Increasing Mental Health Engagement From Primary Care: The Potential Role of Family Navigation

Leandra Godoy, PhD,a,b Stacy Hodgkinson, PhD,a,b Hillary A. Robertson, MPH,a Elyssa Sham, BA,b Lindsay Druskin, BA,b Caroline G. Wambach, BS,a Lee Savio Beers, MD,a,b Melissa Long, MD,a,b

Early engagement in mental health intervention is critical, yet the vast majority of children who are experiencing mental health concerns are not receiving needed services. Pediatric primary care clinics have been recognized as an ideal setting in which to identify and address mental health problems early, although engagement in mental health services within primary care and in community-based settings remains low. Navigators, or individuals with experience in navigating the mental health system, have been highlighted as promising partners in efforts to improve engagement in mental health services. Navigation has a growing body of research support among various populations, including adults and in targeting medical concerns, but there has been limited research on integrating family navigators into pediatric primary care settings to address mental health concerns. Despite this gap in the evidence base, we believe there is significant promise for the use of this model in addressing children’s mental health needs. In this report, we discuss factors contributing to high levels of unmet mental health needs and low levels of engagement in mental health services, the role that navigators can play in increasing engagement in mental health care, and implications and recommendations related to integrating mental health–focused family navigators into pediatric primary care settings.

abstract

Drs Godoy and Long conceptualized and outlined the components of the review article, drafted sections of the manuscript, and revised and organized sections submitted by the coauthors; Dr Hodgkinson, Ms Robertson, Ms Sham, Ms Druskin, Ms Wambach, and Dr Beers drafted sections of the manuscript and reviewed and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Address correspondence to Leandra Godoy, PhD, Child Health Advocacy Institute, Children’s National Health System, 2333 Wisconsin Ave NW, Suite 317, Washington, DC 20007. E-mail: lgodoy@childrensnational.org

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SCOPE OF THE PROBLEM

Up to 20% of children meet diagnostic criteria for a mental health disorder at any given time; however, 80% do not receive needed services. Unmet need is higher among preschoolers, youth in the foster care and juvenile justice systems, immigrants, ethnic minorities, and children in poverty. There are also significant disparities in mental health access and use across racial and ethnic groups, with African American children in urban areas and Hispanic children in rural and urban areas less likely to receive mental health care compared with white children. Because 50% of lifetime mental health conditions begin before age 14 years, the early identification of mental health concerns is key to reducing future morbidity and mortality and to reducing health care costs, particularly for these vulnerable populations.

PRIMARY CARE AS A KEY SETTING IN WHICH TO ADDRESS MENTAL HEALTH CONCERNS

PCPs are uniquely positioned to identify and address mental health concerns early. Most children in the United States routinely access primary care, and PCPs offer an accessible, nonstigmatizing, and familiar space in which to discuss sensitive issues like mental health. Apart from school-based mental health professionals, PCPs are often the first access point for children with mental health problems. Given the significant role that PCPs can play, it is important to acknowledge demographic factors that may lead to variability in the quality of primary care received by children, particularly those from disadvantaged backgrounds.

Recognizing the limitations in PCP training, knowledge, and confidence, the American Academy of Pediatrics Task Force on Mental Health was formed in 2004 to enhance PCPs’ ability to address mental health concerns. The Task Force emphasized the importance of (1) implementing universal mental health screening, (2) increasing provider training to identify and treat common mental health problems, (3) increasing collaboration between psychiatrists and pediatricians, and (4) colocating and integrating mental health services in primary care clinics. Given these and other similar recommendations, more PCPs are identifying mental health concerns. Although PCPs manage many of these concerns within their practice (especially if they partner with integrated mental health clinicians), some children require referral to specialists. Unfortunately, mental health treatment engagement in the specialty setting and, to a lesser extent, in primary care, remains low.

ENGAGEMENT IN MENTAL HEALTH SERVICES

Mental health treatment engagement includes problem recognition, appointment attendance (initial and ongoing), and adherence to the treatment plan. Given the ease of definition and measurement, many studies are focused on initial appointment attendance. Estimates of no-show rates to pediatric specialty mental health appointments vary from 23% to 62%. Several factors influencing mental health service engagement have been identified, including caregiver perceptions and attitudes about mental health, skills and knowledge about navigating the mental health system, motivation and competing demands, caregiver mental health and other stressors, and logistic and environmental barriers.

