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**PUBLIC**  
**HEALTH**

# Massachusetts Department of Public Health

## **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?

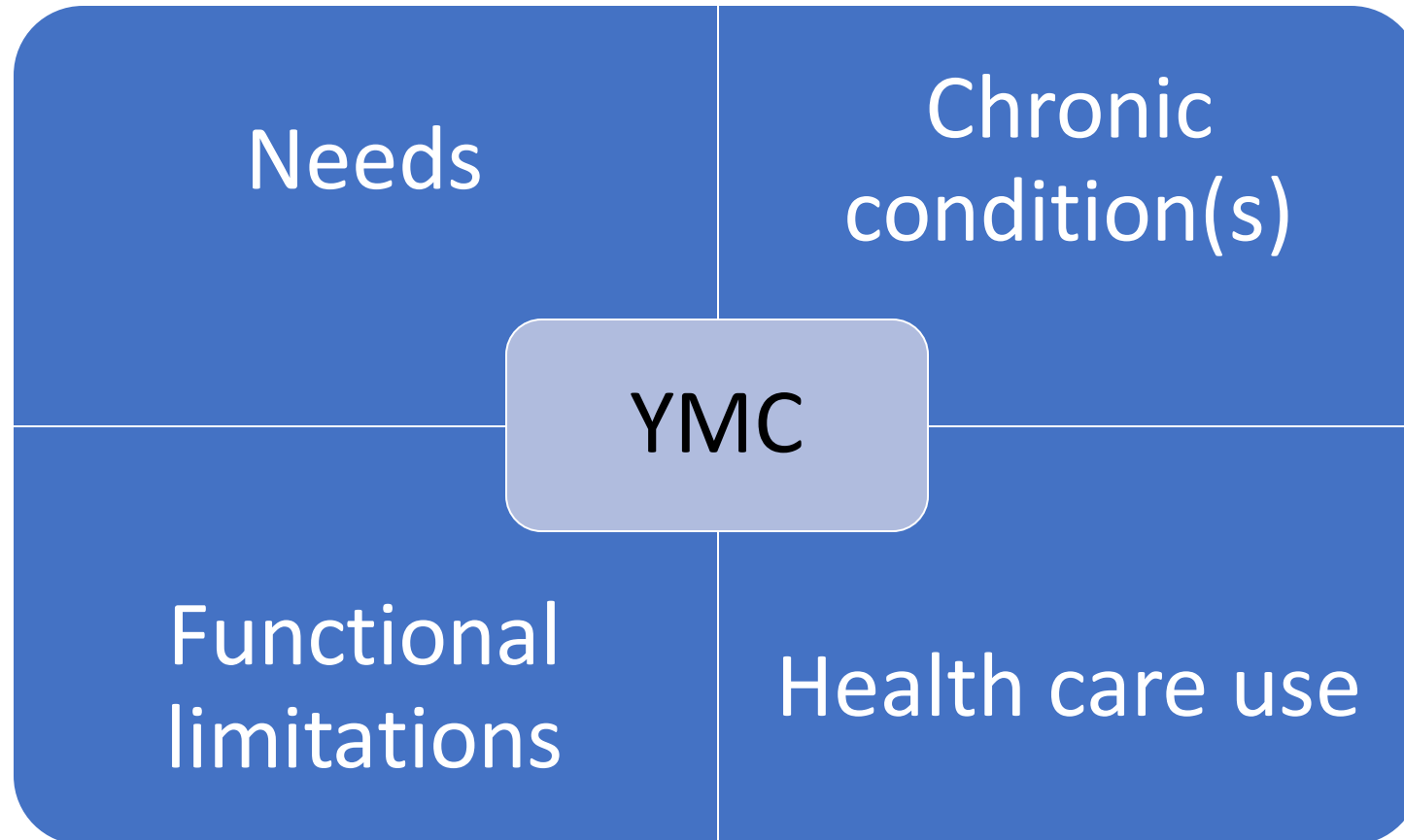
# Who are Youth with Special Health Care Needs?

