TRANSITION TO ADULT CARE FOR MEDICALLY COMPLEX YOUTH & YOUNG ADULTS

The Public Health Perspective

The Arc of Massachusetts 2019 Transition Conference

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Agenda

1. What do we know about youth with special health needs as well as medical complexity in Massachusetts?

2. What are some tools to help manage the transition to adult health care?

3. What DPH programs can assist with Health Care Transition?
Who are Youth with Special Health Care Needs?

The Maternal and Child Health Bureau defines children & youth with special health care needs (CYSHCN) as:

“those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

Who are Youth with Medical Complexity?


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Cohesive concept map indicating the various dimensions associated with youth with medical complexity (YMC). The map highlights the areas of needs, chronic condition(s), functional limitations, and health care use as interconnected factors.
What does DPH mean by Health Care Transition?

• The process of moving from the pediatric to the adult health care system
• Learning self-care & self-management of one’s own health and health-related needs as far as is developmentally possible
How many youth are we talking about?

- ~461,657 youth in MA (ages 12-17)\(^1\)
- ~99,323 have special health needs (YSHN) \(^1\)
  - 1-3% YSHN have medical complexity (~993 to 2,979)\(^2\)
- Many more when ages 18-26 included

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Why is health care transition important?

- All youth must transition from pediatric to adult-centered medical care
- Process especially difficult for youth with special health needs:
  - May not receive age-appropriate medical care
  - May be at risk during this vulnerable time
- Barriers may prevent effective transition
- Protocols have been developed to improve the process
- Health care transition influenced by provider education, but gaps in medical education
- No consistent measures of what constitutes transition success

What are some known concerns with transition?

Transition to adult health care may not be happening in a timely manner due to the following barriers:

• Parental/child attachment to the pediatrician and a hesitancy to transition to adult health care

• Lack of adult health care providers with experience or training in transition and disability

• Lack of sufficient mechanisms for adult providers to adequately bill for longer medical appointments often needed by adults with disabilities

• Lack of adult providers trained in mental health needs

How many received services necessary for health care transition?

- **30.5%** received services necessary to make transitions to adult health care.
  - **U.S. = 18.9%**
- **69.5%** did not.
  - **U.S. = 81% did not**

*Survey*: 2017-2018 National Survey of Children's Health
*Starting Point*: Title V Maternal and Child Health Services Block Grant Measures
*State/Region*: Massachusetts vs. Nationwide (quick edit)
*Topic*: National Performance Measures
*Question*: NPM 12: Transition to adult health care, CSHCN age 12-17 years
How many spent time alone with their health care provider?

- 60% of YSHN spent time alone with health care provider.
  - U.S. = 47%
- 60% of non-YSHN did too.
  - U.S. = 34%

Survey: 2017-2018 National Survey of Children's Health
Starting Point: Child and Family Health Measures
State/Region: Massachusetts vs. Nationwide (quick edit)
Topic: Health Care Access and Quality
Question: Transition Part A: Time alone with health care provider
Sub Group: Had time alone with provider x Special health care needs status
How many understand health care changes at age 18?

- **80%** of YSHN understand health care changes at 18.
- **67%** of non-YSHN did too.
How many report providers discussed shift to adult care providers?

- Only 26% of YSHN discussed the shift.
- Only 22% of non-YSHN did too.
What are some tools to help manage the transition to adult health care?
Charting the Life Course Framework
Re: Health Care Transition
Healthy living is an often overlooked, yet very important part of transition to adulthood. Steps you can take now will help your youth become more knowledgeable about their health, medical needs and disability, and start to take control of making decisions and choices about their own health. It is also time to think about who will provide health care once they are an adult.

- Do you understand and talk about your disability and special health care needs with others?
- What steps are you taking to begin to take control of your own health care?
- How do you find adult health providers who will understand your disability and special healthcare needs?
- Are you learning about the importance of healthy eating and regular exercise?
- Do you understand the changes in your body and your reproductive health?
- Can some of my therapies be replaced with regular physical activities such as working out in a gym, using a treadmill or elliptical, or doing aerobics?
Got Transition: Six Elements of Health Care Transition

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<th>Got Transition™ Six Core Elements of Health Care Transition</th>
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<td><strong>1.</strong> Transition Policy</td>
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<td><strong>2.</strong> Transition Tracking &amp; Monitoring</td>
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<td><strong>5.</strong> Transfer of Care</td>
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<td><strong>6.</strong> Transfer Completion</td>
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What DPH programs can assist with Health Care Transition?
MA Title V CYSHN Program: An array & continuum of linked services

- 1-800 Community Support Line
- Care Coordination
- Catastrophic Illness in Children Relief Fund
- Family Initiatives
- Family TIES of Massachusetts*
- Hearing Aid Program
- Pediatric Palliative Care Network

- MassCARE (Ryan White HIV/AIDS Program Part D)
- MASSTART
- Medical Review Team
- Public Benefits Training & TA
- Universal Newborn Hearing Screening

*DPH-funded program of the Federation for Children with Special Needs
Community Support Line

Statewide toll-free resource line for families with children and youth with special health needs and their providers

1-800-882-1435
1-617-624-5992 (TTY)
1-617-624-6060

Available Monday - Friday 9:00 am to 5:00 pm
Care Coordination Program

- Assess & provide support services for youth/families re: health care transition
- Provide information & connection to adult agencies
- Support seeking guardianship, if applicable
- Send formal written reminders about HCT process at ages 14, 17, 21
- Conduct check-ins at least annually
- Support completion of Health Skills and Transition Readiness Checklist
- Facilitate conversation with PCPs on transition
- Support health care transition as part of the IEP process
- Share information with adult providers as possible
Health Care Transition Timeline

• **Start early! Life is full of transitions.**

• Age 14: Formal health care transition planning begins along with other areas of adult life

• Age 14 & on: What do I need to know to manage my own health care?

• Age 16: Begin the planning process of transfer to adult care
  Who, where, sharing of information

• Age 18: Prepare for changes
  Public benefits, legal issues, work with adult serving agencies

• Age 18-22: Transfer of care to adult practitioners
Other DPH Health Care Transition Activities

• Family TIES of Massachusetts
  • Flags families whose children are 14 & over
  • Shares definition of health & health related transition
  • Provides information & resources
• Public Benefits Training on changes that happen at age 18
• Health Care Transition website
• Programs raise awareness & share information about health transition with sister agencies & community organizations
Health Transition for Youth and Young Adults with Special Health Needs

Resources for youth and young adults, their families, and providers as they move from pediatric to adult health care systems and learn to take charge of their health and related needs.

Youth & young adults with special health needs - especially those with complex medical conditions, disabilities and chronic illnesses - may not move as smoothly from pediatric to adult health care systems as their typically developing peers. This transition generally occurs between the ages of 18 - 22, although timing should be based on the youth or young adult’s developmental level, complexity of their chronic condition(s), and the readiness of the youth or...
DPH Transition Resource

• Community Support Line: 1-800-882-1435
• Family TIES: 1-800-905-TIES (8437)
• Care Coordination for eligible youth & families
• Public Benefits brochure
  “Bridge to Adult Health Care Coverage & Financial Benefits”
• DPH Youth Health Care Transition web site:
  www.mass.gov/dph/youthtransition
Connect with DPH

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Massachusetts Department of Public Health

DPH blog
https://blog.mass.gov/publichealth

www.mass.gov/dph
Thank You!

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