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**The Arc of Illinois Family to Family Health Information Center  
Comments for Illinois Maternal and Child Health Bureau 2019 Block Grant Application and 2017 Annual Report**

August 13, 2018

Dr. Nirav D. Shah  
Director  
Illinois Department of Public Health  
69 W. Washington Street # 3500  
Chicago, IL 60602-3027

Dear Dr. Shah:

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 twelfth year of operation on May 1, 2018. In January 2018, we submitted our Competitive Continuation application to HRSA and were subsequently informed that we have received funding for four more years.

We are part of a national network of over 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 as well as the much larger cohort of CSHCN identified by the CDC (Centers for Disease Control's National Survey of Children).

First, we want to emphasize that here in Illinois we are fortunate to have UIC-DSCC as our Title V CSHCN agency. They continue to 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 UIC-DSCC on a weekly basis. We look forward to informing families about the upcoming expanded medical-diagnostic eligibility categories which UIC-DSCC is preparing to implement.

During the past twelve years of The Arc of Illinois' Family to Family Health Information Center, we are most pleased to regard the very significant decline in the number of uninsured children in our state. However, we are increasingly concerned about the increase in underinsured CSHCN, as evidenced by requests for assistance from families and providers. These underinsured CSHCN consist of two major groups:

1. Children with Marketplace/Private insurance who are confronted by:
  - Growing out-of-pocket costs impacting their families, including higher premiums, deductibles and co-pays.
  - Children covered by self-insured plans not bound by state and federal coverage mandates, thus are lacking in access to-for example-pediatric rehabilitative therapies.
  - Families and providers who continue to contact us regarding increased barriers to having claims for treatment services for their CSHCN approved

2. Children insured by Medicaid/All Kids who encounter significant, new barriers to receiving appropriate care:
  - Children with diagnoses that meet UIC-DSCC's current medical-diagnostic eligibility are still, for the moment, able to remain in Fee-For-Service Medicaid while benefitting from expert, targeted care coordination services. How long they will be able to benefit from this much-needed support system is still unknown.
  - When CSHCN are already participating in Medicaid Managed Care at the time of their diagnosis, they may be confronted by barriers of network adequacy, particularly in terms of access to pediatric specialists and sub-specialists; as well as to pediatric habilitative therapies.
  - In terms of young children identified with developmental delays and referred to Early Intervention (EI) services, an atypical situation exists in Illinois. Our state only accepts into the EI system young children who evidence delays of "greater than 30%". Children who are deemed to be "less delayed" and ineligible for EI services must have their families seek out therapies services covered by their third-party payor. For children with private insurance, this process typically works well. However, when children are insured by Medicaid, but ineligible for EI, their families frequently experience many obstacles to obtaining medically-necessary pediatric therapies for them. The issue of network adequacy plays a large role in determining the futures of these young children.

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.

Sincerely,



Meg Cooch, Executive Director, The Arc of Illinois

*Faye Manaster*

Faye Manaster, Director, The Arc of Illinois Family to Family Health Information Center

Cc:

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*Achieve with us.*