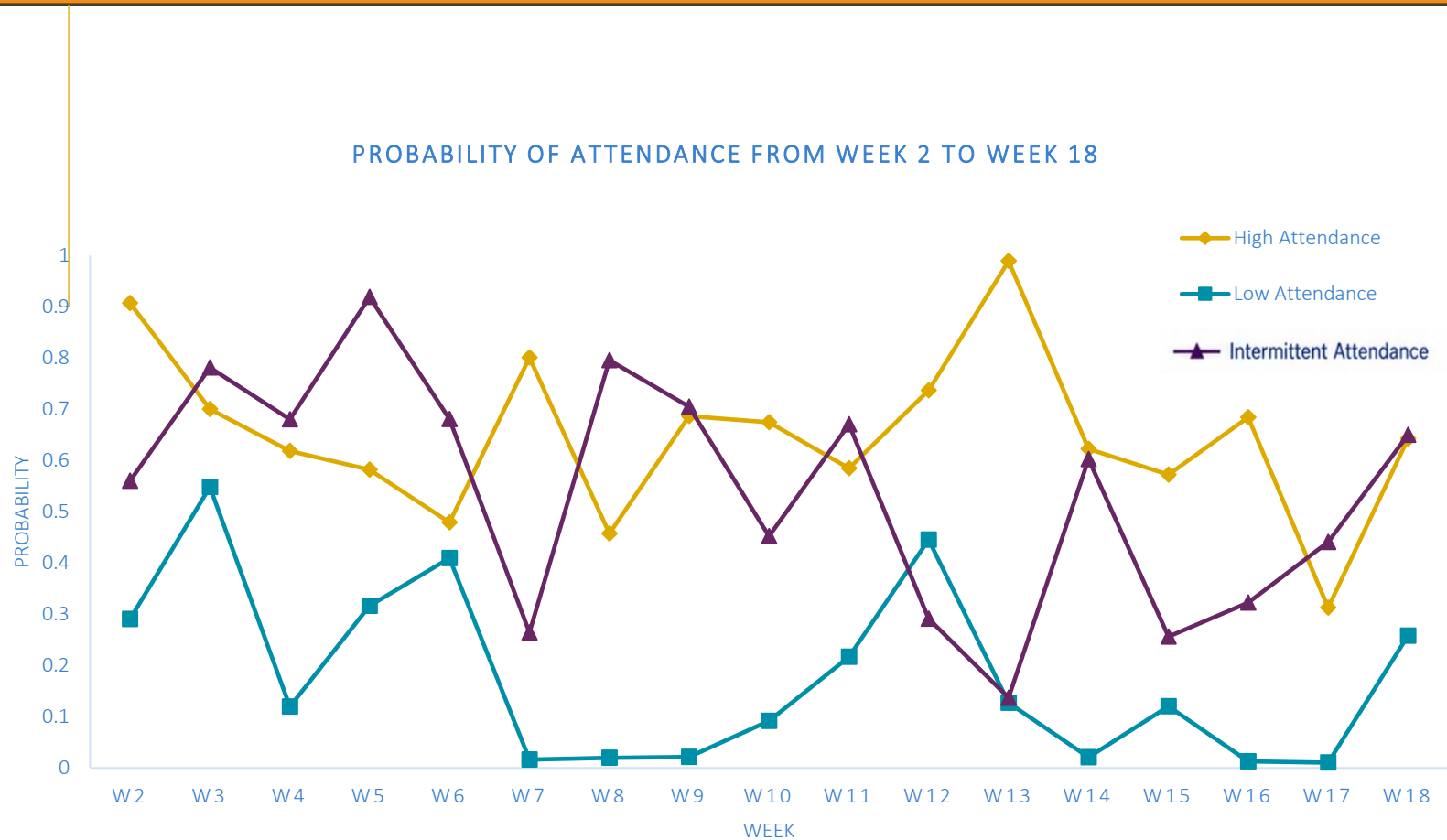


Program Timeline





Mind the Gap: Session Attendance Pattern



7.71

Average attendance
(sessions)

