Transitioning from Pediatric to Adult Healthcare for People with Intellectual and/or Developmental Disabilities (I/DD)

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University of Colorado
April 28, 2021
## Learning Objectives

<table>
<thead>
<tr>
<th>Define</th>
<th>Define transition, and define transfer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss</td>
<td>Discuss healthcare disparities patients with I/DD experience as they age.</td>
</tr>
<tr>
<td>Review</td>
<td>Review research about healthcare for adults with IDD.</td>
</tr>
</tbody>
</table>
| Outline        | Outline the process of an ideal healthcare transition.  
  • (Wait a minute, there is no ideal! It should all be tailored to each patient and family’s unique situation and timeline.) |
| Understand     | Understand the perspective of a patient/family who has undergone transition from pediatric to adult healthcare. |
What is health care transition?

• A dynamic process of moving from pediatric to adult health care system
  • Prepare youth to receive care within the adult health care system.
    • Includes caregivers
  • Transition should be:
    • Patient centered
    • Developmentally appropriate
    • Comprehensive, uninterrupted

Blum, R.W., et al. (2002).
State of evidence-based practices in transition
(Mora et al., J. Adol Health, 2019)

- Over 19,000 articles = > 952 reviewed
- Countries represented
  - US, Canada, UK
- 7 Randomized Controlled Trials
- Focused on specialty populations
- Varied quality, consistency
Got Transition 6 Core Elements of Transition

1. Transition policy
2. Transition tracking and monitoring
3. Transition readiness
4. Transition planning
5. Transfer and/or integration into adult-centered care
6. Transition completion and ongoing care with adult clinician

- Discuss transition policy (Age 12 to 14)
- Track progress (Age 14 to 18)
- Assess skills (Age 14 to 18)
- Develop HCT plan, including medical summary (Age 14 to 18)
- Transfer to adult-centered care
- Integration into adult practice (Age 18 to 21)
- Confirm transfer completion
- Elicit consumer feedback (Age 18 to 26)

Slide from Dr. Miya Asato’s grand rounds
8 Common Principles of Transition

1. Expectation of Transition
2. Yearly Self-Management Assessment
3. Annual Discussion of Medical Condition and Age-Appropriate Concerns
4. Evaluation of Legal Competency
5. Annual Review of Transition Plan of Care
6. Child Neurology Team Responsibilities
7. Identification of Adult Provider
8. Transfer Complete
Goals of Transition

- Medical
- School/Employment
- Legal
Medical Transition

• There are major differences between the **pediatric** model and the **adult** model of care
  • Paternalistic vs. independent
  • Holistic vs. symptom based
  • Level of comfort with developmental and behavioral issues
Goals of Health Care Transition:

- Maximize lifelong functioning and potential
  - Promote self-advocacy, teach self-management skills
- Prevent “bridge to no where”
  - Good communication and uninterrupted services
Successful transition leads to:

- Continuity of care
  - Fewer gaps in clinical follow up
  - Improved access to care
    - Decreased financial barriers to care
- Improved adherence
  - Better disease (for example, seizure) control
  - Fewer emergencies
- Improved quality of life

*Slide content from TSC Conference 2017, Dr. Schultz*
Consequences of poor transition

- Risk for medical complications
- Problems with treatments and medical adherence
- Discontinuity of care
- Higher acute care utilization and costs (Fortuna et al., 2010)

Slide content from Dr. Miya Asato’s grand rounds
The need for transition services

National core indicators (NCI) data - collaboration of state developmental services agencies

Women with ID/DD are less likely to
- Have cervical and breast cancer screenings
- Have ever visited a gynecologist

Adults with ID/DD are less likely to
- Visit the dentist regularly
- Get eye and hearing tests
- Receive vaccines

Lower income households experienced even greater disparities.

Patients with Sickle cell disease have increased risk of mortality during transition.
Figure 1.
“Cascade of Disparities” leading to poor health outcomes in adults with intellectual disabilities.
Transition:
More difficult for youth with chronic conditions/developmental disabilities

MCHB Core Outcome #6: CSHCN age 12-17 years who receive services needed for transition to adult health care, work and independence
CSHCN age 12-17 years only

Nationwide

Outcome successfully achieved
- One or more emotional, behavioral or developmental issues: 28.5%
- No qualifying emotional, behavioral or developmental issues: 46.1%

Outcome not achieved
- One or more emotional, behavioral or developmental issues: 71.1%
- No qualifying emotional, behavioral or developmental issues: 53.9%

90% of children with chronic conditions, including ID/DD, survive to become adults.
SURVEY OF RESIDENTS

- N=412 Residents
- 96% treated a patient with IDD
- 24% received formal education about IDD during their training

How comfortable are you treating patients with IDD?

- Just over half say they feel COMFORTABLE treating patients with IDD...
  - Very uncomfortable 2%
  - Somewhat uncomfortable 15%
  - A little uncomfortable 26%
  - A little comfortable 24%
  - Somewhat comfortable 29%
  - Very comfortable 5%
Transition takes

- Time
  - Locate resources
  - Learn new information
- Advocacy
- Tenacity
#1 Start Early

- Begin discussion at 12-13 years of age
  - Ask your doctor when you will have to transfer to adult care?
    - 18 years
    - 21 years
    - Never
  - Will they help you with this process? How?

