



Strengthen the Evidence Base for Maternal and Child Health Programs

NATIONAL
PERFORMANCE
MEASURE

12

Health Care Transition
Evidence Review



Lan T. Le, MPA
Wendy Wasman, MLS
Beth DeFrancis Sun, MLS
Rachel Hewett-Beah, MA, MSLS
Rachel Brady, PT, DPT, MS
Olivia Pickett, MA, MLS
Deborah F. Perry, PhD
John Richards, MA, AITP
National Center for Education in
Maternal and Child Health
Georgetown University

JULY 2020

Suggested Citation: Le, LT, Wasman, W, DeFrancis Sun, B, Hewett-Beah, R, Brady, R, Pickett, O, Perry, DF, Richards, J. *National Performance Measure 12 Health Care Transition Evidence Review*. Strengthen the Evidence Base for Maternal and Child Health Programs. National Center for Education in Maternal and Child Health. Georgetown University, Washington, DC. 2020.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U02MC31613, MCH Advanced Education Policy, \$3.5 M. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

TABLE OF CONTENTS

REPORT

EXECUTIVE SUMMARY	5
ACKNOWLEDGMENTS	11
INTRODUCTION	12
BACKGROUND	13
National Performance Measure	13
Evidence-based or Informed Strategy Measure	14
National Survey Data	16
Overview	18
History	23
Youth Without Special Health Care Needs	30
Systematic Reviews	31
METHODS	34
Databases and Search Terms	34
Inclusion and Exclusion Criteria	35
Screening Process	36
Grey Literature	38
Evidence Continuum	38
RESULTS	39
Characteristics of Studies Reviewed	40
Intervention Types and Components	40
Data Sources and Outcomes	43
Limitations	45
Evidence Rating and Evidence Continuum	45
Key Findings	48
DISCUSSION AND IMPLICATIONS	50
Data Trends	50
Highlights of Effective Intervention Studies	51
Examples of Promising Practices	53
Health Care Transition in State Title V Programs	55
Youth Without Special Health Care Needs	57
Implications for Practice	60
Health Systems and Policy Change to Support Health Care Transition	68
Research Gaps in Pediatric- to Adult-care Transition Evidence	70
Future Directions	71
FROM EVIDENCE TO ACTION	72
FIGURES AND TABLES	
FIGURE 1: Flow Chart of the Review Process and Results	75
FIGURE 2: Evidence Continuum	76
TABLE 1: Detailed Search Strategies	77
TABLE 2: Evidence Rating Criteria	78
TABLE 3: Study Characteristics	79
TABLE 4: Intervention Descriptions	83

TABLE OF CONTENTS

TABLE 5: Data Sources and Outcomes..... 92
TABLE 6: Limitations..... 102
TABLE 7: Intervention Types and Evidence Ratings 104
TABLE 8: Health Care Transition Components 105

APPENDIX A

Transition Policy Statement..... 107

REFERENCES

..... 113

EXECUTIVE SUMMARY

Overview. 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. Poor health during young adulthood has been shown to negatively impact academic and vocational outcomes for youth and young adults.¹ Further, over 90% of youth with SHCN (YSHCN) now live into adulthood; however, they are less likely than their non-disabled peers to complete high school, attend college, or to be employed.² 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.

Background. Adolescence is recognized as a critical developmental period of transition from childhood to adulthood (Hagan et al., 2017; Jaworska & MacQueen, 2015; Lebrun-Harris et al., 2018; National Research Council Institute of Medicine, 2009a). Increasingly, youth and young adults are being recognized as a vulnerable population, given high rates of behavioral health risks, susceptibility to emerging or worsening chronic medical conditions, and traditionally low use of health care (White et al., 2018). The transition to adult health care is important for all youth and young adults, even if they do not have special needs, 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 and young adults 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

¹ <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NPMDistribution>

² <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NPMDistribution>

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).³

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).

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 Health Resources and Services Administration’s Maternal and Child Health Bureau (HRSA 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).⁴ Considering SHCN status, 18.9% of YSHCN received services necessary for transition to adult health care versus 14.2% of non-YSHCN.⁵

Consensus statement and clinical reports. In 2002, the AAP, American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP)-American Society of Internal Medicine (ASIM) released a consensus statement on HCT for young adults with SHCN (AAP et al., 2002). This professional consensus called for specific transition activities beginning at age 12 years and continuing through young adulthood (ages 23-26) to optimize health and assist youth in reaching their full potential.

In 2011, a clinical report on transition was published as joint policy by the AAP/AAFP/ACP (Cooley et al., 2011). It provided practice-based guidance, including a step-by-step algorithm, on how to plan and implement better HCT for youth and integrated transition planning into the medical home and ongoing chronic care management. At the same time, the HRSA MCHB-funded National Health Care Transition Center (Got Transition) developed the **Six Core Elements of Health Care Transition**TM to align with the clinical report algorithm.⁶

³ <https://www.healthychildren.org/English/news/Pages/HealthCare-Transitions-For-Youth-and-Young-Adults.aspx>

⁴ <https://www.childhealthdata.org/browse/survey/results?q=7121&r=1>

⁵ <https://www.childhealthdata.org/browse/survey/results?q=7121&r=1&g=731>

⁶ Got Transition/Center for Health Care Transition Improvement is a cooperative agreement between the MCHB and The National Alliance to Advance Adolescent Health. The aim is to improve the transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families (<https://www.gottransition.org/about/index.cfm>).

The 2018 clinical report reaffirmed the 2011 report, called for transition planning to begin in early adolescence and continue into young adulthood, refined the previous algorithm, and promoted the application of the Six Core Elements, an evidence-informed, structured process for improving population health outcomes (White et al., 2018). The 2018 report highlighted the critical elements of preparation, transfer, and integration into adult care into the framework for improving HCT and the crucial role of adult clinicians in accepting and partnering with young adults in their health care.

The figure below describes the Six Core Elements approach and timeline for youth transitioning from pediatric to adult health care.⁷



Evidence-informed studies/strategies to improve transitions to adult health care. 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* (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.

⁷ <https://gottransition.org/six-core-elements/>



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

1. 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.
2. 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.
3. 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.
 - a. Most interventions were multicomponent (n=23; 88%) (e.g., A + B + C + D (planning for transition + transfer assistance + integration into adult care + care coordination)).
 - b. Twenty-three of 26 studies (88%) included transfer assistance.
 - c. Studies that looked at single-component interventions focused only on planning for transition (n=3; 12%).⁸
 - d. One of the 26 studies (4%) did not include planning for transition.

⁸ Schmidt et al. (2020) excluded studies that only utilized one component. However, for our review we included studies with “planning for transition” as a single component to demonstrate the continued focus by researchers on transition planning focused 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 evidence 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 HCT 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 adolescents and young adults 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. The final section of this document provides recommendations for intervention implementation strategies and recommendations for development of evidence-based or informed strategy measures (ESMs). This section also directs the reader to implementation resources, additional promising practices, and sample ESMs currently in use by Title V agencies with the goal of providing states a structured and practical approach to support integrating evidence into their work.

ACKNOWLEDGMENTS

We are grateful for the partnerships and collaborations that enabled us to complete this important evidence analysis review. In particular, we would like to extend a special thank you to the following individuals for their time, thoughtful guidance, and constructive feedback.

Cynthia Minkovitz, MD, MPP, Donna Strobino, PhD, and their research team at the Women’s and Children’s Health Policy Center at Johns Hopkins University (JHU) for their assistance during the transition of the initiative. The JHU team originally adapted the evidence continuum and created the report structure in collaboration with federal partners for the evidence analysis reviews.

Our project officer, Jessica Minnaert, MPH, and the Director of the Office of Epidemiology and Research, Michael Kogan, PhD, from HRSA MCHB for the consummate support and guidance. We are extremely grateful to the reviewers, Lydie Lebrun-Harris, PhD, MPH, Marie Mann, MD, MPH, and Keriann Uesugi, PhD, for their valuable perspectives and helpful comments to strengthen the final documents.

We are especially thankful for our partners at Got Transition, Margaret McManus, MHS, Patience White, MD, MA, FAAP, MACP, Annie Schmidt, MPH, and Samhita Ilango, MSPH, for providing generous guidance and feedback on our methodology, enthusiastically supporting our use of their systematic review as a roadmap, and sharing insightful thoughts and recommendations to improve the evidence review.

Margaret Stager, MD, Division Director of Adolescent Medicine, MetroHealth Medical Center, Cleveland, Ohio, for sharing her perspective as a health care provider caring for adolescents and young adults with real world examples of innovative practices being implemented to help improve the transition to adult health care.

Our colleague, Keisha Watson, PhD, for her help summarizing the evidence-based or informed strategy measures (ESMs) currently being used by states and jurisdictions to advance NPM 12.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U02MC31613, MCH Advanced Education Policy, \$3.5 M. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.

INTRODUCTION

Strengthen the Evidence Base for Maternal and Child Health Programs is 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 maternal and child health (MCH) populations in the United States (U.S.). This initiative, carried out through a partnership among the Georgetown University National Center for Education in Maternal and Child Health (NCEMCH), the National Maternal and Child Health Workforce Development Center (NMCHWDC) with assistance from the Association of MCH Programs (AMCHP), CityMatCH, and the Georgetown University Center for Child and Human Development (GUCCHD), was undertaken to facilitate implementation of the transformed State Title V MCH Services Block Grant to States program (hereafter referred to as the MCH Block Grant).⁹

One goal of the Strengthen the Evidence initiative is to conduct reviews that provide evidence of the effectiveness of possible strategies to address the National Performance Measures (NPMs)¹⁰ selected for the 5-year cycle of the MCH Block Grant program, beginning in fiscal year 2016. States select a minimum of five NPMs, according to their identified priority needs, and incorporate evidence-based or evidence-informed strategies to achieve improvement for each NPM selected.

According to HRSA's Maternal and Child Health Bureau (HRSA MCHB), the 15 NPMs were determined using the following criteria:¹¹

- There is a large investment of resources by states on MCH issues;
- The measure is considered to be modifiable by Title V activities;
- States could delineate measurable activities to impact the measure;
- Significant disparities are shown to exist in MCH population groups;
- Research indicates that the condition or activity has large societal costs; or
- Research indicates that health promotion of the behaviors, practices, or policies has resulted in improved outcomes.

Performance Measure 12 Transition is the percent of adolescents with or without special health care needs (SHCN), ages 12 through 17, who have received services to prepare for the transition

⁹ <https://HRSA.MCHB.tvিসdata.hrsa.gov/uploadedfiles/Documents/blockgrantguidance.pdf>

¹⁰ The first NPMs for MCH were instituted in 1997. The three-tiered performance measurement system includes national outcome measures (NOMs), NPMs, and evidence-based/informed strategy measures (ESMs) (Kogan et al., 2015).

¹¹ <https://mchb.tvিসdata.hrsa.gov/PrioritiesAndMeasures/NationalPerformanceMeasures>

from pediatric to adult health care services. Health care transition (HCT) is a structured process that supports youth and young adults as they transition to adulthood and adult-oriented care (Schmidt et al., 2020). SHCN is defined as “*chronic physical, developmental, behavioral, or emotional condition(s) that require health and related services of a type and amount beyond that which is generally required*” (Cruz et al., 2015).¹² Poor health during young adulthood has been shown to negatively impact academic and vocational outcomes for youth and young adults.¹² Further, over 90% of youth with SHCN (YSHCN) now live into adulthood; however, they are less likely than their non-disabled peers to complete high school, attend college, or to be employed.¹³ This report 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.

ONLINE TOOLS

The report is supplemented by implementation resources for Title V programs that can be found in the MCH Evidence website’s NPM 12 Toolkit at <https://www.mchevidence.org/tools/npm/12-transition.php>.

These resources include links to introductory information, a summary of the evidence, examples of promising practices, sample evidence-based or informed strategy measures (ESMs), links to current, related ESMs in process across the country, learning opportunities, and resources from the leading proponents of improving the transition of care for adolescents from pediatrics to adult health services.

BACKGROUND

This section lists Title V programs that selected NPM 12, summarizes the most recent national data, provides an overview of transition services, cites evidence on the impact and effectiveness of interventions, and describes the aim and focus of this evidence analysis review.

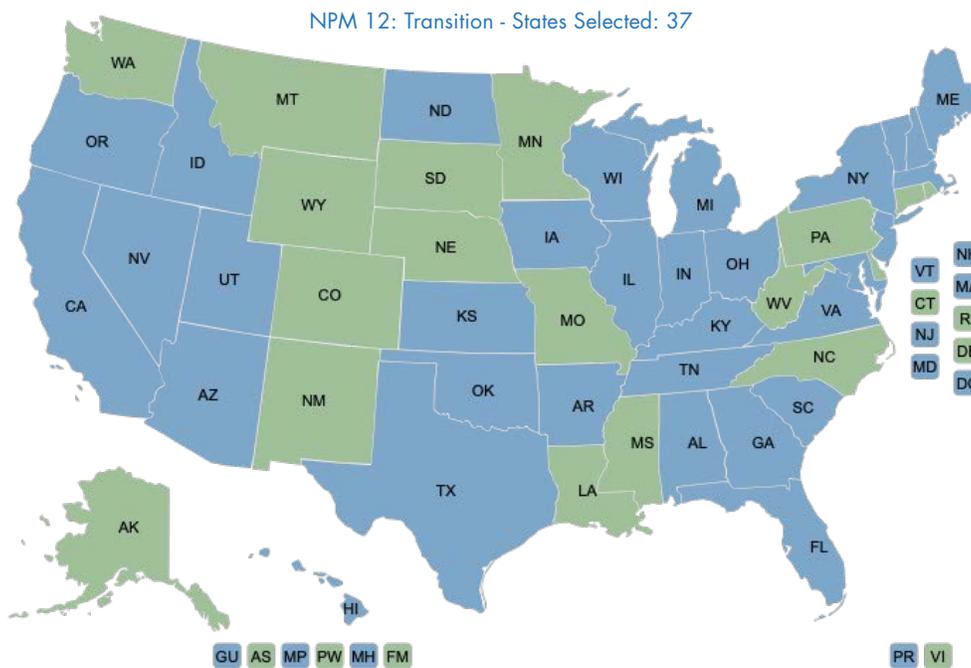
National Performance Measure

Transition as a National Performance Measure. Transition is one of the fifteen MCH NPMs. For 2019, 36 states, territories, and jurisdictions selected NPM 12 Transition. These jurisdictions are Alabama, Arizona, Arkansas, California, Connecticut, District of Columbia, Federated States of Micronesia, Florida, Georgia, Guam, Hawaii, Illinois, Indiana, Iowa, Kentucky, Marshall Islands, Maryland, Massachusetts, Michigan, Minnesota, New Jersey, New Mexico, New York, North Dakota, Oklahoma, Oregon, Puerto Rico, Rhode Island, Tennessee, Texas, Utah, Vermont, Virgin Islands, Virginia, Wisconsin, Wyoming.¹⁴

¹² <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NPMDistribution>

¹³ <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NPMDistribution>

¹⁴ <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/EvidenceBasedStrategyMeasures/12>



States that selected the specified measure are highlighted in blue.

Evidence-based or Informed Strategy Measure

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).

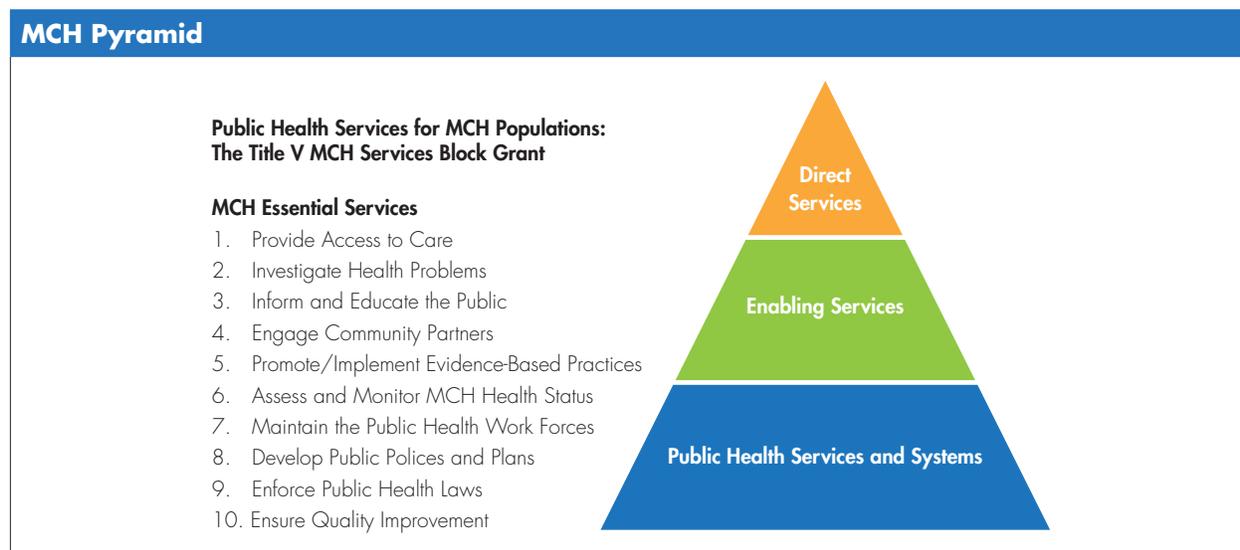
Findings from this report—specifically the evidence-based and evidence-informed interventions identified—can be used by Title V programs as models to strengthen current strategies and improve ESMs or develop new measures to monitor progress for each of these categories.

Sixty-five ESMs currently focus on NPM 12. These can be organized by the levels of the “MCH Pyramid,”¹⁵ the conceptual service framework for the Title V MCH Block Grant program:¹⁶

¹⁵Title V Maternal and Child Health Services Block Grant to the States Program: Guidance and Forms for the Title V Application/Annual Report (OMB No. 0915-0172; Expires 12/31/2020).

¹⁶The 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.tvvisdata.hrsa.gov/Glossary/Glossary> for a graphical representation of the pyramid.

- 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.



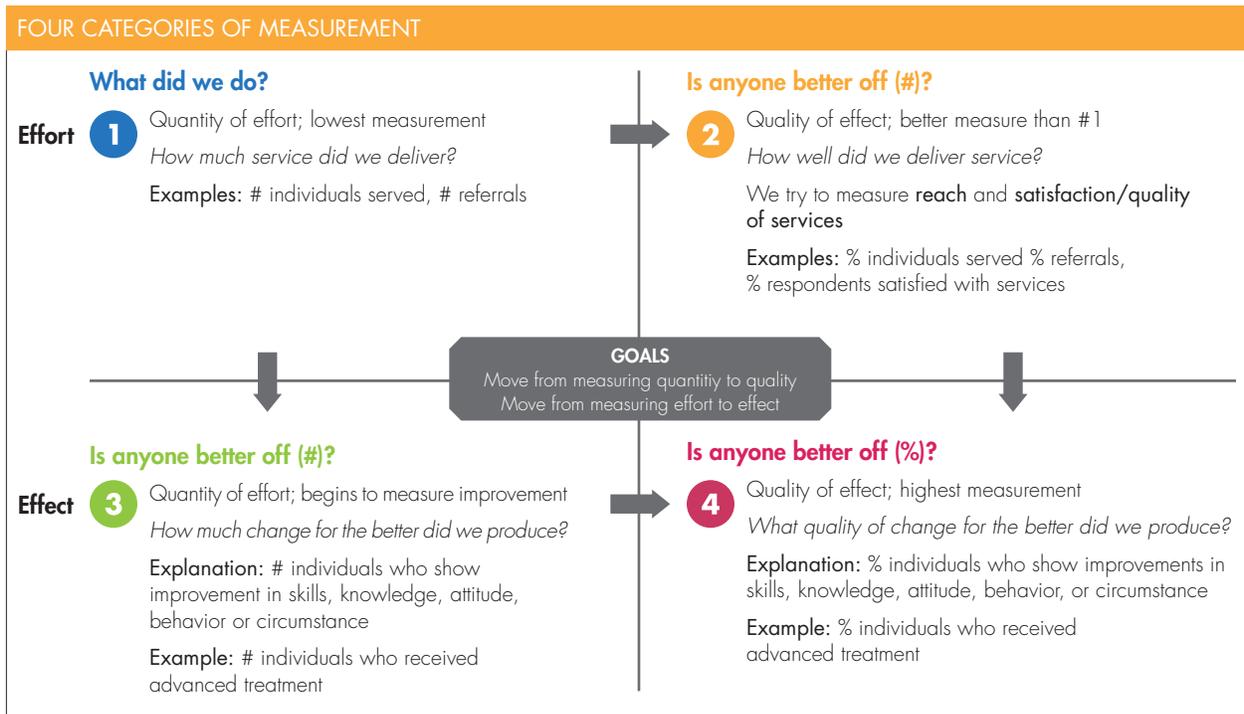
The MCH Evidence Center uses Results-Based Accountability (RBA)¹⁷ as a conceptual framework to track how ESMs are measured. This framework consists of increasing levels of measurement across four quadrants (Quadrant 1 being the simplest measurement and Quadrant 4 being the most complex). States and jurisdictions should focus efforts in expanding how they measure programs by moving up the RBA quadrant scale.^{18, 19}

- 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).

¹⁷ RBA is described in the RBA Implementation Guide <http://raguide.org/index-of-questions/>

¹⁸ ESM Review & Resources: National Summary <https://www.mchevidence.org/documents/ESM-Review-National-Summary.pdf>

¹⁹ To search the MCH Library to find state ESMs, visit: <https://www.mchlibrary.org/evidence/state-esms.php>



Details of interventions tracked through ESMS can be found through the MCH Digital Library’s search page and used as models when considering new programs.²⁰ The final section of this report, **From Evidence to Action**, outlines how to translate the evidence base into meaningful, achievable, and measurable strategies and directs readers to sample ESMS based on this report.

National Survey Data

NPM 12 is measured through data collected from the National Survey of Children’s Health (NSCH). The NSCH provides “rich data on multiple, intersecting aspects of children’s lives, including physical and mental health, access to quality health care, and the child’s family, neighborhood, school, and social context.”²¹ It is funded and directed by HRSA MCHB and fielded annually by the U.S. Census Bureau. Data from the NSCH are used to monitor progress toward the goal of increasing the percent of adolescents with and without SHCN who receive services necessary to make transitions to adult health care. Parents and/or caregivers complete the survey, and NPM 12 is calculated from multiple questions.^{22, 23}

²⁰ <https://www.mchlibrary.org/evidence/state-esms.php>

²¹ <https://www.childhealthdata.org/learn-about-the-nsch/NSCH>

²² <https://www.childhealthdata.org/browse/survey/results?q=7121&r=1>

²³ There were changes in two items that go into scoring this measure: Time spent alone with health care provider and discussion of shift to adult health care providers. In 2018, the time alone with health care provider question changed to refer to the last medical care visit of any kind, not just preventive care. The wording of the item on shifting to adult health care providers changed slightly. Though these changes may have slightly impacted the prevalence of the individual items, the overall concept of transition to adult health care and how it is measured in the survey did not change.

In order to meet the criteria for this measure, youth ages 12-17 years old must attain three components:

1. Doctor spoke with youth privately without an adult in the room during last preventive check-up;
2. If warranted, a discussion about transitioning to adult care was conducted; and
3. Doctors actively worked with youth to gain self-care skills and understand changes in their health care.^{24,25}

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 services necessary for transition to adult health care).²⁶ Considering SHCN status, 18.9% of YSHCN received services necessary for transition to adult health care versus 14.2% of non-YSHCN.²⁷ YSHCN status is determined using a validated instrument for identification of YSHCN as defined by the federal HRSA MCHB. The YSHCN Screener asks whether a child currently experiences a health consequence and, if so, whether that specific health consequence is due to medical, behavioral, or other type of health condition that has lasted, or is expected to last, 12 months or longer.

When looking at the transition elements individually, there was a higher percentage of youth meeting some of those criteria: In 2016, 41% of YSHCN discussed the shift to an adult health care provider, 69% had a provider who actively worked with them to gain self-care skills and/or understand the changes in their health care at age 18, and 44% had time alone with their doctor during their last well-visit (Lebrun-Harris et al., 2018). While YSHCN were more likely than non-YSHCN to meet some of the individual elements for successful transition, youth without SHCN were more likely than YSHCN to discuss the shift to an adult provider (Lebrun-Harris et al., 2018).

“According to the 2017/2018 National Survey of Children’s Health, 81% of youth with special health care needs and 86% of youth without special health care needs do not receive transition preparation services. Youth and families report many barriers to transition, which include feeling unprepared to move to a new doctor and manage their own care, anxiety about leaving their current doctor, difficulty finding a new adult doctor, and understanding the adult health care system.” — GOT TRANSITION²⁸

In sum, with few adolescents with and without SHCN receiving needed transition planning support, it is critical for clinicians to work with youth independently and in collaboration with

²⁴ <https://www.childhealthdata.org/browse/survey/results?q=7121&r=1>

²⁵ If a child has at least one valid positive response to any of these components and the remainder of the components were missing or legitimately skipped, these children were categorized as receiving adequate transition to adult health care in the scoring of this measure. Respondents with “missing” to all items were set to missing.

²⁶ <https://www.childhealthdata.org/browse/survey/results?q=7121&r=1>

²⁷ <https://www.childhealthdata.org/browse/survey/results?q=7121&r=1&g=731>

²⁸ <https://www.gottransition.org/resourceGet.cfm?id=542>

parents and/or caregivers to gain self-care skills and prepare for adult-focused health care throughout adolescence (Lebrun-Harris et al., 2018). Many parents and youth do not consider the transition from pediatric to adult health care until it is suddenly upon them, including adolescents with SHCN who use the health care system more often.²⁹ Akin to other major life developments for youth and young adults, such as going to college, getting a job, and living on their own, the transition to adult health care services takes preparation, self-advocacy, and the cultivation of independence to ensure success.³⁰

“Risk and vulnerability encompass many dimensions of the transition from adolescence to adulthood. Transition from pediatric, parent-supervised health care to more independent, patient-centered adult health care is no exception.” — WHITE ET AL., 2018, P. 1

Overview

Adolescence is recognized as a critical developmental period of transition from childhood to adulthood (Hagan et al., 2017; Jaworska & MacQueen, 2015; Lebrun-Harris et al., 2018; National Research Council Institute of Medicine, 2009a). Increasingly, youth and young adults are being recognized as a vulnerable population, given high rates of behavioral health risks, susceptibility to emerging or worsening chronic medical conditions, and traditionally low use of health care (White et al., 2018). HCT often receives less attention than other transitions, such as post-secondary education, employment, and independent living.³¹ To address this context, there has been an increased emphasis on the HCT process over the last decades. The transition to adult health care is important for all youth and young adults, even if they do not have special needs, 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).

Transition spans pediatric to adult health care. HCT is the process of moving from a pediatric to adult model of care.³² It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination (AAP, 2002). HCT has evolved from a focus on pediatric care responsibility to shared responsibility between pediatric and adult care clinicians (White et al., 2018). HCT should be part of routine care in the medical home, starting at 12-14 years of age and continuing into young adulthood for all youth with and without SHCN. The process should involve individualized planning and ongoing skills development. It can be influenced by early education of patients, families, caregivers, and health care providers (AAP, 2002; Sharma et al., 2014).

²⁹ <https://www.gottransition.org/resource/?hct-family-toolkit>

³⁰ <https://www.gottransition.org/youth-and-young-adults/hct-quiz.cfm>

³¹ <https://www.gottransition.org/youth-and-young-adults/frequently-asked-questions.cfm>

³² <https://www.gottransition.org/youth-and-young-adults/frequently-asked-questions.cfm>

WHAT IS HEALTH CARE TRANSITION?

“Health care transition is the process of getting ready for health care as an adult. During childhood, parents usually help with medical needs—they call for appointments, fill out forms, and keep track of medications. As youth get older, managing medical needs becomes their own responsibility. Achieving this independence requires an organized transition process to gain independent health care skills, prepare for an adult model of care, and transfer to new providers.” — GOT TRANSITION³³

Transition from pediatric to adult health care is part of a larger theoretical framework for transition affecting all youth, young adults, and families (Geary & Schumacher, 2012; Meleis, 2010; Schwartz et al., 2013) with the following guiding principles:

- The importance of youth- and/or young adult-centered, strength-based focus;
- An emphasis on self-determination, self-management, and family and/or caregiver engagement;
- An acknowledgement of individual differences and complexities;
- A recognition of vulnerabilities and need for a distinct population health approach for youth and young adults;
- The need for early and ongoing preparation, including the integration into an adult model of care;
- The importance of shared accountability, effective communication, and care coordination between pediatric and adult clinicians and systems of care (note: this does not require geographic co-location);
- The recognition of the influences of cultural beliefs and attitudes as well as socioeconomic status;
- An emphasis on achieving health equity and elimination of disparities; and
- The need for parents and caregivers to support youth in building knowledge regarding their own health and skills in making health decisions and using health care (White et al., 2018).

The process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care can be confusing and difficult. Youth and families report many barriers to transition, which include feeling unprepared to move to a new doctor and manage their own care, anxiety about leaving their current doctor, difficulty finding a new adult doctor, and understanding the adult health care system.³⁴ As noted by White et al., (2018), research has shown that without a structured transition process, youth and young adults 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).³⁵

³³ <https://www.gottransition.org/youthfamilies/index.cfm>

³⁴ <https://www.gottransition.org/resource/?het-family-toolkit>

³⁵ <https://www.healthychildren.org/English/news/Pages/HealthCare-Transitions-For-Youth-and-Young-Adults.aspx>

The goals of pediatric-to-adult HCT are 1) to improve the ability of youth and young adults, with and without SHCN, to manage their own health care and effectively use health services; and 2) to ensure an organized clinical process in pediatric and adult practices to facilitate transition preparation, transfer of care, and integration into adult-centered care.^{36,37} Transition promotes a seamless continuity of care that is best achieved through advance planning.³⁸ 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).³⁹ Outcomes tend to focus on the “triple aim” domains of population health, patient experience of care, and utilization and cost of care.

HCT may be different for YSHCN. These youth and young adults may require more in-depth planning and ongoing support due to the variety of specialists involved in their care. Evaluation studies have shown that a structured HCT process results in improved population health, patient experience of care, and utilization outcomes for YSHCN with:

- Improvements in:
 - Adherence to care,
 - Self-care skills,
 - Quality of life,
 - Patient satisfaction, and
 - Adult ambulatory care use.
- Reductions in:
 - Morbidity and mortality,
 - Lapses in care,
 - Perceived barriers to care, and
 - Hospital lengths of stay (Gabriel et al., 2017; Schmidt et al., 2020).

In an ideal transition, youth receive uninterrupted, developmentally appropriate medical care (Gray et al., 2018). This may mean youth meet specific health outcomes, such as an A1c <7.0% in diabetes (Chiang et al., 2014), or demonstrate positive health behaviors, such as high adherence (Annunziato et al., 2007), independent self-management skills (Sobota et al., 2015), or attending appointments with an adult provider (Reid et al., 2004). Unfortunately, transition to adult care is associated with many negative outcomes, such as nonadherence (Pai & Ostendorf, 2011), missed medical appointments (Cole et al., 2015), and poor health outcomes (Annunziato et al., 2007). By understanding barriers and facilitators to transition, the likelihood of achieving optimal transition outcomes becomes more realistic.

³⁶ <https://www.gottransition.org/six-core-elements/>

³⁷ The process as laid out describes what should happen with more complex SHCN; HCT for non-YSHCN and those with less complex SHCN is often simpler.

³⁸ <https://www.dhhs.nh.gov/dcbcs/bds/sms/transition.htm>

³⁹ Schmidt et al. (2020) identified care coordination as critical to the HCT process (See Table 4: Health care transition intervention components in the review); therefore, it has been included in this review as a “component.”

“The health care transition frequently occurs concurrently with and has major implications for other life changes, such as graduating from high school, entering the workforce or continuing into higher education and living independently. At this time, youth typically lose access to occupational, physical and speech therapies, medical equipment and other services that were covered by insurance or provided in schools. People with complex conditions often need these specialized services to maintain and improve the ability to function.”

— STEINWAY ET AL., 2017, P. 2⁴⁰

Gaps in transition support. Although the transition to adulthood is expected, the ways in which health care professionals support this transition for adolescents can be uncertain. *“Transition planning, when present at all, can be inexplicit, incomplete, or late, and when necessary, the transfer of care to an adult medical home and to adult medical subspecialists involves more a drift away from pediatric care rather than a planned and executed handoff”* (Cooley et al., 2011).⁴¹ Factors such as inadequate planning, poor service coordination, lack of resources, and gaps in education and training have been identified as obstacles to a proper transition of care (Castillo & Kitsos, 2017). Multiple studies show that most pediatric practices neither initiate transition planning early in adolescence nor offer transition-support services, which are critical for ensuring a smooth transition to an adult health care model. Researchers have also cited the lack of developmentally appropriate tools for assessing child and family readiness for transition as a barrier to transition (Sawicki et al., 2011; Tuchman et al., 2010).

The Policy Lab at the Children’s Hospital of Philadelphia (CHOP) identified the following common challenges faced by young people with intellectual disabilities or other SHCN during the HCT process: 1) Chaotic transfer and poor care coordination; 2) Poor preparation; 3) Loss of comprehensive insurance coverage; 4) Loss of services; and 5) Lack of adult providers (Steinway et al., 2017). Even though the evidence base on HCT outcomes remains limited, several evaluation studies in the U.S. and abroad highlight the beneficial outcomes of a structured transition approach for YSHCN in terms of quality of care and, to a lesser degree, in terms of service use and patient and family experience (White et al., 2018). More outcomes research needs to be conducted to inform transition policies and programs and alleviate these multifaceted problems (Castillo & Kitsos, 2017).

On the provider side, systems of care for children and adults are different; pediatric health care professionals may lack the knowledge and skills to work effectively with young adults.⁴² For families, parents and/or caregivers may not fully appreciate their pivotal role in promoting teens’ independence in seeking and managing their own health care (C.S. Mott Children’s Hospital, 2015;⁴³ White et al., 2018).⁴⁴ On the youth side, some may find it difficult to fully take charge

⁴⁰ https://policylab.chop.edu/sites/default/files/pdf/publications/Transitions_Of_Care.pdf

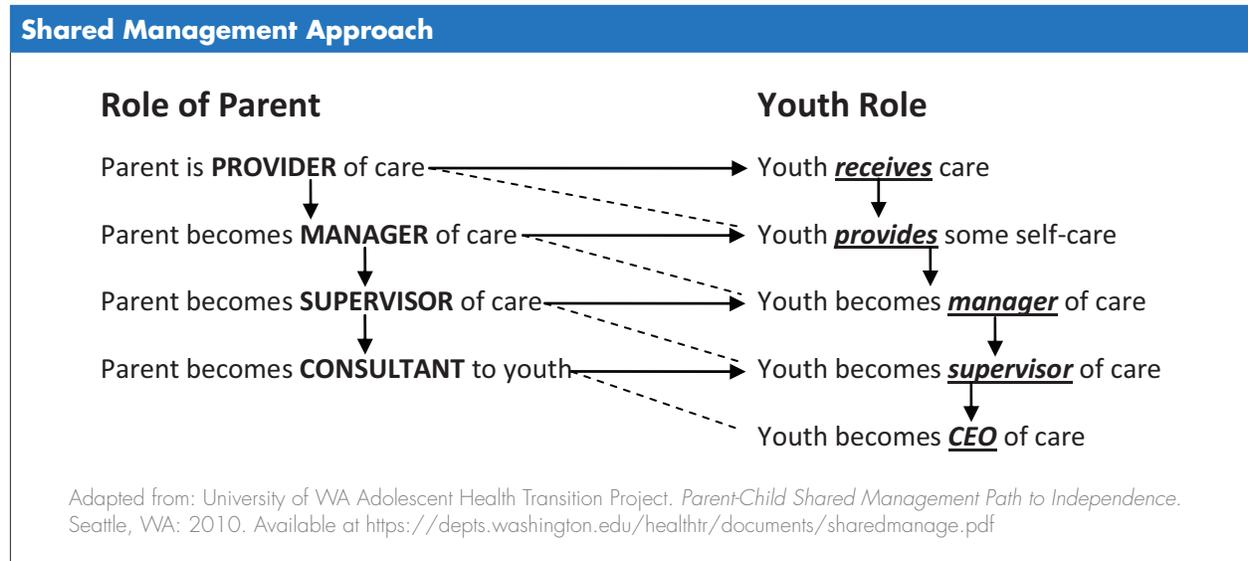
⁴¹ On a national level, parents reported that 79% of adolescents in 2016 had received a preventive medical visit in the past year (Garcia et al., 2018). Given this, the adolescent well-visit could be a good time to talk about HCT.

