



Transition to Adult Health Care and State Title V Program Directions: A Review of 2017 Block Grant Applications

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The Title V Maternal and Child Health Block Grant Program initiated a major transformation process over the past few years. According to Dr. Michael Lu, the Maternal and Child Health Bureau's (MCHB's) Associate Administrator, "this transformation is designed to improve accountability of performance and impact and better demonstrate the returns on investment for Title V in improving the health and well-being of the Nation's mothers, children, and families."¹

Fifteen national performance measures (NPMs) were selected to guide this transformation, including one on transition from pediatric to adult health care: *Increase the percentage of adolescents with and without special health care needs who receive services necessary to make transitions to adult care.* A total of 32 state Title V agencies, including the District of Columbia and five territories, selected transition as a NPM.²

States Title V agencies adopted a measurement framework that involves key stakeholders, incorporates evidence-informed strategies, and demonstrates impacts.³ The key stakeholders in transition include youth, young adults, and parents/caregivers as well as pediatric and adult clinicians, health care plans and payers, and public health programs. The professional guidance for transition interventions is from the Clinical Report on Health Care Transition, jointly developed by the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP).⁴ The "Six Core Elements of Health Care Transition," developed by MCHB's Got Transition and consistent with the AAP/AAFP/ACP Clinical Report, provides a systematic evidence-informed process with sample tools and measurement resources that can be customized for use by practices and plans.⁵

This report presents new information about state Title V transition strategies and evidence-informed measures (ESMs). It begins with an executive summary that includes recommendations. This is followed by examples of innovative transition strategies and information about the new transition measure from the National Survey of Children's Health that will be used to report state and national transition performance.

