



# A Comparison of Health Care Transition Implementation in State Title V Care Coordination Programs Between 2017 and 2018

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## INTRODUCTION

State Title V programs have a long history of supporting care coordination for youth with special health care needs (YSHCN), though the organization and scope of these services vary from state to state. They have also been actively involved in guiding health care transition (HCT) performance improvements using a variety of evidence-informed strategies.<sup>1</sup> This report examines how state Title V agencies are progressing in incorporating the Six Core Elements of HCT into their care coordination programs.<sup>2</sup>

In 2017, Got Transition contacted the 32 state Title V agencies that selected the national performance measure (NPM) #12 on HCT to obtain a baseline assessment of the Six Core Elements implementation in their care coordination programs. One year later, in 2018, the same state Title V agencies were asked again to complete the same assessment of their care coordination programs. This report summarizes states' 2018 assessment results and compares them to the 2017 baseline assessment findings. Got Transition is planning to conduct the same assessment annually to assist the Maternal and Child Health Bureau (MCHB) and state Title V programs in implementing and measuring implementation of evidence-informed HCT strategies.

## METHODS

In summer 2018, Got Transition contacted the 32 state Title V agencies that selected HCT as an NPM in their Title V Maternal and Child Health Services Block Grant and requested their completion of the "Assessment of Health Care Transition Activities in Care Coordination Programs" using Survey Monkey. A total of 29 states responded to the survey in 2018, for a response rate of 91%. The assessment was not sent to the U.S. territories. This same HCT assessment was previously conducted in 2017, providing a baseline for states to measure progress.<sup>3</sup>

Of the 29 responding states, 24 directly fund care coordination programs, four are involved in, but do not directly fund statewide care coordination efforts for YSHCN, and one is not involved in statewide care coordination efforts for YSHCN. In 2018, two new states completed the HCT assessment for the first time; their results are treated in this report as baseline information and are not included in the comparative

results, leaving 26 states that provided two years of assessment results. Two other states that provided baseline results in 2017 did not respond this year and were not included in this report.

Using Got Transition's HCT assessment tool for care coordination programs, states ranked their level of implementation for each of the Six Core Elements of HCT: policy, tracking, transition readiness, transition planning, transfer of care, and transition completion as well as youth and family engagement. Each of the core elements are scored along a continuum from level 1 (basic) to level 4 (comprehensive). Each level is defined by a brief narrative description. Each state received a total score, which ranged from 7 (all core elements at level 1) to 28 (all core elements at level 4). A total score is the summation of reported levels for each core element. A paired t-test was conducted in Microsoft Excel to assess whether there were statistically significant differences between total scores in 2017 and 2018.

Following the 2018 HCT assessment, Got Transition solicited feedback from several states that showed an increase or decrease in three or more core element levels as compared to their 2017 results. These states were asked to describe likely reasons for the changes, and their responses are incorporated into this report to help readers better understand changes in scores. It should be noted these are self-administered assessments.

This report presents results from the 2018 HCT assessment compared to the 2017 assessment. It also offers suggested strategies for states to improve their HCT performance in care coordination programs. Individualized state transition profiles, which compare state scores to the national averages, can be obtained by contacting Got Transition.

## RESULTS

In 2018, overall state transition scores ranged from a low of 7 to a high of 27 (out of a possible 28). Ten states scored in the lower level (between 7 and 12), 12 states scored in the middle level (between 13 and 19), and six states – Alabama, District of Columbia, Indiana, Iowa, Kentucky, and New Mexico – scored in the higher level– between 20 and 28 (Figure 1). Compared to baseline scores from 2017, 13 states showed improvement, seven states decreased, and six states scored the same.

The average overall score increased from 13.8 out of 28 in 2017 to 15.0 in 2018. Specifically, over the course of one year, states showed the greatest improvement in transition readiness, followed by transition tracking, planning, and completion. Similar to last year, states on average showed the highest levels in transition policy (Table 1). While these improvements are notable, no statistically significant changes were found.

States that increased their core element levels described various reasons for their improvement. Some states reported that setting clear procedures for clinic staff about engaging youth in transition planning and defining a distinct age range for transition planning was useful. Others noted creating handouts for youth and families about the transition process and privacy changes that occur at 18 were valuable. Some states stated that they recently implemented a staff requirement to use a HCT readiness assessment and to systematically document transition goals. States also mentioned that soliciting feedback from youth and families (through small groups and advisory councils to review transition tools) as well as clinic staff (through regular feedback surveys) was beneficial.

Most states reported their lowest levels for core elements in youth and family engagement and transfer of care (Figure 2). While each average core element level showed some improvement since 2017, transfer of care levels actually decreased. States that decreased reported reasons for this change. Several states described that their decrease was due to a different staff member filling out the self-assessment this year than in 2017. Some mentioned that they had issues with keeping consistent documentation of HCT elements. Others reported not having a process to share medical summaries and emergency care plans with specialty or primary care providers as a limitation. It was also noted that states had difficulties engaging youth in comparison to adult family members.

