The Arc of Illinois
Family Voices of Illinois
Family to Family Health Information Center
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Chief, Division of Maternal, Child and Family Health Services
Illinois Department of Public Health Office of Women's Health
122 S Michigan 20th Floor
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Re: Comments on Illinois MCH Action Plan for FY2017 Title V Block Grant 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 tenth year of operation on May 1, 2016. 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 and the larger cohort of CSHCN identified by the CDC (Centers for Disease Control's National Survey of Children).

State priority needs:

#1: Assure accessibility, availability, 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.
- Refer families with infants identified in the APORS system to the Family to Family Health Information Center in conjunction with the IDHS High-Risk Infant follow-up program.
- Share information about F2F with members of the IDPH Zika Action Team to enable them to better inform impacted families.
- Ensure that all state breastfeeding initiatives receive training on supporting mothers of CSHCN to initiate and continue breastfeeding.

#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: Integrate services within patient-centered medical homes for all children, particularly for CSHCN.

- Utilize the F2F website and social media platforms, together with those of DSCC and IDPH, to post information for families about the components of a medical home and high-quality care.
- Engage F2F staff, together with DSCC staff, to serve as a resource for educating medical home providers regarding community resources and connecting families to services.
- Improve asthma identification and support services for CSHCN diagnosed with asthma, as well as additional special health needs, to promote family education, inclusion in community-based services, and care coordination training, including the development of appropriate Individualized Education Plans (IEPs) and 504 Plans (school health plans).
- Facilitate in-service training for school-based health centers on meeting the needs of CSHCN with asthma plus additional special needs.
- Collaborate with HFS to develop and support the linkage of medical homes and dental homes for all CSHCN.

#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.
- Provide teen pregnancy prevention education in school and community-based programs geared specifically for teens with developmental disabilities.

#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 (PTICs) for training related to self-advocacy and transition support, including appropriate transition-related IEP goals.
- Share F2F transition resources with all stakeholders.

#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, including, but not limited to, respite care, transportation supports, care coordination training, sibling support, and facilitated enrollment for their child with special needs into NCPS (Nursing Care and Personal Assistance Services) or DHS/DRS Home Services.
- Provide training for family members on Medicaid EPSDT (Early Periodic Screening Diagnosis and Treatment) and provide logistical supports for their participation.

#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.
- Implement a specific HCBS (Home and Community Based Services) 1915 (c) waiver, similar to the Children's Support Waiver, specific for children with mental

health diagnoses.

- 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.
- Explore a partnership with F2F to develop training paradigms for families of CSHCN regarding advocacy, effective medical homes, and adequate transition services and supports.

#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.
- Establish a protocol with HFS and all contracted managed care entities to identify and track all enrolled CSHCN who have intellectual and/or developmental disabilities and ensure that they are referred to their local Independent Service Coordination (ISC) agencies for inclusion in the DHS/DDD Prioritization of Urgency of Need for Services (PUNS) database, the portal to HCBS Medicaid Waiver services for this population.

Thank you for the opportunity to provide comments on the Maternal and Child Health Services Block Grant. Our Family to Family Health Information 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
Tony Paulauski, Executive Director

Faye Manaster
Faye Manaster, F2F Project Director

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