Health care transition from pediatric to adult care is one of the federal Maternal and Child Health Bureau’s (MCHB) new national performance objectives. Specifically, this objective calls for states to increase the percentage of adolescents with and without special health care needs who receive services necessary to make transitions to adult health care.

Nationally, the vast majority of youth and young adults and their families are not receiving health care transition supports despite professional recommendations calling for transition preparation to begin early in adolescence and continue into young adulthood. According to the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP), all youth, particularly those with special needs, should receive health care transition services as part of routine primary and specialty care to enable them “to optimize their ability to assume adult roles and activities and to ensure that health care services are available in an uninterrupted manner.”

Since the 2011 release of these professional recommendations, a new transition model—the Six Core Elements of Health Care Transition—has been developed and tested in various clinical and health plan settings. The Six Core Elements define the basic components of health care transition support with sample tools and measurement resources. The Clinical Report and the Six Core Elements, which are incorporated in the National Standards for Systems of Care for Children with Special Needs, represent the evidence base for MCHB’s transition performance measure.

This report summarizes state Title V transition objectives and strategies included in their Title V State Action Plans for Fiscal Year 2016 and submitted in July 2015. It also contains suggestions for states to consider as they refine and update their transition objectives and evidence-informed strategies as part of their state action plans.
States’ Selection of National Transition Performance Measure

A total of 32 states, including the District of Columbia, selected transition as a priority for their Five-Year Action Plan, as shown below by HHS regions.

Region 1: CT, MA, RI
Region 2: NJ, NY (also PR, VI)
Region 3: DC, MD, VA
Region 4: AL, FL, GA, KY, TN
Region 5: IL, IN, MI, MN, WI
Region 6: AR, LA, NM, OK, TX
Region 7: IA
Region 8: MT, ND, UT, WY
Region 9: AZ, CA, HI (also Federated States of Micronesia, Guam, and Marshall Islands)
Region 10: OR

States’ Transition Objectives

Almost half of the 32 states (15 states/47%) specified their transition objective in terms of an increase in the number or percentage who receive services necessary to transition to adult care. Some states referenced a baseline percentage from the 2009/10 National Survey of CSHCN; a few cited the upcoming National Survey of Children’s Health (NSCH); and still a few others referenced their own state survey. The extent of projected transition improvement varied (from 1% to 10%) and was often not specified; instead, improvement was stated as an increase by 2020.

Overall, eight of the 32 states (25%) included both youth with and without special health needs in their transition performance objective, while 24 (75%) focused on youth with special health care needs (YSCHN). The number of transition objectives selected by each state varied considerably -- from one to seven, though most states selected three or four objectives. Several states articulated their transition objectives in terms of increasing the proportion of youth/families or providers who accomplish specific transition activities -- e.g., % of practices with a written transition policy, % who have a transition readiness assessment and comprehensive plan of care, % of care coordinators who receive transition education). Despite the fact that states often use objectives that are specific, measurable, and include a time-frame, the distinction between objectives and strategies is not always obvious.

States’ Transition Strategies

➢ Evidence-Informed Strategies

Almost half of the 32 states (14/44%) referenced the Six Core Elements, Got Transition, or AMCHP’s National System Standards. In addition, four states mentioned at least one of the core elements as a strategy (e.g., transition policy, readiness assessment, plan of care) without reference to their source. Table 1 shows how many states incorporated specific pediatric and adult transition core elements. No state mentioned encouraging adult practices to develop welcome letters or frequently
Transition Core Elements | # of states (%)
--- | ---
Transition Policy | 6 (19%)  
Transition Registry/Tracking | 6 (19%)  
Transition Readiness/Self-Care Assessment | 4 (13%)  
Transition Plan of Care | 6 (19%)  
Medical Summary/Emergency Care Plan | 4 (13%)  
Transfer Checklist | 1 (3%)  
Consumer Transition Feedback | 1 (3%)  
Welcome Letter/FAQs on Adult Practice | 0 (0%)

Less than half of the 32 states (13/40%) mentioned adult providers in their transition strategies -- most often to build an expanded network of adult providers or to educate medical students, residents, or adult health care providers, described in greater detail below. Four states included quality improvement strategies to implement their transition objectives. Below is a brief summary of the transition strategies selected by the 32 states.

➢ **Health Professional Education and Training Strategies**

Health professional education and training was identified by almost half of the 32 states (15/47%) as a transition strategy. Oftentimes states mentioned identifying or developing transition curriculum for their Title V staff and contracted specialty care centers/providers. Less often states called for providing transition education and training to pediatric practices, medical school students, or pediatric and family medicine residents. A few states mentioned partnering with their AAP chapter, state medical society, or primary care association. No state described an Interprofessional transition training strategy or one involving behavioral health professionals.

