



The Changes in Implementation of Health Care Transition in State Title V Care Coordination Programs: 2017-2021

January 2022

*Prepared by
Samhita Ilango, MSPH; Peggy McManus, MHS; Daniel Beck, MA; Patience White, MD, MA
Got Transition®/The National Alliance to Advance Adolescent Health*

INTRODUCTION

Health care transition (HCT) is the Maternal and Child Health Bureau's (MCHB) national performance measure #12 (NPM 12) for state Title V agencies, with 33 states (including DC) and 4 jurisdictions selecting it as a priority in 2021.¹ According to the combined 2019/20 data from the National Survey of Children's Health, only 22.5% of youth ages 12-17 with special health care needs (YSHCN) and 17.6% of youth 12-17 without special health care needs (non-YSHCN) received services necessary to make transitions to adult health care. In addition to low performance nationally, this data also indicates a decline in recent performance compared to 2019, when 24.8% and 19.0% of YSHCN and non-YSHCN, respectively, received services necessary for transition to adult health care.²

State Title V programs aim to address these low rates of HCT preparation among adolescents through evidence-informed strategies such as needs assessments, education, collaborative partnerships, youth and family leadership support, quality improvement, and policy/systems development. Since 2017, Got Transition, MCHB's national resource center for HCT, has surveyed State Title V Programs for Children with Special Needs to understand their current and ongoing HCT efforts in care coordination programs and offered technical assistance to advance their efforts. Among the 33 states that selected NPM 12 in 2021, 91% (30) fully or partially fund a care coordination program for YSHCN; 6% (2) do not fund a care coordination program, but are involved in or have some leadership role in statewide care coordination efforts. Only 1 out of these 33 states (3%) does not fund and is not involved in statewide care coordination efforts.

This report summarizes progress over 4 years (2017, 2018, 2019, and 2021) of Title V care coordination programs' implementation of Got Transition's Six Core Elements of HCT, the recommended quality improvement approach called for in the 2018 American Academy of Pediatrics/American Academy of Family Physicians/American College of Physicians Clinical Report on HCT.^{3,4} In light of the coronavirus pandemic, this report also offers insight into how HCT programming was impacted by COVID-19.

State Title V agencies have made substantial improvements in their use of evidence-informed HCT strategies since 2016. The range of HCT strategies and innovative examples underscore state Title V agencies' critical public health role in this field. Continued partnership between Got Transition and state Title V agencies provides important shared learning and faster adoption of evidence-informed and promising practices.

METHODS

This is the fourth year Got Transition administered the “Assessment of HCT Activities in Care Coordination Programs” via online survey (Appendix 1) to assess state Title V HCT trends in care coordination programs. This survey was not administered in 2020 due to the coronavirus pandemic. This qualitative survey asked Title V care coordination programs to rank their level of implementation for each of the Six Core Elements of HCT (policy, tracking, transition readiness, transition planning, transfer of care, and transfer completion, as well as youth and family engagement). Each of the Six Core Elements was scored by states along a continuum from level 1 (basic) to level 4 (comprehensive), each defined by a brief description (Appendix 1). The summation of these levels for each of the Six Core Elements produced a total score for each state, ranging from 7 (all Core Elements at level 1) to 28 (all core elements at level 4). These scores make up 3 score ranges marked as low (scores range 7-12), middle (score range 13-19), and high (score range 20-28).

