

Dear Friends:

I am pleased to report that the US Department of Health and Human Services Maternal and Child Health Bureau has issued its request for applications for F2F grants in the amount of \$95,700 per state and DC.. SPAN has served as NJ's Family to Family Health Information Center (F2F) ever since the inception of the F2F program; our current F2F grant expires on May 31, 2018. Our renewal application is due on January 17, 2018.

F2Fs are required to:

- Assist families of children and youth with special healthcare needs (CYSHCN) in making informed choices about health care in order to promote good treatment decisions, cost effectiveness and improved health outcomes;
- Provide information regarding the health care needs of, and resources available to, CYSHCN;
- Identify successful health care delivery models for CYSHCN;
- Develop, with representatives of health care providers, managed care organizations, health care purchasers, and appropriate state agencies, a model for collaboration between families of CYSHCN and health professionals;
- Provide training and guidance regarding the care of CYSHCN; and
- Conduct outreach activities to families of CYSHCN, health professionals, schools and other appropriate entities and individuals.

Through our F2F, SPAN currently engages in the following activities with our F2F staff including Mercedes Rosa, Project Director; Lauren Agoratus, NJ Family Voices Coordinator and Central/South F2F Regional Coordinator; and Shirley Johnson, Northern F2F Regional Coordinator:

- *Provide individualized assistance and support* to families of and youth with special healthcare needs and the professionals who serve them via the phone and in person;
- *Provide training* to families of and youth with special healthcare needs and the professionals who serve them via in-person and web-based trainings on topics including a Health Advocacy workshop Transition to Adult Life workshop in every county; three SPAN Resource Parent training series each year and three regional Transition mini-conferences each year (in collaboration with our Parent Training and Information Center); teleconference series on red flags in child development, talking with families about screening, and including CSHCN in child care, as well as webinars on screening, medical home, health advocacy, transition, supported decision-making, Integrating Health into the Transition IEP, Talking with their Child About their Disability, among others;
- *Provide information* to families of and youth with special healthcare needs and the professionals who serve them via written materials including monthly articles in Exceptional Parent magazine, quarterly articles in the American Academy of Pediatrics NJ Pediatrician magazine, monthly blogs, articles in the monthly SPAN e-newsletter, information dissemination through our SPAN facebook page and groups, and development and dissemination of resources in multiple languages on the web and/or in hard copy, including our manuals/guides (Health Advocacy Toolkit (www.spanadvocacy.org/content/health-advocacy-toolkit), Healthcare Financing Fact Sheet Series, Family Guide to Children's Mental Health in NJ, and Maximizing Coverage under NJ's Autism and

other Developmental Disabilities Mandate Guide), and individual fact sheets (Preparing for a Hospital Stay, Surviving a Hospital Stay with your Child with Special Healthcare Needs...And After!, Mental Health Crisis Fact Sheet, Supported Decision-Making and Alternatives to Guardianship, Transition Tip Sheet for Teens, and many more (www.spanadvocacy.org/content/family-family-health-information-center-family-voices-nj));

- *Convene stakeholders* including families of and children and youth with special healthcare needs and the professionals who support them via quarterly Community of Care Consortium for CYSHCN meetings where workgroups on five of the six core outcomes for CYSHCN (Medical Home and Access to Community Based Services, Early and Continuous Screening, Adequate Healthcare Financing, Effective Transition to Adult Systems of Care) made up of parents, professionals/providers, and state and local agencies, are co-chaired by a parent and a professional, modeling the sixth core outcome, families are engaged at all levels, and youth with special healthcare needs via NJ YELL (Youth Engaged in Leading and Learning); and
- *Support diverse parent and youth leaders to share their voice* on important policy issues such as the NJ Maternal and Child Health Block Grant application, and on state, county and local advisory groups and committees (NJ State Interagency Coordinating Council for Early Intervention, EHDI Advisory Committee, Newborn Screening Advisory Committee, State Rehabilitation Council, State Independent Living Council, NJ Council on Developmental Disabilities, Boggs Center Consumer Advisory Council, etc.) and in coalitions (NJ for Healthcare Coalition, Family Support Coalition, Medicaid Advocates, NJ Time to Care, NJ Statewide Network for Cultural Competence, and NJ Alliance for Immigrant Justice, among others).

Our F2F activities support, and are supported by, other SPAN initiatives such as our NJ Statewide Parent to Parent Program, Family WRAP (Wisdom, Resources, Advocacy and Parent to Parent Support), EHDI Family Leadership and Support project, Parent Training and Information Center, etc.

