



## Strengthen the Evidence Base for Maternal and Child Health Programs

# Health Care Transition

**Health care transition (HCT)** is one of 15 Maternal and Child Health (MCH) National Performance Measures (NPMs) for the State Title V MCH Services Block Grant to States program. The goal of **NPM 12: Transition** is to increase the percent of adolescents with or without special health care needs (SHCN) who have received services to prepare for the transition from pediatric to adult health care. This evidence review highlights individual-level interventions that improve transitional care for youth and young adults, and spotlights changes needed at the program, policy, and systems levels to strengthen transitions to adult health care.

The full report and supplemental implementation resources can be found at: [www.mchevidence.org/documents/reviews/npm-12-transition.pdf](http://www.mchevidence.org/documents/reviews/npm-12-transition.pdf), and [www.mchevidence.org/tools/npm/12-transition.php](http://www.mchevidence.org/tools/npm/12-transition.php). This review was conducted as part of Strengthen the Evidence Base for MCH Programs, a Health Resources and Services Administration (HRSA)-funded initiative that aims to support states in their development of strategies to promote the health and well-being of MCH populations.

## Background

The transition to adult health care is important for all youth and young adults, even if they do not have SHCN, in order to maximize lifelong functioning and well-being through the provision of high quality, developmentally appropriate health care services that continue uninterrupted from adolescence into adulthood (American Academy of Pediatrics (AAP) et al.,

2002; Cooley et al., 2011). HCT is a structured process that supports youth and young adults as they transition to adulthood and adult-oriented care (Schmidt et al., 2020).

Research has shown that without a structured transition process, youth are more likely to have problems with medical complications (Foster, 2015; Majumdar, 2013; Wafa & Nakhla, 2015; Yeung et al., 2008), limitations in health and well-being (Chaudhry et al., 2013; Maslow et al., 2013), difficulties in treatment and medication adherence (Annunziato et al., 2013), discontinuity of care (Bohun et al., 2016; Luque et al., 2017; Montano & Young, 2012; Szymanski et al., 2017; Wojciechowski et al., 2002), preventable emergency department and hospital use (Shaw et al., 2007; Shepard et al., 2018), and higher costs of care (Barr et al., 2017; Cohen et al., 2016; Lochridge et al., 2013; Mosquera et al., 2014).<sup>1</sup>

The HCT process includes components related to planning for transition, transfer assistance, and integration into adult-oriented care. Transition interventions consist of activities within each of these components, as well as activities that indicate use of care coordination (Schmidt et al., 2020). Outcomes tend to focus on the “triple aim” domains of population health, patient experience of care, and utilization and cost of care (Schmidt et al., 2020). Successful HCT efforts are needed to raise awareness among youth, young adults, and their families that maintaining health and continuity of care are central to the attainment of broader adult goals (White et al., 2018).

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<sup>1</sup> <https://www.healthychildren.org/English/news/Pages/HealthCare-Transitions-For-Youth-and-Young-Adults.aspx>

**National survey data.** NPM 12 is measured through data collected from the National Survey of Children’s Health (NSCH). It is funded and directed by the HRSA Maternal and Child Health Bureau (MCHB) and fielded annually by the United States (U.S.) Census Bureau. Parents and/or caregivers complete the survey, and NPM 12 is calculated from multiple questions. The most recent data from the 2017-2018 survey revealed that nationwide 15.3% of youth received services necessary for transition to adult health care (and, conversely, 84.7% did not receive the necessary services).<sup>2</sup> Considering SHCN status, 18.9% of youth with SHCN (YSHCN) received services necessary for transition to adult health care versus 14.2% of non-YSHCN.<sup>3</sup>

**Transition Evidence-based or informed Strategy Measures (ESMs).** Across the states and jurisdictions that chose transition as one of the NPMs, there are 65 ESMs that have been developed by Title V agencies to monitor progress in advancing NPM 12. These ESMs fall into three categories:

- 14 measure activities directed to professionals (e.g., training activities, technical assistance),
- 35 measure activities directed to families and their children (e.g., outreach materials to families, family-to-family support, development of care coordination plans), and
- 16 measure activities related to systems-building (e.g., engagement of stakeholder groups, quality improvement initiatives, collaboration between systems of care).

Findings from this report—specifically the evidence-based and evidence-informed interventions identified—can be used by Title V programs as models to strengthen current strategies and improve ESMs or develop new measures to monitor progress for each of these categories.