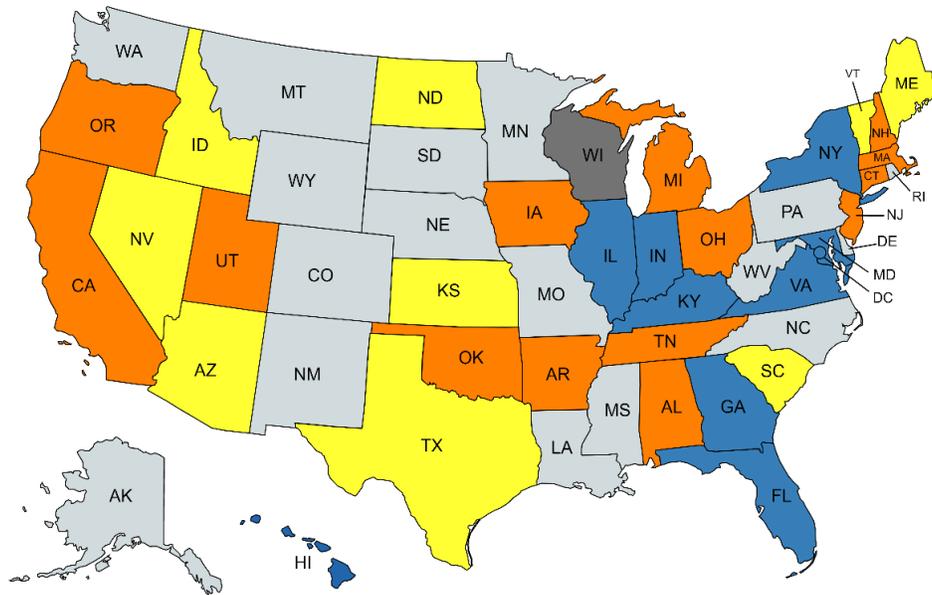
All 33 states (including DC) that selected NPM 12 were asked to complete the survey. This survey was not sent to US territories/jurisdictions. All 33 states responded to the 2021 survey for a response rate of 100%, and all but 1 state are involved in care coordination program efforts. Of these 33 states, 22 consistently completed this survey since 2017; 3 states completed the survey at least once before, and 8 states completed the survey for the first time this year. Based on our analysis, the differences in survey completion over time is due to states adding or dropping HCT as a priority NPM. The results display a current (2021) picture of state HCT performance of all 33 states prioritizing NPM 12 (Figure 1), a comparison of current results to 2019, and an analysis comparing HCT trends since baseline (2017 to 2021, excluding 2020) of the 22 states that consistently provided data for 4 years.

This year, additional questions were added to the survey to understand whether the coronavirus pandemic disrupted HCT efforts and if so, to what extent. States responded to this open-ended question with a variety of answers that were categorized into themes. Key themes were identified based on the most common state responses.

RESULTS

Among the 33 states in 2021 that completed the survey and were involved in care coordination programs, the overall mean HCT implementation score was 17, ranging from a low of 7 to a high of 27, out of a total possible 28 (Figure 1). Compared to 2019, more states (13, 41%) landed in the score range of 13-19. In 2021, more states (28%) scored lower compared to 2019 (14%). The proportion of states that ranked in the highest score range of 20-28 decreased slightly from 38% in 2019 to 31% in 2021. Of the states that consistently participated in this survey since 2017 and are involved in care coordination efforts (21), 76% exhibited an increase in their overall scores.

Figure 1. 2021 HCT Assessment Scores in State Title V Care Coordination Programs



Score Range (lowest possible 7, highest possible 28)	States (n=31)	Key
7-12	AZ, ID, KS, ME, ND, NV, SC, TX, VT (n=9)	Yellow
13-19	AL, AR, CA, IA, MA, MI, NH, NJ, OH, OK, OR, TN, UT (n=13)	Orange
20-28	DC, FL, GA, HI, IL, IN, KY, MD, NY, VA (n=10)	Blue
N/A*	WI (Not part of analysis)	Grey

