Involvement of Families of Children and Youth with Special Health Care Needs in Iowa

* Martha Hanley, Family Navigator
* Sharon Rettinger, Family Navigator Network Coordinator
* Rachell Swanson-Holm, Family Navigator

University of Iowa Division of Child & Community Health
Stead Family Department of Pediatrics
About the Division

University of Iowa
Stead Family Department of Pediatrics

Division of Child & Community Health

Child Health Specialty Clinics (CHSC)

Center for Child Health Improvement & Innovation (CCHII)

- CHSC is a community-based public health agency that serves children with special health care needs and their families
- CHSC’s System of Care includes gap-filling clinical services, care coordination, family to family support, and systems building
- CHSC has a network of regional centers and satellite locations across Iowa

- CCHII was established to promote systems improvement and innovation in pediatric practice through:
  - Conducting health outcomes and system research
  - Developing and evaluating innovative models of care
  - Establishing statewide networks to disseminate best practices
Introduction

This presentation will describe

• The history and development of family support in Iowa
• The implementation of training Family Navigators to provide peer to peer support as part of a larger System of Care in Iowa
• Present barriers and solutions to family involvement
• Current efforts to integrate family involvement in systems change in the state
The “Katie Beckett Waiver”

• Katie was born in 1978, hospitalized for most of her early life, and required the use of a respirator up to 12 hours a day
• Her mother, Julie, lobbied to be able to take Katie home; doctors agreed, but at that time Medicaid required a hospital stay to pay for a respirator
• Katie’s story eventually made its way to President Reagan who cited her case at a news conference in 1981
• The next day, the U.S. Secretary of Health and Human Services waived the rules in order to let Katie return home without the loss of federal support
• Katie’s mother, Julie Beckett, became the first Family Navigator (Parent Consultant) at the University of Iowa in 1984
History of Family Involvement in Iowa

- ARC of Iowa have had volunteer parents reaching out to families since 1954.
- Child Health Specialty Clinics, the Title V Program for Children and Youth with Special Health Care Needs hired the 1st Parent Consultant in 1984.
- Department of Education placed at least one Parent Coordinator in each Area Education Agency as part of the Parent–Educator Connection Program in 1984.
- Access for Special Kids Resource Center established in 1991 by two volunteer parents.
- Family to Family Iowa–Health Information Center and Family Support 360 supported statewide family support in 2009.
- Pediatric Integrated Health Homes team approach includes a Peer to Peer Support Specialist in 2013.
Growth of Parent Support Network

2013: Integrated Health Home Program/Regional Autism Assistance Program

2009: Family 360 Navigator Autism Spectrum Disorder funding

2007: Maternal Child Health/Title V

2006: EHDI/Guide By Your Side Community Circle of Care

2005: Early ACCESS Service Coordinators

1990: Ill & Handicapped Waiver/HDM

1984: CHSC Clinical Services
System of Care Model
Principles of Family Support

• Individualized; “meet families where they’re at”
• Facilitates linkages to agencies, services, and other families
• Respectful and non-judgmental
• Fosters growth and empowerment
• Provides up-to-date information, actively partners with families
• Focuses on outcomes and strengths-based goals
• Broadens horizons
• Promotes advocacy
• Empowers parents to become active agents of change on behalf of their children
Family Navigator Training at CHSC

- 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 through funding from HRSA to develop Family to Family Iowa, Iowa’s Family to Family Health Information Center.
- The Division has built a network to support Family Navigators to provide ongoing monthly training and support.
Family to Family Iowa

- Family to Family is a statewide network of Family Navigators who provide assistance to families of children with special health care needs.
- Also includes Family to Family Health Information Center:
  - Cohesive, coordinated, culturally competent statewide network of Family Mentors/Educators to serve children and their families.
  - Assist families in making informed choices about health care.
  - Support the development and replication of successful models of family/professional partnerships at all levels of decision-making.
Value of family involvement

Family involvement improves program planning by

- Gaining “in the trenches” perspective
- Identifying gaps in services experienced by families
- Detecting possible pitfalls in operationalizing programs
- Enhancing communication with other families
- Providing links to multicultural communities
- Assisting in quality-improvement efforts
- Completing program teams
Barriers/Solutions

• Families lack time, 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 many 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
Opportunities

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 services

Policy level
• Hiring trained family leaders
• Creating family advisory councils
If you coordinate care for a family, things may go well for a while; if you teach a family how to coordinate care, things can go well for a lifetime.

If we truly want care coordination services to be family-centered, we must teach families, and, as they mature, their children, the skills to successfully serve as principal care coordinators over the life course.
Teaching Families to Fish

Families of children with special healthcare needs often feel overwhelmed trying to navigate the complex, fragmented system

BUT... They also consistently assert that they want to be their children’s principal care coordinator

Family Navigators:

- Are parents of children with special health care needs
- Have experience navigating the various service systems
- Have developed networks of community partners and resources
- Provide emotional support to other families
- Collaborate with families to identify strengths and set goals
Standards for Systems of Care for Children and Youth with Special Health Care Needs

A Product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project

http://www.amchp.org/AboutAMCHP/Newsletters/member-briefs/Documents/Standards%20Charts%20FINAL.pdf
National Standards for Systems of Care for Children and Youth with Special Health Care Needs

These standards represent the consensus of national experts across multiple systems and are designed to help communities, states, and the nation build and improve systems of care for CYSHCN. They are meant to supplement, not substitute, federal statute and regulatory requirements under Medicaid, the ACA and other relevant laws and are intended for use or adaptation by a wide range of stakeholders at the national, state and local levels.
National Standards for Systems of Care for Children and Youth with Special Health Care Needs

These standards represent the consensus of national experts across multiple systems and are designed to help communities, states, and the nation build and improve systems of care for CYSHCN. They are meant to supplement, not substitute, federal statute and regulatory requirements under Medicaid, the ACA and other relevant laws and are intended for use or adaptation by a wide range of stakeholders at the national, state and local levels.

