



**The Arc of Illinois
Family Voices of Illinois
Family to Family Health Information Center**

www.familyvoicesillinois.org

familytofamily@thearcofil.org

708-560-6703 (voice) 866-931-1110 (toll free for Illinois families)

July 9, 2015

Andrea Palmer, MPA, MBA, CHSM
Chief, Division of Maternal, Child and Family Health Services
Illinois Department of Public Health Office of Women's Health
122 S Michigan 20th Floor
Chicago, IL 60603
DPH.MCH@illinois.gov

Re: Comments on 2015Needs Assessment/2014 Annual Report/2016 Annual Application

Dear Ms. Palmer:

Thank you for affording us this opportunity to provide public input to the Illinois Department of Public Health for the Maternal and Child Health Bureau (MCHB) Block Grant application. We are very encouraged to learn about the progress that Illinois is making in many important areas related to maternal and child health in our state.

We are proud to inform you that The Arc of Illinois Family to Family Health Information Center celebrated its ninth year of operation on May 1, 2015. Late in May 2015, Health Resources and Services Administration (HRSA), MCHB notified us that our competitive application for three years of new funding was approved through May 2018. We are part of a national network of fifty Family-to-Family Health Information Centers (F2FHICs) funded by HRSA, MCHB. Our mission is to provide information, resources and training opportunities to the families of all Illinois' children and youth with special health care needs, those who meet the medical-diagnostic criteria of our state's Title V CSHCN program together with the larger cohort of CSHCN identified by the CDC (Centers for Disease Control's National Survey of Children).

We continue to maintain a strong collaborative partnership with The University of Illinois at Chicago, Division of Specialized Care for Children (DSCC). We look forward to establishing a collaborative relationship with the Illinois Department of Public Health as well.

Based upon the F2F HIC's mission of supporting families of CSHCN to live and thrive in their own communities, we have the following comments and recommendations for each of the ten components of the Illinois State Action Plan for 2016-2020:

State priority needs:

#1: Assure accessibility, availability and quality of preventive and primary care for all women, particularly for women of reproductive age.

- Require data collection regarding how these initiatives are being tailored to address the needs of teens with special health care needs and/or developmental disabilities and of other women with special needs and/or disabilities.
- Establish collaborative information-sharing on this topic for MCH programs, disability service providers, consumers and families.

#2: Support healthy pregnancies and improve birth outcomes.

- Provide wrap-around services and supports to expectant mothers with CSHCN at home to enable them to obtain adequate prenatal care and follow doctor's orders related to (for example) rest, diet and restrictions on daily activities.
- Establish funding streams for in-home respite to care for CSHCN while their mothers give birth and return home with their newborns.

#3: Support expanded access to and integration of early childhood services and systems.

- Re-establish the Child Care Nurse Consultant program statewide, focused on supporting CSHCN in "regular" day care and other early childhood programs.
- Prioritize funding and support for "blended" early childhood programming, incorporating Headstart and Early Headstart, State Pre-K and other early childhood community-based programs.
- Work with HFS and all Coordinated Care entities to utilize the NCPS (Nursing Care and Personal Assistance Services) component of the Medicaid EPSDT regulation to provide 1:1 support staff to young children in need of this service in order to participate in inclusive early childhood programming.

#4: Facilitate the integration of services within patient-centered medical homes for all children, particularly for children with special healthcare needs

- Establish collaborative agreements with HFS and all Coordinated Care entities to ensure that CSHCN and their siblings can receive primary health care within the same medical home, rather than requiring families to interact with more than one primary care site.
- Establish training protocols to develop and enhance the care coordination skills of the families of CSHCN and fund their implementation.

#5: Empower adolescents to adopt healthy behaviors.

- Require all adolescent health initiatives to be fully inclusive of YSHCN across activities, with financial supports for needed accommodations.
- Recognizing that YSHCN are at even greater risk for poor health outcomes (including higher rates of obesity, depression, smoking and more), provide pre-service and in-service training for staff of community health programs to include YSHCN.

