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Baseline Assessment of Health Care Transition Implementation in Title V Care Coordination Programs

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This report presents a current snapshot of Title V care coordination program implementation of the Six Core Elements of Health Care Transition,[1] the evidence-driven approach that is aligned with the AAP/AAFP/ACP Clinical Report on Transition.[2] This approach to health care transition (HCT) involves 1) developing a transition policy, 2) establishing a process to identify and track transitioning youth, 3) regularly assessing their self-care skills, 4) developing a plan of care that incorporates transition readiness goals and prepares youth for an adult model of care, 5) assisting in the identification and transfer to adult providers with current medical information, and 6) following up to ensure transfer completion. Using quality improvement methods with active engagement of youth and parents and participation of both pediatric and adult clinicians, the Six Core Elements can be implemented in care coordination programs as well as in primary and specialty or behavioral care practices, health plans, and hospitals.

Since many state Title V programs either fund or are involved in statewide care coordination efforts for youth with special health care needs (YSHCN), Got Transition conducted this assessment as a starting point from which to support state Title V programs in their efforts to implement evidence-informed transition strategies and measure progress and impact. In 2016, 32 states, including the District of Columbia, as well as Puerto Rico, Virgin Islands, Guam, Federated States of Micronesia, and Marshall Islands, selected the HCT measure as a focus in the youth with special health care needs (YSHCN) population domain.[3]

This report summarizes the baseline assessment scores for implementation of the Six Core Elements in state Title V care coordination programs. It also describes an upcoming webinar series on how to implement HCT in care coordination programs. Additional reports on state Title V HCT efforts can be found at www.gottransition.org.[3-5]

METHODS

This baseline assessment of HCT activities in care coordination programs was conducted in May 2017. It was sent to the 32 state Title V programs that selected HCT as their national performance measure. A total of 28 states completed the online self-assessment, for a response rate of 88%. Among these 28 states, 20 directly fund care coordination programs, and eight are involved in statewide care coordination efforts for YSHCN. An additional two states were excluded from this analysis because they do not fund or participate in statewide care coordination efforts. Two states did not respond to the survey; the survey was not sent to the U.S. territories.

To obtain consistent information regarding implementation of the Six Core Elements, Got Transition's Current Assessment of HCT Activities was customized for care coordination programs. States were asked to have their care coordination staff complete this self-assessment. To provide a baseline of Six Core Elements implementation as well as of youth and family engagement, states ranked their level of progress 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 could range from 7 (all six core elements and youth and family engagement at level 1) to 28 (all six core elements and youth and family engagement at level 4). See Appendix 1 for the HCT self-assessment tool for state Title V care coordination programs. Participating states also received an individualized transition report, which allows each state to compare its scores with the national averages.

