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Family Navigation Implementation Strategies: Improving Systems of Care

Family Navigation Strategies Implemented in Title V and Community-Based Programs to Better Serve Children and Youth with Special Health Care Needs and their Families (Issue Brief)



Introduction

Background

Families of children and youth with special health care needs (CYSHCN) typically receive support from multiple systems such as health care, education, mental/behavioral health, social services, and respite. However, the difficulties with identifying needs, seeking out pediatric specialties, dealing with financial costs, and ensuring adequate insurance coverage lead to the fragmentation of care for this vulnerable population. In addition to these challenges, families of CYSHCN tend to report higher levels of caregiver burden due to the specialized needs of their child,ⁱ which underscores the need for support from a family navigator as families struggle to traverse the health care system.

Like patient navigation,ⁱⁱ ⁱⁱⁱ family navigation is an evidence-informed strategy intended to guide families through and around barriers in the health care system so that they may overcome obstacles faced when accessing or receiving care. Family navigators can provide psychosocial support, help coordinate services, provide education related to a child's health care needs, and alleviate challenges. With an understanding of a child's health issues, navigators can give informed recommendations to the family. Additionally, navigators can decrease fragmentation of services by coordinating appointments for children and families; by facilitating communication among families and providers; and by providing resources that can alleviate barriers related to transportation, finances, insurance, language, and other issues.^{iv} Some models of family navigation are also designed to help reduce health disparities for children and adolescents in medical settings.^v

Throughout the United States, the terms used to describe family navigation vary, and they are defined differently, and/or implemented differently based on the setting, whether a hospital, health care system, or state system. A one-size-fits-all approach does not work; family navigation requires building unique relationships with the child and the family. This issue brief aims to highlight how family navigation programs are being implemented across the United States and to share specific states' examples of family navigation programs and activities in state systems of care, including state Title V Maternal and Child Health (MCH) programs and community-based programs.

Family Navigation and Title V

State Title V MCH programs share a common mission to improve the health and well-being of women, children (including CYSHCN), and families. Not surprisingly, an environmental scan of the Title V Information System (TVIS)^{vi} revealed that family navigation and similar programs are popular strategies implemented to support women, children, and families. In some cases, the term "family navigator" has been used interchangeably with other terms, such as [nurse navigators](#), [parent navigators](#), [patient navigators](#), [peer support specialists](#), and [resource specialists](#). AMCHP obtained information presented in this issue brief through the TVIS website by searching all Title V program annual reports for the terms 'navigator,' 'specialist,' 'peer support,' 'family,' and 'educator.' By conducting searches using these terms, AMCHP was able to filter and review the narratives in the Annual Report and Plan for the Application Year 2018 for each of the states and territories.

