



# Transition-age youth with special health care needs

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# What is transition?

*“Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in post secondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult agency services and natural supports within the community.”* - from the MA Governor’s Commission on Developmental Services 2007

*“Health care transition is the process of changing from a pediatric to an adult model of health care. The goals of health care transition are to improve the ability of youth and young adults to manage their own health care and effectively use health services, and to ensure an organized clinical process in pediatric and adult practices to facilitate transition preparation, transfer of care, and integration into adult-centered care.”* - from Got Transition, a program of The National Alliance to Advance Adolescent Health

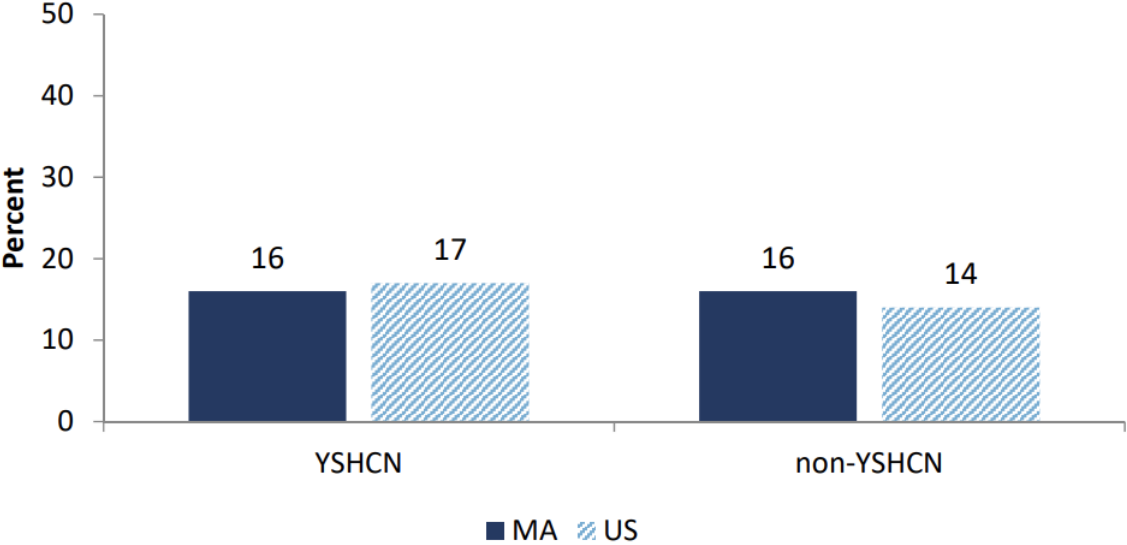


# Definition of the population of focus

- Adolescents and young adults between the ages of 14 and 26 with special needs, including intellectual disability, physical disability, a mental health condition, or other developmental disorder.
- Individuals with disabilities span all languages, socioeconomic status, and cultures:
  - The National Survey of Children with Special Health Care Needs 2009-2010 indicated that in Massachusetts:
    - ~18% of children (0-17 years old) have a special health care need
    - 28% of parents reported stopping work or reducing hours to care for their child
    - 25% of families had incomes below 200% of the federal poverty level
  - Income and savings impacts the eligibility for services, especially in the adult population, including:
    - MassHealth Benefits
    - Supplemental Security Income
  - Communication in this population can be diverse including individuals who are:
    - Non-verbal with little ability communicate
    - Communicate through American Sign Language or tactile sign language



### Percentage of Massachusetts Children Who Received Services Necessary to Make Transitions to Adult Health Care, By Special Health Care Need Status, 2016



SOURCE: NATIONAL SURVEY OF CHILDREN'S HEALTH



# Exploration of interprofessional teams

As a provider, there are many allied professionals that can assist in the transition process:

- Licensed Social workers
- State agency case managers
  - Department of Developmental Services, Department of Public Health, Massachusetts Rehabilitation Commission
- Special education teachers and specialists
- Applied Behavior Analysts
- Other health professionals
  - Occupational Therapy, Physical Therapy, Speech and Language Pathology, etc.

However, important to integrate team to collaborate for an effective transition!



# Population health advocacy

- Table of agencies, purpose, target population
- How to get involved?
  - As primary care or pediatric providers, understand challenges of transition and help families through the process by getting acquainted with local, state, and federal resources
  - Legislative Action
    - Easter Seals Legislative Action Network
    - Citizens' Advisory Board (appointed by DDS Commissioner)- meetings open to public
  - Otherwise, volunteer!
    - Easter Seals
    - Seven Hills
    - JRI
    - Many more



# Transition Timeline\*

## Things to consider throughout...

- Get accustomed to doctor's visits alone
- Medication/diagnosis awareness
- How to make doctor's appointments
- Emergency preparedness
- Provider conducts transition readiness assessments

12-14: Patient and family aware of transition policy; IEP stating transition services needed, student invited to/participates in IEP;

16: Prepare patient for adult model of care; Annual goals, post-school outcomes in IEP (college vs. vocation vs. other)

17: Guardianship planning; Vocational training two years prior to graduation

18-26: Transfer to adult care/specialists; Apply for Social Security Benefits, Medicaid, Disability Insurance; can apply for government subsidized housing