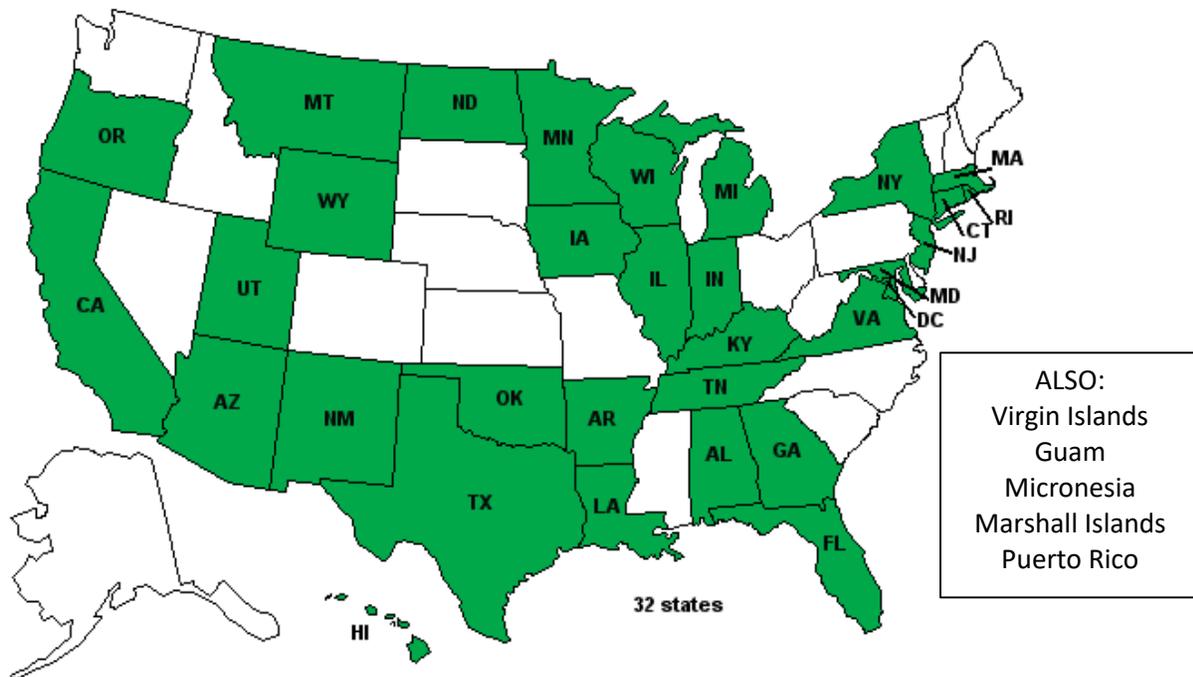
EXECUTIVE SUMMARY

This report summarizes the current efforts of 32 state Title V agencies that selected the transition NPM. Almost two-thirds of these states selected youths with and without special health care needs as their population focus for transition, and three-quarters referenced evidence-informed transition strategies, most often the Six Core Elements of Health Care Transition. State Title V agencies often mentioned developing transition policies and encouraging the use of transition readiness assessments; about half of these states discussed involving both pediatric and adult providers. A variety of strategies were described to achieve improvements in transition performance – consumer and health care professional education, interagency transition planning, communications strategies, and practice improvements. Numerous examples of innovation are summarized below along with a summary of new national and state transition performance data and states’ use of evidence-informed transition measures.

The following suggestions are offered to further enhance state Title V health care transition leadership.

1. Got Transition’s resources, including the Six Core Elements of Health Care Transition sample tools and measurement resources, should be widely used. States can add their own logos to these resources, customize the tools for their own programs/practices, and disseminate widely. Also, consider adding website links to www.GotTransition.org.
2. Continued efforts to involve adult health care providers and health plans as well as state chronic care programs are essential to facilitate effective transitions. In addition, efforts to involve state AAP, AAFP, and ACP chapters in transition education and quality improvement is important.
3. Considering the number of priorities that state Title V agencies are working on, it is important to align transition strategies with related priorities for medical home, adolescent preventive care, well women visits, and adequate health insurance.⁶
4. New national and state-level transition data will be available this year to establish a new baseline from which to track progress over time. Since the new transition questions in the 2016 National Survey of Children’s Health are different from the previous transition questions in the 2009/10 National Survey of Children with Special Health Care Needs, it no longer makes sense to compare these results. These data will be for all youth and for YSHCN.
5. In 2017, the AAP/AAFP/ACP Clinical Report on Health Care Transition will be updated. It will be important to incorporate this new clinical consensus into state programs and to share it with key stakeholders.
6. Recognizing the substantial efforts states are making on health care transition education, it will be important to track numbers and types of providers reached as well as knowledge and skills achieved.
7. Recognizing the increasing need for accountability, states are encouraged to measure their practice improvement strategies annually using the Current Assessment of Health Care Transition Implementation in the Six Core Elements. They should also consider eliciting parent and youth experience using the transition feedback survey in the Six Core Elements.

States Selecting Transition as a Title V National Performance Measure



METHODS

Information for this report was obtained from FY 2017 state Title V block grant applications of the 32 states (including the District of Columbia) that chose NPM #12 on health care transition, available online from MCHB's Title V Information System (TVIS).⁷ Specifically, we examined the state action plan table and narrative description for NPM #12. An abstraction form was created to obtain a consistent set of information. This form addressed the following topics: changes from 2016 on several topics; population target (all youth or YSHCN); mention of AAP/AAFP/ACP Transition Clinical Report, Six Core Elements, and/or the National Standards for Systems of Care for CYSHCN; transition strategies involving both pediatric and adult care; number and type of transition strategies; selection of related measures on adolescent well care, well women visits, medical home, and adequate health insurance; and identification of innovative strategies. Transition information from each state's block grant application was analyzed by both authors from Got Transition. The results of the analysis, including the description of innovations, are limited by state reporting in their block grant applications. Oftentimes, states describe activities planned for the upcoming fiscal year. Any efforts not discussed could not be analyzed. In addition, states that did not select transition as a NPM, but included it as a strategy under a related performance measure, were not included in this report.

TRANSITION FINDINGS

A. Changes in Planned Transition Efforts from 2016

Given the early stages of state Title V transformation, it is not surprising to learn that more than half of the 32 states (18) that selected transition as a NPM changed their planned efforts from the preceding year. This analysis revealed that more states are addressing all youth, referencing transition evidence, selecting fewer strategies, and partnering with adult care practices.

