



# Rhode Island Parent Information Network (RIPIN): The Family-to-Family Health Information Center (F2F) 2014-2015 State 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. We 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.

## 2015 HIGHLIGHT:

This year we worked closely with the Executive Offices of Health & Human Services to better support families with children with behavioral health needs. We are recognized throughout the state for our work in building positive collaborative efforts between parents and professionals where issues are both heard and change is facilitated. These meetings are attended by a broad base of agencies - from the Executive Office of Health and Human Services to the RI Department of Health to parents of children with special health care needs to Disability Specific Agencies. RIPIN now has a full time Director of Government Relations, who works tirelessly advocating for our consumers, mainly at the state level. We also have hired a full time lawyer. Our new personnel have been instrumental in assisting us with staying on top of all the happenings within our state and state agencies.

**CSHCN in RI**

- 39,160 children (17.3%)
- 11,812 children have inadequate insurance
- 10,055 children have conditions that consistently affect their activities
- 12,996 do not receive family-centered care

CSHCN Whose Conditions Cause Financial Problems for the Family:

Category	Percentage
CSHCN Overall	14.7%
CSHCN with Adequate Insurance	7.4%
CSHCN without Adequate Insurance	29.2%

## IMPACT on a FAMILY



*"My family's journey with RIPIN began in the summer of 2012 when the RIPIN NICU family support staff came to the hospital and introduced herself to me and my family. From that day forward, I have been helped by RIPIN many times, including learning about caring for my child's tracheostomy vent, getting advice about medical insurance and pre-existing conditions, finding a pediatrician, and seeking assistance from a feeding team. With the guidance of RIPIN, I've become involved in advocacy work for other families managing special health needs. I've met some of my best friends and biggest supports just because RIPIN walked into our room 3 years ago!"*

## IMPACT on Family/Provider Communications

Families rate the usefulness of the support/information/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.<sup>2</sup>

Usefulness Rating	Percentage
Extremely Useful	32%
Very Useful	32%
Useful	24%
Somewhat Useful	6%
Not Useful	6%

**RI F2F Outreach Activities in FY2015**

- Total Families Served: 31,807
- Total Professionals Served: 16,402
- # People Reached thru Facebook (Organic): 8,635
- Materials Disseminated: 219,864
- Trainings: 364

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<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](http://www.childhealthdata.org).  
<sup>2</sup>FY2015 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2014 through May 31, 2015. 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 of the U.S. Department of Health and Human Services. 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.



## The Value of Family-to-Family Health Information Centers

Imagine a family that is suddenly confronted with a severely premature baby with multiple health problems, or discovers that their child needs a kidney transplant, or has autism, diabetes, epilepsy or a serious mental illness. They are likely to be at a loss for information about how to get the best treatment for their child –how to find the right specialists, therapists, or caretakers – and how to pay for that costly care (autism therapies, private-duty nursing, and medications, for example, can cost tens of thousands dollars per year).

The staff of Family-to-Family Health Information Centers (F2Fs) – who are themselves specially trained family members of children with special health care needs – help families get this vital information and emotional support, help families get their health costs covered, and teach families how to work effectively with their children's health care providers. **As a result, the assistance provided to families by Family-to-Family Health Information Centers can:**

- (1) improve health outcomes for kids;
- (2) reduce government health care spending (i.e., to Medicaid, public clinics, public hospitals) or costs to the health system in general (e.g., to families, insurance companies) by ensuring that children get timely and appropriate care;
- (3) reduce government education spending by helping families get access to early intervention services, thereby reducing the need for special education services;
- (4) enable families to get care for their kids without having to face bankruptcy or spend all their college funds or retirement savings;
- (5) enable parents to continue to work (e.g., because they can get nursing care for their child); and/or
- (6) keep children out of costly and psychologically harmful institutional care.

**The F2F in your state can also help Members of Congress in assisting constituents.** F2F's can share information about Medicaid, CHIP and Maternal and Child Health programs and the state's ACA Exchange. They can also help families access information about the best insurance plans for children with special health care needs and help them handle problems with health insurance coverage.

*For national and state-specific information about F2F HICs, see [http://www.fv-ncfpp.org/f2fhic/about\\_f2fhic/](http://www.fv-ncfpp.org/f2fhic/about_f2fhic/).*

*Family Voices ([www.familyvoices.org](http://www.familyvoices.org)) is an organization of families whose children have special health care needs.*

### Family Voices contacts:

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