Health Care Transition in State Title V Programs: A Review of 2021 Block Grant Applications/ 2019 Annual Reports and Recommendations

August 2021

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INTRODUCTION

Every five years, state Title V Maternal and Child Health (MCH) Block Grant Programs conduct a comprehensive needs assessment to guide their state action plans. In 2020, health care transition (HCT) was identified as the most frequently selected priority need among state Title V programs. As many as 27 states reported HCT as a priority need, an increase from 22 in 2015.[1] Given the low proportion of receipt of transition preparation services among youth with (23%) and without (17%) special health care needs, it is exciting that many states have prioritized HCT efforts in recent years.[2]

HCT is one of the 15 national performance measures (NPMs) that address critical MCH priority areas. States must prioritize a minimum of five NPMs as part of their Five-Year State Action Plan. In the FY 2021 Applications/FY 2019 Annual Reports, a total of 37 states and jurisdictions, including the District of Columbia, Guam, the Northern Mariana Islands, the Marshall Islands, and Puerto Rico, selected NPM #12 on HCT as a priority.[3] Among these 37, eight are states that selected HCT for the first time in FY 2019, while seven states that previously prioritized HCT did not continue to do so.

This report summarizes the HCT strategies that Title V agencies documented in their 2021 Application/ 2019 Annual Report. It highlights examples of states' HCT innovations and offers recommendations for future HCT strategies in state Title V action plans. Previous reports summarizing state Title V HCT efforts were completed by Got Transition in 2016, 2017, and 2018.[4]

METHODS

Information for this report was obtained from the 2021 Application/2019 Annual Report from the 33 states, including the District of Columbia, that selected NPM #12. Since state Title V applications were submitted in 2020, this HCT report will use that year as the date for this information, also referred to as the "current year." State block grant applications/reports were obtained online from MCHB's Title V Information System.

Got Transition created an abstraction form to collect a consistent set of data from each states' description of current and planned HCT efforts. This form covered the following topics: reference to evidence-informed HCT strategies (AAP/AAFP/ACP HCT Clinical Report, Six Core Elements of Health Care Transition™, and National Standards for Systems of Care for CYSHCN); use and measurement of the Six Core Elements; selection of related NPMs and extent to which HCT was incorporated; and use of

transition strategies addressing more than 20 topics (Table 1). Four Got Transition staff members reviewed each block grant application/report and participated in weekly meetings to ensure consistency in reporting, identify innovative strategies, and consider possible technical assistance needs. After each meeting, a final abstraction form was completed. All results were entered by a single member of the team into an Excel spreadsheet. Comparison of findings from 2018 was possible because a similar abstraction form was used for that previous report.

TABLE 1. TRANSITION STRATEGIES FROM GOT TRANSITION'S ABSTRACTION FORM

Mention of transition strategies addressing/targeting:
Both pediatric and adult health care providers/practices
State chapters of the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), or American College of Physicians (ACP)
Racial and ethnic disparities, rural populations, and other underserved populations
Populations with and without special health care needs
Quality improvement methods
Health care professional education and training
Youth/young adult/family/caregiver engagement, education, and training
Youth/young adult/family/caregiver leadership development
Social media/communication
New materials/websites/resources
State interagency transition efforts
HCT payment options development
Managed care contract language around HCT
Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services including HCT
Care coordination program incorporates HCT
IEP/special education transition plans incorporate HCT
Collaboration with school health (college, high school)
Populations with mental health/behavioral health conditions
Populations with medically complex conditions
Populations with intellectual/developmental disabilities
Populations in foster care

The results of the analysis are limited by several factors. Because states self-report their activities in their block grant applications, planned HCT strategies for 2021 may not be implemented by states while any efforts not mentioned in the report could not be abstracted and analyzed. Because Got Transition only abstracted and analyzed states that selected NPM 12, those states that did not select that NPM as a priority but included HCT strategies under a different NPM or as a state performance measure were not included in this report. Guam, the Northern Mariana Islands, the Marshall Islands, and Puerto Rico also chose NPM #12, but their information is not included in this report.