49%

were in the High
Attendance Class

19%

were in the Low
Attendance Class

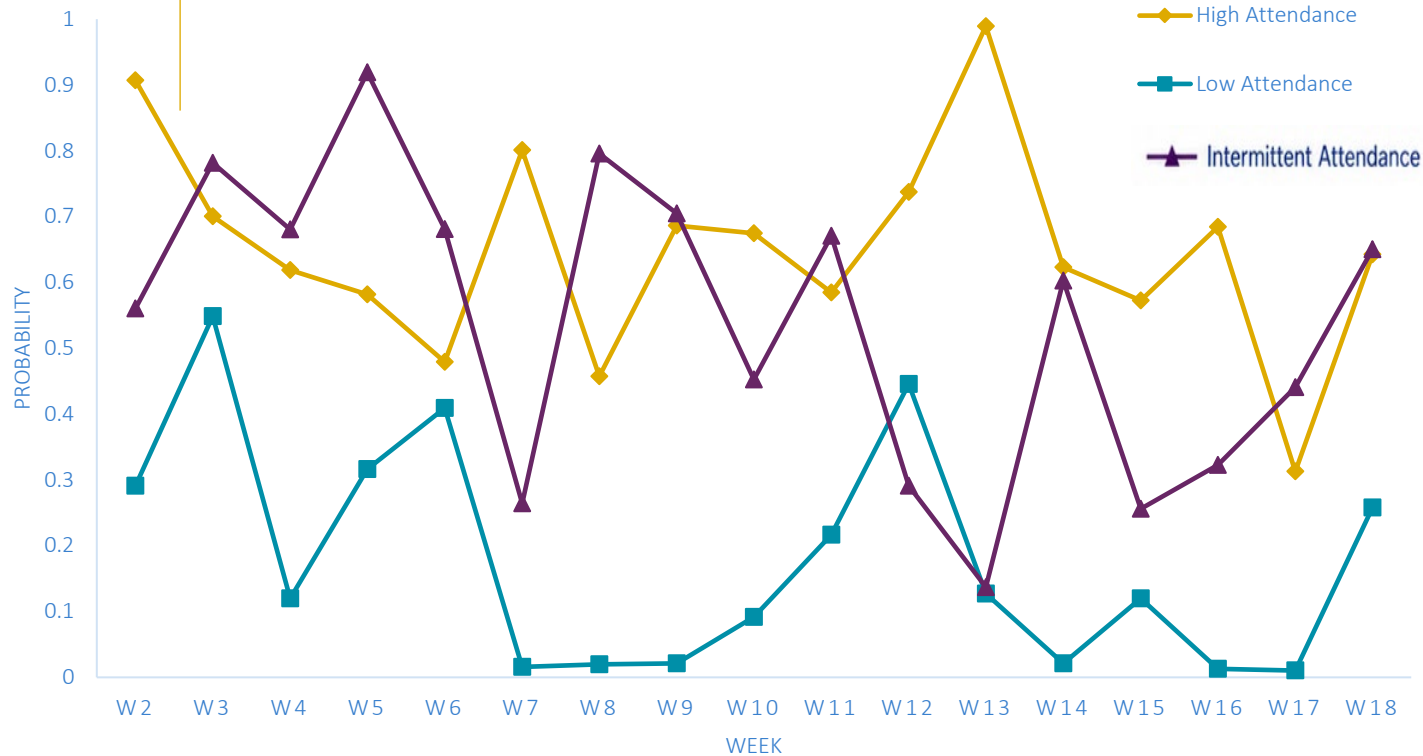
32%

were in the Intermittent
Attendance Class



Mind the Gap: Session Attendance Pattern

PROBABILITY OF ATTENDANCE FROM WEEK 2 TO WEEK 18



Employment status relates to attendance patterns.



Address critical materials earlier



Provide support at the initial sessions to retain employed families



Offer a shorter program to some caregivers



Reassess needs and goals at week 4 or 5



What else do families say?

A Strength-based Approach



Emotional Support



Instrumental Support



Financial Support



Social support relates to **lower levels of caregiver stress, higher levels of caregiver and family wellbeing, and positive parenting attitudes.**