⁴² <https://www.hhs.gov/ash/oah/adolescent-development/physical-health-and-nutrition/healthcare-transition-for-adolescents/what-is-a-healthcare-transition/index.html>

⁴³ https://mottpoll.org/sites/default/files/documents/121415_teenhealthcare.pdf

⁴⁴ <https://pediatrics.aappublications.org/content/pediatrics/142/5/e20182587.full.pdf>

of their own health care.⁴⁵ The graphic below, adapted from the University of Washington Adolescent Health Transition Project, shows the changing roles of parents and/or caregivers and youth in the transition process.⁴⁶ Transition may be particularly difficult for YSHCN given their health care concerns. While navigating the transition process, youth with chronic medical conditions may experience lapses in health insurance coverage and reduced access to necessary health services, along with other negative outcomes.⁴⁷



More specifically, among adolescents with SHCN:

- 62% have difficulty with one or more of the following: feeling anxious or depressed, acting out, fighting, bullying or arguing, making and keeping friends;
- 35% have three or more chronic conditions;
- Nearly 30% miss one week or more of school due to their chronic conditions;
- 14% have developmental disabilities, including intellectual disabilities, cerebral palsy, and autism, that increase their lifelong dependence on family and caregivers; and
- 3% use or need regular physical, occupational, or speech therapy (Data Resource Center for Child & Adolescent Health, 2009; Steinway et al., 2017).

Schwartz and colleagues developed and validated a theoretical model of transition readiness called the **Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART)** to better capture systems-level barriers and facilitators of transition readiness (Schwartz et al., 2011; Schwartz et al., 2013). This model acknowledges the important influences of the patient, parent, and provider in transition and highlights seven modifiable components

⁴⁵ <https://www.hhs.gov/ash/oah/adolescent-development/physical-health-and-nutrition/healthcare-transition-for-adolescents/what-is-a-healthcare-transition/index.html>

⁴⁶ <https://www.gotttransition.org/resource/?het-family-toolkit>

⁴⁷ <https://policylab.chop.edu/evidence-action-brief/transitioning-adult-care-supporting-youth-special-health-care-needs>

of these groups, including knowledge, skills, beliefs and expectations, goals and motivation, relationships and communication, psychosocial functioning and emotions, and patient’s developmental maturity. Factors deemed less amenable include socio-demographics and culture, insurance and access, medical status and risk, and neuro-cognition and IQ (Paine et al., 2014). SMART is generalizable to different medical conditions and offers an innovative framework to identify barriers to transition within and across chronic illnesses (Gray et al., 2018).

History

In the late 1980s and early 1990s, there was a significant gap in policies and services available to help youth with disabilities and chronic health conditions transition from the pediatric to adult health care system.⁴⁸ With childhood mental, behavioral, and developmental disabilities linked to increased long-term morbidity and mortality, HCT planning might mitigate adverse outcomes (Colver et al., 2018; Leeb et al., 2020; National Research Council Institute of Medicine, 2009b). In 1989, the U.S. Surgeon General published a report titled, “*Growing up and getting medical care: Youth with special health care needs*,” that addressed the needs of youth, families, and health care providers with regard to HCT (Reiss & Gibson, 2002). As research efforts grew in the following decade, several state-based policy statements were issued attesting to the need for and challenges of transition planning.⁴⁹ During this time, change was also taking place at the federal level with legislation affecting youth with disabilities and chronic medical conditions.

Since the 1980s, HRSA MCHB has promoted a comprehensive and coordinated system of services for YSHCN. One of the six system outcomes is that YSHCN will receive the services necessary to make appropriate transitions to adult health care, work, and independence. For instance, in 1996, HRSA MCHB launched the Healthy and Ready to Work (HRTW) Initiative to address health, education, and employment transition issues for YSHCN.⁵⁰ In 2000, the HRTW Transition Workgroup developed a 10-year agenda that focused on systems development and youth empowerment (HRTW Transition Work Group, 2000). These goals were incorporated into Healthy People 2010 that defined nationwide health goals for the next decade.⁵¹ Since the early 2000s, health professional organizations and public health agencies have also articulated the importance of HCT planning, especially for YSHCN (Lebrun-Harris et al., 2018).

Consensus statement and clinical reports. In 2002, the AAP, American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP)-American Society of Internal Medicine (ASIM) released a consensus statement on HCT for young adults with SHCN (AAP et al., 2002). This professional consensus called for specific transition activities beginning at age 12 years and continuing through young adulthood (ages 23-26) to optimize health and assist youth in reaching their full potential. The consensus statement articulated six “critical first steps” to ensuring the successful transition to adult-oriented care:

⁴⁸ <https://health.ri.gov/publications/policybriefs/HealthCareTransitionForYouthWithDisabilitiesAndChronicHealthConditions.pdf>

⁴⁹ <https://health.ri.gov/publications/policybriefs/HealthCareTransitionForYouthWithDisabilitiesAndChronicHealthConditions.pdf>

⁵⁰ <https://health.ri.gov/publications/policybriefs/HealthCareTransitionForYouthWithDisabilitiesAndChronicHealthConditions.pdf>

⁵¹ <https://health.ri.gov/publications/policybriefs/HealthCareTransitionForYouthWithDisabilitiesAndChronicHealthConditions.pdf>

1. Ensure that all young people with SHCN have an identified health care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health care planning.
2. Identify the core knowledge and skills required to provide developmentally appropriate HCT services to young people with SHCN; make them part of training and certification requirements for primary care residents and physicians in practice.
3. Prepare and maintain an up-to-date medical summary that is portable and accessible, providing a common knowledge base for collaboration among health care professionals.
4. Develop up-to-date and detailed written transition plans, in collaboration with young people and their families.
5. Ensure the same standards for primary and preventive health care are applied to adolescents.
6. Ensure that affordable, comprehensive, and continuous health insurance is available to young people with chronic health conditions throughout adolescence and into adulthood (AAP et al., 2002).

(See **Appendix A: Transition Policy Statements** for a select listing of transition to adult care policy and position statements by national organizations).

“The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not. This process includes ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood.”

— AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ACADEMY OF FAMILY PHYSICIANS, AND AMERICAN COLLEGE OF PHYSICIANS, TRANSITIONS CLINICAL REPORT AUTHORIZING GROUP, 2011, P. 182

In 2011, a clinical report on transition was published as joint policy by the AAP/AAFP/ACP (Cooley et al., 2011). It provided practice-based guidance, including a step-by-step algorithm, on how to plan and implement better HCT for youth and integrated transition planning into the medical home and ongoing chronic care management. At the same time, the HRSA MCHB-funded National Health Care Transition Center (Got Transition) developed the **Six Core Elements of Health Care Transition**TM to align with the clinical report algorithm.^{52, 53} The 2018 clinical report reaffirmed the 2011 report, stated that HCT should be part of routine care, called for transition planning to begin in early adolescence (12-14) and continue into young adulthood

⁵² Got Transition/Center for Health Care Transition Improvement is a cooperative agreement between the MCHB and The National Alliance to Advance Adolescent Health. The aim is to improve the transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families (<https://www.gottransition.org/about/index.cfm>).

⁵³ Initially, Got Transition translated the 2011 AAP/AAFP/ACP Clinical Report on HCT for clinical practice and obtained extensive feedback to develop and test the Six Core Elements in many practice settings. After being tested in Quality Improvement (QI) learning collaboratives using the research-based Institute for Healthcare Improvement Breakthrough Series QI research approach, and with input from transition expert, the Six Core Elements 2.0 packages were released for different clinical settings in 2014. Most recently, the Six Core Elements were incorporated into the updated 2018 AAP/AAFP/ACP Clinical Report guidance on HCT, and further feedback was obtained from over 300 clinical and family transition experts to produce the updated Six Core Elements 3.0 in 2020 (<https://gottransition.org/six-core-elements/frequently-asked-questions.cfm>).

for all youth with and without SHCN, refined the previous algorithm, and promoted the use of a planned approach, such as the Six Core Elements of HCT, an evidence-informed, structured process for improving population health outcomes (White et al., 2018).

The 2018 report highlighted the critical HCT elements of preparation, transfer, and integration into adult care, and stressed the crucial role of adult clinicians in accepting and partnering with young adults in the management of their health care. The steps called for health care providers to address: 1) transition planning by engaging youth and their parents and/or caregivers in assessing and developing self-care skills for an adult model of care at age 18 years; 2) transfer of care by assisting youth in identifying adult providers and ensuring a smooth handoff with updated medical records; and 3) integration into adult care by orienting new young adult patients about the practice's approach and offering self-care assessment and skills building (White et al., 2018).

Additionally, the 2018 clinical report highlighted common transition barriers, preferences of youth, families, and clinicians, outcome evidence, and recommendations for infrastructure, education and training, payment, and research. HCT includes the process of moving from a child to an adult model of health care—with or without a transfer to a new clinician. That means having time alone with their clinician to respect their confidentiality and to learn how to manage their health on their own to the best of their ability. Physicians can help by recognizing how cultural beliefs and attitudes, as well as social determinants of health, may affect the adolescents' HCT.⁵⁴ The Six Core Elements of HCT have been customized for specific health conditions by many groups, such as the American College of Physicians Council on Subspecialty Societies as part of their High Value Care Initiative.^{55,56}

"Youth do not instantly become adults when they turn 18, regardless of their new legal status. It is important to continue to build self-care skills and greater engagement in care in young adults. This [clinical] report provides the framework to help make that happen."

— DR. MICHAEL MUNGER, PRESIDENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS⁵⁷

Six Core Elements of Health Care Transition. The Six Core Elements were initially developed with the release of the 2011 clinical report to operationalize the transition process outlined in the report. The 2018 clinical report guides clinicians in the development of transition services and has been shown to improve HCT processes in primary care, subspecialty care, school-based health clinics, and Medicaid managed care (White et al., 2018).^{58,59} It outlines how the transition process can be incorporated into various settings such as pediatrics, family medicine, medicine-

⁵⁴ <https://www.aap.org/en-us/about-the-aap/aap-press-room/pages/Updated-Report-on-Health-Care-Transitions-for-Youth.aspx>

⁵⁵ <https://gottransition.org/six-core-elements/frequently-asked-questions.cfm>

⁵⁶ <https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative/condition-specific-tools>

⁵⁷ <https://www.aap.org/en-us/about-the-aap/aap-press-room/pages/Updated-Report-on-Health-Care-Transitions-for-Youth.aspx>

⁵⁸ <https://www.aap.org/en-us/about-the-aap/aap-press-room/pages/Updated-Report-on-Health-Care-Transitions-for-Youth.aspx>

⁵⁹ <https://gottransition.org/six-core-elements/>

pediatrics (med-peds), and internal medicine.⁶⁰ The intensity of the HCT intervention can vary based on the complexity of the health condition, the social determinants of health, and adverse childhood experiences of the youth (White et al., 2018). For instance, more supports could be needed for youth with comorbidities and/or poor adherence to care.

The figure below describes the Six Core Elements approach and timeline for youth transitioning from pediatric to adult health care.⁶¹ Although each young person’s situation is unique, a well-timed transfer should occur from the ages of 18 to 21, with planning for transition occurring much earlier.⁶²



The Six Core Elements of HCT is not a model of care but a structured process with basic components that can be customized for use in various settings and applied to different transition care models (White et al., 2018).^{63,64} All three phases of transition support are included in this approach. Ideally, care coordination support is available to guide the transition process and team-based care in both the pediatric and adult health care settings (White et al., 2018). The Six Core Elements are packaged into three different versions for pediatric practices, adult practices, and clinicians who care for youth throughout their life span, such as family medicine physicians, physicians dually trained in internal medicine-pediatrics, and family nurse practitioners (White et al., 2018).

The figure on the following pages offers a side-by-side comparison of the Six Core Elements intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care (Got Transition, 2020).⁶⁵

Successful transition process. Touraine and Polak (2018) reiterated that a successful HCT process should begin in the pediatric setting when the child is around 11-12 years old and involve sessions with both the child and their parents and/or caregivers as well as the child alone. It may be useful for YSHCN to practice explaining their condition to relatives or trusted individuals to increase understanding of their condition. A mentor who may have the same

⁶⁰ <https://www.gottransition.org/resourceGet.cfm?id=495>

⁶¹ <https://gottransition.org/six-core-elements/>

⁶² <https://www.hhs.gov/ash/oah/adolescent-development/physical-health-and-nutrition/healthcare-transition-for-adolescents/what-is-a-healthcare-transition/index.html>

⁶³ <https://www.gottransition.org/providers/index.cfm>

⁶⁴ <https://gottransition.org/six-core-elements/>

⁶⁵ <https://gottransition.org/6ce/?side-by-side> and <https://www.gottransition.org/6ce/?integrating-full-package>

Six Core Elements of Health Care Transition: Side-by-side Comparison

Transitioning Youth to an Adult Health Care Clinician

(For use by Pediatric, Family Medicine, and Med-Peds Clinicians)

1. Transition and Care Policy/Guide

- Develop a transition and care policy/guide with input from youth and parents/caregivers that describes the practice's approach to transition, an adult approach to care in terms of privacy and consent, and age of transfer to an adult clinician.
- Educate all staff about the practice's approach to transition and distinct roles of the youth, parent/caregiver, and pediatric and adult health care team in the transition process, taking into account cultural preferences.
- Display transition and care policy/guide somewhere accessible in practice space, discuss and share with youth and parent/caregiver, beginning at age 12 to 14, and regularly review as part of ongoing care.

2. Tracking and Monitoring

- Establish criteria and process for identifying transition-aged youth.
- Develop process to track receipt of the Six Core Elements, integrating with electronic medical records (EMR) when possible.

3. Transition Readiness

- Conduct regular transition readiness assessments, beginning at age 14 to 16, to identify and discuss with youth and parent/caregiver their needs for self-care and how to use health care services.
- Offer education and resources on needed skills identified through the transition readiness assessment.

4. Transition Planning

- Develop and regularly update the plan of care, including readiness assessment findings, youth's goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.
- Prepare youth and parent/caregiver for an adult approach to care, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
- Determine need for decision-making supports for youth and make referrals to legal resources.
- Plan with youth and parent/caregiver for optimal timing of transfer from pediatric to adult care. If both primary and subspecialty care are involved, discuss optimal timing for each.

Transitioning to an Adult Approach to Health Care Without Changing Clinicians

(For use by Family Medicine and Med-Peds Clinicians)

1. Transition and Care Policy/Guide

- Develop a transition and care policy/guide with input from youth/young adults and parents/caregivers that describes the practice's approach to transition and an adult approach to care in terms of privacy and consent.
- Educate all staff about the practice's approach to transition and distinct roles of the youth/young adult, parent/caregiver, and health care team in the transition process, taking into account cultural preferences.
- Display transition and care policy/guide somewhere accessible in practice space, discuss and share with youth/young adult and parent/caregiver, beginning at age 12 to 14, and regularly review as part of ongoing care.

2. Tracking and Monitoring

- Establish criteria and process for identifying transition-aged youth/young adults.
- Develop process to track receipt of the Six Core Elements, integrating with electronic medical records (EMR) when possible.

3. Transition Readiness

- Conduct regular transition readiness assessments, beginning at age 14 to 16, to identify and discuss with youth and parent/caregiver their needs for self-care and how to use health care services.
- Offer education and resources on needed skills identified through the transition readiness assessment.

4. Transition Planning

- Develop and regularly update the plan of care, including readiness assessment findings, youth/young adults' goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents.
- Prepare youth/young adult and parent/caregiver for an adult approach to care, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
- Determine need for decision-making supports for youth/young adult and make referrals to legal resources.
- Plan with youth/young adult and parent/caregiver for optimal timing of transfer from pediatric to adult specialty care, if needed.

Integrating Young Adults Into Adult Health Care

(For use by Internal Medicine, Family Medicine, and Med-Peds Clinicians)

1. Transition and Care Policy/Guide

- Develop a transition and care policy/guide with input from young adults that describes the practice's approach to transition, accepting and partnering with new young adult patients, and an adult approach to care in terms of privacy and consent.
- Educate all staff about the practice's approach to transition and distinct roles of the young adult, parent/caregiver, and adult health care team in the transition process, taking into account cultural preferences.
- Display transition and care policy/guide somewhere accessible in practice space, discuss and share with young adult at first visit, and regularly review as part of ongoing care.

2. Tracking and Monitoring

- Establish criteria and process for identifying transitioning young adults.
- Develop process to track receipt of the Six Core Elements, integrating with electronic medical records (EMR) when possible.

3. Transition Readiness

- Identify and list adult clinicians within your practice interested in caring for young adults.
- Establish a process to welcome and orient new young adults into practice, including a description of available services.
- Provide young adult-friendly online or written Frequently Asked Questions about the practice.

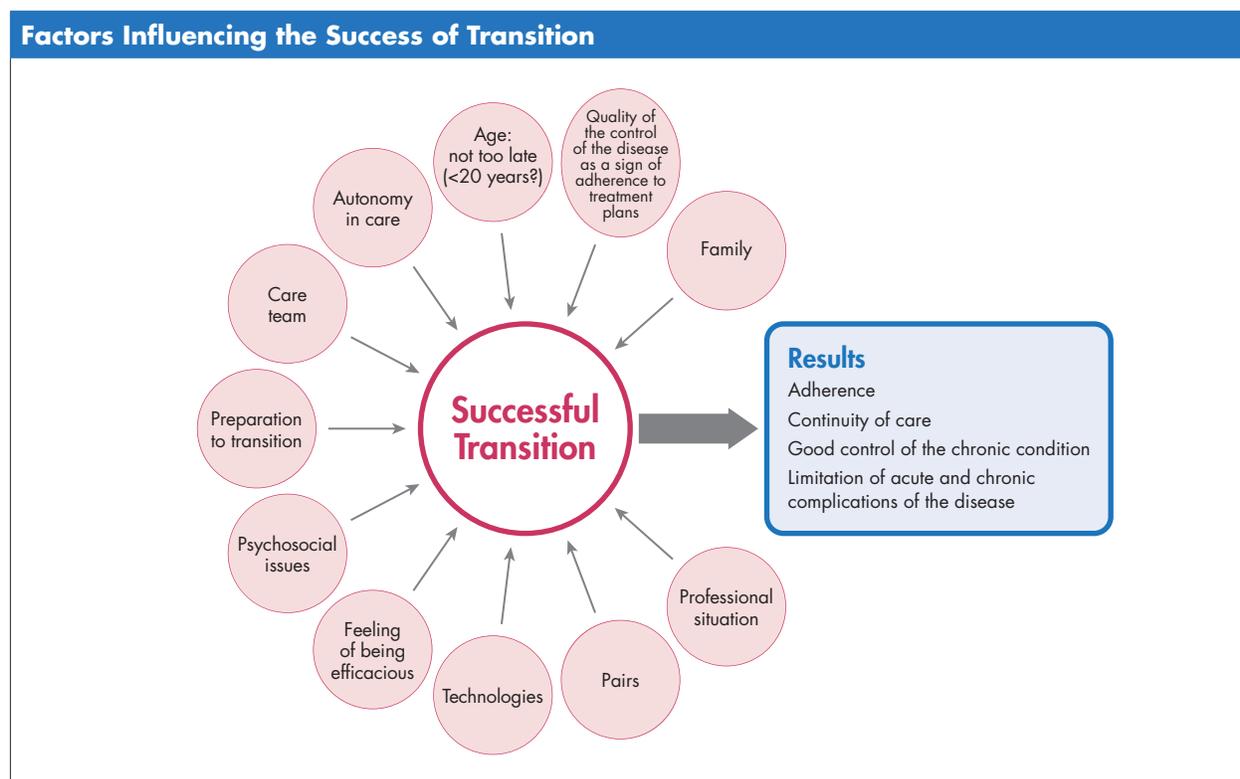
4. Transition Planning

- Communicate with young adult's pediatric clinician(s) and arrange for consultation assistance, if needed.
- Prior to first visit, ensure receipt of transfer package, including final transition readiness assessment, plan of care with transition goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional clinical records.
- Make pre-visit appointment reminder welcoming new young adult and identifying any special needs and preferences.

Six Core Elements of Health Care Transition: Side-by-side Comparison	
Transitioning Youth to an Adult Health Care Clinician <i>(For use by Pediatric, Family Medicine, and Med-Peds Clinicians)</i>	Transitioning Young Adults Into Adult Health Care <i>(For use by Internal Medicine, Family Medicine, and Med-Peds Clinicians)</i>
4. Transition Planning <ul style="list-style-type: none"> Assist youth in identifying an adult clinician(s) and provide linkages to insurance resources, self-care management information, and community support services. Obtain consent from youth/parent/caregiver for release of medical information Take cultural preferences into account throughout transition planning. 	4. Transition Planning <ul style="list-style-type: none"> Provide linkages to insurance resources, self-care management information, and community support services. Obtain consent from youth/young adult/parent/caregiver for release of medical information Take cultural preferences into account throughout transition planning.
5. Transfer of Care <ul style="list-style-type: none"> Complete transfer package, including final transition readiness assessment, plan of care with transition goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional clinical records. Confirm date of first adult clinician appointment. Prepare letter with transfer package, send to adult clinician, and confirm adult clinician's receipt of transfer package. Communicate with selected adult clinician about pending transfer of care. Confirm the pediatric clinician's responsibility for care until youth/young adult is seen by an adult clinician. Transfer youth/young adult when their condition is as stable as possible. 	5. Transfer of Care <ul style="list-style-type: none"> Address any concerns youth/young adult has about transferring to an adult approach to care. Clarify an adult approach to care (shared decision-making, privacy and consent, access to information), adherence to care, preferred methods of communication, and health literacy needs. Conduct self-care skills assessment if not recently completed and discuss young adult's needs for self-care and how to use health care services. Offer education and resources on needed skills identified through the self-care skills assessment. Review youth/young adult's health priorities as part of their plan of care. Continue to update and share with youth/young adult their medical summary and emergency care plan.
6. Transfer Completion <ul style="list-style-type: none"> Contact youth/young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm attendance at first adult appointment. Elicit anonymous feedback from youth/young adult and their parent/caregiver on their experience with the transition process. Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed. Build ongoing and collaborative partnerships with adult primary and specialty care clinicians. 	6. Transfer Completion <ul style="list-style-type: none"> Communicate with pediatric practice confirming completion of transfer into adult practice and consult with pediatric clinician(s), as needed. Assist young adult in connecting with adult specialists, as needed, and provide linkages to insurance resources, self-care management information, and community support services. Obtain consent from young adult for release of medical information. Continue with ongoing care management tailored to each young adult and their cultural preferences. Elicit anonymous feedback from young adult on their experience with the transition process. Build ongoing and collaborative partnerships with other primary and specialty care clinicians.

health condition may also be a special source of support and can provide their own personal perspective on the transition process. It is important for the adolescent to cultivate self-efficacy and self-management skills so they can eventually be autonomous in care and able to handle the challenges of their health condition.

Additionally, the partnership between health care providers in the pediatric and adult systems is crucial as it undergirds the transfer of the adolescent from the pediatric to the adult system of care. A few studies have associated a well-planned transition process with a better quality of life and a better controlled disease; therefore, understanding what makes for a successful transition provides a roadmap of sorts for children, youth, and their families to consider in partnership with their health care providers (Touraine & Polak, 2018). (See the figure below for a schematic representation of the constellation of factors influencing the success of transition).⁶⁶



"It's not enough for a pediatrician to just make a referral—there needs to be a warm handoff to ensure young adults actually land in a family medicine practice and are integrated into that practice."

— LAURA PICKLER, MD, MPH, CHIEF OF FAMILY MEDICINE AT CHILDREN'S HOSPITAL COLORADO IN AURORA⁶⁷

⁶⁶ <https://books.google.com/books?id=nltgDwAAQBAJ&pg=PT9&lpg=PT9&dq=Touraine+%26+Polak+transition&source=bl&ots=H7uPsR3OSI&sig=ACfU3U0KadWZ2qE9EF6WaiShu-CzITQuy&hl=en&sa=X&-ved=2ahUKEwjx4vfc9rjqAhV1JzQIHQ9kB5IQ6AEwA3oECBAQAQ#v=onepage&q&f=false>

⁶⁷ <https://www.aafp.org/news/health-of-the-public/20181031caretransition.html>

Youth Without Special Health Care Needs

While the transition from pediatric to adult health care is particularly challenging for YSHCN (whether physical, emotional, behavioral, and/or intellectual), the transition from adolescence to adulthood is a challenging time for *all* young people. A hallmark of adolescence is a gradual development toward autonomy and individual adult decision-making. However, adolescents are often faced with situations for which they may not be prepared, and many are likely to be involved in risk-taking behaviors, such as use of alcohol, tobacco, and other drugs and engaging in unprotected sex (Alderman et al., 2019). Biological and psychosocial changes that occur during adolescence make this age group unique, and puberty plays a key role in the child-to-adult progression. Just as adolescents undergo a transition into adult bodies and responsibilities, their health care must also transition to meet their evolving needs (Leung et al., 2019).

Although there are few studies that look at the effects of transition on youth without SHCN, research has shown that morbidity and mortality decrease among YSHCN who have undergone a successful transition to adult care. Pediatric and adult medicine differ in terms of service organization, communication between physician and patient, patient responsibilities, and expectations for independent care. If adolescents are not given preparation for HCT, they “*may develop limited health literacy and autonomy, increasing their risk for preventable morbidity and mortality*” (Leung et al., 2019). Similarly, if young adults are not transitioned to adult providers, their medical care could be interrupted leading to overuse of emergency department services, high medical costs, and low adult vaccination rates (Leung et al., 2019).

“It is essential to have systems and resources in place that ensure that all adolescents experience a successful health care transition.” — USDHHS, OFFICE OF POPULATION AFFAIRS⁶⁸

As Leung and colleagues (2019) conclude, “*The transitions of care from pediatric to adult medicine have numerous components, including the triad of the health care provider, adolescent, and caregiver, each playing a vital role in the transition process. Every aspect of the process and its participants bring an additional level of complexity. Transitions of care are critical for all adolescents and young adults, both with and without complex healthcare needs. The process takes time, energy, and dedication to help patients in each step of that journey.*” A successful transition to adult health care for youth without SHCN is not only important for the patients themselves, but also beneficial to society as a whole and should be of greater focus in systems of care.

Additional information on youth without SHCN from other studies can be found in the **Discussion and Implications** section of this report.

⁶⁸ <https://www.hhs.gov/ash/oah/adolescent-development/physical-health-and-nutrition/healthcare-transition-for-adolescents/what-is-a-healthcare-transition/index.html>

Systematic Reviews

Outcomes of pediatric to adult health care transition interventions. A newly published systematic review by Schmidt and colleagues (2020) on the outcomes of pediatric to adult HCT interventions provided the foundation for this evidence review. Schmidt et al. (2020) expanded upon the methodology and evidence from Gabriel et al. (2017), indicating that a structured HCT process for YSHCN can help improve adherence to care, disease-specific measures, quality of life, self-care skills, satisfaction with care, health care utilization, and HCT process of care (Gabriel et al. 2017; Schmidt et al., 2020).⁶⁹ The 19 included studies in Schmidt et al. (2020) examined YSHCN who transitioned from pediatric to adult outpatient health care. The majority of studies included in both reviews focus on specific chronic health conditions, such as diabetes, inflammatory bowel disease, or heart conditions. Some focus on multiple SHCN, which may include a mental health condition, while only a handful focus on any/all types of chronic disease or conditions.

The studies in Schmidt et al. (2020) were required to describe an HCT intervention for youth transferring from pediatric to adult outpatient health care.⁷⁰ Intervention activities within each of the three components, as well as activities that indicated use of care coordination, were extracted from the studies. Regarding the HCT components, all studies mentioned transfer assistance, most studies (95%) described at least one transition planning activity, and almost half (47%) described at least one activity related to integration into adult care (Schmidt et al., 2020). Activities in all three intervention categories were mentioned in eight studies (42%). An additional intervention activity, care coordination, was mentioned by seven studies (37%). Two studies specifically incorporated Got Transition’s Six Core Elements of Health Care Transition.

Schmidt and colleagues found that a structured transition intervention is associated with improvements in outcomes. All of the included studies with positive outcomes reported multiple HCT activities, most often related to transfer assistance, followed by transition planning and, to a lesser extent, integration into adult care. More specifically:

- For **transition planning**, the most mentioned intervention activities were:
 - Disease education/skill-building (74%) and
 - A plan for care/medical summary/electronic medical information (63%).
- For **transfer assistance**, the most mentioned intervention activities were:
 - Identifying an adult provider/scheduling assistance (58%) and
 - A letter of referral/coordination of referrals (58%).

⁶⁹ The conclusions reported in the Gabriel et al. (2017) systematic review are similar to those drawn by Schmidt et al. (2020) regarding the positive effects of a structured transition process. Of the 43 studies included in the Gabriel review of literature published between 1995 and 2016, 28 studies (two-thirds) showed statistically significant positive outcomes resulting from structured transition interventions. Twenty studies reported improvements in population health, 8 studies reported benefits in terms of consumer experience or reduction in transition barriers, and 9 studies cited positive service utilization impacts. Gabriel also notes, however, that the measures used to evaluate health care transition interventions were widely variable and seldom addressed all 3 “triple aim” domains (Gabriel et al., 2017).

⁷⁰ The authors of the Schmidt et al. (2020) review chose to include studies that utilized multiple HCT components, not only planning for transition, given the latest clinical guidelines calling on researchers to incorporate multiple components of HCT.

- For **integration into adult care**, the most mentioned intervention activity was:
 - Scheduling assistance/follow-up with the patient after first adult visit/monitoring appointments (37%).⁷¹

Study outcomes were categorized according to the “triple aim” framework developed by the Institute for Healthcare Improvement,⁷² which includes population health, patient experience of care, and utilization and cost of care (Schmidt et al., 2020). Most of the positive outcomes were related to population health, followed by improvements in utilization of care. None of the studies, however, measured outcomes in all of the triple aim domains. Eighty-four percent of studies in the Schmidt et al. (2020) review reported a significant positive outcome, and 26% reported a significant negative outcome.

More specifically, positive outcomes included:

- **Population health:** Improvement in adherence to care, disease-specific measures, self-care skills, quality of life, and self-reported health.
 - Population health outcomes were measured in 17 of the 19 studies (89%), and statistically significant positive outcomes were found in 11 of these studies (65%).
 - Of these, 7 of the 17 studies (41%) found significant positive outcomes in disease-specific measures, most commonly reported as a decrease in HbA1c levels.
 - Four of the 17 studies (24%) reported significant positive outcomes in patient-reported health and quality of life, with the most common outcome being increased independence.
 - Four of the 17 studies (24%) found positive adherence to care monitoring outcomes, while one (6%) reported a negative outcome of an increase in ambivalence toward medicine.
- **Experience of care:** Increase in satisfaction and reduction in barriers to care.
 - Patient experience of care outcomes was measured in two studies (11%), and no study measured provider satisfaction or barriers to care.
 - Of the two studies, one found positive outcomes regarding patient satisfaction with care coordination and receipt of needed services, while the other study found a decrease in overall satisfaction with transition services.
- **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.
 - Ten of the 19 studies (53%) measured utilization and/or cost of care.
 - Of these, six studies (60%) had significant positive utilization outcomes, including an increase in adult clinic attendance, and a decrease in hospital length of stay.
 - Three studies (30%) found significant negative outcomes related to utilization, which included a lower rate of utilization of an inflammatory bowel disease nurse, longer wait times for the first appointment at the adult clinic, and a decrease in clinic attendance post-transfer to the adult side.

⁷¹ See Table 4 in the Schmidt et al. (2020) review for a list of all the HCT intervention activities.

⁷² <http://www.ihi.org/Engage/Initiatives/TripleAim/Pages/default.aspx>

- Regarding process of care, one study found positive outcomes, including an increase in communication between adult and pediatric providers and an increase in referrals to adult care.
- One study measured cost of care as an outcome. Although the authors found a decrease in cost, they did not test for significance (Schmidt et al., 2020).⁷³

Since none of the 19 included studies described the same set of intervention activities, it was not possible for the authors to report on the correlation between a specific HCT intervention activity and a specific outcome. Therefore, Schmidt et al. (2020) concluded that more research is needed to assess the outcomes of structured transition planning and integration interventions provided to a broader population of youth, both with and without chronic conditions. Future research studies should also utilize interventions that incorporate all HCT components and assess provider experience of care as well as cost of care.

Barriers to transition. In an effort to evaluate significant barriers to transition both within and across chronic illness groups, and in response to research trends that tend to “silo” transition studies by specific health conditions, Gray and colleagues (2018) conducted a systematic review of the pediatric-to-adult-care literature that cuts across pediatric illness populations. The literature search was conducted in August 2017, with 57 studies meeting the inclusion criteria. The aim of Gray’s review was to use the SMART model to summarize barriers to transition that go beyond patient variables within isolated chronic illnesses (Schwartz et al., 2011).

Gray’s review shows that more work is needed to optimize the effectiveness of transition programs and adolescent health outcomes. Linking transition efforts to post-transfer outcomes remains a challenge due to difficulties tracking youth across institutions, lack of established post-transfer markers of success within some chronic illnesses, and limited reimbursement for transition-related services. Collaborations across institutions and disease populations that result in the exchange of innovative solutions is also an important clinical direction that can open the way to sharing resources from many of the currently developing transition interventions (Gray et al., 2018).

A further exploration of barriers can be found in the **Discussion and Implications** section of this report.

Differences in transition care philosophies. Mulvale and colleagues (2019) examined the differences in care philosophies that may influence the transition from child to adult mental health services. The review of the literature (1992-2013) focused on the transition of youth (ages 12-25) with mental health disorders. The research team identified 12 articles that reflect distinct philosophical differences between child and adolescent mental health services (CAMHS)

⁷³ See Table 3 in the Schmidt et al. (2020) review for a summary of significant positive outcomes in population health, patient experience of care, provider experience of care, and utilization and cost of care.

and adult mental health services (AMHS).⁷⁴ The findings reveal consistent differences in care philosophies, with CAMHS taking a developmental approach that considers factors related to the child, family, educational, and social systems, while AMHS uses a diagnostic-based approach geared towards pharmacotherapy, with an emphasis on client autonomy and individual responsibility.

“In children, mental health disorders have deleterious consequences on individual and socioeconomic factors and can impede healthful transitioning into adulthood... Some of the emerging priorities included developing child mental health policies, implementing prevention and early intervention strategies for transition-age youth, and reducing disparities for mental health care use.” — WHITNEY & PETERSON, 2019, P. 389

A key finding from this review is that transitions from CAMHS to AMHS are complex and require early transition planning as well as an individualized approach to care. From a care philosophy perspective, adjustments to the nurturing, cherishing approach of CAMHS may better prepare youth for the responsibility expected of them in AMHS. Similarly, providers in CAMHS may want to initiate discussions that encourage greater independence and less family involvement over time. According to the authors, an important step in preparing youth for adult services may be to explain that there are differences in severity and treatment of mental disorders for different people. It may also help to prepare families for the different roles and philosophies they will face when young people transition out of CAMHS. Several recommendations emerged that may assist in fostering mutual understanding among CAMHS and AMHS providers. Hosting collaborative clinical meetings; undertaking joint CAMHS/AMHS planning sessions; and developing protocols and guidelines that recognize each other’s care philosophies and approaches could lead to improvements in pediatric to adult mental health transitions (Mulvale et al., 2019).

METHODS

This section describes the approach used for the evidence analysis review. It includes information on the search terms used, databases searched, inclusion and exclusion criteria, the multi-phase screening process, the grey literature screening process, and the evidence continuum that was used to rate the level of evidence for the studies.

Databases and Search Terms

Numerous seminal and important documents were examined to provide context and grounding for the evidence analysis review. One systematic review in particular provided the foundation for this review. The review by Schmidt et al. (2020) focused on outcomes of pediatric to adult HCT interventions. (See Schmidt et al., 2020 for their search strategy and study selection criteria).