Sixty-five ESMs currently focus on NPM 12. These can be organized by the levels of the “MCH Pyramid,” the conceptual service framework for the Title V MCH Block Grant program:<sup>4</sup>

- 49 measure activities related to public health services and systems (foundational level of the pyramid),

- 15 measure strategies related to enabling services (middle level of the pyramid), and
- 1 Title V program is currently funding strategies related to direct services in regard to improving transition.

The MCH Evidence Center uses Results-Based Accountability (RBA)<sup>5</sup> as a conceptual framework to track how ESMs are measured. This framework consists of increasing levels of measurement across four quadrants (Quadrant 1 being the simplest measurement and Quadrant 4 being the most complex). States and jurisdictions should focus efforts in expanding how they measure programs by moving up the RBA quadrant scale.<sup>6,7</sup>

- 47 current transition ESMs measure effort:
  - 22 ESMs fall within Quadrant 1 (measuring the quantity of agency effort) and answer the question “what did we do?” (e.g., counts and “yes/no” activities).
  - 25 ESMs fall within Quadrant 2 (measuring the quality of effort) and answer the question “how well did we do it?” (e.g., reach, quality of materials, satisfaction of intervention).
- 18 current transition ESMs measure effect (e.g., increases in skills/knowledge, change in behavior or circumstance):
  - 1 ESM falls within Quadrant 3 (measuring the quantity of the effect) to answer the question “is anyone better off?” (e.g., numbers of providers with increased knowledge).
  - 17 ESMs fall within Quadrant 4 (measuring the quality of the effect) and answer “how are they better off?” (e.g., percentages of families whose self-efficacy improved).

## Methods and Results

The systematic review by Schmidt et al. (2020) focused on outcomes of pediatric to adult HCT interventions and provided the foundation for this evidence review. Nineteen articles were pulled from Schmidt et al. (2020), and additional peer-reviewed studies from 2019-2020 were identified by searching online databases. This report categorized interventions along an evidence continuum from *evidence against* (least favorable) to *scientifically rigorous*

<sup>2</sup> <https://www.childhealthdata.org/browse/survey/results?q=7121&r=1>

<sup>3</sup> <https://www.childhealthdata.org/browse/survey/results?q=7121&r=1&g=731>

<sup>4</sup> The conceptual framework for the services of the State Title V MCH Block Grant is envisioned as a pyramid with three tiers of services and levels of funding that provide comprehensive services. A goal is to “move on down” the pyramid with more states and jurisdictions engaging in public health services and systems. See <https://mchb.tvisdata.hrsa.gov/Glossary/Glossary> for a graphical representation of the pyramid.

<sup>5</sup> RBA is described in the RBA Implementation Guide <http://raguide.org/index-of-questions/>

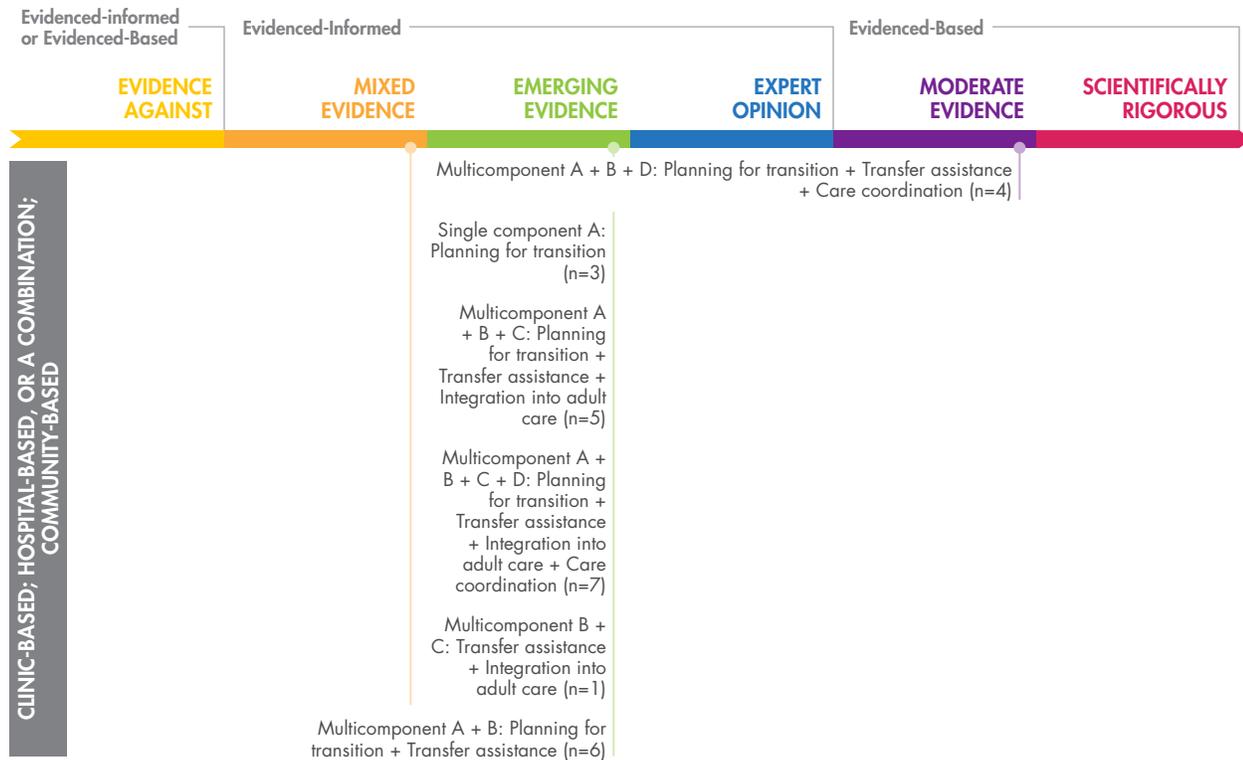
<sup>6</sup> ESM Review & Resources: National Summary <https://www.mchevidence.org/documents/ESM-Review-National-Summary.pdf>

