

# Midwest Regional Genetics Network Summit

October 1, 2018

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**Maternal and Child Health Bureau (MCHB)**

**Health Resources and Services Administration (HRSA)**



# Challenges in Pediatric Healthcare

1. In the 2016 National Survey of Children's Health, approximately 3.55% of children age 0-17 were reported to have a current genetic condition, equating to roughly 2 million children.
2. Although genetic disorders are individually rare, collectively they are common and account for a significant proportion of health care.
3. They occur at all stages of life and in all branches of medicine.
4. More than two thirds of admissions in a pediatric hospital are attributable to diseases that have a recognize genetic component.
5. According to ACOG guidelines, all women should be offered genetic screening during pregnancy.
6. About 5-10% of cancer is due to inherited mutations.
7. There is a shortage of pediatric medical subspecialists, particularly in rural areas.



# Promote patient and family engagement as partners in care



# National Center for Family/Professional Partnership, June 1, 2016-May 31, 2019

**Recipient:** Family Voices.

**Purpose:**

Provide assistance and support to the HRSA-funded F2F HICs and other MCHB investments on topics of family engagement and cultural and linguistic competence; and

Implement family and youth leadership development and training activities, specifically for racially and ethnically diverse minority families of CSHCN and YSHCN.

**Activities:**

- Facilitate the work of a community of family leaders through peer mentoring, training and technical assistance;
- Contributes to the evidence base documenting the value of family/professional partnerships and family-centered care; and
- Engages in reciprocal learning and partnership activities with MCHB national centers, grant program, state and local CYSHCN/MCHB programs and other strategic partners.



# Family to Family Health Information Centers (F2F HIC), June 1, 2016-May 31, 2019

**Recipients 59:** 56 States, Territories, District of Columbia, and 3 centers serving Indian Tribes.

## **Purpose:**

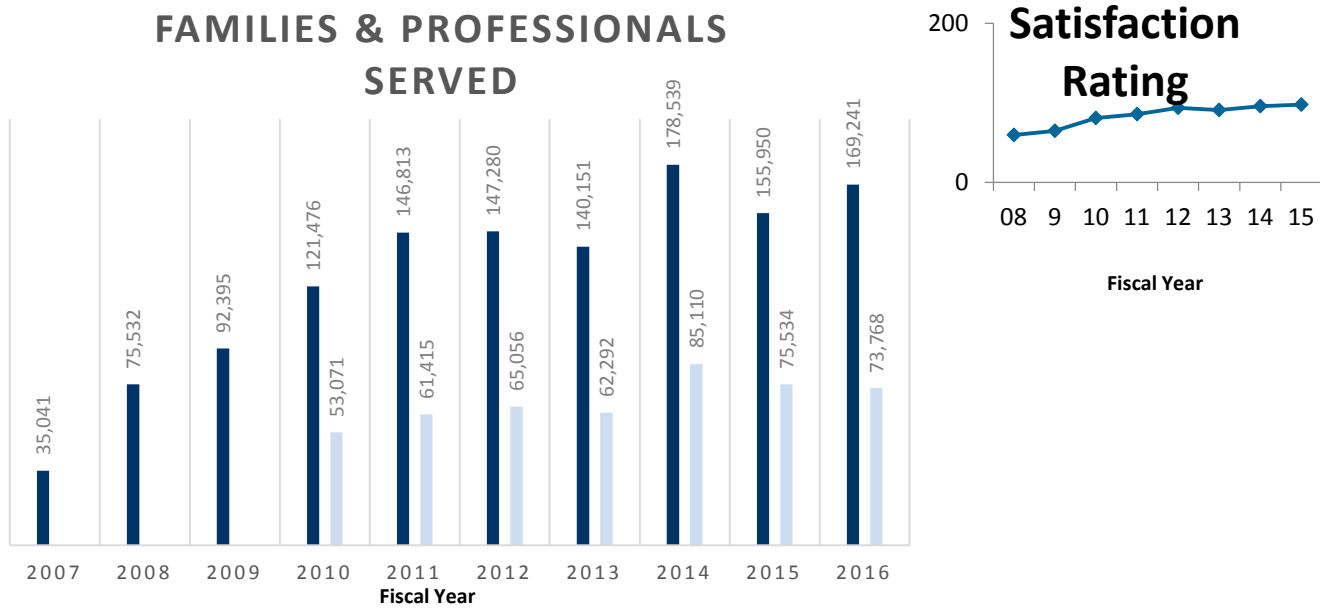
Provide information, education, technical assistance, and peer support to families of CYSHCN and professionals who serve such families.