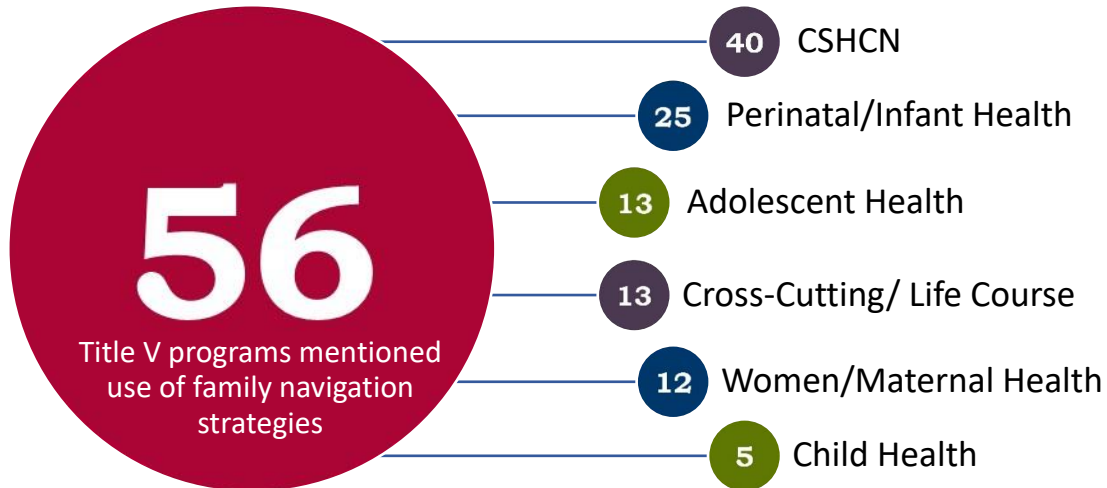
Family Navigation Definitions and Roles

As previously mentioned, the components of family navigation vary widely depending on whether the setting is a hospital, health care system, or state system. Family navigation programs are found in state or community-wide coalitions, health care systems, nonprofit organizations, state departments of health, state department of human services, and family/parent-led organizations. The type of setting influences the type of navigation delivered. In pediatric settings, for example, family and parent navigator programs can support, educate, inform, and empower families to communicate and work with providers as well-rounded advocates for their child's medical needs.^{vii} In health care systems, family navigators help patients and families overcome obstacles and challenges by providing guidance, support, and resources to help families understand the financial, logistical, and sociocultural components of health care. Regardless of the setting, family navigators must assess the population they are serving to identify the most immediate needs.^{viii}

The environmental scan identified the most common roles and activities that family navigators perform^{ix x}:

- Receive professional training to become qualified (including parent/professionals).
- Provide guidance in navigating the health care and/or education systems.
- Help families locate and access community services and supports.
- Build advocacy skills in family members.
- Provide family-to-family support, often through sharing lived experiences and listening.
- Serve as a bridge between different sets of providers and systems.

Figure 1. Mentions of family navigation strategies by Title V population domains



The environmental scan identified states and territories that engage in family navigation activities and aligned their activities to the six MCH population health domains used in the 2017 reporting (maternal/women's health; perinatal/infant health; child health; adolescent health; children with special health care needs; and cross-cutting or life course).

Table 1 provides a broad overview of states and territories that incorporate family navigation activities as a strategy in their 2018 block grant applications. The Title V action plans address priorities across six MCH population health domains mentioned above. Nearly all (56 of 59) Title V programs are using some form of family navigation or similar strategy in their action plans.

Findings

The following are common themes that states are using in their strategies to implement family navigation activities across the six MCH domains:

- The majority (40) are using family navigation activities in strategies to address priority needs related to CYSHCN activities. Examples of these activities include involving the family in the medical home and educating families on care coordination. States are also focusing on activities related to transition services for parents and youth support, and they are guiding families on topics such as financial assistance, insurance, transitioning to adult health care, and independent living.
- The domain for cross-cutting/life course topics included navigator or specialist activities/programs in 13 states on topics such as obtaining adequate health insurance coverage and oral health.
- Women's/maternal health (13 states) and perinatal/infant health (25 states) domains covered many overlapping topics, including the need for breastfeeding and nurse/family partnerships in the search for navigator-supported programs. Across the perinatal/infant health domain, there are many examples of peer counseling using

breastfeeding and lactation support specialists. For example, Texas has a Women, Infants, and Children (WIC) Peer Dad program that provides support and education to fathers on breastfeeding, infant care and behavior, and caring for the mother.

- In the adolescent health domain, 12 states have implemented or planned family navigation or peer support initiatives. Adolescent health in many states focuses on peer counseling programs; youth health care services; and education on mental health, disability, reproductive health, injury prevention, and transition services.

Table 1. Family navigation strategies in state/territorial Title V action plans, organized by domain

Domain	CSHCN	Cross-Cutting/Life Course	Women/Maternal Health	Adolescent Health	Child Health	Perinatal/Infant Health
States/Territories	AL, AK, AS, AZ, AR, CA, CO, DC, GA, ID, IN, IA, KS, KY, LA, MD, MA, MN, MS, MT, NE, NJ, NM, NY, NC, ND, OH, OK, OR, PA, PR, RI, TX, UT, VT, WA, WI, WV, WY	AS, KS, NV, NH, NJ, NM, NC, ND, OH, RI, SD, WA, WI	AK, DE, IL, LA, MS, NJ, OR, RI, SD, TN, UT, WA, WY	GA, IL, IA, MD, NE, NV, PA, TX, VA, WV, WI, WY	AL, IL, KS, NV, VA	AK, AZ, CA, CO, CT, GU, HI, ID, KY, ME, MO, MP, OK, OR, PR, RI, SC, SD, TX, UT, VT, VI, WA, WI, WV

In addition, many Title V programs noted strong connections with family navigation efforts through Family Consumer Partnership activities in their action plans.