⁷⁴ Excluded articles did not discuss care philosophy. Mulvale et al. (2019) noted the distinct differences in care philosophies while comparing the 12 studies.

Articles included in this review were pulled, summarized, and rated for their level of evidence. The same search strategy and similar selection criteria were used when reviewing the most recent literature.

To identify articles from 2019-2020, searches were run in PubMed, the Cumulative Index of Nursing and Allied Health Literature (CINAHL Plus), the Cochrane Database of Systematic Reviews, Web of Science Core Collection, and PsycINFO. Search strategies varied depending on the database due to differences in controlled vocabulary, indexing, and syntax. **Table 1: Detailed Search Strategies** highlights the search terms used for each database. The searches used for this evidence analysis review were performed between March to April 2020 with a supplemental search on May 21, 2020. PsycINFO was searched on May 20, 2020 primarily for reviews, background materials, and articles focused on HCT for youth without SHCN.

For the 2019-2020 literature, a total of 2,696 articles were identified across the databases. Of these, 111 article titles seemed relevant to identify HCT interventions and were selected for abstract review. From these, 44 articles were reviewed in full by members of the research team. After extensive review and discussion by the team members, 7 studies were selected for inclusion in the results from this search of the most recent literature (2019-2020). In total, 26 studies were included, combining the results from the Schmidt et al. (2020) review (n=19) with those from the most recent literature search (n=7).

Inclusion and Exclusion Criteria

The following inclusion criteria were used:

- Studies describing an HCT intervention for youth transferring from pediatric to adult outpatient health care.
- Studies that utilized one or multiple HCT components.⁷⁵
- The components of the intervention and results were clearly described.
- Studies described interventions that fall within the scope of Title V MCH Block Grant programs as deemed by the authors and reviewers. Title V could fund, implement, or partner with others to support these interventions.
- Study designs included pre- and post-intervention comparisons, intervention and non-intervention comparisons, and randomized control trials (RCTs). Studies could be prospective or retrospective.
- At a minimum, studies included a control and intervention group, an appropriate comparison group, or a pretest-posttest design to assess intervention effectiveness.
- Studies were published in English.
- Studies were primarily conducted in high resource countries.
- Studies were published in peer-reviewed journals.
- Grey literature was included as promising practices.

⁷⁵ 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.

The following exclusion criteria were applied:

- Review articles.
- Studies published before May 2016.
- Studies that were not published in English.
- Studies without an intervention.
- Studies that did not indicate a sample size.
- Studies without an evaluation.
- Studies that addressed only self-care skills without demonstrating HCT.
- Studies that focused solely on vocational or educational transition outcomes.
- Studies where HCT from pediatric to adult care was not the primary focus of the intervention.
- Studies that were only qualitative evaluations.

Screening Process

A multi-phase, sequential process was used to sort and identify articles, including the following steps:

• Literature searches:

- Extensive literature searches were used to identify relevant HCT interventions for inclusion in the results.
 - A CINAHL search brought back 35 results (dates covered: 2019-2020), date run: March 12, 2020.
 - A Cochrane Library search uncovered no relevant articles (dates covered: 2019-2020), date run: March 12, 2020.⁷⁶
 - PubMed searches identified 2,592 articles (dates covered: 2019-2020), dates run: March 11, 2020 and April 1, 2020.
 - Supplementary searches uncovered 66 articles (dates covered: 2019-2020), date run: May 21, 2020.
 - A Web of Science Core Collection search brought back 3 articles (dates covered: 2019-2020), date run: March 20, 2020.⁷⁷
- An additional search was conducted to find useful background materials.
 - A PsycINFO search identified 28 articles (dates covered: 2013-2020), date run: May 20, 2020.

• Article title review:

- Of the 28 articles from PsycINFO, run primarily for reviews, background materials, and articles on youth without SHCN, 16 articles were carefully reviewed for pertinent information.
- An initial review of 2,696 article titles across the databases led to the identification of 111 titles that seemed relevant to HCT interventions.

⁷⁶ Schmidt et al., 2020 did not search the Cochrane Library.

⁷⁷ Schmidt et al., 2020 also searched Ovid Medicine. Georgetown University does not have access to this database.

- **Grouping the literature:**

- The research team reviewed 16 systematic reviews, seminal documents, and important resources to get an understanding of the evidence base around HCT. This information was used in the background section of this report; it also informed the framing of the results and discussion sections.
- The Schmidt et al. (2020) systematic review became the foundational document for this report and is summarized in the systematic reviews sub-section. All studies (n=19) from the review were pulled and included in the results.
- Relevant articles from the latest database searches were added to the results as well.

- **Article abstract screening:**

- Abstract reviews (n=111) were divided up and conducted by 1 of 6 members of the research team; together the team discussed any articles that seemed questionable for inclusion into this review.

- **Full text review:**

- The final step was full article review of abstracts that seemed most relevant.
- Full text reviews were divided up and completed by 1 of 6 members of the team (n=44 studies from the database searches).⁷⁸
- Team members extracted data pertaining to the study characteristics, intervention, and results.
- Research team meetings were held to review decisions related to the full articles. Topics covered:
 - Articles marked for exclusion.
 - Articles flagged as maybe or include to make final decisions about what to include in this review.
- The Principal Investigator and Director of Research met with the team leader to review methodology, inclusion/exclusion decisions, and points of discussion.
- Of the 44 articles that went through full review from the database searches, 7 studies met the inclusion criteria.⁷⁹
- Articles that did not describe interventions, did not contain sufficient data, or did not directly measure transition but nevertheless presented lessons learned or critical issues for consideration when developing and delivering interventions to youth and young adults are noted in the discussion.

See **Figure 1: Flow Chart of the Review Process and Results** for a visual display of the identification, screening, eligibility, and inclusion steps.

⁷⁸ Due to time and resource constraints, included studies were divided among the 6 team members and each member summarized and rated an equal share of the studies. Weekly meetings occurred to discuss evidence ratings, and the team came to consensus on the ratings for the vast majority of studies; therefore, issues around inter-rater reliability were likely diminished.

⁷⁹ Four of the 7 new studies are multicomponent. Three of the studies are single component focused on planning for transition. Although Schmidt et al. 2020 revised the inclusion criteria from Gabriel et al. 2017 to include only multicomponent interventions with transfer assistance as a component, the MCH Evidence Center team decided to include the planning for transition only studies to provide a comprehensive view of current research efforts for consideration by Title V programs and state leaders.

Grey Literature

A public health librarian conducted a search of the grey literature to inform HCT interventions. The following types of literature were reviewed: 1) state programs on transition from the Association of Maternal and Child Health Programs (AMCHP) Innovation Station (20 programs – See *Examples of Promising Practices* in the Discussion section for a summary of select programs); 2) policy and position statements from a search of Google and PubMed (transition to adult care policy statement/transition to adult care position statement) (See **Appendix A: Transition Policy Statements** for statements from 12 organizations). The following databases were also searched without finding anything relevant for this report: 1) Catalog of U.S. Government Publications⁸⁰ for publications of federal government agencies; 2) CADTH (Canadian Agency for Drugs and Technologies in Health) looking at *Grey Matters: a practical search tool for evidence-based medicine*;⁸¹ 3) Govinfo.gov for congressional and federal legislative documents; and 4) PHPartners.org, a collaboration of U.S. government agencies, public health organizations, and health sciences libraries, which provides timely, convenient access to selected public health resources on the Internet. There was no set date range for the grey literature; any relevant and helpful resources were compiled and reviewed for inclusion.

Evidence Continuum

An evidence continuum was created⁸² to assess evidence-based and evidence-informed strategies, along with criteria for each category along the continuum. The Robert Wood Johnson Foundation (RWJF) *What Works for Health* evidence ratings⁸³ were adapted to create an evidence continuum tailored toward the Strengthen the Evidence initiative. The evidence ratings include:⁸⁴

EVIDENCE RATING	DEFINITION
Evidence Against ↓	Studies with this rating are not good investments. These strategies have been tested in many robust studies, are not effective, and sometimes produce harmful results.
Mixed Evidence ★	Strategies with this rating have been tested more than once and results are inconsistent or trend negative; further research is needed to confirm effects.
Emerging Evidence ★ ★	Strategies with this rating have limited research documenting effects. These strategies need further research, often with stronger designs, to confirm effects.
Expert Opinion ★ ★ ★	Strategies with this rating are recommended by credible, impartial experts and are consistent with accepted theoretical frameworks. However, the strategies have limited research documenting effects; further research, often with stronger designs, is needed to confirm effects.
Moderate Evidence ★ ★ ★ ★	Strategies with this rating are likely to work, but further research is needed to confirm effects. These strategies have been tested more than once and results trend positive overall.
Scientifically Rigorous ★ ★ ★ ★ ★	Strategies with these ratings are most likely to make a difference. These strategies have been tested in many robust studies with consistently positive results.

⁸⁰ <https://catalog.gpo.gov>

⁸¹ <https://www.cadth.ca/resources/finding-evidence/grey-matters>

⁸² The former Strengthen the Evidence for MCH Programs initiative research team at JHU originally adapted the RWJF evidence ratings to create the evidence continuum for the evidence analysis reports.

⁸³ <http://www.countyhealthrankings.org/take-action-improve-health/what-works-health/our-ratings>

⁸⁴ <https://www.mchevidence.org/tools/>

Using an “*evidence-informed*” approach, a continuum of evidence model was developed to help states use the best available MCH science while also encouraging innovation in evidence-informed programming.⁸⁵ *Evidence-based* strategies are generally those that have either *moderate evidence* or are *scientifically rigorous*, while *evidence-informed* are those that have *emerging evidence* or are based on *expert opinion*.⁸⁶ Evidence-informed is meant to convey that there is information suggesting that a certain strategy could be effective in addressing a NPM. Even though these strategies have not been rigorously tested or evaluated, they may incorporate a theoretical model from other effective public health practices or apply a novel approach grounded in scientific theory.

More specifically, evidence-based strategies have a majority of studies showing statistically significant or favorable findings. These studies tend to be peer-reviewed with results mostly drawn from a mix of RCTs, quasi-experimental studies with pre-post measures, with or without control groups, and/or time trend analyses. Evidence-informed strategies have a growing evidence base consisting of a varying mix of statistically favorable, unfavorable, and/or not significant findings. These studies can include peer-reviewed results as well as grey literature with a mix of study designs. *Evidence against* is a unique category wherein strategies could be labeled as evidence-based or evidence-informed, based on the state of the research, study design, and outcomes, with the preponderance of studies not having statistically significant findings or demonstrating unfavorable effects.

See **Table 2: Evidence Rating Criteria** to learn about the evidence criteria applied to the studies. Evidence ratings were given for each included study, as well as the different intervention types.⁸⁷

RESULTS

This section provides an overview of the study characteristics, intervention components, data sources, outcome measures, study results, and limitations. The studies included in this evidence review varied in terms of the intervention type, setting, sample, design, and data sources. However, they represent attempts by researchers working in countries, states, jurisdictions, and communities to improve HCT from pediatric to adult health services. Interventions were grouped by major intervention type—according to HCT components. The different intervention strategies are then rated for their collective level of evidence.

⁸⁵ The former Strengthen the Evidence for MCH Programs initiative worked to develop a continuum of evidence consistent with the evidence-informed approach.

⁸⁶ This evidence-informed approach was defined by the McMaster group: McMaster University. Health Evidence Glossary. Available: <http://www.healthevidence.org/glossary.aspx#E>

⁸⁷ The evidence continuum was originally created to be applied to intervention types; however, the rating scale was also used to rate each study in this review making some of the overarching criteria difficult to apply at times.

Characteristics of Studies Reviewed

Table 3: Study Characteristics details the characteristics of the transition component interventions selected for this evidence review and details the countries, settings, target populations, sample sizes, and study designs. Of the 26 studies, 2 were RCTs, 1 was a cluster randomized trial, 19 were cohort studies (7 were retrospective cohort, 6 were prospective cohorts, 3 longitudinal, and 4 pilot evaluations), 3 were quasi-experimental studies, and 1 was mixed-methods. Regarding country, 8 studies were conducted in the U.S., 5 in Australia, 3 in Canada, 3 in the Netherlands, and one each in the United Kingdom (U.K.), France, Germany, Italy, Israel, Finland, and Tunisia.

The target populations across the studies were adolescents, youth, and young adults ranging in age from 11 to 28 years of age who primarily had a chronic health condition or a developmental disability. The health conditions included type 1 diabetes (6 studies), inflammatory bowel disease (6 studies), congenital heart disease or cardiac conditions (3 studies), epilepsy (2 studies), endocrine conditions (2 studies), kidney transplant (1 study), mental health condition or addiction (1 study), or Prader-Willi syndrome (1 study). Four (4) studies included adolescents with more than one condition: 1 with a variety of conditions (mental health, autism, cerebral palsy); 1 with chronic conditions; 1 with those needing more than one specialty care provider with or without intellectual or developmental disabilities; and 1 with medically complex conditions. The sample sizes ranged from 24 to 1,052 adolescents, with an average of 168 across all 26 studies.

The settings across the 26 studies were mostly clinic, hospital, or a combination. Thirteen studies (13) were conducted in clinic settings, including tertiary care or outpatient clinics (6 studies), pediatric specialty clinics (5 studies), and transition clinics (2 studies). Six studies were done in adult care or pediatric hospital settings and 5 studies used a combination of clinical and hospital settings. One study was conducted in the home setting and one at a mental health services agency.

Intervention Types and Components

Table 4: Intervention Descriptions describes the interventions, comparison groups, study lengths, and data collection time points.

Interventions were categorized by HCT components with the majority of studies being multicomponent HCT interventions. Three (3) of our studies (12%) were single-component interventions. All three dealt with *planning for transition*. Schmidt et al. (2020) focused on multicomponent studies. However, the MCH Evidence Center included studies with “planning for transition” as a single component to highlight the continued focus by researchers on planning interventions.

Two of these interventions (Flocco, 2019, and Le Marne, 2019) took place in outpatient clinics for adolescents with serious health conditions (congenital heart disease and epilepsy, respectively). The clinics were led by interdisciplinary teams tasked with preparing emerging adults and their parents or caregivers for the transition process through education. Flocco (2019)

described individualized education and counseling, along with scheduling assistance by a nurse-coordinator, while Le Marne (2019) described group educational and mental health sessions. The third study (Huang, 2020) also took place in an outpatient clinic (for patients with inflammatory bowel disease), but the focus was on the use of a Transition EHR (electronic health record) Activity (TEA) to track transition readiness and to prompt provider-patient joint decision-making and review of patient medical histories. The EHR and annual assessments served to aid in the delivery of resources based on individual patient need.

The remaining twenty-three (23) studies were multicomponent interventions. The details of the elements of the multiple components can be seen in **Table 7: Intervention Types and Evidence Ratings**; they can be divided into five major categories:

- Multicomponent A + B (Planning for transition + Transfer assistance)
 - 6 studies (23%)
- Multicomponent A + B + C (Planning for transition + Transfer assistance + Integration into adult care)
 - 5 studies (19%)
- Multicomponent A + B + D (Planning for transition + Transfer assistance + Care coordination)
 - 4 studies (15%)
- Multicomponent A + B + C + D (Planning for transition + Transfer assistance + Integration into adult care + Care Coordination)
 - 7 studies (27%)
- Multicomponent B + C (Transfer assistance + Integration into adult care)
 - 1 study (4%)

The single most common component was *planning for transition*. All but one of our studies (96%) included some type of planning in the transition process. The most common element of transition planning was *disease education/skill building*; 19 of the 26 studies assessed here placed a value on building patients' skills and knowledge about their conditions.

The most common elements were as follows:

- Planning for Transition (96% of studies)
 - Disease education/skill building (73%)
 - Plan of care/medical summary/electronic medical information (62%)
 - Transition readiness/self-care skills assessment (38%)
- Transfer Assistance (88% of studies)
 - Identifying an adult provider/scheduling assistance (58%)
 - Letter of referral/coordination of referrals (50%)
 - Communication between pediatrician and adult provider/joint pediatric and adult meetings (50%)

- Integration into Adult Care (50% of studies)
 - Scheduling assistance/follow-up with patient after adult first visit/monitoring appointments (38%)
 - Ongoing care (19%)
- Care Coordination (42% of studies)
 - Indication of use of care coordination (42%)

Many of the interventions examined here took place in transition clinics. These clinics were specially designed to support adolescents in their transition from pediatric to adult care⁸⁸ and were usually conducted in a hospital setting. Some were specifically young adult clinics, while others were held in the adult clinic but included members of the pediatric team. Transition clinics offered multiple opportunities for youth (and their parents or caregivers) to increase their knowledge of disease and disease-management, and to meet with both pediatric and adult specialists in their preparation to transfer to adult care.

Interventions that took place outside of the transition clinic setting were of short duration (e.g., a single-day patient assessment by the care team, Paepegaey, 2018), compared patients who had finished transition with those who had finished transfer (Bennett, 2016), or involved the creation of the processes that would facilitate transition (Jones, 2017; Razon, 2019; Szalda, 2019).

Team members involved in transition clinics included nurses, psychologists, social workers, education specialists, vocational counselors, and dietitians/nutritionists. Specialist physicians in the clinics included gastroenterologists, neurologists and neuropsychologists, rheumatologists, endocrinologists, and developmental and behavioral practitioners.

In many of our studies, nurses played a prominent role. When patients needed transfer assistance, nurses often served as transition coordinators, identifying adult providers, making referrals and appointments, sending reminders, and re-scheduling appointments when they were missed. Nurses also provided counseling and education on disease management to patients and their parents or caregivers, as well as advice on the transition process. Nurses were also often instrumental in providing patients with their health records and patient histories, and in transmitting those records to adult providers. Two of our five highest-rated studies examined initiatives in which nurses filled primary roles (Lemke, 2018; Mackie, 2018).

Regarding comparison groups, 12 of the 26 studies had no control group whatsoever. In another 12 studies, the comparison group had the usual care (i.e., had received no transition assistance or had not attended a clinic). In one study, both the transition and control groups had enhanced standard care, while only the transition group received assistance from a health care transition nurse. In the final study, the authors compared a cohort of transitioning young adults in a specialized clinic with a group who had previously experienced a lapse in care but who also enrolled in the young adult clinic.

⁸⁸ The three single-component studies also took place in transition clinics.

Study lengths ranged from 9 months to 14 years. Two studies consisted of the authors compiling data from one-time surveys or comparing medical data gathered during different time periods. The authors of 4 studies compared their own results with data collected from other sources over a period of years.

Data collection varied widely. Some studies consisted of gathering data from one-time surveys and medical records. Surveys might have been given to patients who had attended a transition clinic and patients who had made the transition without assistance. Some studies assessing transition clinics and programs solicited data at baseline and several weeks or several months later. The authors of some studies conducted interviews and observations with medical professionals and patients during the transition process, while others collected data two years or more after the transition process was completed.

Data Sources and Outcomes

Data sources and study results are presented in **Table 5: Data Sources, Outcome Measures, and Study Results**.

Data sources include medical records, surveys and questionnaires administered to the patients and providers, consultations with clinicians, semi-structured interviews, and observations of interactions between patients and providers.

Outcome measures obtained from medical records differed according to the medical condition. Kidney transplant patient data included kidney function, graft failure, and patient mortality. Diabetes patients often reported their HbA1c levels and the frequency of monitoring their blood glucose levels. Inflammatory bowel disease patients reported on their rates of complications, surgeries, radiation doses, delayed puberty rates, medical expenditures, sexual life satisfaction, and rates of loose bowel movements. Generally, medical records for patients with various conditions measured dropout rates of transition programs, levels of disease activity, frequency of clinic attendance and disengagement from services. Other studies measured hospital admission rates, emergency care, lengths of stay, and cost of care.

Surveys and questionnaires measured such things as physical, social, and psychological effects of diseases on patients, patients' perceptions of the transition process and satisfaction with services, patient autonomy, knowledge of the diseases and medications, reduction of pain and anxiety, and willingness to adhere to therapy. Some patients completing surveys responded to questions on employment and independence, transition readiness, perceptions of care and care coordination, self-efficacy, and their own behaviors at medical clinics.

The authors of some studies addressed the transition process by measuring population health, whether or not the patient received and utilized a referral to an adult practice, the time gap between the last pediatric visit and the first visit to adult care, and how well patients adhered to care. They were also interested in how often patients utilized services, how well they completed transfers, and how much they used EHR transition support tools.

During direct observations, study authors measured service structures, barriers and facilitators to the transition process, and benefits and clinical outcomes of transition efforts.

Study results can also be viewed through the lens of the triple aims of population health, patient experience of care, and utilization and cost of care, as described in the Schmidt et al. (2020) article:

- **Population health:** Improvement in adherence to care, disease-specific measures, self-care skills, self-reported health and quality of life, and mortality.
 - Population health outcomes were measured in 23 of the 26 studies (88%), and significant positive outcomes were found in 18 of these studies (69%).
 - Of these, 10 of the 23 studies (43%) found significant positive outcomes in *disease-specific measures*, most commonly reported as a decrease in HbA1c levels.
 - Another 10 of the 23 studies (43%) reported on *patient-reported health and quality of life*. 7 of these 10 reported positive outcomes, the most common being increased general satisfaction with life.
 - Five studies (22%) measured *adherence to care monitoring outcomes*. Four of these 5 studies found positive results, including better adherence to medications, better glucose monitoring, and improved attitudes concerning the need for medications. One study reported no increased adherence to medications as a result of the intervention.
 - Of these 23 studies, 10 (43%) reported outcomes having to do with *patient self-care*. Nine of these studies reported positive outcomes. The most cited improvements concerned disease knowledge, self-management, and self-efficacy.
 - One study (4%) discussed patient *mortality*, but it was found that the intervention had no effect on patient survival.⁸⁹
- **Experience of care:** Increase in satisfaction and reduction in barriers to care.
 - Patient experience of care outcomes were measured in 6 of our 26 studies (23%). All 6 studies discussed provider satisfaction, and 2 mentioned barriers to care.
 - Five of the 6 studies (83%) found positive outcomes regarding patient satisfaction with care coordination and receipt of needed services. The 6th study had mixed results; one population experienced increased satisfaction with care, while another subset felt that their satisfaction declined.⁹⁰
 - The authors of 2 studies (33%) discussed *barriers to care* but were inconclusive as to the impact of the interventions on those barriers. Identifying and accessing qualified adult specialists and adequate insurance were cited as barriers to patient care in the transition process. Medical professionals of a transition clinic identified lack of time, planning difficulties, limited involvement of adult care providers, and insufficient financial coverage as their own barriers.

⁸⁹ In the Schmidt et al. (2020) review, one study looked at mortality as an outcome in kidney transplant patients (Kosola, 2018). Additionally, in the preceding Gabriel et al. (2017) review, there was one study that found decreased mortality as an outcome (Annunziato et al., 2013); however, it was not included in this review given its date.

⁹⁰ Schmidt et al, 2020 counted this as a negative result across the board.

- **Utilization and cost of care:** Decrease in time between last pediatric and first adult visit, increase in adult ambulatory visits, decrease in hospital admissions and length of stay, and process of care.
 - Eighteen of the 26 studies (69%) measured utilization and cost of care.
 - Of the 18 studies, 16 (89%) covered *utilization* outcomes, including an increase in adult clinic attendance, and a decrease in hospital length of stay. Positive outcomes in 11 studies most often mentioned were lower hospitalization rates and lengths of stay, shorter transition times, and increase in routine care visits.
 - Negative or neutral outcomes in the remaining studies included a lower rate of utilization of an inflammatory bowel disease nurse, longer wait times for the first appointment at the adult clinic, a decrease in clinic attendance post-transfer on the adult side, and lack of effect on dropout rates.
 - Four of the 18 studies (22%) had positive outcomes regarding *process of care*. These outcomes involved an increase in communication between adult and pediatric providers and an increase in referrals and transfers to adult care.
 - Two studies (11%) discussed *cost of care* as an outcome. The authors found a decrease in costs due to lower hospitalization rates, fewer surgeries, and shorter lengths of stay.

Limitations

Table 6: Limitations describes the limitations reported for each study. All of the studies reported at least one limitation, and most reported two or more limiting the interpretation of their results. Twenty of the studies reported sample issues, including small sample size, low power to detect significant changes, limited geographic or group sampling, low recruitment, or differences between the control and intervention groups that were not measured. Twelve of the studies discussed not having adequate or any information about what the routine care was in the comparison group or not collecting follow up data to understand long term impact of the transition interventions. Low response rates or loss of participants to follow up was cited as a limitation in 8 studies. Lack of a control group, non-randomization, or another control group issue was cited by 4 studies. Reliance on self-reporting was a limitation for 3 of the studies. Three studies also cited the quality of care or transition interventions were not assessed. Variability of data or lack of fidelity implementing interventions was a limitation in 2 of the studies.

Evidence Rating and Evidence Continuum

The assignment of evidence ratings was based on study design and the results described within each individual study. We think a study can be judged on its own merit with regard to the evidence it is contributing to the HCT research portfolio. **Table 7: Intervention Types and Evidence Ratings** lists all the studies selected for inclusion, indicates which intervention component(s) comprise the intervention design, and provides the individual evidence ratings for each study as well as the overall evidence rating for the intervention type. The table is arranged according to intervention type (e.g., Multicomponent A + B (Planning for transition + Transfer assistance)).

Table 8: Health Care Transition Components⁹¹ indicates the intervention activities for each study within the major components of planning for transition, transfer assistance, integration into adult care, and care coordination.

Once grouped, the intervention clusters were rated for their overall level of evidence and then placed along the evidence continuum. The table below summarizes the evidence-based and evidence-informed strategies to improve HCT by setting, intervention type, target audience, examples of intervention components, and evidence rating. Note: For this table, the intervention types include: A = Planning for transition; B = Transfer assistance; C= Integration into adult care; D = Care coordination.

Figure 3: Evidence Continuum visually displays the intervention types and configurations along the evidence continuum from *evidence against* (least favorable) to *scientifically rigorous* (most favorable).

Summary of Evidence-Based and Evidence-Informed Strategies to Ensure Transition				
SETTING	TARGET AUDIENCE	INTERVENTION TYPE	EXAMPLE OF INTERVENTION ACTIVITIES	OVERALL EVIDENCE RATING
Clinic-based, hospital-based, or a combination; Community-based (home, mental health services agency)	YSHCN	Single component A (Planning for transition) (n=3) (Flocco, 2019; Huang, 2020; Le Marne, 2019)	Planning for transition: Transition readiness/self-care skills assessment + Disease education/skill building + Plan of care/medical summary/electronic medical information + Patient/family feedback on transition process	Emerging evidence
		Multicomponent A + B (Planning for transition + Transfer assistance) (n=6) (Bennett, 2016; Burns, 2018; Fu, 2017; Geerlings, 2016; Hergenroeder, 2018; Yerushalmy-Feler, 2017)	Planning for transition: Transition tracking/monitoring + Disease education/skill building + Plan of care/medical summary/electronic medical information + Transfer assistance: Identifying an adult provider/scheduling assistance + Letter of referral/coordination of referrals + Communication between pediatrician and adult provider/joint pediatric and adult meetings	Emerging/Mixed evidence

⁹¹ This is an expanded version of Table 4: HCT intervention components from Schmidt et al., 2020 (pg. 104) with additional intervention activities for the latest studies identified from the 2019-2020 literature search.

Summary of Evidence-Based and Evidence-Informed Strategies to Ensure Transition				
SETTING	TARGET AUDIENCE	INTERVENTION TYPE	EXAMPLE OF INTERVENTION ACTIVITIES	OVERALL EVIDENCE RATING
Clinic-based, hospital-based, or a combination; Community-based (home, mental health services agency)	YSHCN	Multicomponent A + B + C (Planning for transition + Transfer assistance + Integration into adult care) (n=5) (Essaddam, 2018; Jones, 2017; Kosola, 2018; Mackie, 2018; White, 2017)	Planning for transition: Disease education/skill building + Plan of care/medical summary/electronic medical information + Transfer assistance: Identifying an adult provider/scheduling assistance + Transfer summary sent from pediatrician or shared with new adult provider + Integration into adult care: Welcome/orientation process + Scheduling assistance/follow-up with patient after adult first visit/monitoring appointments	Emerging evidence
		Multicomponent A + B + D (Planning for transition + Transfer assistance + Care coordination) (n=4) (Cappelli, 2016; Farrell, 2018; Lemke, 2018; Pyatak, 2017)	Planning for transition: Disease education/skill building + Transfer assistance: Identifying an adult provider/scheduling assistance + Care coordination: Indication of use of care coordination	Moderate/Emerging evidence
		Multicomponent A + B + C + D (Planning for transition + Transfer assistance + Integration into adult care + Care coordination) (n=7) (Agarwal, 2017; Colver, 2018; Razon, 2019; Sattoe, 2020; Schutz, 2019; Szalda, 2019; van Pelt, 2018)	Planning for transition: Disease education/skill building + Plan of care/medical summary/electronic medical information + Transfer assistance: Identifying an adult provider/scheduling assistance + Transfer summary sent from pediatrician or shared with new adult provider + Communication between pediatrician and adult provider/joint pediatric and adult meetings + Integration into adult care: Welcome/orientation process + Scheduling assistance/follow-up with patient after adult first visit/monitoring appointments + Care coordination: Indication of use of care coordination	Emerging evidence

Summary of Evidence-Based and Evidence-Informed Strategies to Ensure Transition				
SETTING	TARGET AUDIENCE	INTERVENTION TYPE	EXAMPLE OF INTERVENTION ACTIVITIES	OVERALL EVIDENCE RATING
Clinic-based, hospital-based, or a combination; Community-based (home, mental health services agency)	YSHCN	Multicomponent B + C (Transfer assistance + Integration into adult care) (n=1) (Paepegaey, 2018)	Transfer assistance: Letter of referral/coordination of referrals + Transfer summary sent from pediatrician or shared with new adult provider + Integration into adult care: Self-care skills assessment	Emerging evidence

Key Findings

Overall, 8 key findings emerged from the analysis:

1. 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.
2. 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.
3. 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.
 - a. The majority of interventions were multicomponent (n=23; 88%) (e.g., A + B + C + D (planning for transition + transfer assistance + integration into adult care + care coordination)).
 - b. Twenty-three of 26 studies (88%) included transfer assistance.
 - c. Studies that looked at single-component interventions focused only on planning for transition (n=3; 12%).⁹²
 - d. One of the 26 studies (4%) did not include planning for transition.
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

⁹² Schmidt et al. (2020) excluded studies that only utilized one component. However, for our review we included studies with “planning for transition” as a single component to demonstrate the continued focus by researchers on transition planning focused interventions.

- 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

This section discusses some key findings, examples of effective interventions and promising practices, study insights with implications for policy and practice, and future directions. This section also highlights important considerations in working with youth of transition age and designing structured HCT interventions.

The purpose of this review was to provide information about evidence-based and evidence-informed interventions to increase the percent of adolescents with and without SHCN who received services to prepare for the transition from pediatric to adult health care. The MCH Evidence Center identified HCT interventions that support youth and young adults with SHCN during a dynamic time in their lives as they transition from pediatric to adult-oriented health care systems.

Data Trends

Systematic attention to HCT for youth dates back more than three decades.⁹³ In that time, researchers have demonstrated the importance of planning for the transition to adulthood especially for youth with disabilities and SHCN. For these young people, the ultimate goal for the transition from pediatric to adult health care services is to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate, and technically sophisticated health care services that continue uninterrupted as the individual moves from adolescence to adulthood (AAP et al., 2002; Institute of Medicine Committee on Disability in America et al., 2007). The studies included in this review demonstrate that multicomponent interventions are becoming more prominent and showing 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, experience of care, and utilization.⁹⁴

⁹³ In 1989, the U.S. Surgeon General convened a conference on the topic of HCT that built on a smaller 1984 conference with the same theme (Magrab & Miller, 1989).

⁹⁴ See Got Transition's tools to measure improvements in process and experience in care outcomes (Prior et al., 2014).

Highlights of Effective Intervention Studies

Below are studies that showed positive results and illustrate some of the intervention strategies being tested to support transition to adult health care services. Each example of an effective intervention (rated as *moderate evidence*) describes the study design, intervention components, and positive results.

#1: Example of an evidence-based HCT intervention with planning for transition + transfer assistance + integration into adult care

Jones (2017) used a team approach to develop a systematic HCT process at an academic medical center using the Six Core Elements of HCT to increase successful transfer of adolescents and young adults with type 1 diabetes from pediatric to adult endocrinology providers. The process was implemented with a study population of 371 youth. The process incorporated sustainable transition practice improvements into existing pediatric and adult subspecialty clinic workflows, including electronic medical records. Pediatric providers used transition readiness assessments, discussed transition with patients, provided referral to adult providers with transfer summaries, and there was two-way communication between pediatric and adult providers. A follow-up tool for patients after transfer was developed to provide patient satisfaction data. The process also had resources for providers, including pediatric and adult policies and a welcome letter.

Results: Compared to baseline, the proportion of patients referred from pediatric to adult endocrinology and the proportion of patients who completed a successful adult visit almost tripled, and clinical outcomes were maintained.

#2: Example of an evidence-based HCT intervention with planning for transition + transfer assistance + integration into adult care

The purpose of Mackie (2018) was to determine if a nurse-led transition intervention for adolescents with congenital heart disease (CHD) impacted lapses in care during the transition and health outcomes. A cluster RCT was conducted in two tertiary pediatric cardiology care centers in Canada using a nurse-led transition intervention for 16- to 17-year olds with moderate or complex CHD versus usual care. The intervention group received two 1-hour individualized sessions targeting CHD education, creating a health passport, setting an education related goal, and self-management skills. A total of 121 participants were randomized to receive the intervention (n=58) or usual care (n=63). Intervention participants were 3.0 times more likely to have an appointment within 1 month. At the recommended time of first adult appointment, intervention participants were 1.8 times more likely to have their appointment within 1 month and at 6 months. The intervention group had higher scores at 1, 6, 12, and 18 months on the MyHeart knowledge survey and the Transition Readiness Assessment Questionnaire (TRAQ) self-management index.

Results: Nurse led care coordination reduced the delay in transition from pediatric to adult care and increased knowledge about their condition and increased self-management skills for youth with CHD.

#3: Example of an evidence-based HCT intervention with planning for transition + transfer assistance + care coordination

Farrell (2018) aimed to a) identify determinants of HbA1c levels at 18 months and 30 months following transition to a youth specific diabetes service in young people with type 1 diabetes mellitus (T1DM); and b) to evaluate the impact of the service on acute admissions with diabetic ketoacidosis (DKA) over a 14-year period at a major metropolitan adult tertiary hospital in Western Sydney. The key features of the clinic model include ensuring interval to first appointment is <6 months from last pediatric visit, SMS text reminders prior to all appointments, rebooking of missed appointments, a central mobile phone contact for the service, a diabetes educator as clinic coordinator, access to multidisciplinary team at a late finishing afternoon clinic, and phone support for sick days to prevent emergency department presentation. Data from 439 adolescents and young adults were analyzed.

Results: The study demonstrates that hospital admission for DKA is preventable if youth with diabetes receive regular follow-up and education with sick day advice at time of crisis. This study represents one of the largest and longest follow-up studies of youth with diabetes after transition from pediatric to adult health care and confirms the benefit of developmentally appropriate diabetes services in the adult health care setting.

#4: Example of an evidence-based HCT intervention with planning for transition + transfer assistance + care coordination

Lemke (2018) assessed the effectiveness of the AAP/AFP/ACP consensus statement on HCT with a nurse care coordinator process for adolescents with SHCN on the quality of chronic illness care and care coordination. Participants were 209 adolescents and young adults insured by single Medicaid-managed care organization for supplemental security income for youth with chronic conditions. They were randomized to receive enhanced usual care (n=104), which included transition care notebook, readiness assessment form, adult care referral list, and information on insurance, or the intervention (n=105), during which participants received enhanced care plus an HCT nurse and care coordination, which included in-person planning and regular phone calls focusing on practice-based and patient-level components of the Six Core Elements of HCT, which were individualized for each patient. Chronic illness care quality and care coordination differences were assessed between groups.

Results: The study demonstrated that the implementation of recommended HCT care coordination practices by a dedicated nurse care coordinator improved patient or caregiver perception of quality of chronic illness care and care coordination, especially among the most complex patients.

