

Contact Family Voices:

About Family Voices:

NCFPP National Staff/Consultants:

NCFPP Co-Project Director: **Nora Wells**
(781) 879-6209, nwells@familyvoices.org

NCFPP Co-Project Director: **Bev Baker**
(207) 458-1009, bbaker@familyvoices.org

Director of Diversity and Outreach: **Trish Thomas**
(888) 835-5669, tthomas@familyvoices.org

Public Policy Co-Director: **Brooke Lehmann**
(202) 333-2770, blehmann@familyvoices.org

Public Policy Co-Director: **Janis Guerney**
(202) 546-0558, jguerney@familyvoices.org

National TA Coordinator: **Diana Autin**
(973) 642-8100 x 105, dautin@familyvoices.org

National TA Coordinator: **Mary Jo Paladino**
(574) 273-6019, mpaladino@familyvoices.org

Data Coordinator: **Peggy Curran**
(781) 592-3935, pcurran@familyvoices.org

Family Voices National Staff:

Financial Administrator: **Lacey Keene**
(505) 872-4774, lkeene@familyvoices.org

Financial Administrative Assistant: **Natasha Tapia**
(505) 872-4774, ntapia@familyvoices.org

IMPACT Project Staff:

Project Director: **Leslie Carrol**
(541) 708-5404, bcarroll@familyvoices.org

Project Coordinator: **Melissa Vickers**
(731) 986-3082, mvickers@familyvoices.org

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Family Voices is a national organization that has worked for over 20 years to ensure that the needs of families of all children/youth with special health care needs/disabilities are voiced to policy makers to improve policies and programs.

Our Mission:

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

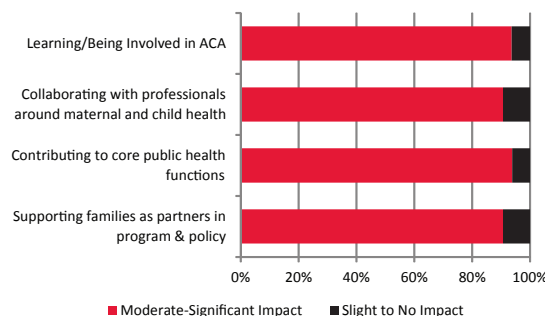
Our Work:

Family Voices has been the National Center for Family/ Professional Partnerships since 2004. The following are some highlights of our work:

1. Provided information, assistance, or training last year to 1,825 families, youth, family leaders, 1830 professionals, and 6,822 uncategorized individuals
2. Developed a scientifically-reliable Family-Centered Care Tool for Families, based on input of over 800 families.
3. Facilitated a survey resulting in over 3,067 responses from families about flu and flu prevention, for a project with Centers for Disease Control (CDC) and Oak Ridge Institute for Science and Education.

Our Impact:

Based on our work last year, Family Leaders at Family-to-Family Health Information Centers rated the impact of the NCFPP:



FAMILY VOICES[®]

National Center for
Family Professional Partnerships

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National Center for Family/Professional Partnerships

Family Voices, Inc.

3701 San Mateo NE, Suite 103 Albuquerque, NM 87110
Tel: (505) 872-4774 or (888) 835-5669 Fax: (505) 872-4780
www.fv-ncfpp.org • www.familyvoices.org

Project Activities

FAMILY VOICES NATIONAL CENTER FOR FAMILY/PROFESSIONAL PARTNERSHIPS

Under the cooperative agreement funded by Maternal and Child Health Bureau in June 2013, the National Center for Family / Professional Partnerships (NCFPP) is charged with accomplishing the following goals:

1. Increase the capacity of families, Title V and other providers to partner around full implementation of Affordable Care Act (ACA),
2. Strengthen the primary care workforce through family / professional learning opportunities, and
3. Improve access to quality care and innovation in the areas of family-centered care, cultural and linguistic competence and shared decision making.

The NCFPP engages in collaborative activities with family leaders and professionals to meet these goals through activities to:

1. DEVELOP FAMILY LEADERSHIP SKILLS

The NCFPP provides family leaders (Family-to-Family Health Information Center Staff, FamilyVoices State Affiliate members and individual members) with opportunities to develop their leadership, knowledge, and skills in a number of priority areas.

SKILLS:

- Health Care Financing
- Policy
- ACA implementation
- Family-Centered Care
- Family/Professional Partnerships
- Outreach
- Cultural & Linguistic Competency
- Quality Improvement
- Organizational Development
- Grants Management
- Sustainability

OPPORTUNITIES:

- Peer to Peer Connections
- Sharing/Learning about Promising Practices
- Mentoring, informal & formal
- Weekly Policy & ACA updates
- One-to-one Technical Assistance
- Trainings/Webinars
- Newsletters & materials
- Resource Exchange
- Providing Family Perspective to National Organizations and Initiatives



2. ENHANCE SKILLS & KNOWLEDGE OF PROFESSIONAL PARTNERS

The NCFPP and family leaders develop and provide trainings for professionals.

TOPICS:

- Family-Centered Care
- Listening & Learning from Families
- Building Partnerships with Families to Improve Care
- Engaging Families as Advisors
- ABC's of Quality Improvement

OPPORTUNITIES:

- Web-based Courses
- F2F hosted trainings for Title V staff
- Webinars
- Newsletters and Materials
- Presentations at National Conferences
- Learning Collaboratives with NICHQ

The NCFPP brings relevant family experiences to policy discussions, helping partners learn what works and what needs improvement. Current partnerships include:

- Children's Health Group
- Consortium of Citizens with Disabilities
- Medical Home Implementation Project Advisory Committee
- Council on Children with Disabilities, AAP
- Technical Expert Panel on the National Survey of Children with Special Health Care Needs
- Indian Health Service
- Regional Genetics Collaboratives
- Patient-Centered Primary Care Collaborative (PCPCC) Expert Workgroup
- Center for Medical Home Improvement (CMHI) Advisory Group
- National Genetics Education Consumer Network (NGECN) Advisory Workgroup.

3. UTILIZE FAMILY NETWORKS TO SHARE INFORMATION

With connected state networks of Family-to-Family Health Information Centers and Family Voices State Affiliate Organizations across the country, the NCFPP has access to hundreds of thousands of families of CYSHCN, providing a platform to both inform and learn from families. The NCFPP can facilitate opportunities for families and other organizations to share information.

HELP FAMILIES LEARN:

- Health care provisions of ACA
- How to provide public input on the rollout of ACA
- Opportunities to work with Title V and other state partners
- National and state policy issues & events
- Partnering with their child's provider to improve care
- What to expect from family-centered care
- Quality improvement strategies

HELP LEARN FROM FAMILIES:

- Family perspectives/experiences with health care services and systems
- Impact of ACA on family access to health care
- Issues for families from diverse populations
- Promising practices in family-to-family support
- ACA successes/challenges in the states

OPPORTUNITIES:

- Surveys
- Social Media: Facebook, Twitter, Blog
- Listservs
- Washington Update (weekly policy happenings)
- Friday's Child (bi-monthly e-newsletter)
- Focus groups
- Feedback on webinars, on-line courses, materials such as Family-Centered Care Tools
- Online course feedback

Visit our website, www-fv-ncfpp.org, to sign up for our newsletters and follow us on Facebook and Twitter or contact us to learn more.

...promoting partnerships to improve care for children and youth with special health care needs/disabilities