

Adapting a patient navigator intervention: Parent and navigator perspectives

BACKGROUND

➤ Significant racial, ethnic, and socioeconomic **disparities exist in access** to services for children with autism spectrum disorder (ASD)

➤ **Family Navigation** (FN) is a care management strategy designed to reduce disparities by providing families with individually tailored support and care coordination

RESEARCH QUESTION

➤ How should FN be **adapted for dissemination** among similarly diverse populations?

METHODS

➤ **Qualitative interviews** with navigators and parents of children with ASD – purposively sampled **from a larger randomized comparative effectiveness trial** of FN in which families worked with their navigator from **the time of identified concern for ASD to 100 days after diagnostic ascertainment**

➤ Rapidly coded and analyzed using **FRAME** (Stirman et al., 2019) and **Core Components of Family Navigation** (Broder-Fingert et al., 2019)

RESULTS

➤ **Participants:** 7 navigators and 21 parents

➤ **Recruitment Sites:** Urban clinics in Massachusetts (n=6 clinics), Pennsylvania (n=2), and Connecticut (n=2)

Table 1. Participant characteristics.

| Parents (n=21) | |
|---|------------|
| Age at interview, years (SD) | 35.8 (6.8) |
| Hispanic/Latino | 38% |
| Born outside of US | 43% |
| Race – non-White | 86% |
| High school graduate or GED | 86% |
| Public insurance | 90% |
| Navigators (n=7) | |
| Female | 100% |
| Bilingual (English-Spanish or English-Haitian Creole) | 29% |
| Hispanic/Latino | 29% |
| Race – non-White | 43% |
| Prior experience working with children with ASD | 14% |

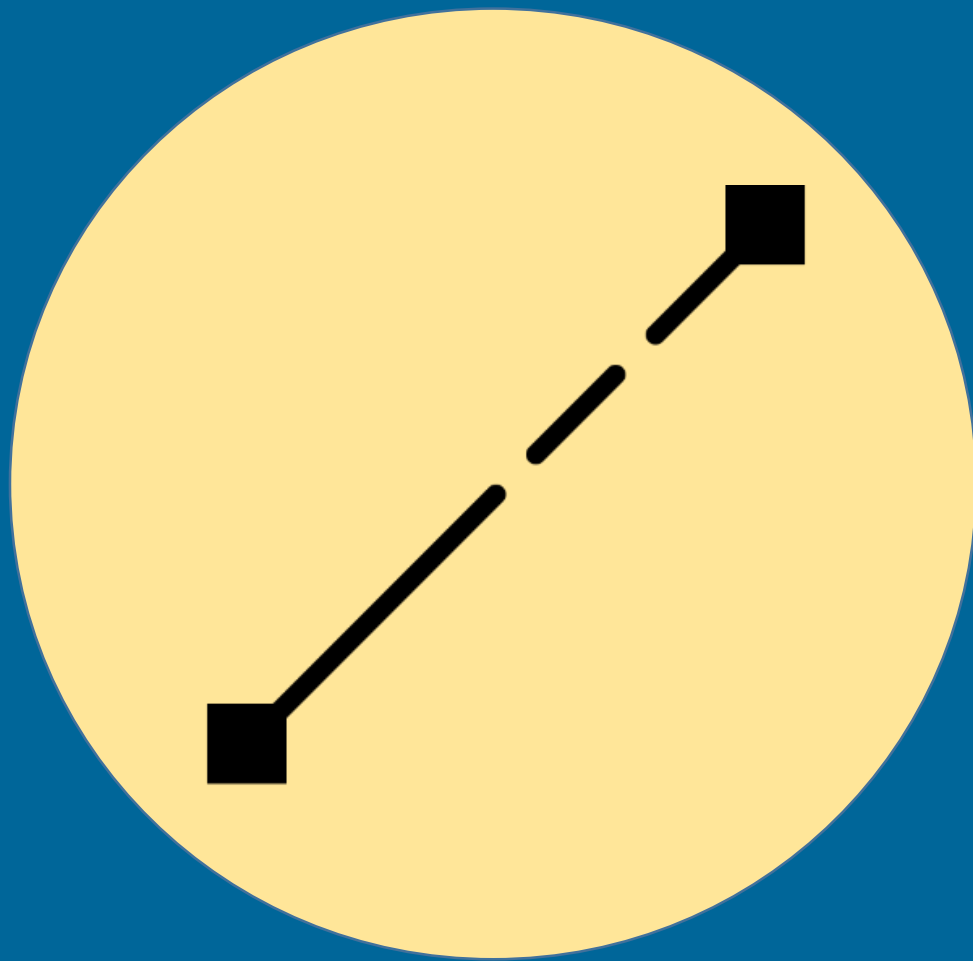
Key findings:

