The Importance of Integrated Services

A system of services is a family-centered network of community-based services that is designed to promote the health and well being of CYSHCN and their families. Ideally, community-based service systems are organized so families can use them easily. Care coordination, access to a medical home, family-centered and culturally competent services are considered key elements of coordinated services for families of CYSHCN. However, many families of CYSHCN face frustration accessing services. Eligibility requirements, policies, procedures, and multiple locations of services can leave families feeling overwhelmed. There are often gaps in services due to agencies that provide limited services or duplication in services from multiple coordinators and service plans. Families may also need to travel great distances to obtain specialized services.

The examples in the following sections, from medical home, care coordination, family-centered care, to cultural competency, as well as the common application forms found in the health information technology section, all address some piece of a coordinated system of care—although no state or community addresses all issues equally well. The following models of care often use strategies recommended by Champions for Inclusive Communities for developing coordinated services: including the use and development of interagency councils, partnerships with coalitions, supporting the development of family leadership and family-directed programs, and promoting linkages at the local and state level. For local level examples, please refer to the Star Communities on the Champions website: www.Championsinc.org.

Family-Centered Care and Family Involvement

At the practice level, family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.

Family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support are integral components of health care, and they promote the health and well-being of individuals and families and restore dignity and control to them. Family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It can lead to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.

At a policy level, developing family-centered care is one aspect of a larger approach to family involvement. When programs talk about family involvement for CYSHCN, they are not referring to families involved in the care of their own children, but rather, a range of activities that involve families in the planning, development and evaluation of programs and polices. Family involvement can mean the hiring of staff to serve as a family involvement coordinator or parent representative at the state or local level, contracting with a parent group such as Family Voices to advise on family issues, or including families as members of advisory groups and boards. Each state configures its family involvement differently, although most share a common view of the importance and value of family input and leadership. The following four models show approaches to family-centered care and family involvement examples at the hospital, medical home, family resource, and state level.

MICHIGAN: MAKING FAMILY-CENTERED CARE AN EXECUTIVE LEVEL FUNCTION

Private
Emerging Practice

Children's Hospital of Michigan in Detroit is often cited as an effective model of care because of its strong partnership between families and providers. The Hospital staff and administration recognize the vital role that families play in ensuring the health and well-being of infants, children, and adolescents. To effectively and accurately identify, diagnose and treat the health care needs of children and adolescents who rely on Children's Hospital for state-of-the-art health care services, families are collaborative partners in every aspect of the care delivery system.

System of Care: The hospital supports families by respecting their decisions; offering comfort as they cope with the child's illness; meeting the social, developmental, spiritual and emotional needs of the child; and fostering family members' confidence in their ability to care for their child. Family-centered

care emphasizes that caregivers must be flexible so they can meet the needs and preferences of all families. The professional staff provides medical information to families and values the personal information families provide about their children. This information exchange builds trust and contributes to the partnership between families and caregivers.

Financing: This program is supported by the Children's Hospital of Michigan.

Evaluation: One critical step that has helped Children's Hospital was hiring a parent of a special needs child (and long-time advocate for kids at the hospital) as Director of Family Centered Care in 2005. Having a parent as an administrator/advocate is especially helpful for patients and their families. While the Director says that "Patient and family-centered care has been going on at the Children's Hospital of Michigan for years," the hiring of a parent has formalized the efforts, including the development of a Family-Centered Care Advisory Council.

In addition, several other changes have occurred to increase family-centered care, such as changing the visitation policy so that family members other than parents can stay with a sick child; creating a family center with educational materials; establishing a relaxation room that offers a quiet, peaceful place to nap, read and rest; creating a Family Information Guide with words of advice from other families at Children's Hospital; and allowing access to a concierge for families to run errands. In addition, the hospital is working on enhancing electronic medical records so families only have to provide a child's medical history one time. Recently, a Youth Advisory Council was created of 11-20 year old current and former patients who meet monthly to evaluate food service, select artwork for the hospital and provide general feedback about their care.

Will it Work in California: Children's Hospitals should look to the experience of Michigan in hiring a parent (and parent advocate) as Director of Family-Centered Care, an executive level position, to formalize family-centered care, as well as adopting policies to support families during hospital stays.

Source in addition to expert interviews: Children's Hospital of Michigan: http://www.childrensdmc.org/upload/docs/About%20Chil%20Sp09_Final.pdf.

MINNESOTA: FAMILY CENTERED CARE IN THE MEDICAL HOME

Public
Emerging Practice

The state of Minnesota has made family-centered care an integral component of its Medical Home efforts. In 2002 the Minnesota Title V Children with Special Health Needs section at the Minnesota Department of Health received an MCHB Medical Home grant to begin the Minnesota Medical Home Learning Collaborative. In 2005, it received additional grant funding to continue this work. Minnesota Medical Home Learning Collaborative is a nationally recognized leader in the movement. The collaborative ended June 30, 2009 when the grant ended.

System of Care: Twenty-one teams worked to spread the medical home concept throughout the state. Each team was formed from a primary care practice within its own community. Teams consisted of at least two parents who have children with special health care needs, a primary care physician, and a person chosen by the primary care physician, who could serve in the role of care coordinator, such as an RN, LPN, or nurse practitioner. The teams met twice a month. Participating practices were compensated $400 per month, and the parent members received stipends for their work.

Three times a year, all the teams gathered for a learning session. Family-centered care and parent/professional collaboration skills were taught to new teams. Veteran parents helped to train new parent members.

Financing: This initiative was funded through an MCHB Medical Home grant.

