



innovation hub

AMCHP | *Explore. Build. Share.*



MCH Innovations Database Practice Summary & Implementation Guidance

Family Navigator Network

The Iowa Family Navigator Network (FNN) includes professionally trained staff members with lived experience as the parent or primary caregiver for a child with special health care needs. Family Navigators in the FNN provide family to family support, assisting parents or primary caregivers of CYSHCN with systems navigation, connecting them to community resources, and providing emotional support from the perspective of similar experiences. Members of the FNN are employed by the University of Iowa Division of Child and Community Health, which encompasses Child Health Specialty Clinics, Iowa's Title V program for CYSHCN.



Location

Iowa



Topic Area

Family/Youth Engagement



Setting

Clinical



Population Focus

CYSHCN



NPM

NPM 11: Medical Home



Date Added

October 2020

Contact Information

Sharon Rettinger, Child Health Specialty Clinics, (319) 283-4135,
sharon-rettinger@uiowa.edu

Section 1: Practice Summary

PRACTICE DESCRIPTION

The Iowa Family Navigator Network (FNN) includes professionally trained staff members with lived experience as the parent or primary caregiver for a child with special health care needs. Family Navigators in the FNN provide family-to-family support, assisting parents or primary caregivers of CYSHCN with systems navigation, connecting them to community resources, and providing emotional support from the perspective of similar experiences. Members of the FNN are employed by the University of Iowa Division of Child and Community Health, which encompasses Child Health Specialty Clinics, Iowa's Title V program for CYSHCN. The FNN builds on the principles of Patient-and Family-Centered Care, an approach to health care that is grounded in mutually beneficial partnerships among health care professionals, patients, and families.ⁱ As members of health care teams, Family Navigators demonstrate respect for family perspectives and preferences for care, share information in a way that invites family participation in decision making, create partnerships with families and members of their care team, and collaborate at all levels: with individual families, in their communities and at systems levels, including the CHSC leadership team. Family Navigators provide skill building and information to empower Iowa families of CYSHCN as they advocate for their children in medical, education and social service settings. As they partner with families, Family Navigators remind families that they and their concerns are central to the System of Care. Typically located in Regional Centers around the state, Family Navigators support family access to gap-filling clinical services, care coordination, family-to-family support, and systems building activities.

Employing families as members of care teams emphasizes the importance of family-professional partnerships and enhances the family experience of receiving care in a well-functioning system. CHSC activities are not designed to replace the activities of primary care providers and the FNN is a supplementary resource in the delivery of a medical home approach to care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.ⁱⁱ

History: CHSC has a long history of training and employing Family Navigators, originally called parent consultants. The first parent consultant was Julie Beckett, who in the early 1980s advocated to care for her medically complex daughter at home, which was not allowed by Medicaid rules. The Beckett family's situation caught the attention of President Ronald Reagan, who directed federal agencies to allow Medicaid to cover medical services at home, regardless of parents' income, as long as the home care cost no more than institutional care. This was the start of Home and Community-Based Services (HCBS) waiver programs, sometimes referred to as Katie Beckett Waivers. In 1984, Julie began work at CHSC to develop programs to support parents caring for their CYSHCN at home. Part of her responsibility was to meet with families, listening to their needs and priorities for care and providing navigation assistance, emotional support, and connections to community resources. She was joined by other parent consultants living in communities across the state. The first leaders of the new network were two fathers.



The FNN has experienced growth over more than 35 years and has built a strong foundation for a professional family workforce in Iowa.

CORE COMPONENTS & PRACTICE ACTIVITIES

Core Components: Structure- Iowa's Family Navigator Network (FNN) works to fill in some of the gaps that prevent systems from best serving families. The FNN provides professional family-to-family support, systems navigation, and connections to community resources to parents of CYSHCN. This is accomplished through a network of over 25 community-based Family Navigators working primarily part time through Regional Centers statewide. All Family Navigators have comprehensive training as well as lived experience as a parent or primary caregiver of CYSHCN. All Family Navigators who are employed by CHSC are encouraged to apply for Family Peer Support Specialist certification through the Iowa Board of Certification.

