

Families of Children with Special Health Care Needs

**Facts You
Should
Know**

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Who are children with special health care needs (CSHCN)?

CSHCN 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.

How does the special health care need affect the child?*

24% of CSHCN are consistently **affected in their daily activities.**

27% of CSHCN **miss over 6 days** of school per year.

57% of CSHCN are affected by **multiple health conditions.**

How does the special health care need affect the family?*

38% of families do **not have adequate insurance** to pay for child's services.

24% of family members **cut back or stopped working** to provide care for their child.

There are 10.2 million CSHCN in the United States, representing 1 in 5 US households.

Where do families get help?

Family-to-Family Health Information Centers, staffed by experienced families who understand public and private insurance and how to navigate community based services, provide the most useful help to other families through:

- ✓ Assistance and support
- ✓ Trainings and education
- ✓ Outreach to underserved communities
- ✓ Speaking up for families on state boards, coalitions and policy forums

How have *Family-to-Family Health Information Centers* helped families? From 7/08-5/09, F2F HICs in 40 states:

- ✓ Trained and assisted over **665,000 families.**
- ✓ Trained and assisted **320,000 professionals** in helping families of CSHCN.
- ✓ Provided families with specific information:
 - **navigating community services** (100,000);
 - **partnering** with doctors (100,000);
 - **financing care** (55,000);
 - **accessing a medical home** (24,000).
- ✓ Disseminated over **1.7 million newsletters** and **631,000 factsheets** and other materials.
- ✓ Recorded over **16 million webhits.**
- ✓ On average, each F2F HIC collaborated with 14 **state-level programs** and 10 **community-based organizations.**
- ✓ Provided preliminary impact data indicating:
 - 83% of surveyed families report that F2Fs help them **partner in decision-making** with their child's provider;
 - 85% of surveyed families report that F2Fs help **them navigate services.**

*Child and Adolescent Health Measurement Initiative. National Survey of CSHCN. Data Resource Center for Child and Adolescent Health website. Retrieved 02.17.2010 from www.cshcndata.org

Family to Family Health Information Centers: Families Helping Families



Family-to Family Health Information Centers in Every State and the District of Columbia:

WORK FOR FAMILIES ONE BY ONE,

. . . COMMUNITY BY COMMUNITY,

. . . PARTNER BY PARTNER

California: Reported that 96% of surveyed families who received assistance increased their ability to access services.

Colorado: Advocated on behalf of the 900 families on HCBS Medicaid Waiver wait lists, and were successful in getting an Interim Committee set up to hear their stories and consider how state legislators may be able to streamline the system.

Connecticut: Assisted numerous families in accessing pharmacy support, Medicaid, respite funding, housing, and food through the Food Angel Ministries Program.

Illinois: Provided intensive assistance to several families involved with the Child Protective Services systems, including complex collaboration across multiple state agencies.

Louisiana: Assisted several families in successfully advocating for Family Medical Leave Act relief from their employers to preserve their jobs, protecting their private health insurance and providing the needed time to attend to their child's care.

Massachusetts: Worked with the Executive Office of Health & Human Services (EOHHS) to create more transparency between the seven state disability agencies that provide services and supports to individuals with special health needs and their families.

Maine: Supported family and youth graduates of the "HI Fidelity Wraparound Program" for youth with complex mental health needs to help them serve on boards that provide oversight to the program at the community and state level.

Michigan: Collaborated with Michigan Early Childhood Investment Corporation (ECIC) to support parent participation in an upcoming Medical Home Summit.

Mississippi: Received this feedback from a parent "Where have you been all this time - It's good to have someone understand what I go through daily."

North Carolina: Facilitated a Family Leaders blog for parents to share family leadership opportunities and effective strategies for family leadership.

New Jersey: Participated in local National Alliance on Mental Illness (NAMI) Program leader meetings and facilitated a Spanish parent support group.

Nevada: Worked with several families and professionals in Positive Behavior Supports Nevada Parent Training, in which the parents reported significant improvement in behaviors.

Oklahoma: Partnered with Title V agencies to develop block grant needs assessment tool and assisted in its distribution to families.

Pennsylvania: Worked with five state agencies to review and change policy to support children with special health care needs to stay in their homes and out of nursing facilities.

Rhode Island: Participated on a state-wide waiver workgroup/coalition of more than 40 agencies/organizations, to address the needs of all constituents (CYSHCN; the developmentally disabled; adults with disabilities; and seniors in need of home and community based care or nursing home care).

South Dakota: Worked with Siouxland Child Protection Council to develop and provide training for mandatory responders on recognizing child abuse and neglect.

Virginia: Received this feedback from a professional – "She (F2F presenter) was TERRIFIC! I'm using the information for my work--I'm a nurse practitioner--as well as for my developmentally delayed son!"

F2F HICs are supported through federal grants from the Maternal and Child Health Bureau, Health Resources and Services Administration, Department of Health and Human Services. These grants represent an expenditure of just \$1.40 per CSHCN. Families of CSHCN need the services of F2F HICs now more than ever in light of the current complexity of health care financing and community services for CSHCN.