

March 23, 2020

Ms. Seema Verma, MPH
Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
Attention: CMS-2324-NC
PO Box 8016
Baltimore, MD 21244-8010

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Suite 460
Washington, D.C. 20036

Re: File Code CMS-2324-NC: Request for Information: Coordinating Care from Out-of-State Providers for Medicaid-Eligible Children with Medically Complex Conditions

Dear Administrator Verma:

The Academy of Nutrition and Dietetics (the “Academy”) is pleased to provide input on the Centers for Medicare and Medicaid Services’ (CMS’s) Request for Information: Coordinating Care from Out-of-State Providers for Medicaid-Eligible Children with Medically Complex Conditions. Representing over 107,000 registered dietitian nutritionists (RDNs)¹ (including RDNs possessing Board Certification as Specialists in Pediatric Nutrition),² nutrition and dietetic technicians, registered (NDTRs), and advanced-degree nutritionists, the Academy is the largest association of nutrition and dietetics practitioners in the world committed to accelerating improvements in global health and well-being through food and nutrition. RDNs are an integral part of the health care team and routinely provide Medical Nutrition Therapy (MNT) to medically complex patients. MNT involves an in-depth individualized nutrition assessment and reassessment, where duration and frequency of care are determined using the Nutrition Care Process to manage and treat disease. This can include nutritional diagnostics, therapy, and counseling services for the purpose of disease management which are furnished by a registered dietitian nutritionist or qualified nutrition professional.³

The Academy believes children with disabilities who are eligible for Medicaid deserve access to comprehensive and quality health care. Given the complexity and nuances that many pediatric chronic conditions present, it is essential that children with disabilities who are eligible for Medicaid have access--regardless of state lines--to medical and health care teams that are specifically trained to provide and manage care for those unique conditions. The Academy appreciates the opportunity to offer input below on barriers and best practices encountered by Medicaid-eligible patients when receiving care from out-of-state providers.

¹ The Academy has approved the optional use of the credential “registered dietitian nutritionist (RDN)” by “registered dietitians (RDs)” to more accurately convey who they are and what they do as the nation’s food and nutrition experts. The RD and RDN credentials have identical meanings and legal trademark definitions.

² Commission on Dietetic Registration <https://www.cdrnet.org/certifications/board-certification-as-a-specialist-in-pediatric-nutrition>. Accessed February 25th, 2020.

³ 42 U.S.C. 1395(x)(vv)(1)

A. Impact of Nutrition on Medically Complex Pediatric Patients

It is well established that pediatric patients with medically complex conditions require increased medical and long-term care services related to either intellectual, developmental, physical disabilities, and/or mental health disabilities. The cost associated with providing care for these individuals is significantly more than age-matched counterparts. The Kaiser Foundation reported since 2013, children who qualified for Medicaid through the disability pathway had an overall spend seven times that of children who qualified for Medicaid through a different channel. Their report further estimates that nearly 18% (13.3 million) of U.S. children have special health care needs. Medicaid, CHIP and other public health insurance programs cover nearly half (47%) of children with special health care needs. Public insurance, including Medicaid, is the sole source of coverage for 39% of these children.⁴

According to the Academy's 2015 position statement on "Nutrition Services for Individuals with Intellectual and Developmental Disabilities (IDD) and Children and Youth with Special Health Care Needs (CYSHCN)," nutrition issues facing these individuals include, but are not limited to, oral health care, mealtime assistance, dysphagia, enteral feedings, medication usage, and wellness. Deficits in any of these areas place these individuals at a higher risk for complex and chronic diseases and health-related problems. Examples of IDD and CYSHCN pediatric patient populations who are at or often present with significant higher nutritional risks include: children with autism spectrum disorder, cerebral palsy, gastro-intestinal disorders, cancer, congenital heart disease, cystic fibrosis, chromosomal disorders such as Down syndrome, neurological disorders, genetic or inherited metabolic disorders, orofacial cleft, Prader-Willi syndrome, and spina bifida. They require continued management of health conditions such as monitoring for weight gain and growth (malnutrition, failure to thrive, growth retardation), poor feeding skills, metabolic or congenital disorders, drug-nutrient interactions, and dependence on nutrition support measures such as enteral or parenteral nutrition.⁵ Access to consistent, timely and cost-effective nutrition interventions and monitoring will help to promote health maintenance and a reduction in risk associated comorbidities; thus helping to achieve functional, cognitive, physical growth, and developmental goals that may prevent more invasive, expensive, and avoidable treatment, comorbid conditions and associated costs. **The Academy recommends that nutrition services should be provided in a manner that is interdisciplinary, family-centered, community based, and culturally competent.**⁵

