

Autism Family Navigation as a Strategy for Documenting and Navigating Families' Barriers to Access in Milwaukee's Urban Core

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Background and Significance

- 1 in 68 children has autism spectrum disorder (ASD).¹
- Median age of ASD diagnosis is 50 months, but 87% had a documented developmental concern before 36 months of age.¹
- Medically underserved at increased risk for under-identification and late diagnosis due to delayed screening and barriers to accessing services.²⁻⁴
- Racial health disparities exist in Wisconsin, with black children ranking in lowest quartile on nearly every indicator of child well-being.⁵
- Health disparities are especially pronounced in Milwaukee, and further map onto geographic regions with lowest socio-economic status.⁶
- Family Navigation (FN) can decrease disparities in timely access to diagnosis, services, and supports for ASD.^{7,8}
- Medically underserved Milwaukee parents need FN that meets unique cultural and health literacy needs.⁸
- Need to develop and test Autism FN models that can address disparities in timely identification, diagnosis, and access to services and supports for medically underserved families.

Purpose of the Project

- The Wisconsin Care Integration Initiative (WiCII) is a federally funded 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
- Focus is on medically underserved communities (low income, racial/ethnic minority, urban and rural) to address access barriers
- Leverages evidence-informed strategies of FN, telehealth, and shared resource to increase timely access to services and supports

Approach

- Support locally relevant, sustainable change by funding “Engaged Community Quality Improvement Projects” (ECQuIP)
- Milwaukee ECQuIP began in Spring 2017
- ECQuIP process:
 1. Document current community assets, service gaps, & barriers to access
 2. Identify leverage points to improve service availability and access
 3. Develop action plan and revise per repeated quality improvement cycles
 4. Utilize Family Navigators and other ECQuIP staff to serve individual families and to drive change

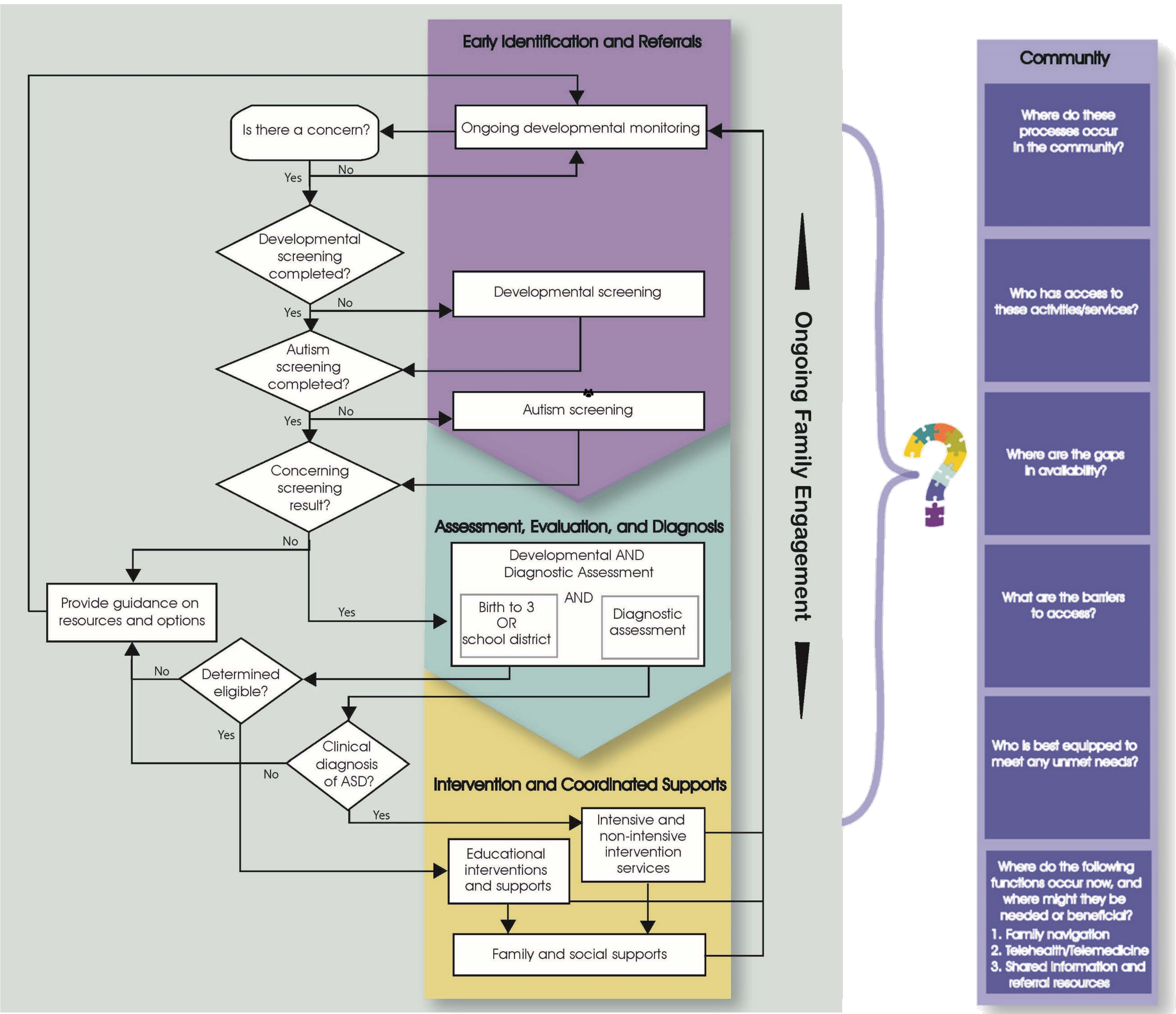
Definition of Family Navigation:

Family Navigators are professional staff members who are often the parent or primary caregiver for a child with special health care needs. They work directly with families and are also the bridge between different sets of providers and systems. Family Navigators provide or facilitate access to family-to-family support by listening to concerns and sharing experiences; focusing on strengths; modeling and coaching healthy coping strategies; locating and accessing community services and supports across multiple systems; helping families identify available treatment services and access health insurance coverage; providing guidance in navigating the education system; and building family knowledge and advocacy skills.

