

Problem: Disparities in Healthcare

- ▶ 43.6% of CSHCN do not receive needed elements of care coordination compared to 28.6% of non-CSHCN.¹
- ▶ More Hispanic (66.9%), Black (66.2%), and Asian (67.1%) families lack coordinated, ongoing, comprehensive care within a medical home compared to White families (51.2%).²
- ▶ 67% of non-English speaking families have higher odds of lacking care through a medical home.³
- ▶ 42% of non-English speaking families have higher odds of reporting inadequate health insurance.³
- ▶ Rural CSHCN are less likely to be seen by a pediatrician than urban children.⁴

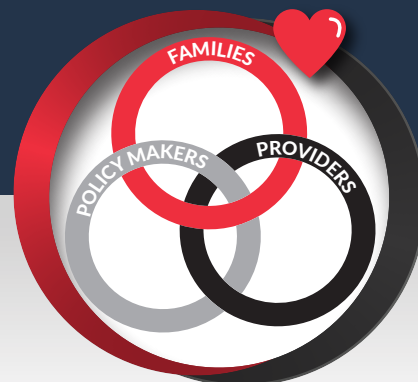
FAMILY VOICES®
... keeping families at the center of children's health care

Since 1992, *Family Voices* has worked for implementation of family-centered care with partners at all levels: families, providers, hospitals and clinics, Title V programs, agencies, and policy-making institutions.

Family Voices is partnering with SPAN of New Jersey to accomplish the NCFPP goals.



Statewide Parent
Advocacy Network



A Key Solution: Enhanced Family Engagement

- ▶ Services are better delivered, more cost effective and more culturally sensitive.⁵
- ▶ Family/professional communication is increased.⁶
- ▶ Awareness of family issues and needs is increased.⁶
- ▶ Families are better able to use services and to help other families.⁵
- ▶ Partnerships for systems change are created.⁶
- ▶ Planning and policies are improved resulting in more responsive services.⁶
- ▶ Communities are healthier as their capacities to better support families are enhanced.⁵

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¹NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. www.childhealthdata.org.

²NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. www.childhealthdata.org.

³Yu S, Lin S, Strickland B (2015). Disparities in Health Care Quality Indicators among US Children with Special Health Care Needs According to Household Language Use. *International journal of MCH and AIDS*. 4(1): 3-12.

⁴Skinner AC1, Slifkin RT. Rural/urban differences in barriers to and burden of care for children with special health care needs. *J Rural Health*. 2007 Spring;23(2):150-7.

⁵Parent Leadership: Successful Strategies. (2002, January). Retrieved from FRIENDS National Resource Center for CBFPS Programs: http://ncwwi.org/files/Community_Context/Parent_Leadership_Successful_Strategies.pdf.

⁶Wells N, Anderson B. 2006. Families in Program and Policy FIPPs CSHCN report: Interviews on family participation with State Title V children with special health care needs programs. [Rev. ed.]. Albuquerque, NM: Family Voices.

FAMILY VOICES®

National Center for Family/Professional Partnerships



Ensuring families of children/youth with special health care needs (CYSHCN) partner at all levels of decision-making

Family Voices National Center for Family/Professional Partnerships (NCFPP)

GOAL: reduce health care disparities of families of CYSHCN by making health care more family-centered through the development and support of family and youth leadership, particularly of those from diverse backgrounds, at the systems or policy-making level

POPULATIONS SERVED: Family-to-Family Health Information Centers (F2Fs); Family Voices State Affiliate Organizations (SAOs); other family organizations; Title V Programs; other MCHB investments; families, particularly those who are underserved, including families of diverse racial and ethnic background, non-English speaking, low-income, living in geographically isolated areas, and/or with low levels of health literacy

FUNDER: Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs

PROJECT PERIOD: June 2016 through May 2019

FOCUS: Preparing family/youth to serve on systems-level teams

FOCUS: Building F2F Capacity to Serve Families of CYSHCN

1. Peer support, technical assistance, training, and information
2. Targeted data and policy support
3. Mentorship for identified family/youth leaders serving at the systems level
4. Resource repository and web portals
5. E-news and media toolkits
6. Customizable tip sheets

1. Train-the-trainer for F2Fs and other family organizations using *Serving on Groups* curriculum
2. Training for family organizations and state agency leaders on *Leading by Convening: The Partnership Way*
3. Technical assistance to trained family leaders
4. Training for families and professionals on building collaborative action teams to facilitate shared leadership and action
5. Targeted support to develop diverse youth leadership

FOCUS: Assisting MCH programs to engage family/youth leaders

1. Training and technical assistance opportunities for State Title V agencies and other MCH investments
2. Partnerships with Association of Maternal & Child Health Programs, the National MCH Workforce Development Center, Association of University Centers on Disabilities, and others
3. Collaborative action teams
4. Documenting and disseminating best practices

Ensuring families of children/youth with special health care needs *partner at all levels of decision-making*