

Access for Special Kids (ASK) Resource Center IOWA FAMILY-TO-FAMILY HEALTH INFORMATION CENTER (F2F) 2016 STATE DATA REPORT

Parents of children with special needs formed Access for Special Kids Resource Center (ASK) in 1992. The F2F project at ASK, Family-to-Family Iowa, is a statewide network of organizations and trained family members who provide various forms of natural supports to families of children with special needs (developmental, behavioral, emotional, and/or physical). Guided by a Family Advisory Council of organizations from across Iowa, ASK works together to help families navigate the health supports and services available for their CSHCN; help families by connecting them with other parents with similar experiences; and help families develop self-advocacy skills through trainings and resources.

2016 Family Story: Providing quality family to family emotional support by observing the best practice standards identified in the research of Parent to Parent USA has raised the confidence of families to feel better prepared, trust their instincts, and respectfully partner with professionals to better manage their child/youth with special health care needs. This is the full circle of health and wellbeing that lowers ER visits and hospitalizations. The training of families focuses on supporting and empowering them to become meaningful partners and ask questions. At a recent public awareness event,

CSHCN in IA1

- 105,815 (15.0%)
 31,825 children have inadequate insurance
- 25,693 children have conditions that consistently affect their activities
- 33,421 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



Michelle, a parent with a disability herself, shared how the F2F has changed the life of her family. Her child received the services needed and her involvement with our organization over the years increased her advocacy skills. This parent is mentoring other families now.

Feedback from a Family: "I truly did not understand the emotional power or understand the phrase 'finding your voice' until I attended Parents As Presenters. Thank you for connecting me with other moms and dads dealing with situations similar to our family. I want to shout from the rooftop 'I found my voice.'"

-a parent who participated in an ASK Resource Center training

2016 Project and Partnership highlights: The lowa transition from Medicaid fee for service to private managed care was delayed and fraught with challenges in 2016. Issues ranged from the simple issuance of multiple information packets to the same individual to the more complex challenges of accurately integrating care plans from one system to another. Additionally, there was concern regarding oversight and accountability for MCOs, provider network adequacy, and physical access of services for Iowa's rural populations. As the only statewide, community-based agency representing families, children, and youth across all disability and special healthcare needs populations, ASK has been, and continues to be, instrumental working with administrators of the three managed care organizations to represent family concerns and to identify possible solutions.

IA F2F Outreach Activities in FY2016 Total Families Served: 8,708 Total Professionals Served: 7,054 Newsletter Subscribers: 4,565 Materials Disseminated: 66,031 Trainings: 826

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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.

²FY2016 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2015 through May 31, 2016.

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