

Raising Special Kids

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



The Arizona Family-to-Family Health Information Center, a project of Raising Special Kids, is a parent-run center that provides free, confidential technical assistance to families raising CSHCN, professionals, and others. Through this project and others, we partner with health care providers, state agencies, programs for medical residents and student nurses, and other community organizations. Our goals are to promote understanding of the value of family-centered, culturally competent care so these principles are put into practice.

HIGHLIGHT: Partners in Preparedness

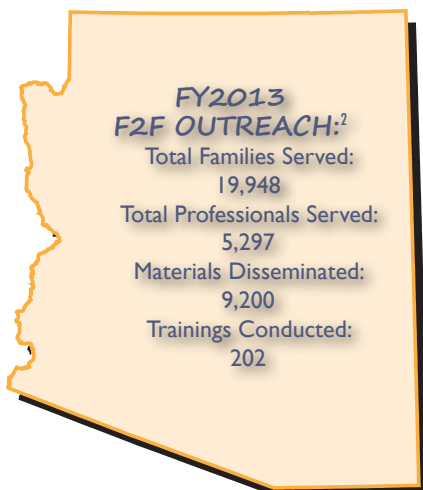
Raising Special Kids has been participating in a statewide Emergency Preparedness workgroup called *Partners in Preparedness*, addressing access and functional needs, since 2012. Raising Special Kids' role is to provide the perspective of families with children who have disabilities and complex medical needs. There are currently 21 community partners in the workgroup. We participated in the planning committee for the 2013 Statewide Partners in Preparedness Conference which 124 people attended, including emergency management personnel, public health staff, seven Native American tribes, and individuals and parents of children with disabilities. As a result of our work, the AZ Department of Emergency Management is forming a subcommittee to address the specific needs of children who are medically fragile. Though the *Partners in Preparedness* workgroup we are participating in the Arizona Department of Emergency Management Arizona Disability Assessment Program.

CSHCN in AZ¹

- 241,067 children (13.9%)
- 84,777 children have inadequate insurance
- 70,074 children have conditions that consistently affect their activities
- 88,998 children do not receive family-centered care

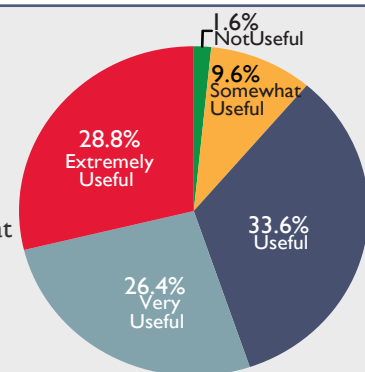
IMPACT on a Family:

The health needs of Adilynn, adopted daughter of Laurie and her husband, have required multiple medical procedures and over a dozen specialists. "We have been hospitalized a total of four times and with every stay we would leave with more doctors, tests, and stress to come," Laurie said. "We were bombarded with paperwork, insurance issues, and the feeling that we were drowning and couldn't catch up." Following Adilynn's surgery, Laurie received a call from Raising Special Kids. "They helped me cope with her new feeding tube and the best help of all was that I got pointed in the right direction on how to get Long Term Care set up!" Through Raising Special Kids, Laurie was connected with another mom who also has a child with complex medical needs. "I could talk to someone who understands and someone who is a few steps ahead of where we were at the time. I now know just how important Raising Special Kids is to those who have kids with special needs."



IMPACT: Family Confidence

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



CONTACT:

Raising Special Kids
5025 E. Washington St. #204, Phoenix, AZ 85034
Phone: (602) 242-4366 • Toll Free: (800) 237-3007 • Fax: (602) 242-4306
Website: <http://www.raisingpecialkids.org/>
Contact: Vickie French, vickief@raisingpecialkids.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.
²FY2013 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2012 through May 31, 2013.