Research demonstrates that caregivers’ perceived barriers are an important predictor of mental health service engagement and are related to the stigma caregivers feel about having a child with a mental health problem, their beliefs about the potential effectiveness of treatment, and their trust in mental health professionals. Fear of being blamed for their child’s mental health problems can be particularly influential in the help-seeking behaviors of families of color who already face discrimination. Additionally, caregivers who do not believe therapy will be beneficial for their children are less likely to have positive attitudes about mental health services, report experiencing more barriers to care, and are reluctant to initiate and continue mental health treatment. Racial and ethnic minorities are more likely to have had previous negative experiences in seeking mental health care and may come to expect worse outcomes that prevent them from engaging in care. Fears of hospitalization, side effects of medications, and stigma may lead some parents to consider whether the benefits of their child receiving mental health services are worth the risks associated with treatment.

Caregiver skills and knowledge about navigating the mental health system also impact treatment engagement. Families report that not knowing how to access mental health services and navigating referrals to specialty mental health providers can be confusing. In a study of mental health referrals from primary care for adolescents with attention-deficit/hyperactivity disorder, parents who better understood attention-deficit/hyperactivity disorder either through PCP education or personal knowledge were more likely to seek services for their children than parents who were not equipped with the same information. This understanding of the problem and of what the child’s mental health appointment will entail is an important part of early treatment engagement.
A family’s ability to connect with mental health care is also influenced by the caregiver’s motivation, including their desire to seek help balanced with other family demands. For many families living in poverty, basic needs such as food, housing, or employment often take priority over mental health services. Families with less social support, single parent-led households, and those living with >4 people are less likely to access mental health care.31,32 Caregivers may be more highly motivated to seek mental health care for their child when they perceive a crisis or feel an urgency for immediate treatment. Studies, however, are mixed as to whether children with more severe mental health concerns are more or less likely to engage with treatment.30 In line with these competing demands, caregiver mental health and life stressors impact a caregiver’s ability to seek help for their child. Children of caregivers who experience more depressive symptoms and stress are less likely to attend the initial appointment33 or complete mental health treatment.36 Maternal depressive symptoms can impact whether mothers seek preventive health care of any type for their children,38 which likely extends to mental health services. Other caregiver stressors negatively impacting engagement include domestic violence, substance abuse, and a history of trauma and toxic stress.31,43

Logistic and environmental barriers also influence engagement. The shortage of pediatric mental health professionals leads to long wait times for appointments. The mental health system in many parts of the country is fragmented, and insurance coverage is inconsistent.3,5,31,32,39 Families also face barriers related to the financial burden associated with mental health treatment, including the cost of transportation, missed work, and copays.37,39

**FAMILY NAVIGATION OVERVIEW**

Navigation is 1 way to improve access to and use of mental health services.44–46 We use the term “navigator” to describe an individual who supports a family or patient in establishing and maintaining health care. Many terms can be used to describe navigation, including peer, family, and/or patient navigator; coordinator; specialist; advocate; or champion.1 Navigators may assist in care coordination within or outside the primary care setting; address practical, social, and psychological barriers to care; and aid in empowering, educating, and bridging the communication gap between providers and families.1 Our focus is on child mental health, but navigators are used to address many health conditions among youth and adults. We draw from this broader literature base given the relative shortage of pediatric-specific literature. Additionally, our focus is on integrating navigators into primary care settings, but we recognize that not all practices have this capacity. In such instances, practices can partner with community-based organizations that provide navigation support.

**Navigation Models**

There are several navigation models, with variability in who serves in the navigator role.1 In clinician-led models, professionals (eg, care coordinators) serve as navigators.46 In peer-led models, individuals with lived experience in obtaining health services provide support.46 The shared experiences of peer navigators and patients is thought to foster rapport and build trust between the patient and the health care provider team because the navigator is perceived as being a credible and empathic source of information and support.47 Another model involves paraprofessionals or community members as navigators. Like peer navigators, paraprofessionals who share a community or cultural background with the family are thought to have an easier time building trust. Lastly, team-led models consist of a combination of individuals, such as peers and health professionals.46,48

Within each model, the level of navigator training and supervision varies and is often insufficiently described.1,46,49 Nonprofessional navigators, including peer navigators or paraprofessionals, often receive brief training in the target area (eg, autism) and on how to access relevant services. There are several navigation certification programs that are focused primarily on adult conditions, such as cancer50 and mental illness.51 The National Federation of Families for Children’s Mental Health currently provides the only national certification for certified parent support providers.52

