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
University of Washington
University of Kansas
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-Frazee, 015; Wetherby et al., 2014).
Identification of Priorities
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?
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

- Check in with parent
- Ask parent about reactions & answer questions
- Complete activity
- Set goals
- Reflect on progress
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)
<table>
<thead>
<tr>
<th>Sessions Attendance</th>
<th># Sessions Attended</th>
<th>% Sessions Attended</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family 1</td>
<td>11</td>
<td>92</td>
</tr>
<tr>
<td>Family 2</td>
<td>12</td>
<td>100</td>
</tr>
<tr>
<td>Family 3</td>
<td>4</td>
<td>33</td>
</tr>
<tr>
<td>Family 4</td>
<td>12</td>
<td>100</td>
</tr>
<tr>
<td>Family 5</td>
<td>12</td>
<td>100</td>
</tr>
<tr>
<td>Family 6</td>
<td>12</td>
<td>100</td>
</tr>
<tr>
<td>Family 7</td>
<td>8</td>
<td>67</td>
</tr>
<tr>
<td>Family 8</td>
<td>1*</td>
<td>8</td>
</tr>
<tr>
<td><strong>Mean (SD)</strong></td>
<td>10.1 (3.1)</td>
<td>84.5 (25.7)</td>
</tr>
</tbody>
</table>
Refinements for larger study based upon feedback:

- Increase flexibility of sessions
- Improve coach/family match
- Simplify data collection

"What am I doing? Fixing the paper shredder."
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*

Measure completion
Primary reason for not meeting eligibility: Income too high
<table>
<thead>
<tr>
<th>Measure</th>
<th>Construct</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Agency Scale</td>
<td>How often caregiver engaged in activities promoting child’s development</td>
</tr>
<tr>
<td>Autism Knowledge Scale</td>
<td>Knowledge of autism re: diagnosis, characteristics, interventions</td>
</tr>
<tr>
<td>Social Dynamics of Intervention (SoDI)</td>
<td>Interview with caregiver about social network supporting their child</td>
</tr>
<tr>
<td>Service Access</td>
<td>Interview with caregiver regarding new services/ waitlists accessed</td>
</tr>
</tbody>
</table>
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
Who did we reach?

Family Race:
- African American: 33%
- Caucasian: 30%
- Other/Multiracial: 37%

Child's Gender:
- Female: 24%
- Male: 76%

Family Income:
- $9,999 or less: 20%
- $10,000 - 19,999: 10%
- $20,000 - 29,999: 17%
- $30,000 - 39,999: 17%
- $40,000 - 49,999: 17%
- >$50,000: 10%
Who did we reach?

English as Primary Language

<table>
<thead>
<tr>
<th>Site</th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>DAVIS</td>
<td>12</td>
<td>20</td>
</tr>
<tr>
<td>PENN</td>
<td>1</td>
<td>22</td>
</tr>
<tr>
<td>UR</td>
<td>2</td>
<td>31</td>
</tr>
<tr>
<td>LA</td>
<td>22</td>
<td>8</td>
</tr>
</tbody>
</table>

Legend: No, Yes
Mean number of services received = 1.95 (SD = 1.54)
87% receiving at least 1 service

Community Services Received

- 0 Services: 67%
- 1 Service: 18%
- 2+ Services: 15%

M = .67 (SD = 1.11)

School Services Received

- 0 Services: 44%
- 1 Service: 22%
- 2 Services: 20%
- 3+ Services: 14%

M = 1.34 (SD = 1.46)
Total Number of Services

**PREDICTIVE**

Peer support networks \( (p = 0.011) \)
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
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
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....
FAMILIES, PROVIDERS, RESEARCH TEAMS, AGENCY PARTNERS

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Photos obtained via Canva