2020 TRANSITION FINDINGS

A. *Evidence-Informed Transition Strategies*

Evidenced-informed[5] transition strategies include the AAP/AAFP/ACP Clinical Report,[6] Six Core Elements of Health Care Transition (Six Core Elements 3.0),[7] and National Standards for Systems of Care for CYSHCN.[8] The AAP/AAFP/ACP Clinical Report represents professional consensus on the timing and content of transition planning, transfer of care, and integration into adult care.[6] The Six Core Elements defines the basic components of a structured transition process, called for in the Clinical Report, with customizable sample tools. The National Standards for Systems of Care include a set of structure and process standards; their HCT standards are based on the Six Core Elements. Two-thirds of the 33 Title V states (21 states) cited one or more of these evidenced-informed transition strategies.

Reference to the Six Core Elements in general was mentioned by 24 states (73%). Certain core elements were mentioned more often than others. Transition policy was mentioned most often (by 14 states, or 42%), followed closely by transition readiness assessment (by 13 states, or 39%). Use of a transition registry, plan of care, transfer of care, and transfer completion were each referenced by 10 states (30%). In terms of measurement of the Six Core Elements, 7 states (21%) utilized Got Transition' Current Assessment of HCT, and 2 states (6%) mentioned use of Got Transition's HCT Process Measurement Tool. Five states (15%) evaluated their use of the Six Core Elements with consumer feedback surveys.

B. Transition Strategies and Examples of Innovation

The HCT strategies described by states are organized into six categories: youth and family education and leadership; health care provider education and outreach; care coordination and clinical improvement; addressing racially and ethnically diverse and underserved populations; interagency and school partnership; and financing and managed care. Below is a summary of findings of states' transition strategies and examples of state innovations. See Appendix for additional examples of state innovation.

Youth & Family Education and Leadership

- All 33 states described offering HCT education/training strategies with and for youth and families, often working closely with their Family Voices or Family-to-Family Health Information Centers, Title V parent staff/consultants, LEND programs, youth advocacy groups, and others.
- During the COVID-19 pandemic, most often states described virtual conferences/meetings and use of online resources covering a variety of topics, such as HCT timelines, self-advocacy, supported decision-making, changes that happen at age 18, and questions to ask your doctor about HCT.
- Almost three-fourths of all states (24) described strategies related to youth/young adult and/or family/caregiver leadership development. These included special training and mentoring opportunities, family or youth-led advisory groups, participation in HCT program and document reviews, and system-wide analysis of family engagement strategies often using Family Voices' tool.
- States that implemented youth and family leadership strategies consistently reported compensating them for their contributions.

State Innovations

- **KENTUCKY'S** Office for Children with Special Health Care Needs (OCSHCN) and Family-to-Family Health Information Center (F2F) held planning discussions with families and administered a Transition Readiness Assessment Checklist. The checklist documents what developmentally-appropriate skills have been achieved, are in progress, or are a part of future expectations. OCSHCN/F2F also attended over 160 meetings and provided information to youth transitioning to an adult provider and those aging out of OCSHCN programs via discussions, fact sheets, and guides. Topics included existing transition services, guardianship, transitioning from high school to college, medical homes, Medicaid, social security income, supported employment options, and vocational rehabilitation. This reached an estimated 5,700 individuals.
- **MASSACHUSETTS'** Community Support Line (CSL) offered HCT technical assistance and parent education on transition to caregivers calling in. The CSL developed a new assessment with specific questions about HCT, which helped resource specialists offer anticipatory guidance to caregivers. They also cover HCT in their community trainings. The Title V program is partnering with the Department of Elementary and Secondary Education, and other state agencies, to implement a Family Engagement Framework across the state's systems as well.