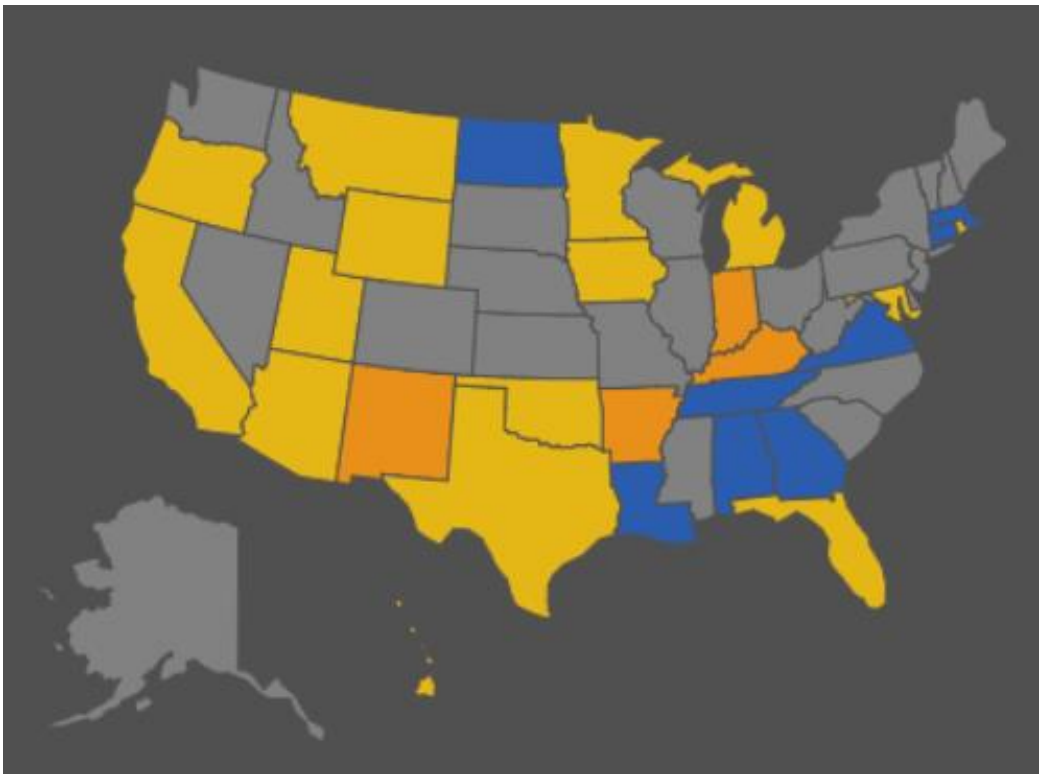
RESULTS

There was wide variation in HCT implementation within care coordination programs for YSHCN among the 28 state respondents, as shown in Figure 1. Overall state scores ranged from a low of 7 to a high of 28, with 15 states scoring between 7 and 12 (out of a potential of 28). Despite the wide variability, this baseline assessment revealed that more than half of state Title V care coordination programs are at level 1 or level 2 for each of the HCT Six Core Elements. More than a quarter of state respondents scored between 13 and 19, with a few of the core elements at level 3 or level 4. Five states – Arkansas, District of Columbia, Indiana, Kentucky, and New Mexico – scored the highest – between 20 and 28. Figure 1 displays the distribution of total scores among state respondents. Table 1 shows that in general states had higher average levels on transition policy and lower levels on transition completion. Figure 2 displays the number of states reporting their level of HCT implementation for each of the Six Core Elements and shows that all had progressively lower scores for transfer of care, transition completion, and youth and family engagement.

CONCLUSIONS AND NEXT STEPS

State Title V programs that selected HCT as their national performance measures, with some exceptions, are in the early phases of incorporating the Six Core Elements of HCT into their care coordination programs. To support continued progress in implementing evidence-driven transition approaches, Got Transition is offering a webinar series beginning in January, on the topics listed in Table 2. These webinars will feature examples of best practices among state Title V Agencies, tools and resources, and problem-solving strategies. State-specific HCT baseline assessment reports have been sent to each state that responded to the survey to allow them to benchmark their results against these national averages. Got Transition plans to conduct this same assessment one year following the initial assessment to track state progress, which can be reported by states in their Title V block grant applications.

Figure 1. Baseline HCT Assessment Scores in State Title V Care Coordination Programs, 2017



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

** 2 states did not have a care coordination program (WI, NY); 2 states who chose transition as a Title V NPM did not respond (IL, NJ); 18 states did not choose transition as a Title V NPM.*

Table 1. Average Levels and Number of States by Level of Implementation of Six Core Elements, 2017

Six Core Elements	**Average Level** 1 (basic) to 4 (comprehensive)	**# of States at Level 1 or 2**	**# of States at Level 3 or 4**
Transition Policy	2.8	9	19
Transition Tracking	2.3	15	13
Transition Readiness	1.9	21	7
Transition Planning	1.9	21	7
Transfer of Care	1.8	20	8
Transition Completion	1.5	24	4
Youth and Family Engagement	1.5	26	2

