Advancing Family-Centered Care Coordination

Implement Strategies To Support Youth Health Transition

Anne Harris

April 23, 2019
Learning Objectives

- Understand expectations of your selected additional focus area (Implement strategies to support youth health transition)
- Understand content of the presentation for families
- Understand resources to support families on this topic
- Be aware of partners available to support your team in fulfilling these expectations
Participating Sites

- Children's Hospital of WI-Complex Care Program
- Children's Hospital of WI/Medical College of WI - Rheumatology Clinic
- UW Health- Pediatric Complex Care Clinic (Sodergren)
## Populations selected for piloting Shared Plans of Care

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Patient Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children's Hospital of WI-Complex Care Program</td>
<td>Children with medical complexity (CMC) who are 12 yrs old or older who are currently enrolled in the program</td>
</tr>
<tr>
<td>Children's Hospital of WI/Medical College of WI - Rheumatology Clinic</td>
<td>Newly diagnosed children/adolescents with chronic rheumatic disease</td>
</tr>
<tr>
<td>UW Health- Pediatric Complex Care Clinic (Sodergren)</td>
<td>Children with medical complexity who are enrolled in the program ages 12-21</td>
</tr>
</tbody>
</table>
Implement strategies to support youth health transition

1. Complete Got Transition’s Current Assessment of Health Care Transition Activities within the first month of the project, by January 31, 2019 (baseline date), and complete again in the fourth quarter to reflect on project impact.
First Quarter Results Current Assessment of Health Care Transition Activities
Range and Mean Value of 2018 Clinic Self-Assessment Levels at **Baseline**

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transition policy</td>
<td>Transition tracking &amp; monitoring</td>
<td>Transition readiness planning</td>
<td>Transition planning</td>
</tr>
<tr>
<td>Transfer of care</td>
<td>Transfer complete</td>
<td>Youth &amp; family feedback</td>
<td>Youth &amp; family leadership</td>
</tr>
</tbody>
</table>
Range and Mean Value of 2018 Clinic Self-Assessment Levels at Baseline

- Transition policy: 3.5
- Transition tracking & monitoring: 2.8
- Transition readiness: 2.5
- Transition planning: 2.8
- Transfer of care: 2.0
- Transfer complete: 2.5
- Youth & family feedback: 1.8
- Youth & family leadership: 2.0
Implement strategies to support youth health transition

2. Complete youth readiness assessment for **10 youth of transition age** (14-21 years old) for whom a shared plan of care is being implemented.
Readiness Assessment

Sample Transition Readiness Assessment for Youth

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date: ___________________________  Date of Birth: ___________________________

Transition Importance and Confidence
On a scale of 0 to 10, please circle the number that best describes how you feel right now.

How important is it to you to prepare for change to an adult doctor before age 18?

0 (not important at all) 1 2 3 4 5 6 7 8 9 10 (very important)

How confident do you feel about your ability to prepare for change to an adult doctor?

0 (not confident at all) 1 2 3 4 5 6 7 8 9 10 (very confident)

My Health

Please check the box that applies to you right now.

<table>
<thead>
<tr>
<th>Yes</th>
<th>Yes, I know this</th>
<th>I need to learn</th>
<th>Someone needs to do this... Who?</th>
</tr>
</thead>
</table>

I know my medical needs.
I can explain my medical needs to others.
I know my symptoms including ones that I quickly need to see a doctor for.
I know what to do in case I have a medical emergency.
I know my own medications, what they are for, and when I need to take them.
I know my allergies to medicines and medicines I should not take.
I carry important health information with me every day (e.g., insurance card, allergies, medications, emergency contact information, medical summary).
I understand how health care privacy changes at age 18 when legally an adult.
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.

