



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

UNEQUAL ACCESS TO PROFESSIONAL SUPPORTERS

IMPORTANCE OF PEER NAVIGATORS

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A photograph of a woman and a young boy smiling and looking at cookies together. The woman is on the left, leaning in towards the boy on the right. They are both holding cookies. The background is a soft-focus outdoor setting.

Autism Post-Diagnosis

- **Timely engagement in relevant services**
- **Build network connections to professionals**
- **Family empowerment to advocate with service providers**

TIMELY FAMILY ENGAGEMENT IN SERVICES CAN HELP CHILDREN WITH AUTISM



Enrich learning opportunities



Capitalize on key development windows



Promote early access for historically excluded communities

SOCIAL NETWORKS CAN HELP FAMILIES LOCATE, SECURE AND NAVIGATE SERVICES



Network
connections to info
and resources



Caregivers build
connections to
coordinate services

ACCESS DISPARITIES

**Race/
ethnicity**

**Heritage
Language**

Income



Disconnect of historically excluded families from service systems

- Information inequitably shared with some cultural groups
- Families from linguistically diverse backgrounds often report difficulty navigating service systems
- Unfamiliar diagnostic terms from heritage language and culture can add the confusion
- Fear of approaching public institutions



Peer Navigator Program



Community Partnered Intervention

Family Resource Binder



What is
ASD



Navigating
the System



Insurance Rights



Coping and Stress
Management



Challenging
Behavior



Parent rights
and advocacy




Communication



Addressing
Stigma

Peer Support

A photograph of two women sitting at a table in a kitchen. The woman on the right, with curly hair, is holding a smartphone and looking at it with a smile. The woman on the left, with long dark hair, is looking at the phone and smiling. The background shows a kitchen counter with various items like a bottle and a sponge.

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

A photograph of a person's hands pouring coffee from a black teapot into a white mug on a wooden table. The image is partially obscured by a dark blue diagonal overlay that contains the text.

PEER NAVIGATOR/ FAMILY SESSIONS

- 12 Sessions (points of contact) over 4–6 months
- Flexible modality (in-person, video conference, app)
- Focus on marginalized families

Structure



01

Check in with
parent

02

Ask parent
about reactions
& answer
questions

03

Complete
activity

04

Set goals

05

Reflect on
progress

FLEXIBILITY/ ADAPTATIONS

TRANSLATION



PARENT LED



Randomized Controlled Trial

Intervention Group: MTG Resource Binder PLUS Family Navigation



Randomized Controlled Trial

Comparison Group: MTG Resource Binder Only



Screening & Enrollment

Allocation

Intervention

Families Screened
N=286

Excluded
N=161
Did not meet inclusion
(income too high,
receive ASD services
already, child not under
9 years of age): 89
Decline to Participate:
14
Lost to Contact: 44
Other: 14