With this email, we are asking for (a) your ideas on activities for our Family to Family Health Information Center; and (b) your letter of collaboration.

Please feel free to reach out to us with any questions or to discuss this further! Thank you in advance for your anticipated support!



Statewide Parent
Advocacy Network

SPAN

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November 20, 2017

Dear Friend of SPAN:

As you know, the Statewide Parent Advocacy Network (SPAN) has served as New Jersey's Family to Family Health Information Center for almost 15 years. We are now re-applying for our four-year federal core funding as New Jersey's F2F for families of infants, toddlers, children, youth and young adults with the full range of special healthcare needs (CFDA 93.504). As our valued partner, we are writing to ask for your assistance in providing a letter of support and collaboration to be included in our application.

In addition, we are inviting you to provide input to SPAN as we fashion our application for funding. There have been many policy and demographic changes in New Jersey since our last application, and we need your knowledge, expertise, creativity, and ideas to help us develop a proposal that will make the most effective and efficient use of the limited F2F funds (\$95,700/year for three years) to meet the needs of New Jersey children with special health and mental health needs and their families. We have created a quick survey, attached, to get your feedback.

Please share your responses to this survey as well as any additional ideas with me, Diana.autin@spannj.org, and Mercedes Rosa, our F2F Director, at Mercedesrosa@spannj.org. The proposal is due on January 17 so time is of the essence.

Thank you for your past support and collaboration, and we look forward to continuing to work with you to improve health/mental health services for New Jersey's children with special healthcare needs and their families across the six core areas of early and continuous screening; adequate healthcare financing; access to a medical home to coordinate all needed services, and to community-based services organized for easy access; effective transition to adult systems of care; and family engagement and satisfaction at all levels!

Very truly yours,

Diana MTK Autin
Executive Co-Director

Mercedes Rosa
Mercedes Rosa
Director, F2F @ SPAN

**SPAN Family to Family Health Information Survey
November 2017**

Name: _____ Organization: _____
 Email: _____ Telephone: _____

| Current Activity | Keep this activity | Do more/different | Do fewer/less | Don't do |
|---|---------------------------|--------------------------|----------------------|-----------------|
| County Health Advocacy workshops (21/year) | | | | |
| Training for health professionals on medical home, screening, etc. (10/year) | | | | |
| Individual technical assistance to families on health resources, services, laws, insurance appeals, partnership, etc. | | | | |
| Create & disseminate resources & tools on health advocacy for families (Healthcare Financing Fact Sheet series, transition fact sheet, etc. | | | | |
| Maintain website with health advocacy resources | | | | |
| Facilitate support groups for underserved families | | | | |
| Facilitate targeted activities for fathers | | | | |
| Facilitate targeted activities for grandmother caregivers | | | | |
| Represent family perspective on task forces | | | | |
| Support the Community of Care Consortium (quarterly meetings, workgroups on core outcomes | | | | |

Additional activities, fact sheets, etc. recommended/other thoughts (be as specific as possible):



Statewide Parent
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_____ (organization) agrees to partner with the Statewide Parent Advocacy Network in their Family to Family Health Information Center project as follows. Please check all that apply; then sign and date this form and fax to 973-642-8080 or email to Diana.autin@spannj.org.

___ Share information about SPAN's F2F and how to access services with the families we serve

Projected # of families: _____ Projected # of professionals: _____

___ Link to SPAN's website including the F2F section of the website

___ Share SPAN's F2F resources (fact sheets, toolkits, etc.) with the families we serve

Projected # of families: _____ Projected # of professionals: _____

___ Partner with SPAN to identify additional needed resources (fact sheets, etc.)

___ Host SPAN F2F health advocacy workshops for the families we serve

___ Provide space for SPAN F2F family support groups for families in our community

___ Assist in connecting fathers to SPAN F2F activities targeting dads of children with special needs

Projected # of dads: _____

___ Assist in connecting grandmothers raising grandchildren to SPAN F2F activities targeting them

Projected # of grandmothers as caregivers: _____

___ Participate in the Community of Care Consortium for CSHCN and their families (quarterly)

___ Identify and connect SPAN with potential parent leaders

Projected # of potential parent leaders to be connected: _____

___ Other collaboration activities (please be specific and include projected #s if possible):

Name: _____ Date: _____

Email: _____ Phone: _____