- **NEW HAMPSHIRE'S** Family Voices (NHFV) staff attended a Youth for Education, Advocacy and Healthcare Council meeting, which inspired youth to create a YouTube video regarding Medical Home/Transition to improve awareness and understanding of this process for youth themselves. Articles highlighting HCT were also featured in the NHFV newsletter, serving to improve parent/caregiver understanding of medical home and how its components make a true difference to youth and caregivers throughout the HCT process.

Health Care Provider Education and Outreach

- Almost all states (30) reported on strategies related to health care professional outreach and education.
- About half (17) of the states described strategies involving both pediatric and adult health care providers.
- A third (11) of states mentioned strategies involving their local AAP, AAFP or ACP chapters to disseminate evidence-informed HCT resources, including the 2018 Clinical Report on HCT and the Six Core Elements.
- In many states, health care professional efforts extended to physicians, nurse practitioners, social workers, other health professionals, and trainees via their regular meetings and conferences.
- A few states worked on creating transition training modules, building on the Six Core Elements, with other state-specific resources.

State Innovations

- **FLORIDA** worked with FloridaHATS on the public health detailing efforts to include promotion of the Six Core Elements to 453 community providers. The state is also working with Got Transition to update and create a uniform HCT education module, which will be an additional resource for health care providers.
- **GEORGIA'S** Children's Medical Services (CMS) care coordinators receive ongoing training, coaching, and monitoring to effectively work with families and youth/young adults with special health care needs. Coaching support is provided to ensure implementation of the policies and procedures. Continuing education is also offered on the Six Core Elements for medical and nursing students, pediatric and adult providers. Through continued partnerships with the Georgia Academy of Family Physicians and the Georgia Chapter of the AA P, the CMS program provided annual health care transition training opportunities to pediatricians, family physicians and pediatric nurse members.
- **THE DISTRICT OF COLUMBIA** supported The National Alliance to Advance Adolescent Health (NA) to partner with Health Services for Children with Special Needs, Inc. (a managed care organization in DC) to create a free, one-hour CME webcast, which included a presentation on the 2018 Clinical Report on HCT and the Six Core Elements. NA also created a new post-CME quiz, which included questions about the likelihood of implementing some of the transition learnings from the webcast. As part of ongoing work to educate health care professionals in DC training programs, NA developed a HCT slide set for ready use by DC area medical, nursing, social work, and public health training programs.

Care Coordination and Clinical Improvement

- About two thirds of states (22) described a range of HCT activities involving their care coordination programs. These included creating HCT training curricula, adding HCT provisions into care coordination policies and contracts, expanding connections to adult health care providers, and measuring that transition goals are part of care plans.

- Between 2017 and 2019, Got Transition conducted annual assessments of HCT Implementation in Title V Care Coordination Programs. This will be repeated in 2021. State Title V-related care coordination programs have been making ongoing progress in implementing evidence-informed HCT practices.
- Some states supported HCT learning communities, while others applied quality improvement (QI) methods when making HCT changes to their care coordination programs.
- Less than half of states (13) mentioned using QI methods to encourage the provision of HCT services in primary and specialty care practices.

State Innovations

- **NEW HAMPSHIRE'S** Bureau for Family Centered Services (BFCS) plans to prioritize educating staff to effectively evaluate completed and returned Transition Readiness Assessment Questionnaire (TRAQ) surveys to identify resources and education needed by youth and their families. In partnership with their Family Voices chapter, training will be provided to all BFCS Health Care and Family Support Coordinators to support the distribution, data collection, and the expectations for consultation related to TRAQ.
- **VIRGINIA** collaborated with several health systems across the state to provide comprehensive pediatric sickle cell services to families. The center located in the Hampton Roads region at Children's Hospital of the King's Daughters provided transition and social work services to patients 15-21 years of age. The Transition Coordinator conducted ongoing assessments for each patient and family to gauge their strengths/needs. All transition aged patients and their parents were provided data to create their individualized health care transition plan, which is documented in their charts. Data was collected via the Transition Coordinator Assessment during clinic appointments.
- **ILLINOIS** plans to provide care coordination on transition issues such as healthcare, education, work, and community independence as evidenced by assessment and appropriate goal development and increase by 5% the percentage of youth served by UIC-DSCC with documented transition assessments with appropriate goals developed, by 2025.