Case Studies: Applying Family Navigation to Improve Systems of Care for Children with Autism Spectrum Disorder and Other Developmental Disabilities

To implement the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act, the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) provides funding to states to improve access to care through referrals, timely diagnosis and feedback, and entry into high-quality, coordinated care across systems of care for children with autism spectrum disorder and other

developmental disabilities (ASD/DD).^{xi} Four states—Delaware, Rhode Island, Washington, and Wisconsin—have current grants to improve state-level systems of services to integrate care for children and youth with ASD/DD, with a special emphasis on improving care for children and youth with ASD/DD in medically underserved populations. With this grant funding, each state is implementing family navigation strategies.

The following case studies discuss the history of family navigation in each of the current grantee states and in one past grantee state, Iowa. The case studies also highlight the state’s current (and in the case of Iowa’s, past) activities, sustainability strategies, successes, and resources. Each of these selected states were provided with a set of questions to address. Because each state program directly responded to these questions, not all programs responded in the same way.



How did family navigation begin in your program/state?

Autism Delaware was started in 1998 by a group of families who shared the common experience of autism. The group soon realized that by working together they could provide much-needed service and support to Delaware's autism community and have a much stronger voice. In 2010, Autism Delaware and the Lower Delaware Autism Foundation (founded in Sussex County) merged to create one strong, united statewide nonprofit organization. Today, thanks to dedicated volunteers, talented staff, and generous supporters, Autism Delaware has grown to become a strong advocate for the autism community and provides services and resources.

What is the main role(s) of family navigators in your program/state?

Autism Delaware provides direct access to knowledgeable family navigators who can help guide new parents through the maze of medical and educational issues that surround an autism diagnosis. Anyone may contact the family navigators to seek answers to general or specific questions or speak to someone who has been through a similar experience. While family navigators cannot answer all questions, Autism Delaware's staff do their best to help parents find the best answers available. Autism Delaware's family support services are resourceful and engaging and help families become advocates for their children. Autism Delaware's staff maintains current and comprehensive knowledge of systems and services to provide the best support and information to families affected by ASD.

Family support team members engage individuals and families as well as the groups and organizations who serve them. Autism Delaware is a statewide organization serving people on the autism spectrum across the lifespan, holding the belief that families should have readily accessible, current information about ASD. This includes information on symptoms, traits, treatments, the latest research, and available services.

Does your program/state provide training to family navigators? If not, who does? What kind of training is provided?

Autism Delaware provides training to new family navigators. This consists of formal training on autism, state services, cultural competence, and working with families. In addition, new family navigators shadow experienced navigators for up to one year.

How is family navigation funded in your program/state?

Until 2016, all family navigation was funded through fundraising revenue by Autism Delaware. In 2016, the General Assembly of the State of Delaware passed legislation that required the state to provide a minimum of \$100,000 in funds for family navigation and parent education. This amount covers approximately 30 percent of the cost to provide family navigation statewide. Also, in 2016, Autism Delaware received a subaward from the HRSA Building Bridges Grant. This funding provides additional resources for family navigation to cover roughly 25 percent more in total family navigation costs. Neither of these funding sources covers expenses related to social and recreational programs that improve the quality of life for families of children with autism.

How do you plan to sustain family navigation activities in your program/state?

Delaware's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. This benefit includes the Family Peer Support Services (FPSS) intervention. Services and outcomes of the FPSS are similar to those of Autism Delaware's Family Navigation program. In order to provide these services in Delaware, family navigators must become certified family peer advocates, and Autism Delaware must become an authorized vendor with the Division of Prevention and Behavioral Health. This service is only available to children/families receiving Medicaid. We continue to explore other ways, such as working with the Title V MCH program, to support family navigation for those who do not qualify or have not yet qualified for Medicaid.

