Engaging Families as a Key Strategy to Address Disparities in Access to Autism Diagnosis and Services

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Background and Significance

- 1 in 71 Wisconsin children has autism spectrum disorder (ASD).[1]
- Median age of ASD diagnosis is 51 months, but 90% had a documented developmental concern before 36 months of age in Wisconsin.[1]
- Black, Hispanic, and low-socioeconomic children are at increased risk for under-identification of ASD, late diagnosis, and facing barriers to accessing services.[2-5]
- Many barriers impede efforts to decrease disparities in access to ASD identification, diagnosis, and intervention, including inefficient systems of care, provider attitudes, and availability of services.[6]
- There is a need to understand families' experiences of these enablers and barriers, and how they impact access in Wisconsin.

Purpose of the Project

- The Wisconsin Care Integration Initiative (WiCII) is a federally funded quality improvement project to improve access to a coordinated, comprehensive state system of services that leads to early diagnosis and entry into services for children with ASD/DD.
- Focuses on increasing access to medically underserved communities (low income, racial/ethnic minority, urban and rural) to address access barriers.
- Leverages evidence-informed strategies of family navigation, telehealth, and shared resource to increase timely access to services and supports.
- Prioritizes family engagement in identifying enablers and barriers to access, and including parents as trained Family Navigators.
- Autism family navigation, led by local community members, implemented in one urban and two rural communities.

Methods

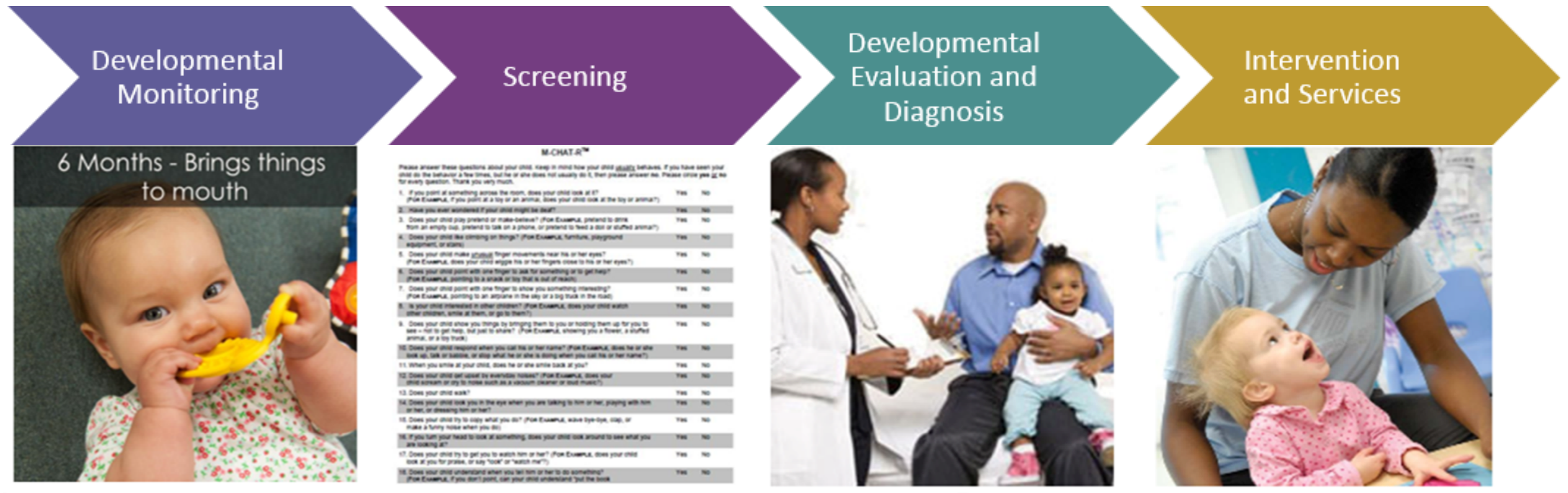
Data about families' experiences are being gathered through several methods:

- **Family Focus Groups** (N = 20 participants)
  - Enablers and barriers to accessing all steps on service pathway
  - Data used to shape community-based quality improvement efforts
  - 2 rural (December 2017) and 1 urban (March 2018) focus groups
- **Statewide Family Survey** (N = 363 respondents)
  - Wisconsin Family Autism Survey developed
  - Administered March 2018; to be repeated spring 2019
- **Family Navigation Quality Improvement Data** (data not reported here)
  - Data from stakeholder meetings (N = 57 participants)
  - Data about time from referral to service access, and enablers and barriers to access, collected from families receiving family navigation (N = 39 families)

