

Family Voices of Illinois

The Family-to-Family Health Information Center (F2F) in Illinois

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.

HIGHLIGHT: Update on Health Care Reform Annual Conference

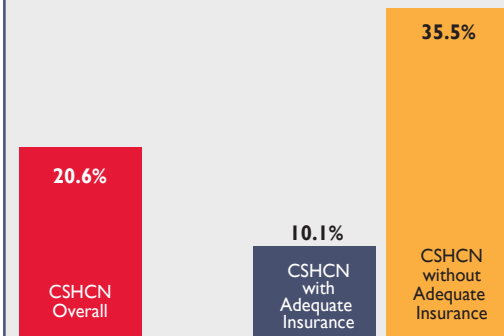
Each fall, Family Voices of Illinois holds an annual *Update on Health Care Reform for CSHCN* seminar featuring presentations by state agency representatives, advocates and family leaders. In this year's seminar 104 individuals participated in workshops on Medicaid Reform, the Affordable Care Act for Special Populations, Private Health Insurance Marketplace, and Disability Advocacy. Scholarships and stipends were available for families and CEUs and CPDUs were provided for professionals.

Feedback: *"This seminar provided clarification on ACA implementation in Illinois especially route of access."* *"This seminar will help me to navigate my child's insurance coverage needs as well as understand more about their Medicaid coverage. I feel much more confident now. I know where to go AND folks to call if I have questions."*

CSHCN in IL¹

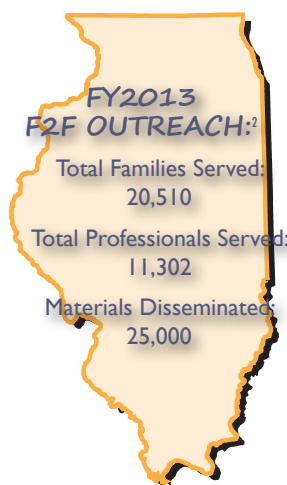
- 452,574 children (14.3%)
- 157,296 children have inadequate insurance
- 122,054 children have conditions that consistently affect their activities
- 145,706 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



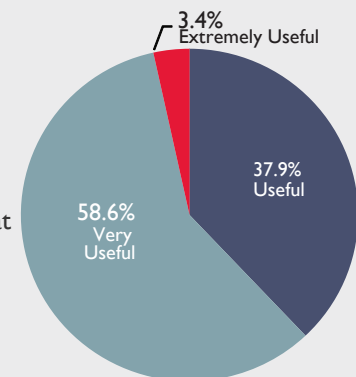
IMPACT on a Family:

We recently assisted a mother and two children, all of whom have a serious genetic disease. They were referred by a pediatric tertiary care center. We helped them to understand the insurance options newly available under the ACA and to learn the difference between Other Health Impaired IEPs and 504 plans and to decide which option is most appropriate for them. We referred them to our state's Title V CSHCN program for care coordination assistance, informed them about pre-registering with the first responders in their community, and how to obtain a Persons With Disability parking placard, as well as a reserved street parking space. We explored possible Medicaid eligibility options for the children and explained SSDI eligibility for the mother. The mother shared her appreciation: *"Thank you for all your valuable information and resources. It is good to know there are people out there looking to help each other out. I will keep you posted on our status."*



IMPACT: Family Confidence

Families rate the usefulness of the support/information/resources they received from the IL F2F in helping them feel more confident about getting their child the health care and services that s/he needs.²



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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.
²FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2014.