Measuring Implementation of Health Care Transition in State Title V Care Coordination Programs: A Five-Year Review

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INTRODUCTION

Thirty-two states (including DC) and 4 jurisdictions selected health care transition (HCT) as a priority national performance measure (NPM 12) in 2022.[1] Twenty-one percent of youth ages 12-17 with special health care needs (YSHCN) and 16% of youth 12-17 without special health care needs (non-YSHCN) received services necessary to make transitions to adult health care.[2]

The goal of this report is to inform state Title V agencies about progress and changes over 5 years (2017, 2018, 2019, 2021, and 2022) care coordination program implementation of Got Transition's Six Core Elements of HCT™.[3] The Six Core Elements is 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.[4] States can utilize these findings and their state specific results to create HCT goals and for future block grant reporting.

METHODS

This is the fifth year that Got Transition has administered the "Assessment of HCT Activities in Care Coordination Programs" via online survey (Appendix) to assess HCT trends in state Title V care coordination programs. The same methods used in prior years were applied this year. (Note: open response questions about the extent to which the COVID-19 pandemic disrupted HCT efforts were only asked in the 2021 survey.)

The 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). 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 three score ranges marked as low (scores range 7-12), middle (score range 13-19), and high (score range 20-28).

The 32 states (including DC) that selected NPM 12 were asked to complete the survey. This survey was not sent to US territories/jurisdictions. 29 states responded to the survey, for a response rate of 91%. Of these states, only one reported that they are not involved in care coordination program efforts. Of the 29 states responding, 17 consistently completed this survey since 2017. The results display a current (2022) picture of state HCT performance (Figure 1), a comparison of current results to 2021, and an analysis comparing HCT trends since baseline in 2017 of the 17 states that consistently provided data for 5 years.

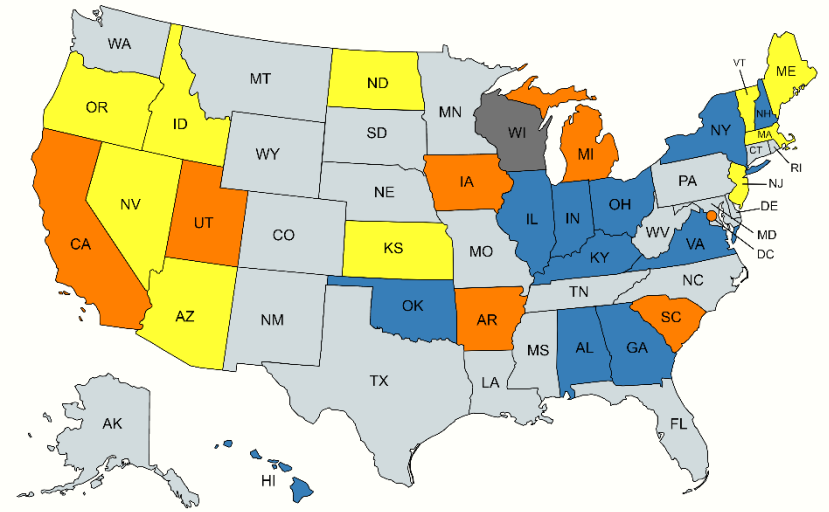
RESULTS

(Note: the survey was not administered in 2020 due to the COVID-19 pandemic).

Among the 29 states that completed the survey in 2022, 79% (23) fully or partially fund a care coordination program for YSHCN; 17% (5) do not fund a care coordination program but are involved in or have some leadership role in statewide care coordination efforts; 1 state out of these 29 states does not fund and is not involved in statewide care coordination efforts. Of the states that completed the survey and were involved in care coordination programs (28 states), the overall mean HCT implementation score was 16, ranging from a low of 7 to a high of 27, out of a total possible 28 (Figure 1).

Compared to 2021, a higher proportion of states landed in the score range of 20-28 this year (39% vs. 32%, respectively). The proportion of states that ranked in the lowest score range of 7-12 increased slightly from 29% in 2021 to 36% in 2022.

Figure 1. 2022 HCT Assessment Scores in State Title V Care Coordination



Score Range (lowest possible 7, highest possible 28)	States *(n=28)*	Key
7-12	AZ, ID, KS, MA, ME, ND, NJ, NV, OR, VT *(n=10)*	
13-19	AR, CA, DC, IA, MI, SC, UT *(n=7)*	
20-28	AL, GA, HI, IL, IN, KY, NH, NY, OH, OK, VA *(n=11)*	
N/A*	WI *(Not part of analysis)*	