#6: Assure appropriate transition planning and services for adolescents and young adults, including youth with special health care needs.

- Collaborate with HFS and all Coordinated Care entities to ensure that all youth with intellectual and/or developmental disabilities have completed the PUNS (Prioritization of Urgency of Need

for Services) with their regional Independent Service Coordination (ISC) agencies.

- Ensure that all youth and families are connected to their regional Centers for Independent Living (CILs), Parent Training, and Information Centers (PTIs) for training related to self-advocacy and transition support, including appropriate transition-related IEP goals.

#7: Assure that equity is the foundation of all MCH decision-making; eliminate disparities in MCH outcomes.

- Assure that disability equity is given equal consideration in all MCH programs and initiatives.
- Implement enhanced wraparound services for families of CSHCN who are also adversely impacted by health disparities.

#8: Support expanded access to and integration of mental health services and systems for the MCH population.

- Ensure that community-based, culturally competent mental health services are available to all CSHCN and their families, those with primary mental health diagnoses and those with additional special needs.
- Establish pre-service and in-service training opportunities to develop and enhance the skills of mental and behavioral health providers in serving CSHCN.
- Develop financial incentives (e.g. student loan forgiveness) to encourage psychiatrists to commit to serving CSHCN and their families.

#9: Partner with consumers, families and communities in decision-making across MCH programs, systems and policies.

- Require consumer and family participation in all MCH programs, supported by budgetary mandates to adequately cover costs such as travel, childcare and equitable consultant fees.
- Collaborate with F2F and other family-run organizations with proven histories of peer-to-peer training initiatives to ensure that consumers and families are prepared to collaborate in decision-making at all levels.

#10: Strengthen the MCH capacity for data collection, linkage, analysis, and dissemination; Improve MCH data systems and infrastructure.

- The National Survey of Children's Health, Illinois State Snapshot of CYSHCN by condition, reveals that our state has significant numbers of children diagnosed with asthma, developmental delays, ADHD and behavioral/conduct problems from low-income families, as indicated by their SSI recipient and/or public insurance status. We recommend, therefore, the development of an interagency strategy to identify, track and appropriately serve these children and their families.
- Establish a joint data collection and data sharing system with the Illinois Department of Healthcare and Family Services, with each of the entities contracted by HFS to operate the Coordinated Care Program to identify, track, and monitor referrals and treatment status of all participating CSHCN, across all diagnoses.
- Establish a collaborative agreement between HFS, all Coordinated Care entities and UIC DSCC to identify all children who meet the medical diagnostic eligibility for the Title V CSHCN program and ensure that they are referred.

Thank you for the opportunity to provide comments on the Maternal and Child Health Services Block Grant. Our Family to Family Health Information and Education Center operates a toll-free information line for families: 866-931-1110 and can be reached via email: familytofamily@thearcofil.org.

We look forward to collaborating with you on behalf of all of Illinois' children and youth with special health care needs and their families.

Sincerely,

Tony Paulauski, Executive Director

Faye Manaster, F2F Project Director

CC:

Stephanie Altman, Assistant Director of Health Care Justice, Shriver National Center on Poverty Law

Dr. Barbara Bayldon, President, Illinois Chapter, American Academy of Pediatrics

Kathy Chan, Director of Policy, Cook County Health & Hospitals System

Greg Fenton, Acting Director, DHS/DDD

Thomas Jerkowitz, Director, UIC-Specialized Care for Children

Janine Lewis, Director, EverThrive Illinois

Barbara Otto, CEO, Health and Disability Advocates

Kathy Sanabria, Associate Executive Director, Illinois Chapter, American Academy of Pediatrics

LaQuanta Smalley, Project Officer, DHHS, HRSA, MCHB, DSCSHN

Nora Wells, Executive Director, Family Voices Inc.

Amy Zimmerman, Director, Chicago Medical-Legal Partnership for Children