B. Transition Population Focus

Almost two thirds of states (20) selected youths with and without special health care needs as their population focus for transition compared to eight states in 2016. Although the transition NPM falls under the children with special health care needs (CSHCN) population domain, the actual performance measure addresses all youth. Going forward, states will have the ability to examine transition performance for youth with and without special needs from the National Survey of Children's Health (see below for more information).

C. Use of Evidence-Informed Transition Strategies

Seventy-five percent of states (24 of 32) referenced evidence-informed transition strategies, up from less than half (14) last year. Most often, states cited the Six Core Elements of Health Care Transition (21), with a smaller number mentioning the AAP/AAFP/ACP Transition Clinical Report (8) and the National Standards for Systems of Care for CYSHCN (4). As shown in Table 1, state Title V agencies most often mentioned developing transition policies and conducting transition readiness assessments. Since 2016, states are far more likely to mention specific element. Importantly also, half of states (16) that selected NPM #12 discussed involving both pediatric and adult providers as stakeholders -- up from 13 states in 2016.

Table 1. State Title V Agency Reference to Six Core Elements in Transition Strategies

| Use of Six Core Elements of Health Care Transition | 2016 | 2017 |
|---|-----------------|-----------------|
| Mention of Six Core Elements of Health Care | 14 (44%) | 21 (66%) |
| - Transition Policy | 6 (19%) | 12 (37.5%) |
| - Transition Registry/Tracking | 6 (19%) | 8 (25%) |
| - Transition Readiness/Self-Care Assessment | 4 (13%) | 12 (37.5%) |
| - Transition Plan of Care | 6 (19%) | 9 (28%) |
| - Medical Summary/Emergency Care Plan | 4 (13%) | 4 (13%) |
| - Transfer Checklist | 1 (3%) | 4 (13%) |
| - Consumer Transition Feedback | 1 (3%) | 1 (3%) |
| - Welcome Letter/FAQs for Adult Practice | 0 (0%) | 5 (15%) |

D. Transition Strategies

States are adopting a variety of transition strategies to improve transition support, most often related to health care professional education and youth and parent training and leadership development. Compared to 2016, fewer transition strategies were selected. Most states listed five or

fewer strategies. Below is a description of states' transition strategies in the following categories: practice improvements, health care professional education, consumer training and leadership, communications, and interagency planning. Examples of innovative approaches are summarized under each category.

1. Practice Improvements

Almost half of states (15 of 32) are involved in transition practice improvements -- a significant increase from the four states reporting similar efforts in 2016. These state Title V agencies often mentioned incorporating the Six Core Elements into their Title V program – either as part of their care coordination program or, less often, as part of their specialty clinics. A few of the states described quality improvement grant efforts that involved working with community and school clinics, office-based practices, and hospital systems.

Innovative State Approaches: Transition Practice Improvements

- Alabama: Title V staff 1) will develop a transition policy, 2) maintain an EMR method for identifying transitioning YSHCN, ages 14-21, to track receipt of Six Core Elements, 3) conduct a transition readiness assessment at age 14 and discuss needed self-care skills in partnership with youth and developing goals, 4) identify adult providers to accept program clients, 5) complete a transfer package for young adults leaving and follow up, and 6) obtain feedback on the transition experience of young adults.
- District of Columbia: Title V funded Got Transition to customize and pilot the Six Core Elements in school-based health centers and develop a transition health education strategy to address needed self-care skills.
- Georgia: With the Department of Public Health, Title V is partnering with an Adult Disability Medical Home (ADMH) initiative to enhance transition services for youth and young adults with intellectual and developmental disabilities, using the Six Core Elements as a framework. Housed within a family physician practice, the ADMH has assembled a health care transition team, completed the “Current Assessment of Health Care Transition Activities” to establish a baseline, developed a transition policy statement, and solicited feedback from youth and caregivers about the transition process.
- Hawaii: Title V is implementing the Six Core Elements and has developed its own data collection form to assess progress on the degree to which Title V facilitates transition to adult health care for YSHCN.
- Rhode Island: Partnering with patient-centered medical home practices and pediatric practice enhancement projects, Title V plans to provide guidance and resources on developing a health care transition policy for YSHCN.
- Wisconsin: Title V has funded a series of pediatric/adult transition quality improvement grants and provides coaching support to promote evidence-informed transition practices aligned with the Six Core Elements. Title V also supports the Waisman Center to support and expand a HCT Learning Community involving physician champions to spread transition QI, including hosting quarterly webinars.

