TRANSITIONING INDIVIDUALS WITH MULTIPLE, COMPLEX MEDICAL NEEDS TO ADULT CARE

The Arc of Massachusetts Transition Conference
College of the Holy Cross
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Presenters

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- **Monica Jennings**, Self Advocate
Disclosures

Suzanne Gottlieb is an employee of the Massachusetts Department of Public Health. She receives no commercial support for her work.

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Learning Objectives

1. Understand what the transition to adult care and health related self management is all about

2. Have a framework for navigating adult care systems

3. Develop communication strategies that help youth to participate in their care

4. Build a library of tools that will help youth and their families to share information with adult service providers
Monica’s Introduction

Filmed in September 2017

Subtitles

https://vimeo.com/237428822
**VISION**
Optimal health and quality of life for children and youth with special health needs and their families.

**MISSION**
Assuming a leadership role in assuring a comprehensive service system for children and youth with special health needs by working in partnership with families, providers and other stakeholders. We do this by: assessing needs, strengthening infrastructure, assuring access, enhancing expertise and knowledge, and engaging in continuous quality improvement.

### Core Outcomes

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<tr>
<th>Outcomes</th>
<th>Details</th>
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<tr>
<td>Families &amp; YSHN partner with us in decision making at all levels about services received.</td>
<td>Infants, children &amp; youth are screened early &amp; continuously for SHN.</td>
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<tr>
<td>Child and Youth Special Health Needs (CYSHN) receive ongoing care within a medical home.</td>
<td>Community-based service systems are organized in ways that families can use them easily.</td>
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<td>YSHN receive the services necessary to make successful adult health transitions.</td>
<td>Families of CYSHN have adequate private/public insurance to pay for services needed.</td>
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### Values-based Methods
- We partner with families in everything we do.
- We promote a comprehensive service system that is family-centered, culturally competent, coordinated, inclusive & community-based.
- We promote healthy equity by applying best practices for racial justice and cultural & linguistic competence to our work.
- We partner with youth with special health needs to improve health transition and promote self-advocacy.
- We collect, analyze, share and report data to inform program needs, monitor policies and programs, and evaluate and research outcomes.
CYSHCN – Who are we talking about?

- The federal 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”
What is Transition?

- **a**: passage from one state, stage, subject, or place to another
- **b**: a movement, development, or evolution from one form, stage, or style to another*

> Transition is a part of life – nothing stays the same

- What makes transition easier?
What DPH Means by Health 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.
Why Focus on Health Transition?

- There are an estimated 18 million adolescents, ages 18-21 in the US
- About 25% have chronic conditions
- Many more when youth 12-26 are included
- National data indicates that less than half of youth & families feel prepared
- Health care providers report no systematic way to support transition from the pediatric to adult system of care
Maternal & Child Health Services Block Grant

**NPM12:** Percent of children with and without special health care needs who received services necessary to make transitions to adult health care

**GOAL:** By 2020 increase the % of CYSHN who received services necessary to transition to adult health care from 47% to 52%

**HOW:** By 2020 90% of youth 14 & older receiving services from DPH Care Coordination Program will have health transition information and support
Care Coordination Activities

- Assess & provide support services to youth/families regarding health & health related transitions
  - *With youth and families*
  - *Provide information and connection to adult serving agencies*
  - *If applicable support families seeking guardianship*

- Formal written communication to families and primary care provider at ages 14, 17, 21

- Annual check-ins, more if needed

- Present & support completion of Health Skills Checklist
  - *Assist family to complete and involve youth when possible*
  - *What do I know, what do I need to learn?*

- Follow up with primary care to share transition information upon request

- Support transition conversations as part of the IEP process

- Partner with state and community agencies working on transition for our population
Other Transition Activities

- Family TIES of Massachusetts
  - *Flag families whose children are 14 and over*
  - *Share definition of health & health related transition*
  - *Provide information & resources*
- Public Benefits Training – Changes at 18
- **Workshops for families & youth**
- Raise awareness & share information about health transition with sister agencies and community organizations
- Maintain Transition website
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 and 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 in public benefits, legal issues, work with adult serving agencies

- **Age 18-22** – Transfer of care to adult practitioners
DPH resources

- Community Support Line
- Public Benefits
  "Bridge to Adult Health Care Coverage & Financial Benefits"
- Care Coordination
- Family TIES
- Website
  www.mass.gov/dph/youthtransition
Health Transition for Youth and Young Adults with Special Health Needs

Health Transition Resources for Parents and Caregivers
Preparing your child to advocate for his needs and make his own decisions.

Youth & young adults with special health needs may have more complex health histories, severe medical conditions or disabilities than typically developing children. This may limit their functioning and impact their ability to move smoothly from the pediatric to the adult health care system.