## **7 Legislative Activities:**

- Help families make informed choices
- Provide information regarding health care needs/resources
- Identify successful health delivery models
- Serve as model of collaboration b/w families and professionals
- Provide training/guidance re. caring for children
- Outreach activities to families, health professionals
- Staffed by families who have expertise and health professionals



# F2F HICs Impact over the years... Trend Data



Data Source: Family Voices Data Collection System



# Family Leadership in Language and Learning (FL3), FY2017-FY2020

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**Recipient:** Hands and Voices

**Purpose:**

To ensure that statewide EHDI systems support the families and caregivers of deaf or hard of hearing infants/children in optimizing their language, literacy, and social-emotional development.

**Priority Areas:**

- Supporting state/territory organizations that provide support to families of deaf or hard of hearing children.
- Coordinating with the NTRC and state/territory EHDI programs in improving family engagement, partnership, and leadership.
- Collaborating with established Deaf Mentor programs for family support.



# Newborn Screening Family Education Program, FY2017–FY2020

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**Recipient:** Genetic Alliance, Inc.

**Purpose:**

To develop and deliver educational programs about newborn screening, counseling, testing, follow-up, treatment, and specialty services to parents, families, patient advocacy and support groups.

- **Overall Goal:** reduce morbidity and mortality caused by heritable disorders in newborns and children by providing newborn screening education to parents and families.
- **Expected Program Impact:** improved health and well-being for infants and children at-risk for or affected with conditions identified through the newborn screening system.





# National Genetics Education and Family Support Center, FY2017-FY2020

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**Recipient:** Genetic Alliance Inc.

**Partners:** Family Voices, Parent to Parent USA.

**Purpose:**

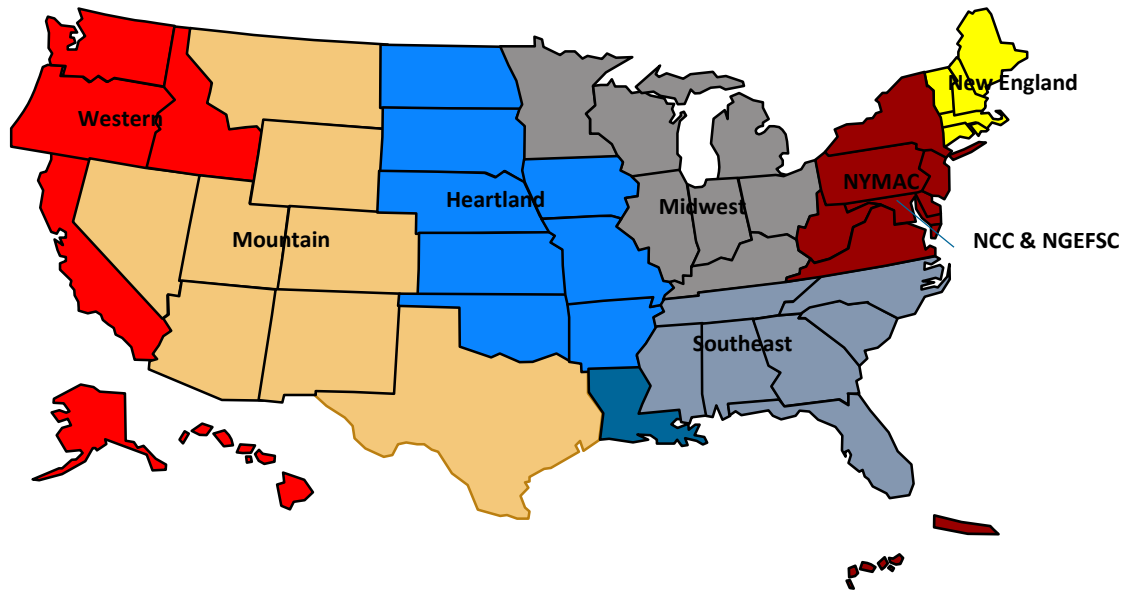
## Family Engagement

- Leadership training of families and RGNs on meaningful family engagement;
- Update of online resources;
- Support existing regional recruitment through advocacy groups;
- Education and Support; and
- Outreach and referral



# Telehealth Activities

## Implement innovative outreach technologies for patient-centered, high quality care



Genetics Programs: Regional Genetics Networks, National Coordinating Center, and Family Support Center.

