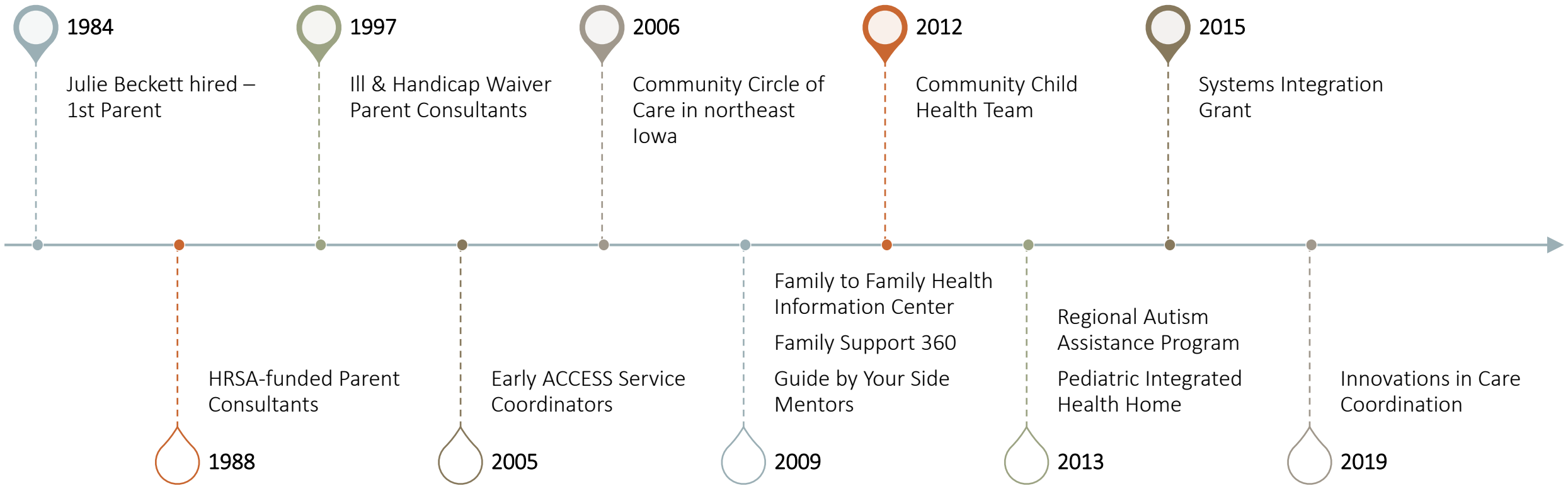


Rachell Swanson-Holm, BS
Program Coordinator
CDC's Act Early Ambassador

Sharon Rettinger
Family Navigator Network
Coordinator

August 11, 2020
AMCHP/SPHARC Peer to Peer
Exchange

DEVELOPMENT OF IOWA'S FAMILY NAVIGATOR MODEL



HISTORY OF FAMILY INVOLVEMENT IN IOWA

HISTORY OF FAMILY NAVIGATOR TRAINING

Family Navigators hired by the Division were originally trained by peer mentors

In 2009, Division staff developed a formal, face-to-face training program for Family Navigators associated with the Community Circle of Care program in northeast Iowa

That training later expanded statewide funded by HRRRSA to develop Family to Family Iowa, Family 360, and Iowa's Family to Family Health Information Center collaborative

Family Peer Support Training Developed

The Division has since built a network to support Family Navigators, including monthly training and mentoring

PRE-REQUISITES

General organization
Group process

CORE CURRICULUM

Confidentiality
Relationship building
Recovery and resiliency
Conflict resolution
Empowerment strategies
Education issues
Special health care
Cultural and linguistic competencies
Resources and referral
Department of Human Services (DHS)
Juvenile Court

SUPPLEMENTAL REQUIREMENTS

DHS OASIS
Certification in Human Subjects Protection
Guardianship and conservatorship
Emergency preparedness
Mandatory Reporting
Impact data collected

FAMILY NAVIGATOR TRAINING

Families lack time and energy

- Many families can make time if they know it will improve outcomes for their children

Families aren't prepared

- Families might need background information and mentoring

We don't know how families can help

- Families can share decision-making and plan policy, among other roles

We don't know how to identify families

- Look in all the usual and unusual places

Is payment required?

- Families are valuable consultants and should be reimbursed

Families aren't available when we need to meet

- Adjust meeting times
- Offer child care



FINDING
SOLUTIONS
TO BARRIERS

FAMILY NAVIGATOR ROLE



Required lived experience as the parent or primary caregiver of CYSHCN



Work within Community-Child Health Teams



Are trained and certified



Meet families where they are, focusing services on family priorities and goals

A large concrete arch bridge spans a river valley. The bridge features a prominent white arch supported by a series of vertical concrete pillars. The surrounding landscape is lush with trees in autumn colors, and a town is visible on the hillside in the background under a blue sky with scattered white clouds. The river flows through the valley below the bridge.