Do you have any successes/resources from your family navigation activities that you would like to share?

In 2016/2017, Autism Delaware's family navigators had more than 1,800 parent contacts. They supported families on issues related to child care, education, evaluation, diagnosis, and entitlement programs. In June 2017, Autism Delaware added two new family navigators, both of whom are bilingual, which substantially increased outreach to the Hispanic community as they could engage directly with families. The organization has also invested resources in improving advertising and communication to the Hispanic community through print and radio ads across Delaware in several publications and media outlets.

Autism Delaware's success stories of assisting families are numerous. One parent shares, "Thank you from the bottom of my heart for all of the good work you do. My husband and I would have been lost without Autism Delaware. I'm not sure how often you or others hear it, but I am incredibly thankful that there is an active, intelligent community to turn to and participate with."

[View Autism Delaware's Fall newsletter](#) focused on family support and the new family navigators.

How did family navigation begin in your program/state?

Julie Beckett, the mother of Katie Beckett, was Iowa's first family navigator. In 1984, Julie was hired by Child Health Specialty Clinics (CHSC), Iowa's Title V agency for CYSHCN, as a "parent consultant."



Julie was soon joined by two more parents, both fathers, to provide emotional support and systems navigation to Iowa's families of CYSHCN. CHSC is part of the Division of Child and Community Health (DCCH) Department of Pediatrics at the University of Iowa.

What is the main role(s) of family navigators in your program/state?

CHSC currently has a statewide Family Navigator Network comprised of 28 parents of CYSHCN. The family navigators work directly with families, partnering with them to identify and prioritize family needs, model and coach healthy coping strategies, locate and facilitate access to community services and supports, provide guidance in navigating the education system, coach families in building advocacy skills. Most importantly, family navigators provide family-to-family support by listening to concerns and sharing experiences.

Does your program/state provide training to family navigators? If not, who does? What kind of training is provided?

In 2009, CHSC staff developed a formal, face-to-face training program for family navigators associated with the Community Circle of Care program in northeast Iowa. Currently, CHSC has a contract with Iowa's Division of Mental Health and Disability Services to develop a "family peer support specialist" training and credentialing program to prepare family members to serve families of children with serious emotional disturbances in the state. Family navigators receive monthly continuing education based on the MCH leadership competencies.

How is family navigation funded in your program/state?

Several funding sources support the statewide Family Navigator Network. Foundationally, the Title V Block Grant supports family navigators working in regional centers. CHSC also receives funding from the Iowa Department of Education for family navigators working in Iowa's Early Intervention program. Additional sources of funding include the Iowa Department of Human Services for family navigators serving in the Pediatric Integrated Health Home and Community Circle of Care locations administered by CHSC; the Iowa Department of Human Services for family navigators working in the Iowa waiver system; and the University of Iowa for a family navigator working in an interdepartmental autism center. Additional funding from Iowa's Division of Mental Health and Disability supports workforce development by training family peer support specialists, including family navigators, across the state.

How do you plan to sustain family navigation activities in your program/state?

Iowa plans to sustain family navigation activities by strengthening and expanding the family navigator model in the

state. “Family Support and Engagement” is embedded in the Division’s Strategic Plan, and “supporting the growth of the Division’s Family Navigator Network” is a key strategy. Additionally, family navigator services are part of every CHSC program and in every submitted grant. DCCH’s family peer support specialist training program will convene a “stakeholder summit” in 2018 to discuss ways to promote and sustain the model.

Do you have any successes/resources from your family navigation activities that you would like to share? A “family navigator consult” process has been developed to facilitate and expedite university provider referrals to family navigator services through the electronic medical record. A process for external referrals has also been developed. In addition, since 2014, family navigators have developed family engagement activities such as developing a family advisory council and family leadership trainings.