Name of Resource	Type <i>(state agency, non-profit, day programs)</i>	Population served	Info/What they do	Contact
<b>Department of Developmental Services (DDS)</b>	State Agency	Children's services under 22 years Adult services <b>at age 22 or older</b> Individuals with significant limitations in adaptive functioning with at least one diagnosis of intellectual disability, ASD, Prader-Willi syndrome, Smith-Magenis syndrome	Children should have referral completed by school starting at 14 years of age Application for eligibility for adult services should be done around 18 years of age Services include: <b>individual transition plans</b> (which acts as a continuation of IEPs, does not guarantee services), family support centers (trainings, networking, case management), residential services, day habilitation, employment services	Kathe Coll, (Transition Services Coordinator) 774-314-3394 kathe.coll@state.ma.us  Becky Gow (Health Services Coordinator) 774-314-3390 rebecca.gow@state.ma.us
<b>Department of Public Health, Division for Children &amp; Youth with Special Health Needs</b>	State Agency	Children and youth with special health needs as defined by the Maternal and Child Health Bureau: "those who have increased risk for a chronic physical, developmental, behavioral, or emotional condition and also require health and related services of a type or amount beyond that required by children generally."	Many programs offered that fall into the categories: Direct Services (ex. MassCare), Enabling Services (ex. Hearing Aid Fund, Catastrophic Illness Fund), Population Health Services (ex. Family TIES, Public Benefits Trainings), Infrastructure Development (ex. Policy Development, Quality Improvement)	Elaine M. Gabovitch, MPA 250 Washington Street Boston, MA 02108 Elaine.Gabovitch@state.MA.US
<b>Massachusetts Rehabilitation Commission</b>	State Agency	All ages wide range of disabilities (physical, emotional difficulties, learning difficulties, substance abuse)	3 divisions: Vocational rehabilitation (14+), Disability determination services, Community Living; need referral by self (if 18+), human service agency (i.e DDS), or Chapter 688 referral by school	Jennifer Stewart (Transition Coordinator, Boston office) <a href="mailto:Jennifer.stewart@massmail.state.ma.us">Jennifer.stewart@massmail.state.ma.us</a>



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<b>Assabet Valley Collaborative - Evolution</b>	State Education Collaborative - Transition Program	Adolescents between the ages of 18 and 22 who have not yet received their high school diploma and are eligible for transition; eligibility is determined by IEP, needs assessments (OT, PT, etc.), and last two progress reports.	Evolution is a school-based transition program that blends education and vocational training to prepare students with disabilities to succeed after high school; services include job coaching, community-based work experiences, travel training, and person-centered planning.	Karen Lasky, Director of Satellite Programs Mary Sharma, Evolution Coordinator 64 Holden Street Shrewsbury, MA 01545 Phone: 508-841-1562 Fax: 508-841-8753
<b>Justice Resource Institute (JRI)</b>	Day Habilitation Program  Community Based Day Supports; Vocational Education	Adults (22+) or high school graduates over the age of 18  Adults (22+) or high school graduates over the age of 18	-More severe/medical based and a day habilitation program -Work programs -Supports a number of small groups in the community to complete volunteer work, paid work experiences and to prepare for competitive employment Examples include: Meals on Wheels, Full Circle Arts	Louise Jeffy Director of Day Habilitation Services 1671 Worcester Rd, Suite 100, Framingham, MA 01701 Office: (508) 872-0669 x2207 Fax: (508) 879-4140 Email: ljeffy@jri.org
<b>Horace Mann Educational Associates (HMEA)</b>	Day Habilitation Program  Community Based Day Supports; Vocational Education	Adults (22+) or high school graduates over the age of 18  Adults (22+) or high school graduates over the age of 18	-Day habilitation program -Specialized for behavioral needs (especially Autism), uses the ABA model -Supports a number of small groups in the community to complete volunteer work, paid work experiences and to prepare for competitive employment Examples include: Meals on Wheels, Panera Bread, Grocery Stores	Heather O'Reilly Program Supervisor, Millbury Day Habilitation 6 Latti Farm Road Millbury, MA 01527 508-298-1708 Office: (508)-865-0568 Fax: (508)-520-6082

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<b>HMEA - Autism Resource Center</b>	Non-profit	Membership is free to people who live within the DDS service area or bordering town and have a child with a diagnosis of autism spectrum disorder	DDS-funded program, administered by HMEA to offer family activities, workshops and trainings, support groups, community outreach, and online resources to support children and adults with autism and their families.	Sue Loring RN 712 Plantation Street Worcester, MA 01605 Phone: 508-835-4278 Fax: 508-835-3723
<b>Seven Hills</b>	Non-profit	All Ages	Offers services for children and adults with physical, emotional, developmental, social and other life challenges. "Through school-based services, supported employment, mental health and substance abuse counseling, child care resources, HIV/AIDS services, advocacy, residential and family services, individuals can work toward living more autonomously and participating more fully in their lives"	Ana Morales <i>Senior Family Support Specialist</i> amorales@sevenhills.org 81 Hope Avenue, Worcester, MA 01603 <b>Phone:</b> 508.755.2340 <b>Fax:</b> 508.849.3882 <b>Tty:</b> 508.890.5584
<b>Easter Seals</b>	Non-profit	Children and adults with physical/ mental disabilities and special needs, as well as support to their families  Closely partnered with Massachusetts Rehab Commission	Assistive Technology College Navigator Program Transition Assessment, Coaching, & Training Intern Training Program <i>(must be MRC-referred)</i> Autism Spectrum Disorder Services Employment and Training Medical Rehabilitation Camping and Recreation	484 Main Street Worcester, MA 01608 800-244-2756 <a href="mailto:transition@eastersealsma.org">transition@eastersealsma.org</a>  MaryEllen MacRae Director of Transition & Employment Services MMacRae@eastersealsma.org

# Acknowledgements



Dr. Beverly Nazarian, MD, Pediatrics  
Dr. Amy Lo, MD, Med/Peds





# References

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