2. Health Care Professional Transition Education

Over three quarters of states (25 of the 32) are engaged in providing transition education to health professionals, up from 15 states in 2016. State Title V education efforts most often are directed to physicians and care coordinators, and to lesser extent to nurses, social workers, medical residents, and nursing students. Few states specified the content of their transition education, but presumably it included the AAP/AAFP/ACP Clinical Report and the Six Core Elements since the majority of these states cited these resources elsewhere in their block grant. States described webinars, grand rounds, lunch and learn sessions, and training seminars as examples of educational methods.

Innovative State Approaches: Health Care Provider Transition Education

- Arkansas: Title V is reaching out to pediatric primary and specialty physicians to share evidence-informed transition resources. In collaboration with tertiary care centers, LEND, and medical home groups, Title V staff are identifying new opportunities for training health professionals. In addition, Title V plans to offer training seminars on health care transition to school nurses and college health staff.
- Florida: Title V aims to increase transition education among its Title V care coordination staff as part of orientation and annual training. All care coordinators are required to complete the state's transition module.
- Indiana: Title V funds the Indiana University (IU) School of Medicine's Center for Youth and Adults with Conditions of Childhood to offer transition education to medical students, pediatric, internal medicine and medicine-pediatric residents and fellows, community primary care providers, and nursing, social work, and genetic counseling students. The Six Core Elements is introduced in all of the educational programs. Interdisciplinary trainees receive an introduction to transition as part of IU's transition clinic. In addition, medical trainees receive a 1- hour didactic session on transition of youth with childhood-onset diseases throughout the year. Transition mentorship opportunities are available for trainees interested in service learning or longitudinal scholarly research projects.
- Louisiana: In response to a Title V physician survey documenting the need for transition education, Title V is partnering with Louisiana State University Health Sciences Center to offer a webinar on transition to pediatric and medicine-pediatric residents. The state plans to expand its transition education to family practice medical residency programs. Title V has also partnered with its University Center for Excellence in Developmental Disabilities on web-based transition webinars. Youth Health Transition is one of four topics in the states' lunch and learn series, which is credentialed for social worker and nursing continuing education.
- Wisconsin: Title V funds its Regional Centers to conduct outreach to both pediatric and adult care practices/health systems to build provider awareness about evidence-informed transition strategies and resources, participation in QI efforts, and availability of adult referral sites.

3. Consumer Transition Training and Leadership

More than 80% of state Title V programs (27 of the 32) are involved in transition training or leadership initiatives involving consumer (youth and/or parents/caregivers), up from 21 states in 2016. Although parents/caregivers are most often the target audience for transition training, over half of the states are involving youth and young adults in their education efforts. Mostly states described general health care transition education efforts offered as workshops, webinars, annual conference, fairs, and peer training. Almost half of state Title V programs involve parents/caregivers and/or youth in leadership roles, assisting in transition planning, participating in advisory groups, or providing consumer feedback. Typically, health is just one of the transition topics discussed with youth and families. Other topics include self-advocacy, secondary and post-secondary education, supported decision-making and guardianship, and employment.

Innovative State Approaches: Consumer Transition Training and Leadership

- District of Columbia: Title V funded Got Transition to identify and train young adult and parent transition leaders to participate in community education and youth peer group education. Each of the consumer leadership groups received training on the Six Core Elements, a suggested transition timeline, as well as questions to talk with your doctor about to prepare for transition and (in the case of young adults) to integrate into adult care.
- North Dakota: Working with the ND Center for Persons with Disabilities at Minot State University, Title V supports the “Teens Entering Adult Medicine (TEAM) Project” to get youth involved in their transition quality improvement efforts. The TEAM project also provided input into a Health Snapshot Pocket Guide. This guide assists youth and young adults in gathering their medical information, including physician contacts, medications, appointments, and special communication needs.
- Rhode Island: Title V has a series of youth education and leadership efforts including the Healthy Lifestyles program, a 16-hour curriculum that promotes self-discovery, self-determination, health, and wellness. The state also sponsors the Dare to Dream conference for middle and high school students with an IEP or 504 Plan to explore transition to adult life, including talking with health care providers in transition planning and transfer from pediatric to adult medicine.

