

Rhode Island Parent Information Network (RIPIN) RHODE ISLAND FAMILY-TO-FAMILY HEALTH INFORMATION CENTER (F2F) 2016 DATA REPORT

Founded in 1991, the Rhode Island Parent Information Network (RIPIN) is a statewide nonprofit organization with a collective programmatic reach that extends to every Rhode Island community, reaching families through schools, associations, and agencies. The F2F project provides health care information, family-to-family support and leadership development for families of children with special health care needs. They work directly with organizations, institutions, and communities to address gaps and deficiencies so that individuals, parents and families are better served and viewed as equal partners.

2016 IMPACT on a FAMILY

A mother called the F2F RIREACH program following the denial of medical equipment for her daughter with spina bifida. The F2F was able to assist the mother with filing an appeal. This family had to appeal 3 times due to continued denials. Through partnership with the MCO, RIREACH staff and the health plan were able to supply the needed equipment. This family-professional partnership literally saved this family thousands of dollars in out-of-pocket expenses for equipment.

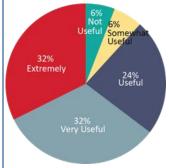
2016 HIGHLIGHTS

Legislative Impact Senator Whitehouse's staff contacted RIPIN F2F to assist with a mother whose son was in trouble out of state. The son was diagnosed with mental health conditions and had been arrested. RIPIN was able to connect with the mother, provide her with emotional peer support, and then help her to work towards rectifying

the issue. All four of RI's Congressmen frequently refer families to RIPIN, especially for their trainings and workshops.

System Impact At the RI Parent Information Network (RIPIN), the F2F HIC continues to represent families at the Executive Office of Health and Human Services, Department of Health, Department of Education, and RI's Medicaid insurance providers. F2F staff attends multiple state level public meetings pertaining to the SHCN population. RIPIN F2F was named the ombudsman for the Integrated Care Initiative for those that are dually eligible for Medicare/Medicaid in the state. The F2F was also awarded a grant to provide care coordination for families who need to access Medicaid in-home therapeutic services such as Home Based Therapeutic Services, Personal Assistance Services and Supports, or Respite Care. Through these services families can have a RIPIN Family Resource Specialist available to them to attend school meetings or help them complete applications for assistance of all kinds.





IMPACT on Family/Provider Communications

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

CSHCN in RI

conditions that consistently affect their activities

➤ 39,160 children (17.3%)

11,812 children have inadequate insurance

➤ 10,055 children have

> 12,996 do not receive

CSHCN Whose Conditions Cause Financial Problems for

the Family:

family-centered care

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.