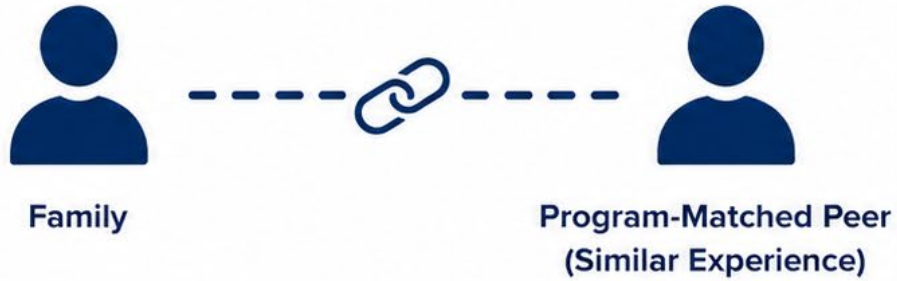


Taking a strength-based approach by leveraging existing social support

Rethinking Peer Support

CURRENT APPROACH

Program-Matched Peer

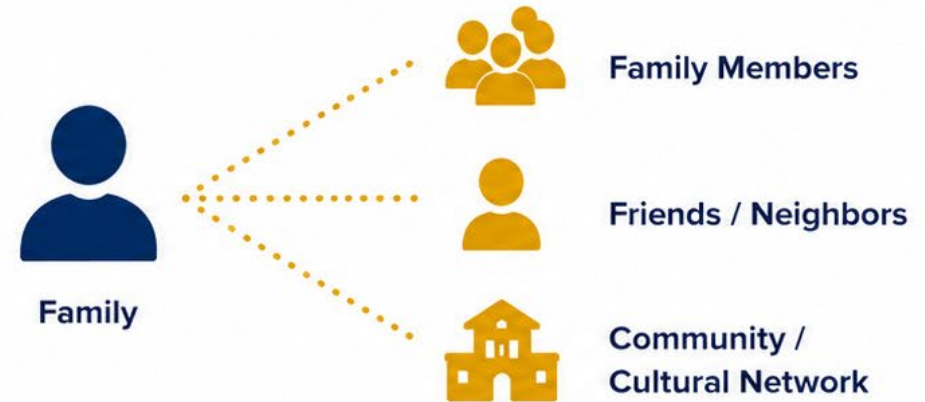


Peers are paired based on similar experiences within the program.

VS.

POTENTIAL APPROACH

Existing Support from Family's Life



Leverage natural, existing support systems that families already trust.

Use of Family/Friend Support in Other Health Interventions



- Integrating family/friend support in intervention programs, e.g., chronic disease, substance use, weight loss programs



- Mobile health intervention, Family/Friend Network Support (FANS) in low-income Latino patients with diabetes



Family/Friend Network Support (FANS)



Type of message	Patient TExT-MED message	FANS corresponding message
Educational/ Motivational message	30 minutes of exercise a day (even walking!) will give you MORE energy not less. Make it part of your routine!	30 minutes of exercise a day (even walking!) will give your loved one MORE energy not less. Help make it part of their routine!
Educational/ Motivational message	Serve food on a smaller dish (like a salad plate). This will make it seem like more food is being served.	Remind Maria to serve food on a smaller dish (like a salad plate). This will make it seem like more food is being served.
Challenge Message	Challenge: Call a friend or family member and go on a 30-minute walk with them today	Challenge: Go on a 30 minute walk with your loved one, but if you live far, text them and go for a 30 minute walk the same time they do.



Use of Family/Friend Support in Other Health Interventions



Positive outcomes

Increased self-monitoring behaviors, improved motivation and relationships with the participating supporter





Provider-Caregiver Partnership



Practice in Natural Settings



Family-Centered Care



Positive Outcomes



KEY BARRIERS TO CAREGIVER ENGAGEMENT



Structural Barriers



Other Stressors



Relationship with Provider



Perception of Treatment

TARGETED STRATEGIES TO SUPPORT ENGAGEMENT



Promote accessibility

- Childcare, flexible scheduling, transportation, appointment reminders



Pre-treatment assessment



Shared goal setting



Assessment and problem solving



MIND THE Gap



POTENTIAL APPROACH

Existing Support from Family's Life



Family



Family Members



Friends / Neighbors



Community / Cultural Network

Leverage natural, existing support systems that families already trust.



Family/Friend Network Support – Early Intervention (FANS-EI)



Study Goals

- Collaboratively adapt a strength-based mobile health program to support caregiver engagement in autism early intervention.
- Examine the effectiveness of the FANS-EI program for improving caregiver engagement.
- Explore how FANS-EI is perceived by caregivers and family/friend members.