The FNN includes a coordinator with lived experience as a parent of a CYSHCN who provides mentorship and coaching to all Family Navigators including networking, training, and professional development opportunities. A leadership team consisting entirely of staff who are parents of CYSHCN provides strategic direction and meets monthly to review processes, forms, and documents utilized by the FNN. The FNN meets twice monthly: one meeting per month is a training meeting and Continuing Education Units (CEUs) are offered. These can be applied toward the Family Peer Support Specialist certification. The other monthly meeting includes process, procedure, and staffing updates. Staff in the FNN live in communities across the state, and as such, these meetings are held through videoconference.

Eligibility for employment as a Family Navigator- A key requirement for employment as a CHSC Family Navigator is status as parents or primary caregivers of CYSHCN. This is to respond to the need for families of CYSHCN to be connected to other families of CYSHCN during their journeys. When families receive a diagnosis of a special health care need, they often find their usual sources of support to be inadequate. Families and friends may not have experience in special needs and are unable to provide information about the condition and emotional support for coping with the diagnosis. Parents access care providers for information and next steps but often prefer to be mentored by other parents, preferably those who live in the same geographic area and whose child has the same or a similar diagnosis. Parents who receive this type of mentoring report increased emotional well-being and adaptation to their situations.ⁱⁱⁱ

Eligibility for Family Navigator Services- Families are eligible for Family Navigator Services if they live in Iowa and are caring for a CYSHCN between the ages of 0 and 22 years old. Families do not need to receive medical care through the University of Iowa Health Care (UIHC) system in order to qualify for Family Navigation services. Special health care needs are broadly defined using the Maternal and Child Health Bureau definition: CYSHCN are those who "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally."^{iv}



Activities- The FNN is committed to promoting family-professional partnerships, developing family leadership skills at all levels and strengthening family centered care. Families are contacted at least once per quarter, and ideally once per month or more if needed. Contacts are documented within the University of Iowa Healthcare (UIHC) Electronic Medical Record platform, EPIC. In calendar year 2020, CHSC Family Navigators directly served over 4,000 children, youth, and families.

Family Navigation service requirements are adapted to meet the needs of various programs serving CYSHCN such as Early Intervention, the Iowa Regional Autism Assistance Program (RAP), the Pediatric Integrated Health Home program, and the Title V CYSHCN program. Family Navigators are part of almost all health teams in CHSC Regional Centers in Iowa, working with Advanced Registered Nurse Practitioners and other professional health care staff. Family Navigators impact not only the families they serve but also the teams in which they work. As a result, health care staff are reminded to recognize that the family is the most important constant in a child’s life and family well-being is a key to child well-being.

Family Navigators accompany families across all service systems and support families in their engagement with community organizations. Doing so builds connections in the communities they serve and supports partnerships that benefit families, the growth of the FNN, and the health of the System of Care. Workforce Development opportunities for FNs assure that they can provide family-to-family support and understand local and statewide resources. Outreach to community partners takes time and intentionality but is necessary to build relationships within the System of Care for CYSHCN.

Core Components & Practice Activities

Core Component	Activities	Operational Details
Workforce Development	Staff recruitment; staff orientation and ongoing training; Family Peer Support Specialist certification; Identify ongoing needs and provide training to staff.	Identify FN staffing needs: consider geographic, racial, ethnic, and linguistic, and diagnosis-specific needs. Having a FN from within the family’s community even if specialty providers are farther away can help families feel supported. Build network pipeline for hiring families/caregivers of CYSHCN. Carry out staff orientation program, encourage completion of Family Peer Support Specialist training and certification
Resource identification and outreach with community partners	Identify community-based organizations, health care and educational systems;	Ongoing relationships and a thorough understanding of systems and supports available to families is key. Each community has different resources available, but there are also broader resources such as Medicaid and waivers, or educational policies.