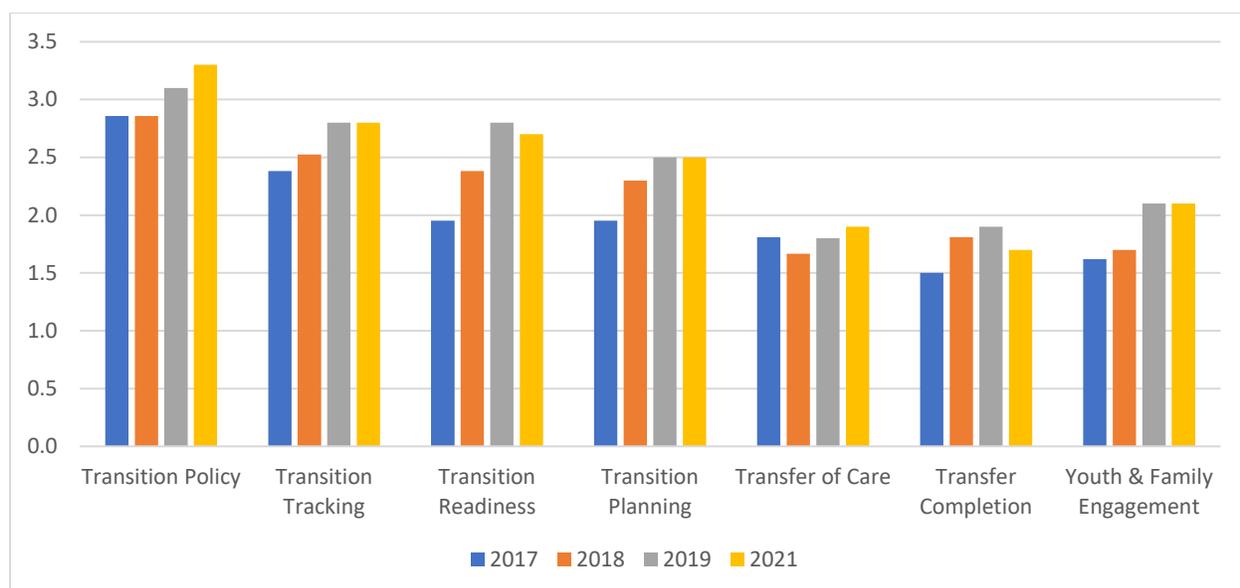
*One state selected NPM 12 but did not fund or participate in a care coordination program

When looking at the current levels of each of the core elements among the 21 states that completed this survey since 2017 and are involved in care coordination activities, states scored best out of 4 on HCT policy (3.3), transition tracking (2.8), and transition readiness (2.7), followed by transition planning (2.5), youth and family engagement (2.1), transfer of care (1.9), and transfer completion (1.9) (Table 1 and Figure 2). Since baseline in 2017, the average level of each core element has increased. However, since 2019, the average level of four of the seven elements has slightly decreased or stayed the same. The greatest decrease since 2019 is seen in transfer completion (from 1.9 in 2019 to 1.7 in 2021).

Table 1. Average Levels of Implementation of the Six Core Elements in State Title V Care Coordination Programs, 2017-2021

Six Core Elements	Average Levels: 1 (basic) to 4 (comprehensive)				Average % increase since 2017 baseline
	2017	2018	2019	2021	
Transition Policy	2.9	2.9	3.1	3.3	14%
Transition Tracking	2.4	2.5	2.8	2.8	17%
Transition Readiness	2.0	2.4	2.8	2.7	35%
Transition Planning	2.0	2.3	2.5	2.5	25%
Transfer of Care	1.8	1.7	1.8	1.9	6%
Transfer Completion	1.5	1.8	1.9	1.7	13%
Youth/Family Engagement	1.6	1.7	2.1	2.1	31%

Figure 2. Comparison of Average Level Between 2017 and 2021, for Each of the Six Core Elements



When states were asked about the impact of the coronavirus pandemic on their HCT efforts from June 2020-July 2021, all states reported they were affected in some way, ranging from 6% who reported “completely,” 40% who reported “very much,” and 54% who reported “some.” When states were asked to describe the impact, their responses often touched upon more than one theme. The most common themes identified include inability to meet in-person with youth and families (n=19), limited available staff (n=16), delays or disruptions in HCT programming (n=11), and the needs of families shifting away from HCT during the pandemic (n=7). A full list of themes and selected quotes from states can be found in Appendix 2.

