

# PATH Parent-to-Parent/Family Voices of CT CONNECTICUT FAMILY-TO-FAMILY HEALTH INFORMATION CENTER (F2F) 2016 DATA REPORT

PATH is a network of families providing informational and emotional support to others who have a child with developmental or health related needs. PATH reaches out to help strengthen families coping with similar situations across the state of Connecticut, and works with the organizations that serve these families to reduce isolation, empower families as advocates for their children and reaffirm their values as parents and caregivers.

#### 2016 IMPACT on a FAMILY

We originally heard about PATH and your parent support specialist, Marni McNiff, at Pediatric Associates. Marni has been of critical help in obtaining services for Charlotte at two Planning and Placement Team (PPT) meetings. Prior to the meetings we met and she gave us ideas and



strategies for the PPT, then she attended the meetings with us, helping us verbalize and justify requests for Charlotte. Charlotte's PPTs have been complex, as she needs services for Occupational Therapy, Physical Therapy, Speech, Adapted Physical Education, Special Education, Bureau of Education and Services for the Blind,

Mobility, and a Paraprofessional. Marni's assistance also helped us keep track of all the topics and requests we wanted to bring up. I have been recommending PATH's Parent Support Specialist services to other families with Special Needs children. I believe having an advocate for the family can be crucial in justifying and getting services, and understanding educational evaluations. This is a

wonderful program and we are very thankful for the help we received. Best Regards, Thomas and Margarita James

#### **SNAPSHOTS OF 2016 PROJECT HIGHLIGHTS**

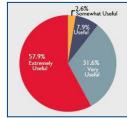
- A Health Information Specialist is embedded as part of the healthcare team in a Pediatric office that functions as an Advanced Medical Home.
- The F2F has a Health Information Specialist who is focusing on Autism Spectrum Disorder (ASD) training to First Responders (Fire Dep., EMT, & Police Dept.).
- The F2F continues to monitor changes in Medicaid and consult with the state Medicaid to respond to questions and concerns that families may have. Staff receives updated training and information so that they are ready to respond to families concerns. The F2F has similar informational and advocacy relationships to support families with all of CT's eligibility programs such as Department of Developmental Services (DDS) or Bureau of Rehabilitation Services (BRS).
- The F2F continues to participate on various state and local boards, such as Consumer Advisory Board, the Practice Transformation Taskforce and the Department of Transportation National EMS Advisory Council.

**Youth Impact** This past year CT KASA was part of a Statewide Conference called *Building a Great Life*. The youth collaborated with two other youth groups throughout the state and discussed ways they can collaborate and begin planning an annual Youth Summit. Additionally, some of the youth began doing presentations in their local schools to speak about CT KASA and to recruit more youth to join. They were able to recruit five more youth to join.

**Training Impact** PATH/FV CT continues to spearhead the Community of Practice, Family Mentoring and Leadership Committee. The F2F has begun to host speaker programs on a six week basis (September - May) on topics that families have requested such as Healthcare, Guardianship, Special Needs Trust Funds, and IEP's.

### **OUTREACH<sup>2</sup>**

Total Families Served: 35,645 Total Professionals Served: 35,523 Newsletter Subscribers: 12.290 Materials Disseminated: 2,760 Trainings: 3



## **IMPACT on Family/Provider Communications**

Families rate the usefulness of the support, information, and/or resources they received from the CT F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.<sup>2</sup>

#### 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 www.childhealthdata.org. 247/2016 EXF data represents families and professionals served through non-to-one contact, training, and broader outreach from June 1, 2015 fithrough 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 on the construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HKS or the U.S. Government.

