American Academy of Pediatrics
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Illinois Chapter

May 18, 2017

Ms. Felicia Norwood, Director
Illinois Department of Healthcare and Family Services
401 South Clinton Street
Chicago, IL 60607

Dear Ms. Norwood,

On behalf of our 2,100 pediatrician members of the Illinois Chapter of the American Academy of Pediatrics (ICAAP), we are writing in response to the Illinois Department of Healthcare and Family Services' (HFS) request for proposals (RFP) issued on February 27, 2017, to rebid the majority of the state's Medicaid managed care program contracts, consolidate multiple programs into a single streamlined program, and expand managed care statewide. Upon review of the RFP by pediatrician leaders in children's health, ICAAP has identified concerns related to the Managed Care Organizations' (MCOs) abilities to provide care coordination for children with complex conditions that require specialized care, many of whom are currently being handled well by the University of Illinois at Chicago (UIC) Division of Specialized Care for Children (DSCC). We also have concerns related to the inclusion of children in foster care in the MCO program.

UIC's DSCC Program

The UIC DSCC has been a resource for children with special healthcare needs in Illinois since 1937. Currently DSCC provides care through two programs: the Core Program and the Home Care Program.

Core Program Services: DSCC's Core program offers free care coordination for children with a medically eligible diagnosis. All eligible children/youth regardless of insurance status may receive care coordination services from DSCC. DSCC Care Coordination staff consists of registered nurses, social workers, speech therapists, and audiologists all of whom are licensed. There are 11 DSCC Core offices positioned throughout the state so that the DSCC Care Coordinators work in the communities which they serve. This enables them to have personal relationships with the children and families for whom they are providing care coordination. DSCC Care Coordinators work with families to develop an individualized plan of care addressing the child's and family's needs as a whole. Care coordination can assist families in providing additional education related to their child's diagnosis, accompanying the caregiver to their child's medical appointments, arranging transportation to appointments, working with the child's school in the development of an Individualized Education Plan (IEP), making plans for transition to adult care, and assisting with making the most of insurance benefits. Additionally, children enrolled in the Core Program with family incomes up to 285% of the federal poverty level are eligible for financial assistance for co-pays, services not covered by insurance, or other gap-filling services (e.g. ramps, lifts, etc.).

Note: The Core Program is funded through the Maternal and Child Health Services Block Grant, part of Title V of the Social Security Act. The U.S. Department of Health and Human Services recommends Title V and Title XIX (Medicaid) programs partner together and ICAAP believes this should continue.

Concerns: Currently, if a DSCC-eligible child lives in a mandatory managed care county in Illinois, he/she is able to choose to disenroll from his/her MCO, enroll in Medicaid fee-for-service, and receive care coordination from DSCC. It is unclear from the RFP if this will continue to be an option in Illinois, but we strongly believe that disenrollment rights and DSCC services should continue to be available for these children. DSCC care coordinators have extensive experience and expertise in how to best serve children with complex medical needs. We believe it is vital for DSCC to continue to be a resource to children/youth and their families due to their significant experience with care coordination, knowledge of community-based resources, and relationships developed in the community and with providers to support care. ICAAP remains supportive of DSCC's strong involvement in coordinating care for children with DSCC-eligible diagnoses.

Current Home Care Program Services: Through an intergovernmental agreement with HFS, DSCC operates the Medically Fragile and Technology Dependent (MFTD) Waiver – one of HFS' Home & Community Based Services (HCBS) waivers. DSCC has been operating the MFTD waiver since the 1980's and is a highly respected agency that providers, patients, and families depend on for life-saving supports and services. In 2014 DSCC also began serving children receiving home nursing through Nursing Personal Care Services (NPCS) and adults over age 21 that had aged out of the MFTD waiver and were able to continue with DSCC as part of a consent decree (*Hampe vs. Hamos*). In addition, DSCC has become the single point of entry for all children and youth with special health care needs (CYSHCN) in the state of Illinois in need of skilled nursing care in their homes on a continuing basis (for both Medicaid and non-Medicaid funded children).