#5: Example of an evidence-based HCT intervention with planning for transition + transfer assistance + integration into adult care + care coordination

Agarwal (2017) studied an adult health care program model for emerging adults with type 1 diabetes transitioning from pediatric to adult health care. Evaluation of the Pediatric to Adult Diabetes Transition Clinic (PADTC) at the University of Pennsylvania non-pediatric hospital included a cohort of 72 emerging adults with type 1 diabetes, ages 18 to 25. Data were extracted from transfer summaries and the electronic medical record, which included sociodemographic, clinical, and follow-up characteristics. The program model was based on the SMART framework (Social-ecological Model of Adolescent and Young Adult Readiness to Transition) that helps identify modifiable and non-modifiable factors that determine the likelihood of transfer success. The modifiable variables were emphasized in the model program's six components, which included care coordination, orientation to adult health care, continuing education, behavioral support, engagement in care, and pediatric partnership.

Results: The emerging adults who attended the PADTC had measurable improved health outcomes and were likely to receive continued care. Findings from the study demonstrate that a transition program for emerging adults with type 1 diabetes based in an adult health care system can not only help retain emerging adults in care, but can also improve glycemic control (A1C) and blood glucose monitoring frequency outcomes.

Examples of Promising Practices

A review of AMCHP's Innovation Station⁹⁵ led to the identification of emerging and promising practices submitted by MCH programs across the country. Below are brief descriptions of select transition programs with noteworthy takeaways for NPM 12 Transition:

Care Connection for Children (*Emerging practice*). Care Connection for Children,⁹⁶ a Virginia state care coordination program for children and youth 0-21 years of age with cystic fibrosis or diabetes, aims to improve health outcomes by having and maintaining a medical home, assisting with and preparing for transition, obtaining medicine and equipment, navigating insurance, and understanding the child's condition. The care coordination services include obtaining adequate insurance, finding specialty providers, understanding treatment plans, finding resources to pay for medication and durable medical equipment, and providing information and referrals. In a 2013 program survey, 65% of parent respondents said they were better able to prepare their child for adulthood after participating in the care coordination program.

Florida Health and Transition Services (FloridaHATS) (*Emerging practice*). Administered by the Florida Department of Health, the mission of the FloridaHATS⁹⁷ program is to ensure successful transition from pediatric to adult health care for all youth and young adults, including those with disabilities, chronic health conditions, or other SHCN. Each of the 22 area offices

⁹⁵ <http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/Pages/Innovation-Station.aspx>

⁹⁶ <https://www.vdh.virginia.gov/care-connection-for-children/>

⁹⁷ <https://www.floridahats.org/>

has a care coordinator (nurse or social worker) who is tasked with identifying resources for the successful transition of adolescents and young adults with SHCN to all aspects of adult life. For example, the program based in Jacksonville aims to develop, test, and evaluate a model system of care for YSHCN in order to facilitate continuity of care during transition from pediatric-based to adult-based health care. Identified challenges included youth having difficulty leaving trusted pediatricians, lack of care providers willing to take YSHCN due to low Medicaid reimbursement, YSHCN losing important health insurance benefits when they turn 21, and many providers being unfamiliar with childhood onset conditions. Program staff gathered patient data regarding the number of emergency room visits and hospitalizations for the year prior to the intervention, which they then compared with similar data for the two years following the program. The data showed that there was a significant reduction in avoidable emergency room visits. When assessing transition readiness for YSHCN, they found that the percentage of youth receiving transition education significantly increased following participation in the program. In addition, there was also an increase in the percentage of youth whose regular source of primary medical care facilitated HCT.

Dare to Dream (D2D) Youth Leadership Development Initiative (*Emerging practice*).

Administered by the Rhode Island Department of Health, Office of Special Health Care Needs (OSHCN), D2D⁹⁸ is a statewide initiative aimed at promoting youth leadership and development by providing a forum (statewide youth led conference) that offers support, services, and opportunities for YSHCN to serve as mentors to other YSHCN. The D2D initiative evaluates the percentage of YSHCN who receive the services necessary to make transitions to all aspects of life, including adult health care, work, and independence. This is accomplished through an annual evaluation that includes process measures, such as number of youth recruited, trained, supported, and outcome measures.

Providers and Teens Communicating for Health (PATCH) Program (*Promising practice*).

PATCH launched its first year of programming in Madison, Wisconsin in 2010. It went national in 2017 with seven communities trained and certified as PATCH Sites. The Core PATCH Package⁹⁹ provides communities with a foundation and platform to improve HCT and overall health care experiences for young people through an innovative, youth-driven, multipronged, community-based approach. Becoming a PATCH Site encourages communities to engage and connect with various stakeholders; to align resources, policies, initiatives, and strategies within and across systems and sectors; and to build skills for convening, planning, and implementing shared/collective impact efforts. PATCH Programs can be aimed at youth, providers, and parents. Teens are trained to become advocates and educators, and they (under the direction of a site coordinator and with direction from the community advisory team) conduct workshops for providers and for their peers. For example, the PATCH for Teens: Peer-to-Peer Workshop is designed to educate and empower youth to learn to manage their own health care and to give them the tools needed to navigate and advocate for their well-being in health care settings.

⁹⁸ [https://health.ri.gov/specialneeds/about/daretodream/index.php#:~:text=Dare%20to%20Dream%20\(D2D\)%20is,they%20move%20through%20transitional%20periods](https://health.ri.gov/specialneeds/about/daretodream/index.php#:~:text=Dare%20to%20Dream%20(D2D)%20is,they%20move%20through%20transitional%20periods).

⁹⁹ <https://patchprogram.org/>

PATCH is seen as a promising and innovative strategy to help address MCH priorities, and it has been a key component of state-based MCH efforts, while also adding robust Collaborative Improvement and Innovation Network (CoIIN) strategies.

Health Services for Children with Special Needs (Incorporating the Six Core Elements of Health Care Transition in Medicaid managed care) (*Promising practice*). Few managed care plans have a systematic process in place for transition from pediatric to adult health care. With funding from the DC Department of Health Title V Program, Got Transition began a pilot project in Washington, DC to improve this transition to adult care in Health Services for Children with Special Needs (HSCSN), a DC-based managed care plan with 6,000 enrollees from birth to age 26 (McManus et al., 2015).¹⁰⁰ The project incorporated the Six Core Elements of HCT into a Medicaid managed care plan by customizing and integrating transition core elements within a Medicaid plan’s existing care management processes. The pilot found that the transition elements can be customized for a managed care organization within a short time frame (e.g., documents for youth must be at 5th grade reading level as required by DC Medicaid); managed care plans are in an excellent position to partner with state professional chapters of physicians and nurses to offer in-service training and best practices; it was a challenge to find adult practices that wanted to accept Medicaid-insured young adults with SHCN; and the transition process should begin at age 12-14 and not wait until the youth is near or at 18 years of age.

Health Care Transition in State Title V Programs

Although significant HCT efforts have been undertaken by State Title V agencies in the past, the NSCH data revealed that greater attention is needed with the vast majority of youth with and without SHCN not receiving transition planning guidance from their health care providers. *“Leadership from state Title V programs is critically needed to advance HCT improvements, in alignment with medical home, preventive care, and insurance performance measures and other statewide health reform initiatives”* (Ilango et al., 2018).¹⁰¹ In 2018, Got Transition provided ten recommendations around HCT for the 2020 grant application that remain worthwhile to consider:

1. **Select HCT as an NPM.** Building on the progress made over the past several years, states that selected NPM 12: Transition in the past are encouraged to continue to prioritize HCT. States that did not select transition in the past are encouraged to consider selecting it in the future; if this is not possible, states may want to identify strategies to incorporate HCT into their existing NPMs (i.e., medical home, adolescent and well women preventive care, and insurance adequacy).
2. **Publicize new HCT data.** State and national findings from the latest NSCH can be shared with key stakeholders to highlight the need for providers to devote attention to HCT as part of routine preventive, primary, and chronic care. States can also create communication strategies around the components of the transition measure, which include time alone with a health care provider, self-care skill development, privacy and consent changes at 18, and the age of eventual transfer to adult care.

¹⁰⁰ <https://pubmed.ncbi.nlm.nih.gov/26239121/>

¹⁰¹ <https://www.gottransition.org/resource/?2018-review-hct-titlev>

3. **Utilize the NSCH information as a baseline NPM objective.** States should use their state-specific NSCH data as baseline information on HCT to establish measurable objectives for the next five-year action plan. States may want to select a conservative aspirational objective, such as a 5% increase from baseline, over the span of five years. States may want to consider offering education to youth and families, health care professionals, and policymakers about HCT findings from the NSCH, with the aim of improving state HCT performance.
4. **Utilize Got Transition measurement tools.** States can utilize Got Transition’s HCT measurement tools to determine their progress in achieving implementation of evidence-informed HCT processes. These measurement tools can address different needs:
 - *Current assessment of HCT Activities*¹⁰² provides a quick snapshot of the level of HCT support available to youth and families in health care practices.
 - *HCT Process Measurement Tool*¹⁰³ provides a scorable assessment of HCT implementation with suggested documentation for each completed core element.
 - *HCT Feedback Survey* (for youth/young adults¹⁰⁴ and parents/caregivers)¹⁰⁵ provides an important way to elicit consumer feedback about the HCT process.
5. **Expand youth and family engagement and demand for a planned HCT process.** State Title V agencies have strong connections with family, disability, and youth organizations. Continued efforts are encouraged to actively engage youth, young adults, and families, especially those from racial and ethnic minority populations, in all aspects of HCT planning, implementation, and evaluation. This engagement is fundamental to the success of HCT and can be addressed through increasing involvement of youth in their own health and health care.
6. **Share new professional recommendations on HCT from 2018 AAP/AAFP/ACP Clinical Report.** States may want to update their websites, curricula, and education resources with this information, if they have not done so already. States may also want to consider partnering with their state AAP/AAFP/ACP chapters to disseminate these recommendations and other HCT resources available in their state and at www.gottransition.org.
7. **Make HCT improvements sustainable.** Title V programs are encouraged to reach out to senior leaders at the state Medicaid agencies and their contracted managed care organizations, as well as to commercial payers and health plans/accountable care organizations, to share evidence-informed HCT strategies and resources. Title V agencies may consider partnering with Medicaid, for example, on value-based transition pilots for YSHCN.
8. **Build partnerships with state agencies working on initiatives for transition-age youth.** Title V agencies have a long history of interagency collaboration efforts around early childhood. Similarly, efforts can be undertaken to incorporate evidence-informed HCT content into all state transition efforts, including those sponsored by the departments of special education, behavioral health, developmental disabilities, child welfare, juvenile justice, and social security.

¹⁰² <https://www.gottransition.org/6ce/?leaving-current-assessment>

¹⁰³ <https://www.gottransition.org/6ce/?leaving-process-measurement>

¹⁰⁴ <https://www.gottransition.org/6ce/?leaving-feedback-survey-youth>

¹⁰⁵ <https://www.gottransition.org/6ce/?leaving-feedback-survey-parent>

9. **Expand HCT quality improvement efforts in care coordination programs.** Since 2017, Got Transition has partnered with Title V agencies that support care coordination to implement and assess the use of evidence-informed HCT supports for YSHCN. Continued quality improvement efforts are needed to increase the level of HCT implementation in these programs. Got Transition will continue to conduct an annual assessment and share the results with each participating state. In addition, Title V agencies, in their systems development capacity, can reach out to other public and/or commercially funded care coordination programs to encourage similar efforts with accompanying measurement.
10. **Align with other NPMs with HCT.** Four NPMs can be aligned with HCT:
- *NPM 11: Medical home*—Title V agencies may consider reaching out to their state medical home leaders and commercial and Medicaid payers to encourage them to incorporate HCT into their medical home efforts, as suggested in Got Transition’s medical home practice resource, or to encourage medical home quality improvement efforts connecting pediatric and adult practices for youth and young adults with SHCN.
 - *NPM 10: Adolescent preventive care*—States may consider working with their adolescent health coordinators and other leaders in their state, including their Early and Periodic Screening, Diagnostic and Treatment (EPSDT) directors, to incorporate HCT into routine preventive care, as recommended in Got Transition’s clinician toolkit.
 - *NPM 1: Well women visits*—States may consider working with their state reproductive health leaders to include HCT in well women visits using the clinician toolkit.
 - *NPM 15: Insurance adequacy*—Title V agencies may want to reach out to their Medicaid officials working on health homes for individuals with multiple chronic conditions to examine potential opportunities for expanding the transitional care services and activities to include pediatric to adult transitional care, not just hospital to home transitional care (Ilango et al., 2018).¹⁰⁶

Youth Without Special Health Care Needs

While HCT research and implementation have focused primarily on YSHCN, there is also a need for youth without SHCN to transition, whether to gain knowledge and skills for navigating through the health care system or due to changes in the health care delivery system (e.g., some children’s hospitals and pediatric practices will not see youth 18 years of age and older). Without proper HCT preparation, youth and young adults 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). Leung and colleagues (2019) reviewed the transition-of-care studies that pertain to healthy and non-complex young adults. From the 9 included articles,¹⁰⁷ the study team concluded that the literature is limited regarding transition of care from pediatric to adult medicine for healthy and noncomplex adolescents and young adults.

¹⁰⁶ <https://www.gottransition.org/resource/?2018-review-hct-titlev>

¹⁰⁷ The inclusion criteria included English-language original research articles involving male and female patients ages 13 to 24 years with diagnoses that may be managed only by a primary care provider. The articles included qualitative and quantitative studies with prospective and retrospective data collections (Leung et al., 2019).

The primary consensus among the studies was a lack of written policies and guidelines regarding transition of care used in clinical practices. The majority of providers reported that their clinics did not have written policies regarding HCT or that many pediatric patients and their caregivers did not know if their clinics had transition policies. The studies also revealed that the goals of HCT, such as identification of an adult provider, familiarity with the health insurance industry, and the importance of attaining medical self-management, were rarely discussed with healthy adolescent patients or their caregivers. While clinicians agreed that talking with their adolescent patients alone was an important step in the transition process, only a fraction spoke one-to-one with young adults who did not have SHCN (Leung et al., 2019).

"With transitions of care positively affecting adolescents with special health care needs, similar effects should be anticipated for healthy or noncomplex adolescents who establish an ongoing source of care."

— LEUNG ET AL., 2019, P. 501

Transition readiness and independence in health care tasks. While most studies of transition in YSHCN focus on outcomes that have to do with maintenance of health, studies of youth without SHCN focus on outcomes having to do with transition readiness and independence in completing medical tasks. Transition readiness, or the degree to which adolescents self-manage health care responsibilities and demonstrate readiness to transfer from pediatric to adult providers, is salient during the emerging adulthood phase (Eaton et al., 2017). One study (Eaton et al., 2017) examined differences in transition readiness, self-involvement and parental involvement in completing medical tasks, and self-efficacy among a sample of adolescents and young adults with medical conditions and those without.

Among the 494 adolescents and young adults (18 to 25 years) surveyed, 378 were identified as healthy and 116 reported having a medical condition. Compared to healthy peers, adolescents and young adults with medical conditions had significantly higher transition readiness and higher involvement in completing medical tasks. YSHCN had significantly lower parent involvement in completing medical tasks than healthy peers (Eaton, et al, 2017). Adolescents with ongoing medical conditions are often given more exposure to transition-focused education before being transferred to adult providers, whereas non-YSHCN have lower rates of health care utilization, suggesting they may not have developed needed transition readiness skills (Eaton et al., 2017).

"Adolescents and young adults with medical conditions appear to have greater transition readiness skills and demonstrate more independence in completing medical tasks than healthy peers."

— EATON ET AL., 2017, P. 727

In a 2017-2018 national text message survey of youth aged 14-24 years, researchers asked three open-ended questions assessing participants' independence on three health care tasks: scheduling appointments, attending appointments, and picking up prescriptions. They also asked one open-ended question assessing their desire to be more, less, or equally involved in their care as

they are now (Schuiteman et al., 2020). Responses were given “independence scores,” with a score of 3 being the most independent. The data showed that overall, 33.9% of the sample had independence scores of 3, while 60.1% had scores of less than 3 (Schuiteman et al., 2020).

The younger adolescents (14-17 years) had the lowest scores, while most of the young adults (18-24 years) had independence scores of 3. Among this older age group, 33% stated that they wanted to be more involved in their health care (Schuiteman et al., 2020). The survey found that 22% of young adults had an independence score of less than 3 and also a desire to be less or equally as involved as they were at the time of the survey, which points to these respondents being at risk for a failed HCT (Schuiteman et al., 2020). Because of this risk, these young adults require special attention from health care providers and policymakers (Schuiteman et al., 2020).

Results and future work. The results of the text-message survey above are important because they show that many young adults have a desire to independently manage their health care and should be viewed as allies in HCT instead of barriers (Schuiteman et al., 2020). The authors suggest that primary care providers and specialists who care for young adults can facilitate their transition by routinely screening them for their current levels of engagement and desire to be more involved in their care. The young adults who are identified as being at high risk for poor transition during screening should be empowered to take control of their care, and their providers should schedule follow-up visits specifically to monitor their progress toward successful HCT (Schuiteman et al., 2020).

Research demonstrates that it is important to prepare all adolescents for successful HCT. Just as YSHCN need to trust that the quality of their care will continue as they transition to adult clinicians, youth without SHCN should be given the tools and confidence to enter the adult health care system. They need to feel that they can make informed decisions that will result in getting the best possible health care as they become adults. 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 adolescents and young adults during this vulnerable time of their lives.

“Future research must focus on the implementation of transition of care processes for all adolescents and young adults through continuous quality improvement methods using available guidelines and resources. Encouraging providers to use available guidelines and resources will improve the consistent delivery of transitional care.” — IEUNG ET AL., 2019, P. 510

Implications for Practice

The research being conducted to improve the HCT process provides valuable insights that can inform current Title V program initiatives and partnerships to better support adolescents moving from pediatric- to adult-oriented health care systems. The major takeaways below, from a broad review of the HCT literature, can inform program design and implementation efforts to provide greater support for HCT.

1. Barriers to successful health care transition

The process of transitioning from a child/family-centered model of health care to an adult/patient-centered model of health care can be particularly fraught for YSHCN. In an ideal transition, adolescents receive uninterrupted, developmentally appropriate medical care; however, many negative outcomes, such as non-adherence, missed medical appointments, and poor health outcomes suggest barriers to achieving optimal transition outcomes (Gray et al., 2018). *“Potential barriers to successful transition include a lack of time and resources to address transition issues, inadequate reimbursement, hesitancy of families and providers to dissolve long-standing therapeutic relationships, and gaps in residency training for both transition processes and medical management of adults with childhood-onset chronic diseases.”*¹⁰⁸ To improve the transition from pediatric to adult health care, it is important to understand the barriers that could prevent successful transitions, and identify practical and innovative solutions to overcome these challenges and improve transitional care.

In a systematic review of 57 studies that presented research on barriers of HCT for YSCHN, Gray and colleagues (2018) noted that even though each specific chronic illness has its own challenges for transition, there are certain barriers that exist across all chronic illness populations. They identified the following categories, in order of most frequently reported:

Relationships: Fear of losing longstanding relationships with pediatric providers and creating new relationships with adult doctors. To overcome this barrier, adolescents and young adults should meet with adult providers before transfer; continuity of communication between pediatric and adult providers may also help allay any feelings of abandonment and increase trust with new providers (Gray et al., 2018). Meeting the adult team is one of the three key features of transitional health care associated with improved outcomes (Colver et al., 2020). This introduction could be in a joint clinic where pediatric and adult clinicians consult together; or the adult clinician might visit the pediatric clinic to be introduced; or the young person might be taken to the adult clinic by a member of the pediatric team to meet the adult team (Colver et al., 2020). Joint planning between adult and child health care providers is likely to improve both transfer of the individual young people and adoption of ways of working which improve the overall health care of this population (Colver et al., 2020).

Further, successful HCT usually requires attention to other dimensions of a young person’s life, including living arrangement, transportation, postsecondary education, work, family and other

¹⁰⁸ <https://effectivehealthcare.ahrq.gov/products/children-special-needs-transition/research-protocol>

social relationships, and financial self-sufficiency (Institute of Medicine et al., 2007).¹⁰⁹ Even though health care providers are not responsible for these aspects in an adolescent’s life, they should be aware of how these factors may support or impede a successful HCT (Institute of Medicine et al., 2007).

Access/Insurance: Difficulty finding qualified providers and navigating insurance issues. YSHCN present broader challenges for transition, including issues related to insurance, entitlements, guardianship, and eligibility for adult community-based services.”¹¹⁰ Large-scale policy changes are needed to overcome barriers related to insurance; however, there are smaller changes that can also be beneficial to increase access. Research-informed recommendations include employing a transition coordinator or utilizing a system or transition navigator to help youth prepare for transfer and post-transfer (Gray et al., 2018). More specifically, have social workers on hand to serve as transition coordinators; they can help connect young adult patients with resources, educate them on how to navigate insurance and health care systems, and teach them how to advocate for themselves (Gray et al., 2018). Nurses could also play a significant role as “transition champions” by coordinating the transition process and working with the young person to prepare them for adult health care services (McCallum, 2017).¹¹¹

Beliefs/Expectations: Negative beliefs about adult health care vs. pediatric care. Pediatric provider ambivalence or negative beliefs about adult care may inadvertently communicate to adolescents that transition is something to be feared (Gray et al., 2018). To overcome any negative beliefs and expectations, families need to be educated about the differences between pediatric and adult care, and they should be encouraged to see the benefits of adult care and to treat transition as a positive milestone, similar to a graduation. Interactions with adult providers before transfer should be allowed, tours of the adult clinic provided, and connections with peers who have already transferred made to provide more perspective (Gray et al., 2018). Child and adult health care providers should also routinely explore with a young person how they approach transition, and they should personalize their clinical approach to allay any fears and best meet the unique needs of each adolescent (Colver et al., 2020). In addition, a structured transition plan can be created to provide a tangible roadmap (Gray et al., 2018).

Knowledge: Limited knowledge about medication, illness, and the transition process. Knowledge was a common barrier suggesting that patients and their families need to have ongoing education on disease management (Gray et al., 2018). Illness education is most commonly provided at the time of diagnosis, and it is usually taken for granted that patients are well-informed about their health conditions in adolescence. The barrier of knowledge is closely linked with the next most reported barrier of *Skills/Efficacy*, which is lack of skills to manage illness, handle medication, etc. Both barriers can be overcome by focusing on improving self-management, which is associated with better health-related quality of life (Sattoe et al., 2015). Parents and/or caregivers

¹⁰⁹ <https://www.ncbi.nlm.nih.gov/books/NBK11432/>

¹¹⁰ <https://effectivehealthcare.ahrq.gov/products/children-special-needs-transition/research-protocol>

¹¹¹ The use of transition coordinators does not address a lack of providers who will take patients with SHCN.

should be given guidance on how to gradually shift responsibility for managing illness to their adolescents before transfer to adult care.

Relational barriers fostering dependency were often cited as impediments to youth self-management skills (Gray et al., 2018). To overcome this barrier, there must be an appropriate level of parental involvement, characterized by the presence or absence of parents in the clinic and who does the talking (Colver et al., 2020). In addition, parents and caregivers can initiate at-home discussions about their adolescent's health and how to manage it (Colver et al., 2020). Appropriate parent involvement is the second key feature of transitional care that is associated with improved outcomes (Colver et al., 2020).

Transition of YSCHN should begin in early adolescence, and pediatric providers can promote self-efficacy and readiness by adopting the core elements of transition: seeing adolescents alone for part of the visit, adopting a structured transition plan, and regularly assessing transition readiness (Gray et al., 2018). Health self-efficacy, or the promotion of a young person's confidence in managing their own health condition and wider health, is the last key feature of transitional health care linked to positive outcomes (Colver et al., 2020), and it needs to be cultivated for a successful transition to be realized.

"It is time to move past descriptive work and begin the theory- and hypothesis-driven research. We need to understand how the experience of barriers impacts objectively measured transition outcomes, such as time to transfer, transfer readiness, and health care outcomes and costs." — GRAY ET AL., 2018, P. 497

Taking care of young adult patients, whether they have SHCN or not, comes with challenges; they take more time, they have more high-risk behaviors, and they need more counseling to get ready for the adult world.¹¹² Because these patients can face barriers to transition, such as the ones noted above, it is important for pediatric providers to establish relationships with their colleagues in adult medicine and make connections outside of their individual silos.¹¹³ *"Fostering collaborations across institutions and disease populations to share innovative solutions is an important clinical direction that can open the way to sharing resources from many of the currently developing transition interventions"* (Gray et al., 2018).

2. Considerations to promote health equity and increase access to health care transitions

Location, Location, Location. The majority of studies included in this review looked at interventions and programs that took place in large multi-specialty or tertiary hospital systems or in outpatient clinics associated with larger hospitals. This type of setting is ideal for YSHCN as they transition to adult health care services. For example, in a large academic hospital system in Cleveland, Ohio, young patients with complex medical needs are seen in pediatric clinics where they stay in one exam room while specialists who are trained across the spectrum of pediatric

¹¹² Phone call on 7/9/2020 with Margaret Stager, MD, Division Director of Adolescent Medicine, MetroHealth, Cleveland, OH.

¹¹³ Phone call on 7/9/2020 with Margaret Stager, MD, Division Director of Adolescent Medicine, MetroHealth, Cleveland, OH.

and adult medicine rotate in to provide seamless care.¹¹⁴ Small communities and rural settings are more problematic; some adult health care providers are not trained to care for children with complex medical needs, so YSHCN who live in rural settings sometimes get fragmented care.¹¹⁵

The two studies included in this review that looked at HCT in community settings (Cappelli, 2016; Colver, 2018) were primarily focused on mental health services and did not offer any insights to inform transition efforts in small or rural settings. One study (Burns, 2018) compared length of hospital stays for youth with diabetes who were seen in specialty clinics of larger hospitals versus those youth who were “unsupported” and seen only by their general practitioners. This latter group of patients came from a more socially disadvantaged area and had less access to after-hours phone support, diabetes education, and nurse educators who had expertise in diabetes care. The authors saw a fourfold increase in hospital admissions from this group compared to the patients who had been seen in specialty clinics, but they acknowledge that there were many unknowns when studying youth in the unsupported group and further study is warranted (Burns, 2018). Because transition opportunities might be more limited in private practice/family or primary care facilities as compared to large multi-specialty or tertiary hospital systems, it is important to consider these geographical and setting differences when framing access issues to promote health equity.

“Care for some patients may be appropriately provided in primary care at the community level; for others, it may be appropriately provided only in highly specialized regional or academic centers.”

— MCPHEETERS ET AL., 2014, P. VI

Education, ethnicity, and economics. Using the 2016 NCSH data on HCT among youth with and without SHCN, Lebrun-Harris and her colleagues (2018) noted different sociodemographic factors that may influence transition outcomes. These are critical to note if transition programs want to promote health equity and increase access.

In terms of the overall transition measure, the data showed that:

- Among non-YSHCN, being uninsured was associated with a 41% decreased prevalence of the overall transition measure compared with being privately insured.
- Older age (15-17 years) was the only sociodemographic factor associated with meeting the overall transition measure and individual elements for YSHCN and non-YSHCN.

In terms of discussing the shift to adult health care providers, the data showed that:

- Having a parent and/or caregiver with some college or a college degree was associated with a decreased prevalence of health care providers discussing the shift to adult health care providers, compared with having only a high school diploma.

¹¹⁴ Phone call on 7/9/2020 with Margaret Stager, MD, Division Director of Adolescent Medicine, MetroHealth, Cleveland, OH.

¹¹⁵ Phone call on 7/9/2020 with Margaret Stager, MD, Division Director of Adolescent Medicine, MetroHealth, Cleveland, OH.

- Non-Hispanic Black or African American non-YSHCN had a decreased prevalence of discussing the shift to adult providers compared with their non-Hispanic white counterparts; however, they had an increased prevalence of working with providers to gain skills or understand changes in health care.
- Non-Hispanic Black or African American youth were more likely to work with their provider to gain skills and understand changes at 18, compared with non-Hispanic white youth, but were also less likely to discuss the shift to an adult provider. In explaining this last point, Lebrun-Harris and colleagues speculated that perhaps a larger proportion of non-Hispanic Black or African American youth are seeking care without parents present and are more likely to be seen by clinics that care for all ages; therefore, they do not need to transfer to a different provider.

When looking at time spent alone with health care providers, the data showed that:

- Male youth of any race with a parent and/or caregiver with a college degree had an increased prevalence of having time alone with their health care provider at their last preventive visit.
- Patients with households between 100% and 199% of the federal poverty level (FPL) had decreased prevalence of having time alone with their health care provider at their last preventive visit compared to households above 200% FPL. Similarly, patients without insurance had a decreased prevalence of having time alone.
- Youth with households between 200% and 399% FPL had an increased prevalence of discussing the shift to adult providers, compared with those from households at or above 400% (Lebrun-Harris et al., 2018).

In discussing the above findings, Lebrun-Harris and colleagues state that *“the findings that youth from households with lower incomes and youth from households with less education were more likely to discuss the shift to an adult health care provider compared with their counterparts from higher income, higher education households are also difficult to explain. More research is needed to shed light on these unexpected findings”* (Lebrun-Harris et al., 2018). Overall, to improve transition performance, health care providers who care for youth should consider how to incorporate transition as part of routine health care visits, including time alone to help prepare youth for managing their own health and health care (Lebrun-Harris et al., 2018).

3. The cost of health care transition

There are multiple costs associated with the transition from pediatric to adult health care. In the triple aim framework developed by the Institute for Healthcare Improvement, population health, experience of care, and per capita cost are considered key dimensions in efforts to optimize health system performance.¹¹⁶ According to Donald Berwick, MD, President Emeritus and Senior Fellow, Institute for Healthcare Improvement, the goal is to improve the health of populations and improve the patient experience of care *while* reducing per capita cost. He explains, *“that is because the needs of the society—the people we serve—go beyond healthcare. They’ve got other things to do with their resources. They may want to go to the movies tonight, or a corporation*

¹¹⁶ <http://www.ihl.org/Engage/Initiatives/TripleAim/Pages/default.aspx>

may want to be more competitive and pay its workers more, and government may need to put more money into roads or schools.”¹¹⁷

The cost of HCT from pediatric to adult care can be experienced on many different levels. Adolescents and young adults may lack health insurance; health care systems may lack human/financial resources; health care practitioners may not be reimbursed by health plans for costs associated with HCT; and federal, state, and local governments may not have the capacity to help reduce the cost of transition services. Current payment structures do not promote innovation in improving HCT.¹¹⁸ Families also struggle to cover costs associated with HCT, particularly when their children have physical, mental, and/or intellectual disabilities. With many YSHCN facing costly and dangerous gaps in care as they transition from pediatric to adult health care systems, there is a need for new, financially sustainable approaches to transition to close these gaps (Vaks et al., 2016).

In a review of the literature addressing the economic impact of transition from youth to adult mental health services, Barr and colleagues (2017) identified 5 studies (4 conducted in the U.S.) that underscore the financial demands placed on youth and their families. These include the loss of employment income and productivity, increases in the cost of care at the time of transition (often related to health insurance status), and informal support provided by unpaid caregivers. Franklin and colleagues (2019), who reviewed the transition literature addressing youth with intellectual disabilities, also note the “costs”—both in terms of financial demands and psychological sacrifices—placed on parents, including the effects on other siblings (a key concern), inability to travel, marriage difficulties, and loss of job opportunities because of the need for health insurance and economic stability. At the same time, however, parents displayed hopefulness, particularly when they had support from peers. They consistently explained that the benefits of having an adolescent or young adult with special needs outweighed the costs, and that their lives were richer as a result (Franklin, 2019).

Despite the significant costs associated with HCT, few research studies have measured cost outcomes that could help reduce the economic challenges experienced by youth, families, providers, health care systems, and public health entities. In their systematic review of the transition intervention literature, Schmidt and colleagues (2020) found only one recent study that measured cost as an outcome. In that single study, Burns and colleagues (2019) report an estimated cost savings of \$250,000 in hospital bed days attributed to support from a youth-specific diabetes clinic. This figure is based on differences in the number of hospital admissions and the median length of hospital stays by youth with type 1 diabetes mellitus who received HCT clinic support compared to those who did not (Burns et al., 2019).

The list of recommendations set forth in the AAP’s guidance on HCT (White et al., 2018) includes the need for research that supports a stronger evidence base. They recommend that

¹¹⁷ “An Overview of the IHI Triple Aim” at https://www.youtube.com/watch?v=a_QskzKFZnI&feature=youtu.be

¹¹⁸ <https://www.health.state.mn.us/docs/people/childreneyouth/cyshn/transitionwp.pdf>

study designs include all 3 components of HCT (preparation, transfer, and integration into adult care) and that HCT processes and outcomes should both be evaluated. Cost savings, including decreased emergency department use and urgent care visits, are among the transition outcomes that should be examined (White et al., 2018).

In efforts to help improve financing for the health care of adolescents and facilitate a smoother transition into adulthood, the AAP also recommends strategies involving HCT payment plans, policies, and collaborative efforts that improve HCT outcomes while addressing health care costs. The following recommendations are included:

- To align HCT delivery system innovations with payment incentives, public and private payers and their contracted plans should:
 - Develop innovative payment approaches to encourage collaboration between pediatric and adult care clinicians in the adoption of the HCT; and
 - Compensate clinicians and systems of care for the provision of recommended HCT support related to planning, transfer, and integration into new health practices (White et al., 2018).
- To provide sufficient payment to physicians and other health care providers for medical services to adolescents, insurers' claims systems should recognize and pay for all preventive medicine Current Procedural Terminology codes related to services for health and behavior assessment, counseling, risk screening, and/or appropriate interventions recommended in *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, 4th Edition* (Hagan et al., 2017).¹¹⁹ These services should not be bundled under a single health maintenance Current Procedural Terminology code (Alderman et al., 2019).
- Government and private insurance payers should increase the relative value unit allocation and level of payment for pediatricians delivering care and clinical preventive services to adolescents to a level that is commensurate with the time and effort expended, including health maintenance services, screening, and counseling (Alderman et al, 2019).
- All health plans should provide preventive services without member cost sharing. In addition, to reduce financial barriers to care for adolescents, payers should limit the burden on families by reducing or eliminating copayments and eliminating coinsurance for visits related to anticipatory guidance and/or treatment of sexual and reproductive health, behavioral health, and immunization visits (Alderman et al, 2019).
- Federal and state agencies should increase their efforts to further reduce the number of adolescents who are not insured or who lack comprehensive and affordable health insurance (Alderman et al., 2019).

4. Insurance and health care transition

Changes resulting from the Affordable Care Act (ACA)¹²⁰ have helped to support the transition from pediatric to adult health care, both by making insurance coverage easier to obtain and by reducing the proportion of young adults with disabilities who report access difficulties due

¹¹⁹ https://brightfutures.aap.org/Bright%20Futures%20Documents/BF4_Introduction.pdf

¹²⁰ <https://www.hhs.gov/healthcare/about-the-aca/index.html>

to cost (Huang et al., 2019). The ACA helped ease the transition for young people and their families, allowing more time to navigate through the transition process (extending coverage for dependents through age 25); eliminating previous coverage exclusions due to pre-existing conditions; and providing health-insurance enrollment options that do not require a disability designation by the Social Security Administration.

As a result of these healthcare system changes—combined with Marketplace Exchanges and Medicaid expansion in adopting states—the percentage of teenagers (ages 13-18) and young adults (ages 19-25) with disabilities who have insurance has risen. Combining both public and private health insurance options, coverage increased 8.96% for young adults and 4.45% for teenagers with disabilities. At the same time, young adults with disabilities report a lower probability of experiencing delayed medical care and not receiving needed medical care (Huang et al., 2019).

While the ACA has helped to eliminate gaps in health coverage during the transition period, Huang and colleagues acknowledge barriers that still need to be overcome. Young adults with disabilities should be encouraged to *access* all beneficial policies, and with this in mind, a policy protocol might be put in place to ensure a smooth transition between health care planning and ACA provisions. Also, the affordability of available health insurance plans remains a concern, and some covered services may not adequately address the health needs of teenagers and young adults with disabilities. Whether or not the coverage provided under the ACA will include the home and community-based services that are needed by many adults with disabilities remains to be seen (Huang et al., 2019).