Outreach to partners who work with CYSHCN and can refer families to a FN	Create and maintain updated resource lists.	Establish relationships with primary care providers in order to supplement medical home approaches to care. Consider becoming part of a pipeline from specialty providers and tertiary health care systems—especially for rural families, this can help bridge geographic support barriers. Establish relationships with educational institutions.
FNs provide services to families	Establish referral networks; build and maintain partnerships with community-based organizations, and health care and educational systems serving CYSHCN	Establish appropriate caseloads, protocols for operations, and support systems. Identify processes for requesting support when needed. Evaluate family perceptions of services.
Ongoing support of FNN staff	Engage families as partners; identify needs; Provide systems navigation, connections to community resources, and emotional support	Leadership provides support for FNs; helps to trouble shoot; meets regularly to evaluate feedback and establish processes.

HEALTH EQUITY

Family Navigators live and work in many of Iowa’s underserved communities, building trust across populations to address social and geographic barriers to health equity. Health inequities have been identified among racial and ethnic minority groups and rural residents living in medically underserved areas. All FNN activities are designed to address the social determinants of health that affect many Iowa families of CYSHCN. Specific populations that have been engaged by CHSC Family Navigators include a growing community of immigrants from the Marshall Islands and members of Iowa’s Spanish-speaking communities. All CHSC Family Navigators have access to translation and interpretation services provided by UIHC.

EVIDENCE OF EFFECTIVENESS

This program has not been formally evaluated.



Section 2: Implementation Guidance

STAKEHOLDER EMPOWERMENT & COLLABORATION

The FNN would not be what it is today without the passion, professionalism and dedication of the Family Navigators. Each Family Navigator is committed to the principle of family-to-family support and family empowerment, often because they benefitted from such support and encouragement themselves. Other primary stakeholders are Iowa's families of CYSHCN, whose courage in the face of adversity and perseverance when resources are limited inspire all CHSC clinical and program staff. Family Navigators work in teams that include nurse practitioners, specialty providers, nurses, and, in some Regional Centers, social workers. Each member of this team works to the highest level of their licensure or certification and as true partners in their service to CYSHCN and their families.

The Division of Child and Community Health, which encompasses CHSC, is housed within the University of Iowa Stead Family Department of Pediatrics and partners with the Iowa Departments of Education, Public Health, and Human Services on a number of programs, including the Maternal and Child Health Title V Program, the Iowa Regional Autism Assistance Program (RAP) and the Iowa Peer and Family Peer Support Specialist Training Program. CHSC also partners with family- and child-serving organizations, including ASK Resource Center, Iowa's Family-to-Family Health Information Center and Family Voices State Affiliate Organization; the Iowa Chapter of the American Academy of Pediatrics; the Iowa Developmental Disabilities Council; and the Center for Disabilities and Development, Iowa's University Center for Excellence in Developmental Disabilities (UCEDD). The FNN administers the CHSC Family Advisory Council, an important stakeholder that assists CHSC with planning, developing, and evaluating its programs and activities. Partnerships that directly benefitted the growth of the FNN were those developed during the period of 2010 to 2013, when CHSC, using braided funding, worked with family-serving organization to form Family to Family Iowa. This effort brought these organizations to the table to define Family Navigator services, enhance their training, and build partnerships for consultation and referral of families. Another more recent collaborative led by CHSC and including ASK Resource Center, the Iowa Chapter of the National Alliance on Mental Illness, and the National Center for Family-Centered Practice developed a nationally recognized Family Peer Support Specialist training program.

REPLICATION

This practice has not been directly replicated.



