



The Progression of Health Care Transition Implementation in State Title V Care Coordination Programs from 2017 to 2019

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INTRODUCTION

Health care transition (HCT) is the Maternal and Child Health Bureau's (MCHB) national performance measure (NPM) #12 for state Title V agencies, with 31 states (including DC) and 5 jurisdictions selecting this NPM.¹ Prioritizing HCT is not surprising, given the persistently low receipt of HCT preparation support among youth with and without special health care needs in all states.² State Title V agencies play a critical role in advancing evidence-based HCT supports for youth with and without special health care needs (SHCN). This is accomplished through needs assessments, education, collaborative partnerships, youth and family leadership support, quality improvement, and policy/systems development.

In an effort to increase states' HCT performance, Got Transition—MCHB's national resource center for HCT—initiated a focused and longitudinal assessment and technical assistance in 2017,³⁻⁵ to reach care coordination programs. Many Title V Children and Youth with Special Health Care Needs (CYSHCN) programs support care coordination efforts in their state. In fact, among the 31 states that

selected NPM 12, 81% (25) fully or partially fund a care coordination program for youth with SHCN and 10% (3) do not fund a care coordination program but are involved in or have some leadership role in statewide care coordination efforts. Only 3 states (10%) do not fund and are not involved in statewide care coordination efforts. Further, among the 25 Title V programs that fully or partially fund a care coordination program, a variety of organizational entities deliver care coordination support. This includes local/public health departments, specialty clinics, family-based organizations, or medical home practices.

This report presents state Title V care coordination programs' progress over 3 years of implementing Got Transition's Six Core Elements of HCT,⁶ 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.⁷ The report also offers suggestions for improvement going forward. Profiles on state-specific HCT progress from their baseline through 2019 have been sent to each state Title V team and are available by contacting Got Transition.

METHODS

Got Transition administered the third annual "Assessment of HCT Activities in Care Coordination Programs" via online survey (Appendix) to assess state Title V care coordination trends. This qualitative survey asked state 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. After completion, states received a total score ranging from 7 (all Core Elements at level 1) to 28 (all Core Elements at level 4). The total score is the summation of reported levels for each of the Six Core Elements. Got Transition plans to continue to conduct this assessment in the coming years.

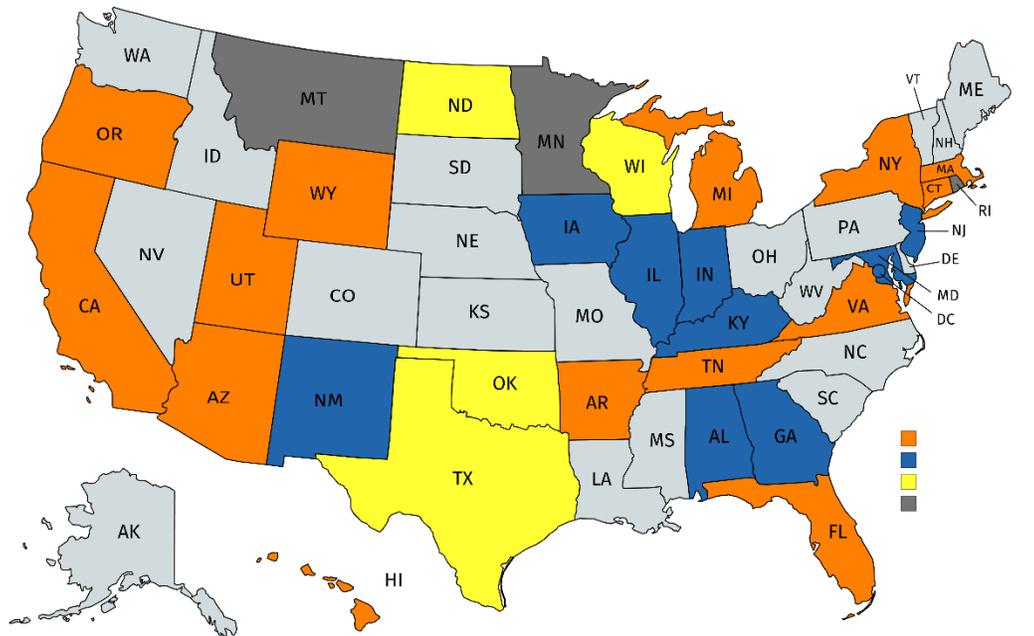
Got Transition reached out to all 31 states (including DC) that selected NPM 12 to complete the survey. This survey was not sent to the US territories. All 31 states responded to the 2019 survey for a response rate of 100%, and all but 3 of those states are involved in care coordination program efforts. Of these 28 states, 24 consistently completed this survey over the past three years; 2 states completed the survey two out of the past three years; 2 states completed the survey for the first time.

