

Family Voices of Illinois, The Arc of Illinois Family-to-Family Health Information Center, offers free services for families of children and youth with special needs. We provide information directly to families and professionals seeking help via toll-free multi-lingual information line, email and in person. We offer in-depth training and technical assistance on health issues for CSHCN; leadership development for parents and organizations; and linkages to local, regional, statewide and national partners.

IMPACT ON A FAMILY



The F2F in IL provided extensive assistance to a family of a newborn with a rare genetic disorder. The baby was released from the NICU with medical complications and needed specialized care services, including a feeding tube. The family struggled to find childcare that allowed them to continue to work so that they could maintain their health insurance. F2F staff connected the family with the Title V CSHCN program to apply for the Medicaid waiver for children who are medically

fragile and technology dependent; linked the family with first responders in the community to include this child in their database of residents with medical needs; guided the family to pursue financial options, including income tax solutions as well as locally-based charitable resources; helped the family understand Medicaid program eligibility; and referred the family to the Rare Disease Council, a group of parents in Illinois who provide telephone-based support to other families. Family Feedback: *I am finally getting some help from local care managers and social workers. Thank you for all your help and information.*"

2016 Program Highlights

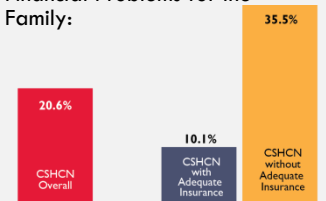
- The F2F coached families regarding how to handle mental health crisis calls with first responders and made legal assistance referrals for youth with disabilities who were arrested in such situations
- The F2F assisted families to search for resources when our state-funded autism program contractors lost their funding
- The F2F taught families about the state and federal EITCs, medical and dependent care tax deductions, other public benefits and assisted some families (with a stipend) to attend a financial planning seminar
- The F2F partners with crucial state agencies to advocate for families at both the practice and systemic levels, such as: the Illinois Department of Public Health, the Illinois Department of Healthcare and Family Services, the Illinois Department of Human Services, and UIC Specialized Care for Children (Title V).

Family Impact The F2F impact on individual families has been most significant in networking; by linking families to advocacy partners, dental providers, behavioral health providers and providing assistance with appeals. The F2F also continued to connect families by hosting large annual events such as the Mom's Retreats (multiple locations around the state), the Family Leaders Conference and the F2F Health Care Reform Conference.

CSHCN in IL¹

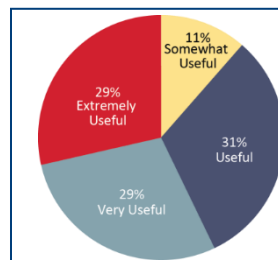
- 452,574 children (14.3%)
- 157,296 children have inadequate insurance
- 122,054 children have conditions that consistently affect their activities
- 154,706 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



OUTREACH²

Total Families Served: 21,470
Total Professionals Served: 15,576
Newsletter Subscribers: 12,000
Materials Disseminated: 40,000
Trainings: 53



IMPACT on Family/Provider Relationship

Families rate the usefulness of the support, information, and/or resources they received from the IL F2F in increasing their ability to partner *with their child's provider*.

CONTACT

Family-to-Family Health Information Center ♥ Website: www.familyvoicesillinois.org ♥ <https://www.facebook.com/ilfamilyvoices/> ♥
20901 S. LaGrange Rd., Ste #209 Frankfort, IL. 60423 ♥ Toll Free for IL Families: 866-931-1110 ♥ Fax: 815-464-5292
Contact: Faye Manaster: familytofamily@thearcofil.org

¹National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 04/03/2014 from www.childhealthdata.org.

²FY2015 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2014 through May 31, 2015.

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