B. Nutrition-Related Care Coordination

Providing care for children with medically complex conditions is challenging, particularly when the health care required to meet children's needs crosses state lines. Lack of consistent coverage and recognition of medically necessary nutrition services provided by RDNs from state-to-state poses further delays in the child's access to and delivery of nutrition care. During hospital admissions or outpatient visits, nutrition regimes (enteral, parenteral or supplemental) are often adjusted to reflect changes to nutrition and medical status. Once feeding regimes change, particularly as it relates to

⁴ Kaiser Family Foundation: June 2019 Issue Brief. Available at <https://www.kff.org/medicaid/issue-brief/medicaids-role-for-children-with-special-health-care-needs-a-look-at-eligibility-services-and-spending> Accessed on February 25th 2020.

⁵Ptomey, Lauren T. et al "Position of the Academy of Nutrition and Dietetics: Nutrition Services for Individuals with Intellectual and Developmental Disabilities and Special Health Care Needs," *J Acad Nutr Diet* 2015; 115:593-608.

pediatric Medicaid patients, multiple additional steps are needed to ensure that the recommended, medically necessary changes made meet state-specific eligibility requirements. It is crucial that the patient's discharge nutrition care plan is monitored by RDNs in the community to oversee nutrition status and prevent an unnecessary hospital readmission.

Providing care solely within state lines does not necessarily translate into efficient and cost-effective care, particularly for those patients living near state lines. Regulations limiting care within one state often mean that individuals seeking specialty care may need to travel several hours from their home to receive services; when, in fact they might otherwise receive those same services closer to their homes with a shorter travel time when located in a neighboring state. An unforeseen consequence many families face when their children are admitted to the local hospital for an acute illness, is that they are not at the same hospital as their primary providers. This can cause undue anxiety and stress for the patient, family, and the medical team; there is also the risk for duplication of tests and services especially if facilities are not equipped or have limitations with access to electronic medical records. Additionally, increased travel and time away from home has financial burdens on a population that is already financially stressed. Not only are these families traveling much further than needed for medical care, but they are also incurring additional costs. There is a very real potential for loss of income as caregivers need to take days off work to travel to appointments; in addition, families incur costs of transportation, the need for overnight lodging, and meals away from home.

Regulatory practices that limit nutrition care—either by limiting access to nutrition services locally or by not having nutrition benefits under Medicaid --place unnecessary hardships on families already dealing with a pediatric patient with an increased complexity of care. Individuals dealing with chronic illnesses or conditions develop a level of trust with their medical team- this team can involve multiple sub-specialties. This is especially true for families caring for children with special health care needs particularly as it relates to complexities of feeding and nourishing a child. A common concern, and a point of confusion for providers and patient families alike, is which medical professional or specialty is responsible for the care and management of the MNT. This stems from the lack of access to qualified nutrition professionals which has resulted in families and providers deferring to the specialty clinics for management of issues that could be handled locally or in the primary care setting. For example, monitoring growth and nutrition intake is a very important outcome in the pediatric population, because a child who does not grow well may have difficulty attaining milestones or may even experience a postponement of a medical procedure. Timely and appropriate access to a local RDN who can critically assess growth and adjust the nutrition plan of care leads to more timely service and overall better patient outcomes. On the other hand, a benefit that limits or does not provide coverage for nutrition services is problematic. Routine follow-up and nutrition care provided by a qualified nutrition professional is a critical part of any health care team treating children with medically complex conditions to ensure that growth and nutrition goals are met. It is well documented that adequate nutrition - the provision of appropriate calories, protein, fats, and vitamins/minerals - is crucial in the first 1000 days (conception through age 2 years) to support a child's neurodevelopment and future mental health. Failure to provide sufficient nutrition during this time of brain development may lead to

lifelong deficits-even with subsequent repletion⁶. Variable access to nutrition care has led to sporadic coverage and increased the risk that nutrition-related imperatives, such as growth monitoring, tube feeding adjustments, and medication-nutrient monitoring, be delayed or all together missed.