**Navigation Services**

Navigators can offer a range of potential services that have been shown to increase engagement,53 although the following 5 types of supports have been identified: informational and/or educational, instructional and/or skill development, emotional and/or affirmational, instrumental, and advocacy (Table 1).46 Although different navigation models (eg, peer-led and clinician-led) can include similar content, the background, educational level, and experience of the navigators and leadership of each program can lead to differences in the content areas that are emphasized. For example, a focus on advocacy and parent well-being is commonly seen within family- or peer-led programs, whereas clinician-led programs tend to be focused on skill development, and team-led programs may offer comprehensive services across all 5 content areas.46,54 Navigation programs will vary in the type of support they can provide, but research suggests that programs offering the most diverse forms of...
support are the most effective, and it may be beneficial to allow for some degree of flexibility to ensure that the support is tailored to family need.55

**Navigation Financing**

Ensuring ways to finance navigation services is important for sustainability. Despite the costs of employing navigators and covering increased service use, research demonstrates that navigation can garner large returns on investment.56 The Centers for Medicare and Medicaid Services (CMS) considers peer support services as being “an evidence-based mental health model of care” and “an important component in a state’s delivery of effective treatment,” thus supporting states in their use of funding for navigation services.57,58 More states are covering navigation via Medicaid payment mechanisms, including fee-for-service billing and Medicaid plan waivers.57,59 As with other billed services, providers must comply with billing regulations, which can sometimes be challenging for navigators, particularly community-based navigators. Additionally, CMS outlines the minimum requirements that are considered critical to peer support, including supervision, care coordination, and training and credentialing.57 Although the focus from CMS has been largely on adults, there is growing support of parent peer programs, with several states developing parent curricula and enabling billing for family-focused services.54 In some states, professional navigators (eg, care coordinators) can bill for certain navigation activities using care management and related current procedural terminology codes.60,61 However, reimbursement varies by state and payer, and many navigation activities are not reimbursable.62

**NAVIGATION OUTCOMES RESEARCH**

Navigation research spans many settings, conditions, and populations, including the primary care setting, mental health conditions, and children, although specific research on navigation for children with mental health concerns in primary care settings is lacking. Most research on navigators comes from adult populations with significant health concerns, such as cancer or severe mental illness.63,64 Pediatric navigation research has addressed chronic disease management (eg, asthma and diabetes)65 and the promotion of early testing and intervention,66 with few studies that are focused on mental health.46,54 Given the limited research on the use of navigators for children with mental health concerns, we draw from research on other settings and populations to fill gaps and highlight the potential for navigators to improve mental health treatment and outcomes for children.61 We focus on the evidence for navigators to improve patient or caregiver knowledge and empowerment, increase service use, and improve health outcomes. When available, we reference pediatric mental health-focused studies within each of these sections.

Research has documented strong satisfaction with navigation46,67–70 and success in targeting factors that are important to mental health treatment engagement, such as increased knowledge of a particular diagnosis and its treatment65,71 and increased patient empowerment.37,72–76 Researchers in a systematic review of studies examining peer support for parents of children with chronic health conditions identified common themes from the 10 qualitative articles reviewed, including enhanced parent feelings of support, empowerment and coping, and decreased feelings of isolation, loneliness, and guilt.76 Navigation may also be beneficial for patients with diagnoses that are socially stigmatized and where stigma represents a barrier to care.77 For example, participants in a peer navigation program for patients who were HIV-positive reported that navigators were an important source of support, particularly in addressing psychological barriers, such as fear and shame, and for those who had not disclosed their diagnosis.77,78

Navigation programs have also been associated with increased service use, including linkages to care, adherence to recommended testing and treatment, and timeliness in obtaining health care services, even for patients who are at high risk for delays in care.44,45,64,79–81 In a meta-analysis of randomized controlled trials (RCTs) of navigation to improve health care use (most were focused on adult patients with cancer), pooled analysis revealed that navigation increased the likelihood of health screening uptake by 2.5 times and attendance at recommended appointments by almost 3 times.64 Similarly, in an RCT of adults with serious mental illness who were presenting for emergency care, patients assigned to a navigator group were more likely to access primary care after a psychiatric crisis compared with those assigned to a control group.82 Within pediatric