INTERNAL CAPACITY

CHSC leadership has supported the FNN all through its history, appreciating its unique character and history and encouraging its deployment across the state and its presence in most CHSC contracts. The FNN figures prominently in CHSC’s Strategic Plan. Leadership has also encouraged Family Navigators’ professional development in the form of attendance at monthly trainings and other trainings required by maintenance of certification. Several Family Navigators have participated in AMCHP’s Leadership Lab and the Iowa Family Leadership Training Institute. The FNN is led by the Family-Professional Partnership Program Manager. An FNN coordinator provides mentorship and coaching to all Family Navigators including networking, training, and professional development opportunities. A leadership team consisting entirely of staff who are parents of CYSHCN meets monthly to provide strategic direction and to review processes, forms, and documents utilized by the FNN. More than 25 Family Navigators are currently employed, serving more than 4,000 children and their families in calendar year 2020. A robust onboarding and training infrastructure is in place. The FNN is a significant component of Iowa’s Maternal and Child Health Title V Block Grant Program for CYSHCN. A number of programs rely on the services of the FNN to fulfill deliverables, including Iowa’s Regional Autism Assistance Program (RAP), some Early Intervention services, and some Pediatric Integrated Health Home services. Funding is braided from several state and federal sources to support the program. The FNN relies heavily on the Regional Center infrastructure through University of Iowa Health Care and the Iowa Title V CYSHCN program.

PRACTICE TIMELINE

Phase: Planning/Pre-Implementation		
Activity Description	Time Needed	Responsible Party
<ul style="list-style-type: none">Define how family engagement and family professional partnerships will be integrated into the mission, vision, and activities of organization.Engage community partners, other family-serving organizations, and family members to serve on Advisory Committee.Conduct needs assessment of the current System of Care for children and youth with special health care needs.	<p>1st-3rd months</p> <p>Program Manager 1.0 FTE</p> <p>Advisory Committee meetings 2 hours, twice a month</p>	<p>Program Manager, organization leadership, Advisory Committee members</p>



<ul style="list-style-type: none"> • Develop Scope of Practice and job descriptions for potential Family Navigators. • Develop communication and marketing materials to educate partners about the role of Family Navigators and recruit potential applicants for Family Navigator positions. 	<p>4th-6th months</p> <p>Program Manager 1.0 FTE</p> <p>Advisory Committee meetings 2 hours, twice a month</p>	<p>Program Manager, organization leadership, Advisory Committee members, human resources staff</p>
---	--	--

Phase: Implementation

Activity Description	Time Needed	Responsible Party
<ul style="list-style-type: none"> • Advertise, interview, and hire Family Navigators. • Develop orientation and training protocols for Family Navigators. • Conduct outreach and education activities to promote the work of Family Navigators. • Provide training to Family Navigators. 	<p>7th-9th months</p> <p>Program Manager 1.0 FTE</p> <p>Human Resources staff 0.2 FTE</p> <p>Advisory Committee meetings 2 hours, once a month</p>	<p>Program Manager, organization leadership, Advisory Committee members, human resources staff</p>



Phase: Sustainability

Activity Description	Time Needed	Responsible Party
<ul style="list-style-type: none"> Develop metrics to assess the caseload and activities of each Family Navigator. Solicit feedback from families receiving Family Navigation services. Provide ongoing continuing education opportunities for Family Navigators. 	10th-12th months Program Manager 1.0 FTE Evaluation staff 0.5 FTE Advisory Committee meetings 2 hours, once a month Family Navigators 0.5 FTE each	Program Manager, organization leadership, Advisory Committee members, Family Navigators, evaluation staff

PRACTICE COST

Budget

Activity/Item	Brief Description	Quantity	Total
Program Coordinator	Coordinates all network activities	1.0 FTE	\$60,000
Family Navigators	Behavioral Health Coordinator	0.5 FTE (\$25,000 x 5)	\$125,000
Fringe Benefits for Staff	FICA, Medicare, Retirement, Health and Life Insurance, Health Reimbursement Account, Unemployment Insurance, and Worker's Compensation	28% for 6.0 FTE	\$51,800



Advisory Council Stipends	\$20 per hour (10 members x 2 hours per meeting x 18 meetings)	10 members	\$7,200
Professional Development	AMCHP Conference (2 Family Navigators x \$1500); guest speaker expenses (4 speakers x \$150); Family Peer Support Specialist Certification (\$60/FN/2 years)	NA	\$3,750
Office Supplies/Postage/Communications	Items used for meeting presentations, postage, and communications	\$120 x 12 months	\$1,440
Evaluation	Impact/Outcome Evaluation	1 year	\$20,000
Total Amount:			\$269,190

LESSONS LEARNED

Family Navigators are a bridge between families and providers and systems. This can include all the systems families travel among, including healthcare, education, and social services. As families travel among health, education and social service systems, Family Navigators accompany them, offering wayfinding; listening for family needs and priorities; helping families communicate, problem solve, resolve conflict, set goals and maintain wellness. While maintaining professional boundaries, a Family Navigator can share through their lived experience how they dealt with a similar challenge, and what services or supports may have worked for their family. There is strength in numbers. If a Family Navigator encounters a challenge or needs help finding resources for a family, they can reach out to the FNN of 25 plus Family Navigators for advice and guidance on how to best approach the situation.