Phase 1












FANS-EI Development and Adaptation

Family/Friend Network Support – Early Intervention



- Text messages adaptation
- Community advisory board: family members, early intervention agency leaders and providers, regional center and family resource center staff
- Identify education materials for supporters



Example Messages	Caregiver	Supporter
 <p>Instrumental Support</p>	 <p>Share it: Ask for help for organizing paperwork for your child’s services.</p>	 <p>Check in: Ask your ___ (friend/relative) if they need help with organizing paperwork for their child’s services.</p>
 <p>Emotional/ Motivational Support</p>	 <p>Challenge: Ask your ___ (friend/relative) to do an activity together.</p>	 <p>Challenge: Ask your ___ (friend/relative) to do an activity together.</p>
 <p>Educational Support</p>	 <p>Share it: Children are more motivated when they play with a toy they like.</p> <hr/> <p>Tell your ___ (friend/relative) what toys your child is most motivated to play with, and play it with your child this week.</p>	 <p>Check in: Children are more motivated when they play with a toy they like.</p> <hr/> <p>Ask your ___ (friend/relative) what toys their child loves to play with.</p>



CAB FEEDBACK



1. Use plain language



2. Self-care messages



3. Positive messages



4. Goal setting



WHEN



FREQUENCY



Change “imitate” to
“**copy what the child does**”



Change “follow your child’s lead” to
“**follow what your child does during play**”

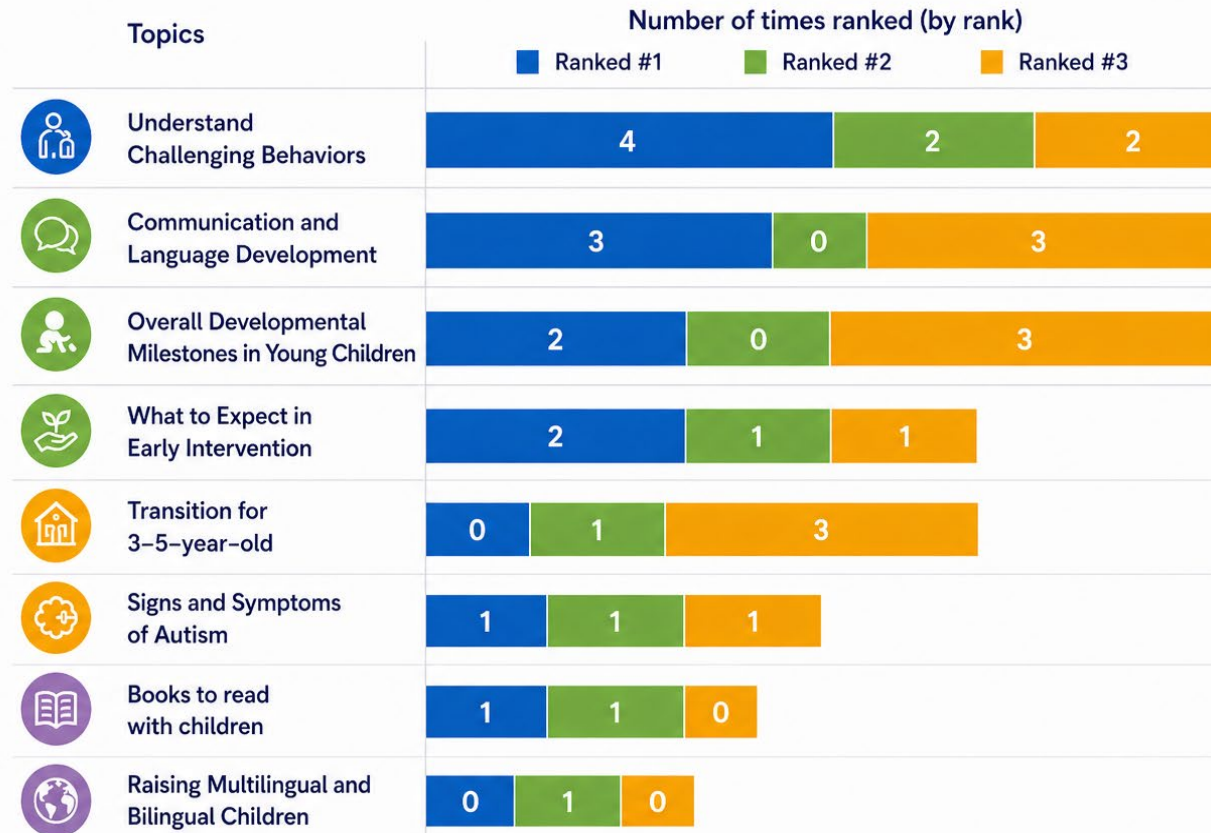
Example Messages	Caregiver	Supporter
<p>Emotional/Motivational Support</p>	<p>Share it: Share something small that you or your child has accomplished today with your ___ (friend/relative)!</p>	<p>Share it: Text your ___ (friend/relative) something positive that they have accomplished recently, praise them for their effort and congratulate them.</p>

Family/Friend Network Support – Early Intervention



Resources for Family/Friends Who Want to Help

Participants ranked their top 3 most important topics



Note: Topics are ordered by the number of times ranked #1 (highest to lowest).
If a topic was not ranked in a particular position, it is shown as 0.