Using Health Care

<table>
<thead>
<tr>
<th>Yes</th>
<th>Yes, I know this</th>
<th>I need to learn</th>
<th>Someone needs to do this... Who?</th>
</tr>
</thead>
</table>

I know or can find my doctor’s phone number.
I make my own doctor appointments.
Before a visit, I think about questions to ask.
I have a way to get to my doctor’s office.
I know to show up 15 minutes before the visit to check in.
I know where to go to get medical care when the doctor’s office is closed.
I have a file at home for my medical information.
I have a copy of my current plan of care.
I know how to fill out medical forms.
I know how to get referrals to other providers.
I know where my pharmacy is and how to refill my medications.
I know where to get blood work or x-rays if my doctor orders them.
I have a plan so I can keep my health insurance after 18 or older.
My family and I have discussed my ability to make my own health care decisions at age 18.

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Implement strategies to support youth health transition

3. In collaboration with your Regional Center for CYSHCN and the Youth Health Transition Initiative, complete a **Build Your Bridge** youth health transition training for families.
Build Your Bridge

Learning Objectives:

- Define youth health care transition: what it is and why it is important.
- Identify activities in daily life where transition occurs.
- Apply tools and resources to take an active role in the health care transition process.
- Start a health transition action plan.
Build Your Bridge

Moving from Child to Adult Health Care

May 18, 2017
Eight Tools

1. Adult Providers
2. Decisions
3. Health Insurance
4. Emergency Contacts
5. Appointments
6. Medications
7. Health Summary
8. About Me
# Transition Action Plan

**Transition Action Plan**

<table>
<thead>
<tr>
<th>Tool</th>
<th>Page #</th>
<th>Next Step(s)</th>
<th>Who is Involved?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Provider(s)</td>
<td>3-4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decisions</td>
<td>5-7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Insurance</td>
<td>8-9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency Contacts</td>
<td>10-11</td>
<td></td>
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Thanks for your insight and information - so much I never thought about.

My kids are 4 and 6 so we don't know what they will look like at the age of transition. This was VERY helpful to know what is to come!

I will start early to allow [my child] to practice skills and being able to make as many decisions for himself as he is able to do.

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**Extent to which Build Your Bridge Participants agreed to**

"The presentation was worth my time"

*Sept 2017 - March 2018; n=35*

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Neither agree nor disagree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent only</strong></td>
<td>51%</td>
<td>43%</td>
<td></td>
<td></td>
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</table>

1. “Thanks for your insight and information-so much I never thought about”

2. “My kids are 4 and 6 so we don't know what they will look like at the age of transition. This was VERY helpful to know what is to come!”

3. “I will start early to allow [my child] to practice skills and being able to make as many decisions for himself as he is able to do.”
CYSHCN Network of Support

Wisconsin Title V Children and Youth with Special Health Care Needs Program
CYSHCN Regional Centers

**Why would a family member or provider contact the CYSHCN Regional Centers?**

- Information on your child’s condition
- Problem-solving
- Partnering with your doctor in a Medical Home
- Health Transition from child to adult health care
- Health insurance / benefits assistance (e.g. Medicaid)
- Services in the community
- Parent-to-Parent support
- Finding doctors and dentists
- Parent training events
- Communicating with schools
Family Voices of Wisconsin

**Why would a parent contact Family Voices of Wisconsin?**

- To serve in a leadership or advisory role to impact health care or long-term supports
- To join our regional Facebook groups, be added to the Family Action Network and our mailing list
- Register for a training
- Have resources printed from our website
- Have suggestions for a newsletter article, fact sheet, or new training
Why would a parent contact Parent to Parent of Wisconsin?

- To request a “match.”
- To register for a Support Parent training.
- To schedule a Support Parent training in their area.
Wisconsin Medical Home Initiative

Why would a family member or provider contact the Wisconsin Medical Home Initiative?

- To learn more about partnering with their child’s doctor.
- To learn more about use of a shared plan of care to facilitate care for CYSHCN.
Wisconsin Youth Health Transition Initiative

Why would a family member contact the Wisconsin Youth Health Transition Initiative?

- Visit the YHTI website for information, tools and resources to help prepare and plan for health transition.

- Seek and receive more information through training programs sponsored by partners including things to consider at different ages as well as ways they can support their child to become more involved in their health care.
Discussion Questions
Thank You!