



Illinois Chapter

Illinois Department of Healthcare and Family Services
Attn: Waiver Management
201 South Grand Ave, East, FL 2
Springfield, IL 62763
Re: Statewide Transition Plan

December 9, 2016

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To Whom It May Concern:

The Illinois Chapter of the American Academy of Pediatrics (ICAAP) and The Arc of Illinois Family-to-Family Health Information Center (F2F) support the comments on the Healthcare and Family Services Transition Plan for New CMS Rules on Home & Community Based Services (HCBS) submitted by the Arc of Illinois December 6, 2016. **Below are additional comments related to the pediatric population for the revised Illinois Statewide Transition Plan.**

ICAAP and F2F encourage the Illinois Department of Human Services (DHS), including the Division of Developmental Disabilities (DDD) and the Division of Rehabilitation Services (DRS), and the Illinois Department of Healthcare and Family Services (HFS) to come together and establish a pediatric focus for children (ages birth to 21 years) across all six of Illinois' current nine Medicaid waivers which serve children with emphasis on coordinating services to support families to keep children living at home, in their own communities, whenever possible. This process should start with formalizing a "no wrong door" policy for all children and families currently receiving any type of services/supports from DHS (any division) and/or HFS (including children and families enrolled in Family Health Plans).

We recommend that HFS establish a **pediatric specialist role** within the HFS Bureau of Interagency Coordination as well as establish a Children's Waiver Central Office in Springfield (analogous to the current arrangement established by HFS and DHS specific to the Medically Fragile and Technology Dependent (MFTD) waiver: Central Office (CO) 238, which is part of the Bureau of Local Office Transactions and Support Services (LOTS).

http://www.dhs.state.il.us/page.aspx?item=70579#a_toc2

In this way, families of children and youth with special health care needs (CYSHCN) currently receiving any type of services/supports from DHS and HFS can be supported by direct linkage to potential HCBS waiver-specific programming designed to enable them to raise their children in their own communities.

Based on presently available information, our current system in Illinois appears to have some capacity to serve more children with disabilities and/or chronic illnesses with home-based services and supports, but accessing them can be a daunting task for many families, as well as for providers and service professionals. There is a paucity of current, definitive data that continues to be a barrier to both child-specific program and policy.

Below are observations and comments on waivers' status and recommendations on ways to improve:

DHS/DRS Home Services Program

Status

- Waiver reporting indicates available capacity
- Unknown how many CYSHCN are served annually
- Unknown how many families of CYSHCN seek DRS Home Services annually and outcome of their applications

Recommendations

- HFS/Illinois Health Connect (IHC)/all Family Health Plans (FHPs) should be required to implement a data match to identify CYSHCN potentially eligible for DRS Home Services and refer them in a timely manner
- DHS/DRS should designate a Pediatric Liaison to work with HFS/IHC/FHPs, DRS local offices and medical providers to facilitate referral and enrollment
- DHS/DRS should jointly develop a pediatric-specific determination of need (DON) assessment tool for which ICAAP can assist in providing training to providers on how to complete
- DHS/DRS should provide annual reports on the Persons with Disabilities Waiver to include a section on annual child census, geographic distribution of CYSHCN, and services provided
- HFS/DHS should collaborate on Early Periodic Screening, Diagnostic and Treatment (EPSDT) training for all stakeholders, including scope of services
- HFS/DHS/all Medicaid Managed Care Organizations (MCOs) must develop capacity by contracting with provider agencies to serve a broader range of CYSHCN, beyond those requiring nursing care, or consider revamping an ineffective managed care system

DHS/DDD Children's Support Waiver

Status

- Waiver reporting indicates some available capacity, which has increased slightly over the past five years
- Prioritization of Urgency of Need of Services (PUNS) reporting indicates increase in number of children waiting for HCBS services
- PUNS reporting does not currently include children who are waiting to enroll in Medicaid (i.e. based on family income) who could potentially access HCBS services under EPSDT; children should be able to enroll in DRS Home Services while they are waiting for PUNS similar to what some young adults do when they leave school but are waiting for DD service access
- Legislation was passed this year to require school districts to inform families about PUNS (A similar approach should be implemented with medical providers and insurance companies, including Medicaid MCOs)

Recommendations

- DHS/DDD, DHS/DRS and UIC-Specialized Care for Children should establish a collaborative agreement for the referral of children whose MFTD waiver applications are not accepted to arrange for them to be served by either DRS Home Services or DDD Children's Support Waiver
- DHS/DDD should re-establish the model of regional trainings (not connected to a service provider agency) for potential Personal Support Workers and respite workers in First Aid, CPR, Universal Precautions and medication administration, in order to increase the pool of direct care staff for CYSHCN with DD and medical complexity across the state (they did this over 30 years ago)
- The HFS Bureau of Interagency Coordination should include a CSYCHN Ombudsperson to work with families, Independent Service Coordination Agency (ISC) staff, Early Intervention personnel, DRS Home Services personnel and medical providers to ensure timely and appropriate access to services

Another important area which needs to be addressed is the incorporation of appropriate home and community-based supports for the (small) number of CYSHCN who have both developmental disabilities and varying degrees of medical complexity. Little data are currently available on this cohort of children and youth. Their needs are typically brought to the attention of F2F as well as to medical providers when their applications for the MFTD waiver are denied based on not meeting the “medical need” criterion. However, when their families seek services via PUNS and the Children’s Support Waiver, they may encounter barriers related to their medical needs (e.g. seizure management and medication, trach care, tube feedings, oxygen). At the present time, families of children and youth selected for the Children’s Support Waiver can opt for the self-directed program model. Under this option, however, there is currently no requirement for the Personal Support Workers to be trained in First Aid, CPR or Universal Precautions (the agency-based option does include this, but leaves the family with less monthly funding for in-home caregivers). Administration of medication under this model is also a grey area.

ICAAP and F2F support the implementation of the new CMS Rules on Home & Community-Based Services. The rules’ focus will lead Illinois to a more family- and person-centered system based upon the needs of the individuals we are here to provide care for and support. A high priority should be placed on providing ways to secure new funding which is necessary to attract and retain direct support professionals as well as to develop a truly person-centered service system. We stand ready to assist with implementing improved services.

Thank you for the opportunity to provide these comments.

Sincerely,

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