INTRODUCTION

In 2015, the Title V Maternal and Child Health Services Block Grant Program revised the performance measurement framework to address the priority needs of the maternal, infant, child, and adolescent populations, including those with special health care needs and their families. Fifteen national performance measures (NPMs), including one on health care transition (HCT), were selected by the federal Maternal and Child Health Bureau (MCHB). In 2018, 37 states and jurisdictions, including the District of Columbia, Puerto Rico, Virgin Islands, Guam, Marshall Islands, and Federated States of Micronesia, elected to prioritize HCT (NPM #12) as one of their five selected priority NPMs. This report summarizes the HCT efforts of Title V agencies reported in states’ 2018 Application/2016 Annual Report,” provides ten recommendations around HCT for the 2020 block grant application, and finally, highlights examples of states’ HCT innovations. Previous reports summarizing state Title V transition efforts were completed by Got Transition in 2016, 2017.

EXECUTIVE SUMMARY

In 2018, state Title V agencies reported on a notable variety of HCT strategies. The strategies most often mentioned were 1) HCT education and leadership development with families and youth, often in tandem with state chapters of Family Voices and Family-to-Family Health Information Centers; 2) outreach and education efforts with health care professionals, including physicians, residents, nurses, social workers, and care coordinators, sometimes in partnership with their state American Academy of Pediatrics (AAP) and American Academy of Family Physicians (AAFP) chapters, and with Leadership and Education in Neurodevelopmental and Related Disabilities (LEND) programs; 3) communication/social media efforts to update and disseminate current HCT information; 4) systems development initiatives ranging from participating in interagency transition work groups to partnering with sister agencies; and 5) implementing and evaluating HCT practice improvement initiatives, often within their care coordination programs and, in a few instances, with pediatric and adult primary or specialty care practices.

When describing their HCT strategies, 21 of the 33 states and jurisdictions (64%) referenced evidenced-informed HCT strategies including the 2011 AAP/AAFP/ACP Clinical Report on HCT.
Six Core Elements of HCT,6 and/or AMCHP’s Standards for Systems of Care for Children and Youth with Special Health Care Needs.7 Sixteen states (48%) mentioned involving both pediatric and adult providers in their strategies; 13 states (39%) included strategies for both youth with and without special health care needs. In general, states elected to focus on a smaller number of interrelated HCT strategies compared to previous years.

RECOMMENDATIONS FOR THE 2020 STATE TITLE V ACTION PLAN

States will be conducting their next five-year needs assessment as part of the 2019 Title V Block Grant Application/Annual Report and identifying priorities to improve the health of maternal and child health populations (MCH), including those with special health care needs (CYSHCN). Although significant HCT efforts have been undertaken by state Title V agencies in the past, the 2016 National Survey of Children’s Health (NSCH) revealed that continued attention is still needed. Parents/caregivers reported that 83% of their youth with special health care needs (YSHCN) and 86% of their youth without special needs did not receive transition planning support from their health care providers.8 Transition planning support, as measured in the NSCH, includes adolescent time alone with their health care provider and anticipatory guidance relating to gaining self-care skills, understanding changes that happen at age 18, and discussing the eventual transition to an adult health care provider. The following recommendations are offered to increase state Title V’s leadership on HCT as they begin their new five-year reporting cycle.

1. Select HCT as an NPM. Building on the progress made over the past several years, states that selected HCT (NPM #12) in the past are encouraged to continue to prioritize HCT as one of their NPMs for the next five years. States that did not select HCT in the past are encouraged to consider selecting HCT as an NPM; if this is not possible, states may want to identify strategies to incorporate HCT into their existing NPMs (i.e., medical home, adolescent and well women preventive care, and insurance adequacy). The need for HCT performance improvement, according to the findings from the NSCH, is urgent and widespread among all states. When HCT processes are not in place, the literature shows adverse impacts in terms of low health care literacy, gaps in access and use of primary and specialty care, worsening health conditions, dissatisfaction of care, and preventable emergency room visits and hospitalizations.9

