Learning Objectives

- Review transition principles applicable to all youth, with particular focus on youth with special health care needs
- Understand the resources available through the National Center on Health Care Transition – known as Got Transition? (www.gottransition.org)
- Understand how the process of transition exemplifies the medical home approach
- Understand how health care transition is a vital component of Colorado’s youth system

The Transition Process

Transfer of Care

Pediatric Care  ↓  Adult Care

Transition

Rosen DS. Grand Rounds: all grown up and nowhere to go: transition from pediatric to adult health care for adolescents with chronic conditions. Presented at: Children’s Hospital of Philadelphia; 2003; Philadelphia, PA

What do you need

- Time
- A process or template to work from
- Supportive team who understand the goals of transition planning
- A partner in the adult health care setting to receive patients

Findings From the Community

- Thoughts from families
- Thoughts from youth
- Thoughts from providers

Families

- Families are afraid that they will not be able to find a quality adult provider.
- Families who have YSHCN are going through a new grief cycle.
- They don’t know that it is actually okay to step aside.
- They are learning the new adult system which, for YSHCN is eligibility based not entitlement based.
- Need to learn more about the guardianship process.
Community
- There are no supports to help families through this process.
- Specialists are hard to engage.
- Building a medical home team is vital.
- Policies are important, but each family is unique.

Provider
- Transition is different if the person has an intellectual disability than if they do not.
- Pediatric providers should promote independence of the patient.
- Adult providers need succinct information/data in order to have successful transitions.
- They felt that the hardest people to transition were not the patients with a genetic condition, but rather those patients without a Medical Home.

Core Elements of Transition

<table>
<thead>
<tr>
<th>Pediatric Health Care Setting</th>
<th>Adult Health Care Setting</th>
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<tbody>
<tr>
<td>Transition Policy</td>
<td>Young adult privacy and consent policy</td>
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<tr>
<td>Patient registry</td>
<td>Patient registry</td>
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<td>Transition Readiness</td>
<td>Transition Readiness Assessment</td>
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<tr>
<td>Assessment</td>
<td>• Reception preparedness</td>
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<tr>
<td>Transition Planning</td>
<td>Transition Planning</td>
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<tr>
<td>• Action Plan</td>
<td>• Request planning materials</td>
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<tr>
<td>• Portable Medical Summary</td>
<td>• Offer tours/get acquainted visit</td>
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<td>• Emergency Plan</td>
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Youth Transition Readiness
- I know my diagnosis.
- I can explain my diagnosis and/or health needs to others.
- I carry information about my diagnosis to share with other doctors.
- I know when I need to seek urgent medical attention related to my diagnosis.
- I know what to do if I have a medical emergency related to my diagnosis.
Youth Transition Readiness

- I carry important health care information with me daily (such as your insurance card, emergency, doctor, and pharmacy phone numbers, medications, allergies, diagnosis, and medical summary).
- I know what medications I take and why.
- I know when my prescriptions need refilled and how to refill them.
- I call to make my own appointments and cancel appointments.

Youth Transition Readiness

- Before my appointments, I prepare a list of questions or concerns that I want to ask the doctor.
- I know I have the option to see the doctor by myself.
- I collect and organize medical records from my doctors visits.
- I pay the co-payments for my medical visit.

Youth Transition Readiness

- I co-sign the privacy and consent forms.
- My family and I have a plan so I can keep my healthcare insurance after I turn 18.
- I know the doctor I plan to visit when I turn 18 for adult care.
- I know the doctors I plan to use for specialty care (cardiologist, neurologists, ENT, etc.) as an adult.

Transition Readiness for Parents/Caregivers

- Yes my child does this
- I want my child to do this
- No my child is not able to do this, why?
- My child needs to learn this
- Someone else will have to do this – Who and Why?

Being Real with Youth

- Of the questions on the front page, which one do you think you are doing BEST?
- Of those questions, is there something you think you will never do?
- Which of those questions would you like to do but just don't know how to do it?
- Of those questions, is there something keeping you from being able to do them?
- How can we help out?

An intentional shift from a dependency model to a partnership model.
Top 5 Strategies for Parents to Support Youth for a Successful Health Transition

1. Expose your youth early in the process to the reasons behind strength-based vs. deficit-based language and how it impacts them.
2. Embrace the difference between health and health-care and understand your role in both.
3. Be proactive in seeking guidance about whom you should add to your child’s medical home team – think about who, why and when.
4. Critical information, including insurance card, health diagnoses, medications and treatment guidance should always be accessible to the youth – noted in their Blackberry, backpack, iPad, etc.
5. Establish a partnership with health care providers, grounded in trust and respect.

Top 5 Strategies for Youth to be Advocates in Transition:

1. Know your condition, be a teacher, and have confidence that you are the expert in your life.
2. Swallow your pride- Know when to ask for and accept help
3. Accept the support of your parents/providers to learn ways to take responsibility yourself
4. Broaden circle of support. Make others comfortable vs. fear of the unknown
5. Think outside the box, don’t let your condition control your life. **Diagnosed but not defined**

Lessons Learned

- Relationship building is often at the core of successful medical care
- Relationships between pediatric and adult providers are difficult to build, maintain, and sustain
- Trust is a key component of a successful handoff
- The medical system does not foster collaborative, trust-based team care

When is it a good time to think about transfers?

- When there is a natural break (like going to college or moving).
- When medical and psychosocial situations are stable.
- When the transition can be celebrated (like a graduation not a funeral).

When should you wait?

- When there is an acute medical or psychosocial issue.
- When the patient/family is vocal about not being ready.
- When the provider is vocal about not being ready.

How does our process look?

- Transition is discussed at every adolescent visit.
- Transfers are discussed (not forced) starting after age 21y.
- Physician role.
- Case Management role.
- Transition Navigator role.
- Parent role.
- Patient role.
Helpful Resources

Got Transition? National Center for Health Care Transition
www.gottransition.org

Family Voices
www.familyvoices.org

El Grupo Vida
www.elgrupovid.org

American Academy of Pediatrics
www.medicalhomeinfo.org

It's Time To Transition Workbook
www.cdphe.state.co.us/ps/hcp/transition/workbook.pdf

Contact Information

Dr. Laura Pickler, MD MPH
Laura.Pickler@coloradochildrens.org

Eileen Forlenza
Eileen.Forlenza@state.co.us