Racially and Ethnically Diverse and Underserved Populations

- Transitioning to adult health care is an important part of every young person's life, for those both with and without special health care needs. While NPM #12 specifically addresses YSHCN, a total of 11 states (33%) are addressing both populations as part of their Title V HCT efforts.
- Among all 33 states that chose to emphasize YSHCN, almost half (15) described in their plans to focus additional attention to HCT preparation supports on Black, Hispanic/Latinx, and Native Americans; rural populations; and other populations who have limited access to health care.
- Several states noted their HCT efforts emphasized cultural inclusion and translation services.
- More than a third of states (12) described HCT efforts that focused on youth and young adults with intellectual and developmental disability (IDD), followed by 10 states focusing on those with medical complexity; 6 states addressing mental/behavioral health conditions; and 6 states mentioning those in foster care.

State Innovations

- **ARIZONA** continues to work with their Leadership Education in Neurodevelopmental Disabilities (LEND) program following the completion of a survey to evaluate pediatric and adult practitioners using the Got Transition model and materials, as well as to determine the

impact of existing HCT policies. The state developed a HCT implementation program as a curriculum to assist providers without policies to incorporate transition into regular practice. Approximately 8 providers are currently enrolled with expected completion within 24 months, and recruitment for more providers is ongoing. Upon completion, providers will be able to apply for and obtain MOC Part 4 credit supported by the program.

- **GEORGIA'S** Autism Initiative developed materials and resources for health care providers to offer services aimed at helping young people with autism spectrum disorder adopt a more independent and empowered lifestyle as they transitioned into adulthood. In collaboration with the CMS program and Emory Autism Center, education was provided to educators, pediatricians, and family practice physicians on supporting young adults in transitioning to adult healthcare services through various training modalities (webinars, lectures presentations, and grand rounds for medical residents).
- **IOWA'S** Division of Child and Community Health (DCCH) investigated the needs of youth and their families from underrepresented backgrounds who are transitioning from pediatric to adult health care. DCCH compiled information from existing resources and data, along with conversations with primary care providers about the influence of race, ethnicity, geography, and diagnoses on the preparation for transition to adult health care. Findings showed disproportionate access to care and resources. Recommendations from this study included incorporating equity-based interventions in transition to adulthood and early education on transition to adulthood services for all CYSHCN and particularly for traditionally underserved populations.

Interagency and School Partnership

- Over half of states (20) reported participating in interagency efforts at the state or regional level. Several of these multi-agency efforts focus exclusively on HCT, while others have a broader focus with transition as part of a larger agenda. These groups typically include family/disability advocates along with representatives from Departments of Developmental Disabilities, Behavioral Health, Education, and Child Welfare, in addition to Title V.
- About half of state Title V programs (17) mentioned collaborating with schools around HCT. One of the most reported strategies was participating in annual transition conferences for students in special education.
- About a quarter of states (9) mentioned that they are working with their Department of Education (DOE) to advocate for HCT to be included as part of special education transition planning, including a few that mentioned participating in their state's Community of Practice on Transition.
- Several states described working with their school-based health centers (SBHC) to encourage the provision of transition services as part of routine preventive and primary care, customizing SBHC tools available on Got Transition's website.

