



The National Academy of Science, Engineering & Medicine

Optimizing Care Systems for People with Intellectual and Developmental Disabilities: A Workshop

12/08/2021

Family Voices & Family to Family HIC (F2F)

Family Voices is a national organization and grassroots network of families and friends of children and youth with special health care needs and disabilities that promotes partnership with families—including those of cultural, linguistic and geographic diversity—in order to improve healthcare services and policies for children.

Family-to-Family Health Information Centers (F2Fs) are family-led centers funded by the Health Resources and Services Administration (HRSA).

Through the Leadership in Family/Professional Partnership (LFPP) project provide training and to technical assistance

- To F2F's in 59 and territories across the country
- F2F's collectively have provided support and services to over 1 million families of CYSHCN



CYSHCN/Individuals with I/DD

Children and Youth with Special Health Care Needs (CYSHCN) are children and youth who have or are at increased risk for chronic, physical, developmental, behavioral, or emotional conditions who also require health and related services beyond that required by children generally

- **68%** have 2 or more health conditions
- **45.5%** have health conditions that affect their daily activities
- **37.5%** require specialized medical care
- **33.2%** require mental health care
- **47.2%** needed mental/behavioral health care but did not receive it (2)

Individuals diagnosed with intellectual and developmental disabilities (I/DD) are impacted by severe, chronic conditions that are due to mental and or physical impairments.

- They usually require long-term care for daily activities such as:
- Mobility, healthcare, education,
- Self-care, independent living and more.



HIGHLIGHTS - Telehealth

- 56 of 59 participated in mini grant – process
- 900 responses Family Readiness Surveys
- 26 F2F's purchased equipment to increase families access to TH
- 30 F2F purchased equipment to increase staff capacity
- 17 F2F's expanded hours or contacted with cultural liaison
- 35 F2F's developed new partnerships to increase TH services for families (Title V's , state agencies, family led CBO's, FQHC's, AAP chapters, RGN's
- **Funding from CARES ACT 2020**



HIGHLIGHTS – Family Engagement

FESAT TOOL

Family Voices Family Engagement in Systems Assessment Tool (FESAT) that promotes meaningful engagement of families in creating or improving policies, practices and services.

The tools can be used to plan, assess and improve family engagement in systems-level initiatives.

Learn more at <https://familyvoices.org/fesat/>

- Can used to measure family engagement on Family Advisory Boards/Councils
- Partnership between PATH CT and The CT Children's Newborn Screening and Diagnostic Center (The Network).
- The Network requested assistance with recruitment, development, training and facilitation of a Family Advisory Group (AG) to identify gaps in the newborn screening and diagnostic process.
- The AG provided input into priorities areas and is working on strategies to improve new-born screening process for families
- The team utilized the Family Voices FESAT Tools to identify priorities areas, measure meaningful engagement and conduct quality improvement strategies as needed.



Challenges : Family Engagement in Systems

Data from Data Resource Center/CAHMI

(2019-2020)

National Outcome Measure 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17 who

- **Do not** receive care in a well-functioning system: 85.6 %
- Youth 18-plus struggling with transition to adult healthcare
- Families not adequately involved in healthcare system as equal partners



Challenges – Telehealth /Family Engagement

FAMILY ENGAGEMENT

**Data from Data Resource Center/CAHMI
(2019-2020)**

National Outcome Measure 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system

- Receive care in a well-functioning system: 14.4%
- Do not receive care in a well-functioning system: 85.6 %

TELEHEALTH

- Youth 18 - plus impacted by access to Telehealth for healthcare services including mental health
- Families still impacted by equitable access to Telehealth for healthcare services
 - Non-English speakers
 - D/HH community
 - Limited modality



EQUITY IN HEALTHCARE

To ensure equity in all aspects of healthcare delivery:

- Training healthcare providers about impact of how systemic racism in healthcare of individuals with intersecting identities such as race, disability, gender etc.
- Engaging families in co-designs of health care programs/policies including
- Engaging families in co-design of Telehealth services
- Coordinating of care (not just sub-specialty but across systems) especially for youth with special health care needs & I/DD



Health Equity: Family Voices United to End Racism for CYSHCN & their families (FAMU)

- **This project was a direct result of what was going on in the country in the spring of 2020 with murders of George Floyd and other Black lives and resulting protests**
- **Our network of national family organizations which are predominantly white needed to be educated about how to support the families that they serve**



Health Equity: Family Voices United to End Racism for CYSHCN & their families (FAMU)

PROJECT OBJECTIVES

Build Competence by learning about the history of race in the U.S. and racial disparities in healthcare

Foster Connectedness by creating opportunities to connect and engage in raw, honest, uncomfortable conversations necessary to bring about change

Encourage confidence to act with the creation of materials and guidance to equip network members to start, lead and sustain conversations to dismantle racism in healthcare of children and youth with special healthcare needs (CYSHCN)



Health Equity: Family Voices United to End Racism for CYSHCN & their families (FAMU)

PROJECT HIGHLIGHTS

- **8 TOWN HALLS**
- 2 open dialogue sessions with Family Voices Network
- Six town halls addressed the following topic areas:
 - Racism, Segregation and Schools
 - “The Talk”
 - Mental Health
 - Justice-School to Prison Pipeline
 - Health
 - Black Culture

PROJECT HIGHLIGHTS

- Disseminated 12 resource documents before and after each town hall to support further learning related to the topic area
 - 6 "Toe Dip" Docs
 - 6 "Deeper Dive" Docs
 - 597 total participants
- **TOOLKIT WEBSITE**
 - Launched 11/30
 - 130 attendees from family orgs. Title V and other MCH groups



Health Equity: Family Voices United to End Racism for CYSHCN & their families (FAMU)

How does this relate to your work? ?

- According to the AAP: "Racism is a core social determinant of health that is a driver of health inequities."
- In order to serve Black families you need to understand their history and who they are as a people
 - Learn how systemic racism affects the healthcare of Black families and Black Children and Youth with Special Health Care Needs (CYSHCN) and I/DD
- Learn how you can meaningfully engage with Black families by partnering with them (not tokenizing)



Health Equity: Family Voices United to End Racism for CYSHCN & their families (FAMU)

VISIT WEBSITE