Evaluation: All of the participating primary care practices have made significant changes to their practices and clinics that have been tailored by and to the specific needs of the people in each clinic setting. Examples of positive changes include:

- The identification within the clinic of children with special needs, and the development of a registry
- The development and implementation of care plans
- Chronic care management improvements, such as longer appointments, special appointment times, and special access to physicians or care coordinators
- Improvements in the physical space within the clinic, such as having a wheelchair scale and pictoboards
- Coordination to meet the needs of the family in the community
- Promotion of family networking opportunities.

As a result of the Medical Home collaborative, the state scaled up its concept called "health care home" for all Medicaid enrollees, state employees, and fully insured plan subscribers. "Health Care Homes" will be certified by the Commissioner of Health beginning in Fall 2009.

Minnesota's program had a state-level leadership team consisting of 12 to 15 members, including physicians, state government employees, academicians, and two parent leaders, which met monthly. This leadership team collected data and worked on outcome surveys, which included information from patients and families that were used to help measure improvements in outcomes.

Will it Work in California: Minnesota's success depended on a strong commitment from the state to involve families, by providing mentorship to new parents and stipends to parent members of the team.

Source in addition to expert interviews: http://www.familycenteredcare.org/tools/downloads.html

COLORADO: FROM FAMILY INVOLVEMENT TO FAMILY LEADERSHIP

Public
Emerging Practice

Colorado's Title V CSHCN program has employed parent consultants for twenty years. Originally, the consultants worked with families to access resources and support groups, but as Colorado's CSHCN program moved away from providing direct services, parent consultants evolved into conduits to the community. Parent consultants now serve as equal partners with Title V staff, with key roles in program and policy planning.

System of Care: Colorado currently employs one person full-time as family staff (known as a family consultant) at the state level, and fourteen family staff (some full/some part-time) at the local level. In addition, the state contracts with other family leadership staff on part-time basis to work on family leadership training and cultural brokering projects. Local parent consultants are located in health departments throughout the state. State family staff are official employees of the state on a salaried basis.

Collaboration: Local family staff help recruit families to participate on local committees and discussion groups. Parent groups such as Family Voices and Family to Family Health Information Centers also help identify families. In addition, the state supports several non-profit organizations that specialize in cultural brokering for Spanish-speaking families, Asian-Pacific and African American families. Among the major activities of Colorado are the following:

- *Family Leadership Registry:* (See Colorado Medical Home description)
- *Parent Leadership Training Institute (PLTI):* Colorado has recently contracted with the state of Connecticut to provide a Parent Leadership Training Institute, an evidence based curriculum that has been implemented in Connecticut for almost twenty years. The trainer model will help families acquire a core set of competencies in civic involvement to better equip them for policy leadership. By the end of 2009, Colorado hopes to graduate almost 80 family leaders as a result of offering this curriculum in local communities across the state.

Financing: Each local office where family staff is located has a $2500 line item from Title V for family activities. Decisions as to how to use the money are made locally, but funds are often directed to help family staff attend regional and national conferences and trainings.

Will it Work in California: Colorado has a unique focus on creating family leaders by building leadership at the community and state level, and developing a family registry and Parent Training Institute. These activities depend on extensive partnership and support from multiple levels.

Source in addition to expert interviews: "State Profiles in Family Involvement," Association of Maternal and Child Health Programs, 2009. In process.

HAWAII: FAMILY TO FAMILY WORKING DIRECTLY WITH MEDICAID

Public
Emerging Practice

Hawaii's Hilopa Family to Family Health Information Center is working with Medicaid to promote family-centered care in Medicaid Managed care. Similar to California, Hawaii's fiscal crisis may lead to an increase in the Medicaid eligible population. This program also uses a family peer model to advocate on behalf of families directly with managed care plans. Access to insurance, and insurance coverage, are critical parts of family-centered care, and this program creates partnerships to help assure access to family-centered care.

System of Care: Hilopa's Family to Family Health Information Center is designated as the state Medicaid Managed Care (QExA) Ombudsman by the state Medicaid agency to implement an independent access point into the system to address concerns and issues. The program works to bring individuals from fee for service Medicaid into managed care. Hilopa's Family to Family Information Center engages directly with the medical directors and administrators for each health plan on behalf of CYSHCN regarding plan performance. The program serves individuals in Medicaid who are either aged, blind or disabled and has served approximately 40,000 people to date. The numbers are increasing every month due to the economic downturn.

This program operates with a family perspective at the forefront, working in collaboration with families, medical providers and medical plans to achieve family centered care. The broad partnership with the state Medicaid agency, Medicaid Managed Care Health Plans, Hawaii state legislature, consumer advocacy organizations, provider organizations, including the state chapter of the AAP, the Children's Community Council, and the Developmental Disabilities Council has been helpful in implementing family-centered care.

Financing: This program is financed through Medicaid.

Evaluation: The model has the ability to deliver accurate information and resolve concerns in a timely manner with the direct access to Medical plans and their directors. The evaluation is done through a phone interview.

Will it Work in California: California communities (and/or the state) could consider using a Family to Family Health Information Center to take the lead in working to assure managed care plans are family-centered. This approach simply expands the roles of an already existing parent resource (with proven and trained staff). Similar to California, Hawaii has a very diverse population and may be experiencing an increase in Medicaid population as the economy worsens.

Source in addition to expert interviews: Joint Meeting of the Family to Family Health Information Center Grantees and State Implementation of Systems of Services for CYSHCN Grantees 2009. http://www.familyvoices.org/pub/general/Activities_05-01-2009.pdf. Retrieved August 14, 2009.