



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

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Re: Comments on Illinois MCH Action Plan for FY2018 Title V Block Grant Application

Dear Andrea:

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 eleventh year of operation on May 1, 2017. 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).

Our comments this year focus primary on the State Action Plan and our recommendations specific to those children in Illinois with special health care needs who do not meet eligibility criteria for services through UIC – Specialized Care for Children (DSCC), our state's Title V CSHCN Agency.

First, we want to emphasize that here in Illinois we are fortunate to have DSCC as our Title V CSHCN agency. They do an exemplary job of serving the children who meet their medical diagnostic eligibility criteria and their families statewide. We have had a close working relationship with them over the years, and look forward to ongoing collaboration with their new personnel. We continue to refer families and professionals to DSCC on a weekly basis.

DSCC reports serving 8,098 children across the Core Program and the Home Care Program (p.113). In addition, DSCC provides outreach services to another 17,000 children, per the FY 2016 Annual report.

Illinois has 39,635 children under age 18 in Illinois who are SSI recipients as of 12/15. When we compare these numbers, there are an additional 31,537 CSHCN about whom all of us need to know more.

<https://www.ssa.gov/policy/docs/statcomps/supplement/2016/7b.html#table7.b8>

We can safely assume, based upon SSA’s methodology for counting parental income and assets until the disabled child’s 18th birthday that the majority of children in Illinois who receive SSI are also insured by Medicaid. Please note that only 10% of CSHCN in Illinois receive SSI prior to their 18th birthdays. <http://www.familyvoicesillinois.org/wp-content/uploads/2012/06/SnapshotStatFeb2017.pdf>

Since we have about 30,000 CSHCN in Illinois who come from low-income families and have disabling conditions/illnesses severe enough to be eligible for SSI payments, it stands to reason that many of them are members of families who receive other MCH services.

Our hope for the coming year is that we can work together with you and our state’s MCH programs to focus on mobilizing all partners, including the families of “non-DSCC” CSHCN at the state and community levels to jointly make decisions about leveraging resources, integrating and improving systems of care, promoting inclusive and high quality public health services and developing policies that are supportive for all families, while accommodating supports for families with include CSHCN.

Our chart below lists components of Illinois’ Five-Year State Action Plan and examples of suggested programmatic strategies that could further our mutual goal of inclusive support for CSHCN and their families.

State Action Plan Priority	CSHCN-specific strategy suggestions
Women/Maternal Health	<ul style="list-style-type: none"> • 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. • Coordinate funding streams for in-home respite to care for CSHCN while their mothers give birth and return home with their newborns.
Perinatal/Infant Health	<ul style="list-style-type: none"> • Ensure that all state breastfeeding initiatives receive training on supporting mothers of CSHCN to initiate and continue breastfeeding. • Work with HFS, all Coordinated Care entities and birthing hospitals and APORS program to utilize the NCPS (Nursing Care and Personal Assistance Services) component of the Medicaid EPSDT regulation to provide 1:1 support to infants to enable them to thrive at home.
Child Health	<ul style="list-style-type: none"> • Re-establish the Child Care Nurse Consultant program statewide, focused on supporting CSHCN in “regular” day care and other early childhood programs. • 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

	<p>coordination training, including the development of appropriate Individualized Education Plans (IEPs) and 504 Plans (school health plans).</p> <ul style="list-style-type: none"> • Facilitate in-service training for school-based health centers on meeting the needs of CSHCN with asthma plus additional special needs.
<p>Adolescent Health/Youth with Special Health Care Needs (YSHCN)</p>	<ul style="list-style-type: none"> • 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.
<p>CSHCN</p>	<ul style="list-style-type: none"> • 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. • 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.
<p>Cross-Cutting/Life Course</p>	<p>Strengthen the MCH capacity for data collection, linkage, analysis, and dissemination. Improve MCH data systems and infrastructure by including data on CSHCN outside of DSCC.</p> <ul style="list-style-type: none"> • 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. • Collaborate 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.

	<ul style="list-style-type: none"> • 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. <p>Assure that equity is the foundation of all MCH decision-making; eliminate disparities in MCH outcomes.</p> <ul style="list-style-type: none"> • 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. <p>Support expanded access to and integration of mental health services and systems for the MCH population.</p> <ul style="list-style-type: none"> • 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.
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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 at 866-931-1110 and we can be reached via email at 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,

Meg Cooch, Executive Director

Faye Manaster, F2F Project Director

Cc:

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

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

Greg Fenton, Director, DHS/DDD

Thomas Jerkovitz, Director, UIC-Specialized Care for Children

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