



# 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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[www.familyvoices.org](http://www.familyvoices.org)  
[www.fv-ncfpp.org](http://www.fv-ncfpp.org)

# Family Voices Core Values

## *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 (NCBDDD)**
- **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 **11.23 – 14.6 Million CYSHCN** in the U.S.

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.**

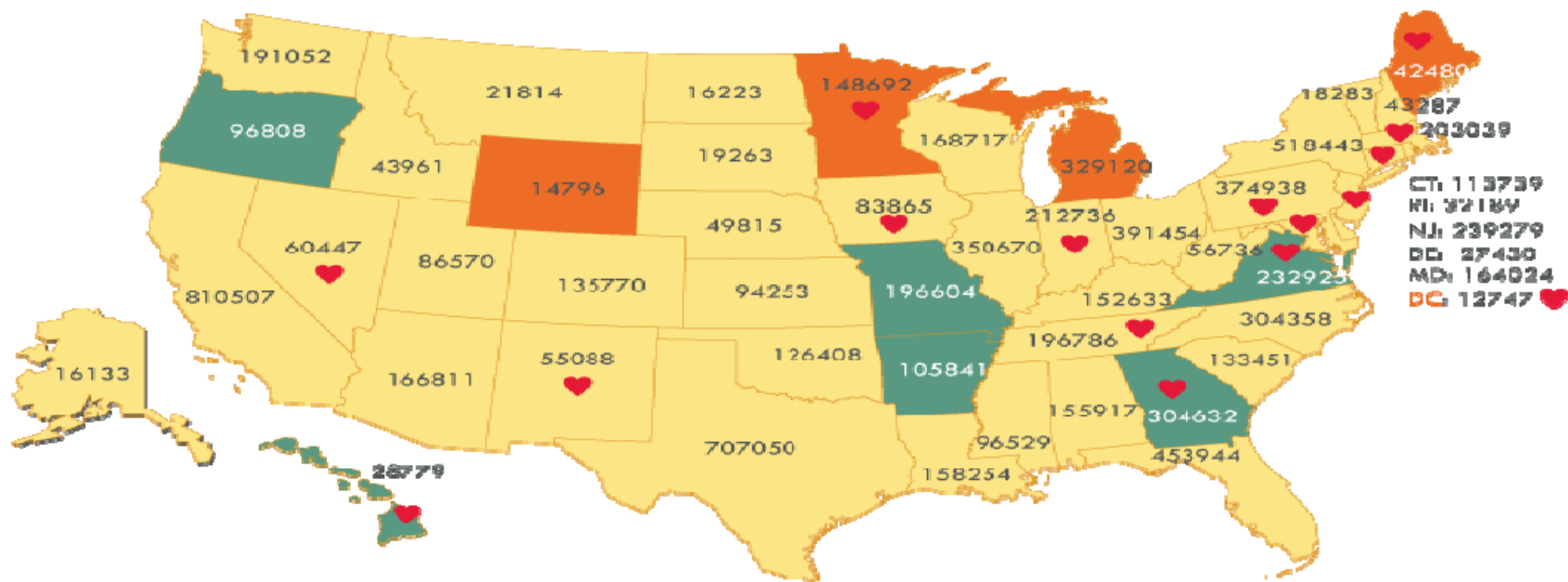
To serve families of diverse backgrounds, F2Fs host support groups and conferences in multiple languages, creates culturally competent materials, works with community liaisons, and provides leadership training and support.

**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](http://www.familyvoices.org)

# Family Voices, State Affiliates & F2F HIC

**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!**



**nn // of Families with CSHCN in state**

- States where SAO and F2F is within the same organization
- States with F2F only, SAO in progress

- States where SAO is within a different organization from the F2F
- States with National Family Voices staff/consultant/national board member

# Community based Family Leaders

***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....

It takes unimaginable strength to continually endure, persist & overcome. People with disabilities aren't weak. They're the strongest human beings you'll ever meet.



[nationalautism.org](http://nationalautism.org)

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

***Keep Moving Forward because...***  
***Together we make a Difference!***

# Resources:

## **Family Voices**

[www.familyvoices.org](http://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**

[http://www.fv-ncfpp.org/files/9514/8949/7007/2015-2016F2FDataReport\\_03-01-2017-r.pdf](http://www.fv-ncfpp.org/files/9514/8949/7007/2015-2016F2FDataReport_03-01-2017-r.pdf)

## **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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