The transition to adult providers generally occurs between the ages of 18 - 22, although the timing of the transition process should be individualized based on the youth or young adult's developmental level, the complexity of his or her chronic condition(s), and the readiness of the youth or young adult and family to begin the planning process.

The characteristics of the current medical home and the ability to identify a suitable adult medical home should be taken into consideration. A good medical home provides health care and related services that are coordinated, comprehensive, community based, patient-centered, accessible and culturally competent.

- About the Health Transition Program
- Important Points about Health Transition
- Health Transition Resources
- Health Transition Resources for Parents and Caregivers

Friendly URL: www.mass.gov/dph/youthtransition

Tips for Youth
Tips for Parents
Tips for Providers
Community Support Line 800-882-1435
A Family Perspective

Whose transition is it anyway?

Parent and child
Consider

Who do you turn to with health questions?

- Current providers
- Other professionals
- Family, friends, co-workers/colleagues
- Community members
- Personal research\Internet
Trusted Resources

Who Does What? Why?

- Parent/Guardian
- Allies
- Siblings
- Other relatives
- Friends
- Adult peers
- Former providers

Likes/Preferences

- Self Awareness
- Own body responses
- Own emotions
- Responsibilities
Skills You’ve Been Developing

Critical Thinking

Asking Questions and Questioning Answers

Collaborative and Independent Decision-making

Knowledge of Systems

- Health Literacy
- Legal issues, rights, protections and responsibilities
- Healthcare provider policies
- Health insurer rules and regulations
- Program eligibility
- Navigation and access points
What does a successful Transition look like to your youth?

- Healthcare access
- Healthy choices
- Asking advice
- Supported decisions
- Independence
- Friendships
- Respect
- Responsibility
- Self-determination

Will you know it when you are there?
Congratulations!

You (or your child) are growing up!
American Academy of Pediatrics advises active planning by age 12-14 years

... but important to develop strengths even from birth

© Dr. Jack Maypole
1st Tip: Communicate about Transition

- "What is your practice’s policy about transitioning to adulthood?"
- "When will we transfer care to an adult provider?"
- "Who do you recommend that we see next?"
- "How can we work together to make this change as smooth as possible?"
As youth get older, they are more ready to participate in their own health care and health care decisions. And since once they turn 18 they are legally in charge of their care, it's a good idea for them to learn the ropes well before then.

The majority of Boston Children's Primary Care patients will transition to an adult health care provider between the ages of 18 and 22 years. Depending on your child's developmental readiness, your provider will begin spending time alone with your child at some of their visits as they approach adolescence (12-14 years of age).

During this time, we will also begin working with families to make the transition to an adult care model. Between the ages of 14 and 18, we will continue working with your child to practice this adult model of care, encouraging them to practice the skills necessary to take responsibility for their own health.

Youth with special health care needs may need more time to transition to adult care and may also need assistance with issues around guardianship. Boston Children's Primary Care has resources dedicated to facilitating these transitions to adulthood. If you need help or have any questions, please let our staff or your provider know.
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Primary Care at Longwood Transition Policy

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2nd Tip: Build Health Care Skills

Can you/your child:

- Make a doctor’s appointment?
- Fill a prescription?
- Describe health conditions?
- Know what medicines are taken?
- Know about any allergies?
- Know what to do in an emergency?
3rd Tip: Consider How Decisions are Made

Age 18 = adulthood in Massachusetts; assume the individual is independent in decisions

- Medical
- Social
- Financial
Healthcare Proxy

- Authorizes the representative to make any and all health care decisions for the individual
  - Decisions to accept or refuse any treatment, service or procedure used to diagnose or treat physical or mental conditions

- Patient signs with 2 witnesses
  - Must be competent to sign

All of us should have a healthcare proxy!
Guardianship

- Designed to provide support with medical, financial, and social decisions
- Is a legal process that involves the probate courts
- Most formal level of support
Advanced Directives

- Living Will
- 5 Wishes
- MOLST (Massachusetts Medical Orders for Life-Sustaining Treatment)

4th Tip: Get Organized!

- Write a Medical Summary
- Make copies of HCP or Guardianship papers
- Make copies of Advanced Directives
- Collect medical records
  - Don’t forget copies of images from tests (Xrays, EKG’s, MRI’s, etc)
- Update list of Durable Medical Equipment & suppliers
- Sign records releases
  - Doctors’ Offices, Hospitals, School, and DDS
PORTABLE MEDICAL SUMMARY (Adapted from HRTW National Center form)