As the single point of entry, DSCC Home Care staff help facilitate the medical eligibility for nursing, eligibility for waiver, Medicaid financial eligibility for all waiver participants, SSI categorical eligibility for all home care participants, and redeterminations for waiver eligibility/in-home nursing/financial eligibility. DSCC Care Coordinators also work with the family in selecting their home nursing agency, participate in care conferences, assist the family in addressing home nurse staffing needs, and facilitate child-specific training for home nurses. For MFTD waiver participants, the coordinators work with HFS to coordinate services such as environmental modifications, vehicle modifications, electrical modifications, and extermination services. Additionally DSCC provides oversight of the home nursing agencies and transitional care facilities providing care for this fragile population.

Concerns: According to information HFS released on March 29, 2017, DSCC will continue to be the provider of care coordination and operation of the MFTD waiver in partnership with MCOs. The RFP initially includes the HCBS waiver as part of service package two and intermediate care facility services for individuals with intellectual or developmental disabilities (I/DD) in service package three, but bidders must be capable of assuming responsibility for both of these services with 180 days' notice if the state decides to include them in the managed care service package at a future date. ICAAP recommends that DSCC continue to be the provider of care coordination and operator of the MFTD waiver program. The RFP does not provide information on how MCO bidders would be expected to provide care coordination services for these medically complex patients nor does it state how HFS will assess these MCO bidders for readiness should the state determine that these children's care should be coordinated by MCOs.

ICAAP recommends that DSCC remain the single point of entry for all CYSHCN in need of home nursing services throughout the state. DSCC's continued involvement is needed with these children and DSCC should become the single point of entry and care coordination entity for all children under age 21 in waiver programs in the state of Illinois. On December 9, 2016, ICAAP wrote a letter to HFS supporting DSCC as the single point of entry for all pediatric waivers. We also believe it is important for DSCC to have a continuing role in the quality assurance they currently provide as is done with audits of home nursing agencies to prevent unsafe nurses from working in a child's home.

The Model Contract in the RFP appendix covers behavioral and social risks but doesn't address medical complexity. Children who are medically complex are those requiring ongoing medical care from subspecialists or for multiple chronic conditions. They are a subset of CYSHCN who have needs for more frequent, complex, or intense medical care than average children. Within the Technical Proposal Structure and Prompts section of the RFP, prompt 5.2.4 refers to "High-needs Children" and the value is only 50/900 points (see page 26 of RFP). Additionally, the corresponding vignettes don't address CYSHCN (all examples are behavioral-health related). Coordination of services and transitions under 5.2.4.4 should require MCOs to show that they have pediatric specialists geographically accessible to all children with special health care needs. The absence of discussion about the needs of medically complex children in the RPF leads to the following questions.

- What is the rationale for HFS to specifically "include" children who are exempt from Medicaid Managed Care participation under the regulations of the Social Security Administration in this RFP?
- Is Illinois planning to apply for a new waiver/exception to policy to implement this?
- How has HFS assessed the ramifications of potentially relocating care coordination services for children who are currently served under the MFTD waiver?

Children cared for under the MFTD waiver are a subset of children who are medically fragile or technology dependent and require frequent changes in medical management and are dependent on a daily basis on devices or machines to support their lives, including ventilation, daily use of intravenous infusions, artificial airways, and tubes for feeding. Caregivers must be properly trained and in-home nursing personnel monitored to ensure appropriate and safe delivery of complex care. MCOs are likely incapable of providing this level of scrutiny and monitoring of care for these patients.

Another concern is data collection and sharing components that should be required for MCOs related to 1) fulfillment of Early and Periodic Screening, Diagnostic and Treatment (EPSDT) requirements in each MCO and 2) protocol for diagnosis and active treatment of children in MCOs under age three years identified with any type of special need. If these responsibilities are assigned to MCOs, how will they and the state track data without a single point of entry? Just a few examples of critical data points include:

1) Numbers of children referred to Early Intervention (EI) accepted for a diagnosed condition and by diagnosis and geography
2) Numbers of children referred to EI found to be not eligible for services but who need continued follow up
3) Identification of children and adults served by each MCO who have developmental disabilities and evidence of their referral to the Prioritization for Urgency of Need for Services (PUNS)
4) Access to Personal Assistance services (under EPSDT) for CYSHCN, in addition to those who require skilled nursing care

