Perspectives on Family Navigators for Early Identification of Autism Spectrum Disorder

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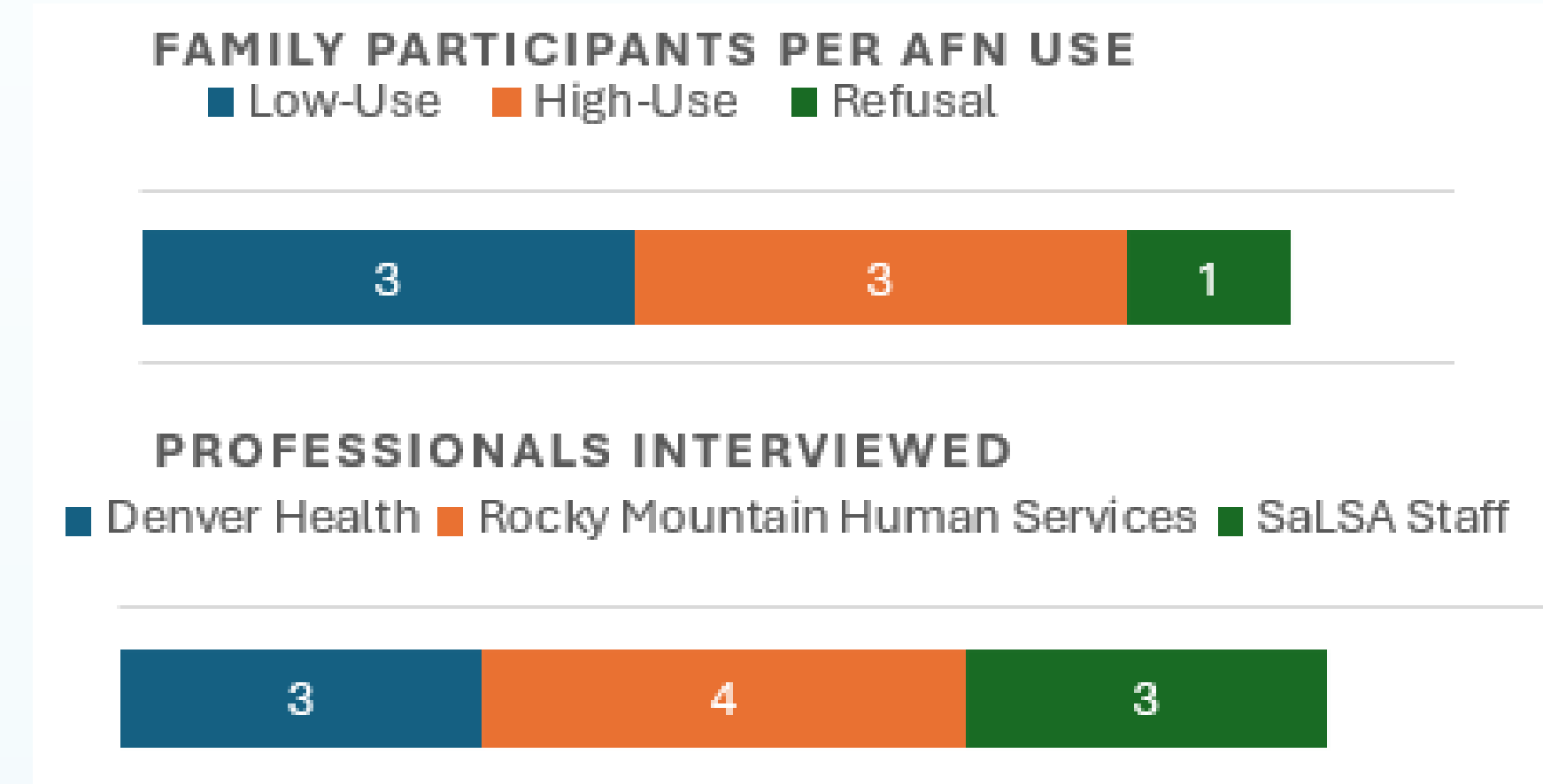University of Colorado Anschutz Medical Campus

Background

- CDC estimates that 1 in 36 children have autism spectrum disorder (ASD).

- ASD remains underdiagnosed and undertreated in young children.

- Underdiagnosis and undertreatment is more prevalent in low-income and underrepresented minority families.

- Early identification of ASD in young children improves developmental outcomes.

- Screening and diagnostic process for ASD is complex and can be overwhelming for families, and there are disparities among non-White families compared to white counterparts.

- Autism Family Navigation (AFN) has demonstrated improved likelihood of diagnostic completion for young children at risk for ASD.