<sup>7</sup> To search the MCH Library to find state ESMs, visit: <https://www.mchlibrary.org/evidence/state-esms.php>

(most favorable). Each individual study was rated and intervention types were also grouped and rated as a category to speak to the public health impact.

In total, 26 studies met either Got Transition’s or the MCH Evidence Center’s inclusion criteria. These studies utilized strategies to increase the percent of adolescents who received

services to prepare for the transition from pediatric to adult health care. The studies were implemented in clinic- or hospital-based settings, or a combination of both, as well as community-based settings, such as a mental health services agency or in home. The target audience for all studies were YSHCN. The studies (n=26) were categorized by HCT components and placed along the evidence continuum below.



**Key findings.** Overall, 8 key findings emerged from the analysis:

- Of the 26 included studies, pediatric-to-adult HCT interventions primarily occurred in clinic- (n=13; 50%) or hospital-based (n=6; 23%) settings, or a combination of both clinical and hospital settings (n=5; 19%). Two studies (n=2; 8%) were conducted in community-based settings. One study took place at a mental health services agency, and the other study occurred in the home.
- All included studies (100%) focused on youth with SHCN or chronic medical conditions (singular or multiple health conditions). The most frequently studied health conditions were Type 1 diabetes (n=6; 23%) and inflammatory bowel disease (n=6; 23%). No studies examined transition for non-YSHCN.
- The recommended HCT process includes components related to planning for transition, transfer assistance, and integration into adult-centered health care, as well as activities that indicated use of care coordination.
  - Most interventions were multicomponent (n=23; 88%) (e.g., A + B + C + D (planning for transition + transfer assistance + integration into adult care + care coordination)).
  - Twenty-three of 26 studies (88%) included transfer assistance.
  - Studies that looked at single-component interventions focused only on planning for transition (n=3; 12%).<sup>8</sup>
  - One of the 26 studies (4%) did not include planning for transition.

<sup>8</sup> Schmidt et al. (2020) excluded studies that only utilized one component. However, we included studies with “planning for transition” as a single component to highlight the continued focus on planning interventions.

