

# Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs

## Executive Summary



### Main Points

- With only a single exception that showed no benefit, we found that for all outcomes and interventions the evidence was insufficient to draw conclusions because the uncertainty of evidence was too high. Insufficient evidence does not mean that the intervention is of no value to children with special healthcare needs (CSHCN).
- Transition clinics may not improve hemoglobin A1C levels at 12 or 24 months in youth with type 1 diabetes mellitus compared with youth who received usual care (low-strength evidence).
- While significant barriers impede implementation of interventions, some approaches to reduce these barriers in future interventions include dedicating time and resources to support transition planning, developing a workforce trained to care for the needs of this population, and creating structured processes and tools to facilitate the transition process.
- No globally accepted definition exists for effective transition of care from pediatric to adult services for CSHCN, nor is a single measure or set of measures consistently used to evaluate effectiveness of transitions of care.
- The literature identifies only a limited number of available trainings or other implementation strategies, generally focused on specific clinical specialties in targeted settings.
- No included studies measured the effectiveness of providing linguistically and culturally competent healthcare for CSHCN.
- Trainings and interventions to prepare pediatric patients and their families for transitioning CSHCN to adult care vary considerably in their components, structures, and processes.



## Background and Purpose

In the United States, nearly 20 percent of children under age 18 have special healthcare needs,<sup>1</sup> defined as having or being at increased risk for chronic physical, developmental, behavioral, or emotional conditions—and this population is growing.<sup>2</sup> Often, these children will require lifelong health-related services. Between 2011 and 2017, approximately 4.5 million CSHCN ages 12–18 transitioned from pediatric to adult healthcare providers.<sup>3</sup> Such transitions are often difficult and can lead to gaps in care, adverse health outcomes, and frustration for patients and families.<sup>3-5</sup>

This review sought to evaluate the effectiveness and harms of (1) healthcare interventions targeted toward CSHCN and their families/caregivers, (2) strategies to implement interventions for healthcare transitions including provider-related training, and (3) tools to facilitate communication between pediatric and adult providers. Further, this review discusses definitions and measures for effective healthcare transition for CSHCN, training and implementation strategies available to prepare pediatric patients, families, and healthcare providers for transitioning to adult medical care (including culturally competent approaches), and strategies to increase the availability of adult care providers in the transition process. The target audience for this review includes not only CSHCN, their families, caregivers, and providers, but also policymakers, all of whom rely upon current evidence for interventions to support healthcare transitions for CSHCN. The National Cancer Institute will use our findings to help develop its own independent recommendations regarding future research and funding.



## Methods

The methods for this systematic review follow the Agency for Healthcare Research and Quality Methods Guide for Effectiveness and Comparative Effectiveness Reviews. See the review protocol (<https://effectivehealthcare.ahrq.gov/products/transitions-care-pediatric-adult/protocol>) and the full report of the review for additional details. We searched Ovid MEDLINE®, Ovid Embase®, the Cochrane Central trials (CENTRAL) registry, and CINAHL® to identify randomized controlled trials and quasi-experimental designs published and indexed in bibliographic databases through September 2021.



## Results

We identified 9,549 unique references of which 440 represented empirical research using quantitative or qualitative method; of these, we categorized 154 as describing or examining a care transition intervention with enough detail to be potentially eligible for inclusion in any of the Key Questions. Of the 154 potentially eligible studies, which comprised 16 major disease categories, 96 met comparator criteria to undergo risk of bias assessment; however, only nine were assessed as low or medium risk of bias and included in our analytic set. We did not combine data quantitatively due to variability of interventions, comparison groups, outcomes measured, and study timing.

Populations in the studies included those diagnosed with conditions common among CSHCN such as diabetes mellitus, cystic fibrosis, congenital heart disease, inflammatory heart disease, juvenile idiopathic arthritis, cancer, and others. Interventions were implemented across the age range eligible for transition, with some studies conducted in early adolescence (e.g., 14–15) and others in young adult populations (e.g., 19–23). Care interventions ranged widely, from transition programs and clinics to educational workbooks and care coordinators. Intervention approaches varied both within and across disease conditions. Transition outcomes from these studies included measures ranging from transition readiness to ongoing care. Studies also used a diverse set of outcome measures to evaluate intervention effects. Most interventions were conducted within specialty settings, transition clinics, and integrated health systems, with a notable lack of studies in primary care settings.

Low-strength evidence showed transition clinics may not improve hemoglobin A1C levels at 12 or 24 months in youth with type 1 diabetes mellitus compared with usual care.<sup>6,7</sup> For all other interventions and outcomes, we found the evidence insufficient to draw conclusions. Insufficient evidence does not mean that the intervention is of no value to CSHCN. Rather, it means that, due to the uncertainty of the evidence, we cannot draw meaningful conclusions at this time.