Phase 2



FANS-EI Pilot

Participants



Providers

- Providers who include caregiver-coaching in their EI practices.



Caregiver/Child Dyads

- Child is **12-60 months** of age
- Child has a diagnosis of autism

Study Questions

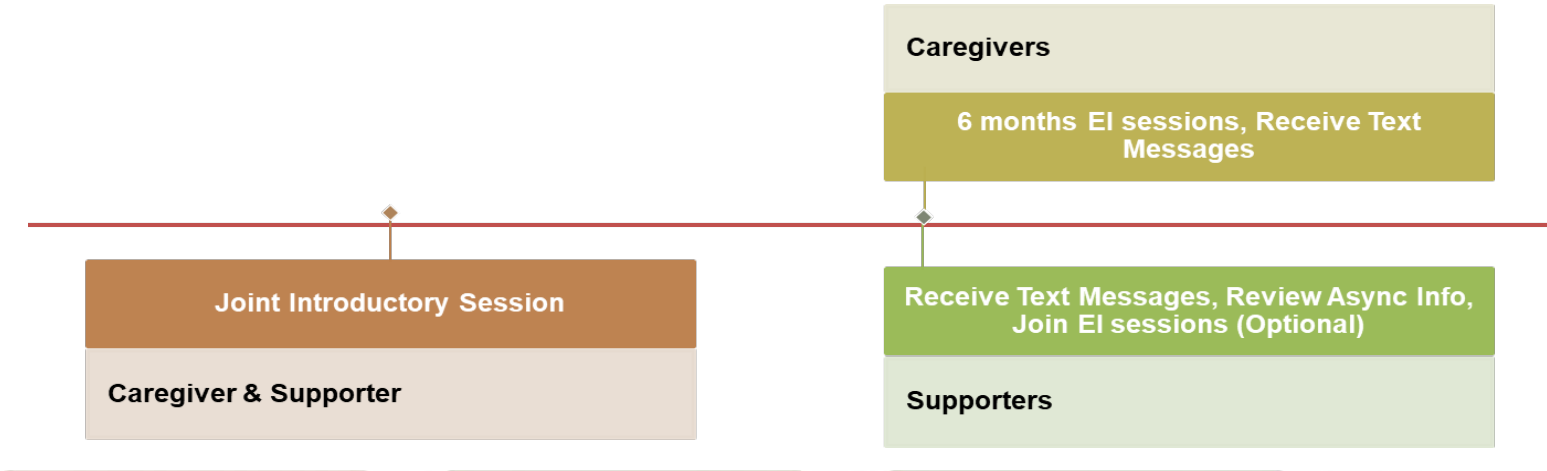
- Does FANS-EI improve caregiver engagement?
- Does FANS-EI group report higher levels of social support and self-efficacy?
- How is FANS-EI perceived by participants?

Measure Caregiver Engagement

- **Attitudinal Engagement:** Caregiver Buy-In to EI survey
- **Behavioral Engagement:** attrition, numbers of sessions attended and cancellations, and Parent Participation Engagement Measure



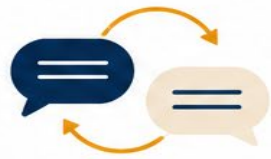
Family/Friend Network Support – Early Intervention



WHEN
In the evening



FREQUENCY
Three times a week
for 6 months



CONTENT
One message from each
category each week:

- Instrumental support
- Emotional/motivational support
- Educational support



ORDER
Messages sent in
random order
(predetermined
at enrollment)

Next Steps

- Recruitment and data collection
- Larger trial, mechanism of change
- Family/friend support needs
- Mobile health approach



Acknowledgement

- MTG Community Advisory Board
- Mentors: Aubyn Stahmer, PhD (UC Davis MIND Institute); Rachel Haine-Schlagel, PhD (San Diego State University); Sandy Magaña, PhD (University of Texas at Austin); James Marcin, MD, MPH (UC Davis Health)
- Team: Walter Cervantes, BA; Collab START lab
- Research reported has been supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through grant number UL1 TR001860 and linked award TL1 TR001861, and is supported by the National Institute of Mental Health of the National Institutes of Health under Award Number K23MH141316.

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Thank you!