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.”***

McPherson M, Arango P, Fox H, et al. “A new definition of children with special health care needs”, *Pediatrics*, 1998; 102: 137-140

# Who are Youth with Medical Complexity?



Cohen, E., Kuo, D., Agrawal, R., Berry, J., Bhagat, S., Simon, T. et al. (2011). Children with medical complexity: An emerging population in clinical and research initiatives. *Pediatrics*, 127(3), 529-538.

# 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)<sup>1</sup>
- ~99,323 have special health needs (YSHN)<sup>1</sup>
  - 1-3% YSHN have medical complexity (~993 to 2,979)<sup>2</sup>
- Many more when ages 18-26 included

Child and Adolescent Health Measurement Initiative (2019). *2017-2018 National Survey of Children's Health*. Data Resource Center for Child and Adolescent Health, supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Available at [www.childhealthdata.org](http://www.childhealthdata.org). Revised 10/7/2019.

Barnert, E., Coller, R., Nelson, B., Thompson, L., Tran, J., Chan, V., et al. (2019). Key population health outcomes of children with medical complexity: A systematic review. *Maternal & Child Health Journal*, (23): 1167-11176.

# 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

Sharma, N., O'Hare, K., Antonelli, R.C. & Sawicki, G.S. (2014). *Transition care: Future directions in education, health policy, and outcomes research*. *Acad Pediatr* (2), 120-127.

# 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:

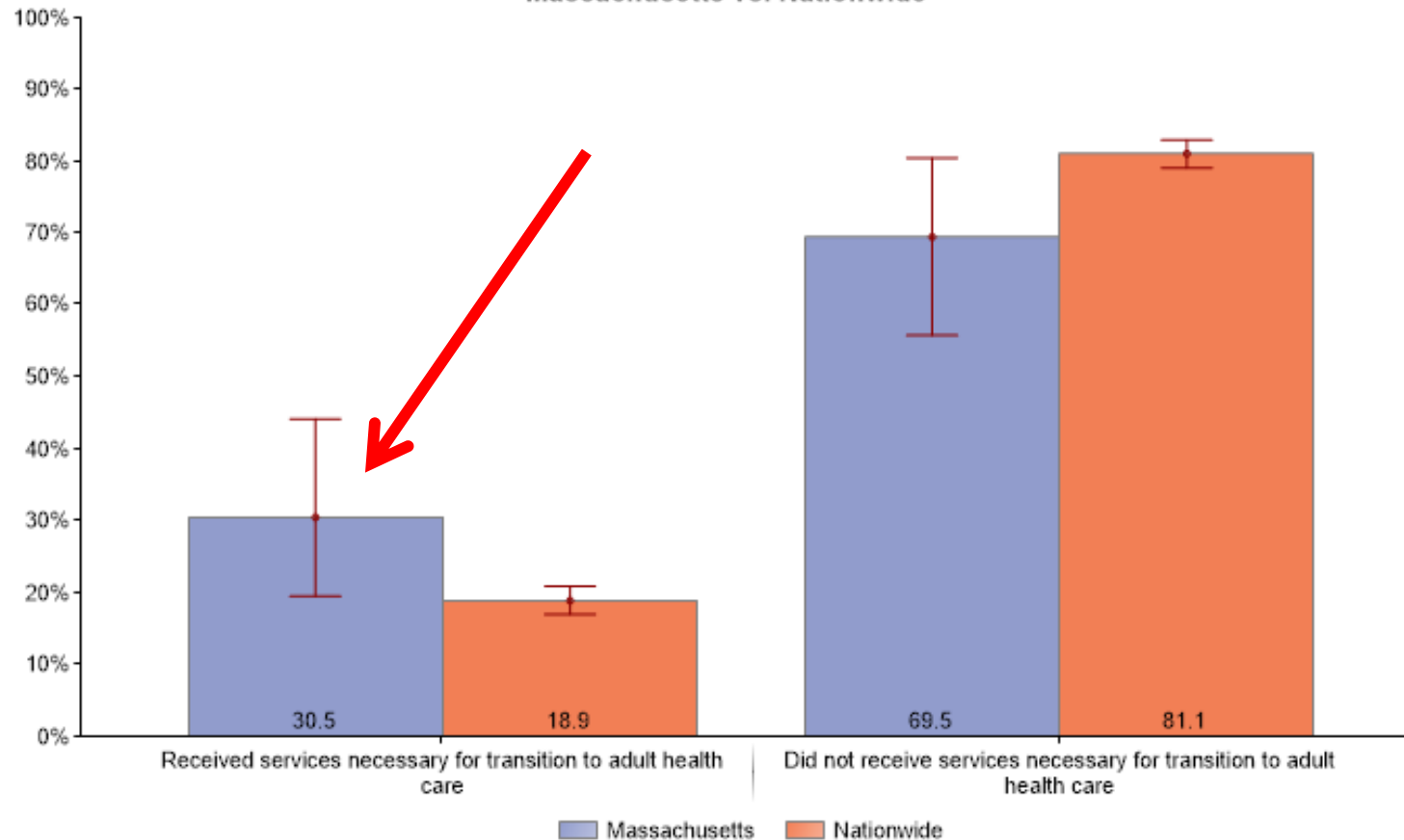
- Parental/child attachment to the pediatrician and a hesitancy to transition to adult health care
- Lack of adult health care providers with experience or training in transition and disability
- Lack of sufficient mechanisms for adult providers to adequately bill for longer medical appointments often needed by adults with disabilities
- Lack of adult providers trained in mental health needs