CONCLUSIONS

Despite significant setbacks due to COVID-19, state Title V agencies that selected HCT as an NPM continue to make progress in implementing the Six Core Elements of HCT in their care coordination programs. Between 2017 and 2021, states reported the highest increases in HCT scores for transition readiness, youth and family engagement, and transition planning. The dip in scores between 2019 and 2021 is likely due to COVID-19, given that most states reported that their care coordination efforts were greatly impacted. COVID-19’s adverse impacts were felt by all states participating in the 2021 survey, most notably inability to meet with families, staff changes, and disruptions in HCT and care generally. Going forward, Got Transition plans to continue to conduct this assessment and analyze trends in the coming years.

APPENDIX 1: Assessment of HCT Activities in Care Coordination Programs

Assessment of Health Care Transition Activities in Care Coordination Programs

1. Transition Policy

- Level 1.* The care coordination program has no uniform approach or written policy that it shares with YSHCN and families on HCT.
- Level 2.* Care coordinators follow a similar, but not a written policy that they share with YSHCN and families on HCT.
- Level 3.* The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at age 18, and the age when Title V eligibility ends. The HCT policy is not consistently shared with youth and families.
- Level 4.* The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at age 18, and the age when Title V eligibility ends. Care coordinators consistently share and discuss the HCT policy with all YSHCN and families beginning at ages 12 to 14. The policy is publicly posted and used by all care coordinators.

2. Transition Tracking and Monitoring

- Level 1.* Care coordinators vary in the identification of transition-age YSHCN, but most wait close to the age of transfer to prepare youth for HCT.
- Level 2.* Care coordinators use patient records to document certain relevant HCT information (e.g. adult doctor information, date of transfer to adult doctor).
- Level 3.* The care coordination program uses an individual transition flow sheet or registry for identifying and tracking a subset of transition-age YSHCN, ages 14 and older, as they complete some but not all the Six Core Elements of HCT.
- Level 4.* The care coordination program uses an individual transition flow sheet or registry for identifying and tracking all transition-age YSHCN, ages 14 and older, as they complete all the Six Core Elements of HCT, using an EHR if possible.

3. Transition Readiness

- Level 1.* Care coordinators vary in whether they assess HCT readiness/self-care skills.
- Level 2.* Care coordinators assess HCT readiness/self-care skills, but do not consistently use a HCT readiness assessment tool.
- Level 3.* Care coordinators assess HCT readiness/self-care skills using a HCT readiness/self-care skill assessment tool.
- Level 4.* Care coordinators consistently assess and re-assess each year HCT readiness/self-care skills beginning at ages 14 to 16, using a HCT readiness/self-care assessment tool.

4. Transition Planning

- Level 1.* Care coordinators vary in whether they include goals and action steps related to HCT in the plan of care for YSHCN.
- Level 2.* Care coordinators consistently include goals and action steps related to HCT for YSHCN, but vary in addressing privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care.
- Level 3.* Care coordinators consistently include goals and action steps related to HCT for YSHCN based on the results from a HCT readiness/self-care assessment tool. Care coordinators consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. This plan of care is regularly updated.
- Level 4.* The care coordination program has incorporated HCT into its plan of care template for all YSHCN. Care coordinators consistently include YSHCN goals and action steps related to HCT based on the results from a HCT readiness/self-care assessment tool. Care coordinators consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. This plan of care is regularly updated and shared with YSHCN and families.

5. Transfer of Care

- Level 1.* Care coordinators vary in whether they give YSHCN and families a list of adult providers. They rarely share plans of care with HCT information to adult providers for their transitioning YSHCN.
- Level 2.* Care coordinators consistently give YSHCN and families a list of adult providers and share the plan of care, including HCT information to the adult provider(s) for transitioning YSHCN.
- Level 3.* The care coordination program is actively involved in outreach to identify potential adult providers for transitioning YSHCN. Care coordinators share the plan of care with HCT information to the adult provider(s) for their transitioning YSHCN.
- Level 4.* The care coordination program is actively involved in outreach to identify potential adult providers for transitioning YSHCN. Care coordinators consistently share the plan of care with HCT information for YSHCN transferring to the adult provider(s). In addition, care coordinators routinely communicate with adult providers to ensure information was received and transfer was completed.