Webb and colleagues summarized some of the key characteristics of youth transitioning to adult care, noting the importance of increasing health insurance enrollment for individuals both with and without SHCN (Webb et al., 2015). Compared to the general population, young adults are likely to change jobs and geographic locations more frequently. They are likely to have lower incomes and experience higher rates of unemployment. They are also more likely to be self-employed or work for smaller companies that may not supplement health insurance. And while they live in various settings—whether independent living, colleges or universities, or their parents' homes—they all face many of the same challenges as they transition into adult care. A growing number of young adults believe that it is important to have health insurance, but they are concerned with the cost (Webb et al., 2015). Not surprisingly, young adults are more likely to be uninsured than older adults, who have greater access to employer-sponsored health insurance, as well as children, who have greater access to either private health insurance through parental coverage or through government programs including Medicaid and the Children's Health Insurance Program (Webb et al., 2015).

Youth whose insurance coverage during childhood allowed them to see the providers they needed are more likely to make a successful transition (Oswald et al., 2013). For that reason, it is optimal to prevent gaps in health coverage during the pediatric-to-adult care process.

Studies indicate that healthy adults and young adults lack sufficient knowledge regarding health insurance (Leung et al., 2019), which presents a “teaching opportunity” for parents, providers, and health care administrators. Suggestions proposed by Webb and colleagues (2015) include HCT training and education for health care providers and specialized training for “navigators” and consumer assistants who can help transition young adults from pediatric to adult health services. Enrollment of youth in health insurance plans (including college students, immigrants, and youth transitioning out of foster care) should be approached using strategies that both foster awareness and facilitate the process of bridging pediatric and adult care systems, Webb explains, adding that successful recruitment of this population will support the financial viability of the ACA while providing health, social, and monetary benefits to enrolled youth.

Health Systems and Policy Change to Support Health Care Transition

For many young people with serious disabilities and SHCN, successful HCT will also depend on health systems changes and public policies that support access to health insurance, assistive technologies, personal care services, housing, vocational training or postsecondary education, and income support, as well as public policies that support nondiscrimination in employment and the physical accessibility of transportation and public spaces (Institute of Medicine et al., 2007). Policy decisions that affect specific provisions for transition planning or transfer assistance for young people are critical environmental factors that directly or indirectly support or complicate the HCT process. In 2017, Steinway and colleagues from the Policy Lab at CHOP¹²¹ identified policies, processes, and obstacles surrounding the transfer of care process.

These challenges from the pediatric provider perspective include: 1) insufficient time and low adherence to transition guidelines; 2) lack of consensus on transition policies and procedures; 3) poor documentation of transition discussions or activities in the health record; 4) inadequate access to adult providers with sufficient medical expertise; and 5) failure to address medical decision making (Steinway et al., 2017). For adult providers, similar barriers also emerged: 1) inadequate time for office visits and care coordination between visits; 2) lack of information on community resources, care coordination reimbursement and legal issues; and 3) inconsistent levels of communication from pediatric providers (Steinway et al., 2017).

Informed by the growing literature on transition for YSHCN, recommendations for practices and providers to overcome the aforementioned challenges and to ensure a smooth transition for all include:

- Start early in preparing adolescents, or their proxy caregivers, to take on the role of primary medical decision maker in managing their care once they reach adulthood.
- Sending and receiving providers should develop methods that facilitate bidirectional communication.
- Consistently follow the transition guidelines developed by Got Transition.
- Develop strategies that improve care coordination, implementation of transition readiness assessments, checklists, and clinical pathways (Steinway et al., 2017).

¹²¹ <https://policylab.chop.edu/>

To better support providers in carrying out best practices and offering the highest standard of care, recommendations for actions that health care systems can take to assist in improving the transition process include:

- Institutions can enhance opportunities for pediatric and adult providers to interact by eliminating barriers that prevent communication and collaboration in patient care.
- Pediatric hospital systems with high volumes of adolescent and young adult patients with chronic illness should designate an entire clinical practice or consulting service to coordinating the transition of young adult patients, particularly those with complex chronic illness.
- Health systems should invest in and utilize EHR supports.
- Health systems should address means to access and support the decision-making of maturing youth (Steinway et al., 2017).

“An interprofessional team approach can help large pediatric healthcare systems address the multi-faceted needs of patients who are medically and psychosocially complex as they enter adulthood.”

— RAZON ET AL., 2019, P. 136

The availability of supports, such as access to health insurance and a sufficient pipeline of providers, depends on policymakers establishing needed policies and funding structures. Actions that state and federal policymakers can take to support providers, adolescents and their families through the transition process include:

- State Medicaid directors should help to prevent the often predictable gaps in health care coverage and access.
- The Centers for Medicare and Medicaid Services (CMS) should utilize innovative, consistent, and thorough transition payment models that would allow compensation for transition-related services, thus incentivizing their use.
- CMS should shift care coordination and care management to payers.
- CMS, state Medicaid programs, and private insurers should create more flexible billing policies to allow both pediatricians and adult primary care providers to bill for the same patient during the transition and transfer process.
- Medicaid, which covers the majority of the cost teaching hospitals spend on training medical residents, should increase training opportunities and residency slots for physicians working with medically complex youth and young adults.
- The Patient-Centered Outcomes Research Institute (PCORI), an independent organization dedicated to funding research projects that enhance patient, provider, and policymaker clarity around informed health care decision making, and the U.S. Department of Health and Human Services’ Agency for Healthcare Research and Quality should continue to fund research around the transition process from pediatric to adult health care (Steinway et al., 2017).

“Providers, health systems, and policymakers should work to address these avoidable barriers... These concrete action steps can help to ensure that young people with complex medical needs accomplish a smooth and successful transition between pediatric and adult health systems, and continue to receive the care they need to lead full and healthy lives” (Steinway et al., 2017). Widespread implementation of HCT systems requires this type of strategic thinking and planning to ensure progress. Policy changes are just as instrumental in supporting young people’s transition from child to adult health care services.

Research Gaps in Pediatric- to Adult-care Transition Evidence

Hart and colleagues (2019) conducted a review of reviews that focus on transition from pediatric to adult-oriented health care. Their efforts resulted in an “evidence map” that identifies gaps in the transition literature that can help guide future research. Out of 37 reviews that met the authors’ eligibility criteria—including the requirement that at least one study evaluated included a quantitative health care outcome for youth with a chronic illness—71 unique primary studies were identified.¹²²

With type 1 diabetes being the chronic illness most prominently represented in the transition literature—both among the reviews and the trials included in those reviews—the authors concluded that more research is needed regarding more common childhood onset conditions, such as asthma, attention deficit hyperactivity disorder, autism, and depression.¹²³ They also note that they were unable to find reviews focused on individual mental health diagnoses, such as anxiety and depression, distinct from reviews focused on all mental health diagnoses in general, stating that the *“transition needs of those with depression or anxiety may be different from those with more severe mental illness, such as bipolar disorder or schizophrenia.”* They add that *“a more nuanced review or set of reviews looking at mental health diagnoses individually may allow for greater understanding of the similar and unique transition needs of these populations.”*

“We strongly believe that clinical and research efforts should go hand in hand. Currently, there is no existing infrastructure to facilitate collaborations across chronic illnesses. Fostering collaborations across institutions and disease populations to share innovative solutions is an important clinical direction that can open the way to sharing resources from many of the currently developing transition interventions.” — GRAY ET AL., 2018, P. 497-498

Among their key findings, Hart and colleagues reported a lack of transition interventions focused on the *adult care* portion of transition. They suggest that research in transition consider a wider breadth of interventions in the adult realm and consider testing tools that support adult transition,

¹²² The reviews themselves most commonly sought to describe transition interventions (14 of the 37 reviews overall and 8 of the 20 reviews without a specific diagnosis of interest). The next most common focus was a review of the literature in general (9 of the 37 total reviews and 4 of the 20 reviews without a diagnosis of interest).

¹²³ Most of the systematic reviews (20) did not focus on a specific diagnosis. Among those reviews that focused on a specific diagnosis, type 1 diabetes was the most common diagnosis of interest (7 reviews), followed by mental health problems (2 reviews). And while the diagnosis of interest in the included studies varied, type 1 diabetes was the focus in 24 of the 71 primary studies evaluated by Hart et al. (2019).

such as provider education, meetings with social workers at the first visit, and efforts by adult clinics to re-schedule missed appointments. *“Integration into adult care and measurement of longer-term outcomes for young adults with childhood-onset conditions after their transfer to adult care are key needs,”* they report.

Hart and colleagues also identified the lack of papers focused on transition in primary care settings as another gap to address in future transition research. Although interventions in specialty settings have been well-received by patients and families, they can be resource intensive—for example, involving a social worker focused on transitioning patients or requiring “dual visits” where a pediatric and adult care provider see the patient simultaneously. Such models are difficult to translate directly to primary care, however, where only one physician is paid. The authors therefore recommend that *“when considering research in primary care transition, investigators are encouraged to test novel interventions that would augment or adapt the previous transition work that has been done”* (Hart et al., 2019).

Future Directions

With young adults increasingly recognized as a vulnerable population due to high rates of behavioral health risks, susceptibility to emerging or worsening chronic health conditions, and traditionally low use of health care (White et al., 2018), it is critical to support youth of transition age as they move into adulthood by engaging in a structured HCT process. Since many youth regard health care as a low priority compared to other dimensions of their adult transition, such as education, employment, housing, relationships, and recreation, it is important to change attitudes, beliefs, and perceptions so adolescents and their families see health maintenance and continuity of care as central to the attainment of broader adult goals (White et al., 2018).

To this end, especially for YSHCN, a greater focus on appropriate parent involvement, promotion of youth self-efficacy, and building a bridge between the pediatric and adult health care systems so adolescents can meet the adult health care team prior to transfer, can vastly increase the likelihood of positive transition outcomes (Colver et al., 2020). 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). In addition, linking transition efforts to post-transfer outcomes is vital to evaluating the effectiveness and value of transition intervention services (Gray et al., 2018). While this can be challenging, due to an absence of established markers of success for HCT, the difficulty of tracking young adults across institutions, and limited reimbursement for HCT-related services, the efforts are needed in order to ensure the effectiveness of transition programs and to optimize health outcomes (Gray et al., 2018).

A structured HCT process can avoid a meandering path to adult care or an abrupt transfer to a new system of care that could leave millions of youth floundering and without access to needed health services during their emerging adulthood. Supporting patients who feel anxious about transition requires a multidisciplinary approach involving physicians, nurses, psychological

specialists, social workers, and other relevant personnel, and it takes a long time in terms of transitional medical care throughout adolescence and young adulthood (Kubota et al., 2018). That is why the financial support of administrative agencies is necessary for practical implementation of transition support (Kubota et al., 2018). As so aptly stated by Schmidt and colleagues (2020), 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 SHCN and chronic conditions.

FROM EVIDENCE TO ACTION

The MCH Evidence Center developed this report as 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. Interventions identified by this process form the cornerstone by which Title V agencies can construct programs and measures that will affect change with their unique populations and advance their NPM topic areas. As such, this is a first step in a long process for meeting National Outcome Measures (NOMs).

If you are looking to build or strengthen efforts to improve the transition of care for adolescents from pediatrics to adult health services in your state or jurisdiction, moving “from evidence to action” can seem daunting. The MCH Evidence Center has developed the following framework, tips, and resources to help you through the process. We have developed resources and provide TA for you at every step of this process:

1. Evaluate the evidence to guide your work. Aligning programs and measures with the evidence base helps to ensure programs meet the needs of infants, children, youth, and their families and have the most potential to affect change. We invite you to read through this report to understand the way each intervention identified root causes that were preventing change, produced a new, desired behavior change, and engaged partners and resources that yielded measurable effects.

You can also access additional evidence resources through our NPM 12: Transition Toolkit (<https://www.mchevidence.org/tools/npm/12-transition.php>) including:

- A summary of the evidence identified by this report.
- Promising practices as identified by AMCHP’s Innovation Station.
- Current ESMs used by other states and jurisdictions to use as examples.
- Examples of ESMs that include link back to the evidence and show ways to measure effect.

In developing programs based on the available evidence, a critical factor is to ensure that identified interventions are applicable and adaptable to your population needs. The MCH Evidence Center utilizes Harvard University’s Science-Based Intervention Framework to ensure effectiveness by asking the following questions: *What* about the intervention works? *How* does it work? *In what contexts* does it work? And finally, *for whom does it work* and for whom does it *not* work?¹²⁴ Details about this approach are included in the NPM Toolkit.

As you use resources from the Toolkit, we encourage you to share your thoughts and feedback. This will enable the MCH Evidence Center to track use of the resources in a consistent manner to learn how to better design implementation strategies, monitor uptake and use of interventions, and provide platforms for future research driven by the field.

2. Use a structured approach to integrate evidence into your work to measure process and outcomes. There are many effective approaches for identifying needs and developing programs to address those needs. The MCH Evidence Center uses Results-Based Accountability (RBA) as a suggested method to align program performance (performance-based accountability, e.g., measurement of ESMs) with population goals (population-based accountability, e.g., NPMs and NOMs) and improve measurement of activities.

RBA helps you decide which outcome you would like to address. Begin the process of selecting an intervention by deciding which outcome you would like to address and how you will measure your success in changing that outcome. Choosing the most fitting intervention for your community, setting, population, and context benefits from careful attention to the expected/intended outcomes of the strategy.

- RBA helps to ensure that ESMs align with and advance achievement of NPMs (and eventually NOMs) through a series of 7 performance accountability questions that address:
 - Desired impact change on a targeted group.
 - Mechanisms to deliver services effectively.
 - Ways to engage appropriate partners.
 - How to identify what specifically works to produce measurable outcomes.
- RBA works to strengthen measurement of ESMs through a 4-quadrant system to increase measurement of ESMs by addressing:
 - Quantity of the effort (what did we do?—most basic measure).
 - Quality of the effort (how well did we do it?).
 - Quantity of the effect (is anyone better off?).
 - Quality of the effect (how are they better off?—most advanced measure).

¹²⁴ Center on the Developing Child, Harvard University <https://developingchild.harvard.edu/>

3. Incorporate MCH principles and needs to focus your work. We are mindful of the needs of MCH programs and the need to strategically use and document Title V resources to advance NPMs. This is done by:

- Linking your work back to MCH priorities in that interventions developed are meaningful, measurable, and achievable.
- Ensuring that ESMS always measure the work that is directly related to the appropriate NPM, addresses inequities to advance health equity, and is effective with multiple population groups.
- Leveraging the resources of and coordinating with HRSA MCHB-funded centers.

To accomplish these goals, the MCH Evidence Center suggests using Harvard University's *Frontiers of Innovation* approach to ask the following questions about evidence-based and evidence-informed interventions as you incorporate them into your work:

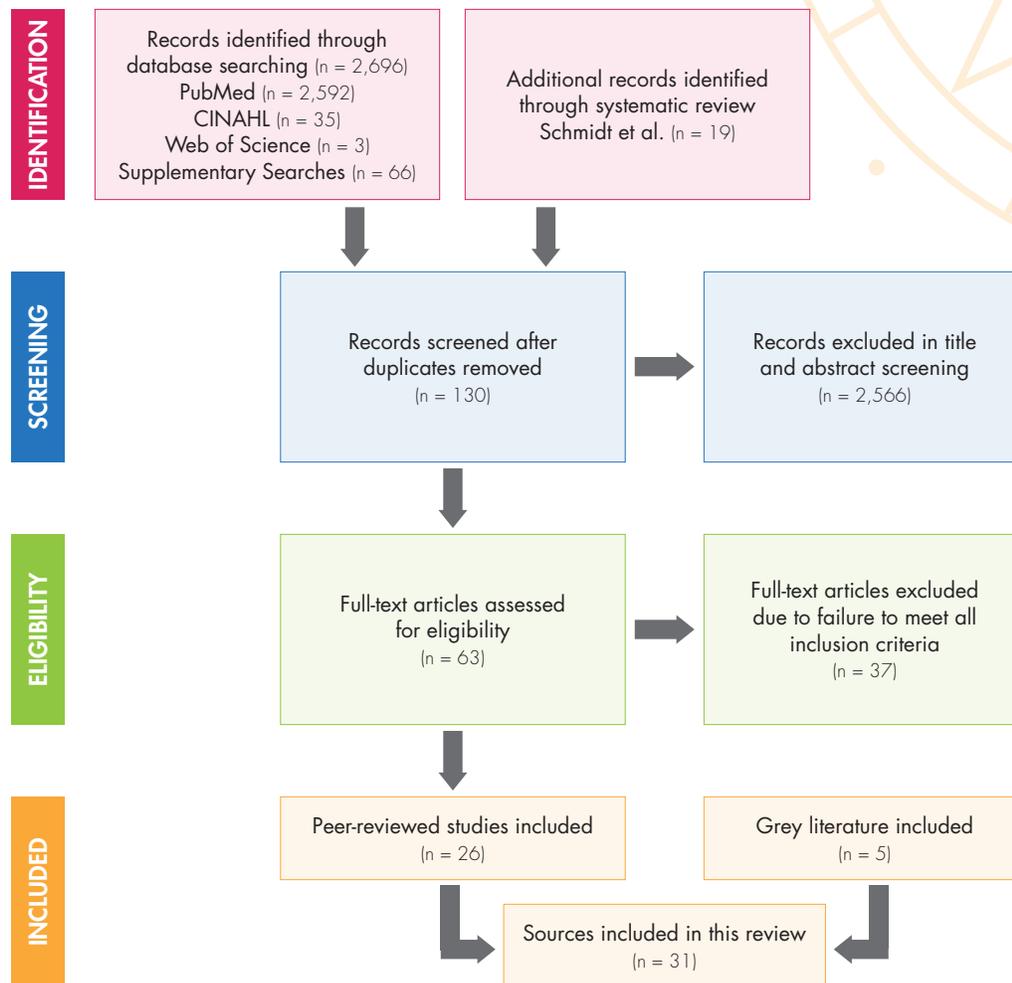
- **What about it works?** If we understand the key ingredients, we can replicate them.
- **How does it work?** Being specific about the underlying mechanisms can help us increase the impact.
- **For whom does it work, and for whom does it *not* work?** When we know who is and isn't responding, we can make targeted adaptations to improve outcomes.
- **In what contexts does it work?** By evaluating the context in which a program is implemented, we can adapt it for other settings.

With all the time, effort, and resources that go into incorporating evidence-based and evidence-informed interventions into your programming, it is critical to share your successes with Title V state and national programs, legislators, and others who can help support policy change and provide funding for initiatives to improve HCT. To aid in this task, we encourage you to gather and report information on your use of these interventions to Title V program leaders to shine the spotlight on progress being made at the practice level to support transitional care for youth with and without SHCN. These data points could be used to leverage additional funding and/or policy change in the future.

As you work through the process of moving from evidence to action, please reach out to our staff with questions and for technical assistance. We are available to assist you when you need help. Email us at mchevidence@ncemch.org.

FIGURES AND TABLES

FIGURE 1. FLOW CHART OF THE REVIEW PROCESS AND RESULTS



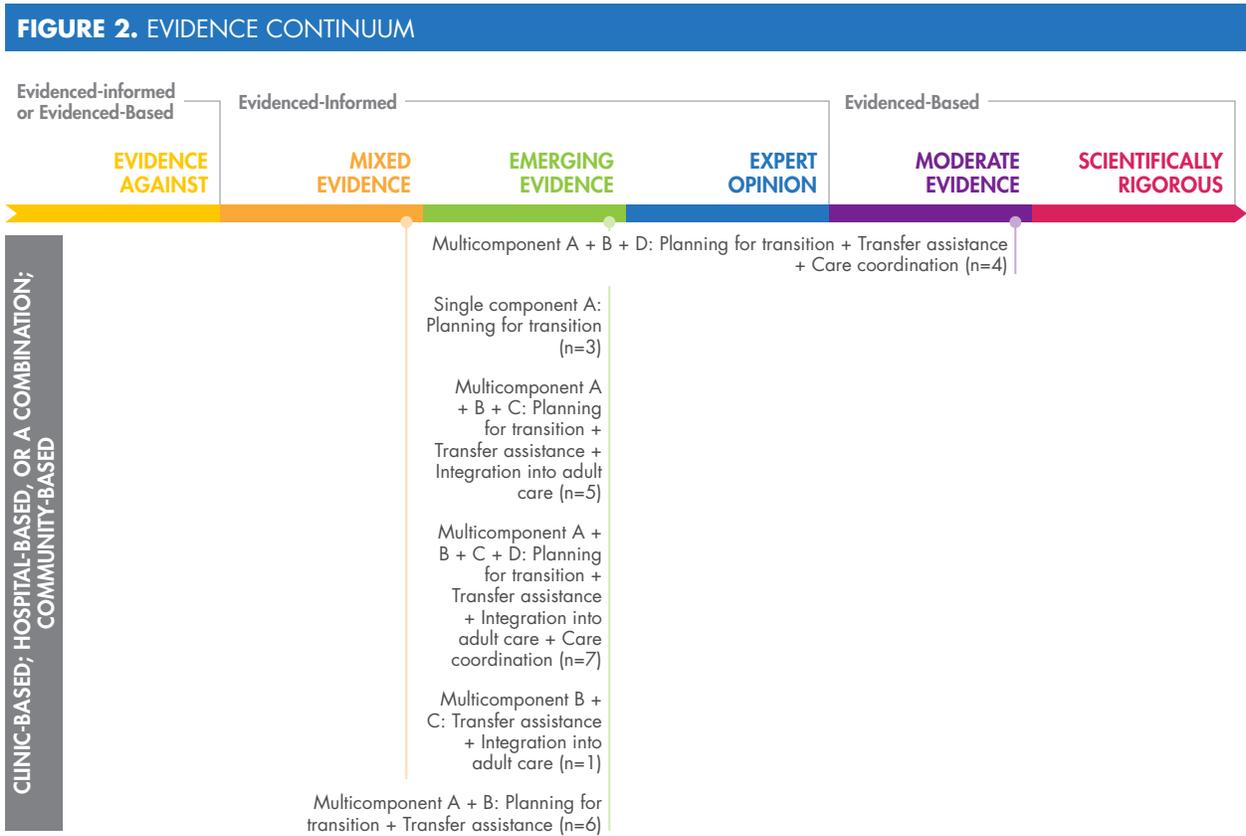


TABLE 1: DETAILED SEARCH STRATEGIES

DATABASES SEARCHED	SEARCH TERMS USED	NUMBER OF RESULTS
PubMed	transition to adult care or transferring to adult care or transfer to adult care or pediatric transition to adult care AND satisfaction or barriers or needs AND cost or health care costs Limited to 2019-2020	57
	New search: pediatric to adult healthcare (2019-2020) Subset: AND transition (210) Subset: AND intervention or program or study (188) Subset: AND intervention (151)	2371
	New search: transition to adulthood AND “2019/01/01”[PDat] : “2020/12/31”[PDat] AND chronic or disabilities or disability or special needs Search C: Add adult care (81) Search C: Add and intervention (50) Search D: Add and study not intervention (31)	164
CINAHL	transition from pediatric to adult care OR transferring to adult care OR transfer to adult care OR pediatric transition to adult care	35
Web of Science Core Collection	TITLE: (((adolescent* OR young adult OR teen* OR pediatric OR paediatric* OR young adults) AND (transition* OR transfer*)) AND (adult OR adults))) AND TOPIC: ((evaluation OR evaluations OR outcome OR outcomes OR comparison OR assessment))	3
Supplementary searches	(transition to adult care [MeSH Terms]) AND ((transition tools) AND (“2015/12/31”[Date - Publication] : “3000”[Date - Publication]))	27
	(transition to adult care[MESH Terms] AND protocols AND “2015/12/31”[Date - Publication] : “3000”[Date - Publication])	39
PsycINFO	Title search: (pediatric or paediatric or adolescen* or youth or teen* or young adult* or child*) AND adult* AND (transition or transfer*), 2013-2020	28

TABLE 2: EVIDENCE RATING CRITERIA

LEVEL OF EVIDENCE	EVIDENCE RATING	EVIDENCE CRITERIA: TYPE	EVIDENCE CRITERIA: STUDY RESULTS
Evidence-Based	Scientifically Rigorous	Peer-reviewed study results are drawn only from: <ul style="list-style-type: none"> • Randomized controlled trials, and/or • Quasi-experimental studies with pre-post measures and control groups 	Preponderance of studies have statistically significant favorable findings
	Moderate Evidence	Peer-reviewed study results are drawn from a mix of: <ul style="list-style-type: none"> • Randomized controlled trials • Quasi-experimental studies with pre-post measures and control groups • Quasi-experimental studies with pre-post measures without control groups • Time trend analyses 	Preponderance of studies have statistically significant favorable findings
Evidence-Informed	Expert Opinion	Grey literature	Experts deem the intervention as favorable based on scientific review
	Emerging Evidence	Peer-reviewed study results are drawn from a mix of: <ul style="list-style-type: none"> • Randomized controlled trials • Quasi-experimental studies with pre-post measures and control groups • Quasi-experimental studies with pre-post measures without control groups • Time trend analyses • Cohort studies 	Studies with a close-to-evenly distributed mix of statistically favorable and not significant findings Only cohort studies with preponderance of statistically significant favorable findings
		Grey literature	Experts deem the intervention as favorable
	Mixed Evidence	Peer-reviewed study results are drawn from a mix of: <ul style="list-style-type: none"> • Randomized controlled trials • Quasi-experimental studies with pre-post measures and control groups • Quasi-experimental studies with pre-post measures without control groups • Time trend analyses • Cohort studies 	Studies with a close-to-evenly distributed mix of statistically favorable, unfavorable, and/or not significant findings
		Grey literature	Experts deem the intervention as having mixed evidence
	Evidence Against	Peer-reviewed study results are drawn from a mix of: <ul style="list-style-type: none"> • Randomized controlled trials • Quasi-experimental studies with pre-post measures and control groups • Quasi-experimental studies with pre-post measures without control groups • Time trend analyses • Cohort studies 	Preponderance of studies do not have statistically significant findings or have statistically significant unfavorable findings
Grey literature		Experts deem the intervention as being ineffective or unfavorable	

TALBE 3: STUDY CHARACTERISTICS

STUDY	COUNTRY	SETTING	STUDY SAMPLE			STUDY DESIGN
			TARGET SAMPLE	SAMPLE SIZE	AGE RANGE	
Agarwal (2017)	United States (Pennsylvania)	Clinic-based (Pediatric to Adult Diabetes Transition Clinic at academic institution (UPenn))	Emerging adults with type 1 diabetes	N=72	18-25 years	Pre, post, and retrospective cohort
Bennett (2016)	Australia	Hospital-based (Public pediatric gastroenterology service at Women's and Children's Hospital (Royal Adelaide Hospital))	Patients with Inflammatory Bowel Disease (IBD), aged > 18 years, who had moved from pediatric to adult care within ten years	N=46 (transition survey respondents) N=35 (non-transition survey respondents)	18-28 years	Retrospective cohort study
Burns (2018)	Australia	Hospital-based (Non-pediatric hospitals in western Sydney)	Youth with type 1 diabetes mellitus	1052 patients aged 15-25 years with T1DM living in the area serviced by the four hospitals; 492 linked to a youth-specific diabetes clinic; an estimated 560 receiving non-specialized care within the community setting only	15-25 years	Retrospective cohort study
Cappelli (2016)	Ontario, Canada	Children and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS)	Youth with mental health and/or addiction problems transitioning to Adult Mental Health and Addiction Services	215 seen by the transition coordinator; 127 completed their transition and were seen by an AMHS provider; 41 youth had yet to transition and remained on a waitlist for AMHS	16-20 years	Prospective cohort
Colver (2018)	United Kingdom	Community (Home)	Young people from across England and Northern Ireland with one of three conditions: 1) type 1 diabetes mellitus, 2) autism spectrum disorder (ASD) and additional mental health problems, or 3) cerebral palsy (CP)	374 young people (150 for diabetes, 118 for ASD, and 106 for CP); 369 parents/caregivers	14-18.9 years at recruitment	Longitudinal, observational cohort study
Essaddam (2018)	North Africa (Tunisia)	Clinic-based (Pediatric diabetes clinics)	Patients treated by two pediatric endocrinologists in clinics from the center of Tunis	65 patients with type 1 diabetes	14 years and older (no maximum age limit) (range 14.5-23.2 years)	Pre-post and prospective cohort

TABLE 3: STUDY CHARACTERISTICS

STUDY	COUNTRY	SETTING	STUDY SAMPLE			STUDY DESIGN
			TARGET SAMPLE	SAMPLE SIZE	AGE RANGE	
Farrell (2018)	Australia	Clinic-based (Referral from pediatrics services to a multidisciplinary transition service)	All youth with diabetes referred to the young adult diabetes service since 2001	439 adolescents and young adults	Median age: 18 years	Pre-post and retrospective cohort
Flocco (2019)	Italy	Clinic-based (Outpatient clinic of a facility for CHD)	Adolescents with congenital heart disease (CHD)	224	11-18 years of age	Quasi-experimental, non-randomized, using a pre/post-intervention approach
Fu (2017)	Canada	Clinic-based (Tertiary center-based dedicated irritable bowel syndrome (IBD) offices/control: university affiliated gastroenterology offices)	Adolescent patients with IBD	112 total; 59 attended transition clinics	18-21 years	Prospective study
Geerlings (2016)	Netherlands	Clinic-based (Epilepsy transition clinic)	Adolescent patients who had attended the Epilepsy Transition Center from six months to three years previously	66	15-25 years (mean age 18.9 at baseline and 20.8 at follow-up)	Prospective study
Hergenroeder (2018)	United States	Clinic-based (Children's hospital pediatric cardiology clinic)	Adolescent patients with moderate to severe congenital heart disease (CHD)	25 intervention, 30 control	Intervention 16-25 years, control 18 years or older	Prospective study
Huang (2020)	United States	Clinic-based (Pediatric gastroenterology clinic)	Adolescents with IBD	53	12-18 years (median age 16)	Cohort pilot
Jones (2017)	United States	Hospital-based (Academic medical center)	Adolescent and young adult patients who attended at least one outpatient visit with the pediatric endocrinology division during the 34-month study period	371 (pre-intervention 191, postintervention 180)	18-26 years	Retrospective cohort

TABLE 3: STUDY CHARACTERISTICS

STUDY	COUNTRY	SETTING	STUDY SAMPLE			STUDY DESIGN
			TARGET SAMPLE	SAMPLE SIZE	AGE RANGE	
Kosola (2018)	Finland	Hospital/clinic-based	Adolescents who received kidney transplants	132	18 years (at time of study)	Quasi-experimental retrospective pre-post design
Le Marne (2019)	Australia	Clinic-based (Adolescent clinic)	Current epilepsy patients at Sydney Children's Hospital Randwick (SCH) aged 12-17 years (and their parent/carer), who were on anti-epileptic medications and of mild intellectual disability or above	45	12-17 years (mean age 15.7 years)	Cohort pilot evaluation
Lenke (2018)	United States	Hospital/clinic-based	SSI Medicaid MCO recipients with chronic conditions who spoke English and could complete surveys	209 (105 intervention, 104 control)	16-22 years	Randomized controlled trial
Mackie (2018)	Canada	Clinic-based (Outpatient clinic)	Adolescents attending outpatient clinics in 1 of 2 tertiary care pediatric cardiology programs in Canada	121 (58 intervention, 63 control)	16-17 years	Cluster randomized-clinical trial
Paepegay (2018)	France	Hospital/clinic-based	Age 16 or older with Prader-Willi syndrome	95; 31 Intervention group, 64 Non-intervention group	16-19 years	Retrospective cohort study
Pyatak (2017)	United States	Hospital-based	Young people with type 1 diabetes	Continuous care = 51; Lapsed care = 24	19-25 years of age	Prospective cohort
Razon (2019)	United States	Hospital/clinic-based (Large tertiary-care children's hospital and ambulatory network located in an East Coast urban community)	Patients aged 18 and older who had not transitioned from pediatric to adult care who need specialty care from at least two specialties and/or had an intellectual or developmental disability	197 patient referrals; at analysis, 97 were seen in consultation	Mean age 20.4 years	Cohort pilot evaluation
Sattoe (2020)	The Netherlands	Clinic-based (2 outpatient IBD (Inflammatory Bowel Disease) clinics)	Young people with IBD transitioning to adult care	54 patients	16-25 years of age	Controlled mixed-methods evaluation (control group and other controls)
Schutz (2019)	Germany	Clinic-based (Pediatric department of a health clinic)	Patients with IBD transferring to adult care	24 patients with transition care	17-22 years of age	Retrospective study design

TABLE 3: STUDY CHARACTERISTICS

STUDY	COUNTRY	SETTING	STUDY SAMPLE			STUDY DESIGN
			TARGET SAMPLE	SAMPLE SIZE	AGE RANGE	
Szalda (2019)	United States	Hospital-based (Free-standing tertiary pediatric academic hospital (Children's Hospital of Philadelphia (CHOP))	Patients aged 17-43 who had not transitioned from pediatric to adult care for medically complex patients	Total number not given, but there were 80 consults given over 2 years; 74 were deemed appropriate referrals	17-43 years (median age 20)	Cohort pilot evaluation
van Pelt (2018)	The Netherlands	Clinic-based (Out-patient clinics of university hospitals)	Juvenile idiopathic diabetes 1 patients transferring to adult care	64 patients	14-17 years of age	Longitudinal transition cohort study
White (2017)	Australia	Hospital/clinic-based (One hospital and 8 clinics)	Young adults with type 1 diabetes transferring from pediatric care to adult clinics	60 patients	17-19 years of age	RCT
Yerushalmy-Feler (2017)	Israel	Hospital-based (Pediatric and adult IBD centers in a hospital)	36 IBD patients who started the transition process (January 2013-December 2015) in the adolescent transition clinic in the institute/hospital	36 patients	17-27 years of age (median: 18.5)	Quasi-experimental pre post

TALBE 4: INTERVENTION DESCRIPTIONS

STUDY	COMPARISON GROUP	DESCRIPTION OF INTERVENTION	STUDY LENGTH	DATA COLLECTION
Agarwal (2017)	No comparison group	A cohort of 72 emerging adults (EAs) with type 1 diabetes were evaluated to determine the extent to which the Pediatric to Adult Diabetes Transition Clinic at the University of Pennsylvania 1) had an effect on health outcomes such as glycemic control and blood glucose monitoring frequency; 2) impacted the likelihood of retaining EAs in care; and 3) would be acceptable to participating parents and providers. Participants were eligible for inclusion in the study if they had type 1 diabetes for at least 6 months prior to transfer, had formerly received pediatric diabetes care at the Children's Hospital of Philadelphia (CHOP), and if their first outpatient visit with an adult diabetes provider was in the PADTC. Data extracted from transfer summaries and electronic medical records included socio-demographic, clinical, and follow-up characteristics. Pre- and post-program assessment at 6 months included mean daily blood glucose monitoring frequency (BGMF) and glycemic control (A1C). Paired t tests were used to examine change in outcomes from baseline to 6 months, and multiple linear regression was used to adjust outcomes for baseline A1C or BGMF, sex, diabetes duration, race, and insulin regimen. Open-ended survey responses were used to assess acceptability amongst participants.	November 2014-November 2015	Baseline within 3 months of adult visit or point-of-care testing at adult visit; 6 months after receiving care at PADTC
Bennett (2016)	Non-transition patients	A cohort of IBD patients diagnosed in pediatric services who had moved to adult care was identified and surveyed. The case records of these transition patients were then examined to verify their histories and to review clinician recorded data on transition plans and doctor-patient discussions. A non-transition cohort of young adults with IBD was surveyed for purposes of comparison. The purpose of the study was to assess the disease and psychosocial outcomes and perspectives of a transition cohort.	2003-2013 (Data from ten years; study took place 2013)	Survey of IBD patients, identified through IBD databases at 3 tertiary hospitals, who had transitioned from pediatric to adult care during 10-year-period
Burns (2018)	Youth with type 1 diabetes mellitus not linked to a youth-specific diabetes service	The aim of the study was to assess the impact of a youth-specific diabetes service for youth ages 15-25 with a known history of type 1 diabetes mellitus (T1DM) who presented with diabetic ketoacidosis (DKA) at hospitals in western Sydney. The researchers analyzed data from the National Diabetes Services Scheme (NDSS), together with electronic medical records and hospital files from two hospitals with youth-specific diabetes clinics and two without such clinics, hypothesizing that attendance at a youth-specific diabetes clinic reduces hospital admission rates and length of stay (LOS) for diabetic ketoacidosis (DKA).	Jan-Dec 2011	Review of electronic medical records, hospital files, and data from the National Diabetes Services Scheme (NDSS)
Cappelli (2016)	No comparison group	The study used a set of tracking tools, intake procedures, and standardized questionnaires in efforts to assess whether a transitional program based on the shared management model (referred to as the Youth Transition Project) is effective in maintaining continuity of care for youth transitioning from CAMHS to AMHS. Participants were tracked over the course of their transition from Children and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) at three separate time points: upon referral to the Youth Transition Project; during intake assessment by Transition coordinator; and during transition to AMHS.	June 2011-Dec 2013	At time of referral to program; during initial assessment with coordinator; following transition (if completed)