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

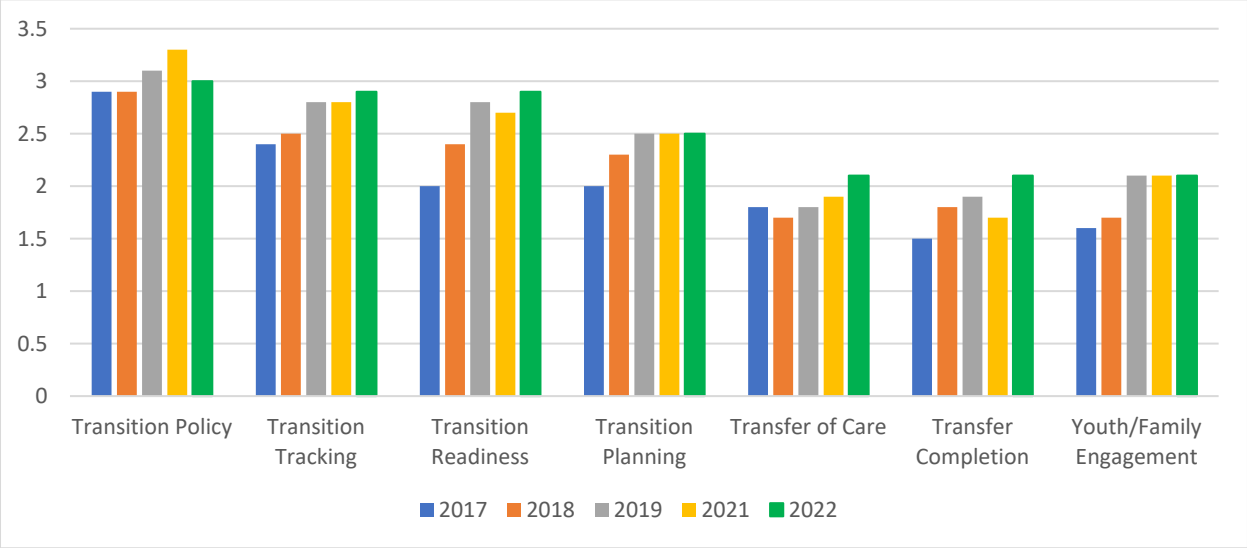
Among the seventeen states that consistently participated in this survey since 2017:

- Nine states (53%) exhibited an increase in their overall scores while seven (41%) decreased in their overall scores, and 1 state's score remained the same.
- When looking at the current levels of each core element (Table 1 and Figure 2), states scored best out of 4 on HCT policy (3.0), transition tracking (2.9) and readiness (2.9), followed by transition planning (2.5). There was a tie between performance on transfer of care (2.1), transfer completion (2.1), and youth and family engagement (2.1) (Table 1 and Figure 2).
- From baseline, the average level of each core element has increased with the greatest improvement in transition readiness (from 2.0 to 2.9), followed by transition completion (from 1.5 to 2.1) and youth/family engagement (from 1.6 to 2.1).

Table 1. Average Levels of Implementation of the Six Core Elements in State Title V Care Coordination Efforts, 2017-2022

Six Core Elements	Average Levels: 1 (basic) to 4 (comprehensive)					Average % increase since 2017 baseline
	2017	2018	2019	2021	**2022**	
Transition Policy	2.9	2.9	3.1	3.3	**3.0**	3%
Transition Tracking	2.4	2.5	2.8	2.8	**2.9**	21%
Transition Readiness	2.0	2.4	2.8	2.7	**2.9**	45%
Transition Planning	2.0	2.3	2.5	2.5	**2.5**	25%
Transfer of Care	1.8	1.7	1.8	1.9	**2.1**	17%
Transfer Completion	1.5	1.8	1.9	1.7	**2.1**	40%
Youth/Family Engagement	1.6	1.7	2.1	2.1	**2.1**	31%

Figure 2. Comparison of Average Level Between 2017 and 2022, for Each of the Six Core Elements



State Spotlight: Michigan Children's Special Health Care Services

Based on Got Transition's Six Core Elements of HCT and their Assessment of HCT Activities in Care Coordination Programs, Michigan's Children's Special Health Care Services (CSHCS) program created a HCT assessment survey for Local Health Departments (LHDs) across the state. An electronic survey was formatted using the Qualtrics online survey platform and was comprised of six (6) multiple choice questions and one (1) free text response field. Each question was based on the Six Core Elements of HCT and provided four possible response levels from level 1 (basic) through level 4 (comprehensive). The free text response field provided LHD staff the opportunity to offer feedback on HCT policies, documents, and trainings within the CSHCS program.

Each of Michigan's 45 LHD's received and responded to an emailed survey link. The goal of this initial survey was to acquire baseline HCT data that will be tracked annually and used to enhance CSHCS health care transition program development. CSHCS partnered with the Michigan State University Institute for Health Policy to provide technical assistance and support for this project. Aggregated survey data and feedback results were presented to the LHD's during a monthly meeting, and individual survey results were emailed to each LHD. On average out of a possible score of 4, LHD's scored the highest (2.29-2.6) on Transition Policy, HCT Tracking and Monitoring, Transition Readiness, and Transition Planning, while scoring lower (1.6-2.0) on Transfer of Care and Transition Completion. Based on the survey results and feedback received, Michigan's CSHCS program updated several HCT documents, revised the CSHCS Transition to Adulthood website, and expanded the monthly CSHCS client transition report. Additionally, Michigan's CSHCS program is creating a Transition Resource Manual for LHDs and will be offering training sessions on HCT to LHDs.

CONCLUSIONS

The improvements over 5 years from states is impressive. Despite small dips in scores between each of the five years, it is remarkable to note that states have progressed in each of the Six Core Elements, particularly since the COVID-19 pandemic. Still, there is room for growth. States can begin to think about how they can progress over the next five years. Using their current levels from this report as a baseline, states can select one or more of the core elements and work toward implementing small-scale pilot quality improvement efforts that align with the next level description in the assessment (see Appendix) for the selected core elements. Got Transition's Implementation Guides offer practical guidance, resources, and examples for conducting HCT quality improvement.

State Title V agencies can also consider collaborating with other care coordination programs in state agencies such as Medicaid and departments of behavioral health, developmental disabilities, child welfare, and juvenile justice to integrate HCT using a similar measurement and implementation process. Additional strategies can be found in Got Transition's *Health Care Transition in State Title V Programs: A Review of 2018 Block Grant Applications and Recommendations for 2020*.

REFERENCES

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APPENDIX: 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 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 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 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.

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