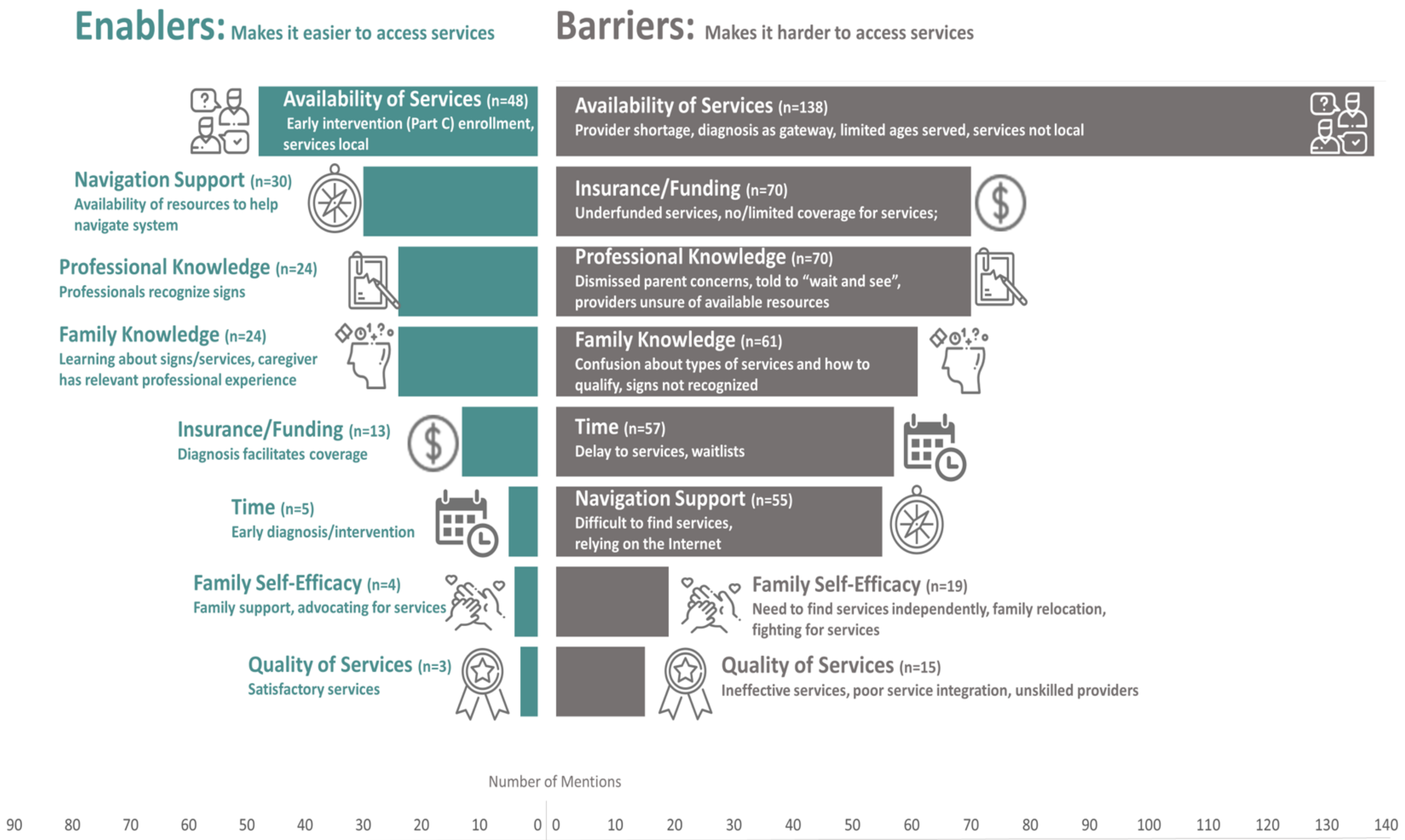
Enablers and Barriers to Accessing Services

Service Pathway

- Diagram of the ideal minimum set of services available to children at risk for, or identified with, ASD.
- Diagram progresses from services that should be universally offered (i.e., developmental monitoring and screening) to those that should be offered to children identified with concern (i.e diagnosis and evaluation) and those that should be available to children identified with ASD or another qualifying need (i.e., intervention).
- Pathway used as basis for community inquiry to identify community assets, service gaps, barriers to access, and leverage points for systems change.



Frequency and Type of Enablers and Barriers Mentioned by Focus Group and Survey Respondents



Initial Findings

- **Barriers were mentioned three times more frequently** than enablers.
- **Availability of services** has the most impact on accessing services.
- Families who accessed services frequently mentioned **navigation support** as an enabler. Support was described as coming from:
  - Provider with whom parent had long-term relationship,
  - Knowledgeable family member or friend, or
  - Parent-to-Parent agency navigator from local community.
- Lack of **navigation support** was mentioned less than most other barriers, which may indicate a lack of awareness of options for navigation support.
- Some barriers seem to act as **gateways restricting access** to subsequent services. These include:
  - Parent or providers knowledge of signs of ASD
  - Access to diagnosis, and
  - Availability of a way to pay for services.
- **Parent and provider knowledge** has an impact on accessing services.

Recommendations and Next Steps

- Increase number of well-trained service providers.
- Increase local access to service providers (e.g., telehealth).
- Better inform families about availability of existing navigation supports.
- Increase the availability of number of navigation support from providers with whom parents are likely to have a long-term relationship (e.g., primary care providers, early intervention program, ASD interventionists).
- Increase parent and provider knowledge about the signs of ASD, services along the service pathway, and family navigation supports.
- Continue to collect data about enablers and barriers to service access from families most impacted by disparities based on race, ethnicity, socio-economic status, and region of residence.
- Determine which barriers most often close pathways to accessing subsequent services.
- Continue to mobilize parents to inform and guide systems change.

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Image Credits:

a. Robins, D. L. (2018). *Modified checklist for autism in toddlers (M-CHAT).* Accessed from: https://mchatscreen.com/
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