State Innovations

- **MICHIGAN** continues to support HRSA's Children and Youth with Epilepsy grant partners to improve transition for youth with epilepsy in rural areas. The project provided training and education, community outreach, and user-friendly technologies to help clinic sites related to self-management, care coordination, and transition of adolescents to adult providers.
- **UTAH** worked with partner organizations that serve youth and young adults in transition. These include the Employment Partnership (Utah Office of Rehabilitation), Child Mental Health (Utah Department of Human Services), the Utah Children's Care Coordination Network and the Medical Home Portal (University of Utah Department of Pediatrics), the Utah Parent Center,

Utah Family Voices, the Utah State Board of Education, and the Coordinating Council for Persons with Disabilities. Collectively, these groups worked together on several committees that coordinate activities to prepare youth and young adults to transition to the adult world.

- **VERMONT'S** Children with Special Needs programs' engagement with regional Transition Teams has allowed for opportunity to grow necessary transition planning more holistically. Transition Teams have historically been education and employment focused, so the integration with CSHN has provided opportunity to bridge to other care and services within a youth's support network, most notably the Medical Home. There is now an annual statewide transition summit for each regional team to attend together for the purposes of learning and improvement, and youth engagement has been such a priority area that this year a Youth Summit specific to transition was planned and lead by and for transitioning youth.

Financing and Managed Care

- Advocating for financing improvements or managed care provisions for HCT was each mentioned by fewer than 20% of states (6).
- Examples of strategies included examining Medicaid fee schedules for HCT-related services to identify potential advocacy opportunities; partnering with Medicaid managed care organization to pilot value-based transition payment approaches; educating families about public benefits options; offering suggestions for improving Medicaid managed care contract provisions on HCT; and collaborating with Medicaid health home programs to assess their transitional care efforts.

State Innovations

- **FLORIDA** is working with The National Alliance to Advance Adolescent Health on a value-based payment pilot with the Children's Medical Services Managed Care Plan to plan a project related to exploring, developing, and implementing a small pilot focused on VBP to increase the percentage of members, ages 17 and older who transition from a pediatric provider to an adult care provider. Elements of this may include coordinated exchange of current medical information, plan of care, communication between pediatric and adult providers, and facilitated integration into adult care consistent with Got Transition's Six Core Elements.
- **MASSACHUSETTS'** SSI Public Benefits Training and Policy Specialist provided training and technical assistance to providers and families on public benefits to aid families of CYSHCN in financing their child's health care. Presentations were made to providers who work with older youth transitioning into the adult service system. Information included tips on changes in eligibility for SSI and MassHealth and steps to ensure retention of MassHealth after age 18. Individual technical assistance was provided by phone or emails. A brochure, *A Bridge to Adult Health Coverage and Financial Benefits*, was also distributed to families at trainings and phone consultations.
- **NEW YORK** provided subject matter and technical support to its state Medicaid program to implement and enhance care coordination and HCT support services for youth with special health care needs through the Medicaid Children's Health Homes (CHH). Title V participated in site visits to 12 CHH agencies to assess their planning for transitional youth.

TABLE 2. USE OF TRANSITION STRATEGIES

Mention of transition strategies involving, addressing, or targeting:	% States (# out of 33)
Both pediatric/adult health care providers/practices	52 (17)
State AAP, AAFP, or ACP chapters	33 (11)
Racial and ethnic disparities, rural populations, and other underserved populations	45 (15)
Populations with and without special health care needs	33 (11)
Quality improvement methods	39 (13)
Health care professional education and training	91 (30)
Youth/young adult/family/caregiver engagement, education, and training	100 (33)
Youth/young adult/family/caregiver leadership development	73 (24)
Social media/communication	42 (14)
New materials/websites/resources	67 (22)
State interagency transition efforts	61 (20)
HCT Payment options development	18 (6)
Managed care contract language around HCT	18 (6)
Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services including HCT	3 (1)
Care coordination program incorporates HCT	67 (22)
IEP/special education transition plans incorporate HCT	27 (9)
Collaboration with school health (college, high school, etc)	52 (17)
Populations with mental health/behavioral health conditions	18 (6)
Populations with medically complex conditions	30 (10)
Populations with intellectual/developmental disabilities	36 (12)
Populations in foster care	18 (6)

C. *Changes in Use of Evidence-Informed Transition Implementation, 2015 - 2020*

Table 3 summarizes the proportion of Title V states referencing the Six Core Elements (in general and with respect to specific core elements) from Got Transition analyses in 2016, 2017, 2018, and 2021. Between 2016 and 2021, almost three quarters of state Title V programs referenced using the Six Core Elements to guide their HCT strategies, which was an increase from less than half in 2016. Among individual core elements, the greatest changes were in reference to transition readiness assessments and transition policy.