FAMILY NAVIGATORS ARE THE BRIDGE
BETWEEN DIFFERENT SETS OF PROVIDERS
AND SYSTEMS



FAMILY NAVIGATORS ARE
PARENTS OR CAREGIVERS WHO
HAVE:

- Had similar challenges
- Felt the same feelings of grief, sadness, loss, and joy
- Found ways to take care of themselves and their families

Family Navigators embedded in care teams can explain providers' recommendations in ways families understand and help overcome real-world obstacles to following through

WHAT ARE THE BENEFITS OF PARENT SUPPORT SERVICES?

Early research suggests that parent peer support offers parents and other caregivers:



Increased sense of collaboration: Receiving skills training and support from parent support providers helps family members collaborate effectively with treatment professionals. (Hoagwood, et al., 2010)



Increased sense of self-efficacy: Family support services increase family members' confidence in their abilities to care for their child. (Hoagwood et al., 2010; Obrochta et al., 2011)



Increased empowerment to take action: Receiving education about service systems, navigation skills, advocacy skills, and rights helps empower families to become active participants in their child's services. (Kutash, Duchnowski, Green, & Ferron, 2011)



Decreased internalized blame: By providing education and connections with others, parent support services help family members reframe their experiences and debunk damaging myths about behavioral health conditions and emotional distress. (Obrochta et al., 2011)



Recognition of the importance of self-care: Parent support providers help families increase their awareness of the need for self-care. (Obrochta et al., 2011)



Decreased family isolation: Parent support providers assist family members with identifying and accessing community supports that help them feel less alone. (Obrochta et al., 2011)

"I don't know what I would have done without our parent support provider. She understood what I was going through, and she didn't judge me. She was available whenever I needed her, not just during business hours. She helped my family get back on our feet."

—Stacey

(Source: Obrochta et al., 2011)

REFERENCES

Eversen, C., & Tierney M. (2012). *Results of evaluation of JJA data. Memo to keys for networking for the No Place Like Home project.* Washington, DC: American Institutes for Research.

Hoagwood, K.E., Cavalieri, M.A., Olin, S.S., Burns, B.J., Slaton, E., Gruttadaro, D., Hughes, R. *Family Support in Children's Mental Health: A Review and Synthesis. Clinical Child and Family Psychology Review* (2010) 13:1-45.

Koroloff, N. M., Friesen, B. J., Beilly, L., & Binklin, J. (1996). *The role of family members in systems of care.* In B. A. Stroul (Ed.), *Children's mental health: Creating systems of care in a changing society.* Baltimore, MD: Paul H. Brookes Publishing Co.

Kutash, K., Duchnowski, A.J., Green, A.L., & Ferron, John M. *Supporting Parents Who Have Youth with Emotional Disturbances Through a Parent-to-Parent Support Program: A Proof of Concept Study Using Random Assignment. Administrative Policy in Mental Health and Mental Health Services Research* (2011) 38:412-427.

Leggatt, M., & Woodhead, G. (2015). *Family peer support work in early intervention youth mental health service. Early Intervention in Psychiatry.* doi: 10.1111/eip.12257

Obrochta, C., Anthony, B., Armstrong, M., Kall, J., Hust, J., & Kernan, J. (2011) *Issue brief: Family-to-family peer support: Models and evaluation.* Atlanta, GA: ICF Macro, *Outcomes Roundtable for Children and Families.* Retrieved from <https://www.icfmacro.org/sites/default/files/Issue-Brief-Family-to-Family-Peer-Support-Outcomes-Roundtable-2011.pdf>

Purdy, F. (2010). *The core competencies of parent support providers.* Rockville, MD: National Federation of Families for Children's Mental Health. Retrieved from <https://www.nffcmh.org/sites/default/files/2349%20-%20Competencies%20of%20PSPs.pdf>

Robbins, V., Johnson, J., Barnett, H., Hobstetter, W., Kutash, K., Duchnowski, A. J., & Annis, S. (2008). *Parent to parent: A synthesis of the emerging literature.* Tampa, FL: University of South Florida, The Louis de la Parte Florida Mental Health Institute, Department of Child & Family Studies. Retrieved from http://cfs.cbcs.usf.edu/_docs/publications/parent_to_parent.pdf



HOW FAMILY TO FAMILY SUPPORT MAKES A DIFFERENCE

Early research suggests that parent peer support offers other caregivers:

- Increased sense of collaboration with professionals
- Increase self-efficacy
- Increased empowerment to take action
- Decrease self-blame and isolation
- Recognition of the importance of self care

https://www.samhsa.gov/sites/default/files/programs_campaigns/brss_tacs/family-parent-caregiver-support-behavioral-health-2017.pdf