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

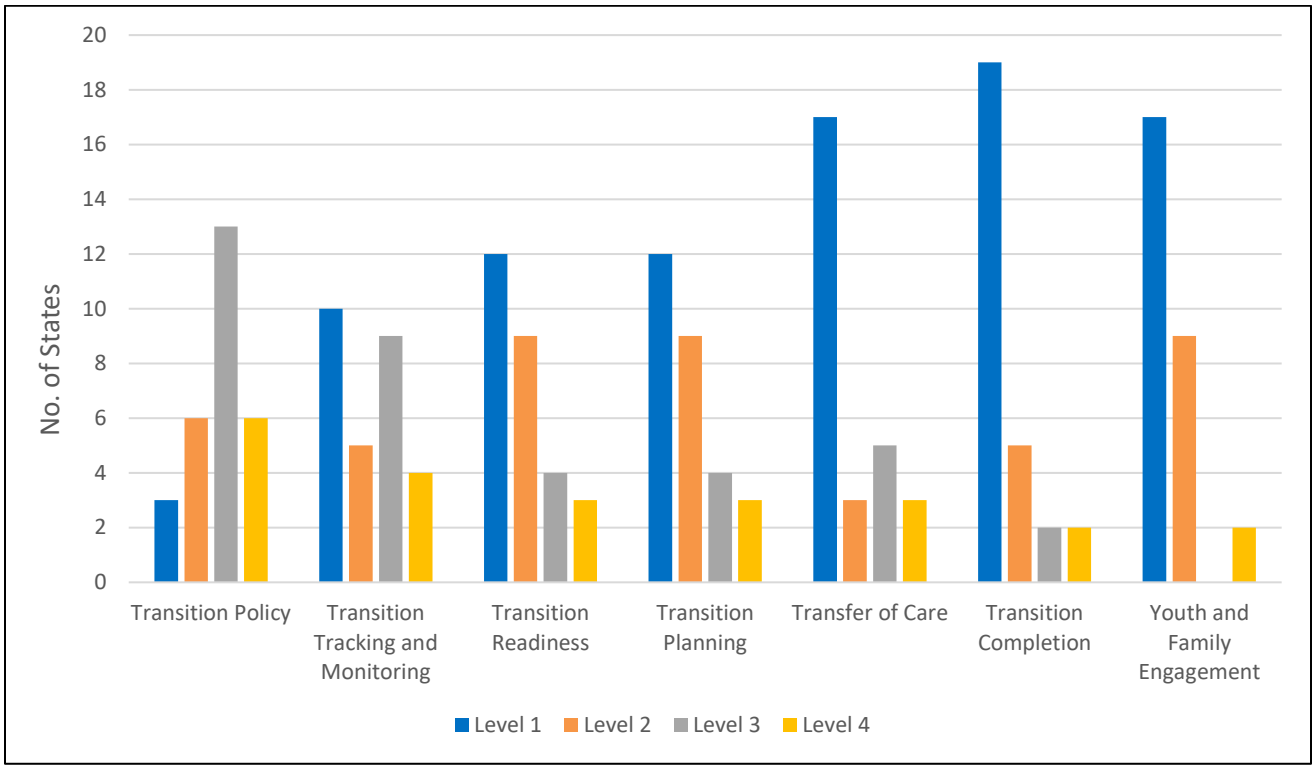


Table 2. Got Transition Webinar Series
Health Care Transition Implementation in Title V Care Coordination Programs

Starting in January 2018

Session 1	**Starting A Transition Improvement Process Using the Six Core Elements of Health Care Transition**
	• Review of Six Core Elements and overview of Title V HCT assessment results • Forming a HCT quality improvement team with youth/young adults/parents • Defining HCT pilot population, timeline, measures of success • Selecting HCT core elements and delineating roles of care coordination program and YSHCN providers
Session 2	**Transition Preparation**
	• Identifying key components of HCT policy that families/youth want to know • Customizing transition readiness assessment (RA) • Piloting and disseminating HCT policy and RA • Incorporating RA skill needs into plan of care and educating youth and families on needed skills • Preparing medical summary and emergency care plan with youth and families and their providers
Session 3	**Transfer to Adult Care**
	• Identifying willing adult primary and specialty providers • Sequencing plans for transferring young adults with multiple providers • Identifying ways to support adult practices (consultation, care coordination) • Preparing transfer package and communicating with pediatric and adult practices
Session 4	**Integration into Adult Care**
	• Ensuring welcome and orientation FAQs from the adult practice to transferring young adults and pediatric practice • Facilitating initial appointment to adult doctor, including confirmation of receipt of transfer package • Supporting adult practice with assistance in linking to adult disability resources
Session 5	**Youth/Young Adult and Parent Engagement**
	• Identifying youth/young adults/parents to participate in Title V HCT initiatives • Providing transition education and training and mentoring opportunities • Eliciting consumer feedback with HCT care coordination process • Building youth/young adult/parent leadership roles on HCT within state Title V programs

APPENDIX 1: Assessment of Health Care Transition Activities

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 it shares 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 progress 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 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. 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 YSCHN 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 parents 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.

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