Do you have any lessons learned from your family navigation activities that you would like to share? We know that the greatest needs for families after a special health care diagnosis are for emotional support, followed by information about how to manage their children’s conditions.^{xii} Family navigators are invaluable for providing that emotional support and access to community resources. They are masters of finding strengths in every family and building relationships, so that families will reach out to them in success and crisis.

How did family navigation begin in your program/state?



The Rhode Island (RI) Department of Health implemented a family navigation program ([Pediatric Practice Enhancement Project, or PPEP](#)) following a Title V needs assessment in 2004. The survey showed that doctors were committed to caring for children with special health care needs, but they were not confident they met all the needs of the children they served. RI had resources but finding and accessing them was time-consuming, and the medical practices didn’t have the additional resources or knowledge to help families. The Department of Health created a pilot program that provided parent consultant services to physicians and specialists supporting CYSHCN and their families. The outcomes were impressive in terms of quality of care and cost savings. In 2005, The Autism Project hired a part-time parent consultant to support the families in the organization’s programs.

What is the main role(s) of family navigators in your program/state?

Family navigators are the bridge between physicians and state resources. Their job is to provide information, resources, and support. Navigators educate parents on positive advocacy during individualized education program (IEP) meetings and other interactions with professionals. Their goal is also to decrease the feeling of isolation that so many parents of children with special health care needs experience. Family navigators do this through training, workshops, family events, and support groups.

Does your program/state provide training to family navigators? If not, who does? What kind of training is provided?

The Autism Project provides extensive training for the family navigators. All new hires complete a 10-hour, in-person training with experienced navigators. The goal is to educate them on autism spectrum disorders, The Autism Project’s philosophy, interventions, state and local resources, financial information, insurance, how to speak with and support families. It is most important to teach family navigators how to “meet families where they are” in their journeys. Rhode Island Parent Information Network (RIPIN) provides training on resources, advocacy, and facilitating support groups, among other topics.

How is family navigation funded in your program/state?

The navigators at The Autism Project are funded by fundraising revenue and the HRSA State Planning and Implementation Grants for Improving Services for Children and Youth with ASD/DD. Prior to receiving the grant, The Autism Project only dedicated 50 hours of staff time to navigation support. Currently, The Autism Project dedicates 170 hours.

How do you plan to sustain family navigation activities in your program/state?

There is a program for certified community health workers that The Autism Project is planning to utilize for family navigators on staff. This will result in some changes to the work already being done, and The Autism Project will need to investigate the impact the program may have on the role of family navigators on staff. This program provides an opportunity to strengthen The Autism Project's involvement in communities and sustainability efforts.

Do you have any successes/resources from your family navigation activities that you would like to share?

The HRSA State Planning and Implementation Grants for Improving Services for Children and Youth with ASD/DD enabled The Autism Project to provide additional training to their repertoire. This training enables navigators to circulate into the community. While there, the navigators connect with families and/or people working with families and can provide on-the-spot support or assist families in making appointments. This strategy is much more proactive than waiting for the phone to ring in the office. It is important for navigators to be present at community events on a consistent basis so that groups and their members, families, and friends are familiar with the services provided and how these services can potentially help constituents. The greatest success is seeing a once sad and overwhelmed parent advocating for their child with confidence. They have a new attitude and think, "I can do this. I'm helping my child!" Giving parents tools to advocate for their children is so much more powerful than doing it for them.

Do you have any lessons learned from your family navigation activities that you would like to share?

The greatest lesson learned is that navigators need extensive training to obtain the information and tools necessary to support families. Navigators need to know more than the families and to show confidence that they can help the families. That said, it is equally important to empower the navigators to inject their personality into their work. Each navigator has different strengths, which should be developed, to create a high quality, sustainable program that can reach a diverse set of people. Additionally, it is crucial to make sure navigators have the base of information that instills confidence in their position, thus building sustainable staff members. The Autism Project has learned that it is critical to have navigators who are bilingual, because having support and receiving information in a family's native language greatly improves outcomes for families and children.

Washington State Department of Health's CYSHCN Program, Autism Spectrum Disorders & Other Developmental Disabilities "AS3D" Grant

How did family navigation begin in your program/state?