In addition we believe it is important that the contracts for MCOs provide that:

5) All MCOs include psychiatrists and all other specialists in their networks who are trained and willing to serve children and adults who have disabilities and/or chronic illnesses in addition to behavioral health providers
6) All MCOs need to comply with network adequacy standards, including, but not limited to, in-network therapists who provide physical therapy, occupational therapy, speech therapy, applied behavior analysis therapy, behavioral therapy, feeding therapy, and other therapies prescribed by a patient's physician. There are longstanding shortages of many kinds of therapists in many areas of the state. This is an area that the MCO must at least develop a plan for handling.

Who will be responsible for the development and execution of policies and procedures to transition the care of the young adult with special needs to adult in-network primary care providers and specialists, including out-of-network agreements for enrollees requiring care from subspecialists? What plans are there to ensure families have input on proposed changes to the delivery of the Illinois Medicaid system?

Department of Children and Family Services (DCFS)

The RFP advises a separate contract will be awarded to one statewide bidder for children who are or have previously been under the care of the Department of Children and Family Services (DCFS). It is our understanding that it has been determined by HFS that youth cared for under DCFS will be mandatorily enrolled in managed care, except for those children who have been adopted or entered a guardianship, who will have the opportunity to opt-out of managed care. HFS has indicated it will carve out children in foster care and have their care coordination done by a single contractor. This may be intended to provide better coordination between primary care and behavioral health for this group of patients who are known to have a high need for services. ICAAP strongly recommends that children in foster care should be eligible to receive wrap-around services and remain with their current primary care providers if those providers agree to continue to see them. Provisions should be granted that allow a foster family with a mixed household of biological and foster children to have the foster children enrolled in same MCO as biological children if the families' established primary care provider is not in the MCO serving the foster children. The impact of requiring children who are wards of DCFS to participate in Medicaid managed care will require careful monitoring. Another concern is what is the ability of a provider, a patient, a foster family, or a family of origin to access child abuse pediatricians without a prior approval for acute evaluations? Is it legal to only offer one managed care option for these children? What is the plan for children and youth being cared for through DCFS to receive nursing care through the MFTD waiver or NPCS?

Summary

ICAAP recommends DSCC remain the single point of entry and source of care coordination for all CYSHCN in need of home nursing services throughout the state. ICAAP recommends that DSCC continue to be the provider of care coordination and operator of the MFTD waiver program. DSCC's continued involvement as a trusted partner providing oversight for these children's care is necessary. DSCC should become the single point of entry and care coordination entity for all children under age 21 in waiver programs in the state of Illinois. ICAAP supports DSCC as the single point of entry for all pediatric waivers. ICAAP remains supportive of DSCC's strong involvement in coordinating care for children with DSCC-eligible diagnoses. Children with chronic medical conditions, medical complexity, intellectual/developmental disabilities, and those in foster care have different needs from children in general or from those with behavioral complexity as a sole chronic condition. ICAAP looks forward to a continued partnership with the DSCC in caring for complex CYSHCN that require intensive supports and services so they may achieve a high quality of life and reach their full potential.

Additional information on how MCOs plan to manage the differing needs of CYSHCN is necessary. Any new system or plan will require ongoing close monitoring to demonstrate that the plan is effective. Consideration as to how CYSHCN fit into the proposed Integrated Health Home Model needs further scrutiny and monitoring. Children who need specialized care should continue to have the option to enroll in Medicaid fee-for-service if it better meets the needs of the child and family. ICAAP members seek to have the opportunity to dialogue with the IDHFS on these concerns and are available to provide additional input to Medicaid Managed Care Programs impacting children and families in Illinois. Thank you for consideration of our collective comments.

Sincerely,

Alison S. Tothy, MD, FAAP
President, Executive Committee
Illinois Chapter, American Academy of Pediatrics

cc: Representative Robyn Gabel, Chair, House Human Services Committee
Senator Julie Morrison, Chair, Senate Human Services Committee
Senator Heather Steans, Chair, Senate Human Services Special Issues Subcommittee