Randomized
N=125

Peer Coaching
n=62

Resources only
n=63

Exit (1 year)
n=53

Exit (1 year)
n=59

**Schedules too busy; lost to follow up
and became unresponsive

**Lost to follow up and
became unresponsive

MEASURES



**PRIMARY
OUTCOME:
SERVICE
ACCESS**



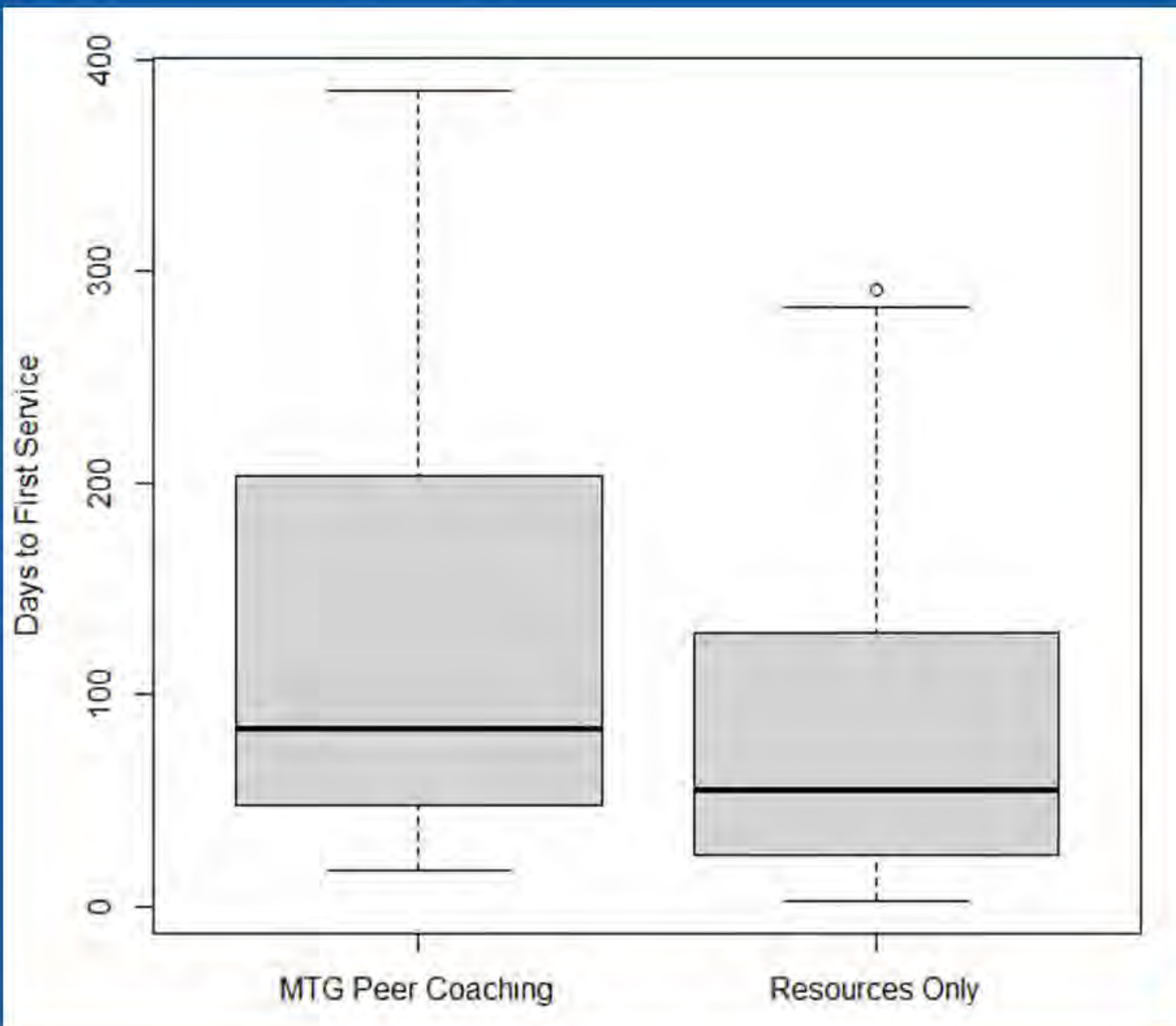