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**TABLE 1 Components of Family Navigation**

<table>
<thead>
<tr>
<th>Service Area</th>
<th>Example Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informational and educational support</td>
<td>Teaching families about child development or mental illness</td>
</tr>
<tr>
<td>Instructional and skill development support</td>
<td>Instruction on parenting strategies or crisis management</td>
</tr>
<tr>
<td>Emotional and affirmational support</td>
<td>Ensuring communication between families and providers and promoting caregiver well-being</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>Providing resources for respite care and transportation</td>
</tr>
<tr>
<td>Advocacy support</td>
<td>Informing caregivers about rights and negotiation strategies</td>
</tr>
</tbody>
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populations, working with lay navigators has been found to increase adherence to recommended services for newborns with abnormal hearing screens\textsuperscript{71} and children with suspected autism.\textsuperscript{80,83} In a study of navigation for children with emotional disturbances who are receiving special education services, families receiving weekly telephone calls from a parent peer navigator received more school-based mental health services and increased parent involvement in these services than those who did not, with particular differences noted among highly stressed parents.\textsuperscript{69,84} Lastly, in a study of parent peer navigators working with families of children with mental health concerns, those receiving navigation (in this case, emotional support and help addressing tangible barriers) were more likely to initiate mental health services compared with families receiving usual care.\textsuperscript{85}

Although the ultimate goal of navigation programs may be to improve health outcomes, findings are more limited in this domain.\textsuperscript{72,86} In an RCT of African Americans with severe mental illness who were experiencing homelessness, participants receiving peer navigation demonstrated improvements in self-reported physical and mental health status and quality of life compared with participants receiving treatment as usual.\textsuperscript{87} Additionally, a study in an adult mental health inpatient setting found that patients working with professional navigators showed significantly better clinical outcomes than those receiving treatment as usual, including greater improvement on measures of psychopathology and distress, less time spent in the ICU, and lower rates of readmission in the month after discharge.\textsuperscript{88} In the study referenced above of children with emotional disturbances receiving special education services, children in families receiving peer navigation received fewer suspensions.\textsuperscript{84} Lastly, in a study of youth with special health care needs and their families who received professional and peer navigation within a medical home, families reported fewer unmet needs and improved parent ratings of child health and family functioning.\textsuperscript{70}

**RESEARCH GAPS AND RECOMMENDATIONS**

Research across multiple populations and settings has demonstrated that navigation can successfully target factors that are considered important to mental health engagement. However, gaps remain in our understanding of navigation. There is significant variability in the navigator role. This includes differences in navigator background (eg, education level), their level and type of training, the type of supervision provided, and the scope of services delivered. This variability allows for flexibility in implementation of navigation across settings and studies, but it also poses challenges, such as difficulty comparing results between studies and drawing conclusions. Therefore, an important next step is to standardize navigation implementation and research definitions, measures, and protocols.\textsuperscript{89,90}

Rigorous research (eg, RCTs), particularly within mental health–focused pediatric navigation literature, is limited. Few studies have examined mechanisms of change, specifically which components of a program or characteristics of a navigator are most important. Increasing rigor and examining specific components of navigation interventions, mediators and moderators of change, and cost outcomes will help to advance the field. Research could also be expanded in scope. It has been focused heavily on initial engagement (ie, attendance at intake) rather than ongoing engagement in services,\textsuperscript{29} and there is limited research on navigation in the pediatric primary care setting. Given the growing need to support families identified in the primary care setting as needing additional developmental or behavioral services, expanding efforts into early-childhood mental health prevention and early intervention domains would be beneficial.

**RECOMMENDATIONS FOR INTEGRATING FAMILY NAVIGATORS INTO PEDIATRIC PRIMARY CARE SETTINGS**

The literature suggests strategies for using navigators in pediatric primary care settings to promote mental health service engagement and to help ease the burden placed on PCPs to manage their patients’ mental health concerns. Where possible, recommendations are drawn from research and guidelines, such as those from the Pillars of Peer Support Services summits.\textsuperscript{91} However, given limited research in certain areas, recommendations are also informed by the author team’s experience in implementing navigation programs. We provide both general and specific suggestions across the 5 main areas of navigation support. Suggestions are applicable regardless of the type of navigation employed (eg, peer-led versus clinician-led) because there can be overlap in tasks, although we note places in which recommendations are more relevant to 1 model.