TABLE 3. STATE TITLE V REFERENCE TO THE SIX CORE ELEMENTS OF HCT, 2016-2021

	2016 (n=32)	2017 (n=32)	2018 (n=33)	2021 (n=33)
General Reference to Six Core Elements	14 (44%)	21 (66%)	19 (58%)	24 (73%)
Transition Policy	6 (19%)	13 (41%)	17 (52%)	14 (42%)
Transition Registry/Tracking	6 (19%)	8 (25%)	7 (21%)	10 (30%)
Transition Readiness/Self-Care Assessment	4 (13%)	12 (38%)	18 (55%)	13 (39%)
Transition Plan of Care	6 (19%)	10 (31%)	19 (58%)	10 (30%)
Medical Summary	4 (13%)	4 (13%)	6 (18%)	6 (18%)
Transfer Checklist	1 (3%)	4 (13%)	6 (18%)	n/a
Transfer of Care	n/a	n/a	n/a	10 (30%)
Consumer Transition Feedback Survey	1 (3%)	1 (3%)	1 (3%)	5 (15%)

RECOMMENDATIONS

The following recommendations are offered to support state Title V's leadership role in advancing continued improvements in the provision of recommended HCT services for youth, young adults, and their families.

IMPLEMENT CURRENT EVIDENCE BASE

Utilize HCT Data to Inform Strategy Development
Data from the 2019 NSCH are now available. States can take advantage of these important data to make the case for needed HCT preparation services as well as to document HCT changes over time. States are also encouraged to create messaging around the components of this HCT measure, which include having time alone with a health care provider, discussing the transition to adult care, understanding changes in their health care as an adult, and HCT skill-building. A new article using NSCH data found that receipt of HCT preparation was positively associated with other components of a well-functioning system of care – family partnership in decision-making, medical home, early and continuous screening for special health care needs, continuous and adequate health insurance, and access to community-based services.

EXPAND PARTNERSHIPS

Build and Report on Interagency Partnerships
States are encouraged to continue to expand their reach to sister state agencies recognizing the lack of attention to health and to provide more details of their specific interagency/school/behavioral health/ foster care strategies.

Expand Partnerships with Adult-Serving Programs
State Title V agencies have an incredible network of child and family programs and leaders. States are encouraged to convene collaborative meetings, forums, and trainings with both child and adult health care providers and programs. Working with state Medicaid agencies and MCOs as partners in this pediatric-adult collaboration may also be a useful strategy.

Use School Health Transition Tools
States are encouraged to use and customize Got Transition tools for use with SBHCs, school mental health programs, and special education transition planning efforts. The SBHC tools include a welcome and care poster, a readiness assessment, and a resource on finding an adult doctor (add ref). The school mental health program tools include a transition readiness assessment for youth with mental health needs, a post-graduation wellness plan, and a resource on finding adult medical and mental health providers. The special education tools include a transition readiness assessment for students in special education and a corresponding IEP goal setting resource for special educators.

DISSEMINATE HCT EFFORTS

Share Innovative HCT Care Coordination Efforts
State Title V programs have adopted important advances in putting HCT into their care coordination initiatives and policies. They are encouraged to share their learnings, tools, measurement resources, and expertise to other care coordination efforts within their state – e.g., health home programs, waiver programs, chronic care management programs.

