

Promoting Family-Centered Care for Children with Special Health Care Needs

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There are approximately 10.2 million children in the United States with special health care needs, which translates into one out of every five households (MCHB 2007). Like other children and youth, those with special health care needs deserve a happy, healthy childhood and youth – attending school, enjoying community events, living with their families – as well as the opportunity to become productive adults. However, unlike other children and youth, children with special health care needs also have challenging health conditions – physical, mental, or emotional – that can make their lives and their families' lives more complicated. Any child or youth at any time could develop a disability or chronic health condition.

Institutionalizing children with disabilities or chronic illness was once a commonly accepted practice. But with the advent of federal legislation regarding the treatment of people with disabilities, civil rights, special education, and other related issues, as well as an attitude shift in how we approach caring for children with special health care needs, that method lost merit. The thought that children, disabled and nondisabled, with chronic health conditions and without, belonged with their families, in their communities, with their friends, and at home, gained widespread agreement.

In the late 1970s, the federal Maternal and Child Health Bureau (MCHB) began to look at issues for children with special needs and their families, and determined that there was a “mismatch” between what was being offered to families and what was needed. The identified “missing piece” was the meaningful involvement and support of families.

Since that time, much has changed, including the recognition that family organizations, such as Family Voices

(www.familyvoices.org) and the Family-to-Family Health Information Centers (F2F HICs), which exist in every state and Washington, DC, can be a source of information and support for children with special health care needs, their families, and their professional partners.

A PUSH FOR FAMILY-CENTERED CARE

Family Voices' goal is to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

Because families are at the center of a child's life, they must be equal partners in decisionmaking and all aspects of the child's care. Family-centered care is community-based, coordinated, culturally and linguistically competent, and guided by what is best for each child and family.

To ensure that families have the tools and resources, and an active role in making decisions, Family Voices worked with MCHB and with congressional leaders to secure funding for F2F HICs. Family Voices also provides leadership and technical assistance to them.

EQUIPPING FAMILIES

F2F HICs are nonprofit, family-staffed organizations funded by the MCHB with authorization renewed through the Affordable Care Act of 2010. Funding has been available for F2F HICs in every state and the District of Columbia since June 2009 (and in many states since 1999).

F2F HICs provide support, information, resources, and training to families of children and youth with special health care needs and the professionals who serve them. F2F HICs are staffed by family members who have firsthand experience navigating the maze of health care services and programs, making them uniquely qualified to understand the issues that families face and to help families partner with professionals and make informed decisions. Each F2F HIC is unique, reflecting the needs and character of the community and state

Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

– (McPherson et al. 1998)

CHALLENGES NAVIGATING THE SYSTEM

A large number of agencies and systems, both public and private, affect children and families' lives and the services and supports they receive. Because agencies rarely use common definitions or frameworks, it is frequently left to families to figure out what they need and which agencies can meet those needs. Even when knowing what is needed and where it is available, actually "extracting" services from the system is a challenge families often describe.

that it serves. Organizational structure, locations, partnerships, and specific initiatives vary; however, all F2F HICs carry out the following activities:

- assist families and professionals to navigate health care systems;
- provide information, education, training, support and referral services;
- reach out to underserved/underrepresented populations;
- provide guidance on health programs and policy;
- collaborate with other F2F HICs, family groups, and professionals in efforts to improve services for children with special health care needs; and
- evaluate and assess outcomes.

SELECT STATE F2F HIC ACTIVITIES

- **Louisiana F2F HIC** – During Community Days this F2F HIC brings its staff and community partners to underserved and distant communities to provide actual "on-the-spot" services to families, such as assistance signing up for Medicaid and LaCHIP. They also offer small mini-workshops for families who may have to wait to see specialists.
- **Colorado F2F HIC** – Family Leaders in communities across the state receive updated training regarding access to health care and related services, as well as training on Colorado's Medical Home Initiative. Once training has been delivered, navigators, in conjunction with health care providers in their communities, will provide training and outreach to other families to become better informed about how to access health care and be better consumers of health care. They are supported by "fast fact" guides on relevant topics.
- **Wisconsin F2F HIC** – This center convenes "Advocacy for Change," a learning and action forum for parent advocates to gain new information and skills that enhance their efforts to improve the lives of children and young adults with disabilities and/or special health care needs. Participants learn about the Survival Coalition state budget priorities affecting families and youth, including

health care, waiting lists, special education, and children's long-term supports.

WHAT CAN PHILANTHROPY OFFER?

1. Recognize that even with gains in many areas, children with special needs and disabilities are a vulnerable population in need of many services and supports. Consider incorporating their needs with existing funding priorities such as preventive dental care or efforts to improve cultural competence.
2. Get to know the needs of children and their families in your state or area and raise awareness through convenings and public education campaigns.
3. Make it a point to get to know the family organizations in your state or area. Learn what they know and offer, and consider ways to form partnerships.
4. Include language in grant guidance that addresses children with special needs/disabilities and that encourages family organizations to apply.

HELPFUL DATA SOURCES

The National Survey of Children with Special Health Care Needs is a significant survey funded by the U.S. Department of Health and Human Services and was most recently carried out in 2005–2006. Both national and state data are available through the Data Resource Center – www.childhealthdata.org.

Title V of the federal Social Security Act is the nation's oldest program to improve the health of all mothers and children, including children with special health care needs. Funds in the form of block grants go to each state and territory. One of the requirements to states is to carry out a significant needs assessment every five years. Those for 2010 are available on the federal web site: <https://perfddata.hrsa.gov/mchb/TVISReports/NeedsAssessment.aspx>. Data are available by state.

SOURCES

Maternal and Child Health Bureau, Health Resources and Services Administration, *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006* (Rockville, Maryland: U.S. Department of Health and Human Services, 2007).

McPherson, M., P. Arango, H. Fox, et al., "A New Definition of Children with Special Health Care Needs, *Pediatrics*, 102(1 Pt 1):137–40, 1998.

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