TABLE 4: INTERVENTION DESCRIPTIONS

STUDY	COMPARISON GROUP	DESCRIPTION OF INTERVENTION	STUDY LENGTH	DATA COLLECTION
Colver (2018)	No comparison group	<p>The international research literature proposes service features that might promote better healthcare transition; however, there is a lack of evidence about whether these Proposed Beneficial Features (PBF) improve outcomes. Recommendations for particular service features should be supported by robust evidence that indicate improved outcomes across a range of conditions and settings before they are adopted into practice. This research study was designed to examine patient-level outcomes that would be applicable across a range of conditions. The study team focused on 9 PBFs to test whether exposure to these PBFs is associated with better outcomes for young people with long-term conditions, namely satisfaction with services, mental wellbeing, participation and autonomy in appointments (<i>1. age-banded clinic, 2. meet adult team before transfer, 3. promotion of health self-efficacy, 4. written transition plan, 5. appropriate parent involvement, 6. key worker, 7. coordinated team, 8. holistic life-skills training, and 9. transition manager for clinical team</i>). Local researchers visited the young people and parents, usually at home, took informed consent, and administered independently completed questionnaires. To maximize young person engagement and retention, outcome measures could be completed by mail or electronically. At the baseline visit, the nature of the PBFs was discussed with the young person and a logbook was provided. Before each of 3 subsequent annual visits, the researcher consulted the young person's medical records to seek evidence of the PBFs having been provided. Then, at the visit, the researcher and young person completed a summary sheet recording whether each PBF had been experienced or not in the previous year; the information gathered from medical notes acted as additional prompts for the discussion.</p>	<p>Recruitment between June 2012 and October 2013; visits arranged annually for 3 years</p>	<p>Baseline visits usually in the home; 3 annual visits</p>
Essaddam (2018)	No comparison group	<p>This structured transition intervention from pediatric to adult diabetes care included a 1) transition meeting (organized once or twice a year during the school holidays in the pediatric department; each meeting lasted 2-3 hours depending on the patients' and families questions; whole pediatric team was present (2 physicians, 1 nutritionist, 1 nurse) accompanied by the adult staff, including adult endocrinologists, diabetes nurse educators, nutritionists, and secretaries), 2) a specially developed diabetes health passport (summarizing medical history, medications, complications, and type 1 diabetes related issues, in addition to their social and psychological profile) that accompanied the patient throughout the transition process, and 3) transfer to a single health system, when patients expressed their wish to drop out from pediatric care, where they were followed by one of the 4 adult endocrinologists who remained the provider for the duration to strengthen the bonds and trust.</p>	<p>This transition program began in September 2012 and lasted until December 2017 (63 months)</p>	<p>Meetings of transition organized once or twice a year during school holidays (9 meetings organized)—clinical data and psychosocial outcomes collected after transition meetings; follow-up duration at the adult clinic ranged from 7 to 60 months</p>

TABLE 4: INTERVENTION DESCRIPTIONS

STUDY	COMPARISON GROUP	DESCRIPTION OF INTERVENTION	STUDY LENGTH	DATA COLLECTION
Farrell (2018)	No comparison group	Youth with diabetes are vulnerable to acute diabetes complications, so it is critical to maintain follow-up to achieve a reduction in acute diabetes related complications. Youth with a longer duration of diabetes have been reported as having suboptimal glycemic control, which may further deteriorate following transition of care. A previous publication demonstrated that attendance can be maintained and HbA1c improved at the transition by changing the model of care to incorporate a number of components. This study aimed to a) identify determinants of HbA1c levels at 18-months and 30-months following transition to a youth specific diabetes service in young people with type 1 diabetes mellitus (T1DM); and b) to evaluate the impact of the service on acute admissions with diabetic ketoacidosis (DKA) over a 14-year period at a major metropolitan adult tertiary hospital in Western Sydney. The key features of the clinic model include ensuring interval to first appointment is <6 months from last pediatric visit, SMS text reminders prior to all appointments, rebooking of missed appointments, a central mobile phone contact for the service, a diabetes educator as clinic coordinator, access to multidisciplinary team at a late finishing afternoon clinic, and phone support for sick days to prevent ED presentation.	12-year study from 2001 to 2012 with each participant followed for two years post transition (14 years total)	Retrospective audit of data at 18-months and 30-months post transition of youth
Flocco (2019)	No comparison group	A multidisciplinary team of health care professionals took part in the transition clinic, which was based on three pillars. The first pillar was designed to improve the understanding of the clinical condition through tailored education. The educational package was delivered in the outpatient setting when each patient was enrolled. The second pillar aimed to support the development of functional coping strategies by way of discussion with a peer-counselor and psychologist. Each counselor was a CHD patient trained to be a counselor. The third pillar was designed to improve the engagement of CHD adolescents and their families with the help of a transition coordinator (a specialized nurse). This person facilitated the transition process by scheduling the events in pillars 1 & 2 and was the center of the network of various healthcare providers involved in the patients' care. The TC also reviewed the educational goals of individuals and helped to customize specific needs in person or by telephone debriefings.	1 year	Baseline and 1 year later
Fu (2017)	Adolescents who were being treated at a university affiliated gastroenterology office but who did not attend IBD transition clinics.	Participants completed an on-line questionnaire regarding their disease and their adherence to prescribed medical therapy. Attitudes and beliefs about medical therapy were addressed using the Beliefs About Medicine questionnaire (BMQ), a validated tool. The study also examined differences in disease-specific knowledge and adherence to medical therapy. Disease specific knowledge among the adolescents was assessed by comparing answers to the questionnaire with information in their clinical charts. If needed, the patient's healthcare professional was consulted for clarification.	Enrollment July 2012-June 2013	One-time collection of data for individuals who had/had not attended a transition clinic, plus examination of previously collected data

TABLE 4: INTERVENTION DESCRIPTIONS

STUDY	COMPARISON GROUP	DESCRIPTION OF INTERVENTION	STUDY LENGTH	DATA COLLECTION
Geerlings (2016)	No comparison group	Participants completed a questionnaire regarding their medical, educational/vocational status, and independence. The study compared information from the questionnaire to previously collected information about the participants.	March 2012-September 2014	One-time collection of data for individuals who had attended a transition clinic plus previously collected baseline statistics
Hergenroeder (2018)	Patients who transitioned from the pediatric CHD clinic into adult care at the Texas Children's Hospital before the introduction of the transition planning program	The Texas Children's Hospital (TCH) implemented a health care transition program that included an electronic medical record (EMR)-based transition planning tool (TPT) that was used by research nurses to work with eligible patients; in addition to completing the EMR documentation, the nurses provided verbal and written educational materials.	February 2012-August 2013; control group transitioned from 2002-2011	Baseline was data from EMR at last pediatric visit, compared with data from first adult visit; time between visits was 13 +/- 8.3 months for intervention group and 26 +/- 19.2 months for control group
Huang (2020)	No comparison group	In order to address the identified gap of care, specifically the lack of systematic methods for tracking delivery of transition resources/services, the authors developed a Transition HER (electronic health record) activity (TEA) to track patients through a process where transition preparation needs are assessed and resources/services distributed on a scheduled basis. The authors evaluated the utility and feasibility of the TEA in the clinical workflow of a dedicated inflammatory bowel disease ambulatory clinic through evaluation of TEA distribution and patient tolerability (as measured through survey). The activity entailed annual assessment of key transition skills and setting of transition skill goals through provider-patient shared decision-making, review of patients' own medical histories for familiarity, and resource delivery based on individual need.	8 months between April 2018 and December 2018; Data analyzed was from 2006-2009 & 2011-2015	Distribution of survey to patients between April 2018-December 2018
Jones (2017)	Patients who transitioned into adult care before the process was developed	A team of pediatric and adult endocrinology providers at the University of Rochester (NY) Medical Center developed a formal transition process using the Six Core Elements (6CEs) of health care transition and implemented the transition practice improvements into existing pediatric and adult subspecialty clinic workflows.	Study period November 2012-August 2015; creation of new process: 17 months (April 2014-August 2015)	Data from chart review before new process was implemented (November 2012-March 2014) compared with data during the intervention period

TABLE 4: INTERVENTION DESCRIPTIONS

STUDY	COMPARISON GROUP	DESCRIPTION OF INTERVENTION	STUDY LENGTH	DATA COLLECTION
Kosola (2018)	Patients who received kidney transplant before the transition model was implemented	<p>Pediatric kidney transplant patients attended a transition outpatient clinic after the start of puberty, usually ≥13 years of age. During the visits, adolescents were prepared to take responsibility for the treatment of their own condition, including ensuring they were familiar with their condition and course of illness, that they understood the effects and possible side effects of their medications, understood the importance of control visits, had some knowledge of their future outcome, dangers of substance use, sexual health, and information on fertility. A structured form was used during visits to ensure that all topics had been covered. A pediatrician met patients alone for part of the appointment to support self-management from an early age. Family members were also prepared for transition. An adolescent psychiatrist and a social worker formed an integral part of the transition team. Transition readiness was assessed holistically, and the actual transfer of care occurred individually at age 17-20 years. The pediatrician prepared a detailed referral letter for the adult team. Patients from the metropolitan Helsinki area had follow-ups at the Department of Nephrology of the Helsinki University Hospital, located on the same campus as the Children’s Hospital. A visit to the adult care facilities and a meeting with the adult team were organized prior to the transfer of care. The adult team arranged the first visit, which lasted longer than regular visits, and the goal was follow-up with the same nephrologist. Follow-up visits for adolescents were organized more frequently (every 3rd month) than for older adults. When the relationship between the adult nephrologist and young patient was well established, and the patient showed signs of coping with the treatment, the frequency of visits changed based on physician’s discretion.</p>	Data used: 2005-2016	Cohort kidney transplant outcome data from before 1986-2005 compared to cohort data 2005-2016
Le Marne (2019)	No comparison group	<p>Implementation and appraisal of a new model of care to improve patient knowledge of epilepsy, readiness for transition, mood support, and clinic experience in a new purpose-built facility for adolescents and young adults. Requirements of the study included patients and parents: completing baseline questionnaires, attending their neurology appointment and group epilepsy education session on the same day, completing follow-up surveys distributed 1 week post-clinic, attending a separate group mental health (MH) education session (scheduled monthly), and completing the follow-up Strengths and Difficulties Questionnaire (SDQ) and questions evaluating MH supports received at a minimum of 3 months post-clinic attendance. Group epilepsy education sessions (80 min) for patients and their parent/carer were scheduled during regular epilepsy clinic visits at the new adolescent facility. Epilepsy education was delivered by the epilepsy clinical nurse consultant, epilepsy coordinator, neurology fellow, and transition staff.</p>	December 2016-December 2017	Baseline; follow-ups at 1 week and 3 months

TABLE 4: INTERVENTION DESCRIPTIONS

STUDY	COMPARISON GROUP	DESCRIPTION OF INTERVENTION	STUDY LENGTH	DATA COLLECTION
Lemke (2018)	Control group received enhanced usual care along with study cohort, but no services from the HCT nurse	Both the control and intervention groups received enhanced usual care. All participants received a care notebook that included the clinic's transition policy, a blank transition readiness assessment form, a local adult doctor referral list vetted by the study team, and information on insurance, guardianship, and advance directives. At enrollment, all participants were entered into the clinic's HCT transition registry to facilitate tracking and communication. The intervention group received all usual care but were also assigned a Health Care Transition (HCT) nurse who coordinated delivery of the transition interventions: 1) face to face review of readiness assessment, 2) status assessment of ongoing HCT planning and preparation, 3) monthly phone calls to update and fill gaps in action plan. All focused on the 6 core elements of the AAP/AFP/ACP consensus statement. HCT nurse assisted in identifying adult providers and helped with the transfer and transition.	2012-2014 (2 years)	Baseline, 6, and 12 months post enrollment
Mackie (2018)	Control group received usual cardiac care	Nurse care coordination transition intervention consisted of 2 nurse-led 1-on-1 sessions without parents present. The first session was held in person on the day of a cardiology clinic appointment. The second session was held 2 months later, either in person or by teleconference for participants living far from the hospital. Session 1 involved the creation of a MyHealth passport. This passport included review of the participant's CHD anatomy, previous cardiac interventions, and name, dose, and rationale of cardiac medications; discussion of potential future cardiac complications; review of the names and location of local adult CHD cardiologists; introduction to relevant youth-friendly health care websites; discussion of 3 third-person scenarios (alcohol, smoking/street drugs, and sexuality/contraception); an introductory visit to the adult CHD clinic; and the setting of 1 education-related goal. Session 2 included review of the education-related goal; discussion of 6 short videos illustrating young adults with poor versus strong communication skills with health care providers; viewing and discussion of a video titled "Talking With Your Doctor"; role-play of 2 standardized health care scenarios; discussion of effective goal-setting; review (and take home) of the booklet "When You're 18"; and review of the "Health Care Transitions" website. Both sessions were followed by text message or e-mail interaction between the study nurse and participant within 7 days. Nurses documented the completion of each element of the intervention after each session. Intervention fidelity and quality assurance are described in the published protocol.	24 months	Baseline, 1, 6, 12, 18, 24 months
Paepegay (2018)	Individuals with Prader-Willi syndrome that did not receive transition	Transition group received specialized and multidisciplinary pediatric care including endocrine follow-up in one of six children hospitals with expertise in the follow-up of children with PWS. In late adolescence (16-19 years), these patients were referred to the adult unit of the Reference Center. The intervention was a care team meeting at the time of transition. A pediatrician then provided the medical file and transferred all medical data of the pediatric follow-up to the adult physician. A first multidisciplinary assessment was then carried out in the adult department during a day hospitalization. An endocrinologist with specialized nutrition training, a dietician, psychologist, nurse, and social worker were all present for this first evaluation.	10 years (2007-2017)	Anthropometric and endocrine data from medical check in visits, questionnaires for patient and family sent to sample of patients who received intervention after transition (timeline not specified)

TABLE 4: INTERVENTION DESCRIPTIONS

STUDY	COMPARISON GROUP	DESCRIPTION OF INTERVENTION	STUDY LENGTH	DATA COLLECTION
Pyatak (2017)	Type 1 diabetes patients who had lapsed from care but then established care at the young adult clinic at the time of study enrollment	The transition program incorporated case management, access to young adult diabetes clinic, and developmentally tailored diabetes education. Continued care participants at the time of enrollment attended one of two pediatric clinics and transferred to the young adult diabetes clinic during the study period. Lapsed care participants established care at the young adult clinic at the time of study enrollment. Participants received developmentally tailored diabetes education at each quarterly clinic visit. Case managers assisted CC participants in transferring their care and managing insurance, and they encouraged adherence to scheduled clinic visits (reminder calls, follow-up). All participants had access to group carb counting classes and a private social networking website.	12 months	Medical records, A1c readings at baseline, six and twelve months later; questionnaires at baseline and 12 months later
Razon (2019)	No comparison group	The hospital-funded Adult Consult Team connects patients and their families to appropriate medical and psychosocial services as they enter adulthood and become eligible for transfer to adult-focused care. The Adult Consult Team’s clinical service focuses on patients with high and highest medical complexity to provide a consulting service that coordinates preparation for transfer to adult-oriented care. Any inpatient or outpatient provider from the children’s hospital or its ambulatory network may refer new patients to this service. Patients at least 18 years old are eligible if two or more specialty teams follow them and/or if they have a diagnosis of intellectual or developmental disability (IDD).	July 1, 2017 - June 30, 2018	Patient consults and referrals between July 1, 2017 - June 30, 2018. The mean time between referral and transfer to adult care was 191 days (SD=84)
Sattoe (2020)	54 patients who had direct handover to adult care	The TC was organized in an adult care setting; the multidisciplinary team consisted of two pediatric gastroenterologists, one adult gastroenterologist, one pediatric nurse specialist, and one family counselor working in pediatric care. In the direct handover care setting, only one pediatric gastroenterologist was involved in care before transfer. At the TC, young people aged 16 to 18 visited every 3 months before actual transfer to adult care. Three out of the four consultations per year were held with pediatric care professionals; the other consultation was with the adult care professional. Although this TC did not provide joint consultations, there was intensive collaboration and alignment between pediatric and adult providers (joint care). Prior to each TC, the pediatric and adult team together discussed the patients. In both settings, during consultations attention was given to the medical aspects of IBD, such as dealing with the treatment and with treatment side effects. Young people’s own ideas and responsibilities were also discussed in both settings, as well as the upcoming transfer. However, at the TC, more attention was given to non-medical topics, such as leisure, sports, independent living, work, family situation, and psychological counselling, as well as differences between the pediatric and adult healthcare setting.	Interviews and observations May 2014-August 2015; data analyzed from two years before to two years after transition	Medical records two years before and two years after transition; interviews and observations of consultations during transition

TABLE 4: INTERVENTION DESCRIPTIONS

STUDY	COMPARISON GROUP	DESCRIPTION OF INTERVENTION	STUDY LENGTH	DATA COLLECTION
Schutz (2019)	11 patients who did not have transition assistance (transfer group)	The authors compared the clinical long-term course of 24 patients with and 11 patients without structured transition care within 24 months before and 24 months after transfer from pediatric to adult health care. Socioeconomic parameters and quality of life were assessed by IBD Questionnaire (IBDQ-32) and additional measures. Treatment costs were calculated for medication, surgery, and hospitalization. The program at the transition clinic includes a joint consultation at the age of 18 years before the first visit at the adult clinic with the pediatric and a local adult gastroenterologist, as well as a specialized IBD nurse and the patient. Topics of the visit are disease-related knowledge, career plans, medical history, current and further treatment, as well as personal concerns of the patient about the future. The adult specialist is introduced through regular seminars with physicians, patients, and their families, when the concept of transition is explained. The pediatric gastroenterologist sends a structured written summary of the previous medical patient history to the adult gastroenterologist immediately after the joint consultation. In addition, the pediatric gastroenterologist empowers the patient to autonomous disease management and provides disease-related knowledge years before the joint transition appointment.	9 months (June 2016-February 2017); data collected from 2007-2014	Questionnaires and records for 2 years before and 2 years after transition were collected 3-8 years after the transfer occurred
Szalda (2019)	No comparison group	The Multidisciplinary Intervention Navigation Team (MINT) for pediatric to adult care transitions was created (1) to develop health system level innovations to increase institutional capacity surrounding transitions from pediatric to adult care, and (2) to perform consults for complex individual patient transfers. Throughout the 2-year grant period, the team developed tools to support population-based transition for divisions. These tools included a transition policy template, electronic medical record (EMR)-based clinical decision support tools, a transfer note template, and a registry template. In addition, the team saw individual patients in consult to create and execute transfer plans. MINT conceptualized a population-based approach by which all patients would receive transition services, and the more medically complex patients would be eligible for individual patient consult. Seven medical and surgical divisions volunteered to partner with the MINT initiative: general pediatrics, urology, hematology, rehab medicine, gastroenterology, neurology, and developmental and behavioral pediatrics. Each division was charged with (1) identifying a transition champion, (2) using EMR-based transition tools, (3) developing a written transition policy, (4) holding psychoeducational events surrounding transition for patients and caregivers, (5) creating a transition registry, and (6) identifying adult provider counterparts in their specialty.	July 1, 2015-June 30, 2017	Patient consults and referrals between July 1, 2015-June 30, 2017; feedback survey sent in year 2 of project
van Pelt (2018)	Pediatric (aged 10-13) and adult care (aged 18-27) patients	Patients aged 14-17 years at study onset were transferred at some point during the three-year follow-up from the pediatric to the adult clinic (transition group). The process of transition, which starts approximately one year before and ends one year after transfer, was coordinated by the transition-coordinator. This specialist rheumatology-nurse is responsible for process-related items during transition, e.g., monitoring appointments at adult care, and counselling of patients and parents, including enhancing self-management.	3 years	Baseline, then yearly collections of demographic and disease-related information (medical records)

TABLE 4: INTERVENTION DESCRIPTIONS

STUDY	COMPARISON GROUP	DESCRIPTION OF INTERVENTION	STUDY LENGTH	DATA COLLECTION
White (2017)	Current care patients	The study was a randomized, open-label, controlled trial of patients aged 17-19 years with type 1 diabetes. Participants were recruited from a tertiary pediatric diabetes service at the Royal Children's Hospital (Melbourne, VIC, Australia) and had to be scheduled for transition to adult services at one of eight centers in Melbourne. We randomly assigned participants (1:1), using sequential sealed opaque envelopes, to either appointment management (intervention) or current care (control). The appointment manager acted as the point of contact between intervention group participants and the relevant adult clinics and provided personalized pre-appointment telephone and short message service (SMS) reminders with automatic rebooking of missed appointments. No contact was initiated with the control group after recruitment, and any self-initiated contact with the investigating team was directed to the participant's previous treating pediatric physician. The intervention continued throughout the trial until at least 12 months of follow-up data were obtained for all participants. We assessed the mean frequency of adult clinic attendance and disengagement from services during 0-12 months after transition (primary outcomes) and 12-24 months after transition (secondary outcomes), analyzed by intention to treat. We used regression analyses, adjusted for clinic attendance, and glycated hemoglobin concentration pre-transition, to analyze the effect of the intervention.	3 years	Medical records at baseline, 12 months after transition, and 24 months after transition
Yerushalmy-Feler (2017)	No comparison group	Each patient is proactively invited to attend at least three meetings scheduled over a period of 6 months. The first meeting includes an introduction to the members of the adolescent transition team and familiarity with the aims of the clinic, that is, improving the patients' readiness for transfer by improving their knowledge of IBD and their self-efficacy skills. In addition, the patient's history, previous laboratory and endoscopy results, as well as previous and current medications are reviewed thoroughly. The second meeting deals with improving the patient's knowledge of IBD and self-management skills by educating the patients specifically on the nature of their disease and medical treatment and by encouraging them to self-manage their disease (i.e., make their doctor appointments by themselves, be familiar with medication doses and side effects, etc.). The third meeting is dedicated to summation and short-term (upcoming laboratory tests, changing medication dose) and long-term (obligatory military service) planning. Although the whole family is invited to attend the first and second meetings, the patient is invited to the last meeting alone. Sessions with the psychologist are conducted separately. All decisions in the clinic are made by the multidisciplinary team. Additional meetings are held according to need.	2 years	Questionnaires completed at the beginning and after the transition process (an average of 6.9 months later)

TALBE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
Agarwal (2017)	Transfer summaries and electronic medical records, including pre- and post-program assessments	Population health: <i>Adherence to care monitoring</i> ; Increase in blood glucose monitoring frequency; <i>Disease-specific measures:</i> Attendance at Pediatric to Adult Diabetes Transitions Clinic (PADTC); mean daily blood glucose monitoring frequency (BGMF) and glycemic control (A1C); (change in outcomes from baseline to 6 months).	The findings of this study demonstrate that a transition program for emerging adults (EAs) with type 1 diabetes based in an adult health care system can 1) improve health outcomes, such as glycemic control and BGMF, 2) retain EAs in care, and 3) be acceptable to participating patients and providers. From baseline to 6 months, mean A1C decreased by 0.7% (8 mmol/mol), and BGMF increased by 1 check per day. Eighty-eight percent of participants attended ≥2 visits in 6 months, and the program was rated highly by participants and providers (pediatric and adult).
Bennett (2016)	IBD databases at three hospitals; medical records; surveys	Population health: <i>Patient-reported health and quality of life:</i> Self-reported medication and side-effects; IBD complications; physical, psychological, and social side-effects of IBD; occupational and social/relationship outcomes. Utilization and cost of care: <i>Utilization:</i> Number of hospital admissions per patient (during adult care) and use of multidisciplinary team members.	Although there were no significant differences in health outcomes between the transition and non-transition cohorts, the majority (44/46, 96%) of the transition cohort felt that a structured transition plan was important. Non-transition patients also endorsed this statement (32/35, 91%). The transition cohort identified 1) the task of establishing a new relationship with a practitioner, 2) lack of communication, and 3) patients' own lack of understanding of IBD as potential barriers to successful transition. Similar responses were proposed by the non-transition group. The majority of transition respondents thought that the timing of transition should be "age 18 years," compared with the non-transition cohort who nominated "patient readiness." The majority of study participants were regularly reviewed by a gastroenterologist (42/46 (91%), transition patients and 30/35 (86%), non-transition patients). Among transition patients reviewed, 15% were reviewed 3 monthly or more often, 60% 6 monthly and 25% annually. Utilization of members of other the multi-disciplinary team was generally low in both cohorts, except for their general practitioners.
Burns (2018)	Electronic medical records and hospital files; data from the National Diabetes Services Scheme (NDSS)—a government-initiated body that provides support services and information to patients with diabetes, recording age, type of diabetes, and address	Population health: <i>Disease-specific measures:</i> Increase in admission pH levels; Severity of diabetic ketoacidosis (DKA) in relation to patients' association with a youth-specific diabetes clinic. Utilization and cost of care: <i>Utilization:</i> Hospital admission rates; <i>Cost of care:</i> length of stay (LOS), cost of care, reduction in bed days	Those who were supported by youth-specific diabetes services had a better outcome with less severe DKA at presentation and a shorter length of stay (LOS). There was a statistically significant ($P < 0.05$) shorter LOS of 1.5 days in patients who were supported by a youth-specific diabetes clinic. Based on a difference in median LOS of 1.5 versus 3.0 days in supported versus unsupported arms, and a total number of admissions in 2011 of 10 versus 45, respectively, the estimated cost saved by the transition service using reduction in bed days alone was \$250,500. Additionally, the researchers found a significant difference in pH at admission, potentially reflecting milder DKA at presentation in those youth with diabetes (YWD) supported by a youth specific diabetes service. Unsupported youth were 4 times more likely to be admitted/readmitted to the hospital.

TABLE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
Cappelli (2016)	<p>The Ontario Common Assessment of Need–Self (OCAN–Self)—a self-report indicator; youth tracking tools (modified from Singh et TRACK measures); The Global Appraisal of Individual Needs Short Screener (GAIN–SS)—a 27-item self-report measure used to screen for mental health and addictions problems; and the adult needs and strengths assessment for transition to adulthood (ANSA–T), completed by caregiver</p>	<p>Utilization and cost of care: <i>Utilization:</i> Outcome measures include the average transition time across program years (2011–2013); variables related to transition and transition lag time; diagnosis and presenting problems of youth; and self-reported problems and needs of youth.</p>	<p>Evaluation of the shared management model for youth transitions showed positive results in shortening transition times, with decreases seen over each subsequent program year. However, mixed results were seen in the distribution of youth who transitioned, with close to 60% of youth being seen by adult providers while the rest remained on waitlists or canceled services. The results demonstrate that the sample of youth enrolled in the program were in high need of services, fulfilling the objective of the Youth Transition Project in identifying an appropriate group of youth in need of transition. The Youth Transition Project also achieved the objectives of providing counseling services to youth and coordinating their transition to AMHS.</p> <p>Of the 215 young people seen by the transitions coordinator over an 18-month period, 127 completed their transition and were seen by an AMHS provider; 41 had yet to transition and remained on a waitlist for AMHS; and 47 youth canceled services (declined further services, did not return phone calls, or moved away) and did not complete their transition: 16 canceled services after being seen by the coordinator while 31 canceled after being referred to AMHS.</p> <p>Youth who transitioned reported being more psychologically distressed and displayed more significant internalizing disorders. These youth may have shown a greater need for immediate treatment or were potentially given priority over those displaying a lesser degree of urgency. It took an average of 100 days for youth to transition to AMHS.</p> <p>Chi-square tests revealed that a significantly greater proportion of transitioned youth had a greater number of prior emergency department visits, and that canceled youth scored significantly higher on the ANSA’s measure of antisocial behavior. Also, a greater proportion of canceled youth were diagnosed with Anxiety Disorder</p> <p>Transition times for youth significantly differed across AMHS provider, and they were significantly longer for youth referred to project-partner AMHS than for youth referred to non-project-partner AMHS.</p> <p>The distribution of youth seen by project-partner providers was as follows: general hospitals (English: 15.0%; n=19; French: 4.7%; n=6); mental health centers (38.6%; n=49); community youth service agencies (6.3%; n=8), and substance abuse treatment centers (3.1%; n=4); and non-project partners (32.3%; n=41). Significant differences were also found between project partners and non-project partners for youth’s reports on questionnaire measures. On the OCAN–Self assessment, youth seen by project partners reported significantly more unmet needs than those seen by non-project partners on items related to time spent on activities, physical health, psychological distress, and intimate relationships.</p> <p>Youth referred to the program presented with various mental health disorders and other problems, including anxiety (71%), mood disorders (62%), substance-related disorders (21%), and disorders usually first diagnosed in infancy, childhood, or adolescence (~40%). The majority of youth were currently on medication and had other health conditions aside from their mental illness. At the time of initial referral, 78.7% (n=133) of youth lived with their parents, 6.5% (n=11) in shelters or were homeless, 5.9% (n=10) on their own, 4.1% (n=7) in group homes, 2.4% (n=4) with relatives or friends, 1.8% (n=3) with a grandparent, 0.6% in foster homes (n=1), and 14.1% (n=31) of youth were involved with a child welfare agency.</p>

TABLE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
Colver (2018)	Baseline demographic questionnaire; Scaled questionnaires – Mind the Gap, Warwick Edinburgh Mental Wellbeing Scale, Rotterdam Transition Profile, Autonomy in Appointments	<p>Population health: <i>Patient-reported health and quality of life</i>: participation in health care services and aids/education/employment; <i>Positive self-care</i>: Mental well-being; Participation and autonomy in appointments (relevant across conditions and settings); <i>Disease specific measures</i>: (Type 1 diabetes, cerebral palsy, autism spectrum disorder).</p> <p>Patient experience of care: <i>Satisfaction</i>: Satisfaction with services.</p>	<p>Of the 9 Proposed Beneficial Features (PBFs) of transitional healthcare, recommended in policy documents, 3 PBFs had significant positive associations with better outcomes, namely appropriate parent involvement, promotion of health self-efficacy, and meeting the adult team before transfer. The other 6 PBFs had few statistically significant positive associations with better outcomes in the year-by-year analysis, had a number of negative associations, and had no positive associations with the consolidated indicator of exposure to PBFs. Two of the three key features which help (appropriate parent involvement and promotion of health self-efficacy) are not specific to transitions; rather, they are features of developmentally appropriate healthcare for all young people. This finding reinforces the view that much of the essence of good transitional care is actually good developmentally appropriate healthcare. Additionally, the study team found a quality of experience of transitional healthcare for young people with a long-term illness (diabetes) compared with those with a long-term disability. These gaps in current practice need to be addressed through service development.</p>
Essaddam (2018)	Demographic and clinical data	<p>Population health: <i>Disease specific measures</i>: metabolic and clinical outcomes such as HbA1c level.</p> <p>Patient experience of care: <i>Satisfaction</i>: patient satisfaction (72%).</p> <p>Utilization and cost of care: <i>Utilization</i>: Transition meeting attendance; Clinic attendance rate post- and pre-transfer; Rate of hospitalization.</p>	<p>This program was beneficial to 75% of patients who demonstrated an improvement in their metabolic control the year following transition to adult care service. This study is the first one in North Africa to report on the outcome of a structured transition program from pediatric to adult diabetes care. 72% of the participants in the transition process considered their experience to have been positive. The data stresses the fact that close collaboration between pediatric and adult diabetes care teams in the transition program is the key to ensure continuity of care, and results in successful transfer of adolescents to adult care, with almost 50% of young adults establishing adult care within 6 months. Overall, the study showed good attendance at transition clinic after transfer, and 67% of the patients attended three or more visits per year. A structured transition program can thus positively influence attendance post-transfer, whereas an unstructured transition with lack of communication between pediatric and adult clinics can negatively influence it. This successful implementation of a structured program for adolescents with type 1 diabetes is pioneering in Africa and appears to provide a structure for ensuring continuity of care and effective transition.</p>
Farrell (2018)	Administrative database	<p>Population health: <i>Disease specific measures</i>: HbA1c.</p> <p>Utilization and cost of care: <i>Utilization</i>: Admissions and readmissions for DKA; Length of stay in hospitalization for acute DKA admissions.</p>	<p>This study represents one of the largest and longest follow-up series of youth with diabetes after transition from pediatric to adult care and confirms the benefit of developmentally appropriate diabetes services in the adult health care setting. The key outcomes of the program were that diabetes control was maintained following transition in the 76% attending at 30-months post-transition with median frequency of visits of 3 per year, loss to follow-up rates of 8.6%, and significant reduction in DKA admissions were achieved and maintained. In the Delphi study, interval to first appointment of <6 months was considered an important benchmark for service provision in young adults with chronic disease and achieved by 95% of the cohort. Of note was the unchanged HbA1c throughout the follow-up period up to 30-months. The study demonstrates that hospital admission for DKA is preventable if youth with diabetes receive regular follow-up and education on sick day management. DKA admissions, readmission, and length of stay rates were significantly reduced in the first year after commencement of service and have been maintained over the period of the study. Face-to-face education on sick day management is further enhanced by a mobile phone service which allows youth with diabetes to directly contact service for sick day advice at time of crisis. In sum, continuing engagement with the multidisciplinary transition service prevented deterioration in HbA1c following transition. Age-appropriate education and regular follow-up prevents DKA admissions and significantly reduced admission LOS.</p>

TABLE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
Flocco (2019)	Self-report questionnaires and medical records	<p>Population health: Self-care: Improvement of disease knowledge using the CHD Knowledge Questionnaire; <i>Patient-reported health and quality of life:</i> Reduction of pain and anxiety, increase in life satisfaction; perception of health status and quality of life, increased self-advocacy and decision-making – using the EQ-5D Health Questionnaire.</p>	The clinic showed improvement in knowledge, QOL, and overall health perception in adolescents with CHD. This model allowed for customization of the educational package, promoting patients' communication, self-care, self-advocacy, and decision-making abilities, as well as their responsibility and self-sufficiency. Improvements were greater for adolescents with simple to moderate heart disease than for those with severe CHD.
Fu (2017)	Online questionnaires, consultation with clinicians	<p>Population health: Adherence to care monitoring: Beliefs in medication overuse, harm, necessity, and concerns; <i>Self-care:</i> disease-specific knowledge.</p> <p>Utilization and cost of care: <i>Utilization:</i> adherence to medical therapy, continuation of care.</p>	Self-reported adherence to medication rates were poor (67.4% transition, 56.8% control); adolescents in transition cohort had significantly higher belief that medications were necessary but were less skeptical (6.8% vs 20.8%) and more ambivalent (61% vs 34%) to treatment.
Geerlings (2016)	Questionnaires, clinic data (previously collected baseline)	<p>Population health: Disease-specific measures: Seizure frequency; <i>Patient reported health and quality of life:</i> independence from parents, social participation, employment, studying or in an internship, unemployment, source of financial support.</p> <p>Utilization and cost of care: <i>Utilization:</i> Change in use of polytherapy or anti-epileptic drugs (AEDs).</p>	Overall, 54.5% of risk improvement could be predicted by interventions and 45.5% by patient-related intrinsic factors. The improvement in the risk profile score was not statistically significant. Patient-related intrinsic factors combined are a strong predictor of improvement in medical outcome (72.7%). The transition interventions on the other hand are an equally strong predictor as patient-related factors for improvement in educational/vocational outcomes, independence, and the improvement in the overall risk score.
Hergenroeder (2018)	Electronic medical records; New York Heart Association Functional Assessment of Heart Failure instrument	<p>Population health: Disease-specific measures: functional classification of heart failure status.</p> <p>Utilization and cost of care: <i>Utilization:</i> Number of months between the last pediatric and first adult clinic visits (a measure reflecting gap in medical care).</p>	Intervention patients waited 13 +/-8.3 months for first adult appointment, control patients waited 26 +/-19.2 months. Control patients had a gap over three times the size of intervention patients in the difference between the recommended number of months for the follow-up appointment and the actual first adult appointment. Seven patients in the control group (23%) and no patients in the intervention group had deteriorated functional status by the time of their first adult appointment.