# Sickle Cell Disease Treatment Demonstration Project (SCDTDP), FY2017-FY2018

## Telehealth Focus: Project Echo.

- To improve health outcomes in individuals with sickle cell disease, reduce morbidity and mortality caused by sickle cell disease, reduce the number of individuals with sickle cell receiving care only in emergency departments, and improve the quality of coordinated and comprehensive services to individuals with sickle cell and their families.
- Sickle Treatment and Outcomes Research in Midwest (STORM) is a regional sickle cell disease (SCD) network using an ECHO model to increase primary care provider knowledge in treating individuals with SCD.
- STORM TeleECHO Clinics include:
  - Didactic presentations from nationally recognized multi-disciplinary experts
  - HIPAA protected case discussions on management of challenging clinical scenarios
- **Recipients 5 SCDTDPs:** Pacific; Northeast; Midwest; Heartland; and Southeast.



# Innovation in Care Integration for Children and Youth with Autism Spectrum Disorders and other Developmental Disabilities (ASD/DD), FY2016-FY2019

## Telehealth Focus: Distance Learning.

- To improve access to a coordinated, comprehensive state system of services that leads to early diagnosis and entry into services for children with ASD/DD within the state and their families, emphasizing medically underserved and rural populations.
- Implement innovative, evidence-informed models of:
  - family support and navigation;
  - shared resources; and
  - telehealth and/or telemedicine (including mobile health) health information technologies to improve access to a coordinated, comprehensive state system.
- **Recipients 5:** University of Delaware; University of Wisconsin; Washington State Department of Health; and The Autism Project, Rhode Island



# Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy, FY2016-FY2019

## Telehealth Focus: Direct clinical services.

- To facilitate the delivery of quality health care for children and youth with epilepsy (CYE)
  - Implement evidence-based and innovative models of telehealth and/or telemedicine using health information technologies;
  - Implement the Got Transition Six Core Elements Framework to help youth successfully transition from the pediatric to adult system of health care; and
  - Facilitate outreach and education regarding epilepsy among pertinent stakeholders.
- **Recipients 7:** University of Michigan; Michigan Department of Health and Human Services; Boston Medical Center; Cleveland Clinic; Children's Hospital of Philadelphia; Epilepsy Foundation of Western Central Pennsylvania; Epilepsy Foundation of Texas.



# ZIKA Maternal and Child Health Services Program

## 12/1/2016-11/30/2019

**Telehealth Focus:** Direct clinical services and clinical support, distance learning, and Project ECHO.

- **Recipient:** Puerto Rico Department of Health
  - To assist with a comprehensive Zika response that ensures infants and toddlers exposed to Zika virus during pregnancy are identified, screened, assessed and monitored until age three.
- **Recipient:** US Virgin Islands Department of Health
  - To enhance the capacity of current home visiting efforts to improve access to services for infants and children born to mothers who tested positive for Zika virus infection during pregnancy and their families.
- **Recipient:** America Samoa Department of Health
  - To assist with the development of a Zika care coordination system for mothers and their infants to be delivered primarily through Zika Client Navigators and improving access to transportation.



# Universal Newborn Hearing Screening and Intervention Program, FY2017-FY2020

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- **Telehealth Focus:** Tele-audiology services for newborns and children.
  - Improve diagnoses capabilities;
  - Explore options for early intervention services;
  - Provide audiology services in rural areas; and
  - follow up audiology services for children already identified with hearing loss.
- **Recipients:** 9 Departments of Health – Alaska, New Mexico, Puerto Rico, Hawaii, Arkansas, Tennessee; Federal States of Micronesia; Republic of Palau; and Ear Foundation Arizona.



# Contact Information

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