



Advocates for Justice and Education, Inc.

The Family-to-Family Health Information Center (F2F) in Washington, D.C.

Since 1996, Advocates for Justice and Education, Inc. (AJE) has endeavored to empower youth and parents to be effective advocates to ensure that children with disabilities receive appropriate services to meet their needs.

The F2F at AJE, in partnership with Mary's Center for Maternal and Child Care, provides training and workshops to families of CSHCN, trains parents and caregivers to be Family Navigators to provide emotional support to other families, produces resources and publications on best practices and programs affecting CSHCN, educates professionals working with CSHCN, and partners with stakeholders in the medical and health care fields.

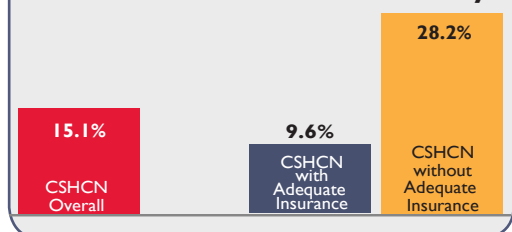
HIGHLIGHT: Leadership Institute for Spanish-Speaking Families

Recently AJE collaborated with Mary's Center and other agencies serving CSHCN to host a *Parent-to-Parent Leadership Institute for Spanish-speaking Families* at the Mary's Center Medical Home location. Forty-eight parents and caregivers of CSHCN attended the two-day training to become Certified Family Navigators. The *Parent-to-Parent Leadership Institute* offers a comprehensive training that focuses on health care and educational advocacy, the laws that supporting health care, education and related services, and most importantly empowering families and developing their leadership skills. Some of the topics of this years' two-day training included: Youth Mental Health Advocacy, Nutrition and Child Development, Multi-systemic Therapy, Transfer of Educational Rights, Understanding the Special Education Process, D.C. Health Benefits Exchange, Overview of Autism Spectrum Disorders, and Working Effectively with Doctors.

CSHCN in DC¹

- 18,819 children (16.6%)
- 5,628 children have inadequate insurance
- 4,043 children have conditions that consistently affect their activities
- 7,533 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:



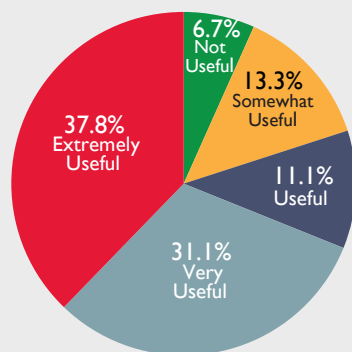
IMPACT on a Family:

A parent sought assistance from AJE with obtaining educational, medical, and community-based supports after her daughter had recently been diagnosed with epilepsy. AJE helped the parent to obtain Supplemental Security Income and to access a local support group for teens with epilepsy. We're pleased with not only the outcomes the family achieved, but also with the growth and leadership of the youth. The youth was able to effectively communicate with her teachers, school administrators, and medical providers about the accommodations she desired during her Individualized Educational Planning (IEP) meeting, resulting in a modified Individualized Health Plan (IHP). Following the IEP meeting, the youth informed AJE that she felt empowered and prepared to advocate for herself when needed.

IMPACT:

Family/Provider Communications

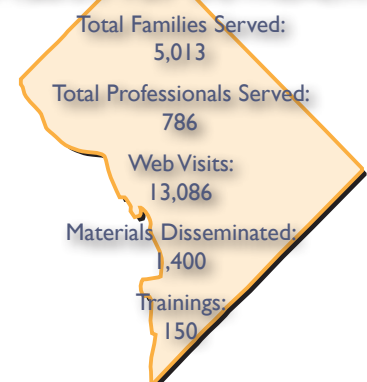
Families rate the usefulness of the support/information/resources they received from the DC F2F in helping them partner with (communicate with, talk with, work with) professionals to make decisions about their child's health care.²



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FY2013 F2F OUTREACH:²



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.