2. Publicize new HCT data. In the fall of 2018, data from the 2017 NSCH data will be available online at the Data Resource Center for Child and Adolescent Health, a project of the Child and Adolescent Health Measurement Initiative (CAHMI). CAHMI will be preparing combined 2016/2017 NSCH data to allow for more comprehensive state-specific estimates of HCT. States can use these new data as part of their needs assessment comparing state versus national estimates for both youth with and without special health care needs. They will be able to examine HCT results by sociodemographic, health condition, and health care characteristics to identify disparities. State and national HCT findings from the NSCH can be shared with key stakeholders to highlight the need for health care professionals to devote attention to HCT as part of routine preventive, primary, and chronic care. States can also create communication strategies around the components of the transition measure, which include time alone, self-care skill development, privacy and consent changes at age 18, and the age of eventual transfer to adult care. A new article examining national HCT performance results from the 2016 NSCH will be published in Pediatrics in September 2018.8
3. **Utilize the 2016/2017 NSCH information as a baseline NPM objective.** States are encouraged to use their state-specific 2016/2017 NSCH data as baseline information on HCT to establish measurable objectives for their upcoming five-year action plan. Since these are new data, it is difficult to predict what levels of improvement states should aim for. Given this uncertainty, states may want to select a conservative aspirational objective, such as a 5% increase from baseline, over the span of five years. States may want to consider offering education to youth and families, health care professionals, and policymakers about HCT findings from the NSCH with the aim of improving state HCT performance.

4. **Utilize Got Transition measurement tools.** States can utilize Got Transition’s HCT measurement tools to determine their progress in achieving implementation of evidence-informed HCT processes. These measurement tools can address different needs.

   To assess whether health practices, care coordination programs, and/or health plans have implemented an evidence-informed HCT process, states can use either of the following tools as a baseline measure and repeat annually:

   - **Current Assessment of HCT Activities**, provides a quick snapshot of the level of HCT support available to youth and families in health care practices.
   - **HCT Process Measurement Tool**, provides a scorable assessment of HCT implementation with suggested documentation for each completed core element.

   To assess youth/young adult and parent/caregiver feedback about their HCT experience, states can use the following surveys:

   - **HCT Feedback Survey** (for youth/young adults and parents/caregivers), provides an important way to elicit consumer feedback about the HCT process.

5. **Expand youth and family engagement and demand for a planned HCT process.** State Title V agencies have strong connections with family, disability, and youth organizations. Continued efforts are encouraged to actively engage youth, young adults, and families, especially those from racial and ethnic minority populations, in all aspects of HCT planning, implementation, and evaluation. This engagement is fundamental to the success of HCT and can be addressed through increasing involvement of youth in their own health and health care. Youth and parents/caregivers can ask their health care providers to assist them in planning for a smooth transition to adult care. In addition, states can seek youth and family as active partners in advisory groups, in HCT feedback surveys, and in focus group sessions.

6. **Share new professional recommendations on HCT from 2018 AAP/AAFP/ACP Clinical Report.** This joint consensus report will be published in *Pediatrics* in November 2018. States may want to update their websites, curricula, and education resources with this new information. States may also want to consider partnering with their state AAP/AAFP/ACP chapters to disseminate these recommendations and other HCT resources available in their state and at [www.gottransition.org](http://www.gottransition.org).

7. **Make HCT improvements sustainable.** State Title V agencies are encouraged to reach out to senior leaders at their state Medicaid agencies and their contracted managed care organizations (MCOs), as well as to commercial payers and health plans/accountable care organizations (ACOs) to share evidence-informed HCT strategies and resources, including the 2018
AAP/AAFP/ACP Clinical Report, the state’s transition resources, and Got Transition’s 2018 Transition Coding and Reimbursement Tip Sheet. The coding tip sheet includes a set of transition-related CPT codes that payers are encouraged to recognize. In addition, Got Transition will be releasing a new report on value-based payment strategies in October 2018. This report offers payers and health plans specific strategies for implementing HCT payment pilots. State Title V agencies may consider partnering with Medicaid, for example, on value-based transition pilots for YSHCNs.