TABLE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
Huang (2020)	Surveys; self-assessment	Patient experience of care: <i>Satisfaction:</i> standardized delivery of transition services to adolescents and young adults with pediatric IBD.	After the launch of the electronic health record (EHR) activity, 96% IBD patients 12 years and older (N=53) seen in our IBD clinic received transition preparation services. The remaining 4% (N=2) that did not receive TEA were deemed ineligible because of developmental delay. TEA recipients reported high satisfaction with, and acceptance of transition preparation services provided.
Jones (2017)	Electronic medical records, patient charts	Population health: <i>Disease-specific measures:</i> glycemic control. Utilization and cost of care: <i>Process of care:</i> Primary: Proportion of AYAs with type 1 diabetes among those eligible for transfer who (1) received a referral from their pediatric practice to the academic adult practice, and (2) attended a visit at this practice. Additional: whether processes in the transition protocol were followed, patient age at first adult visit, whether patient had an adult care visit, average gap between last pediatric and first adult visit, and tertiary care utilization.	Proportion of patients referred to adult practice almost tripled (11% vs 30%); proportion of patients who completed an adult visit also almost tripled (10.5% vs 27.8%). Pediatric providers continued to have discussions about the need to transfer in the year prior to the last pediatric visit (85.7% vs 87.0%); started to use transition readiness assessments (0% vs 13%); created more summaries for adult providers (52.4% vs 72.2%). Adult providers communicated back to pediatric providers at the time of the first adult visit (10.0% vs 46.0%). Attendance for referred patients at any adult visit after referral was maintained (95.2% vs 92.6%), and attendance at the visit without cancelling or failing to show was comparable (66.7% vs 70.4%). Mean patient age at time of referral and visit remained at 21 years. The gap between last pediatric and first adult visit decreased by 82 days (264 days vs 19=82 days), not statistically significant. No immediate improvement in clinical outcomes of tertiary care utilization or glycemic control were noted, nor was there evidence of significant decompensations in these measures.
Kosola (2018)	Finnish Registry of Kidney Diseases; date of transplant, demographics, etiology of kidney disease, number of operations, type of donor, rejection episodes, date/age of transition, and health/morbidity/death data	Population health: <i>Disease-specific measures:</i> Kidney function, graft loss; <i>Mortality:</i> patient death.	No significant difference was found in PS and GS rates before and after the implementation of the TM. Altogether, 114 patients (86%) completed five years of follow-up after transfer. In 63% of the cases (N = 83), KT function remained stable after transfer. In 13% (N = 17), KT function deteriorated progressively, and in 24% (N = 32), the KT lost function. The proportion of patients with stable function, deteriorating function, or graft loss, was evenly distributed in the TM and before TM cohorts.
Le Marne (2019)	Questionnaires, surveys	Population health: <i>Adherence to care monitoring;</i> medication adherence; <i>Self-care:</i> improvement in epilepsy knowledge and management; improvement of mental health well-being, transition readiness. Patient experience of care: <i>Satisfaction:</i> the service was well-received.	The major findings of the study are that the new adolescent service was well-received by adolescents and parents, and adolescents felt their knowledge improved; however, medication adherence and transition readiness did not improve, and psychosocial supports require further modeling. There was no significant improvement in self-reported medication adherence, transition readiness, or mental well-being at follow-up.

TABLE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
Lemke (2018)	Patient Assessment of Chronic Illness Care (PACIC)15 and the Client Perceptions of Coordination Questionnaire (CPCQ)	<p>Patient experience of care: <i>Satisfaction</i>; Perceptions of chronic illness care and perceptions of care coordination.</p> <p>Utilization and cost of care: <i>Process of care</i>: increased communication.</p>	<p>Intervention participants had a Patient Assessment of Chronic Illness Care score at 12 months of 3.6 vs 3.3 compared with participants in the control group. Intervention participants had higher average scores for patient activation (3.7 vs 3.4), problem solving (3.8 vs 3.4), and coordination/follow-up (3.0 vs 2.5). The Client Perceptions of Coordination Questionnaire revealed that intervention participants had 2.5 times increased odds to endorse mostly or always receiving the services they thought they needed and had 2.4 times increased odds to have talked to their provider about future care.</p>
Mackie (2018)	Questionnaires	<p>Population health: <i>Self-care</i>: change in patient knowledge of congenital heart disease, change in self-management scale scores.</p> <p>Utilization and cost of care: <i>Utilization</i>: visit beyond recommended time; incidence of cardiac re-intervention.</p>	<p>A total of 121 participants were randomized to receive the intervention (n = 58) or usual care (n = 63). At the recommended time of first adult appointment (excess time = 0), intervention participants were 1.8 times more likely to have their appointment within 1 month. This hazard increased with time; at an excess time of 6 months, intervention participants were 3.0 times more likely to have an appointment within 1 month. The intervention group had higher scores at 1, 6, 12, and 18 months on the MyHeart knowledge survey and the Transition Readiness Assessment Questionnaire self-management index.</p>
Paepegay (2018)	Medical records, survey	<p>Population health: <i>Disease-specific measures</i>: Anthropometric and endocrine status; <i>Patient reported health and quality of life</i>: perceptions of patient and family (social and psychiatric outcomes).</p>	<p>A coordinated care pathway with specialized pediatric care and organized transition from a pediatric hospital to a Reference Center for transitioning pediatric patients with Prader-Willi syndrome (PWS) was associated with improved endocrine, metabolic, anthropometric, and psychiatric traits in adulthood. Two times more patients in the transition group had a GH stimulation test in childhood than those without transition. Only about one-third of patients in the cohort received GH treatment during childhood, but two times more patients in the transition group had GH treatment than those without transition. This difference remained significant after exclusion of patients for whom the diagnosis of PWS was received after the age of 15 years. There was a trend toward more GH stimulation test after completion of growth in patients who received GH treatment in childhood. Patients in the transition group had improved anthropometric parameters. They weighed significantly less and had a lower BMI and lower body fat, whether expressed as percentage of body weight, absolute FM, or when taking into account height (FMI). They also had a more favorable body fat repartition than patients without transition as assessed by the trunk-to-appendicular FM ratio. They also had an improved metabolic profile, as only one patient in the transition group had HBP compared to 16 without transition (P = 0.02). The percentage of type 2 diabetes was lower in the transition group, but this difference did not reach significance. Most patients of the whole cohort had behavioral or psychiatric disorders: 1/3 had a history of hospitalization in a psychiatric department during adolescence or adulthood, 2/3 displayed skin picking, half of the subjects received neuroleptics, and 1/3 had antidepressant or another psychotropic treatment. However, fewer patients in the transition group had psychiatric disorders, as fewer received antidepressants or neuroleptics. The aim of the patient survey was to obtain the perspective of patients and their families on emerging medical and social problems, particularly in adulthood. There were no significant differences depending on transition status.</p>

TABLE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
Pyatak (2017)	Surveys, A1c readings, medical records	<p>Population health: <i>Disease specific measures:</i> Decrease in HbA1c levels; <i>Patient-reported health and quality of life:</i> Increase in life satisfaction, decrease in perceived stress, increase in global well-being in the past month; <i>Self-care:</i> Increase in knowledge of diabetes, increase in self-efficacy.</p> <p>Utilization and cost of care: <i>Utilization:</i> Increase in number of routine diabetes care visits, decrease in episodes of severe hypoglycemia, decrease in emergency visits and hospitalizations in those with lapsed care.</p>	<p>During the 12-month program, both groups maintained a similar frequency of routine diabetes care visits, and both groups improved their glycemic control. LC also decreased their incidence of hypoglycemia and emergency department utilization during the study period, but this group also had higher levels of depressive symptoms throughout, and their life satisfaction declined over the 12 months. The CC groups reported modest improvements in psychosocial outcomes.</p>
Razon (2019)	Medical records	<p>Population health: <i>Self-care:</i> development of medical and psychosocial care plan.</p> <p>Utilization and cost of care: <i>Utilization:</i> free up hospital beds and outpatient appointments for pediatric patients; <i>Process of care:</i> transfer planning and consultation; transfer to adult care within 6-12 months.</p>	<p>At the time of this analysis, 97 (49%) referrals were seen in consultation, and 30 (15%) patients were successfully transferred to adult care. The mean time between referral and transfer to adult care was 191 days (SD=84). 24 outpatient visits were scheduled for future dates. Of note, the short-term goal of referrals was not always full transfer to adult care; out of the 42 inpatient referrals, the plan for 35 (83%) consults was to receive ongoing care from pediatric providers but with coordination assistance from the Adult Consult Team. It was estimated that transferring these initial 30 patients made 300 inpatient bed-days and over 150 outpatient appointments available for other pediatric patients in the hospital and ambulatory network.</p>

TABLE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
Sattoe (2020)	Semi-structured interviews, observations during consultations, medical charts, and patient questionnaires	<p>Population health: Self-care: Improved self-management outcomes and experiences, increased independence during consultations; <i>Patient reported quality of life:</i> increased satisfaction and quality of life; <i>Disease-specific measures:</i> decrease in clinically active IBD disease; <i>Adherence to care monitoring:</i> Adherence to treatment measured with the validated 5-item Medication Adherence Rating Scale, differences in biologics medication usage.</p> <p>Patient experience of care: <i>Satisfaction:</i> Transfer experiences as measured using the On Your Own Feet Transfer Experience Scale, satisfaction with transfer processes. <i>Barriers to care:</i> Good: For providers: service structures and daily routines of the TC, Barriers to success experienced by staff, facilitators of success, and benefits of the clinic. Bad: time restrictions, planning difficulties, limited involvement of adult care providers and insufficient financial coverage.</p> <p>Utilization and cost of care: <i>Utilization:</i> Increased health care usage by youth in the TC, decrease in missed appointments, decreased hospital admissions.</p>	<p>At the Transition Clinic, multidisciplinary team meetings and alignment of care between pediatric and adult care providers were standard practice. Non-medical topics received more attention during consultations with young people at the TC than in the practice where adolescents were directly handed over to adult care.</p> <p>The young people who received care at the TC on average had significantly more planned consultations in the year before transfer than those in direct handover care. As for missed consultations, those who received care at the TC had significantly fewer missed consultations in the second year after transfer. Over the whole period, young people treated at the TC had significantly fewer planned and unplanned hospital admissions related to IBD. For young people at the TC, the department and hospital they had been transferred to was more often recorded in the patient chart compared with those in direct handover care.</p> <p>Significantly more young people in direct handover care had clinically active disease during transfer compared with those seen at the TC. The young people in direct handover care also more often experienced a relapse in the year before transfer. Also, the use of medications differed significantly between both groups. In the direct handover group, more young people used biologics compared with the TC group. This difference was found at all data collection points.</p> <p>Regarding transition experiences, young people treated at the TC were more positive on whether their adult healthcare providers were familiar with their personal situation and whether they had met their adult healthcare provider(s) before transfer. Overall, the young people treated at the TC tended to report higher scores for transition experiences compared with those treated in direct handover care. This difference was not statistically significant, but the effect size was medium. The same was the case for reported satisfaction with the transfer.</p> <p>The perceived patient-centeredness score was slightly higher at the TC, as was the case for self-efficacy, adherence to treatment, self-management, and health-related quality of life. On the other hand, young people in the direct handover care setting reported a slightly higher score on independence during consultations. However, none of the differences in healthcare-related and self-management-related outcomes were statistically significant, and effect sizes were small.</p> <p>Barriers experienced by professionals of the TC were time restrictions, planning difficulties, limited involvement of adult care providers, and insufficient financial coverage. Facilitators experienced high professional motivation and a high case load. During the year before transfer, young people at the TC had more planned consultations. They showed a positive trend in better transfer experiences and more satisfaction. Those in direct handover care more often experienced a relapse before transfer and had more missed consultations after transfer. Still, no significant differences were found in self-management-related experiences of young people with IBD treated at the TC compared with those in the control setting, suggesting there is room for improvement in the TC model.</p>

TABLE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
Schutz (2019)	Medical records, patient questionnaires	<p>Population health: <i>Disease-specific measures:</i> Decrease in delayed puberty rates, decrease in rates of loose bowel movements; <i>Patient reported care and quality of life:</i> increase in sexual life satisfaction.</p> <p>Utilization and cost of care: <i>Utilization:</i> Decreased rate of IBD complications, surgeries, and radiation doses; <i>Cost of care:</i> decreased medical expenditures for those in the transition group (attributed to increased disease knowledge and management skills)</p>	<p>The percentage of transfer group patients with an IBD-related intestinal complication was higher compared to the transition group (64% vs. 21%, $p=0.022$). We also found a tendency towards a higher number of IBD-related surgery in the transfer group compared to the transition group (46% vs. 13%, $p=0.077$). Transfer group patients received higher mean cumulated doses of radiation compared with the transition group ($4.2\pm 5.3\text{mSv}$ vs. $0.01\pm 0.01\text{mSv}$, $p=0.036$). Delayed puberty was only noted in the transfer group (27%, $p=0.025$). Mean expenditures for surgeries and hospitalization tended to be lower in the transition group compared to transfer group patients ($744\pm 630\text{€}$ vs. $2,691\pm 4,150\text{€}$, $p=0.050$). Sexual life satisfaction was significantly higher ($p=0.023$), and rates of loose bowel movements tended to be lower ($p=0.053$) in the transition group.</p>
Szalda (2019)	Transition Readiness Assessment Questionnaire; electronic medical records; surveys	<p>Population health: <i>Self-care:</i> provision of psychoeducational events; improvement in disease knowledge.</p> <p>Utilization and cost of care: <i>Utilization:</i> increase in number of divisions with drafted transition policies; increased utilization of electronic medical record-based transition support tools; development of a clinical pathway for HCT; <i>Process of care:</i> transfer completion.</p>	<p>Between July 2015 and March 2017, MINT identified 11 transition champions, increased the number of divisions with drafted transition policies from 0 to 7, increased utilization of electronic medical record-based transition support tools from 0 to 7 divisions, held seven psychoeducational events, and developed a clinical pathway. 80 consults were referred over the two-year period; 74 were deemed as appropriate referrals. Referring pediatric providers ($n = 25$) reported that MINT helped identify adult providers and coordinate care with other Children's Hospital of Philadelphia specialists (78%), and that MINT saved greater than 2 hours of time (48%).</p>
van Pelt (2018)	Medical records	<p>Population health: <i>Disease specific measures:</i> Decrease in disease activity.</p> <p>Utilization and cost of care: <i>Utilization:</i> Decrease in dropout rates.</p>	<p>In contrast to what is currently suggested, we found in this longitudinal study of JIA-patients transferred from pediatric to adult health care that the process of transition is not associated with increased disease activity. Disease activity over time is comparable to patients treated at either pediatric or adult clinics. However, transition is a risk factor for dropout, as frequency of dropout is significantly higher in patients in transition compared to pediatric and adult care (Transitional patients = 22%; $n=14$ compared to the pediatric (3%; $n=2$) and adult group (10%; $n=5$; $p=0.01$). The process of transition in JIA is not associated with an increase in disease activity; however, this period carries a risk for dropout, especially in patients with low disease activity.</p>

TABLE 5: DATA SOURCES AND OUTCOMES

STUDY	DATA SOURCE	OUTCOME MEASURES	STUDY RESULTS
White (2017)	Medical records	<p>Population health: <i>Disease-specific measures:</i> Differences in glycoated hemoglobin concentration.</p> <p>Utilization and cost of care: <i>Utilization:</i> Increase in frequency of clinic attendance, decrease in disengagement from services.</p>	<p>During 0-12 months after transition, the mean number of clinics attended was 2.3 (SD 1.1) in the intervention group and 2.3 (1.4) in the control group (p=0.84; adjusted β 0.1, SE 0.2, p=0.88); three (6%) of 49 participants in the intervention group and six (11%) of 55 in the control group disengaged from services (p=0.38; adjusted odds ratio [OR] 0.5, 95% CI 0.1-2.3, p=0.36). At 12-24 months post-transition, mean clinic attendance was 2.5 (SD 1.3) in the intervention group and 1.4 (SD 1.8) in the control group (p=0.001; adjusted β 0.9, SE 0.4, p=0.009); two (6%) of 32 in the intervention group and 18 (49%) of 37 in the control group disengaged from services (p=0.001; adjusted OR 0.1, 95% CI 0.1-0.2, p=0.001). Neither the intervention nor pre-transition clinic attendance had an independent effect on glycoated hemoglobin after transition. Appointment management did not increase clinic attendance and did not decrease disengagement with services 0-12 months after transition to adult services but had a positive effect during 12-24 months after transition.</p>
Yerushalmy-Feler (2017)	Questionnaires	<p>Population health: <i>Self-care:</i> Self-efficacy and self-management skills, increased knowledge of IBD and its treatments and diagnostic tests, increase in autonomy in appointments, increase in knowledge about the transfer process, increase in overall transfer readiness of both patients and their families; <i>Adherence to care monitoring:</i> Increase in medication adherence at the outpatient clinic; <i>Patient reported health and quality of life:</i> increased independence.</p>	<p>The results were significantly favorable in all transition domains after completing the transition process (self-efficacy, knowledge of IBD, IBD treatment, and coping with IBD, knowledge of diagnostic tests and the transition process, actual behavior at the outpatient clinic, and overall readiness). Our findings suggest that older age correlates with better coping with IBD after transition. The females in this study had significantly better transfer readiness. We also observed that the longer the disease duration, the less improvement in the domain of coping with IBD. Duration was positively correlated with transition readiness, implying that not only the quality of transition but also its duration is important for the success of this kind of process in terms of understanding and assimilating the massive quantity of information and guidance provided in the transition clinic. This important finding is opposed to the model of one-time joint visits just before transfer (pediatric and adult gastroenterologists) that are likely to be insufficient in preparing patients. We conclude that an adolescent IBD transition clinic should be implemented in all IBD centers and aimed to tailor a personalized transition program to meet the needs of every adolescent with IBD.</p>

TABLE 6: LIMITATIONS

STUDY	LIMITATIONS
Agarwal (2017)	Retrospective cohort with no comparison group, therefore not known if intervention better than usual care, significant number of participants lost for follow-up before transition, not all measures available in retrospective data search, health outcomes seen after transition may not necessarily be due to the transition intervention.
Bennett (2016)	The survey response rate was low —only ~25% in each cohort. While the data suggests that transition practice does not appear to adversely affect disease or psychosocial outcomes, it remains unclear which current practices could be optimized to achieve better outcomes among IBD children and youth.
Burns (2018)	Small sample size, unable to accurately calculate the number in the whole population sampled due to data inaccuracies, and there was no data on the routine care received by the comparison group.
Cappelli (2016)	No follow-up measures were taken to assess the youth’s experiences with the Youth Transition Project.
Colver (2018)	Lower average recruitment from a group with a special need for transitional care, namely those from areas of greater socioeconomic deprivation. There was also lower than intended recruitment from the two disability groupings, so that analyses controlling for condition may have been underpowered. A further potential limitation was the accuracy of exposure to PBFs.
Essaddam (2018)	This is an observational study that provides data on diabetes outcomes during the transition program without a comparison control group. Thus, the study team cannot indicate whether the benefits are due to unique features of the transition program or to other confounding factors.
Farrell (2018)	As the data was retrieved using an existing administrative database, information about socio-economic status, education level, or family characteristics were not available. Another limitation is the number of youth with diabetes who did not attend either 18 +/- 3-month or 30 +/- 3-month follow-up appointments.
Flocco (2019)	No control group. The sample was not randomized, and only one clinic was involved in the trial. No assessments of clinical data were available.
Fu (2017)	Adherence rates have the potential to be inflated due to self-reporting. The control cohort may have received education from their physicians comparable to the education given in the IBD transition clinics (typically attended once or twice per individual). Not mentioned in the article as a limitation, but adolescents selected to attend the clinics may have differed from those in the control group.
Geerlings (2016)	Use of self-reported data (in the pilot phase of this study many patients indicated they would not come back for an interview due to distances involved, since they were all graduated from the pediatric clinic where the intervention took place); no ability to re-evaluate unsupportive family environment (which was the most significant variable in a previous study); non-responders had significantly worse psychosocial outcome at baseline, so responders probably had a better chance for a better outcome. Results might not be generalizable to the adolescent and young adult population.
Hergenroeder (2018)	Adolescent and young adults with congenital heart disease who transitioned to adult care outside of the Texas Children’s Hospital were not included in the study. The control and intervention groups in the study may have differed on important variables not measured in this study.
Huang (2020)	Limited to one IBD cohort at a single medical institution; prior delivery of transition preparation services had no such tracking mechanism, and thus was assumed to be low
Jones (2017)	Patients at the pediatric clinic who may have visited adult providers outside of the medical center were not included in the study. Generalizability to other settings may be limited by this study’s focus on a single academic medical center.
Kosola (2018)	Historical comparison group may have received older treatments, changing the outcome of kidney transplants independent of transition, and retrospective data may not have complete information. Patients in the transition model group were younger than the historical comparison cohort and had longer follow up. Despite the strong study design, survival and morbidity are rough measures of transition success and may not give a clear picture of the elements of successful transition.
Le Marne (2019)	Short duration of follow-up, poor attendance at mental health sessions, and poor return of follow-up surveys

TABLE 6: LIMITATIONS

STUDY	LIMITATIONS
Lemke (2018)	Convenience sampling prone to selection bias, limited geographic and demographic participants reducing generalizability, when participants could not fill out the questionnaires caregivers did, making those results not as accurate. The questionnaires do not necessarily measure clinically meaningful differences or associations with improved patient outcomes.
Mackie (2018)	Potential participant bias since the participants showed higher than typical levels of knowledge of their condition, nurse-led intervention was not implemented consistently across participants, drop out of some participants in follow up, and although the researchers looked at when participants and controls had their first adult care appointment, the quality of care was not tested.
Praepageay (2018)	The cohorts studied had late diagnosis of Prader-Willi, which is now done in the neonatal period. Earlier diagnosis may have an impact on the health and wellness parameters tested in this study, including receiving GH which has an impact on BMI. Behavior disorders disrupt care, and it is not known if the small sample size had individuals who had more or less incidence of behavioral disorders that could have affected the outcomes. The sample was also limited to a specific geographic region, and the groups were not randomized making generalizability difficult.
Pyatak (2017)	Small sample sizes. Significant loss to follow up, especially in the LC ("loss of care") group; some participants transferred to other providers, leading to lack of data. LC and CC ("continued care") groups differed significantly at baseline, most notably by being in different states of transition at the time of study enrollment. LC group's level of preparation for transition was not assessed as part of the study, so comparisons to the CC group cannot be made.
Razon (2019)	Intervention was implemented at a single site without a control group for comparison; no feedback from patients and families.
Sattoe (2020)	Insufficient statistical power to demonstrate significant differences in patient-reported outcomes between settings, since the response rate on the questionnaires was low (37%-46%); patients transferred to other hospitals could not be included in the post-transfer measurements, despite repeated efforts to collect these.
Schutz (2019)	The number of study participants was small and non-randomized. This transition program differs from others found in locations such as England.
Szalda (2019)	Replicability is limited due to time intensity of implementing hospital operations-level changes; many of the outcomes identified are longitudinal in nature, making this work time and labor intensive; although transfer completion was measured as an outcome here, the definition of a "successful" transition remains one of substantial research.
van Pelt (2018)	Missing data on disease activity. Disease activity was obtained from the attending physician, which implies in transitional care two (different) observers for the same patient.
White (2017)	Limitations of our trial included that the appointment manager was a medical specialist who undertook the project as part of a research degree, which is unlikely to be feasible in terms of resource and funding allocation outside the research setting. Another limitation was the number of participants for whom follow-up data were available, an issue that we attempted to address with the use of multiple imputation analyses to account for missing data. Emergency department attendance and occurrence of severe hypoglycemia were not recorded because of the absence of previously available centralized databases, limiting assessment of the clinical effects of the intervention.
Yerushalmy-Feler (2017)	One possible limitation is the wide range of patients' ages. As the average age was 19±1.8 years, the data are pertinent to adolescents. It is noteworthy that the wide age range is affected by the inclusion of a single 27-year-old patient who requested to continue follow-up at the clinic, as would sometimes occur in real life. Second, parents' and providers' reports were not included, leading to some missing points of view. In addition, the lack of a control group to compare the improvement in transition readiness without attendance in a transition clinic could be considered a limitation.

TABLE 7: INTERVENTION TYPES AND EVIDENCE RATINGS

STUDY	INTERVENTION TYPE [Health care transition intervention components]	INDIVIDUAL EVIDENCE RATINGS	OVERALL EVIDENCE RATINGS
Flocco (2019)*+	Single component A (Planning for transition)	Emerging evidence	Emerging evidence
Huang (2020)*+	Single component: A (Planning for transition)	Emerging evidence	
Le Mame (2019)*+	Single component: A (Planning for transition)	Mixed evidence	
Burns (2018)	Multicomponent: A + B (Planning for transition + Transfer assistance)	Emerging evidence	Emerging/Mixed evidence
Hergenroeder (2018)	Multicomponent: A + B (Planning for transition + Transfer assistance)	Emerging evidence	
Yerushalmy-Feler (2017)	Multicomponent: A + B (Planning for transition + Transfer assistance)	Emerging evidence	
Bennett (2016)	Multicomponent: A + B (Planning for transition + Transfer assistance)	Mixed evidence	
Fu (2017)	Multicomponent: A + B (Planning for transition + Transfer assistance)	Mixed evidence	
Geerlings (2016)	Multicomponent: A + B (Planning for transition + Transfer assistance)	Mixed evidence	
Jones (2017)	Multicomponent: A + B + C (Planning for transition + Transfer assistance + Integration into adult care)	Moderate evidence	Emerging evidence
Mackie (2018)	Multicomponent: A + B + C (Planning for transition + Transfer assistance + Integration into adult care)	Moderate evidence	
Essaddam (2018)	Multicomponent: A + B + C (Planning for transition + Transfer assistance + Integration into adult care)	Emerging evidence	
White (2017)	Multicomponent: A + B + C (Planning for transition + Transfer assistance + Integration into adult care)	Emerging evidence	
Kosola (2018)	Multicomponent: A + B + C (Planning for transition + Transfer assistance + Integration into adult care)	Mixed evidence	
Farrell (2018)	Multicomponent: A + B + D (Planning for transition + Transfer assistance + Care coordination)	Moderate evidence	Moderate/Emerging evidence
Lemke (2018)	Multicomponent: A + B + D (Planning for transition + Transfer assistance + Care coordination)	Moderate evidence	
Pyatak (2017)	Multicomponent: A + B + D (Planning for transition + Transfer assistance + Care coordination)	Emerging evidence	
Cappelli (2016)	Multicomponent: A + B + D (Planning for transition + Transfer assistance + Care coordination)	Mixed evidence	
Agarwal (2017)	Multicomponent: A+B+C+D(Planning for transition + Transfer assistance + Integration into adult care +Care coordination)	Moderate evidence	Emerging evidence
van Pelt (2018)	Multicomponent: A+B+C+D(Planning for transition + Transfer assistance + Integration into adult care +Care coordination)	Emerging evidence	
Razon (2019)*	Multicomponent: A+B+C+D(Planning for transition + Transfer assistance + Integration into adult care +Care coordination)	Emerging evidence	
Sattoo (2020)*	Multicomponent: A+B+C+D(Planning for transition + Transfer assistance + Integration into adult care +Care coordination)	Emerging evidence	
Schutz (2019)*	Multicomponent: A+B+C+D(Planning for transition + Transfer assistance + Integration into adult care +Care coordination)	Emerging evidence	
Szalda (2019)*	Multicomponent: A+B+C+D(Planning for transition + Transfer assistance + Integration into adult care +Care coordination)	Emerging evidence	
Colver (2018)	Multicomponent: A + B + C + D (Planning for transition + Transfer assistance + Integration into adult care + Care coordination)	Mixed evidence	
Paeppegay (2018)	Multicomponent: B + C (Transfer assistance + Integration into adult care)	Emerging evidence	Emerging evidence

* Studies identified from most recent literature review (2019-2020).
 + 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.

TABLE 8: HEALTH CARE TRANSITION COMPONENTS

Component	Agarwal (2017)	Bennett (2016)	Burns (2018)	Cappelli (2016)	Colver (2018)	Essaddam (2018)	Farrell (2018)	Flocco (2019)	Fu (2017)	Gerlings (2016)	Hergenroeder (2018)	Huang (2020)	Jones (2017)	Kosola (2018)	Le Marne (2019)	Lemke (2018)	Mackie (2018)	Papegacy (2018)	Pyatak (2017)	Razon (2019)	Satoe (2020)	Schutz (2019)	Szalda (2019)	van Pelt (2018)	White (2017)	Yerushalmy-Feler (2017)
A. PLANNING FOR TRANSITION																										
Transition policy — pediatric side																										
Transition tracking/monitoring				X																						
Time alone with pediatrician																										
Transition readiness/self-care skills assessment				X				X																		
Disease education/skill building																										
Plan of care/medical summary/electronic medical information																										
Patient/family feedback on transition process																										
B. TRANSFER ASSISTANCE																										
Identifying an adult provider/scheduling assistance																										
Letter of referral/coordination of referrals																										
Transfer summary sent from pediatrician or shared with new adult provider																										
Communication between pediatrician and adult provider/joint pediatric and adult meetings																										
Introductory visit to adult setting																										
Pediatric provider consultations with adult provider																										
EVIDENCE RATINGS	Moderate evidence	Mixed evidence	Emerging evidence	Mixed evidence	Mixed evidence	Emerging evidence	Moderate evidence	Emerging evidence	Mixed evidence	Mixed evidence	Emerging evidence	Emerging evidence	Moderate evidence	Mixed evidence	Mixed evidence	Moderate evidence	Moderate evidence	Emerging evidence								

TABLE 8: HEALTH CARE TRANSITION COMPONENTS

Component	C. INTEGRATION INTO ADULT CARE							Evidence Rating
	Transition policy —adult side	Welcome/orientation process	Self-care skills assessment	Scheduling assistance/follow-up with patient after adult first visit/ monitoring appointments	Ongoing care	Patient/family feedback on transition process		
D. CARE COORDINATION	Agarwal (2017)	X		X				Moderate evidence
	Bennett (2016)							Mixed evidence
	Burns (2018)							Emerging evidence
	Cappelli (2016)							Mixed evidence
	Colver (2018)				X			Mixed evidence
	Essaddam (2018)					X		Emerging evidence
	Farrell (2018)							Moderate evidence
	Flocco (2019)							Emerging evidence
	Fu (2017)							Mixed evidence
	Geertings (2016)							Mixed evidence
EVIDENCE RATINGS	Hergenroeder (2018)							Emerging evidence
	Huang (2020)							Emerging evidence
	Jones (2017)	X	X	X	X	X		Moderate evidence
	Kosola (2018)				X			Mixed evidence
	Le Marne (2019)							Mixed evidence
	Lemke (2018)							Moderate evidence
	Mackie (2018)		X		X			Moderate evidence
	Paepcgaey (2018)			X				Emerging evidence
	Pyatak (2017)							Emerging evidence
	Razon (2019)				X			Emerging evidence
	Satoo (2020)	X			X	X		Emerging evidence
	Schutz (2019)	X				X		Emerging evidence
	Szalda (2019)				X		X	Emerging evidence
	van Pelt (2018)				X			Emerging evidence
	White (2017)				X			Emerging evidence
	Yerushalmy-Feler (2017)							Emerging evidence

APPENDIX A

TRANSITION POLICY STATEMENTS

The MCH Evidence Center team searched Google and PubMed in June 2020 for transition to adult care policy/position statements. The following are select statements from different organizations regarding HCT. Please refer to the table below for a link, citation, and/or short description of transition statements.