- There is limited literature exploring qualitative perspectives regarding AFN.

- **The aim of this study is to add family, staff, and provider perspectives on the acceptability and feasibility of AFN in an urban safety-net setting serving low-income families, many of whom speak Spanish.**
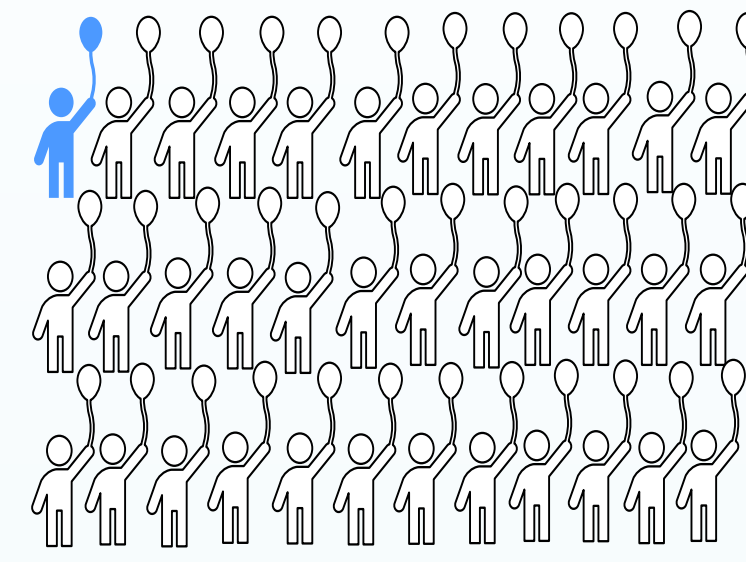
Methods

- The Screening and Linkage to Services for Autism (SaLSA) trial was an RCT developed and implemented among largely low-income, Hispanic/Latine families seen at Denver Health. Families were randomized to receive AFN or services as normal.

- Purposive sampling of 27 families randomized to receive AFN services who were identified and classified as "high-use", "low-use", and "refusal".

- Staff and providers at Denver Health, Rocky Mountain Human Services, and personnel in the trial were invited to interview.

- Semi-structured phone interviews were conducted, and qualitative content analysis was performed.

- Community focus group among five Hispanic/Latine mothers of children with autism was held to re-contextualize and triangulate data interpretation. Field notes were also used to supplement contextual information.

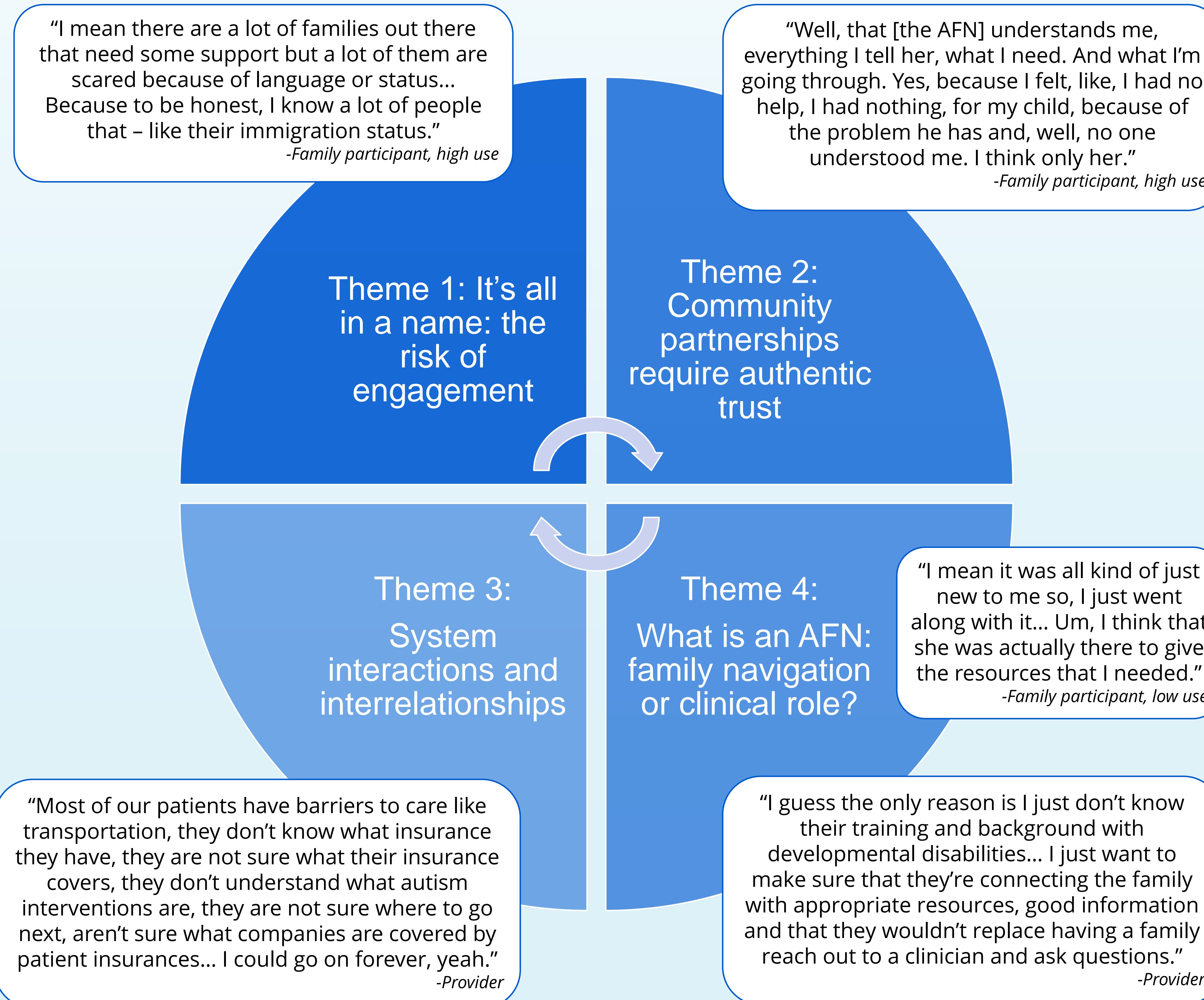- Transcripts of interviews were analyzed using inductive and deductive team-based approach.