8. **Build partnerships with state agencies working on initiatives for transition-aged youth.** State Title V agencies have a long history of interagency collaboration efforts around early childhood. Similarly, efforts can be undertaken to incorporate evidence-informed HCT content into all state transition efforts, including those sponsored by the departments of special education, behavioral health, developmental disabilities, child welfare, juvenile justice, and social security administration.

9. **Expand HCT quality improvement efforts in care coordination programs.** Since 2017, Got Transition has partnered with State Title V agencies that support care coordination to implement and assess the use of evidence-informed HCT supports for YSHCN. Continued quality improvement efforts are needed to increase the level of HCT implementation in these programs. States may want to establish an objective for improving the level of implementation of specific core elements over the course of the five-year period. Got Transition will continue to conduct an annual assessment and share the results with each participating state. In addition, state Title V agencies, in their systems development capacity, can reach out to other public and/or commercially funded care coordination programs to encourage similar efforts with accompanying measurement. For information about Got Transition’s care coordination webinar series and resources, please visit [www.gottransition.org](http://www.gottransition.org).

10. **Align other NPMs with HCT.** Four NPMs can be aligned with HCT: medical home (NPM #11), adolescent preventive care (NPM #10), well women visits (NPM #1), and insurance adequacy (NPM #15).

   - *With respect to aligning with medical home,* state Title V agencies may consider reaching out to their state medical home leaders and commercial and Medicaid payers to encourage them to incorporate HCT into their medical home efforts, as suggested in Got Transition’s [medical home practice resource](http://www.gottransition.org), or to encourage medical home quality improvement efforts connecting pediatric and adult practices for youth and young adults with special health care needs.

   - *With respect to aligning with adolescent preventive care,* states may consider working with their adolescent health coordinators and other adolescent leaders in their state, including their EPSDT directors, to incorporate HCT into routine preventive care, as recommended in Got Transition’s [clinician toolkit](http://www.gottransition.org).

   - *With respect to aligning with well woman visits,* states may consider working with their state reproductive health leaders to include HCT into well woman visits using the clinician toolkit.

   - *With respect to aligning with health insurance adequacy,* state Title V agencies may want to reach out to their Medicaid officials working on health homes for individuals with multiple chronic conditions to examine potential opportunities for expanding the transitional care services and activities to include pediatric to adult transitional care, not just hospital to home transitional care.
METHODS

Information from this report was obtained from the FY 2018 state Title V block grant applications from the states that chose NPM #12. For this report, Got Transition is reporting on 33 states and two jurisdictions (the District of Columbia and Puerto Rico). Information from the Federated States of Micronesia, Guam, Marshall Islands, and the Virgin Islands also chose NPM #12 but their information is not included in this report. State block grant applications were obtained online from MCHB’s Title V Information System. Got Transition created an abstraction form to collect a consistent set of information from states’ description of current and planned HCT activities. If states mentioned either current or planned HCT strategies, they were given credit in the abstraction form. This form analyzed the following topics: population target (all youth or YSHCN); reference to evidence-informed strategies (2011 AAP/AAFP/ACP Transition Clinical Report, Six Core Elements of HCT, and National Standards for Systems of Care for CYSHCN); selection and measurement of transition strategies; alignment with other NPMs (adolescent well care, well women visits, medical home, and health insurance adequacy); and examples of innovative strategies.

The results of the analysis are limited by state reporting in their block grant applications. States’ planned HCT strategies that were reported may not be implemented. Any efforts not discussed in the application were not analyzed. States that did not select NPM #12 but included HCT as a strategy under a different NPM, were not included in this report.