## CONCLUSIONS AND SUGGESTED STRATEGIES FOR IMPROVEMENT

State Title V agencies have made measurable health care transition improvements in their care coordination programs from 2017 to 2018, based on their overall scores from Got Transition's Assessment of HCT Activities in Care Coordination Programs. Out of all the core elements, transition readiness increased the most across states reporting in 2018, followed by improvements in transition tracking, planning, and completion.

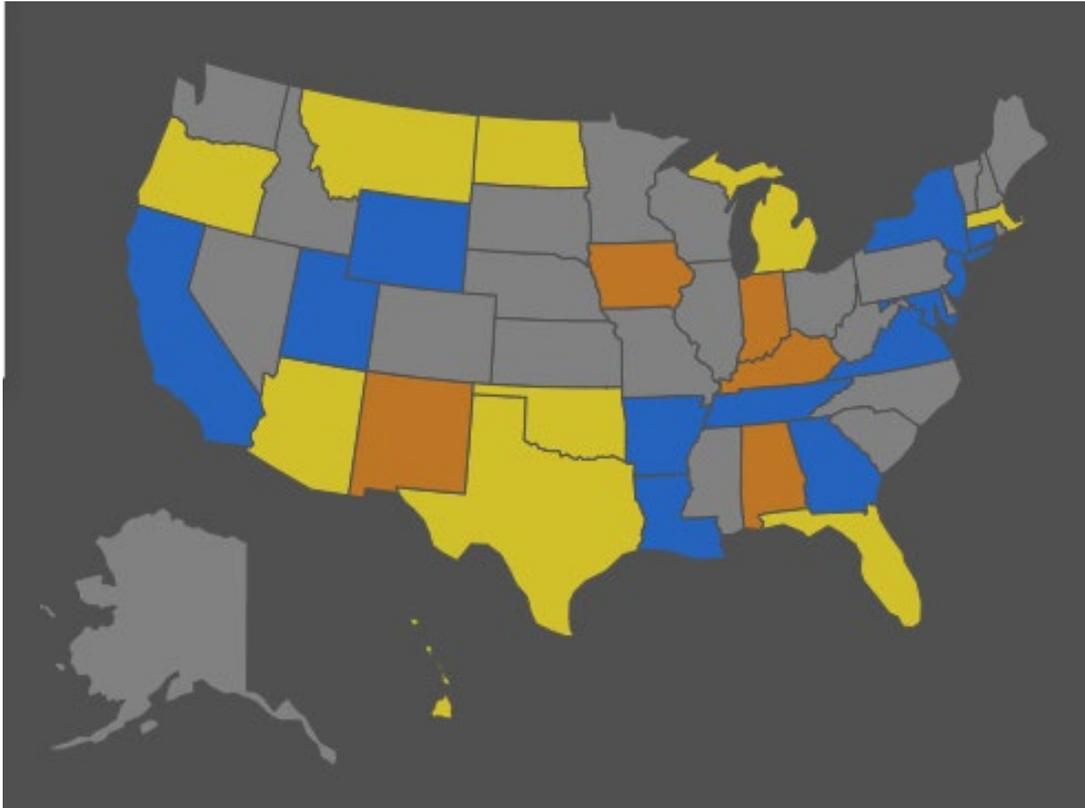
As states continue their efforts to improve implementation of the Six Core Elements in care coordination programs, it will be important to examine what is necessary to meet levels 3 and 4 in the Current Assessment (Appendix 1). Got Transition recommends that states develop aim statements or objectives for some or all of the core elements within their care coordination programs over the coming year, which will be measured again through Got Transition's assessment in summer 2019. Below is an example of how an aim statement could be written for transition policy, using the terminology from level 4 in the Current Assessment.

*Transition Policy. By 2019, 100% of care coordination programs supported by \_\_\_\_\_'s Title V Program will have 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 will consistently share and discuss the HCT policy with all youth and YSHCN and their families beginning at ages 12 to 14. The policy will be publicly posted and used by all care coordinators.*

Recognizing the importance of youth and family engagement and the comparatively low scores for this element in 2017 and 2018, states may want to work with their care coordination programs to address this need. Again, using the terminology from level 3, state Title V care coordination programs can offer HCT education to provide training on the Six Core Elements to youth and family, and involve them in Title V HCT program development and evaluation.

Implementing evidence-informed HCT strategies is still in its early and formative stages. Title V's leadership role in advancing improvements in its own care coordination programs as well as in other publicly financed care coordination programs will go a long way to ensuring a coordinated system of care for YSHCN who will eventually be moving into adult care systems. For additional information about HCT and care coordination, Got Transition has an online [webinar series](#) on HCT and care coordination. Recordings and handouts from its this five-part webinar series features examples of best practices and problem-solving strategies.