Document and Disseminate HCT Best Practices
State Title V agencies are supporting innovative HCT work, including quality improvement efforts, youth and family leadership development, health professional training, and new measurement

strategies. To increase the impact and knowledge of these efforts, states are encouraged not only to include details in future block grant applications/reports but to document them in reports, peer-reviewed journals, conferences, and webinars.

IMPLEMENT PRACTICE IMPROVEMENT

Promote Racial and Health Equity
Compounded by the effects of the COVID-19 pandemic, reductions in use of primary, chronic, and behavioral health care have been widespread among adolescents, particularly among communities of color in disadvantaged neighborhoods. State Title V agencies are encouraged to promote and prioritize transition-aged youth and families with disabilities from ethnic, racial, rural, low-income population groups to encourage them to return to care, virtually or in person.

Align HCT with Medical Home and Adolescent Well-Visit
States can continue to promote HCT as a routine part of medical home and adolescent preventive care, whether through their work with state AAP chapters, SBHCs, learning communities, youth and family-led education and advocacy efforts, or Medicaid or managed care partnerships. Such alignment of NPMs can further states' efforts at reaching youth without special health care needs.

GOT TRANSITION TOOLS AND RESOURCES

The updated Six Core Elements 3.0, Implementation Guides, and Measurement Tools on Got Transition's new website can help states meet their goals.

- In 2020, Got Transition updated the Six Core Elements and created new corresponding implementation guides that include tips to integrate the Six Core Elements using quality improvement methods, sample tools and resources customized for youth with specific conditions in different settings, and measures.
- New and updated measurement tools are also available, including a new HCT Feedback Survey for Clinicians, and updated feedback surveys for youth/youth adults and parents/caregivers.
- States can add these updated resources to their websites and utilize them in their education and improvement efforts with health professionals, training programs, and care coordination initiatives.
- A new webpage has also been designated for state Title V agencies with block grant and care coordination resources related to HCT.

CONCLUSIONS

State Title V agencies have made substantial improvements in their use of evidence-informed HCT strategies since 2016. The range of HCT strategies and innovative examples underscore state Title V agencies' critical public health role in this field. Continued partnership between Got Transition and state Title V agencies provides important shared learning and faster adoption of evidence-informed and promising practices.

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Appendix:
Additional Examples of State Innovation

Youth and Family Education and Leadership

- **Texas'** Parent to Parent (P2P) held their annual statewide parent conference with sessions on HCT that included Spanish translations. The Children with Special Health Care Needs Systems Development Group (CSHCN SDG) funded the P2P Peer to Peer Summit for teens and young adults with and without disabilities as well as P2P's Pathways to Adulthood workshops across the state, which featured all major transition topics.
- **Wisconsin's** Youth Health Transition Initiative offered their curriculum for transition-age youth and families, *Build Your Bridge,* to groups of school parents and one medical provider organization. Wisconsin's Family Voices conducted 15 "What's After High School?" trainings to groups such as Parenting Connections, Aiming for Acceptance, Navigating Autism Wisconsin, Autism Society of Fox Valley, a variety of high schools, the Wisconsin Statewide Parent-Educator Initiative, county human services and Aging and Disability Resource Centers (Regional Centers).

Health Care Provider Education & Outreach

- **Illinois'** Department of Public Health School Health Program hosted its annual School Health Days virtually for 2020. Discussions included sessions on transition care and adolescent health. Nearly 1300 school nurses across the state attended the sessions.
- **Kentucky's** Office for Children with Special Health Care Needs (OCSHCN) has identified adult HCPs in each of KY's 11 regions who are willing to take YSHCN into their practice. To assist with transition, they conduct preparation assurance activities, which include providing a portable medical summary.
- **Maryland** integrated Got Transition's Six Core Elements of HCT 3.0 in pediatric family medicine, internal medicine practices, specialty clinics, care coordination programs and utilized partnerships and funding to engage adult primary care physicians around HCT and support initiatives focused on increasing adult provider education.
- **Michigan** reviewed the FloridaHATS' and Got Transition training programs for physicians, nurse practitioners, physician assistants, nurses, social workers, and other health care providers. Michigan is in the process of establishing a marketing plan, partnering with the Michigan AAP, and promoting existing, established programs to improve provider understanding of health care transition.

