

Utah Family Voices The Family-to-Family Health Information Center (F2F) in Utah

The F2F at Utah Family Voices provides families with quality information and resources and expands family/professional partnerships to help families make informed decisions. They provide information, training, and guidance, and develop and implement strategies for collaboration. They conduct activities that are culturally and linguistically relevant to families and professionals around home and community based services and supports, and help families assess their potential eligibility for programs and services.

2016 IMPACT on a FAMILY

A family came to the F2F for help when their daughter's surgeries were denied because the sub-specialist was providing the incorrect information and because one of the surgeries (orthodontia) was deemed "cosmetic." After collecting and submitting the correct data and information, the F2F helped insurance understand that the orthodontia work was to treat a rare genetic condition and had to be done prior to, and to ensure success of, the more extensive surgery. All were approved and successfully completed!



System Impacts As clinics that were administered by the state CSHCN program were transferred to one of the large health systems, the F2F stepped in as a neutral and stable

CSHCN Whose Conditions Cause Financial Problems for the Family:

CSHCN in UT

>31,788 children have conditions that consistently affect their activities

>38,686 children have inadequate

>34,087 do not receive family-

>112,278 children (13.0%)

insurance

centered care





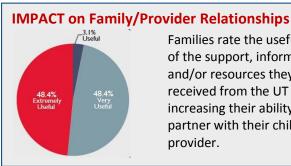
resource. Combating rumors, misinformation, etc., we disseminated correct information to many of the family groups through social media. Additionally, we met with families onsite before, during and after the transition of administration of the clinics.

When Durable Medical Equipment (DME) providers denied medical supplies for many families due to a misunderstanding in a Medicaid policy, the UFV F2F worked with community and agency partners to break down the problem, facilitate communication, and get the correct information out. For example, when "chux pads" (the disposable bed pads) were denied due to cost, we were able to help define how it is medically necessary supply for some children with special health care needs to prevent skin breakdown and infection leading to much more expensive treatment.

Legislative Advocacy UFV staff collaborates with the Legislative Coalition for People with Disabilities, Utah Health Policy Partnership, Voices for Utah Children and the Disability Law Center to bring the voices of families of children with special health care needs in education and advocacy efforts. The staff also provides stories, current issues, and data to Senator Hatch's staff as a part of his disability committee.

OUTREACH²

Total Families Served: 21,690 **Total Professionals Served: 18,898** Newsletter Subscribers: 10,004 Materials Disseminated: 10,686 Trainings: 73



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

CONTACT

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National 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 w.w.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. This report was developed by Family Voices National Center for Family/Professional Partnerships (www.fv-ncfpp.org) under grant number U40MC00149, funded by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.