➤ 32 unprompted suggestions:

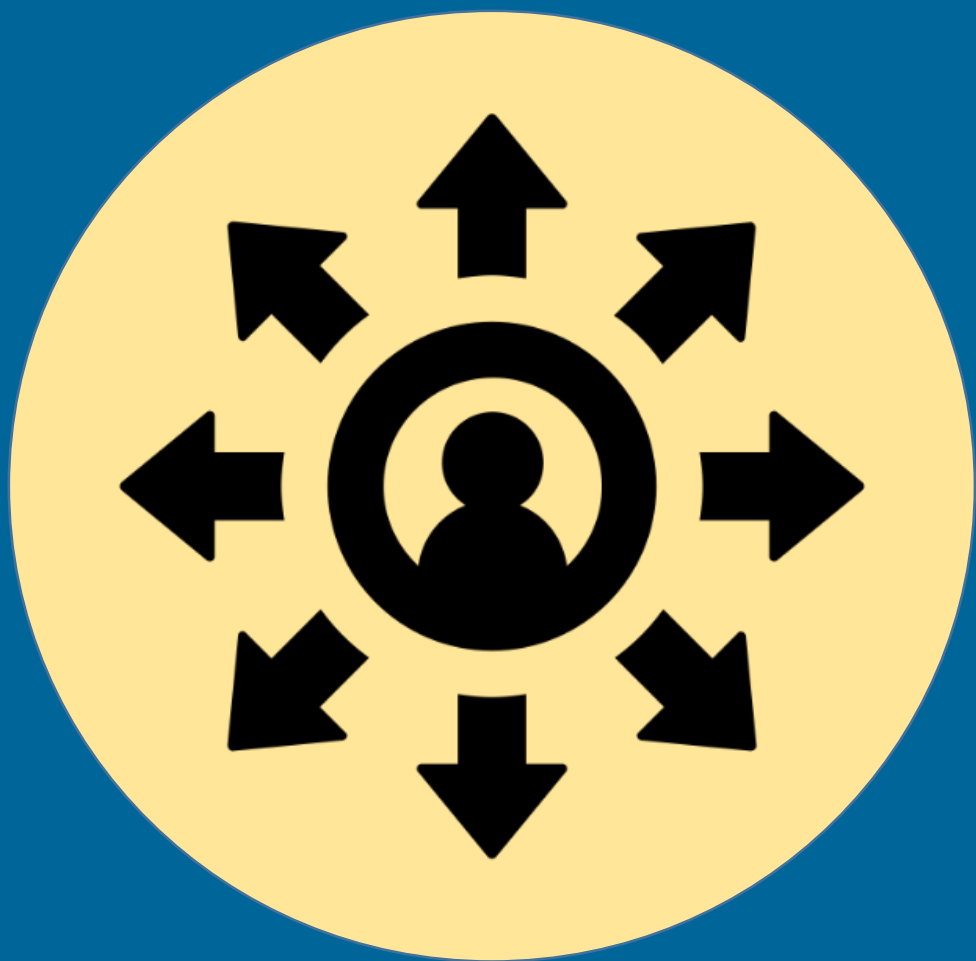
- 24 **new ideas** for adaptations to the intervention and/or expansion into a program (i.e. true adaptations)
- 8 **lapses in fidelity** to the intervention, demonstrating challenges in (1) training/supervision, (2) hiring navigators, and (3) integration into the healthcare system

➤ Although probes targeted critical feedback, parents and navigators were **overwhelmingly positive** about FN