TRANSITION FINDINGS

A. Changes in Transition Efforts from 2017

Compared to 2017 year, states and jurisdictions that selected HCT as one of their NPMs were less likely to reference evidence-informed transition strategies (2011 AAP/AAFP/ACP Transition Clinical Report, Six Core Elements of HCT, or the National Standards for Systems of Care for CYSHCN) than in 2018. However, more states mentioned using specific elements from the Six Core Elements of HCT than in the previous year, which suggests that states may simply not have repeated the HCT evidence source in their block grant applications. In 2018, more states mentioned implementing HCT strategies for youth with special health care needs, and fewer states mentioned implementing HCT strategies for youth without special health care needs compared to 2017. Overall, states selected a smaller, more focused number of strategies and were more involved in HCT training, education, or leadership initiatives involving consumers (youth and/or parents/caregivers) compared to 2017.

B. Evidence-Informed Transition Strategies

Evidence-informed HCT strategies include the 2011 AAP/AAFP/ACP Clinical Report, the Six Core Elements of HCT, and the AMCHP Standards for Systems of Care for Children and Youth with Special Health Care Needs. The 2011 AAP/AAFP/ACP Clinical Report represents professional consensus on the timing and content of HCT planning for youth. The Six Core Elements operationalizes the Clinical Report with sample tools. The AMCHP CYSHCN Standards for Systems of Care sets out a set of structure and process standards, including HCT standards based on the Six Core Elements. Almost two-thirds of the 33 Title V agencies (67%) referenced the use of one or more of the evidenced-informed HCT sources.
Table 1 summarizes states’ use of the Six Core Elements in general and with respect to specific core elements between 2016 and 2018. All core elements, except for transition registry/tracking, increased in use since 2016. The elements mentioned most often in 2018 were an HCT plan of care, a transition readiness assessment, and an HCT policy. A smaller number of states mentioned a transition registry, a medical summary/emergency care plan, and a transfer checklist; only one state mentioned obtaining consumer feedback.

<table>
<thead>
<tr>
<th>General Reference to Six Core Elements*</th>
<th>2018 (n=33)</th>
<th>2017 (n=32)</th>
<th>2016 (n=32)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition Policy</td>
<td>17 (52%)</td>
<td>13 (41%)</td>
<td>6 (19%)</td>
</tr>
<tr>
<td>Transition Registry/Tracking</td>
<td>7 (21%)</td>
<td>8 (25%)</td>
<td>6 (19%)</td>
</tr>
<tr>
<td>Transition Readiness/Self-Care Assessment</td>
<td>18 (55%)</td>
<td>12 (38%)</td>
<td>4 (13%)</td>
</tr>
<tr>
<td>Transition Plan of Care</td>
<td>19 (58%)</td>
<td>10 (31%)</td>
<td>6 (19%)</td>
</tr>
<tr>
<td>Medical Summary/Emergency Care Plan</td>
<td>6 (18%)</td>
<td>4 (13%)</td>
<td>4 (13%)</td>
</tr>
<tr>
<td>Transfer Checklist</td>
<td>6 (18%)</td>
<td>4 (13%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Consumer Transition Feedback</td>
<td>1 (3%)</td>
<td>1 (3%)</td>
<td>1 (3%)</td>
</tr>
</tbody>
</table>

*Numbers do not total since states often mentioned the Six Core Elements generally and also mentioned specific core elements

C. Transition Strategies and Examples of Innovation

The HCT strategies described by states are organized into five categories: youth and family education and leadership development, health care professional workforce development, communication and social media, practice improvements, and systems development strategies. On average, states mentioned four strategies which most often related to family and youth HCT education, health care professional training, and communication/social media strategies. Below is a summary of states’ transition strategies with examples of state innovations.
1. Youth and Family Transition Education and Leadership Development Strategies

Almost all 33 Title V programs (31 states, 94%) described either transition education and/or leadership development initiatives involving youth/young adults and parents/caregivers/families. More often, states focused on transition education compared to leadership development (29 states vs. 16 states, respectively), often working closely with their Family Voices and Family-to-Family Information Centers as well as with other disability organizations to share HCT training opportunities and resources. Transition education efforts described often were educational conferences and online resources on a range of HCT topics, such as HCT timelines, self-determination and self-management skills, alternative decision-making support, and questions to ask doctors. Transition leadership efforts varied – some states mentioned offering special training for youth/young adults and families on HCT, and others discussed forming transition advisory groups or including consumer leaders in their HCT quality improvement efforts.