**SECONDARY
OUTCOMES:
CAREGIVER
SUPPORT
NETWORK AND
FAMILY
EMPOWERMENT**



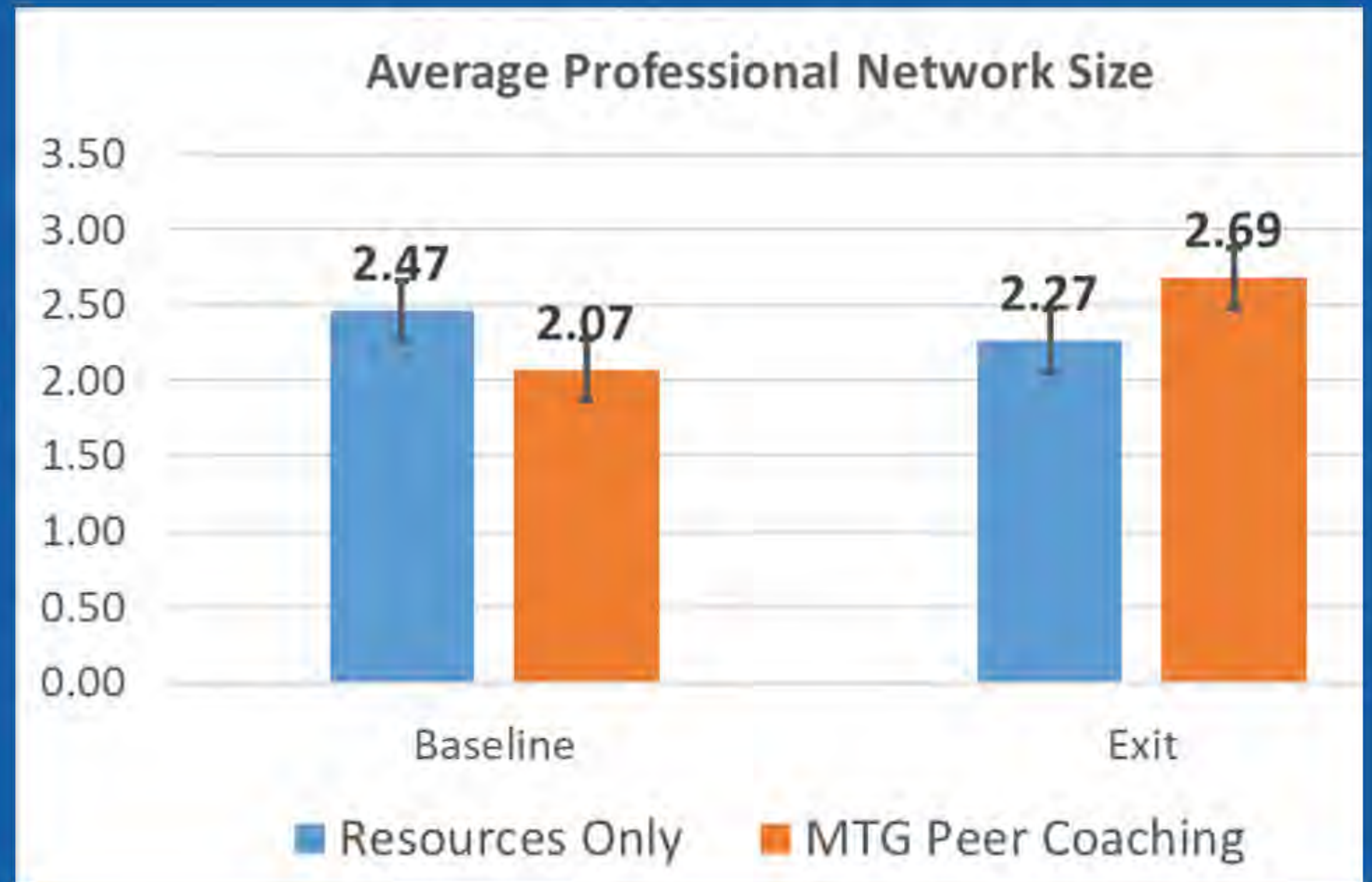
DATA ANALYSIS

- **Group assignment on time to new services: Cox proportional hazard model**
- **Group assignment on social network size/ family empowerment: generalized linear mixed models**