6. Transition Completion

- Level 1.* Care coordinators vary in whether they follow-up with YSHCN and parents/caregivers about the HCT support provided by the care coordination program.
- Level 2.* Care coordinators consistently encourage YSHCN and parents/caregivers to provide feedback about the HCT support provided by the care coordination program, but do not use a specific HCT feedback survey.
- Level 3.* Care coordinators consistently obtain feedback from YSHCN and parents/caregivers using a HCT feedback survey.
- Level 4.* The care coordination program uses the results from its HCT experience survey as part of its transition performance measurement for the Title V block grant reporting.

7. Youth and Family Engagement

- Level 1.* The care coordination program offers general information about HCT to YSHCN and parents/caregivers, but has limited involvement of YSHCN and parents/caregivers in Title V HCT program development and evaluation.
- Level 2.* The care coordination program, in addition to its HCT education efforts with YSHCN and parents/caregivers, has trained YSHCN and parent leaders about the Six Core Elements of HCT.
- Level 3.* The care coordination program offers HCT education to YSHCN and parents/caregivers, has trained YSHCN and parent leaders about the Six Core Elements, and involves them in Title V program development and evaluation on HCT.
- Level 4.* The care coordination program offers HCT education to YSHCN and parents/caregivers and involves YSHCN/parent HCT leaders, knowledgeable about the Six Core Elements, in statewide efforts to advance HCT improvements.

The Six Core Elements of Health Care Transition™ are the copyright of Got Transition®. This version of the Six Core Elements has been modified and is used with permission.

APPENDIX 2: The Impact of COVID-19 on State Care Coordination HCT Efforts - Key Themes

THEME	# OF STATES	SELECTED QUOTE FROM STATE
Unable to meet in-person with families	19 (54%)	“Visits were done virtually via telehealth. Therefore, transition assessment completions were low and support group meetings were low in attendance.”
Limited staff/staff changes/staff redirected to serve COVID-19	16 (46%)	“Decrease in manpower during hiring freezes.” “All of our public health care coordinators were full time deployed to contact tracing for well over a year.”
Delays/disruptions in HCT and care	13 (37%)	“Transition was not a priority during the pandemic. Well child visits with PCP were halted during the pandemic. Our medical clinics were halted during the pandemic.”
Needs of family shifted away from HCT	7 (20%)	“Family needs shifted, and family crisis became more prevalent.”
Families hesitant to transition/transfer to new adult providers during pandemic	4 (11%)	“Some participants and their families are hesitant to transition to new providers during the pandemic.”
Families did not have access to internet or other technology	3 (9%)	“Families often did not have access to broadband or Wi-Fi to participate in virtual visits.”
Limited availability of adult providers during pandemic	2 (6%)	“Outreach for transition to adult providers was and continues to be a challenge, especially now that they are focused on the pandemic.”
Funding changes due to pandemic	1 (3%)	“Pandemic led to closure of the funded Family Voice’s partner and a change to a university partner to fill this role.”

REFERENCES

1. Maternal and Child Health Bureau. Title V MCH Block Grant Program: National Performance Measure Distribution. [cited 2021 December 3]; Available from: <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/NPMDistribution>.
2. Ilango S, McManus M, Beck D, White P. Health Care Transition in State Title V Programs: A review of 2021 block grant applications/2019 annual reports and recommendations. Washington, DC: The National Alliance to Advance Adolescent Health/Got Transition; August 2021. Available from: <https://gottransition.org/resource/2021-bg-review-hct-title-v>.
3. White P, Schmidt A, Shorr J, Ilango S, Beck D, McManus M. Six Core Elements of Health Care Transition™ 3.0. Washington, DC: Got Transition, The National Alliance to Advance Adolescent Health; July 2020.
4. White PH, Cooley WC, Transitions Clinical Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5).

ACKNOWLEDGMENTS

The authors acknowledge the thoughtful reviews from our MCHB project officer and advisor, Sarah Beth McLellan.



This project (U1TMC31756) was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. For more information about our work and available publications, contact our office at info@GotTransition.org. Also visit us on our website at www.GotTransition.org.

Copyright © 2022 by The National Alliance to Advance Adolescent Health

All Rights Reserved.