Family navigation services for families with children with autism spectrum disorders and other developmental disabilities (ASD/DD) have been in existence for decades in Washington state. A variety of services are offered by different organizations and agencies across the state, including but not limited to the Family to Family Health Information Center- PAVE; WithinReach, and Parent-to-Parent of Washington. A major strength of family navigation and support in Washington is that most models use parents or family members of CYSHCN as navigators, because they have unique knowledge and expertise about the needs of families and about local health care systems for CYSHCN, as well as effective advocacy strategies and the empathy needed to support other families. A major challenge is the variability in the scope, reach, and expertise of these organizations. Some of the models are statewide, while many are implemented at the local or community level. Through the AS3D grant, the Washington State Department of Health's Children with Special Health Care Needs (CSHCN) Program is partnering with three prominent organizations who offer family navigation services to families with children with ASD/DD – Open Doors for Multicultural Families, Northwest Autism Center, and Washington Autism Alliance and Advocacy - to empower families and increase access to culturally and linguistically appropriate information and health care systems and services.

What is the main role(s) of family navigators in your program/state?

Within our AS3D grant, 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. Family navigators work with families to share helpful resources and make connections to services. Often, they share components of their personal story as part of the process to acknowledge a shared experience with the family, which helps engender trust and safety.

Does your program/state provide training to family navigators? If not, who does? What kind of training is provided?

Through the AS3D grant, the CSHCN Program currently has three contracted partners who are providing ASD/DD specific training on a variety of helpful topics to family navigators and care coordinators who work for many different organizations and agencies around the state. Training topics include, but are not limited to, how to empower and partner effectively with culturally and linguistically diverse families, how to navigate public and private insurance benefits for ASD/DD in Washington, and how to help families understand the multiple systems of health care and related services needed by families and children with ASD/DD.

How is family navigation funded in your program/state?

As mentioned above, some funding for family navigation is provided through the AS3D grant. Additionally, Washington's CSHCN Program has a full-time Family Engagement Coordinator who provides support to family navigators through a variety of means, including sharing resources and training, connecting them to other partnerships, modeling collaboration, sharing policy and program information, and contract management. Washington's behavioral health agency has a wraparound program which includes peer mentoring and navigation services which are billable to Medicaid for individuals who meet eligibility criteria. There are several communities that train family members to be community health workers, who provide family navigation services to families on specific health needs and are located within and funded by a variety of organizations depending on community resources. Examples include local health departments, doctor's offices, and managed care organizations (MCOs).

How do you plan to sustain family navigation activities in your program/state?

The family navigator training offered through the AS3D grant is free for participants and is designed to build lasting skills, knowledge and capacity among the many organizations and agencies that provide family navigation services across the state. Offered trainings include a variety of beginner and intermediate level topics. Once the grant ends, some of our AS3D partners have plans to offer fee-for-service trainings, based on feedback from participants about what advanced training they may need to be successful. We also hope to continue to build a strong focus on evaluation and data-driven outcomes in family navigation, which can demonstrate the value of these services when responding to future funding opportunities from health systems, MCO's or local and regional governments.

Do you have any successes/resources from your family navigation activities that you would like to share?

Our state is very geographically broad, and the AS3D grant has allowed us to create new partnerships with family navigators in other parts of the state that were not previously represented. This has given us a greater reach across the state of Washington. We plan to compile and share some highlights and successes from our AS3D family navigation strategies once the grant ends.

Do you have any lessons learned from your family navigation activities that you would like to share?

Open Doors for Multicultural Families, who specializes in cultural brokering, has shared the ways in which the strategies they use in their family navigation model differ from those used when working with dominant culture populations. This has taught us that information and services do not always directly translate from the dominant culture to culturally and linguistically diverse families. The reality is that the different methods of communication, the extra time for translation and interpretation, and the extra support that may be needed while adapting to the needs of culturally and linguistically diverse families can be more time-consuming and involved. These items must be

taken into consideration when allocating resources, to ensure that diverse families can be reached, and their needs can be met in a timely manner.



