



## **FAMILY VOICES COMMENTS TO THE TASK FORCE ON PUERTO RICO**

Submitted by: Family Voices ([www.familyvoices.org](http://www.familyvoices.org)), a national nonprofit organization representing families of children and youth with special health care needs.  
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### **Recommendations**

In order to reduce child poverty, and to promote long-term economic growth and stability in Puerto Rico, Family Voices urges the Task Force to recommend:

- (1) that Congress authorize and provide adequate funding for the establishment of a Family-to-Family Health Information Center in Puerto Rico; and
- (2) that Congress increase Medicaid payments to Puerto Rico on a permanent basis.

### **Discussion**

Family-to-Family Health Information Center. Family Voices respectfully proposes that the Task Force recommend that Congress authorize and provide adequate funding for the establishment of a Family-to-Family Health Information Center (F2F) for Puerto Rico. Family-to-Family Health Information Centers, staffed by families of children and youth with special health care needs (CYSHCN), help other families of such children to navigate the health care system so they can obtain needed services. F2Fs also assist families in partnering with professionals caring for their children, thus improving health outcomes and the cost-effectiveness of care.

The F2F grant program was established on a bipartisan basis by the Family Opportunity Act, part of the Deficit Reduction Act of 2005. The program is administered by the Maternal and Child Health Bureau at the Health Resources and Services Administration in the Department of Health and Human Services. Pursuant to Section 501(c)(1) of the Social Security Act, as amended most recently by the Medicare Access and CHIP Reauthorization Act of 2014 (Sec. 216), Congress has provided direct funding for the F2F grant program (i.e., no appropriations are needed) through FY 2017. Since 2009, the program has been funded at \$5 million per year.

Currently, there is one F2F in each state and the District of Columbia, each of which receives a federal grant of less than \$95,000 per year. Under current law, territories are not eligible for F2F grants. (In December 2013, however, the Senate Finance Committee approved, on a voice vote, bipartisan legislation<sup>1</sup> that would have permitted F2F grants to US territories and increased funding for the program from \$5 million to \$6 million annually.

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<sup>1</sup> This amendment to the F2F program was in Section 223 of the "SGR Repeal and Medicare Beneficiary Access Improvement Act" (S. 1871, 113<sup>th</sup> Congress).

An F2F in Puerto Rico would be of great help to families whose children are affected by the Zika virus, as well as other families of children and youth with special health care needs. Due to the significant number of Zika cases on the island, there are, sadly, likely to be numerous infants born with microcephaly and/or other serious, Zika-related birth defects. In addition, many children may contract the virus, the complications of which are not yet entirely clear, but include Guillain-Barre syndrome, which can be life-threatening or chronically debilitating.

Families of children with microcephaly and/or other disabilities caused by the Zika virus will need to figure out how to find and finance appropriate care for their children. Their treatment may involve the use of medical technology, various types of therapies, and frequent appointments with a variety of pediatric subspecialists. Given the complexity of the health system, it can be very difficult for families to figure out how to get the care their children need. A Family-to-Family Health Information Center for Puerto Rico would provide this help, and do so in a culturally and linguistically appropriate manner. Of course, an F2F in Puerto Rico would also help families of other children and youth with special health care needs or disabilities, such as those with autism, epilepsy, intellectual disabilities, or mental health conditions. (Please see attached information on the characteristics and value of F2Fs.)

Helping families to secure needed health care for their children will help to reduce childhood and family poverty. In fact, medical debt is the most common cause for family bankruptcies. F2Fs can help families enroll in the Medicaid program, work with their insurance companies, and/or find other sources of funding to care for their children, allowing families to afford the care their children need. In some cases, getting appropriate care for their children can help parents go back to work, which will contribute to the economic well-being of Puerto Rico.

Medicaid. Medicaid is a vital program for children and youth with special health care needs (and their families), as well as healthy children whose families have low incomes, as do so many in Puerto Rico. Given the likely increase in the number of children with special health care needs due to the Zika virus, Medicaid will be more important than ever. Without adequate Medicaid funding Puerto Rican children will not have access to adequate care, be it care for Zika-related complications, care for other special health needs, or routine care that all children need.

Significantly, children covered by Medicaid are more likely to receive preventive services, such as immunizations (hopefully to include a vaccine against the Zika virus one day), and health screenings. It is well-established healthy children are more likely to become healthy, productive adults who can contribute to the economic well-being of Puerto Rico. Accordingly, we strongly recommend that the Task Force recommend additional Medicaid funding for Puerto Rico on an ongoing basis.

Attachments:

- Fact sheet on Family-to-Family Health Information Centers
- The Value of Family-to-Family Health Information Centers
- Puerto Rico Comments to the Task Force



## **FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2Fs)**

- Throughout the US, there are approximately 14.6 million children and youth with special health care needs (CYSHCN), constituting nearly 20 percent of the child population. More than one in five households with children has at least one child with special health care needs. Out of insured CYSHCN, 34.3 percent have families who report their insurance is inadequate to meet their needs.
- It is very difficult for families to figure out how to finance their children's care, given the great expense and complexity of potential funding sources – private insurance, Medicaid, CHIP, state Maternal and Child Health programs, the school system – each with different eligibility and coverage criteria.
- Family-to-Family Health Information Centers (F2Fs) help families of children/youth with special health care needs learn how to navigate the complex health care system and to make informed choices about health care in order to promote good treatment decisions, cost-effectiveness and improved health outcomes.
- There is one F2F in every state and the District of Columbia, each of which receives less than \$95,000 per year from a federal grant. Despite their shoestring budgets, F2Fs trained and assisted nearly one million families and over 350,000 health professionals in 2014-2015.
- F2Fs also provide leadership and training for health care providers and policymakers to work toward the goal of a family-centered “medical home” for every child.
- F2Fs are staffed by families of CYSHCN who have extensive personal experience and professional training in accessing and financing health care for CYSHCN.
- The F2F grant program, administered by the Maternal and Child Health Bureau, was established with bipartisan support by the Family Opportunity Act, part of the Deficit Reduction Act of 2005. Through subsequent laws, most recently the Medicare Access and CHIP Reauthorization Act of 2015, the F2F program has been reauthorized and funded through FY 2017 at the level of \$5 million per year. (No appropriations are necessary.)
- A CMS-funded outside evaluation of F2F HICs noted: “The accomplishments of these Grantees are impressive, particularly in light of their modest grant funding,” and “Through their work to promote family-centered, culturally competent, and linguistically appropriate care and medical homes for CYSHCN, [F2Fs] are contributing to improvements in the quality of health care.”
- Said one parent, “Since I now know about Family Voices, my life has changed a lot as far as being strong to make sure my daughter's needs are met. This is a huge change for me.”

*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/).*

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

Imagine a family that is suddenly confronted with a severely premature baby, who is likely to have multiple health problems or disabilities, 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).

When a family receives help from a Family-to-Family Health Information Center, they can get this vital information, emotional support, and help in finding ways to get their costs covered. Your state's Family-to-Family Health Information Center can provide examples of how they have helped families in one or more of these ways.

This assistance:

- (1) improves health outcomes for kids;
- (2) reduces 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) reduces government education spending (i.e., where early intervention helps to avoid or reduce the need for special education);
- (4) enables families to get care for their kids without having to face bankruptcy or spend all their college funds or retirement savings;
- (5) enables parents to continue to work (e.g., because they can get nursing care for their child); and/or
- (6) keeps children out of costly and psychologically harmful institutional care.

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/).

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