Got Transition provided a national snapshot of the 2019 state HCT performance of all 31 states (Figure 1) and compared HCT trends from 2017 to 2019 of the 24 states that consistently provided data for 3 years (Table 1 and Figure 2). Got Transition also solicited feedback from the states whose total score decreased since 2018. Their responses are incorporated into this report.

RESULTS

In 2019, the overall HCT implementation scores, out of a possible 28, ranged from a low of 7 to a high of 27 among the 28 states that completed the survey and were involved in care coordination programs (Figure 1). The proportion of states that ranked in the lowest range (7-12) decreased sharply, from 54% in 2017 to 14% in 2019, while the proportion of states that ranked in the highest range (20-28) more than doubled, from 18% in 2017 to 38% in 2019. Of the 24 states that consistently completed this survey over the last 3 years, 58% exhibited an increase in their overall scores since 2017.

Figure 1. 2019 HCT Assessment Scores in State Title V Care Coordination Programs



Score Range (lowest possible 7, highest possible 28)	States (n=31)	Key
7-12	ND, OK, TX, WI (n=4)	Yellow
13-19	AR, AZ, CA, CT, FL, HI, MA, MI, NY, OR, TN, UT, VA, WY (n=14)	Orange
20-28	AL, DC, GA, IA, IL, IN, KY, MD, NJ, NM (n=10)	Blue
N/A*	Not part of analysis (n=3)	Grey

*Three states selected NPM 12 but did not fund or participate in a care coordination program (MN, MT, RI)

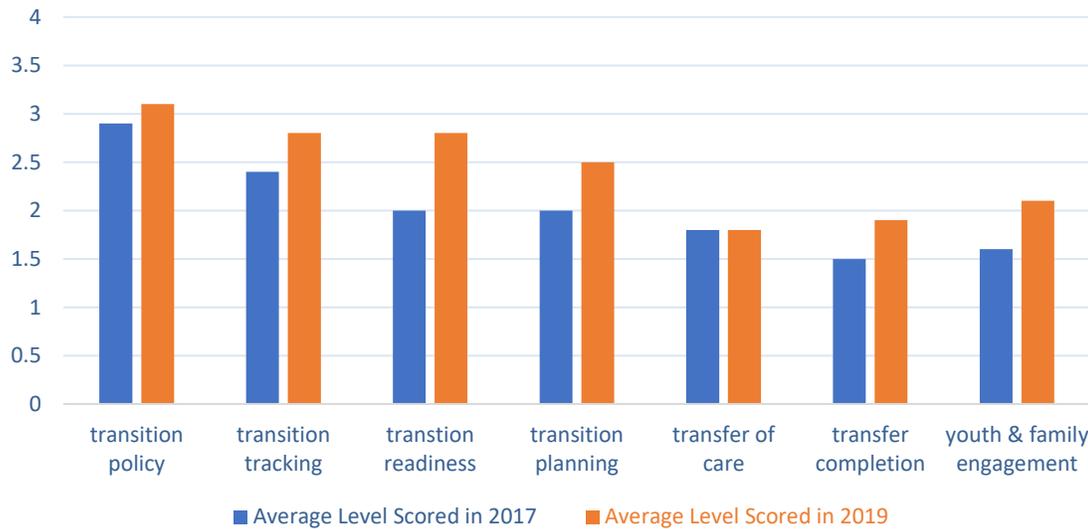
Looking at the 24 states that completed this survey over the last 3 years, states scored best on HCT policy (3.1), followed by tracking (2.8), transition readiness (2.8), transition planning (2.5), and youth and family engagement (2.1). States scored lowest on transfer completion (1.9) and transfer of care (1.8) (Table 1).

Table 1. Average Levels of Implementation of the Six Core Elements in State Title V Care Coordination Programs, 2017-2019

Six Core Elements	Average Level in 2017 1 (basic) to 4 (comprehensive)	Average Level in 2018 1 (basic) to 4 (comprehensive)	Average Level in 2019 1 (basic) to 4 (comprehensive)	Average Percent Increase over 3 years
Transition Policy	2.9	2.9	3.1	7%
Transition Tracking	2.4	2.5	2.8	18%
Transition Readiness	2.0	2.4	2.8	40%
Transition Planning	2.0	2.3	2.5	27%
Transfer of Care	1.8	1.7	1.8	-5%
Transfer Completion	1.5	1.8	1.9	24%
Youth and Family Engagement	1.6	1.7	2.1	34%

Compared to the 2017 baseline assessment, the 24 states that consistently completed this survey over the last 3 years showed an average increase in implementation for most of the Six Core Elements (Table 1 and Figure 2). The greatest improvement was in transition readiness, moving from 2.0 to 2.8, transition planning (from 2.0 to 2.5), and youth and family engagement (from 1.6 to 2.1). No change in the average was found in transfer of care from 2017-2019 (Table 1).

