Transition & Care Coordination
JFK Partners / CDPHE HCP Webinar
October 22, 2015
10:00-11:30 MDT

Introductions:

• Mallory Cyr, MPH, CDPHE HCP Program Support

• Paul Dressler, MD, Developmental Behavioral Pediatric Fellow, Children’s Hospital Colorado

• Teresa Nguyen, Transition Consultant, MPH Student
What is Transition?

- Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.
- Maternal Child Health Bureau (MCHB) Definition

- Youth with special health care needs, as adults, must be able to expect good health care, employment with benefits, and independence.
- Appropriate adult health care options must be available in the community and provided within developmentally appropriate settings.
- Health care services must not only be delivered in a family-centered manner, but must prepare individuals to take charge of their own health care and to lead a productive life as they choose.

Medical & Non-Medical:
More than a doctor’s visit

- Employment/Vocation (how are the days spent?)
- Health Care (adult model of care)
- Social/Relationships
- Educational
- Financial- shift from entitlement to eligibility based system
- Support system, Decision Making
Measuring Transition

12-17 year old CSHCN must meet four components:

1) If a discussion about transitioning to adult care was needed it must have happened

2) If a discussion about changing health care needs as child becomes an adult was needed it must have happened

3) If a discussion about transitioning insurance to maintain eligibility was needed it must have happened

4) Doctors usually or always encouraged responsibility for self-care, such as taking medication, understanding his/her diagnosis or following medical advice.
What is a Medical Home?

Five key features of the medical home model:

- Patient-centered.
- Comprehensive.
- Coordinated.
- Accessible.
- Committed to quality and safety.

Why Does a Medical Home Matter?
6 Core Elements

<table>
<thead>
<tr>
<th>Pediatric Health Care Setting</th>
<th>Adult Health Care Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Transition Policy</td>
<td>● Young adult privacy and consent policy</td>
</tr>
<tr>
<td>● Patient registry</td>
<td>● Patient registry</td>
</tr>
<tr>
<td>● Transition Readiness Assessment</td>
<td>● Transition Readiness Assessment</td>
</tr>
<tr>
<td>● Transition Planning</td>
<td>● Transition Planning</td>
</tr>
<tr>
<td>● Action Plan</td>
<td>● Request planning materials</td>
</tr>
<tr>
<td>● Portable Medical Summary</td>
<td>● Offer tours/get acquainted visit</td>
</tr>
<tr>
<td>● Emergency Plan</td>
<td></td>
</tr>
</tbody>
</table>

http://www.gottransition.org/resourceGet.cfm?id=220

Get the Conversation Started!

Things to Remember:

- Independence is a spectrum (who can help with this?)
- There is no “one size fits all” for transition
- Strengths based planning- what are they good at? What do they enjoy doing? What is fulfilling?
- Suggestions & steps to think about, NOT a to do list
- Meet families where they’re at-
  - Trauma informed- transition is not always a celebration (but for many it is!)

- **Starting late is better than never! You have not failed.**
Equip vs. Enable

Transition Clinic

• Clinic at Special Care Clinic then Child Development Unit from 6/2014-12/2015

• Youth ages 12-26 years old who have a developmental disability

• 2-hour visit:
  – 1 hour with medical provider
  – 1 hour with Transition Consultant
**TRANSITION CLINIC**

**AFTER VISIT SUMMARY**

**Diagnoses:**

**Plan:**

Medical Transition Action Plan

<table>
<thead>
<tr>
<th>Goals</th>
<th>Issues/Concerns</th>
<th>Actions</th>
<th>Person Responsible</th>
<th>Target Date</th>
</tr>
</thead>
</table>

**Recommendations for Primary Care Provider:**

TRANSITION POLICY: consider drafting a transition policy to share with adolescents and their families starting around the ages of 12-14 years. This policy should include a transition time frame (When are youth expected to leave your practice?) and an explanation of the practice’s transition approach (What will your practice offer youth and families to assist them in transition?). It should also explain the legal changes that take place in privacy and consent at age 18, even if the youth has not left your practice. An example can be found in the Got Transition Toolkit 2.0 at [http://gottransition.org/providers/staying-1.cfm](http://gottransition.org/providers/staying-1.cfm).
# Transition Planning Roadmap for PCP

<table>
<thead>
<tr>
<th>Transition Guidelines for Adolescents with Developmental Disabilities</th>
<th>12 years</th>
<th>14 years</th>
<th>16 years</th>
<th>17 years</th>
<th>18-26 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adaptive testing</td>
<td>X</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Contact Community Center Board for adult services wait list</td>
<td>X</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Share written practice policy on medical transition with family</td>
<td>X</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Discuss school’s transition plan</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Assess medical transition readiness</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Develop and place patient on office’s medical transition registry</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Develop brief portable medical summary</td>
<td>X</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discuss possible ACT/SAT testing accommodations</td>
<td>X</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discuss driving/transportation options</td>
<td>X</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td></td>
</tr>
<tr>
<td>Discuss applying for SSI if qualifies</td>
<td>X</td>
<td>*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discuss guardianship, shared decision making, medical power of attorney</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discuss possible need for day programming</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Share compiled list of adult primary and specialty care providers with an interest in patients with special needs</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Send brief letter and portable medical summary to adult care provider</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- X = Recommended at this age
- * = If not already done, recommended at this age

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# CUMULATIVE PATIENT PROFILE

For adults with IDDD

Adapted from template originally developed by the Department of Family and Community Medicine, Faculty of Medicine, University of Toronto, and Electronic Medical Record, DFCM, St. Michael’s Hospital, Toronto

Initial Assessment Completed: ___/___/___
Consider annual review and update sooner when changes occur, e.g., decision-making capacity

Etiology of DD:__________________________

☐ Definite ☐ Probable ☐ Possible ☐ Unknown

Last/First Name:__________________________
Address:__________________________
Phone:__________________________ DOB:___/___/___ Gender:________

Medical Record Number:__________________________

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# MEDICAL SUMMARY AND EMERGENCY ACTION PLAN

**LAST UPDATED:**

<table>
<thead>
<tr>
<th><strong>PATIENT CONTACT INFORMATION</strong></th>
<th><strong>EMERGENCY CONTACT</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
<td>Name:</td>
</tr>
<tr>
<td>Goes by:</td>
<td>Goes by:</td>
</tr>
<tr>
<td>Date of Birth:</td>
<td>Phone number:</td>
</tr>
<tr>
<td>Address:</td>
<td></td>
</tr>
</tbody>
</table>

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10/20/2015
Preliminary Data from First 5 of 6 PDSA Cycles

8 of 41 excluded: 3 did not have a PCP; 1 did not have a developmental disability; 2 were follow-up as PCP not interested in engaging in process; data pending on most recent 2 visits.

Useful vs. Doing

- Yes - No

Found at least 1 recommendation useful (p = 0.01)
Engaged in at least 1 core element of transition (p = 0.16)
Barriers to Engaging

• Education
• SSI
• Employment
• Guardianship
• Independence: transportation, housing, etc.

All Influence Health Care
Tips for Success

• Keep up to date with community organizations and resources
• Empower youth or young adult patient during this conversation and process

Resources
Resources:

- Quick guide to managing health and employment/career goals: http://www.gottransition.org/resourceGet.cfm?id=372
- Tip Sheet for patients w. ID/DD: http://www.gottransition.org/resourceGet.cfm?id=367

Questions?

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