

Delaware Family Voices (DE FV) is a non-profit run by families of children with special health care needs (CSHCN), whose mission is to achieve family-centered care and help families be full partners at all levels of decision making. This mission is achieved by: assisting families as they navigate health systems, insurance plans, and Medicaid; educating families and health care providers about access to services and resources; promoting family-centered care and medical homes for CSHCN; working with families, health care providers, agencies, advocacy and support groups; linking families to providers, managed care programs and public programs; and promoting discussion among groups that serve children.

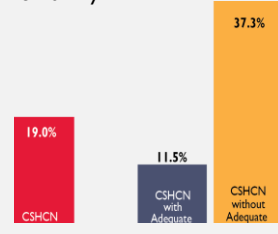
IMPACT on a FAMILY

"I sat on the Medical Assistance paperwork for some time. It was daunting. I heard it would take 6 months to be accepted. I heard it would be denied for further information. I wasn't quite sure how to fill it out so that my daughter could get the help she so desperately needed. The DE F2F explained to me what Medical Assistance was looking for in each question. I went back home and filled out my paperwork and included the necessary documentation. Voila! It was accepted, took only 6 weeks for Medical Assistance to approve and the worker actually thanked me for including all the information that I had. Thank you, DE FV, for making the process easy." DE Parent

CSHCN in DE

- 46,000 children (22.4%)
- 8,916 children have inadequate insurance
- 7,112 children have conditions that consistently affect their activities
- 19,044 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



Category	Percentage
CSHCN	19.0%
CSHCN with Adequate	11.5%
CSHCN without Adequate	37.3%




2016 HIGHLIGHT:

Medicaid Crises Impact When one of Delaware's Children's hospitals lost their contract with one of the two Medicaid MCOs in the state, many families were left with no options and forced to disrupt continuity of care. Additionally, the MCO that continued their contract with the hospital denied services, equipment, supplies, and therapies that were approved in the past; they limited the network of approved vendors and cut Private Duty Nursing services for children with ventilators. DE F2F is advocating in monthly MCO calls, holding meetings with the Medicaid Director and Deputy Director, and facilitated a meeting between the Medicaid Director and eight families of children with complex medical needs where they expressed frustration and inability to obtain basic needs. Progress is being made.

Medicaid Crises Impact DE F2F alerted the state Medicaid Director to a situation they knew nothing about: 6,000 letters were sent from social security to dual eligible Medicare and Medicaid young adults indicating that the state was no longer paying their Medicare premiums, and they would be losing their SSI and Medicaid. DE F2F worked with the Director to identify the source of the error, to issue explanatory letters and ensure everyone was reinstated. The state Medicaid Director acknowledged the reason a major catastrophe was averted was due to our work.

OUTREACH



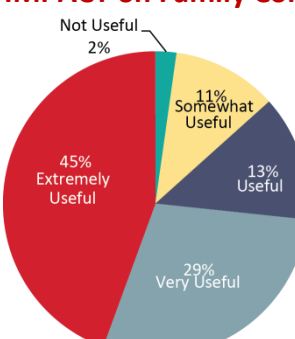
Total Families Served:
1,284

Total Professionals Served:
715

Materials Disseminated:
2,219

Trainings:
95

IMPACT on Family Confidence



98% of families rate the usefulness of the support, information, and/or resources they received from the DE F2F in helping them feel more confident about getting their child the health care and services that s/he needs as somewhat to extremely useful.

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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.
 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.