



2016 DATA REPORT

The Oregon Family-to-Family Health Information Center provides information to families who are navigating the complex world of special health care needs. OR F2F is run by family members who have firsthand experience raising a child or youth with a chronic health condition, developmental delay, disability, or emotional/behavioral challenges.

2016 IMPACT on FAMILIES

Policies prevent families of children and youth with Muscular Dystrophy/Spinal Muscular Atrophy from receiving respite and/or nursing support through Oregon’s two primary programs. For one program (Developmental Disabilities Services) the children do not meet eligibility due to lack of intellectual disability. The other program (Children’s Intensive In Home Services—the OR version of the Katie Beckett waiver) has a multiple-year wait list. The OR F2F is working with policymakers to address this inequity. When accomplished, the impact to individual families of children with MD and SMA will be tremendous.

2016 HIGHLIGHTS

Mental Health Crisis Oregon only has a few pediatric psychiatric beds. Our F2F participates weekly in a telemedicine effort to keep rural youth out of psychiatric residential care. We provide resources, information, and the opportunity for rural providers to communicate with families of children/youth being treated for psychiatric illness.

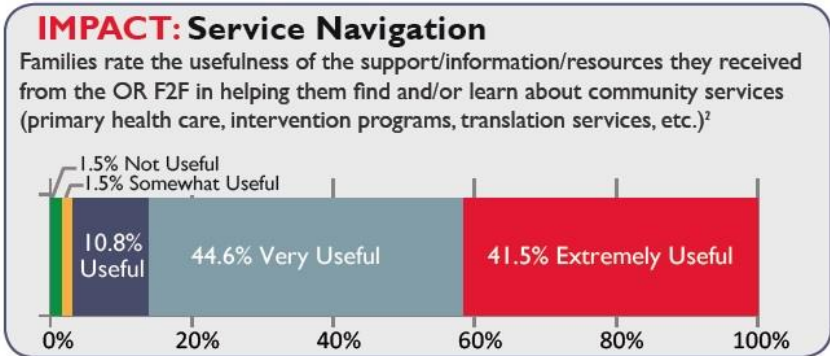
Training Impact Because of the quality and frequency of the OR F2F HICs training of parents and professionals in rural communities, we have received more requests for assistance. For example, we are routinely invited to other family-driven activities, including the Sustaining Families Group, Families as Leaders, and the Family Leaders Group and all seven of the Developmental Disabilities Family Networks. The OR F2F HIC has been invited to present to each major Medical Home initiative in the state, including the Oregon Pediatric Improvement Partnership, the Children’s Health Alliance, and the Oregon Pediatric Society. The OR F2F HIC continues to impact families in rural and frontier areas by providing resources and presentations where families are informed about life-changing programs such as the Oregon Health Plan, Developmental Disabilities, In Home Intensive Services, etc.

CSHCN in OR¹

- 119,187 children (13.7%)
- 42,944 children have inadequate insurance
- 34,542 children have conditions that consistently affect their activities
- 40,630 do not receive family-centered care

OUTREACH²

Total Families Served: 4,178
 Total Professionals Served: 1,278
 Newsletter Subscribers: 827
 Materials Disseminated: 284
 Trainings: 43



CONTACT

Oregon Family-to-Family Health Information Center
 707 SW Gaines Street CDRC, Portland, OR 97239-3011
Phone: (503) 494-0865 ♥ Toll-Free: (855) 323-6744 ♥ Fax: (503) 494-2755
Website: <http://www.oregonfamilytofamily.org>
Contact: Tamara Bakewell, bakewell@ohsu.edu

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.
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