Starting in 2000, the Wisconsin Children and Youth with Special Health Care Needs (WI CYSHCN) Program (Title V) has supported a network of regional centers. Staff at five CYSHCN regional centers help families across the state navigate the care system for their children with ASD/DD and special health care needs (SHCN). CYSHCN regional center staff include professionals from disciplines such as social work as well as parents of CYSHCN. Additional Title V-affiliated family navigation support is offered through the Family-to-Family Health Information Center (Family Voices of Wisconsin) and Parent to Parent of Wisconsin. In both agencies, parents of CYSHCN assist other parents through education, information, leadership development, and emotional support.

Wisconsin's ABC for Health (health benefits counseling) and First Step programs round out the Title V family navigation support. First Step offers a searchable online resource database and a 24-hour information and referral hotline. These supports for navigating service systems have been available to all families of CYSHCN, not just those with a member who has ASD. An even broader set of organizations offer more specialized help to families. These organizations include local chapters of the Autism Society; Alianza Latina Aplicando Soluciones; Wisconsin Family Ties (social, emotional, behavior, and mental health problems); and Wisconsin Family Assistance Center for Education, Training, and Support (education and special education). Together, these organizations help families navigate the range of services they need. In most situations, they can help families who have a child identified with a SHCN to seek out support. Family navigation services are also offered by some clinic-based services, which can include emotional support and information and referral prior to, during, and after a clinic visit.

The Wisconsin Care Integration Initiative is piloting a specific "Autism Family Navigation" model that builds on this network of existing supports and the 2015 Act Early State Plan to help families navigate autism systems of care. A unique part of the Autism Family Navigation pilot is that family navigators are helping to identify families whose children do not yet have a specific concern for ASD, which has meant working with community partners to understand service gaps and opportunities for reaching families who have fallen through the cracks.

The Autism Family Navigation model is drawing from two approaches to family navigation. The first is a patient navigation model applied to navigating services such as screening, diagnostic assessment, and interventions. The second is a peer-to-peer model in which navigation support is offered by a parent member of the local community, facilitating a mutual understanding of specific community needs. Family navigators are offered a training plan that combines online training, local training, and live practice opportunities. Core training requirements are supplemented by training that might be more specific to local needs and practices that are culturally relevant. Family navigators also have access to the research-based "Family-Centered Autism Navigation" (Family CAN) interview tool, which helps family navigators support families to develop a plan of action that matches families' needs and priorities for accessing services and supports for their child with ASD.

Conclusion

As shown in the background information, findings from the environmental scan, and case studies, the work of family navigators occurs in many ways. Family navigators are tasked with locating and accessing community services and supports, providing guidance in navigating the education system, building advocacy skills in family members, and, most importantly, providing family-to-family support by listening to concerns and sharing experiences. This issue brief provides a high-level

overview of the types of family navigation activities that state and territorial programs are implementing. Family navigators need to understand the importance of culturally sensitive communication with the families and children they work with is a crucial component to forging this relationship. Furthermore, cultivating relationships with community partners when caring for the CYSHCN population is crucial when allocating resources and information on grants that will fund navigator training programs. The role of a family navigator requires widespread advocacy for the

family, the child, the training program, the specialists, and the continued education and partnerships within the program.

Next Steps

Information included in this issue brief provides a systematic overview of family navigation roles and approaches and references specific state efforts that highlight successful family navigation programs. In coming years, AMCHP hopes that this continued work through the State Public Health Autism Resource Center (SPHARC) will assist Title V programs in continuing to implement family navigation as a key strategy in improving the systems of care for CYSHCN and their families. Additionally, the data will guide AMCHP's continued efforts to create meaningful technical assistance opportunities to help states advance the use of family navigation. Furthermore, AMCHP hopes to learn more on how

state Title V programs communicate the value of family navigation, by using the data included in this issue brief on the benefits of family navigators. These resources will expand the repository of promising policies and practices featured on the [State Public Health Autism Resource Center](#) website, which is accessible to all Title V programs and their state and national partners.

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The Association of Maternal & Child Health Programs is a national resource, partner, and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

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