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
</table>
| **Screening, Assessment and Referral** | • Early identification including newborn screening  
• Needs identified by insurance plans  
• EPSDT and Bright Futures  
• Documented, transportable plans of care |
| **Eligibility and Enrollment** | • Outreach & coordination with community organizations  
• Policies for transitions between plans and for gaps in coverage  
• Comprehensive member services with specialty staff |
| **Access to Care** | • Statewide access  
• Physical, mental health, dental and specialty care - with provider choice  
• Transportation and interpreter supports |
| **Medical Home:** Pediatric Preventive and Primary Care | • Medical team; care coordination  
• 24-7 access; additional time for visits  
• Prevention and Treatment  
• Routine, emergent and urgent needs are met |
| **Community-based Services and Supports** | • Patient and family centered  
• Respite services; home-based services  
• Palliative and hospice care  
• Transportation and interpreter supports |
| **Families are active members of the team** | • Youth engagement  
• Transition and transfer of care policies and processes  
• Transition assessment and plan in place and current  
• Coordination between pediatric and adult providers |
| **Family Professional Partnerships** | • Use of electronic health record systems; meaningful use  
• Families are partners in electronic health information (EHI)  
• HIT incorporates CMS health policy priorities  
• EHI is accessible and shared across care settings |
| **Transition to Adulthood** | • Quality assurance and improvement processes for CYSHCN  
• Child medical record reviews include sample of CYSHCN  
• Utilization review/appeals for CYSHCN include integrated care team |
| **Health Information Technology** | • Plans are affordable and no risk for loss of benefits  
• Coverage/payment facilitates access to needed providers  
• Comprehensive habilitative services coverage  
• Promote care coordination and medical homes |
| **Insurance and Financing** | • Families are active members of the team  
• Connection with family organizations, peer support  
• Strength-based; Informed  
• Culturally and linguistically appropriate |

**Note:** Each category (Screening, Assessment and Referral, Eligibility and Enrollment, Access to Care, Medical Home, Community-based Services and Supports, Family Professional Partnerships, Transition to Adulthood, Health Information Technology, Insurance and Financing) is further detailed in columns with specific requirements and considerations for effective systems of care for CYSHCN.
Family-driven services

• The Division of Child and Community Health has infused family involvement and input into all programs and activities
• The Division has a Family Advisory Council whose members have committed to assisting with the planning, development, and evaluation of programs and policies that impact the System of Care for children and their families in Iowa
• Through training and outreach, the Division is committed to develop the next generation of family leaders
Systems Integration Project for Children and Youth with Special Healthcare Needs
Shared Resource- What and How

• Purpose
  • Families can
    • Use service database searchable by geographic area
    • Complete and submit referral questionnaire
    • E-mail providers
  • Providers can
    • Access workforce development resources: care coordination, integrated systems, family to family support, treatment interventions
• Portal examples
  • [http://www.medicalhomeportal.org/](http://www.medicalhomeportal.org/)
Family Advisory Council

- **Purpose:** The Child Health Specialty Clinics (CHSC) Family Advisory Council (FAC) vision will align with CHSC’s: *Assuring a system of care for Iowa’s children and youth with special health care needs.*

- **Mission:** Members of the CHSC FAC will assist with the planning, development, and evaluation of programs and policies that will assure a system of care for Iowa’s children and youth with special health care needs. Special emphasis will be placed on the introduction of Maternal and Child Leadership Competencies and the training of family leaders. The FAC’s purpose is supported by the Maternal and Child Health Bureau's core performance measure: "Families of children with special health care needs are partners in decision-making at all levels and are satisfied with the services they receive."
Size and Structure

- The FAC membership will include two CHSC staff members (currently employed Family Navigators) and 15 non-CHSC family or youth members. At least two youth members are desired.

Length of Service

- Members will be offered one- or two-year terms.

Duties

Family Members

- Serve as advisory resource to CHSC administration and staff.
- Provide input into policy and program development.
- Review recommendations from CHSC staff or administration.
- Channel information, needs and concerns of families of CYSHCN to staff and administration.
- Promote respectful, effective partnerships between families and public health professionals.
- Contribute to planning that insures that programs really meet the needs of families of CYSHCN.
- Develop personal leadership skills through training sessions, with the goal of serving as a model of family leadership and advocacy statewide.
CHSC Family Advisory Council
I live in Mason City, IA.

The impact I would like to make in Iowa’s system of care…
* To establish a system of checks and balances to ensure our families are receiving care from properly and professionally trained individuals.

One fact about myself I’d like to share…
* I am the president of Special Kids Special Love, a non-profit for autism & special needs. I am also getting my BCBA certification so I can help!
Partners

- University of Iowa Center for Child Health Improvement & Innovation
- National Resource Center for Family Centered Practice
- NAMI Iowa
- ASK Resource Center
- CHSC
This training is made possible through funding from the Iowa Department of Human Services through its contract with the University of Iowa for Peer Support Training and Coordination (MHSD-15-006).
Questions?

* Martha Hanley, 319-356-0886
* Sharon Rettinger, 319-283-4135 ext. 102
* Rachell Swanson-Holm, 515-955-8326