**Figure 1. HCT Assessment Scores in State Title V Care Coordination Programs, 2018**



<b>Score Range</b> <i>(lowest possible 7, highest possible 28)</i>	<b>State</b>	<b>Key</b>
7-12	AZ, FL, HI, MA, MI, MT, ND, OK, OR, TX	Yellow
13-19	AR, CA, CT, GA, LA, MD, NJ, NY, TN, UT, VA, WY	Blue
20-28	AL, DC, IA, IN, KY, NM	Orange
N/A*	Not part of analysis	Grey

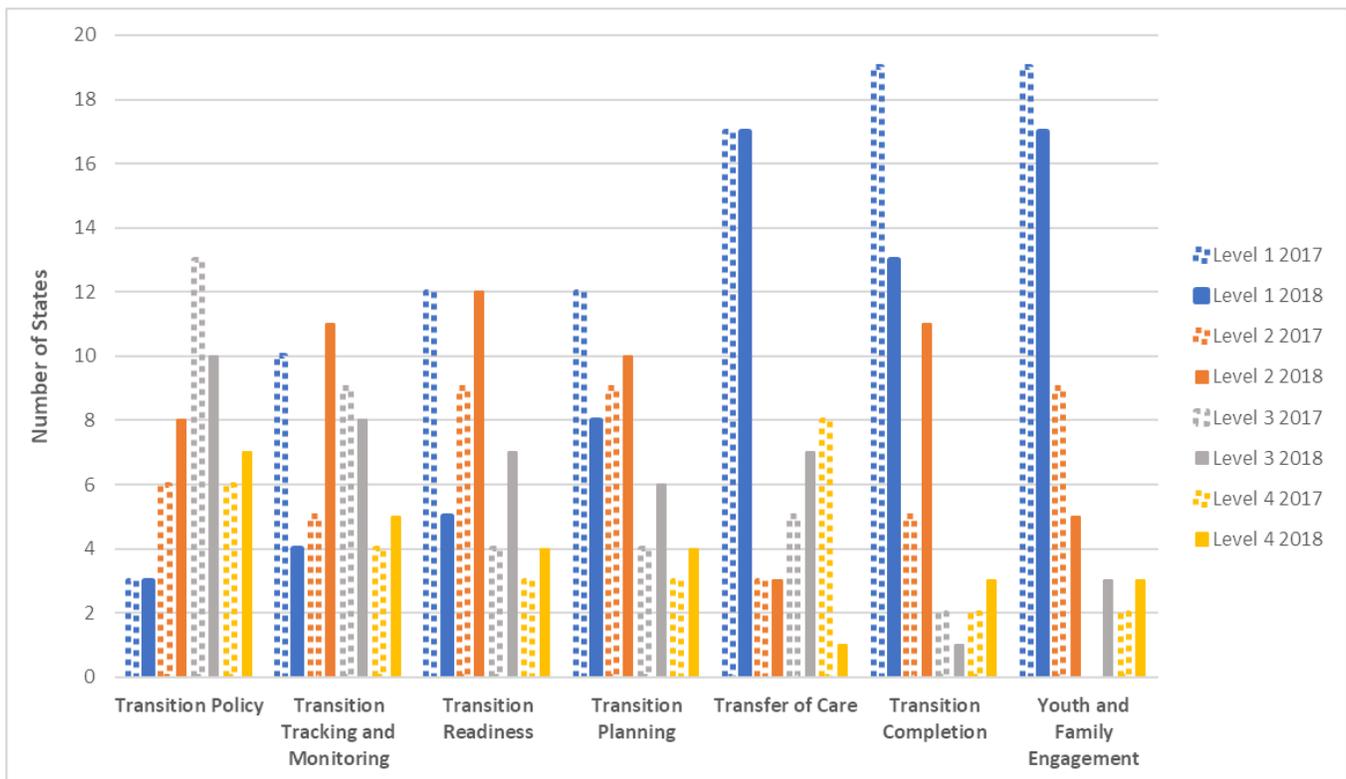
*\*Three states did not fund or participate in a care coordination program (MN, RI, WI); one state did not respond (IL); 18 states did not choose HCT as a Title V Priority NPM.*

**Table 1. Average Levels of Implementation of Six Core Elements, 2017 and 2018**

Six Core Elements	Average Level in 2017	Average Level in 2018
Transition Policy	2.8	2.8
Transition Tracking	2.3	2.5
Transition Readiness	1.9	2.4
Transition Planning	1.9	2.2
Transfer of Care	1.8	1.7
Transition Completion	1.5	1.8
Youth and Family Engagement	1.5	1.7

NOTE: The measurement scale used is 1 (Basic) to 4 (Comprehensive).

**Figure 2. Number of States Reporting Specific Levels of Implementation of Six Core Elements, 2017 and 2018**



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## REFERENCES

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2. Got Transition. Six Core Elements of Health Care Transition.  
<http://www.gottransition.org/resources/index.cfm>. Last accessed October 8, 2018.
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## Appendix 1: 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.