Results

FAMILY PARTICIPANTS PER AFN USE
- Low-Use
- High-Use
- Refusal

| 3 | 3 | 1 |

PROFESSIONALS INTERVIEWED
- Denver Health
- Rocky Mountain Human Services
- SaLSA Staff

| 3 | 4 | 3 |

Five of six mothers receiving AFN services identified as Hispanic or Latine

Four of these mothers identified Spanish as their native language

All six families who received AFN services were enrolled in Medicaid

"I mean there are a lot of families out there that need some support but a lot of them are scared because of language or status... Because to be honest, I know a lot of people that – like their immigration status."
-Family participant, high use

"Well, that [the AFN] understands me, everything I tell her, what I need. And what I'm going through. Yes, because I felt, like, I had no help, I had nothing, for my child, because of the problem he has and, well, no one understood me. I think only her."
-Family participant, high use

Theme 1: It's all in a name: the risk of engagement

Theme 2: Community partnerships require authentic trust

Theme 3: System interactions and interrelationships

Theme 4: What is an AFN: family navigation or clinical role?

"I mean it was all kind of just new to me so, I just went along with it... Um, I think that she was actually there to give the resources that I needed."
-Family participant, low use

"Most of our patients have barriers to care like transportation, they don't know what insurance they have, they are not sure what their insurance covers, they don't understand what autism interventions are, they are not sure where to go next, aren't sure what companies are covered by patient insurances... I could go on forever, yeah."
-Provider

"I guess the only reason is I just don't know their training and background with developmental disabilities... I just want to make sure that they're connecting the family with appropriate resources, good information and that they wouldn't replace having a family reach out to a clinician and ask questions."
-Provider

Discussion

- Our study adds important qualitative perspectives to consider when adapting AFN services on a larger scale, especially among urban, underserved, largely Hispanic/Latine families.

- The larger policy context of healthcare, how services are named, and community perceptions matter to participants.

- There is stigma associated with autism spectrum disorders and disability within Hispanic/Latine culture and communities. Working with an AFN who spoke the same primary language and provided cultural understanding was important to utilizing services offered.

- Complex health systems impacted AFN program participation by family, clinical, and service providers. Some also cited these complexities as reasons to pursue use of an AFN.

- The role and responsibilities of an AFN need to be clarified, could benefit from standardization, and should be communicated to or clinical providers and families.

Conclusions

- AFN is an efficacious intervention for families who screen positive for autism and demonstrates potential to decrease barriers to receiving timely diagnosis of ASD. These qualitative results add to current perspectives regarding factors relevant to AFN implementation.

- AFN program delivery may be improved by providing navigators whose language and culture is congruent with patient populations, appropriate cultural training of navigators, standardization of navigator training, and embedding navigators in clinical settings. Program outreach and education to clinical partners would also likely improve acceptability of AFN programs.

- After this original trial ended, Denver Health and Rocky Mountain Human Services worked towards establishing a specialist position and external funding for a continued family navigator position to support referrals and developmental evaluation services.

References

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