➢ **Consumer Education/Training and Involvement Strategies**

Transition education and involvement of youth, young adults, and parents/caregivers were mentioned by two thirds of the 32 states (21/66%). Most often these strategies were quite general – eg, “support transition training for families” or “plan an education campaign for YSHCN and families.” Half of the 32 states mentioned either family or youth involvement and feedback in their transition strategies. Although states were more apt to emphasize parent or family rather than youth or young adult education and engagement, a total of 13 states (40%) mentioned youth or young adult consumers. One state, for example, called for recruiting young adults to fill leadership positions in state and local organizations and transition programs; another state mentioned engaging young adults in online and social media campaigns.
Development and Dissemination of Transition Materials and Communication Strategies

Fourteen states (44%) listed the development, updating, and/or dissemination of transition materials among their strategies. Several states mentioned conducting an environmental scan of existing transition materials and approaches, and several also discussed developing or updating a community transition resource guide. A handful of states mentioned creating new educational materials or transition toolkits. A variety of communication strategies were mentioned, most often directed at social media and updating websites, and, to a lesser extent, at live events such as health fairs.

State Leadership Development and Interagency Planning Strategies

Ten states (31%) described a state health care transition work group or a state plan for transition in their list of strategies. State interagency transition planning was also mentioned in 13 states (41%) -- most often related to special education and the IEP process, and, to a lesser extent, related to developmental disability programs, employment, or Medicaid.

Suggestions for Refining and Updating State Title V Transition Objectives and Strategies

1. Transition Population. Transition is identified under the CSHCN population domain and, as such, states can start with this important population group. In the future, states might want to consider expanding their transition objectives to include both youth with and without special health care needs.

2. Transition Objectives. Recognizing that the National Survey of Children’s Health transition questions are changing and may show different results than the previous transition results from the National Survey of Children with Special Health Care Needs, states may want to consider articulating their transition objective as follows:

   ✓ Establish a baseline on state transition performance based on upcoming estimates from the 2015/16 National Survey of Children’s Health.

In addition, states may want to articulate one or more transition objectives that link to the Clinical Report and the Six Core Elements. The following are examples that could be considered.

   ✓ By 2020, increase the number of Title V contracted providers (or medical home providers or specialty care clinics) who are implementing the Six Core Elements of Health Care Transition.
   ✓ By 2020, expand the number of education and training opportunities for pediatric and adult health care providers and trainees on the use of evidence-informed transition recommendations from the AAP/AAFP/ACP Clinical Report on Transition and the Six Core Elements of Health Care Transition.
   ✓ By 2020, increase the identification, availability, and linkage of adult health care providers to pediatric medical home and specialty care practices.

3. Transition Strategies
Depending on the objectives selected, several of the following transition strategies can be considered.

- Establish a baseline of Title V contracted providers (or medical home providers or specialty clinics or health plans) regarding their current level of transition implementation using the Six Core Elements’ measurement tools.
- Identify and implement strategies that expand the availability of adult providers accepting new young adult patients with special needs, including those with intellectual/developmental disabilities, complex medical conditions, and mental health conditions.
- Partner with state chapters of the American Academy of Family Physicians, the American College of Physicians, and the American Association of Nurse Practitioners to promote the use of evidence-informed transition services.
- Partner with state Title V grantees and American Academy of Pediatrics’ chapters to promote the use of evidence-informed transition services.
- Increase the number of transition quality improvement initiatives using the Six Core Elements with involvement from both pediatric and adult practices and parent and young adult consumer partners.
- Increase the number of Title V recipients who report that they have been informed of Title V’s transition policy; who have received a transition readiness assessment, a written plan of care that incorporates transition, a medical summary and emergency care plan; and who have received assistance identifying an adult provider.
- Partner with state Medicaid agency to develop managed care contract requirements for health care transition and to secure payment for transition services.
- Increase the availability of health care transition information and resources, including linking with national health care transition resources at Got Transition’s website, www.GotTransition.org.
- Integrate strategies linking transition to medical home, adolescent preventive care, well care for women, and adequate health insurance.

Conclusion

This is a critically important period to adopt evidence-informed transition objectives and strategies within Title V programs and among pediatric and adult primary and specialty care providers, health plans and payers, medical societies and health professional training programs, and consumer and disability organizations. This report is intended to offer states specific suggestions for refining and updating their transition efforts and linking with the national resource center, Got Transition, and its Six Core Elements of Health Care Transition.

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References

3 The Six Core Elements of Health Care Transition is available at www.gottransition.org.