Innovative Youth and Family Education and Leadership Development Strategies

- **Arizona’s** Title V agency plans to increase the number of Young Adult Advisors as well as expanding the number of young adult and family advisors who are bilingual, tribal members or from more rural areas.

- **North Dakota** provides ongoing transition education, including presentations at the North Dakota Transition and Youth Leadership Conference sponsored by the Federation of Families for Children’s Mental Health. The state has developed three transition packets for youth ages 14-21, including helpful resources to assist with the transition process.

- **Rhode Island** supports several efforts to develop youth leadership, including forums that help youth understand their chronic condition, how to advocate for themselves, and gain knowledge necessary to navigate the health care system. Each year, the state sponsors an annual Dare to Dream Conference for transition-age youth and sponsor several meetings to recruit, train, and support youth leaders, including a youth advisory committee, Transition Academies, youth centers, and youth groups.

- **Tennessee** includes a mix of strategies for building youth and parent leadership, including partnering with Family Voices to provide HCT training and conferences, working with LEND to replicate youth advisory groups throughout the state, and involving youth in Title V policy and advocacy efforts.

- **Wisconsin** has developed a curriculum in youth health transition for parents, called “Build Your Bridge.” This free presentation and conversation helps parents and youth understand what HCT is and why it is important, identify activities in daily life where transition occurs, apply tools and resources to take an active role in the HCT process, and starts an HCT action plan.
2. Health Care Professional Workforce Development Strategies

As many as 28 of the 33 Title V agencies (85%) reported providing HCT education to health professionals, often referencing efforts to increase knowledge about evidence-informed HCT approaches. States trained care coordination staff as well as physicians, nurse practitioners, nurses, social workers, and others (e.g., LEND program staff). Several states also mentioned training medical residents and school nurses.

Innovative Health Care Professional Workforce Development Strategies

- **Florida’s** Title V program updated its HCT training for health professionals, incorporating Got Transition’s Six Core Elements in its practice resource reports. Up to four free continuing education hours are available for physicians, physician assistants, nurse practitioners, social workers, mental health counselors, and allied health professionals through the Florida Area Health Education Center network. Their website, [www.floridahats.org](http://www.floridahats.org), provides links to additional HCT offerings, including maintenance of certification, other continuing education courses, graduate medical and public health education, and a graduate level, online certificate in education and HCT offered by the University of Florida.

- **Louisiana’s** workforce development strategy includes several health care provider education initiatives. In the state’s care coordination partner practices, medical residents are trained in the provision of youth health transition services. As part of Louisiana State University’s pediatric, family medicine, and medical-pediatrics development rotation, residents must complete a webinar on transition as well as receive training on the use of evidence-informed transition tools.

- **Michigan** is partnering with its state chapters of the AAP, AAFP, ACP, and American Academy of Nurse Practitioners (AANP) to disseminate evidence-informed transition resources to primary care practices, specialty physicians, and local health departments. They also plan to partner with the Michigan State Medical Society to disseminate transition tools and resources to primary care providers throughout the state.

- **Minnesota** is developing a combination of strategies to identify available physicians who will accept young adults with childhood-onset conditions. This includes identifying adult providers who specialize in specific chronic diseases. For example, the state is participating on a task force convened by a pediatric hematologist to address the workforce shortages for young adults with sickle cell disease. The state also plans to offer trainings for adult health care providers, including transition podcasts and other free training, some of which offer continuing medical education credits. In addition, it plans to survey medical-pediatrics physicians to determine their availability to serve young adults with childhood-onset conditions.
3. Communications and Social Media Strategies

Of the 33 states and jurisdictions, 28 (85%) selected HCT strategies directed at communications and social media. These activities included a variety of information dissemination approaches, such as updating their websites, using Facebook pages, creating online portals and toolkits, and producing targeted email messaging, listserv announcements, and newsletters. Many states have dedicated websites on HCT or sections of their websites on HCT, often in tandem with information about other transitions related to education, employment, insurance and public benefits, and independent living.

