Supporting families of CYSHCN Nationally

AUTISM CARES 2017: Pathways to Progress: Overcoming Barriers to Access, Translating Research to Practice, and Reducing Health Disparities
Objectives

• Overview of Family Voices and the National Center for Family Professional Partnerships

• Overview of Family Voices engagement with other partners and community stakeholders

• Overview of Family Voices local, national work and how we serve families and leverage impact

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Family Voices believes in:

- Social Justice and the Promotion of health equity.

- **Authentic family-centered care** that recognizes family as the center of a child’s life and as an equal partner in decision making about all aspects of the child’s care.

- **Effective family/professional partnerships at the local, state and national level.**

- **Inclusion and connection** of underserved families representing the cultural, linguistic and geographical diversity of the country.

- Connected and informed Family Leaders and Youth Leaders as powerful change agents.

- **CYSHCN and their families become empowered self-advocates.**

- **Family engagement in prevention, health and wellness in clinical and community settings.**
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Family Voices Partners

- American Academy of Pediatrics (AAP)
- Administration on Intellectual and Developmental Disabilities (AIDD)
- Administration for Community Living (ACL)
- Association of Maternal and Child Health Programs (AMCHP)
- Association University Centers on Disabilities/Centers on Disease Control (AUCD/CDC)
- Association of State and Territorial Health Officials (ASTHO)
- CAHMI - Well Visit Planner Tool Kit
- CityMatch
- HRSA/MCHB - National Center for Professional Partnerships (NCFPP) & Supplement to the Territories (Puerto Rico, Virgin Islands, American Samoa)
- Patient Centered Outcomes Research Institute (PCORI) - Family Wisdom
- National Center Birth Defect Developmental Disabilities (NCBDDDD)
- National Academy for State Health Policy (NASHP)
- National Conference of State Legislatures (NCSL)
- KASA
- National Disability Navigator Resource Collaborative
- Society for General Internal Medicine (SGIM)
There are between 11.23 and 14.6 MILLION CYSHCN in the United States. These families are often faced with many challenges; Family Voices, Family-to-Family Health Information Centers (F2Fs) provide critical support to families caring for CYSHCN, particularly families of children with complex needs and those from diverse communities. Last year, the F2F’s provided information to almost 1 million families of CYSHCN and over 350 thousand professionals.

To serve families of diverse backgrounds, F2Fs host support groups and conferences in multiple languages, creates culturally competent materials, works with community liaisons, and provides leadership training and support.

At Family Voices, our mission is to promote partnership with families (including those of cultural linguistic and geographic diversity) in order to improve healthcare services and policies for children.

www.familyvoices.org
Family Voices State Affiliate Organizations and Family-to-Family Health Information Centers Helping Families of Children with Special Health Care Needs and Assisting Professionals across the United States

We are now in Every State and the District of Columbia!
Our Family Leaders live in the communities they serve. They are often parents of CSHCN who have first hand experience and training navigating the very complex healthcare systems they now work to support and help other parents.

Our family Leaders know that parents of CYSHCN often manage economic, financial, personal and social burdens that are unequal to those experienced by a parent with a typically developing child. These families experience more stress. http://www.kidsdata.org/topic/457/special-needs-parents-stress

Our family Leaders provide support through; direct referrals, in-person support, webinars, phone calls, conference calls, advocating, listservs, emails, and various other outreach methods.
Just think....

Keep advocating....
Keep collaborating...
Keep networking...

Keep Moving Forward because...
Together we make a Difference!
Resources:

Family Voices
www.familyvoices.org

National Center for Family and Professional Partnerships (locate your state partner)
http://www.fv-ncfpp.org (our state affiliates have many resources!)

National Center for Family and Professional Partnerships – Data Report

National Center for Family and Professional Partnerships
http://www.fv-ncfpp.org/activities/zika-resources

CDC – Autism Resources
https://www.cdc.gov/ncbddd/autism/data.html

Autism Speaks
https://www.autismspeaks.org/

Autism Society
https://www.autism-society.org/

National Center for Birth Defects and Developmental Disabilities (NCBDDD)
https://www.cdc.gov/ncbddd/index.html
For More Information:

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