ORGANIZATION	TRANSITION STATEMENTS
American Academy of Pediatrics	<p>Alderman EM, Breuner CC; Committee on Adolescence. Unique needs of the adolescent. <i>Pediatrics</i>. 2019 Dec;144(6):e20193150. doi: 10.1542/peds.2019-3150. Epub 2019 Nov 18. PMID: 31740496</p> <p>This policy statement outlines the special health challenges that adolescents face on their journey and transition to adulthood and provides recommendations for those who care for adolescents, their families, and the communities in which they live.</p> <p><i>Also see:</i> Adolescent Health: A Compendium of AAP Clinical Practice Guidelines and Policies. AAP, published 4/15/2020</p>
American Academy of Pediatric Dentistry	<p>Policy on Transitioning from a Pediatric-Centered to an Adult-Centered Dental Home for Individuals with Special Health Care Needs (Revised 2016): https://www.aapd.org/research/oral-health-policies--recommendations/transitioning-from-a-pediatric-centered-to-an-adult-centered-dental-home-for-individuals-with-special-health-care-needs/</p> <p>In: The Reference Manual of Pediatric Dentistry 2019-2020, p. 143-146</p>
American Diabetes Association and others	<p>Peters A, Laffel L, American Diabetes Association Transitions Working Group. Diabetes care for emerging adults: Recommendations for transition from pediatric to adult diabetes care systems: A position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children With Diabetes, The Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (Formerly Lawson Wilkins Pediatric Endocrine Society). <i>Diabetes Care</i>. 2011 Nov;34(11):2477-85. doi: 10.2337/dc11-1723.</p>

ORGANIZATION	TRANSITION STATEMENTS
<p>American Society of Pediatric Neurosurgeons</p>	<p>Rocque BG, Weprin BE, Blount JP, Hopson BD, Drake JM, Hamilton MG, Williams MA, White PH, Orrico KO, Martin JE. Health care transition in pediatric neurosurgery: A consensus statement from the American Society of Pediatric Neurosurgeons. <i>Journal of Neurosurgical Pediatrics</i>. 2020 Feb;14:1-9. DOI: 10.3171/2019.12.PEDS19524</p> <p>Abstract Objective: The number of children with complex medical conditions surviving to adulthood is increasing. A planned transition to adult care systems is essential to the health maintenance of these patients. Guidance has been established for the general health care transition (HCT) from adolescence to adulthood. No formal assessment of the performance of pediatric neurosurgeons in HCT has been previously performed. No “best practice” for this process in pediatric neurosurgery currently exists. The authors pursued two goals in this paper: 1) define the current state of HCT in pediatric neurosurgery through a survey of the membership of the American Society of Pediatric Neurosurgeons (ASPN) on current methods of HCT, and 2) develop leadership-endorsed best-practice guidelines for HCT from pediatric to adult neurosurgical health care.</p> <p>Methods: Completion of the Current Assessment of Health Care Transition Activities survey was requested of 178 North American pediatric neurosurgeons by using a web-based questionnaire to capture HCT practices of the ASPN membership. The authors concurrently conducted a PubMed/MEDLINE-based literature review of HCT for young adults with special health care needs, surgical conditions, and/or neurological conditions for the period from 1990 to 2018. Selected articles were assembled and reviewed by subject matter experts and members of the ASPN Quality, Safety, and Advocacy Committee. Best-practice recommendations were developed and subjected to peer review by external expert groups.</p> <p>Results: Seventy-six responses to the survey (43%) were received, and 62 respondents (82%) answered all 12 questions. Scores of 1 (lowest possible score) were recorded by nearly 60% of respondents on transition policy, by almost 70% on transition tracking, by 85% on transition readiness, by at least 40% on transition planning as well as transfer of care, and by 53% on transition completion. Average responses on all core elements were < 2 on the established 4-point scale. Seven best-practice recommendations were developed and endorsed by the ASPN leadership.</p> <p>Conclusions: The majority of pediatric neurosurgeons have transition practices that are poor, do not meet the needs of patients and families, and should be improved. A structured approach to transition, local engagement with adult neurosurgical providers, and national partnerships between pediatric and adult neurosurgery organizations are suggested to address current gaps in HCT for patients served by pediatric neurosurgeons.</p>
<p>Association of Pediatric Hematology/Oncology Nurses, American Society of Pediatric Hematology Oncology</p>	<p>Bryant R, Porter JS, Sobota A, Association of Pediatric Hematology/Oncology Nurses, American Society of Pediatric Hematology Oncology. APHON/ASPHO policy statement for the transition of patients with sickle cell disease from pediatric to adult health care. <i>Journal of Pediatric Oncology Nursing</i>. 2015 Nov-Dec;32(6):355-9. doi: 10.1177/1043454215591954</p> <p>Abstract With advances in medical care, the majority of children with sickle cell disease are surviving to adulthood. Patients, families, and providers now face the need for this growing population to move from pediatric- to adult-focused care. In order to facilitate a successful transfer to adult health care and prepare young adults for greater independence, it is recommended that all pediatric patients with sickle cell disease receive transition preparation.</p> <p>Association position: As the professional voice of pediatric hematology/oncology healthcare practice, the Association of Pediatric Hematology/Oncology Nurses (APHON) and the American Society of Pediatric Hematology Oncology (ASPHO) recommends that the discussion of transition begin early and is presented as part of the natural process of becoming an adult; that patients, providers, and families are all involved in creating a transition plan and assessing transition preparedness annually; and that transfer of care involve direct communication between the pediatric team and the accepting adult provider.</p> <p>© 2013 by the Association of Pediatric Hematology/Oncology Nurses and the American Society of Pediatric Hematology Oncology</p>

ORGANIZATION	TRANSITION STATEMENTS
Canadian Task Force on Adolescents and Young Adults with Cancer	<p>Wilkins KL, D'Agostino ND, Penney AM, Barr RD, Nathan PC. Supporting adolescents and young adults with cancer through transitions: Position statement from the Canadian Task Force on Adolescents and Young Adults With Cancer. <i>Journal of Pediatric Hematology and Oncology</i>. 2014 Oct;36(7):545-51. doi: 10.1097/MPH.000000000000103.</p> <p>Abstract Objective: This position statement from the Canadian Task Force on Adolescents and Young Adults with cancer aims to (1) conceptualize the numerous transition experiences encountered by adolescents and young adults (AYA) with cancer; and (2) provide recommendations on how to help AYA regain a sense of control over their lives as they adjust to these transition experiences.</p> <p>Methods: We reviewed and synthesized a heterogeneous sample of studies and recommendations, ranging from well-designed case-controlled investigations to opinions of respected authorities based on clinical experience, as well as reports of expert committees.</p> <p>Results: We describe the key factors that have an impact on different transitions during the cancer journey, and the need for developmentally appropriate services for AYA with cancer that consider both the system issues and individual transition issues. Our recommendations are not intended to be prescriptive, but they are broad enough to be applicable in different types of settings (e.g., family doctor, cancer center, specialty service) and systems beyond health care (e.g., school system, social system).</p> <p>Conclusions: The Task Force urges health care providers, parents, and AYA with cancer to work together in planning and implementing strategies that will enable individuals to successfully navigate the transitions they encounter along the cancer journey and strive for meaningful participation in life situations, achieving their potential as fully functional members of society.</p>
International Children's Continence Society	<p>Bower WF, Christie D, DeGennaro M, Latthe P, Raes A, Romao RLP, Taghizadeh A, Wood D, Woodhouse CRJ, Bauer SB. The transition of young adults with lifelong urological needs from pediatric to adult services: An International Children's Continence Society position statement. <i>Neurourology and Urodynamics</i>. 2017 Mar;36(3):811-819. doi: 10.1002/nau.23039. Epub 2016 May 13</p> <p>Abstract Introduction: Children with urinary tract disorders managed by teams, or individual pediatricians, urologists, nephrologists, gastroenterologists, neurologists, psychologists, and nurses at some point move from child-centered to adult-centered health systems. The actual physical change is referred to as the transfer, whilst the process preceding this move constitutes transition of care. Our aims are twofold: to identify management and health-service problems related to children with congenital or acquired urological conditions who advance into adulthood and the clinical implications this has for long-term health and specialist care; and, to understand the issues facing both pediatric and adult-care clinicians and to develop a systems-approach model that meets the needs of young adults, their families, and the clinicians working within adult services.</p> <p>Methods: Information was gleaned from presentations at an International Children's Continence Society meeting with collaboration from the International Continence Society that discussed problems of transfer and transitioning such children. Several specialists attending this conference finalized this document, identifying issues and highlighting ways to ease this transition and transfer of care for both patients and practitioners.</p> <p>Results: The consensus was urological patients with congenital or other lifelong care needs are now entering adulthood in larger numbers than previously, necessitating new planning processes for tailored transfer of management. Adult teams must become familiar with new clinical problems in multiple organ systems and anticipate issues provoked by adolescence and physical growth. During this period of transitional care, the clinician or team assists young patients to build attitudes, skills, and understanding of processes needed to maximize function of their urinary tract, thus taking responsibility for their own healthcare needs. Preparation must also address negotiating adult health care systems, psychosocial, educational or vocational issues, and mental wellbeing.</p> <p>Conclusions: Transitioning and transfer of children with major congenital anomalies to clinicians potentially unfamiliar with their conditions require improved education both for receiving doctors and children's families. Early initiation of the transition process should allow the transference to take place at appropriate times based on the child's development and environmental and financial factors.</p>

ORGANIZATION	TRANSITION STATEMENTS
International Society of Nephrology/International Pediatric Nephrology Association	Watson AR, Harden P, Ferris M, Kerr PG, Mahan J, Ramzy MF. Transition from pediatric to adult renal services: A consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA). <i>Pediatric Nephrology</i> . 2011 Oct;26(10):1753-7. doi: 10.1007/s00467-011-1981-z. Epub 2011 Aug 13
LIVESTRONG Young Adult Alliance	<p>Zebrack B, Mathews-Bradshaw B, Siegel S, LIVESTRONG Young Adult Alliance. Quality cancer care for adolescents and young adults: A position statement. <i>Journal of Clinical Oncology</i>. 2010 Nov 10;28(32):4862-7. doi: 10.1200/JCO.2010.30.5417. Epub 2010 Sep 20.</p> <p>Abstract Purpose: This consensus-based position statement on behalf of the LIVESTRONG Young Adult Alliance (Alliance) offers recommendations to enhance oncologic care of adolescent and young adult (AYA) patients with cancer.</p> <p>Background: In 2005 to 2006, the National Cancer Institute and the Lance Armstrong Foundation jointly sponsored the Adolescent and Young Adult Oncology Progress Review Group (PRG). The PRG report included the directive to develop standards of care for AYA patients with cancer and to disseminate these guidelines to the community. To this end, the Alliance convened a meeting of experts (clinicians, researchers, and advocates) in June 2009 and derived this position statement.</p> <p>Results: Quality care for AYAs depends on four critical elements: timely detection; efficient processes for diagnosis, initiation of treatment, and promotion of adherence; access to health care professionals who possess knowledge specific to the biomedical and psychosocial needs of this population; and research that will ultimately derive objective criteria for the development of AYA oncology care guidelines. Achieving quality care for AYAs will require assistance with management of disease and treatment effects; cognizance of the unique psychosocial context for AYA growth and development; assessment of and attention to cognitive, psychiatric, and psychosocial issues; facilitated transition to treatment care; and referral to age-appropriate information and support services.</p> <p>Conclusion: Dissemination of recommendations stated here will raise awareness of the need for AYA-specific care guidelines and assist providers in the delivery of care that is responsive to the distinct needs of AYAs with cancer.</p>
Society of Adolescent Health and Medicine	<p>Transition to adulthood for youth with chronic conditions and special health care needs. <i>Journal of Adolescent Health</i>. 2020 May;66(5):631-634. doi: 10.1016/j.jadohealth.2020.02.006.</p> <p>Abstract In 2003, the Society for Adolescent Medicine issued a position paper joining the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians in endorsing a national consensus statement regarding successful transition to adult care for all young people, including youth with special health care needs. This consensus statement was followed by a clinical report in 2011, which was updated in 2018. Since the original publication, the development of professional guidelines, several iterations of U.S.-based national survey data, and a growing global evidence base characterizing the consequences of suboptimal transitions have advanced the field of health care transition substantially. Barriers to and facilitators of successful transition have been described along with a number of social-, economic-, and health care systems-level issues that require coordinated professional advocacy. The goal of this revised position paper is to review the interim developments in health care transition for youth with special health care needs and refine Society of Adolescent Health and Medicine’s position to align with the most recent evidence and professional consensus, including the incorporation of insights and recommendations from the latest revised clinical report.</p>
Society of Pediatric Nurses	Betz CL. SPN Position statement: Transition of pediatric patients into adult care. <i>Journal of Pediatric Nursing</i> . 2017;35:160-164.

ORGANIZATION	TRANSITION STATEMENTS
<p>Unclear; published by European Association of Urology</p>	<p>Wood D, Baird A, Carmignani L, De Win G, Hoebeke P, Holmdahl G, Manzoni G, Nijman RJM, Taylor C, Tekgul S. Lifelong congenital urology: The challenges for patients and surgeons. <i>European Urology</i>. 2019 Jun;75(6):1001-1007. doi: 10.1016/j.eururo.2019.03.019. Epub 2019 Mar 29.</p> <p>Abstract</p> <p>Context: Patients born with complex congenital genitourinary anomalies (including bladder exstrophy, cloacal exstrophy, epispadias, neurogenic bladder, hypospadias, and posterior urethral valves) often require major reconstructive surgery in childhood. These conditions, their treatment, and sequelae require lifelong follow-up. This has created the need for adult urologists to provide care as these patients grow into adults.</p> <p>Objective: To evaluate current strategies for transition and to provide a current position statement with examples of the challenges faced by patients and their health care teams as a result of these conditions and their treatment.</p> <p>Evidence acquisition: Each of the authors was asked to provide a 500-word synthesis, based on current literature, to highlight the challenges faced in an area of their expertise.</p> <p>Evidence synthesis: The authors assembled in March 2018 to form a consensus based on the data gathered. The aforementioned sections were reviewed and, following the consensus discussion, the paper was formulated and reviewed.</p> <p>Conclusions: Lifelong care of congenital problems is challenging and essential for many but not all. Expertise is needed to provide the best care for patients and make the best use of resources. Specialist centers appear to be the most effective and safe model. In the long term, it would be ideal to establish an evidence base focused on the common long-term problems with these conditions to ensure excellent care with appropriate expertise.</p> <p>Patient summary: Patients born with complex congenital anomalies of the genitourinary system require specialist care in childhood. Many will need lifelong care to manage their condition and the treatment of it. There is growing interest in this area of medicine, and this consensus statement addresses the need for lifelong care in this group. The aim is to ensure that all patients that need care at any age are able to find what they need.</p>

REFERENCES

Agarwal S, Raymond JK, Schutta MH, Cardillo S, Miller VA, Long JA. An adult health care-based pediatric to adult transition program for emerging adults with type 1 diabetes. *The Diabetes Educator*. 2017 Feb;43(1):87-96. doi:10.1177/0145721716677098.

Alderman EM, Breuner CC; Committee on Adolescence. Unique needs of the adolescent. *Pediatrics*. 2019;144(6):e20193150. doi:10.1542/peds.2019-3150. Epub 2019 Nov 18.

American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*. 2002 Dec;110(6 Pt 2):1304-1306.

American Academy of Pediatrics, Department of Research. Survey: Transition services lacking for teens with special needs. *AAP News*. 2009;30(11):12.

Annunziato RA, Baisley MC, Arrato N, et al. Strangers headed to a strange land? A pilot study of using a transition coordinator to improve transfer from pediatric to adult services. *Journal of Pediatrics*. 2013;163(6):1628-1633.

Annunziato RA, Emre S, Shneider B, Barton C, Dugan CA, Shemesh E. Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatric Transplant*. 2007;11:608-614. doi:10.1111/j.1399-3046.2007.00689.x

“An Overview of the IHI Triple Aim” at https://www.youtube.com/watch?v=a_QskzKFZnI&feature=youtu.be. Accessed July 26, 2020.

Barr NG, Longo CJ, Embrett MG, Mulvale GM, Nguyen T, Randall GE. The transition from youth to adult mental health services and the economic impact on youth and their families. *Healthcare Management Forum*. 2017;30(6):283-288.

Bennett AL, Moore D, Bampton PA, Bryant RV, Andrews JM. Outcomes and patients’ perspectives of transition from paediatric to adult care in inflammatory bowel disease. *World Journal of Gastroenterology*. 2016 Feb 28;22(8):2611-2620. doi: 10.3748/wjg.v22.i8.2611.

Blum RW. Improving transition for adolescents with special health care needs from pediatric to adult-centered health care. *Pediatrics*. 2002;110:1301-1303.

Bohun CM, Woods P, Winter C, et al. Challenges of intra-institutional transfer of care from paediatric to adult congenital cardiology: The need for retention as well as transition. *Cardiology in the Young*. 2016;26(2):327-333.

Burns K, Farrell K, Myszka R, Park K, Holmes-Walker DJ. Access to a youth-specific service for young adults with type 1 diabetes mellitus is associated with decreased hospital length of stay for diabetic ketoacidosis. *Internal Medicine Journal*. 2018;48(4):396-402.

Cappelli M, Davidson S, Racek J, et al. Transitioning youth into adult mental health and addiction services: An outcomes evaluation of the youth transition project. *Journal of Behavioral Health Services Research*. 2016;43(4):597-610. doi:10.1007/s11414-014-9440-9.

REFERENCES

- Castillo C, Kitsos E. Transitions from pediatric to adult care. *Global Pediatric Health*. 2017;4:2333794X17744946. Published 2017 Dec 4. doi:10.1177/2333794X17744946.
- Chaudhry SR, Keaton M, Nasr SZ. Evaluation of a cystic fibrosis transition program from pediatric to adult care. *Pediatric Pulmonology*. 2013;48(7):658-665.
- Chiang JL, Kirkman MS, Laffel LM, Peters AL. Type 1 diabetes through the life span: A position statement of the American Diabetes Association. *Diabetes Care*. 2014 Jul 1;37(7):2034-54.
- Cohen E, Gandhi S, Toulany A, et al. Health care use during transfer to adult care among youth with chronic conditions. *Pediatrics*. 2016;137(3):e20152734.
- Cole R, Ashok D, Razack A, Azaz A, Sebastian S. Evaluation of outcomes in adolescent Inflammatory Bowel Disease patients following transfer from pediatric to adult health care services: Case for transition. *Journal of Adolescent Health*. 2015;57:212-217.
- Colver A, McConachie H, Le Couteur A, et al. A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. *BMC Medicine*. 2018;16(1):111. Published 2018 Jul 23. doi:10.1186/s12916-018-1102-y.
- Colver A, Rapley T, Parr JR, et al. Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services—implications of a 5-year research programme. *Clinical Medicine (London)*. 2020;20(1):74-80. doi:10.7861/clinmed.2019-0077.
- Cooley WC, Sagerman PJ, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182-200.
- C.S. Mott Children's Hospital. Back off: Parents impeding teens' healthcare independence? 2015. Available at: https://mottpoll.org/sites/default/files/documents/121415_teenhealthcare.pdf. Accessed July 6, 2020.
- Cruz S, Neff J, Chi DL. Transitioning from pediatric to adult dental care for adolescents with special health care needs: Adolescent and parent perspectives—part one. *Pediatric Dentistry*. 2015;37(5):442-446.
- Data Resource Center for Child & Adolescent Health. National Survey of Children with Special Health Care Needs. <http://childhealthdata.org/learn/NSCH>. Published 2009. Accessed January 5, 2017 by the Policy Lab at the Children's Hospital of Philadelphia.
- Eaton CK, Davis MF, Gutierrez-Colina AM, LaMotte J, Blount RL, Suveg C. Different demands, same goal: Promoting transition readiness in adolescents and young adults with and without medical conditions. *Journal of Adolescent Health*. 2017;60(6):727-733.
- Essaddam L, Kallali W, Jemel M, et al. Implementation of effective transition from pediatric to adult diabetes care: Epidemiological and clinical characteristics—a pioneering experience in North Africa. *Acta Diabetologica*. 2018;55(11):1163-1169. doi:10.1007/s00592-018-1196-x.
- Farrell K, Fernandez R, Salamonsen Y, Griffiths R, Holmes-Walker DJ. Health outcomes for youth with type 1 diabetes at 18 months and 30 months post transition from pediatric to adult care. *Diabetes Research and Clinical Practice*. 2018;139:163-169. doi:10.1016/j.diabres.2018.03.013
- Flocco SF, Dellafiore F, Caruso R, et al. Improving health perception through a transition care model for adolescents with congenital heart disease. *Journal of Cardiovascular Medicine (Hagerstown)*. 2019;20(4):253-260. doi:10.2459/JCM.0000000000000770.
- Foster BJ. Heightened graft failure risk during emerging adulthood and transition to adult care. *Pediatric Nephrology*. 2015;30(4):567-576.

- Franklin MS, Beyer LN, Brotkin SM, Maslow GR, Pollock MD, Docherty SL. Health care transition for adolescent and young adults with Intellectual Disability: Views from the parents. *Journal of Pediatric Nursing*. 2019;47:148-158.
- Fu N, Jacobson K, Round A, Evans K, Qian H, Bressler B. Transition clinic attendance is associated with improved beliefs and attitudes toward medicine in patients with inflammatory bowel disease. *World Journal of Gastroenterology*. 2017;23(29):5405-5411.
- Gabriel P, McManus M, Rogers K, White P. Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *Journal of Pediatrics*. 2017;188:263-269.
- Garcia S, Yarborough C, Pelaez D, Strobino D, Minkovitz C. National Performance Measure 10 Adolescent Well Visit Evidence Review. Strengthen the Evidence Base for Maternal and Child Health Programs. Women's and Children's Health Policy Center, Johns Hopkins University, Baltimore, MD. 2018.
- Geary CR, Schumacher KL. Care transitions: Integrating transition theory and complexity science concepts. *Advances in Nursing Science*. 2012;35(3):236-248. pmid:22869210.
- Geerlings RP, Aldenkamp AP, Gottmer-Welschen LM, van Staa AL, de Louw AJ. Long-term effects of a multidisciplinary transition intervention from paediatric to adult care in patients with epilepsy. *Seizure*. 2016;38:46-53. <https://doi.org/10.1016/j.seizure.2016.04.004>.
- Ghandour RM, Jones JR, Lebrun-Harris LA, et al. The design and implementation of the 2016 National Survey of Children's Health [published online ahead of print May 9, 2018]. *Maternal and Child Health Journal*. doi:10.1007/s10995-018-2526-xpmid:29744710.
- Gray WN, Schaefer MR, Resmini, Rawlinson A, Wagoner ST. Barriers to transition from pediatric to adult care: A systematic review. *Journal of Pediatric Psychology*. 2018;43(5):488-502.
- Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for health supervision of infants, children, and adolescents*. 4th ed. Elk Grove Village, IL: American Academy of Pediatrics, 2017.
- Hardin AP, Hackell JM, AAP Committee on Practice and Ambulatory Medicine. Age limit of pediatrics. *Pediatrics*. 2017;140(3):e20172151.
- Hart LC, Patel-Nguyen SV, Merkley MG, Jonas DE. An evidence map for interventions addressing transition from pediatric to adult care: A systematic review of systematic reviews. *Journal of Pediatric Nursing*. 2019;48:18-34. doi:10.1016/j.pedn.2019.05.015.
- Healthy and Ready to Work Transition Work Group. Draft of 10-year HRTW/Transition plan. Healthy and Ready to Work Initiative, Maternal and Child Health Bureau, 2000.
- Hergenroeder AC, Moodie DS, Penny DJ, Wiemann CM, Sanchez-Fournier B, Moore LK, Head J. Functional classification of heart failure before and after implementing a healthcare transition program for youth and young adults transferring from a pediatric to an adult congenital heart disease clinic. *Congenital Heart Disease*. 2018;13(4):548-553. <https://doi.org/10.1111/chd.12604>.
- Huang J, Porterfield SL. Changes in health insurance coverage and health care access as teens with disabilities transition to adulthood. *Disability and Health Journal*. 2019;12(4):551-556.
- Huang JS, et al. Harnessing the electronic health record to distribute transition services to adolescents with inflammatory bowel disease. *Journal of Pediatric Gastroenterology and Nutrition*. 2020;70:200-204.
- IHI Triple Aim Initiative <http://www.ihl.org/Engage/Initiatives/TripleAim/Pages/default.aspx>. Accessed July 28, 2020.
- Ilango S, McManus M, Beck D, Got Transition/The National Alliance to Advance Adolescent Health. Health care transition in State Title V programs: A review of 2018 block grant applications and recommendations for 2020. 2018 Report No. 5. <https://www.gottransition.org/resource/?2018-review-hct-titlev>. Accessed on July 21, 2020.

REFERENCES

- Institute of Medicine (US) Committee on Disability in America; Field MJ, Jette AM, editors. *The Future of Disability in America*. Washington (DC): National Academies Press (US); 2007. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK11434/doi:10.17226/11898>
- Jaworska N, MacQueen G. Adolescence as a unique developmental period. *Journal of Psychiatry & Neuroscience*. 2015;40(5):291-293. pmid:26290063.
- Jones MR, Robbins BW, Augustine M, Doyle J, Mack-Fogg J, Jones H, White, PH. Transfer from pediatric to adult endocrinology. *Endocrine Practice*. 2017;23(7):822-830. <https://doi.org/10.4158/EP171753.OR>.
- Kogan MD, Dykton C, Hirai AH, Strickland BB, Bethell CD, Naqvi I, Cano CE, Downing-Futrell SL, Lu, MC. A new performance measurement system for maternal and child health in the United States. *Maternal and Child Health Journal*. 2015;19(5):945-957.
- Kosola S, Ylinen E, Finne P, Ronnholm K, Fernanda O. Implementation of a transition model to adult care may not be enough to improve results: National study of kidney transplant recipients. *Clinical Transplantation*. 2018;33(1):p. e13449-n/a. <https://doi.org/10.1111/ctr.13449>.
- Kubota, W., Honda, M., Okada, H. et al. A consensus statement on health-care transition of patients with childhood-onset chronic kidney diseases: Providing adequate medical care in adolescence and young adulthood. *Clinical and Experimental Nephrology*. 2018;22:743-751. <https://doi.org/10.1007/s10157-018-1589-8>.
- Lebrun-Harris LA, McManus MA, Ilango SM, et al. Transition planning among US youth with and without special health care needs. *Pediatrics*. 2018;142(4): e20180194.
- Leeb RT, Danielson ML, Bitsko RH, et al. Support for transition from adolescent to adult health care among adolescents with and without mental, behavioral, and developmental disorders—United States, 2016-2017. *MMWR Morbidity and Mortality Weekly Report*. 2020;69:1156-1160.
- Le Marne FA, et al. Implementing a new adolescent epilepsy service: Improving patient experience and readiness for transition. *Journal of Paediatrics and Child Health* 2019;55: 819-825.
- Lemke M, Kappel R, McCarter R, D'Angelo L, Tuchman L. Perceptions of health care transition care coordination in patients with chronic illness. *Pediatrics*. 2018;141(5):e20173168.
- Leung S, Walgrave M, Mennito S. Improving transitions of care for healthy adolescents and young adults. *Southern Medical Journal*. 2019;112(10):501-511.
- Lochridge J, Wolff J, Oliva M, O'Sullivan-Oliveira J. Perceptions of solid organ transplant recipients regarding self-care management and transitioning. *Pediatric Nursing*. 2013;39(2):81-89.
- Lotstein DS, Kuo, AA, Strickland B, Tait F. The transition to adult health care for youth with special health care needs: Do racial and ethnic disparities exist? *Pediatrics*. 2010;126:S129-S136.
- Luque Ramos A, Hoffmann F, Albrecht K, Klotsche J, Zink A, Minden K. Transition to adult rheumatology care is necessary to maintain DMARD therapy in young people with juvenile idiopathic arthritis. *Seminars in Arthritis and Rheumatism*. 2017;47(2):269-275.
- Mackie AS, Rempel G, Kovacs AH, Kaufman M, Rankin KN, Jelen S, Hons B, Yaskina M, Sananes R, Oechslin E, Dragieva D, Mustafa S, Williams E, Schuh M, Manlhiot C, Anthony S, Magill-Evans J, Nicholas D, McCrindle BW. Transition intervention for adolescents with congenital heart disease. *Journal of the American College of Cardiology*. 2018;71(16):1768-1777. <https://doi.org/10.1016/j.jacc.2018.02.043>.
- Magrab P, Millar HEC. Surgeon General's conference: Growing up and getting medical care: Youth with special health care needs: A summary of conference proceedings. Washington, DC: Georgetown University Child Development Center; 1989.

- Majumdar S. The adolescent with sickle cell disease. *Adolescent Medicine: State of the Art Reviews*. 2013;24(1):295-306, xv.
- Maslow G, Adams C, Willis M, et al. An evaluation of a positive youth development program for adolescents with chronic illness. *Journal of Adolescent Health*. 2013;52(2):179-185.
- McCallum C. Supporting young people's transition from children's to adult services in the community. *British Journal of Community Nursing*. 2017;22(1):668-674. doi: 10.12968/bjcn.2017.22.1.66.
- McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics*. 2013;131:1090-1097. doi:10.1542/peds.2012-3050.
- McManus M, White P, Pirtle R, Hancock C, Ablan M, Corona-Parra R. Incorporating the Six Core Elements of Health Care Transition into a Medicaid managed care plan: Lessons learned from a pilot project. *Journal of Pediatric Nursing*. 2015 Sep-Oct;30(5):700-13. doi: 10.1016/j.pedn.2015.05.029. Epub 2015 Aug 1. PMID: 26239121.
- McPheeters M, Davis AM, Taylor JL, Brown RF, Potter SA, Epstein RA. Transition care for children with special health needs. Technical brief no. 15 (Prepared by the Vanderbilt University Evidence-based Practice Center under Contract No. 290-2012-00009- I). AHRQ Publication No.14-EHC027-EF. Rockville, MD: Agency for Healthcare Research and Quality. June 2014. www.effectivehealthcare.ahrq.gov/reports/final.cfm.
- Meleis AI, ed. *Transitions theory: Middle Range and Situation Specific Theories in Nursing Research and Practice*. New York, NY: Springer Publishing Company; 2010.
- Montano CB, Young J. Discontinuity in the transition from pediatric to adult health care for patients with attention deficit/hyperactivity disorder. *Postgraduate Medical Journal*. 2012;124(5):23-32.
- Mosquera RA, Avritscher EB, Samuels CL, et al. Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: A randomized clinical trial. *Journal of the American Medical Association*. 2014;312(24):2640-2648.
- Mulvale GM, Nguyen TD, Miatello AM, Embrett MG, Wakefield PA, and G. E. Randall. Lost in transition or translation? care philosophies and transitions between child and youth and adult mental health services: A systematic review. *Journal of Mental Health*. 2019;28(4):379-388.
- National Research Council. *Investing in the Health and Well-Being of Young Adults*. Washington, DC: The National Academies Press; 2015. https://doi.org/10.17226/18869.
- National Research Council, Institute of Medicine. *Adolescent Health Services: Missing Opportunities*. Washington, DC: The National Academies Press; 2009a.
- National Research Council, Institute of Medicine. *Preventing Mental, Emotional, and Behavioral Disorders Among Young People: Progress and Possibilities*. Washington, DC: The National Academies Press; 2009b.
- Oswald DP, Gilles DL, Cannady MS, Wenzel DB, Willis JH, Bodurtha JN. Youth with special health care needs: Transition to adult health care services. *Maternal and Child Health Journal*. 2013;17(10):1744-1752.
- Paepegaey AC, Coupaye M, Jaziri A, Menesguen F, Dubern B, Polak M, Oppert JM, Tauber M, Pinto G, Poitou C. Impact of transitional care on endocrine and anthropometric parameters in Prader-Willi syndrome. *Endocrine Connections*. 2018;7(5):663-672.
- Pai ALH, Ostendorf HM. Treatment adherence in adolescents and young adults affected by chronic illness during the health care transition from pediatric to adult health care: A literature review. *Children's Health Care*. 2011;40:16-33. doi: 10.1080/02739615.2011.537934.

REFERENCES

- Paine CW, Stollon NB, Lucas MS, Brumley LD, Poole ES, Peyton T, Grant AW, Jan S, Trachtenberg S, Zander M, Mamula P, Bonafide CP, Schwartz LA. Barriers and facilitators to successful transition from pediatric to adult inflammatory bowel disease care from the perspectives of providers. *Inflammatory Bowel Disease*. 2014 Nov;20(11):2083-91. doi: 10.1097/MIB.000000000000136. PMID: 25137417; PMCID: PMC4328150.
- Prior M, McManus M, White P, Davidson L. Measuring the “triple aim” in transition care: A systematic review. *Pediatrics*. 2014;134(6):e1648-e1661.
- Pyatak EA, Sequeira PA, Vigen CL, et al. Clinical and psychosocial outcomes of a structured transition program among young adults with type 1 diabetes. *Journal of Adolescent Health*. 2017;60(2):212-218. doi:10.1016/j.jadohealth.2016.09.004.
- Razon AN, et al. A multidisciplinary transition consult service: Patient referral characteristics. *Journal of Pediatric Nursing*. 2019;47:136-141.
- Reid GJ, Irvine MJ, McCrindle, BW, Sananes R, Ritvo PG, Siu SC, Webb GD. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex Congenital Heart Defects. *Pediatrics*. 2004;113:e197-e205. doi: 10.1542/peds.113.3.e197.
- Reiss J, Gibson R. Health care transition: Destinations unknown. *Pediatrics*. 2002;110(6):1307-1314.
- Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM; Society for Adolescent Medicine. Transition to adult health care for adolescents and young adults with chronic conditions: Position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*. 2003;33(4):309-311.
- Rothstein DH, Dasgupta R, Delivery of Surgical Care Committee of the American Academy of Pediatrics Section on Surgery. Transition of care from pediatric to adult surgery. *Pediatrics*. 2016;138(3):e20161303.
- Sattoe JNT, Peeters MAC, Haitsma J, van Staa A, Wolters VM, Escher JC. Value of an outpatient transition clinic for young people with inflammatory bowel disease: A mixed-methods evaluation. *BMJ Open*. 2020;10(1):e033535. doi:10.1136/bmjopen-2019-033535.
- Sawicki GS, Lukens-Bull K, Yin X, et al. Measuring the transition readiness of youth with special healthcare needs: Validation of the TRAQ—Transition Readiness Assessment Questionnaire. *Journal of Pediatric Psychology*. 2011;36(2):160-171.
- Scal P, Davern M, Ireland M, Park K. Transition to adulthood: Delays and unmet needs among adolescents and young adults with asthma. *Journal of Pediatrics*. 2008 Apr;152(4):471-5, 475.e1. doi: 10.1016/j.jpeds.2007.10.004. Epub 2008 Feb 20. PMID: 18346498; PMCID: PMC3189852.
- Schmidt A, Ilango SM, McManus MA, Rogers KK, White PH. Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *Journal of Pediatric Nursing*. 2020;51:92-107.
- Schor EL. Transition: Changing old habits. *Pediatrics*, 2015;135(6):958-960.
- Schuiteman S, Chua K-P, Plegue MA, Ilyas O, Chang T. Self-management of health care among youth: Implications for policies on transitions of care. *Journal of Adolescent Health*. 2020;66(5):616-622.
- Schütz L, Radke M, Menzel S, Däbritz J. Long-term implications of structured transition of adolescents with inflammatory bowel disease into adult health care: A retrospective study. *BMC Gastroenterology*. 2019 Jul;19(1):128. DOI: 10.1186/s12876-019-1046-5.
- Schwartz LA, Brumley LD, Tuchman LK, et al. Stakeholder validation of a model of readiness for transition to adult care. *JAMA Pediatrics*. 2013;167(10):939-946pmid:23959392.
- Schwartz LA, Tuchman LK, Hobbie WL, Ginsberg JP. A social-ecological model of readiness for transition to adult-oriented care for adolescents and young adults with chronic health conditions. *Child Care, Health and Development*. 2011;37(6):883-895. doi:10.1111/j.1365-2214.2011.01282.x

- Sharma N, O'Hare K, Antonelli RC, Sawicki GS. Transition care: Future directions in education, health policy, and outcomes research. *Academic Pediatrics*. 2014 Mar-Apr;14(2):120-7. doi: 10.1016/j.acap.2013.11.007. PMID: 24602574; PMCID: PMC4098714.
- Shaw KL, Southwood TR, McDonagh JE; British Society of Paediatric and Adolescent Rheumatology. Young people's satisfaction of transitional care in adolescent rheumatology in the UK. *Child: Care, Health and Development*. 2007;33(4):368-379.
- Shepard CL, Doerge EJ, Eickmeyer AB, Kraft KH, Wan J, Stoffel JT. Ambulatory care use among patients with Spina Bifida: Change in care from childhood to adulthood. *Journal of Urology*. 2018;199(4):1050-1055.
- Shulman R, Fu L, Knight JC, Guttman A, Chafe R. Acute diabetes complications across transition from pediatric to adult care in Ontario and Newfoundland and Labrador: A population-based cohort study. *CMAJ Open*. 2020;8(1):E69-E74.
- Sobota A, Umeh E, Mack JW. Young adult perspectives on a successful transition from pediatric to adult care in Sickle Cell Disease. *Journal of Hematology Research*. 2015;2:17-24. doi: 10.12974/2312-5411.2015.02.01.3.
- Steinway C, Gable JL, Jan S., and MINT. Transitioning to adult care: Supporting youth with special health care needs. PolicyLab at Children's Hospital of Philadelphia; 2017. Retrieved from http://bit.ly/E2A_TransitionsOfCare.
- Szalda D, et al. Developing a hospital-wide transition program for young adults with medical complexity. *Journal of Adolescent Health*. 2019;65:476-482.
- Szymanski KM, Cain MP, Hardacker TJ, Misseri R. How successful is the transition to adult urology care in spina bifida? A single center 7-year experience. *Journal of Pediatric Urology*. 2017;13(1):40.e1-40.e6.
- Touraine P, Polak M. Challenges of the transition from pediatric care to care of adults: "Say goodbye, say hello." *Endocrine Development*. 2018;33:1-9.
- Tuchman LK, Schwartz LA, Sawicki GS, Britto MT. Cystic fibrosis and transition to adult medical care. *Pediatrics*. 2010;125(3):566-573.
- Vaks Y, Bensen R, Steidtmann D, Wang TD, Platchek TS, Zulman DM, Malcolm E, Milstein A. Better health, less spending: Redesigning the transition from pediatric to adult healthcare for youth with chronic illness. *Healthcare (Amsterdam, Netherlands)*. 2016 Mar;4(1):57-68.
- van Pelt PA, Dolhain RJEM, Kruize AA, et al. Disease activity and dropout in young persons with juvenile idiopathic arthritis in transition of care: A longitudinal observational study. *Clinical and Experimental Rheumatology*. 2018;36(1):163-168.
- Wafa S, Nakhla M. Improving the transition from pediatric to adult diabetes healthcare: A literature review. *Canadian Journal of Diabetes*. 2015;39(6):520-528.
- Webb L, Shah PK, Harisiades JP, Boudos R, Agrawal R. Health care transition from pediatric care to adult care: Opportunities and challenges under the Affordable Care Act. *Journal of Pediatric Rehabilitation Medicine*. 2015;8(1):53-64.
- 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 (TrAcCeD): A randomised, open-label, controlled trial. *The Lancet Child & Adolescent Health*. 2017;1: 274-283.
- White PH, Cooley WC, Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5):e20182587.
- Whitney DG, Peterson MD. US national and state-level prevalence of mental health disorders and disparities of mental health care use in children. *JAMA Pediatrics*. 2019;173(4):389-391.

REFERENCES

Wojciechowski EA, Hurtig A, Dorn L. A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: A need for case management services. *Journal of Pediatric Nursing*. 2002;17(1):18-27.

Yerushalmy-Feler A, Ron Y, Barnea E, et al. Adolescent transition clinic in inflammatory bowel disease: Quantitative assessment of self-efficacy skills. *European Journal of Gastroenterology & Hepatology*. 2017;29(7):831-837. doi:10.1097/MEG.0000000000000864.

Yeung E, Kay J, Roosevelt GE, Brandon M, Yetman AT. Lapse of care as a predictor for morbidity in adults with congenital heart disease. *International Journal of Cardiology*. 2008;125(1):62-65.