

WV Parent Training and Information, Inc. WEST VIRGINIA FAMILY-TO-FAMILY HEALTH INFORMATION CENTER (F2F) 2016 DATA REPORT

Established in 1991, the West Virginia Parent Training and Information Center, Inc. (WVPTI) is a statewide, cross-disability, parent/professional, and nonprofit group. The F2F at WVPTI works to improve health care and health care supports throughout West Virginia for children with developmental delays, chronic illnesses and special needs by empowering families to advocate for their children and youth. The statewide Health Information Center reflects a family-directed focus.

2016 IMPACT on a FAMILY

"I never knew what it was or how hard it was to care for a handicapped child until my baby son was diagnosed with an Astrocytoma Stage 2 located in his spinal cord. The surgery left him paralyzed from the chest down and incontinent. I can honestly say that the help I have received from the F2F program has been so helpful to me. You have made my life much easier. Through your help, I have built a relationship with the companies that provide supplies for Trevor that is now much more cooperative. I appreciate that you take the time to listen to me and call even if I am not having a problem, just to see how Trevor is doing. Thank you from the bottom of my heart."

CSHCN in WV

- >70,609 children (18.5%)
- >21,901 children have inadequate insurance
- 19,602 children have conditions that consistently affect their activities
- >21,928 do not receive familycentered care

CSHCN Whose Conditions Cause Financial Problems for the Family:





2016 HIGHLIGHTS

Public Health Crisis Impact Floods devastated 1,200 homes, schools were flooded, roads washed away and 26 lives were lost. The WV F2F supported families that were dislocated, getting them the services and supports needed, both medically and academically. They also let families know about FEMA, and other resources and shelters that were open for families.

System Impact The WV F2F has worked to improve the quality of service delivery related to care coordination and medical homes for children with special health care needs (CSHCN) by helping to redesign state policies and procedures related to CSHCN. The WV F2F has started to implement this

process, by assisting with needs assessments and improving access to medical homes by attending home visits, clinic participation, and assisting with the assessment and care plan development for CSHCN. The WV F2F has also promoted family involvement in advocating for improved systems through serving on various state boards and advisory councils.

Total Families Served: 14,210 Total Professionals Served: 6,491 Newsletter Subscribers: 2,496 Materials Disseminated: 24,362 Trainings: 112

IMPACT on Family/Provider Relationships



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

CONTACT

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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

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).