Diverse & Special Populations

- **Oklahoma** provides families of youth with special health care needs with information and support to access and navigate ongoing, culturally effective, community-based, coordinated, comprehensive care which includes health care transition. They worked to develop a plan to increase HCT awareness among the CYSHCN population, to include addressing health disparities for CYSHCN, by 2022. Oklahoma Family Support 360° Center participated in Health Care Transition subcommittee meetings to give a voice to the underserved, low-income Hispanic population in the ongoing development phase of a transition toolkit for families and providers.
- **Oregon** plans to provide technical assistance and training on topics as they relate to transition planning and shared care plans. These include topics such as meaningful care for the LGBTQIA+, African American, and Latinx populations. The Family-to-Family Health Information Center plans to train Spanish-speaking families on HCT concepts. Oregon's CMC CoIIN team undertook a quality improvement project focused on transition from pediatric to adult primary care for young adults with medical complexity.

Interagency & School Partnership

- **Georgia** participated in the state's Interagency Transition Council. State agencies and leaders shared resources, collaborated, and created synergy surrounding transition work. Partner agencies included Department of Education, Vocational Rehabilitation, Legal Aid, Colleges and Georgia's Inclusive Postsecondary education programs, Independent Living, Department of Behavioral Health and Developmental Disabilities, Assistive Technology Centers, and the Marcus Autism Center.
- **Illinois** partnered with SBHCs and conducted a transition care needs assessment. Based on the information generated from the assessment, it was determined that centers would establish criteria and processes for identifying and tracking transitioning youth and young adult SBHC clients 14 years of age and older. In addition, SBHCs will conduct regular transition readiness assessments beginning at age 14 to identify and discuss with youth their needs and goals in self-care.
- **Minnesota, Texas, and Wisconsin** have conducted presentations on the inclusion of health as part of the Individual Education Plan (IEP) and is working with Got Transition and other state Title V programs on expanding HCT efforts in special education.
- **North Dakota's** Division of Special Health Services (SHS) participated in the North Dakota Interagency Task Force on Transition where key partners shared opportunities to collaborate and provided education and feedback to stakeholders. SHS staff were also actively engaged in the North Dakota Department of Public Instruction Transition Community of Practice, which provided opportunities for collaboration with school personnel, vocational rehabilitation, developmental disabilities program managers, State Council on Developmental Disabilities, and many others working with transition-aged youth. In addition, SHS staff provided technical assistance to contract grantees to aid in the transition assessment and education process.
- **The District of Columbia** supported The National Alliance to Advance Adolescent Health to customize Got Transition's readiness assessment for special education settings. The customized readiness assessment has a corresponding goal setting resource for special educators to use in the IEP transition plans.

Financing & Managed Care

- **The District of Columbia** supported The National Alliance to Advance Adolescent Health (NA) to develop the report*, Medicaid Opportunities for Supporting Innovations in Transition from Pediatric to Adult Care for DC Youth and Young Adults*. This report included HCT policy recommendations for population health, managed care, Medicaid fee schedule, EPSDT, and health homes.
- **Illinois** plans to partner with its state Medicaid agency, Medicaid Managed Care organizations, Medicaid waiver operation programs, and/or private insurance providers to provide education and recommendations on practices pertaining to preparation for transition to adulthood.
- **New Hampshire's** Children and Youth with Special Health Care Need's Director and Clinical Program Manager worked with Medicaid on projects related to managed care contract oversight, quality improvement, and evaluation in order to assure access to and continuity of care.

ACKNOWLEDGMENTS

The authors acknowledge the thoughtful reviews from our MCHB project officer and advisor, Sarah Beth McLellan.

This project (U1TMC31756) was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government. 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.