Modeling Navigation of Service Pathway

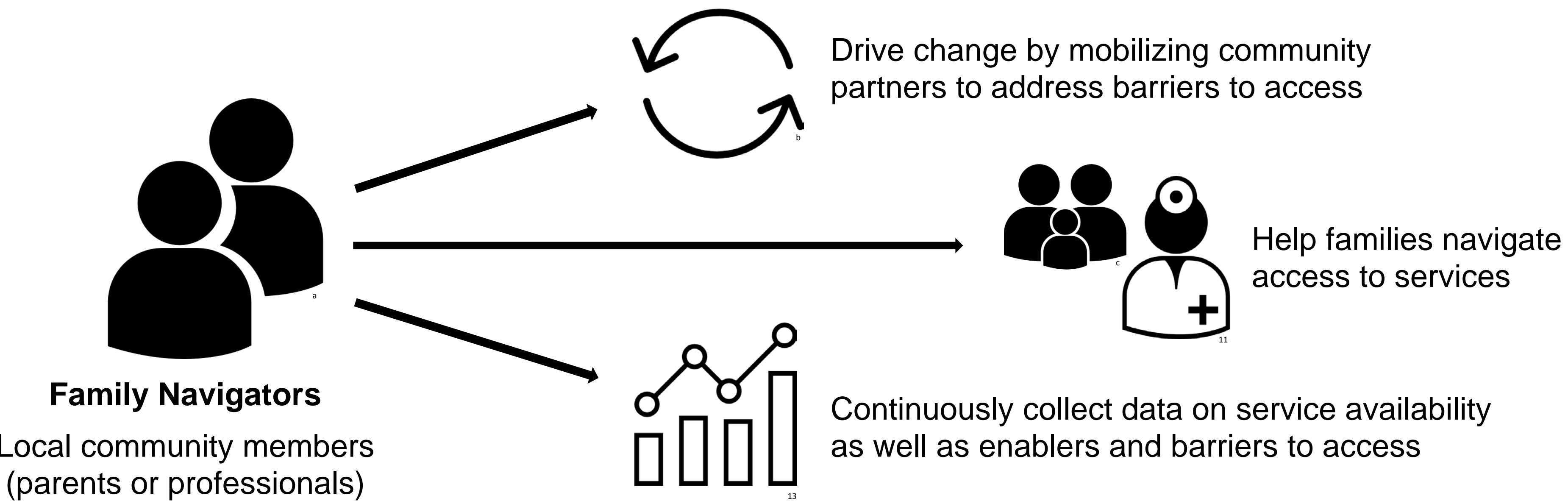
Child and Family Pathway

- Ideal minimum set of services available to children at risk for, or identified with ASD
- Three sections progress from what should be universally offered to what should be offered to children identified with ASD or another qualifying need
- Pathway used as basis for community inquiry to identify assets, gaps, barriers, and leverage points



ECQuIP Family Navigation Model

Draws on evidence for Family Navigations from “community health worker” and “patient navigation” models^{7,8,10}



Initial Findings

Barriers to Documenting Assets and Service Gaps

- Obtaining information about experience and barriers to access because families in target population underrepresented in community discussions
- Documenting service availability and gaps for the large geographic area
- Mapping community assets, gaps, and barriers with community partners impacted by challenging dynamics of race and systemic racism
- Relying on autism resource guides for greater Milwaukee that do not accurately reflect resources available to target population in urban core nor provide enough detail (e.g., funding accepted, service capacity, waiting lists)

Enablers to Documenting Assets and Service Gaps

- Engaging a wide group of knowledgeable and impassioned stakeholders
- Utilizing a multi-pronged approach to gathering information

Barriers to Helping Families Navigate the Pathway

- Addressing low diagnostic capacity in Milwaukee's urban core
- Enrolling families in FN due to lack of screening in urban core
- Helping parents access an autism screening tool if the child is older (i.e., free MCHAT-R/F only used up to 30 months old)
- Overcoming parental unawareness of, or misinformation about, service and support systems

Enablers to Helping Families Navigate the Pathway

- Utilizing an experienced parent/professional from the community as the FN

Recommendations and Next Steps

- Involve families from target population earlier in process through family listening sessions, focus groups, and interviews
- Map families’ experiences and barriers navigating the pathway
- Understand the supports families access to help with navigating the pathway
- Identify more community members to serve as Family Navigators
- Develop better methods for mapping service availability, gaps, and barriers in urban core
- Drastically improve screening availability to target population
- Consider how to address service systems that aren't operating as intended (e.g., county requiring SSN to access Medicaid waiver evaluation)

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