Gabovitch, E.M., Lauer, E. & Dutra, C. (2016). *Healthy People 2020 Roadmap Report for Massachusetts Children and Youth with ASD/DD: Understanding Needs and Measuring Outcomes*. Boston, MA: University of Massachusetts Medical School, E.K. Shriver Center.



# How many received services necessary for health care transition?

**NPM 12: Percent of adolescents with special health care needs who received services necessary to make transitions to adult health care**  
Children with special health care needs age 12-17 years  
Massachusetts vs. Nationwide



- **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*

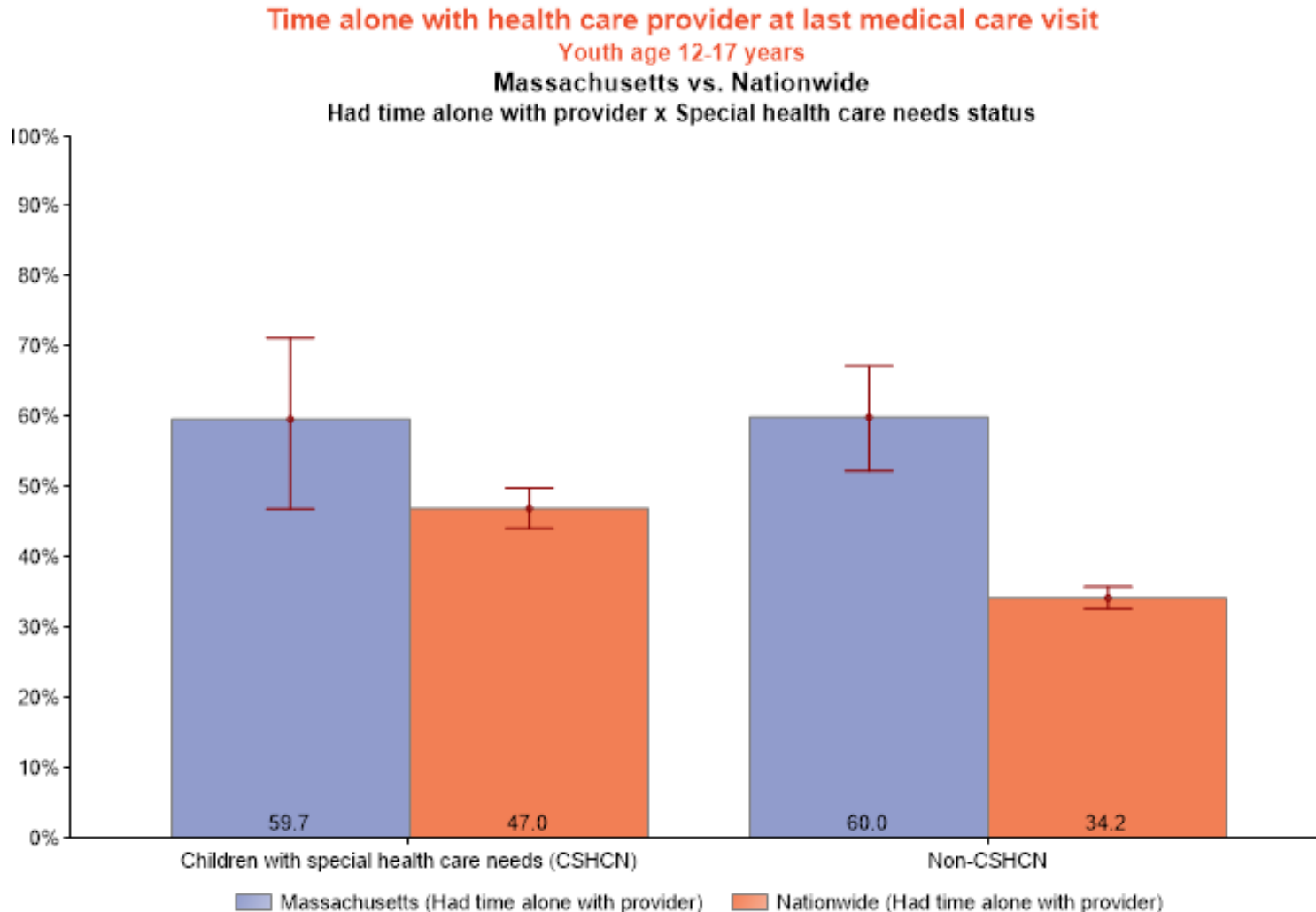
Survey: 2017-2018 National Survey of Children's Health  
Starting Point: Title V Maternal and Child Health Services Block Grant Measures