4. Transition Communications

Of the 32 states choosing transition as a NPM, well over half (19) have selected strategies dedicated to transition communication, up from 14 states in 2016. These communication activities include social media efforts and other information dissemination campaigns, such as transition fairs/conferences, presentations, interactive online portals and toolkits, targeted email messaging, listserv updates, and newsletters. Half of the states (16) mentioned updating their website with current transition resources and information. Many states have dedicated websites on health care transition, while others have sections or pages on their state’s department of health or Title V websites with transition-related content and links. Generally, these websites provide state-specific transition information, tips, events, important links (such as www.GotTransition.org), and other transition resources.

Innovative State Approaches: Transition Communications

- Several states host noteworthy, user-friendly, and interactive sites such as Florida (<http://www.floridahats.org/>), Iowa (<http://www.iowachildhealthconnections.com/>), Louisiana (<https://www.smoothmovesyht.org/>), and Wisconsin (<http://www.healthtransitionwi.org/>). In addition, Idaho, Montana, Nevada, New Mexico, Rhode Island, and Utah all utilize a Medical Home Portal (<https://www.medicalhomeportal.org/>), which is an online portal that includes a section dedicated to health care transition.
- Minnesota: With Family Voices of Minnesota, Title V is disseminating online transition tools for health care providers, families, youth and young adults. The health care provider tools include Six Core Elements sample tools and measurement resources as well as Got Transition tip sheets for starting a transition improvement project and coding and reimbursement. Title V has also prepared business cards with the site URL and QR code for distribution at conferences and meetings, through list-serves and newsletters. This web-based dissemination strategy allows for tracking the website hits.
- New Mexico: In collaboration with the Center for Development and Disability at the University of New Mexico Health Science Center, Title V developed an online training portal with Got Transition resources that covers topics relevant to the transition process and is accessible to medical providers (including those in rural and frontier areas). A curriculum committee composed of Title V staff, youth, families, Medicaid staff, medical providers and other experts developed training on topics, such as guardianship, New Mexico Medicaid waiver programs, family-centered care, post-secondary success, and specific childhood-onset diagnostic conditions (e.g., cerebral palsy).

5. Interagency Transition Planning

Health care transition is only one aspect, albeit an important aspect, of a youth's transition to adulthood. In every state, transition efforts are underway related to postsecondary education, career and employment, independent living, and other aspects of transition to adult life, particularly for special populations (e.g., youth in foster care, in juvenile justice). Almost two-thirds of state Title V programs (20 of 32) reported participating in interagency efforts, up from 13 states in 2016. Several states mentioned involvement in a statewide transition task force or workgroups. Numerous agencies or departments were cited in terms of transition collaboration, including education, developmental disability, rehabilitation, behavioral health, Medicaid, and Social Security Administration offices.

Innovative State Approaches: Interagency Transition Planning

- Illinois: Title V plans to partner with Medicaid's Early and Periodic, Screening, and Diagnosis (EPSDT) Program as well as with its state AAP chapter to educate and encourage pediatric providers to incorporate health care transition into routine adolescent well visits and to use a transition readiness assessment.

- Maryland: Title V participates in the Governor's Interagency Transition Council for Youth with Disabilities. This governor-appointed council includes representatives from the State Departments of Education, Health & Mental Hygiene, Human Resources, Juvenile Services, Labor, Licensing, & Regulation, MD's Commission on Disabilities, and Higher Education Commission. The Council reviews and updates a statewide interagency plan.
- Massachusetts: To keep families of transition-age youth with disabilities informed about Supplemental Security Income, including changes at age 18, Title V supports a public benefits specialist who provides training and consultation. This ensures important linkages not only with the Social Security Administration but also with Medicaid and Special Education.
- Minnesota: Title V is participating in a cross-agency effort to incorporate health assessments and health-related goals into the individualized education plan and annual plan processes. The state is piloting specific tools and practices as part of this transition planning effort.
- Rhode Island: Like many state Title V programs, Rhode Island's Title V participates on numerous statewide policy advisory committees pertaining to transition-aged youth, including ones sponsored by the Departments of Education, Behavioral Health, Developmental Disabilities, and Hospitals.

