

In 2007, to meet the needs of Hawaii families of children with special health care needs, the Hawai'i Pediatric Association Research and Education Foundation (HPAREF) and Family Voices of Hawai'i, partnered together to form the Hilopa'a Family-to-Family Health Information Center. The name Hilopa'a, was given by Kupuna Kahauanu Lake to exemplify the driving force behind the center, to "braid firmly" the service system for HI children and youth. The F2F is staffed by parents and friends of CSHCN and provides free, confidential assistance, information and referral, and training to families raising children and youth with special health needs, self-advocates and the professionals who serve them.

### IMPACT on a FAMILY

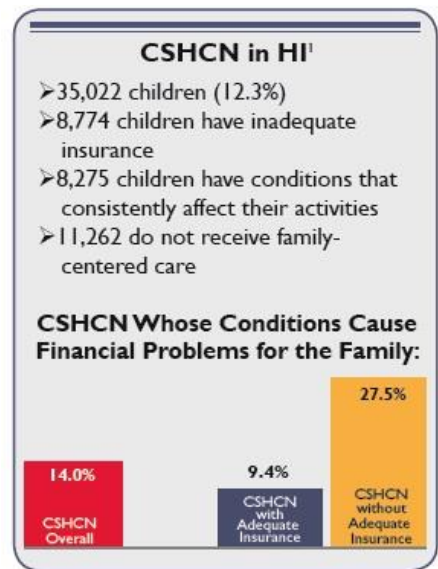
The Hilopa'a F2F HIC assisted a family in obtaining retroactive Medicaid eligibility in excess of 4 months for a child with an extensive stay in a hospital's intensive care unit. The family was contemplating filing for bankruptcy as they were unable to see how they would be able to pay their child's extensive and ongoing hospital bills. The Medicaid coverage eliminated the considerable out-of-pocket expenses the family was facing and they were relieved that Medicaid would be able to cover future hospital expenses. In addition, the family now has more options through the Medicaid Long Term Care Services and Supports when the child is able to be discharged, as the family's private insurance would only provide a nominal amount of in-home care.

### 2016 HIGHLIGHTS

**Preventative Impact** The state is spending a lot of effort on health prevention. As such, the F2F is intimately involved in three screening initiatives for alcohol and substance abuse in pediatrics, obstetrics and adult primary care settings. The F2F is developing and deploying training content for pediatrics and obstetrics, and working on facilitating discussions for support and referral processes. Although not yet measurable, the F2F anticipates a reduction in total cost of care through the inclusion of alcohol and substance abuse as part of universal screening in all three care settings listed above.

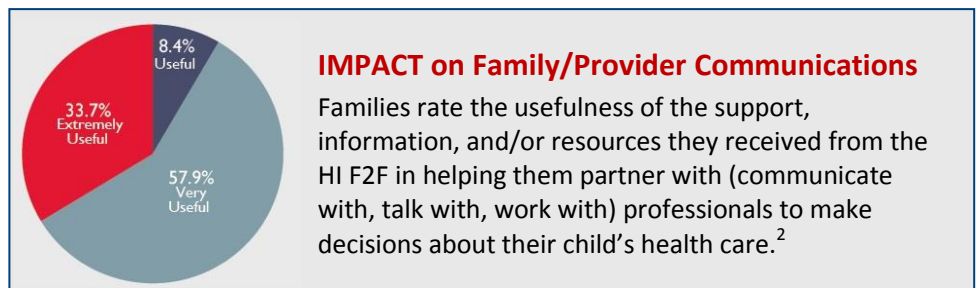
**Family Impact** The F2F assisted many families of children with children with complex needs obtain coverage with the DD/ID Medicaid Waiver to access respite and personal assistance/habilitation services. These services eliminate out of pocket costs for non-covered respite and in home paraprofessional support. One family in particular attempted twice on their own to obtain waiver services but was unsuccessful. The F2F intervened for a third application and obtained a successful outcome.

**Systems and Process Impact** Through the advocacy of the F2F, the state Developmental Disabilities Division has expanded its intake processes to include referrals from professionals. Prior policy only allowed for self-referral by the consumer or families. With this expansion, time and effort has been saved as referring professionals, including the F2F, are better able to address eligibility questions and the intake process.



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

**Total Families Served: 2,980**  
**Total Professionals Served: 2,525**  
**Newsletter Subscribers: 2,758**  
**Materials Disseminated: 4,809**  
**Trainings: 392**



### CONTACT

**Hilopa'a Family-to-Family Health Information Center**  
 1319 Punahou Street Room 742, Honolulu, HI 96826 ♥ Phone: (808) 791-3467 ♥ Fax: (808) 531-3595  
**Website:** <http://www.hilopaa.org/> ♥ **Contact:** Leolinda Parlin, leo@hilopaa.org

<sup>1</sup>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.  
<sup>2</sup>FY2016 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](http://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.