Figure 2. Comparison of Average Level Between 2017 and 2019, for Each of the Six Core Elements



Several states reported a decrease in their HCT implementation levels since their 2017 baseline for certain Core Elements. When queried about this decrease, states reported that this change was primarily the result of internal changes within their care coordination programs or different staff completing the survey. For example, one state noted that their care coordination program was recently contracted out to a different entity, while another state noted they no longer administer care coordination programs.

CONCLUSIONS AND SUGGESTIONS FOR IMPROVEMENT

Overall, state Title V programs made considerable progress in introducing HCT into their care coordination programs for YSHCN. There was an average increase in each of the Six Core Elements and youth and family engagement since 2017, except in transfer of care, which remained at a consistent level over the three years. The Core Elements with the greatest improvement were transition readiness, transition planning, and youth and family engagement. The lowest levels of improvement were in transfer of care and transfer completion.

Got Transition offers the following suggestions for state Title V agencies and care coordination programs in their continued efforts to implement a structured HCT process for YSHCN.

GENERAL SUGGESTIONS

- Widely disseminate this report and your state-specific HCT results with your care coordination programs and other key stakeholders, including family-based organizations, state Medicaid agencies, and other pediatric and adult care coordination programs. The results from this survey

can serve as a HCT needs assessment as well as for information to report on your state Title V block grant application.

- States can consider using these results at an annual meeting or training session of care coordinators and encourage small group discussions to exchange ideas on ways to increase the level of implementation in one or more of the Six Core Elements. States can develop aim statements like the one below, considering what is necessary to achieve a Level 3 or 4 in each of the Six Core Elements (Appendix). States could also encourage monthly or quarterly calls with their care coordination programs to share examples of best practices, challenges, and feasible next steps.

By 2020, ___ (state's) care coordination program will increase its HCT implementation of ___ (element)___ from level ___ to level ___ by doing ___ (action)___, for ___ (population group)___.

TRANSFER OF CARE SUGGESTIONS

- Since transfer of care is a challenge for most states, a combination of strategies that aligns with Levels 3 or 4 in the Assessment of HCT Activities in Care Coordination Programs (Appendix) could be considered. Progress in transfer of care requires 1) efforts to facilitate connections to adult providers, and 2) preparing and sharing a transfer package.

Connecting with Adult Providers:

- With respect to connecting with adult primary and specialty care providers, state Title V agencies could consider reaching out to state Medicaid officials and their contracted health plans to discuss the availability of adult providers qualified and interested in caring for young adults with childhood-onset conditions aging out of pediatric care and care coordination programs. Please contact Got Transition for a sample survey that states may want to use or adapt to help identify available adult providers.
- For youth at risk of losing Medicaid coverage as an adult, states could consider creating a handout on how to find an adult doctor that lists local community health centers, mental health service helplines, sexual/reproductive health sites, local adult disability programs, and links to the state's insurance marketplace website.

Sharing a Transfer Package:

- With respect to preparing and sharing a transfer package with the young adult and adult provider, state Title V programs could, for example, create a transfer package which includes their latest transition readiness assessment results, a plan of care with transition goals and future actions steps, and a transfer letter. Additional information could be added, such as a handout on how find an adult doctor (described above) and Got Transition's [Questions to Ask Your Doctor About Transitioning to Adult Health Care](#).⁸
- This transfer package could be prepared with youth and parents/caregivers one year before Title V care coordination eligibility ends and updated and shared near the transfer period.
- State Title V care coordination programs could also create an alert in their electronic medical records or information systems as a reminder to utilize the process and track receipt of sending the transfer package to the adult provider.

TRANSFER COMPLETION SUGGESTIONS

- State Title V programs could consider following up with YSHCNs three to six months after they transfer out of the care coordination program and inquire if they found an adult primary care provider and adult disability supports.
- The state can ask about the youth and young adult's HCT experience and whether they have feedback to improve the HCT process. Got Transition has a [Feedback Survey](#)⁹ as part of the Six Core Elements that can be customized.
- Building collaborative partnerships with care coordination programs for adults that are supported by chronic disease programs, Medicaid, or commercial managed care plans is another strategy to consider. This could help not only with creating and updating a master list of adult disability services but could also be useful for transferring youth and young adults to better prepare them for what care coordination support may or may not be available as they become adults.

State Title V agencies and their care coordination programs and partners play a critical role in the implementation and spread of comprehensive HCT supports for youth with special health care needs and their parents/caregivers.

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APPENDIX: ASSESSMENT OF HEALTH CARE TRANSITION ACTIVITIES IN TITLE V 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 of 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 transition 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. Transfer 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.