E. Measuring National and State Transition Performance

The 2016 National Survey of Children's Health (NSCH), which will be available later in 2017, contains a set of questions that provides a national and state snapshot of transition performance for all youth and for youth with special needs. The following transition questions are asked of parents whose youth are ages 12 through 17:

- Have your child's doctors or other health care providers talked with you about having this child eventually see doctors or other health care providers who treat adults?
- Have the child's doctors or other health care providers actively worked with this child to gain skills to manage his or her health (for example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he or she may need?)
- Have the child's doctors or other health care providers actively worked with this child to understand the changes in health care that happen at age 18? For example, by understanding changes in privacy, consent, access to information, or decision-making?
- At his or her last preventive check-up, did this child have a chance to speak with a doctor or other health care provider privately without you or another adult in the room?

State-specific transition composite scores from these four questions will be pre-populated into MCHB's reporting system, TVIS. In addition, the Child and Adolescent Health Measurement Initiative will make available these data for states to obtain more detailed information about NPM performance.

F. Evidence-Informed Transition Measures (ESMs)

To supplement this new national performance data, MCHB, AMCHP, Strengthen the Evidence Center at Johns Hopkins, and Got Transition held a series of webinars in 2016 and suggested the following transition ESMs. The majority of states (26 of 32) selected one or more of them.

1. *Increase the number or percentage of programs/practices/plans tracking improvements in levels of health care transition implementation related to transition planning, transfer, and integration into adult care.* Fourteen states mentioned measuring transition practice improvements, though few noted how they intended to measure this. Several states noted that they will assess whether their program or others have implemented a health care transition policy, use of transition readiness assessments, and/or a transition plan of care. Closely related to this measurement strategy, a few states also noted plans to track receipt of specific core elements among their Title V YSHCN, most often evidence of receipt of a transition plan.
2. *Increase the number of health care providers and consumers participating in health care transition quality improvement initiatives involving both pediatric and adult practices using the Six Core Elements of Health Care Transition.* A handful of states mentioned that they plan to track the number of participating health care providers and/or families.
3. *Increase the number of health care providers and consumers participating in health care transition education and training on evidence-informed health care transition strategies.* Eight states plan to use this measure as one of their ESMs, although states seldom highlighted what the transition training would entail.
4. *Partner with provider groups to encourage the use of transition readiness assessments within adolescent well visits.* Although DC and Rhode Island's Title V programs mentioned working with their Medicaid agencies and managed care organizations to encourage the use of transition readiness assessments, no specific measurement strategy was described.

CONCLUSIONS

The 32 states that selected health care transition as one of their national performance measures have made impressive gains since 2016 through the adoption of evidence-informed transition interventions. Numerous examples of best practices are underway, and new opportunities for sharing lessons learned have emerged. Many states are focusing their transition improvements within their own Title V care coordination and specialty clinic programs. Others have begun to reach out to a variety of health professional groups and training programs to encourage the adoption of evidence-informed transition approaches. They are also expanding collaborative efforts with state agencies involved in transition efforts to encourage greater attention to the health aspects of transition planning.

Acknowledgements

The authors acknowledge the thoughtful reviews from our Got Transition colleague, Dr. Patience White, our MCHB project officers, Dr. Marie Mann and Sarah Beth McClellan, and Got Transition's Cabinet Executive Team.



Got Transition™/Center for Health Care Transition Improvement is a program of the National Alliance to Advance Adolescent Health and is funded by cooperative agreement U39MC25729 HRSA/MCHB ("Transition Services in Adolescent Health - Healthy and Ready to Work"). The authors of this practice resource are solely responsible for its contents. No statement in this practice resource should be construed as the official position of the Maternal and Child Health Bureau. For more information about our work and available publications, contact our office at info@GotTransition.org. Also visit us on our website at www.GotTransition.org.

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