4. Specific intervention activities were identified within each of the three components, as well as activities that indicated use of care coordination (Schmidt et al., 2020).
  - a. For transition planning, the most mentioned intervention activities were disease education/skill building (n=19; 73%); plan of care/medical summary/electronic medical information (n=16; 62%); and transition readiness/self-care skills assessment (n=10; 38%).
  - b. For transfer assistance, the most mentioned intervention activities were identifying an adult provider/scheduling assistance (n=15; 58%); letter of referral/coordination of referrals (n=13; 50%); communication between pediatrician and adult provider/joint pediatric and adult meetings (n=13; 50%); and transfer summary sent from pediatrician or shared with new adult provider (n=11; 42%).
  - c. For integration into adult care, the most mentioned intervention activities were scheduling assistance/follow-up with patient after adult first visit/monitoring appointments (n=10; 38%); ongoing care (n=5; 19%); and patient/family feedback on transition process (n=4; 15%).
  - d. Eleven of 26 studies (42%) gave an indication of use of care coordination.
5. HCT interventions tend to result in positive outcomes related to the triple aim domains of **population health** (improvement in adherence to care, disease-specific measures, self-care skills, quality of life, and self-reported health); **patient experience of care** (increase in satisfaction and reduction in barriers to care); and **utilization** (decrease in time between last pediatric and first adult visit, increase in adult ambulatory visits, and decrease in hospital admissions and length of stay).
  - a. Most of the positive outcomes were related to population health (n=23; 88%), followed by improvements in utilization and cost of care (n=18; 69%). Patient experience of care was measured in 6 of the 26 studies (23%).
  - b. One study (4%) measured all domains of the triple aim framework.
  - c. Across all domains, 25 of the studies (96%) reported positive effects in favor of the intervention, with these same 25 studies (96%) also reporting statistically significant findings.
6. The ability to compare studies was limited due to variability in the intervention design, comparison group, setting, and outcome measures. Although similar studies were grouped into clusters by HCT component, no two studies were the same with regards to intervention activities. It was also difficult to figure out why a study with the same general configuration of components led to positive results, while others reported mixed results. One possible explanation could be intervention fidelity and/or reach into the study population. However, the “why” remained elusive, despite a deep dive into the intervention types.
7. Of the 26 studies included in this evidence review:
  - a. The rating of *scientifically rigorous* was not given to any studies.
  - b. The rating of *moderate evidence* was given to 5 studies (19%).
  - c. The rating of *emerging evidence* was given to 14 studies (54%).
  - d. The rating of *mixed evidence* was given to 7 studies (27%).
  - e. The rating of *evidence against* was not given to any studies.
8. Overall, the evidence base for structured HCT interventions is accumulating.
  - a. There was primarily *emerging evidence* regarding interventions to improve pediatric-to-adult HCT.
  - b. The highest level of evidence (*moderate evidence*) was found for individual studies across different component configurations.
    - i. Multicomponent A + B + C (planning for transition + transfer assistance + integration into adult care) (n=2)
    - ii. Multicomponent A + B + D (planning for transition + transfer assistance + care coordination) (n=2)
    - iii. Multicomponent A + B + C + D (planning for transition + transfer assistance + integration into adult care + care coordination) (n=1)
  - c. The multicomponent A + B + D (planning for transition + transfer assistance + care coordination) intervention category (n=4) yielded the highest intervention type evidence rating (*moderate/emerging evidence*).
  - d. Title V programs interested in improving HCT are encouraged to review these effective studies.

## Discussion and Implications

Over the last decades, researchers have demonstrated the importance of planning for the transition to adulthood, especially for youth with disabilities and SHCN. The studies included in this review demonstrate that multicomponent interventions are more prominent and show value in improving transitions to adult health care. The studies also demonstrate that a structured HCT process results in positive outcomes in the triple aim domains of population health, patient experience of care, and utilization.

**Youth without special health care needs.** Research demonstrates that it is important to prepare all adolescents for successful HCT. Without proper preparation, youth may be at risk for limited health literacy, overuse of emergency department services, high medical costs, and increased morbidity and mortality (Leung et al., 2019). Health care providers who care for youth should look at ways to incorporate transition as part of routine health care visits, including planning for time alone to prepare youth to manage their own health care (Lebrun-Harris et al., 2018). By listening to youth and focusing on their needs as they approach adulthood, providers can promote health care independence, identify barriers that prevent youth from taking ownership of their care, and set them up for success as adults (Schuiteman et al., 2020). Additional research is needed to overcome transition obstacles and to tailor interventions to help healthy and noncomplex youth during this vulnerable time of their lives.

**Future directions.** With the vast majority of U.S. youth not receiving transition preparation, shared accountability, effective communication, and care coordination are needed between pediatric and adult clinicians and systems of care (White et al., 2018). A multicomponent, structured HCT process can avoid a meandering path to adult health care or an abrupt transfer to a new system of care that could leave millions of adolescents floundering and without access to needed health services each year. A future investment is needed by public and private funders and systems of care to support more developmental evaluation studies and other more rigorous designs to assess the outcomes of structured transition planning, transfer, and integration interventions provided to a broader population of youth with and without chronic conditions (Schmidt et al., 2020).

## From Evidence to Action

This review is part of a series of scholarly works focused on each NPM to identify and describe evidence-based and informed strategies from peer-reviewed and grey literature. The 26 studies analyzed in this review provide an overview of the scientific literature that can inform Title V program design, implementation, and measurement to improve transitional care. If you are looking to build or strengthen transition efforts in your state or jurisdiction, moving “from evidence to action” can seem daunting. The MCH Evidence Center has developed a framework, tips, and resources to help you through the process. An NPM 12: Transition Toolkit is also available at <https://www.mchevidence.org/tools/npm/12-transition.php>. Email us with questions, comments, and requests for technical assistance at [mchevidence@ncemch.org](mailto:mchevidence@ncemch.org).

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