SHARED DECISION- MAKING

Supporting	Supporting parent participation using active listening
Helping	Helping parents explore options and available evidence-based treatments
Assessing	Assessing parents' values and preferences
Reaching	Reaching a decision with the parents
Evaluating	Evaluating and/or monitoring the decisions made

CHSC FAMILY NAVIGATORS

CLEMENTINE KARL, DES MOINES

ANGIE DROESSLER, DUBUQUE

ANN MOHR, WATERLOO



Karl-Musser Family

Clementine Karl, Family Peer Support Specialist

A resident from Des Moines, IA, Clementine enjoys reading, the outdoors, baking, and any activity done with her family.



Peer support undermines the isolation families can feel from their child's disability.



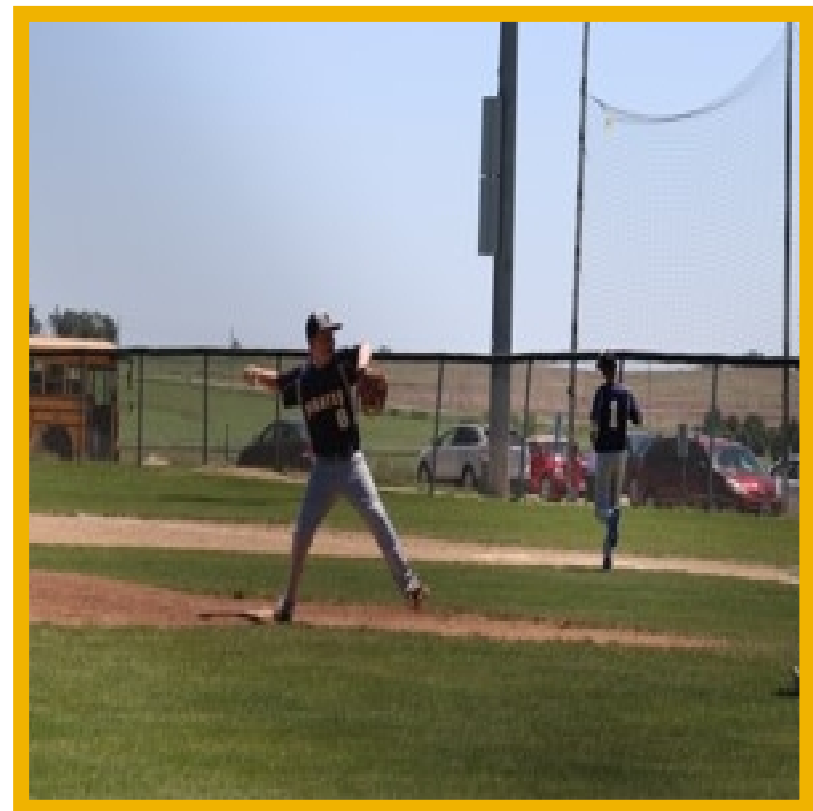
THE DROESSLERS
ANGIE, MAX,
AND MILES

DUBUQUE, IA



I love watching my son play baseball

All children receive testing and treatments deemed necessary by medical providers. No child should be denied needed services due to cost or any other reason.



THE MOHRS
Mark, Ann, Andrew and
Rylan
Hudson, IA

Enjoying the challenges and rewards of assisting individuals
and families with special healthcare needs.



Iowa Family Story Project

- Based on the “Super Parents” project developed by the Lucile Packard Foundation for Children’s Health
- Illustrates the daily joys and struggles of caring for children, youth, and young adults with special health care needs or disabilities
- Photographer Thomas Langdon shadowed eight Iowa families
- Each family’s story is featured on a full-size banner, in an accompanying booklet, and on the CHSC website



FAMILY
NAVIGATOR
PARTICIPATION
IN AMCHP
ACTIVITIES

Conference attendees

Leadership activities (committees, panels, meetings)

Leadership Lab (formerly Family Scholar/Family Mentor Program)

Family Delegate Program

State Public Health Autism Resource Activities and Technical Support Programs



ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Strategic Plan 2017-2020

Child Health Specialty Clinics/Division of Child & Community Health



VISION

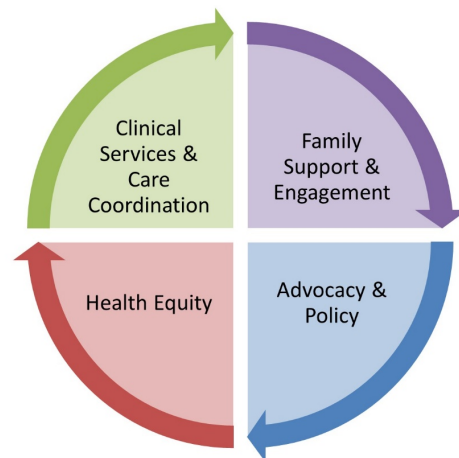
To assure a systems-oriented approach to care for Iowa's children and youth with special health care needs and their families.