Innovative State HCT Websites

Several states host noteworthy, user-friendly, and interactive sites for providers, youth/young adults, and parents.

- **Florida**: Florida Health and Transition Services at [https://www.floridahats.org](https://www.floridahats.org) includes a HCT tool box that contains resources and links to a variety of local, state, and national resources.

- **Louisiana**: Smooth Moves Youth Health Transition site at [https://www.SmoothMovesYHT.org](https://www.SmoothMovesYHT.org) is a youth/young adult-friendly website with activities and tools to help build skills needed for independence.

- **Maryland**: Office for Genetics and People with Special Health Care Needs at [https://phpa.health.maryland.gov/genetics/Pages/Health_Care_Transition.aspx](https://phpa.health.maryland.gov/genetics/Pages/Health_Care_Transition.aspx) offers fact sheets, videos, and a “My Health Care” notebook for parents and caregivers of YSHCN.

- **Michigan**: Michigan Department of Health and Human Services Transition to Adulthood site at [https://www.michigan.gov/mdhhs/0,5885,7-339-71547_35698-135030--,00.html](https://www.michigan.gov/mdhhs/0,5885,7-339-71547_35698-135030--,00.html) contains several transition tools for youth, their families, and providers, including a transition guidebook and readiness assessment and transition plan.

- **Wisconsin**: Health Transition Wisconsin at [https://healthtransitionwi.org/](https://healthtransitionwi.org/) provides a variety of tools, materials, and resources to help teens, families, and health care providers.
4. Practice Improvements Strategies

Ten of the 33 states and jurisdictions (30%) mentioned current or planned efforts aimed at HCT practice improvements. These state Title V agencies often described incorporating the Six Core Elements into their Title V program – either as part of care coordination or, less often, as part of their primary or specialty clinics. A few states described practice improvement grant efforts that involved working with community and school clinics, office-based practices, interdisciplinary training programs, hospital systems, and health plans.

**Innovative Practice Improvements Strategies**

- **Arizona**, working with its LEND Program, is introducing a transition implementation pilot to assist clinicians to incorporate HCT into regular practice. Their work plan includes an evaluation plan, data collection instruments, stakeholder involvement, and a pilot training program.

- The **District of Columbia** is piloting a transition quality improvement effort with two school-based health centers (SBHCs). This involved creating a welcome and care policy, a transition readiness assessment, and a one-page fact sheet on finding an adult doctor. Also, DC initiated a HCT quality improvement project with school mental health counselors, which involves customizing the Six Core Elements and linking school-based mental health therapy services with adult community-based mental health services for high school seniors.

- Hawaii’s Title V agency established a data collection form to track completion of planned HCT activities for YSHCN served by Title V programs. For each of the Six Core Elements, the state lays out a specific set of planned activities that needs to be accomplished each fiscal year.

- Kentucky’s Commission for Children with Special Health Care Needs, as part of its statewide system of care coordination, has incorporated transition improvements, including age-specific checklists, a transition policy developed with feedback from its youth advisory council, identification of adult providers, and consumer feedback. Care coordinators work to transfer YSHCN well before they turn 21 so that care coordination support can follow the YSHCN into adult care.

- Louisiana’s Title V agency is part of a ‘Super Uber User’ workgroup to incorporate youth HCT service documentation into their electronic health record system, which is used by all Title V-supported clinics.
5. Systems Development Strategies

State Title V agencies reported a range of systems development efforts related to HCT. Often these included participation in a statewide interagency council on transition (21 states, or 64%). Less often, states mentioned other systems development strategies which included working with their states’ Department of Education to incorporate HCT into special education transition planning (7 states, or 21%); working with intellectual and developmental disability groups to jointly sponsor meetings, including their state’s Developmental Disability Council and LEND (9 states, or 27%); partnering with their state’s Behavioral Health Department to address the needs of transition-aged youth with behavioral health conditions or youth in foster care (6 states, or 18%); and advocating for transition payment improvements or contract requirements (5 states, or 15%).