**Overarching Recommendations**

In determining how to integrate navigators into their workflow, practices can consider existing resources and infrastructure, including team composition and role definition, to ensure that the navigation support provided addresses existing gaps in patient care and complements current patient care processes. For example, practices with case managers may be focused on recruiting peer navigators, whereas practices without such support may prioritize hiring clinicians. Practices with more limited
resources can consider partnering with community-based programs to provide navigator support. Developing clear role definitions for navigators and providing adequate training and supervision are critical, particularly for supporting peer navigators when setting boundaries and stress management may be more relevant. This work can be used to build off of the National Federation of Families for Children’s Mental Health’s National Certification for Certified Parent Support Providers. PCP and staff training is essential to ensuring that practices can effectively work with navigators. This includes increasing provider and staff capacity to understand barriers to family engagement in mental health care and the unique role that team members can play in increasing treatment engagement. To the extent that PCPs can gain exposure to the concept of care coordination and family navigation in their education and training programs, they will grow increasingly skilled at working collaboratively with care teams. Additionally, efforts to clarify clinical processes (eg, who requires case management versus peer navigation), strengthen communication among staff, and increase the interdisciplinary diversity of teams will likely increase the success of navigation programs. A continued focus on creating sustainable navigation funding is also critical. By building on the success of Medicaid payment mechanisms, such efforts could expand coverage to more states, ensure states have clear financing plans for family navigation (as opposed to just adult models), and address coverage gaps and billing concerns.

**Informational and Educational Support**

As more PCPs engage in routine mental health screening and increasingly attend to mental health issues, they face challenges of time limitations and how best to shepherd families from problem identification through treatment. Navigators can support families through this process. This may include ensuring the parent understands information provided by the PCP and providing additional education about mental health screening results, treatment options, and the referral process (eg, expectations about wait times). Because the timing of navigation may be associated with its success, initiating navigation services at the visit in which the mental health concern is first raised or soon thereafter is ideal. At a practice level, navigators can identify community-based referral options and provide feedback on practice referral lists because navigators, particularly peer navigators, may have a sense of community perceptions of local providers. While providing information and educational support to families, navigators can address caregiver attitudes about mental health, thus potentially increasing their engagement in treatment.

**Emotional and Affirmational Support**

A caregiver’s well-being and stress can impact their ability to engage in services. Thus, navigators can fill a critical role in providing emotional or affirmational support to families, particularly in primary care in which limited time makes it hard for PCPs to provide the depth of support that many families need. PCPs can solicit navigation support for parents who may feel ambivalent about engaging in mental health services, have difficulty trusting the process, or who are experiencing difficulty adjusting to or managing their child’s mental health issues. The provision of such support can also help to model healthy relationships for parents. Although this type of support is typically provided by peer navigators because of their lived experience, all types of navigators can provide emotional support, particularly by engaging in reflective listening.

**Instrumental Support**

Process-oriented tasks, such as coordinating transportation and assisting parents to complete forms, are among the many ways in which navigators can provide instrumental support. Instrumental support can be used to help families overcome environmental and logistical barriers to accessing mental health treatment of their child and address the caregiver’s own self-care needs. Within pediatric primary care settings, some research has revealed that navigators were more successful when they focused on process-oriented needs rather than other concerns that required behavioral change by patients and families.

**Advocacy Support**

Navigators can also help parents advocate for mental health services and other resources in their community. Such support can be critical to ensuring that caregivers have the knowledge, skills, and...
confidence to address barriers to mental health engagement. Advocacy-related tasks may include accompanying a parent to a school meeting or visiting with service providers in the community. Navigators can also provide advocacy support by either directly sharing or encouraging parents to share their challenges, fears, and desires with the child’s health care providers.

CONCLUSIONS

We commend the increased focus placed on mental health in pediatric primary care as a way to increase the early identification, prevention, and treatment of mental health concerns. Despite these efforts, many families still struggle to engage with mental health services. Innovative solutions are imperative. We see the integration of navigators into pediatric primary care as a promising way to increase mental health engagement and reduce unmet mental health needs. Efforts to address the above-mentioned research and practice gaps can be used to strengthen the evidence base and inform how such programs are best designed and implemented.

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ABBREVIATIONS

CMS: Centers for Medicare and Medicaid Services
PCP: primary care provider
RCT: randomized controlled trial

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