State/Region: Massachusetts vs. Nationwide ([quick edit](#))

Topic: National Performance Measures

Question: NPM 12: Transition to adult health care, CSHCN age 12-17 years [i](#)

# 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 [i](#)  
Sub Group: Had time alone with provider x Special health care needs status

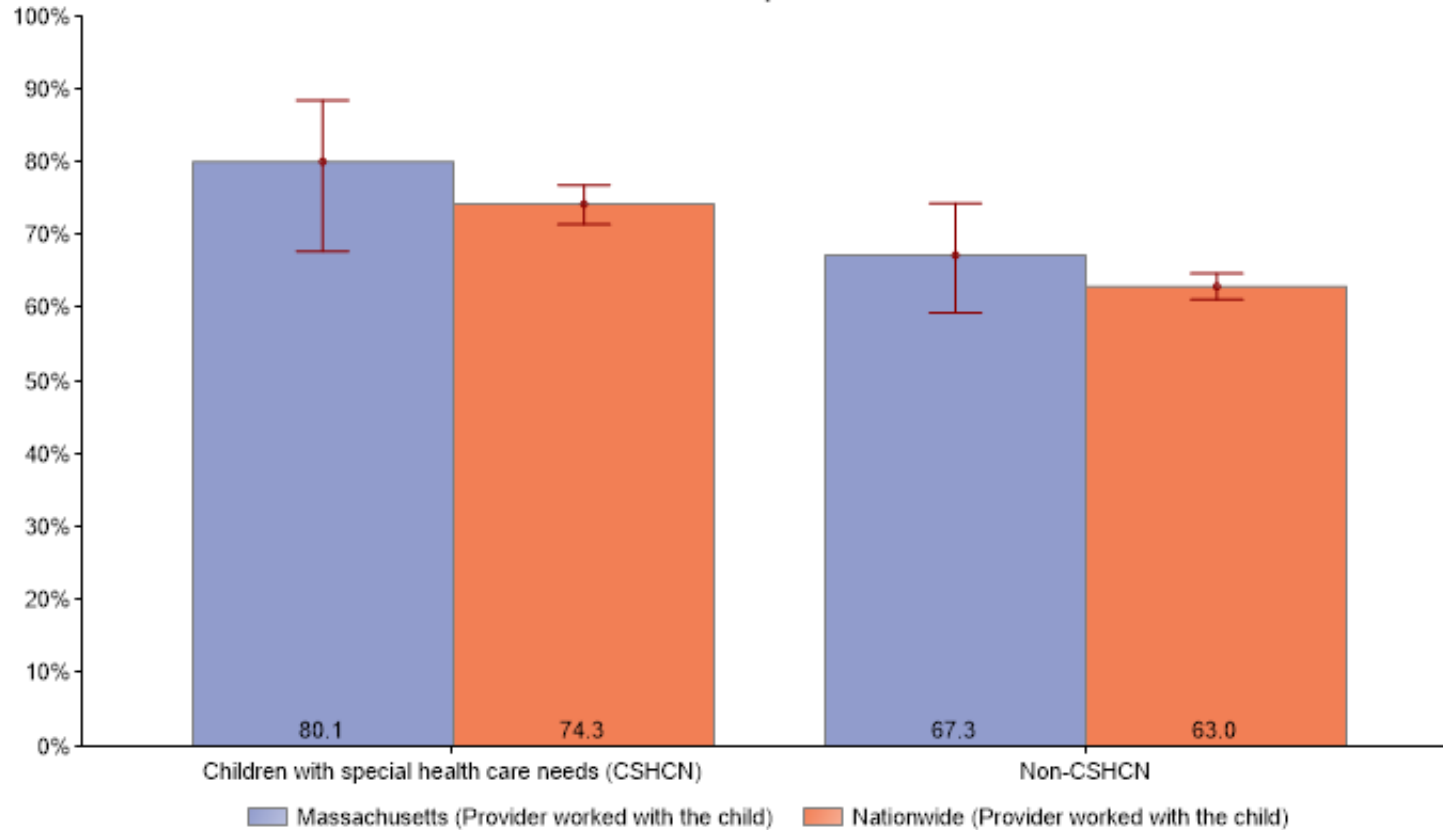
# How many understand health care changes at age 18?