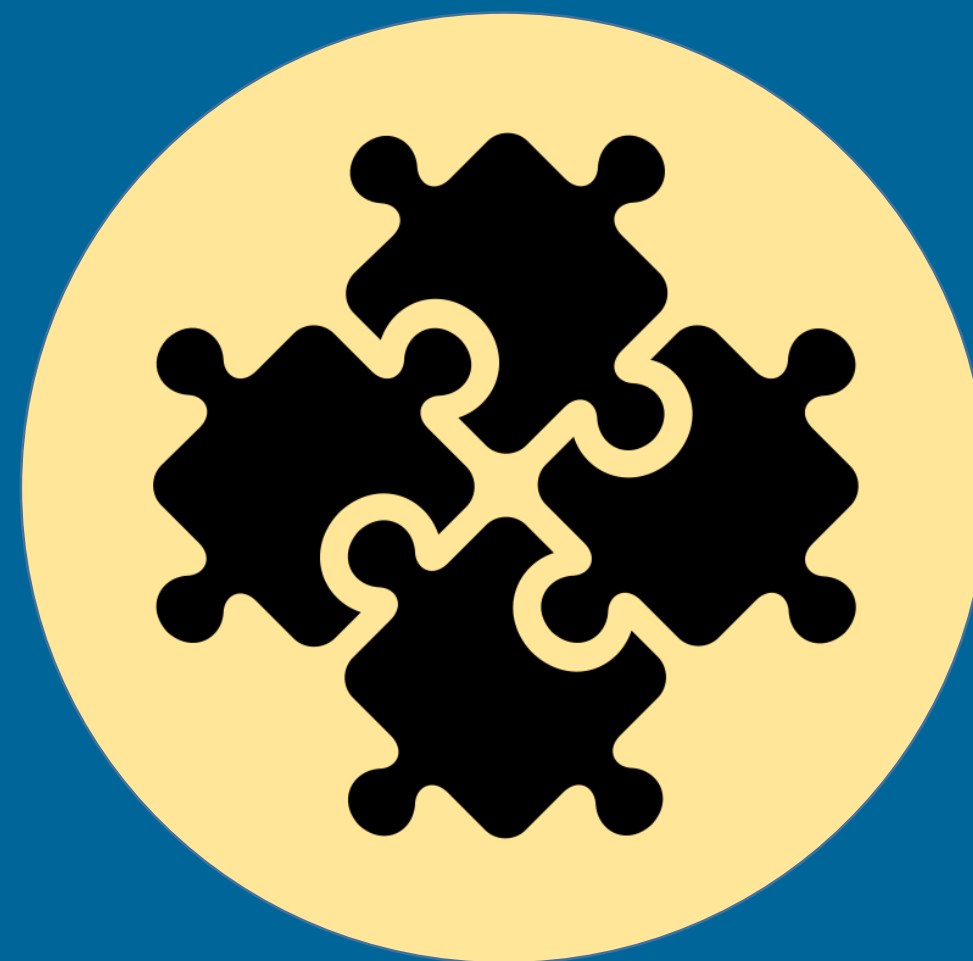
Parents of children with autism and their navigators identified **four areas of adaptation** for a family navigation intervention to address disparities in autism diagnosis:



Content:
Extend duration and add autism education



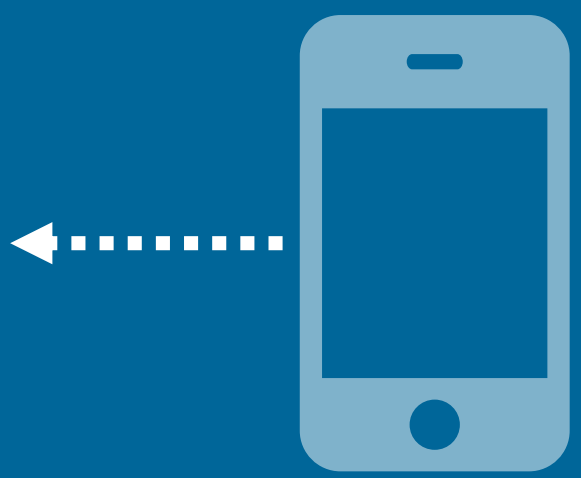
Scale-up:
Increase access



Context:
Integrate into health systems



Training:
Improve support for navigators



Take a picture to view the poster online

Content

- **Most frequently endorsed:**
 - Extend duration of FN
 - Offer more formalized education about ASD and parenting children on the spectrum
- The majority of suggestions represent **true adaptations**
- **Example:** “Just like when you have a newborn, I think [Navigators] should have some type of classes for how to deal with kids that have autism.” - Parent 2

Context

- **Most frequently endorsed:**
 - Focused hiring of bilingual/bicultural navigators with ASD experience
 - Better integration into primary care
- The majority of suggestions represent **true adaptations**
- **Example:** “[Families] trust their doctor better than anybody. So when the doctor refers them to somebody, they will take it seriously – more serious than if it was anybody else.” - Parent 18

Training and evaluation

- **Most frequently endorsed:**
 - Ensure that all navigators receive a complete orientation that includes behavior change strategies such as motivational interviewing
- All suggestions represent **lapses in fidelity**
- **Example:** “I was [supported], but not so fully like in the case of the families who lived in the shelter. I think what she needed [was] much harder than I could provide.” - Navigator 3

Implementation and scale-up

- **Most frequently endorsed:**
 - Increase access to FN for all families with children at risk for ASD or other disabilities
- All suggestions represent **true adaptations**
- **Example:** “I feel like any type of family that is dealing with some type of ‘devastating’ news about their child would benefit from a Family Navigator.” - Parent 12

CONCLUSIONS

➤ Dissemination of FN interventions must be informed by key stakeholder groups

➤ Suggestions raised by parents and navigators have the potential to inform improvement of existing navigation programs and development of new programs in similarly diverse populations



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