

### PARENT EDUCATION & ADVOCACY LEADERSHIP CENTER

# THE PENNSYLVANIA FAMILY-TO-FAMILY HEALTH INFORMATION CENTER (F2F)

2016 DATA REPORT

The Parent Education & Advocacy Leadership Center (PEAL) was established in October 2005 as an organization of parents of children with disabilities reaching out to assist other parents of children with disabilities and special health care needs, and professionals. The PEAL F2F provides individual assistance and training on access to health care, insurance, and community support services statewide. The mission of the PEAL Center is to ensure that children, youth, and adults with disabilities and special health care needs lead rich, active lives and participate as full members of their schools and communities, by providing training, information, parent leadership, and technical assistance based on best practices to individuals and families and all people who support them.

**FAMILY IMPACT:** The PEAL Center assisted a mother whose son, with a life-threatening allergy, was misdiagnosed by his school district. PEAL staff were able to walk the mother through her son's Individualized Education Program (IEP) and develop a health care plan with the school. When the school did not follow through and there was a delay in care, PEAL staff advocated for the family, forcing the school to recognize their error and correct the misdiagnosis. "My family has been fortunate to have PEAL. Their presence is noted and respected by all of the individuals in

CSHCN in PA

> 469,906 children (17 %)
> 119,132 children have inadequate insurance
> 116,309 children have conditions that consistently affect their activities
> 149,823 do not receive family-centered care
CSHCN Whose Conditions
Cause Financial Problems for the Family:

| 16.5% | 8.6% | CSHCN | CSHCN

the school meetings. Without a doubt, my children would not be receiving the respect or services that they are if PEAL were not involved."

#### **2016 HIGHLIGHTS:**

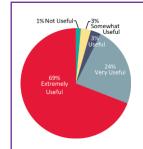
Medicaid and Waivers Impact The PEAL F2F offered multiple health insurance workshops on Pennsylvania's unique Medical Assistance Program for Children with Disabilities, CHIP, and ACA in communities across the state, particularly targeting low-income neighborhoods in Philadelphia and Pittsburgh. F2F and state experts taught how to understand waivers, how to qualify, what's covered and what to do if coverage is denied. Many of the workshops touched on aspects of the ACA that may be at risk and how that might affect CYSHCN. The workshops particularly emphasized the critical changes at ages 18 and 21 that are critical to understand for transitions in care.

Transition Impact In 2016 the Pennsylvania Department of Health asked the PEAL F2F to present our Youth Development Leadership Institute (YDLI) on self-advocacy and youth leadership in 6 communities across the state. The YDLI promotes the development of advocacy and leadership skills in youth with disabilities. The goal of the YLDI is to provide a safe, accepting environment to cultivate the growth of self-acceptance, confidence, and self-advocacy skills. Youth leaving the YLDI program should feel more accepting of themselves with a disability, more confident in their abilities and choices, and a connection to the other youth attending the YLDI, as well as to the disability community as a whole.

Training Impact The PEAL Center hosted its 10th Annual Inclusive Communities Conference, *Recipe for Inclusion: We All Bring Gifts to the Table*, in conjunction with Dan Miller's 3rd Annual Children & Youth Disability & Mental Health Summit. This year's conference featured local and national experts in the areas of education, inclusive practices, transitions to adult life, special health care needs, and legislative policies. The Keynote speaker, Torrie Dunlap, addressed how to help others in the community shift from the problems to possibilities and adopt an inclusive mindset, with her talk on the *Promise & Possibility of Inclusion*. Over 1,100 parents, youth, and professionals attended.

## 2016 OUTREACH:2

Total Families Served: 20,820
Total Professionals Served: 21,585
Newsletter Subscribers: 12,400
Materials Disseminated: 82,760
Trainings: 77



# IMPACT on Family/Provider Relationship<sup>2</sup>

99% of families rate the usefulness of the support, information, and/or resources they received from the PA 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.

### **CONTACT**

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