Doctor or health care providers worked with youth to manage health/health care or understand health care changes at age 18

Youth age 12-17 years

Massachusetts vs. Nationwide

Provider worked with the child x Special health care needs status



- **80%** of YSHN understand health care changes at 18.
- **67%** of non-YSHN did too.

Survey: 2017-2018 National Survey of Children's Health

Starting Point: Child and Family Health Measures

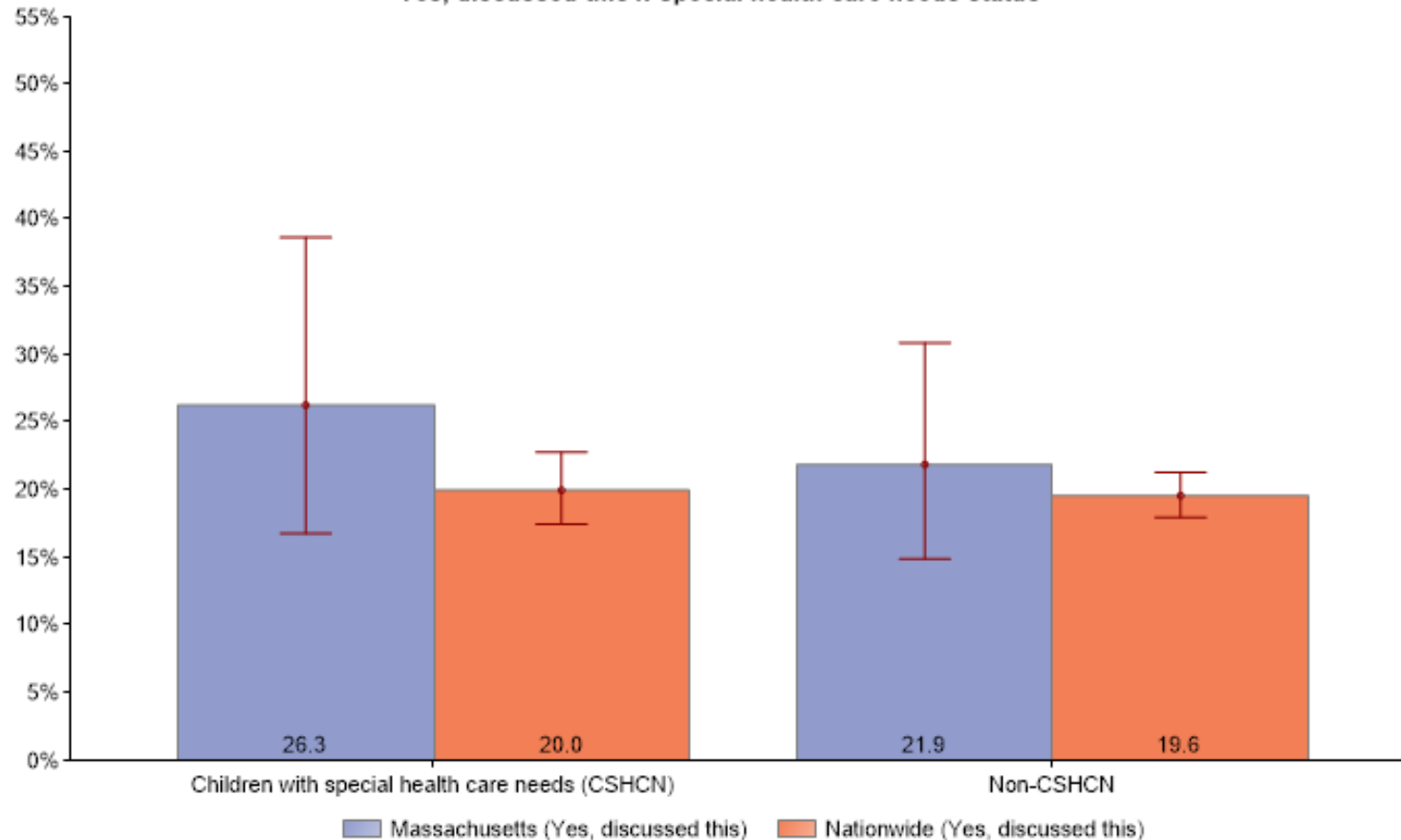
State/Region: Massachusetts vs. Nationwide ([quick edit](#))

Topic: Health Care Access and Quality

Question: Transition Part B: Actively worked with the child to manage care transition [i](#)

# How many report providers discussed shift to adult care providers?

Provider discussed shift to adult health care providers if needed  
Youth age 12-17 years who needed a discussion about transitioning to adult health care provider  
Massachusetts vs. Nationwide  
Yes, discussed this x Special health care needs status



- **Only 26%** of YSHN discussed the shift.
- **Only 22%** of non-YSHN did too.

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 C: Discussed shift to providers who treat adults [i](#)



# Massachusetts Department of Public Health

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

# Charting the Life Course Framework

## Re: Health Care Transition

### CHARTING the LifeCourse™

RESOURCES ▾ LIFECOURSE IN ACTION ▾ TRAINING ▾ CONNECT ▾



# Charting the Life Course Framework re: Healthy Living

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?



## Healthy Living

Managing and accessing health care and staying well – medical, mental health, behavioral health, developmental, wellness and nutrition

# Got Transition: Six Elements of Health Care Transition

## Got Transition™? Six Core Elements of Health Care Transition

1. Transition Policy	Create a written practice policy on transition including timeframes for when youth leave practice.
2. Transition Tracking & Monitoring	Track health care transition progress among all youth ages 12 and older, with and without chronic conditions.
3. Transition Readiness	Assess youth's transition readiness and self-care skills.
4. Transition Planning	Plan for transition as a collaborative and continuous process with youth and families.
5. Transfer of Care	Creating a transfer of care checklist for the practice, preparing a transfer package for youth leaving the practice, and communicating with the new adult provider.
6. Transfer Completion	Confirming transfer completion, arranging for pediatric consultation (as needed), and assessing youth and family experience with transition support





# Massachusetts Department of Public Health

**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

# Transition Web Page on mass.gov

## 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

### SOCIAL

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# 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](http://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](http://www.mass.gov/dph)



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# Thank You!

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