Innovative Systems Development Strategies

- California’s Title V agency collaborated with its Medicaid (Medi-Cal) Managed Care Quality and Monitoring Division in facilitating the provision of HCT services for YSHCN as they transition to adult care. California is also identifying options to track whether Title V clients completed their initial adult visit within a given managed care organization.

- Connecticut’s Title V agency is partnering with its Department of Education, community organizations, care coordinators, and providers to advance health care and educational/vocational planning for 14-18 year-olds with special health care needs.

- Illinois plans to collaborate with its State Board of Education, Department of Human Services’ Division of Rehabilitation Services and Division of Developmental Disabilities, Statewide Independent Living Council, Community and Residential Services Authority, State Advisory Council on the Education of Children with Disabilities, and Illinois Assistive Technology Program/Work Incentives Planning and Assistance to plan a transition conference in Chicago.

- Kentucky’s Title V staff plans to collaborate with its Departments of Community- Based Services (child welfare) and Behavioral Health to create medical transition plans for their respective populations and serve as a resource to assist with transitioning youth to adult medical and adult behavioral health care.

- Louisiana partnered with its Departments of Education, Medicaid, Medicaid MCOs, Department of Children and Family Services, Social Security Administration, and the Office of Behavioral Health to plan and host information workshops that offer national and state transition resources.

- Minnesota’s Title V staff is participating in a cross-agency pilot effort focused on incorporating health related goals into the IEP and annual plan processes, beginning with two pilot sites, using specific tools and practices to incorporate health-related assessments and goals into the IEP and annual plan processes, and involving school nurses, public health nurses, or student’s primary care clinic team members.
6. Aligning Other National Performance Measures with HCT

State Title V agencies have the flexibility to align related NPM strategies to ensure a coordinated and efficient state action plan. According to the 2018 block grant analysis, states most often mentioned aligning HCT with their medical home NPM (16 states or 43%) and to a less extent with their adolescent preventive care NPM (7 states or 21%).

Innovative Alignment of NPMs

- Minnesota’s Title V program is implementing HCT quality improvement efforts in several primary care clinics and measuring the extent to which YSHCN in these practices completed a transition readiness assessment. They are also disseminating their online HCT toolkit that includes that Six Core Elements as part of a collaborative effort with the Minnesota Department of Health Care Homes Program, a statewide health reform initiative focused on the redesign of care. Minnesota’s Title V program has also participated in an MCHB-funded Adolescent and Young Adult Collaborative Innovation Network to increase access to and quality of preventive care to adolescents and young adults. HCT training has been included as part of this effort.

- New Mexico is partnering with adult medical home providers to utilize its Title V social work staff to help bridge the gap between pediatric and adult care, to improve the transition and transfer process, and to increase satisfaction among providers, youth, and families. New Mexico’s Title V program is also part of an AMCHP/NASHP Action Learning Network, working with Medicaid officials to identify options for including HCT as an integral component of care provided by MCOs.

- New Mexico’s Title V team provided recommendations to Medicaid during the public comment phase for the 1115 waiver renewal process. Transition was identified by the state’s managed care organizations and Medicaid as an essential component of care that needs to be addressed by contracted providers.

- Michigan’s Children with Special Health Care Services is collaborating with its Managed Care Division and Medicaid health plans to determine feasible ways for health plans to introduce HCT.
CONCLUSION

This report summarizes state Title V approaches to HCT, highlighting innovative examples for states to consider as they prepare for their 2020 Title V block grant application. States are encouraged to maintain their momentum to expand evidence-informed transition strategies as part of a comprehensive system of care. The 2016 NSCH data reveal that the vast majority of youth with and without special health care have not received transition planning guidance from their health care providers. Therefore, leadership from state Title V programs is critically needed to advance HCT improvements in alignment with medical home, preventive care, and insurance performance measures and other statewide health reform initiatives.

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REFERENCES