Significant barriers impede the implementation of interventions, tools, and trainings for transitioning CSHCN from pediatric to adult services. Examples of barriers include challenges with the adaptability of interventions, complex social challenges for patients (e.g., insurance, employment), lack of dedicated resources to support transitions, lack of care team training, and lack of a structured transition processes. The interventions and trainings identified by this literature set vary considerably in their components, structure, and processes. Additionally, no globally accepted definition exists for effective care transitions for CSHCN; instead, current definitions encompass a broad range of clinical and patient-centered factors. Similarly, no single measure or set of measures is used in this body of research. Even within a single domain, such as transition readiness or quality of life, multiple measures are used. Further, the literature has identified only a limited number of available trainings and other implementation strategies, generally focused on specific clinical specialties in targeted settings, and none of the included studies measured the effectiveness of providing linguistically and culturally competent healthcare care for CSHCN who are transitioning from pediatric to adult services. CSHCN, their caregivers, providers, and other stakeholders may initially draw from evidence and best practices outside of this population by using a few systematic reviews and organizational trainings that inform culturally and linguistically competent healthcare in general populations and settings, but these are not specific to CSHCN.



## Limitations

We applied a broad definition of care interventions, implementation strategies, and trainings in order to enlarge the scope of studies and thus better understand the range of interventions used in this population. However, we did not include care interventions for transitioning CSHCN to non-healthcare adult services. Educational and vocational

interventions may contribute meaningfully to successful transitions for CSHCN, but were beyond the scope of our review.



## Implications and Conclusions

Despite identifying a diverse range of intervention components and implementation strategies, our review was unable to provide a synthesized robust evidence base for which interventions work for effectively transitioning CSHCN from pediatric to adult medical care. The lack of sufficient evidence provides no clear answers for CSHCN, their families, caregivers and providers, or for funders and policymakers. Healthcare transitions are complex and multi-dimensional; however, stakeholders rely on institutional policies and professional organization position statements to determine whether to disseminate or implement specific interventions in their populations or care settings as the field continues to emerge.<sup>8</sup>

Many aspects of interventions for CSHCN need more thorough evaluation. Importantly, we found that study designs used in this literature lacked the necessary rigor to provide a solid evidence base. Future research for this population is crucial to generate quality evidence—not only to understand the most effective interventions, but also to understand how these interventions support adaptability across diverse disease conditions and sub-populations (e.g., race/ethnicity, sex/sexual orientation, socioeconomic status, and care setting).



## References

1. HRSA Maternal and Child Health. Children and Youth with Special Health Care Needs. <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs#ref1>. Accessed on April 30, 2021.
2. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998 Jul;102(1 Pt 1):137-40. doi: 10.1542/peds.102.1.137. PMID: 9714637.
3. McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics*. 2013 Jun;131(6):1090-7. doi: 10.1542/peds.2012-3050. PMID: 23669518.
4. Sadak KT, Dinofia A, Reaman G. Patient-perceived facilitators in the transition of care for young adult survivors of childhood cancer. *Pediatric Blood and Cancer*. 2013;60(8):1365-8. doi: 10.1002/pbc.24494. PMID: 369155822.
5. Bloom SR, Kuhlthau K, Van Cleave J, et al. Health care transition for youth with special health care needs. *J Adolesc Health*. 2012 Sep;51(3):213-9. doi: 10.1016/j.jadohealth.2012.01.007. PMID: 22921130.
6. Spaic T, Robinson T, Goldbloom E, et al. Closing the gap: Results of the multicenter Canadian randomized controlled trial of structured transition in young adults with type 1 diabetes. *Diabetes Care*. 2019;42(6):1018-26. doi: 10.2337/dc18-2187. PMID: 2002045490.
7. White M, O'Connell MA, Cameron FJ. Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. *The Lancet Child & Adolescent Health*. 2017. doi: 10.1016/s2352-4642(17)30089-5. PMID: 30169183.

8. Quinn S, Chung R, Kuo A, Maslow G, et al. Transition to adulthood for youth with chronic conditions and special health care needs. *J Adolesc Health*. 2020: 631-634. doi.org/10.1016/j.jadohealth.2020.02.006

## Full Report

Parsons HM, Abdi HI, Nelson VA, Claussen A, Wagner BL, Sadak KT, Scal PB, Wilt TJ, Butler M. Transitions of Care From Pediatric to Adult Services for Children With Special Healthcare Needs. Comparative Effectiveness Review No. 255. (Prepared by the Minnesota Evidence-based Practice Center under Contract No. 75Q80120D00008.) AHRQ Publication No. 22-EHC027. Rockville, MD: Agency for Healthcare Research and Quality; May 2022. DOI: <https://doi.org/10.23970/AHRQEPCCER255>. Posted final reports are located on the Effective Health Care Program [search page](#).