MISSON

To improve the health, development, and well-being of children and youth with special health care needs in partnership with families, service providers, communities, and policymakers

VALUES

Strengths-based; family-drive and youth-guided; collaborative and coordinated; home and community-based including natural supports; individualized; data driven



Clinical Services & Care Coordination

Provide comprehensive, gap-filling services and care coordination to Iowa children and youth with special health care needs and their families.

- ✓ Expand statewide access to pediatric services through telehealth.
- ✓ Develop partnerships with primary care providers, tertiary care providers, community-based providers, and Maternal & Child Health agencies across Iowa.
- ✓ Conduct targeted activities to assure workforce development and succession planning.
- ✓ Assess the effectiveness of clinical services and care coordination services provided by staff.

Family Support & Engagement

Assure meaningful family engagement in Iowa's System of Care for children and youth with special health care needs through family-professional partnerships at all levels

- ✓ Support the growth of the Division's Family Navigator Network.
- ✓ Provide family support and training to Iowa families of children and youth with special health care needs.
- ✓ Develop and utilize Shared Plans of Care for children and youth with special health care needs and their families.
- ✓ Present the Division and CHSC as experts in family-centered and family-driven care for children and youth with special health care needs.

Advocacy & Policy

Provide a leadership role in pediatric advocacy and policy efforts at the local, state, and national levels

- ✓ Advocate for children and youth with special health care needs and their families with state agencies, legislators, and other stakeholders
- ✓ Articulate how CHSC differs from other child- and family-serving organizations in Iowa.
- ✓ Assure broad participation on boards, in education and advocacy efforts, and at meetings and conferences
- ✓ Develop partnerships to participate in research activities targeting system improvements for children and youth with special health care needs and their families.

Health Equity

Promote health equity and honor diversity among Iowa's children and youth with special health care needs and their families.

- ✓ Recognize the importance of providing culturally sensitive clinical care to all families including underserved or diverse populations.
- ✓ Identify underserved populations and health disparities among Iowa families of children and youth with special health care needs.
- ✓ Expand culturally-sensitive learning opportunities to support health equity-based principles

1. Professionals recognize families as equal partners
2. Everyone respects the skills and expertise brought to the partnership
3. Trust is fundamental
4. Information is shared openly
5. Decisions are made together
6. All are willing to negotiate



PRINCIPLES OF FAMILY PROFESSIONAL PARTNERSHIPS

FAMILY PROFESSIONAL PARTNERSHIP OPPORTUNITIES

- Parent training provides more opportunities for networking and personal connections with other family professionals
- Iowa Family Leadership Training Institute, Virtual Family Training Lunch and Learns
- CHSC Family Advisory Council
- CHSC Advocacy Committee
- Promoting and supporting families and Family Navigators to attend legislative “Day on the Hill”
- Local legislative forums and town hall meetings
- Support Family Navigators to apply for AMCHP Leadership Lab



OPPORTUNITIES FOR FAMILY ENGAGEMENT

Individual Level

- One to one care planning
- One to one training on education goals

Community Level

- Offering parenting classes
- Inviting families to discuss barriers to service

Policy Level

- Hiring trained family leaders
- Creating family advisory councils

MOVING THE NEEDLE

FAMILY ENGAGEMENT

The intentional practice of working with families for the ultimate goal of outcomes in all areas through the life course

FAMILY-PROFESSIONAL PARTNERSHIPS

Families of children with special health care needs partner in decision-making at all levels and are satisfied with the services they receive





Plan

Objective

Questions and predictions (why?)

Plan to carry out the cycle (who, what, where, when)

Plan for data collection



Do

Carry out the plan

Document problems and unexpected observations

Begin data analysis



Study

Complete the data analysis

Compare data to predictions

Summarize what was learned



Act

What changes are to be made?

Next cycle?

STATE BREAKOUT GROUPS

How can your state move from Family Engagement to Family Professional Partnerships?

Plan

- ✓ Objective
- ✓ Questions and predictions (why)
- ✓ Plan to carry out the cycle (who, what where, when)
- ✓ Plan for data collection

How can your state implement aspects of this model to:

- ✓ Add additional Family Navigators?
- ✓ Utilize current Family Navigators differently?
- ✓ Expand training activities for Family navigators?
- ✓ Support statewide family navigation?
- ✓ Collect additional data

STATE TEAMS SHARE
(2 MINUTES EACH)



QUESTIONS?