<table>
<thead>
<tr>
<th>NAME:</th>
<th>Address:</th>
<th>Home Phone:</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Alternate Phone:</td>
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<tr>
<td></td>
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</tr>
<tr>
<td>Date of Birth:</td>
<td>SS#:</td>
<td>DNR Signed:</td>
</tr>
<tr>
<td>Age:</td>
<td>Height:</td>
<td>N/Y Date Signed:</td>
</tr>
<tr>
<td>Supports Needed:</td>
<td>Weight:</td>
<td>Blood Type:</td>
</tr>
<tr>
<td>Communication Preferences:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legal Decision Maker:</td>
<td><strong>Self</strong> Guardian (If Guardian, Guardianship: <strong>Limited</strong> <em>Full</em>_)</td>
<td></td>
</tr>
<tr>
<td>Guardian Name:</td>
<td>Guardian Address:</td>
<td></td>
</tr>
<tr>
<td>Guardian Phone:</td>
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</tbody>
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Diagnoses (include ICD-9 codes if known) | Allergies (N/Y – If Yes, list below)

Special notes:

<table>
<thead>
<tr>
<th>DOCTORS</th>
<th>HOSPITAL</th>
</tr>
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<tbody>
<tr>
<td>Name:</td>
<td>Specialty:</td>
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</tbody>
</table>

| MEDICATIONS (List name of medication, condition being treated, dosage and how often taken) | IMMUNIZATIONS |
| Name | Condition | Dosage | Time |
| Type | Date |

| PRIMARY INSURANCE COMPANY INFORMATION | OTHER INSURANCE COMPANY INFORMATION |
| Name of Company: | Name of Company: |
| Subscriber: | Subscriber: |
| Plan Code #: | Plan Code #: |
| Subscriber #: | Subscriber #: |
| Customer service: | Customer service: |
| Case Manager: | Case Manager: |

Additional contact information

<table>
<thead>
<tr>
<th>Residential Provider</th>
<th>Name:</th>
<th>Phone:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Manager</td>
<td>Name:</td>
<td>Phone:</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Name:</td>
<td>Phone:</td>
</tr>
<tr>
<td>Dentist</td>
<td>Name:</td>
<td>Phone:</td>
</tr>
<tr>
<td>Legal Health Surrogate</td>
<td>Name:</td>
<td>Phone:</td>
</tr>
</tbody>
</table>
In case of emergency, please contact Name: Phone:
5th Tip: Gather Your Team

- How will your systems of support carry over into adulthood?
- What needs to change?
- Where do you want your “health home” to be?

Courtesy of Cristin Lind and Dr. Richard Antonelli
http://www.childrenshospital.org/care-coordination-curriculum/care-mapping
Choosing a PCP (Primary Care Provider)

- Consider your preferred hospital network
- Consider your insurance
  - Massachusetts has special programs for patients with both Medicare and Masshealth
- Consider proximity to your residence
- Consider who is on the team
  - Nurse, social worker, pharmacist, psychologist...
- Consider the services offered
  - Evenings/weekends, online communication, urgent care...
- Consider any special accommodations needed (e.g. accessible by stretcher transport)
6th Tip: Prepare for your Visit

- Notify the office of any special needs
- Deliver records in advance
- Allow for mutual getting-to-know-you
- Request shorter follow up intervals
Last Tip:
Take Time to Celebrate!

Pass on what you’ve learned.

And please help us to do it better for the next family.
More Resources

Got Transition?
- Six Core Elements of Health Care Transition package, including measurement tools
  http://www.gottransition.org/resources/index.cfm##six

Transition Policy
- Boston Children’s Hospital Primary Care at Longwood transition policy and resource directory
- Communication Matters: a guide for sharing information about a child’s care (addressing confidentiality between families, providers and schools)
  http://www.mhq.org/EmailLinks/Communication_Matters.pdf
- Dr. Right/Dr. Knotright transition training videos for providers/staff
  https://www.youtube.com/watch?v=6EJkOYmkxmE
  https://www.youtube.com/watch?v=W1CVs7j5x3U
Transition Readiness

• Transition Readiness Assessment Questionnaire (TRAQ)
  http://www.hscj.ufl.edu/JaxHATS/TRAQ/
• Bright Futures Adolescent Health Guidelines
  https://brightfutures.aap.org/pdfs/Guidelines_PDF/18-Adolescence.pdf
• Boston Children’s Hospital Teen Advisory Board transition video for adolescent patients
  http://childrenshospitalblog.org/teens-time-to-take-more-responsibility-for-your-health/

Transition Planning

• Boston Children’s Hospital Guide to Care Mapping
  http://www.childrenshospital.org/care-coordination-curriculum/care-mapping
• AAP Emergency Information Sheet for Children with Special Health Care Needs
  http://www2.aap.org/advocacy/blankform.pdf
• Boston Children’s Hospital Guardianship Planning Guide
  http://www.childrenshospital.org/~media/Centers%20and%20Services/Programs/A_E/Cerebral%20Palsy%20Program/Guardianship_CP.ashx
Monica’s Video

https://vimeo.com/241154674
Thank You!

- Questions?
- Need more information
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  - Dr. Kitty O’Hare
    - transition@childrens.Harvard.edu
  - Lisa Jennings
    - lisamjenn@aol.com