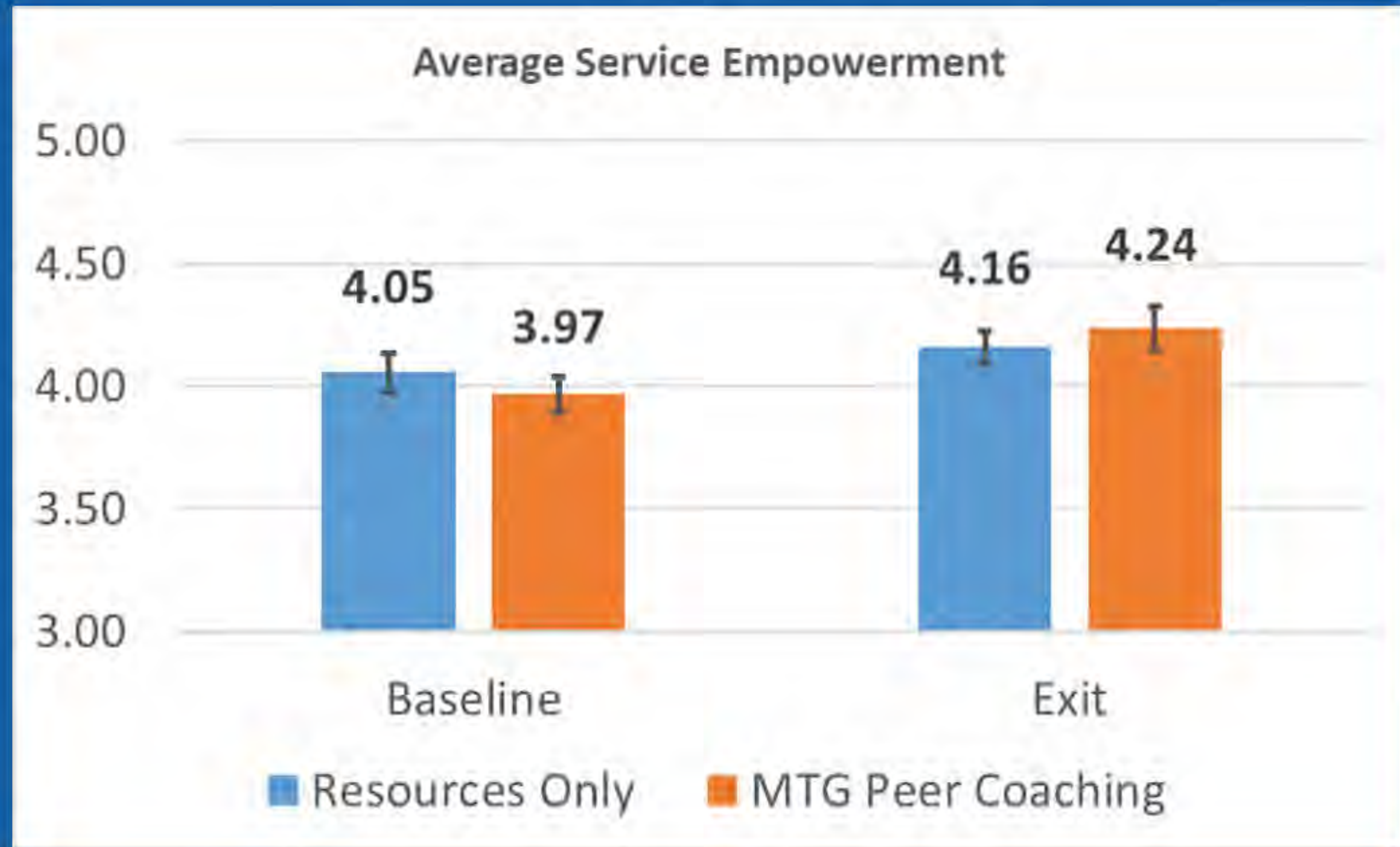
**Time to
service:
No group
differences***



**Professional
network size:
significant
increase**



**Family
empowerment
significant
increase**





CONCLUSIONS



Family Navigation plus Resources helps build networks and empowerment



Interventions supporting these outcomes can be affected in groups that have been excluded by our service systems



Scale up and implementation of family navigation programs within the disability community are warranted



LIMITATIONS

Reliance on self-report

Adapted measures used

Lack of movement in service access

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