C. Network Adequacy

This RFI raises a bigger concern about overall access to Medical Nutrition Therapy. Medicaid's benefit package **does not require** coverage for nutrition services (MNT), thus access to nutrition care is dependent on several factors, including state definitions of medically necessary services. There are significant gaps in care in the pediatric Medicare, Medicaid, and CHIP populations, including nutrition services available for pediatric patients with medically complex conditions. RDNs may provide MNT for children deemed to be at "nutritional risk" via the Early Periodic Screening, Diagnosis and Treatment program when nutrition intervention is determined to be medically necessary per state guidelines, and may also provide MNT for other pediatric populations in states that have added benefits for nutrition counseling. Uncertainty and inconsistency of coverage and regulatory barriers for nutrition services across state lines lead to delay in care and increased financial burdens for families, and increased workload for specialty clinic staff. In other words, **current Medicaid policies present barriers to patient access to medically necessary MNT**. Ideally, Medical Nutrition Therapy would be a Mandatory Benefit for Medicaid beneficiaries. Recognizing that would require legislation, **the Academy strongly urges Medicaid to specifically list Medical Nutrition Therapy on the list of Optional Benefit for states as an important step toward ensuring more consistent access across state lines to MNT provided by RDNs**.

D. The Registered Dietitian Nutritionist

The Academy is appreciative of CMS's recognition of the role nutrition therapy plays in the care of individuals with special health care needs. Sections 1945A (i)(6) of the Affordable Care Act, provides a list of providers that may be included as members of the health care team; both dietitians and nutritionists⁷ are listed as separate members of the team. While this nuance may appear arbitrary, the implications are quite broad as it relates to provision of MNT for complex medical conditions. The key difference between the RDN and a nutritionist lies in the depth, scope, length, and type of formal education and training received. The term nutritionist is not regulated in most states, so there is not a standard of education, supervisory practice or examination requirement for an individual to use or practice as a nutritionist. The Registered Dietitian Nutritionist has earned a minimum of a bachelor's degree from a program, approved by the Academy's Accreditation Council for Education in Nutrition and Dietetics, and has completed an accredited, supervised practice program (minimum 1000 hours) in diverse settings such as health-care facilities, community agencies and foodservice corporations. RDNs are also required to pass a standardized national examination administered by the Commission on Dietetic Registration and are required to complete continuing professional education to maintain registration.⁸ This process differentiates the rigorous credential requirements and highlights that **all registered dietitians are nutritionists but not all nutritionists are registered dietitians**. The National

⁶ Schwarzenberg SJ, et al. Advocacy for Improving Nutrition in the First 1000 Days To Support Childhood Development and Adult Health. *Pediatrics*. 2018;141(2):e20173716

⁷ [Request For Information, Section I: Background](#)

⁸ [Commission on Dietetic Registration https://www.cdrnet.org/rd-eligibility](https://www.cdrnet.org/rd-eligibility). Accessed March 5, 2020

Academy of Medicine, formerly the Institute of Medicine, has identified the registered dietitian nutritionist as the **single identifiable group** of health-care professionals with standardized education, clinical training, continuing education and national credentialing requirements necessary to be directly reimbursed as a provider of nutrition therapy.⁹

The Academy strongly believes that RDNs must be part of any health home care team providing care to pediatric patients with complex medical conditions and special health care needs where management and treatment of MNT is considered a standard part of care based on clinical guidelines. The Academy strongly encourages CMS to recognize MNT as a key component of care for Medically complex pediatric beneficiaries with chronic conditions and improve access to RDNs as qualified providers of such services.

Conclusion

Thank you for your consideration of the information the Academy has provided to inform CMS's future rulemaking on addressing barriers and best practices in caring for Medicaid-eligible pediatric patients. The Academy looks forward to continued opportunities to work with CMS to help inform aspects of nutrition care of this vulnerable population and meet the needs of all stakeholders. Please do not hesitate to contact Jeanne Blankenship by phone at 202-775-8277 ext. 1730 or by email at jblankenship@eatright.org or Marsha Schofield at 312-899-1762 or mschofield@eatright.org.

Sincerely,



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⁹ [Institute of Medicine. 2000. *The Role of Nutrition in Maintaining Health in the Nation's Elderly: Evaluating Coverage of Nutrition Services for the Medicare Population*. Washington, DC: The National Academies Press. https://doi.org/10.17226/9741. Accessed on March 4, 2020](https://doi.org/10.17226/9741)