

September 16, 2020

Scientific Resource Center
Portland VA Research Foundation
3170 SW U.S. Veterans Hospital Road
Mail code: R&D 71
Portland, Oregon 97239

120 South Riverside Plaza
Suite 2000
Chicago, Illinois 60606-6995
800.877.1600

1120 Connecticut Avenue NW
Suite 460
Washington, D.C. 20036

Reference: Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs

Dear Scientific Resource Center Staff:

The Academy of Nutrition and Dietetics (the “Academy”) appreciates the opportunity to submit these comments to the Agency for Healthcare Research and Quality relative to its August 27, 2020 request for comment on the Key Questions for its research project: *Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs*. Representing more than 107,000 registered dietitian nutritionists (RDNs),¹ nutrition and dietetics technicians, registered, and advanced degree nutritionists, the Academy is the largest association of food and nutrition professionals in the world and is committed to a vision of the world where all people thrive through the transformative power of food and nutrition. Every day our members provide medical nutrition therapy for patients with many diagnoses, including children and adults with special health care needs.

The Academy supports this evidence review to further define the state of science and improve care for this highly vulnerable population. We offer the below comments and suggestions to enhance the utility of the planned review and especially to improve awareness of the importance of effective data exchange as well as the need for reimbursement coverage for underserved populations.

I. The Importance of Data Exchange

In individuals with special health care needs, multiple risk factors requiring nutrition intervention by an RDN may be present, “including growth alterations (*e.g.*, failure to thrive, obesity, or growth retardation), metabolic disorders, poor feeding skills, drug-nutrient interactions, and sometimes partial or total dependence on enteral or parenteral nutrition.”² Therefore, it is critical that the RDN’s notes are effectively transmitted and available to successive care settings and providers.

Accordingly, the Academy participates in IT standards development by collaborating with organizations, such as Health Level 7 (HL7). One of these IT standards is the Transitions of Care

¹ The Academy 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 Ptomey LT, Wittenbrook W. 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(4):593-608. doi:10.1016/j.jand.2015.02.002

Technical Implementation Guide. The purpose of this initiative is to make available a technical guidance manual for health IT vendors (specifically those who develop electronic health records) and others to ensure a standardized approach when exchanging data about care process data across care settings.³ This means data from the RDN's nutrition notes can be included seamlessly in a patient transfer between settings. For this reason, the Academy suggests adding a question specifically about the potential impacts of poor data exchange between electronic health records, which may fit within Key Questions 1 and 3.

II. Care Quality Is Dependent on Financial Access

Quality of care begins with access--both physical as well as financial. To this end, one of our members reports:

Many of my patients have Medicaid for their insurance. Unfortunately, the reimbursement for medical nutrition therapy is abysmal or nonexistent for patients on Medicaid. The all-too-common scenario that I see in practice is a child who has been cared for by me or my colleagues for years transitioning to no nutrition provider once they become an "adult." Because they have reached an arbitrary age, their nutritional needs do not dissipate. These children are often profoundly neurologically impaired and exclusively gastrostomy tube fed. Their nutritional needs have been carefully assessed and managed for their entire lives and then once they are an adult they are transitioned to a primary care physician with no [RDN] on staff. The simple reason for lack of a Registered Dietitian on staff is due to insufficient reimbursement. It is very disheartening to care for a child for years and then essentially hav[ing] to say to the family "you're on your own" with managing the tube feeds because of inadequate monetary support from insurance. The physicians that these patients are transitioned to are also put in a precarious position of trying to manage nutrition support, an area [in which] they have received little if any formal training. If transition of care is ever going to improve, the root cause of the issue, reimbursement, must be addressed.

Accordingly, the Academy recommends adding one or more questions specifically focused on Medicaid patients and the impacts of being a Medicaid participant in a care transition, including effectiveness and outcomes, provider access and geographic differences.

III. Other Suggestions for Key Questions

Regarding Key Questions 1, 2, and 3:

Outcomes: Consider adding questions comparing the outcomes grouped by length of time post-transition (*e.g.*, 0-6 months, 6-24 months, and more than two years post-transition).

³ HL7 CDA® R2 Implementation Guide: C-CDA R2.1 Supplemental Templates for Nutrition, Release 1 - US Realm. http://www.hl7.org/implement/standards/product_brief.cfm?product_id=478

Regarding Key Questions 1a, 2a, and 3a:

Outcomes: Implementation strategies and Communication Tools: Consider including in analysis grouping outcomes by goal targeted in the Got Transition program, such as Goal 1: To improve the ability of youth and young adults with and without special health care needs to manage their own health care and effectively use health services; and Goal 2: To ensure an organized process in pediatric and adult health care practices to facilitate transition preparation, transfer of care, and integration into adult-centered health care. The adult health system may not have the capacity or skillset to provide the level of care needed by youth with special health care needs who transition to adult providers.⁴ The review may benefit from hypothesizing a higher statistical significance or clinically meaningful change from elements targeted towards self-empowerment. However, even advocating for self may be limited by the adult care provision framework.

Regarding Key Questions 1b, 2b and 3b:

Population: patient subgroups: consider including status based on patient's degree of independence (independent, under guardianship, emancipated), living situation (parent, foster, intermediate care facility, long term care facility, homeless, etc.), and patient age up to at least 23 years or as long as covered by one's parents' health insurance (although currently not defined in the proposal).

Regarding Contextual Question 6:

Consider specifying the various types of care providers for which recruitment strategies are sought, such as RDNs, care coordinators, occupational and physical therapists, speech language pathologists, social workers, and other specialists. For example, it may be far more challenging to identify a provider to manage long-term nutrition support especially outside of specialized care settings such as oncology programs.

The Academy appreciates your consideration of our comment for the *Transitions of Care from Pediatric to Adult Services for Children with Special Healthcare Needs* review. Please contact either Jeanne Blankenship at 312-899-1730 or by email at jblankenship@eatright.org or Mark Rifkin at 202-775-8277 ext. 6011 or by email at mrifkin@eatright.org with any questions or requests for additional information.

Sincerely,


Jeanne Blankenship, MS, RDN
Vice President
Policy Initiatives and Advocacy
Academy of Nutrition and Dietetics


Mark E. Rifkin, MS, RDN
Manager
Consumer Protection and Regulation
Academy of Nutrition and Dietetics

⁴ LoCasale-Crouch J, Johnson B. Transition from pediatric to adult medical care. *Adv Chronic Kidney Dis.* 2005 Oct;12(4):412-7. doi: 10.1053/j.ackd.2005.07.004.