
Transition Issues for Youth with Special Health Care Needs in Massachusetts

Summary of Findings and Recommendations



*Prepared for the
Massachusetts Consortium
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Transition Issues for Youth with Special Health Care Needs in

Massachusetts was prepared as a background brief for the Massachusetts Consortium for Children with Special Health Care Needs. The full brief presents an overview of transition resources and challenges for youth with special health care needs in the Commonwealth of Massachusetts, and is available online at www.neserve.org/maconsortium. The brief's findings and recommendations have been reprinted here.

The Consortium is committed to promoting and realizing the Healthy People 2010 national objectives of building a more responsive and family centered system of care. These objectives include one specifically focused on transition: *All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.* (A 10-year Action Plan to Achieve Community-based Service Systems for Children & Youth with Special Health Care Needs and Their Families, U.S. Dept. of Health & Human Services, 2001).

National 2010 Objective

All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

Summary of Findings

The findings and recommendations presented below have been developed over the course of more than a year and derive from a number of sources and findings, beyond those cited in this brief. These include:

- An exhaustive review of web-based resources, project reports and published resources (local, state and national).
- Conversations with family members and other specialists from a variety of fields (health care, disability and special education among others).
- Discussion among the members of the Transition Task Force (see Appendix B for a list of Task Force members). This Task Force was formed for the express purpose of evaluating the state of transition services in Massachusetts, preparing this brief and making recommendations to the Massachusetts Consortium for Children with Special Health Care Needs related to transition activities.

The Transition Task Force's conclusions are as follows:

- “Transition Services” is itself a **confusing** term. The term implies a large, complex set of activities and planning. It also means different things to different people at different times. Because “Transition Services” for a young adult with special health care needs is *not* a concrete set of activities and because there is no single system (e.g., health, education, social services) responsible for addressing transition needs, approaches for optimizing transition to adulthood remain elusive and confusing.
- The existing **state service systems** which support adults with special health care needs tend to serve those who have **more involved** conditions and more constant support needs. Young adults who require fewer or periodic supports to maximize their autonomy are much less likely to receive state agency supports.
- Where there are transition-related initiatives, they are sporadic, fragmented and, for the most part, driven by temporary funding. The changing priorities of state and federal funding **challenge the sustainability** of programs whatever their findings and outcomes.
- Families find planning and preparing for their child’s adulthood **overwhelming and often unsupported**. Families’ limited knowledge of “next steps” is compounded by the reality of the limited availability of services for their adult children.
- Transition planning should be as **varied and unique** as the individuals themselves. There is no one “recipe” for preparing for adulthood.
- Transition is very **different for each child** depending on his/her level of physical, cognitive and/or medical and mental health issues. Achieving successful transition is more challenging for young adults with more complex conditions.
- Federal education laws require public schools to work with young adults and families around transition planning. **Even with the impetus of federal law** and with transition training programs for families, too many youth with special health care needs who are entitled do not receive the help needed to prepare for successful transition.
- Although they are not well versed about inclusive education or transition, **primary care providers are a constant, respected and important influence** in the life of children with special health care needs and their families. The medical universe offers opportunities for making positive interventions in transition planning.
- Care coordinators are one set of providers who interface frequently with CSHCN and their families. Since **good care coordination should include attention to transition issues**, there is a need to enhance the knowledge and skills about transition planning and resources of those who work as care coordinators.

What Can the Massachusetts Consortium for Children with Special Health Care Needs do to Support Transition for Youth with Special Health Care Needs?

The Transition Task Force recommends that the Consortium focus its efforts to improve transition services by strengthening the capacity of existing care coordination services in this area. The Consortium should seek funding to develop and deliver a curriculum and training for care coordinators and case managers who are in contact with families across multiple systems of care. Training materials should include: timelines, mandates and entitlements of the transition planning process and a comprehensive review of the resources available. Training would seek to involve care coordinators from a variety of settings: hospitals, doctors' offices, state agencies, health plans, Medicaid, and MASSTART (Massachusetts Technology Assistance Resource Team). The specific features of the training initiative would include:

- A "Transition 101" workshop, which will help care coordinators find what they need and focus on the uniqueness of each individual's planning process. The curriculum should emphasize personalized planning for individual youth and highlight the importance of partnering with schools, family organizations, state agencies and others to ensure prompt follow-up on action items in a transition plan.
- A conference for parents, care coordinators and others to network and learn about approaches and resources for transition planning and post-school opportunities
- Piloting, demonstration and evaluation of the effectiveness of such a training program.