Community outreach is essential for understanding systems and for educating community providers about the availability of Family Navigator services. Building support for Family Navigators throughout communities of parents as well as providers in the System of Care requires a thoughtful, intentional approach. Systems, providers, and families need to be provided with educational materials about the type and quality of support that can be offered through Family Navigation. Materials, websites, and word of mouth can be helpful in building trust with stakeholders.



Collect information to identify areas that could be strengthened. For example, CHSC staff were surveyed regarding their comfort in serving families of transition-age youth. Findings indicated that staff needed more information about certain aspects of transition. In response, a transition to adulthood workforce development program was implemented. Recent trainings have included: Transition to Adulthood: Intellectual Disabilities and Mental Illness, Vocational Rehabilitation and the Transition to Adulthood, and Substitute Decision Making and the Rights of Adults with Disabilities. Family Navigators were able to receive Family Peer Support Specialist Continuing Education Credits for these trainings. Process level data is routinely collected and evaluated by the FNN Leadership team at standing monthly meetings. Practice improvements come through several mechanisms. Family Navigator contacts are evaluated each month. These data are shared with CHSC executive leadership members quarterly and are used to determine staffing needs and assure efficient use of resources. This data sharing helps keep the executive leadership team informed and the FNN visible.

Seek ongoing input from stakeholders. All new processes receive input from the Family Advisory Council. As numbers of families served by Family Navigators increase each year, and as demographics change, program modifications are implemented to assure that family-to-family support is available statewide. Evaluating the needs of families in different areas of the state allows the leadership team to determine where Family Navigators should be placed. Family Navigators should reflect the communities CHSC serves. Recent success in recruiting Family Navigators from ethnically diverse populations has led to a richer FNN and new discoveries about the families CHSC serves. Over recent years, CHSC has placed or made plans to place new Family Navigators in more medically underserved areas.

NEXT STEPS

The incorporation of the FNN into all aspects of the CHSC organization will assure sustainability. The FNN is included as one of four major strategies in the 2021 revision of the strategic plan. In addition, the FNN is a key component of Iowa's five-year State Action Plan through the Title V CYSHCN Block Grant program and receives support from other federal and state funding streams. In addition, FNN activities are written into nearly all new and existing state and federal contracts grants.

In the upcoming year, an annual survey to families receiving services from CHSC will be implemented in order to measure family perception of improved access, satisfaction, and outcomes, and including measures of cultural sensitivity and participation in treatment. Additionally, a greater focus will be placed on professional development opportunities for Family Navigators in the areas of cultural responsiveness, ethics, and documentation.

RESOURCES PROVIDED

- [Family Peer Support Specialist Training](#)



- [Family Peer Support Specialist Certification](#)
- [CHSC Family Navigator Network webpage](#)

APPENDIX

- N/A.

ⁱ <https://www.ipfcc.org/bestpractices/sustainable-partnerships/background/pfcc-defined.html>

ⁱⁱ <https://www.medicalhomeportal.org/clinical-practice/the-patient-centered-medical-home>

ⁱⁱⁱDeHoff B., Staten, L., Rodgers, R., Denne, S. "The Role of Online Social Support in Supporting and Educating Parents of Young Children With Special Health Care Needs in the United States: A Scoping Review." J Med Internet Res 2016; vol. 18, iss. 12, e333, p.3.

^{iv}McPherson M., Arango P., Fox H., et al "A New Definition of Children with Special Health Care Needs." Pediatrics 1998, vol. 102, iss. 1, pp. 137-139.