- Begin to set goals and expectations
  - Obtain optimal independence
#2 Self-Care Assessment

<table>
<thead>
<tr>
<th>My Health</th>
<th>Yes, he/she knows this</th>
<th>He/she needs to learn</th>
<th>Someone needs to do this... Who?</th>
</tr>
</thead>
<tbody>
<tr>
<td>My child knows his/her medical needs.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child can explain his/her medical needs to others.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child knows his/her symptoms including ones that he/she quickly needs to see a doctor for.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child knows what to do in case he/she has a medical emergency.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child knows his/her own medicines, what they are for, and when he/she needs to take them.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child knows his/her allergies to medicines and medicines he/she should not take.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child carries important health information with him/her every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child knows he/she can see a doctor alone as I wait in the waiting room.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child understands how health care privacy changes at age 18.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My child can explain to others how his/her customs and beliefs affect health care decisions and medical treatment.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Make emergency plan

- Medical Alert bracelet/necklace or tag
- Wallet card
  - Diagnoses, seizure type
  - Medications
  - Allergies
  - Emergency contact information
  - Medical contact information

Slide content from TSC Conference 2017, Dr. Schultz
#3 Annually Discuss Medical Condition and Age-Appropriate Concerns:

Discuss:

- The youth’s **medical condition**
- Current **medications** and potential side effects
- Signs and symptoms of concern
- **Genetic counseling** and reproductive implications of the condition
- Issues of **puberty** and **sexuality**
- Driving, alcohol and substance use, and other risks
- **Emotional/psychological** concerns and **wellness**.
#4 Discuss Legal Competency

- Medical and Financial Power of Attorney
- Proxy Decision Maker
- Supported Decision-Making
- Guardianship Alliance of Colorado offers classes to discuss each option in detail and help families decide what is best.

- Full guardianship means having the court appoint a guardian; individual is then considered “adjudicated.”
- Can be a difficult decision
Developed in collaboration with youth, health, school, and vocational professionals.

Should address:

- Health care finance and legal concerns
- Primary care
- Other specialty care
- Education to employment
- Housing
- Community services
#6 Define Responsibilities of team members
Identify Adult Provider(s)

• How can we help our patients access adult providers?

• Give adult providers tools to feel confident accepting the transition-age patient:
  • Provide plan of care
  • Provide information about the condition
  • Provide prior records, for example, imaging or genetic testing
Transfer to Adult Provider
Transition Clinic

- Occurs monthly
- Held within Developmental Pediatrics
- Patients age 14-26
- 2 hour visit:
  - 1 hour with MD
  - 1 hour with social work
# Portable Medical Summary

**SPECIAL HEALTHCARE NEEDS** (common emergency problems, communication, sensory triggers, procedures to avoid/adapt, important behaviors around health care, recommendations for exams, certain labs or procedures needed, etc)

**CURRENT PROBLEM LIST** (include date of onset, current status, provider managing)

**CURRENT MEDICATIONS** (dose, date started, targeted symptoms, positive and negative effects and prescribing provider)

## MEDICAL SUMMARY AND EMERGENCY ACTION PLAN

<table>
<thead>
<tr>
<th>LAST UPDATED:</th>
</tr>
</thead>
</table>

<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>Phone number:</td>
</tr>
<tr>
<td>Date of Birth:</td>
<td>Relation to Patient:</td>
</tr>
<tr>
<td>Address:</td>
<td>Preferred emergency care location:</td>
</tr>
<tr>
<td>Phone number:</td>
<td></td>
</tr>
<tr>
<td>Email:</td>
<td></td>
</tr>
<tr>
<td>Insurance:</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>MEDICAL DECISION-MAKING</strong></th>
<th><strong>CONTACT INFORMATION OF DECISION-MAKER</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Can make own medical decisions? YES NO</td>
<td>Same as emergency contact? YES NO</td>
</tr>
<tr>
<td>Substitute decision-maker? YES NO</td>
<td>Title (guardian, power of attorney):</td>
</tr>
<tr>
<td>Name:</td>
<td>Goes by:</td>
</tr>
<tr>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Phone number:</td>
<td>Relation to Patient:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>ALLERGIES</strong> (include type of reaction)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th><strong>PRIMARY DIAGNOSES:</strong> (date of onset, etiology, current status)</th>
</tr>
</thead>
</table>
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>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

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# Transition Planning Roadmap for PCP

## Transition Guidelines for Adolescents with Developmental Disabilities

<table>
<thead>
<tr>
<th>Activity</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></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Share written practice policy on medical transition with family</td>
<td></td>
<td></td>
<td>X</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></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Develop brief portable medical summary</td>
<td></td>
<td></td>
<td></td>
<td>X</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></td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Discuss possible need for day programming</td>
<td>X</td>
<td></td>
<td></td>
<td>X</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></td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Send brief letter and portable medical summary to adult care provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

X = Recommended at this age

* = If not already done, recommended at this age
Transition clinic is a resource for patients with developmental disabilities to plan for the future in both medical and non-medical aspects of life, which will look different for everyone!
Adult Developmental Disabilities Clinic at UC Health

- Brand new clinic with Dr. Jessi Solomon Sanders
- Consultations for adults with Developmental Disabilities
- Within the Behavioral Neurology Clinic at UC Health
- **Phone:** 720-848-2080
- **Address:** UCHealth Central Park Medical Center
  - 3055 Roslyn Street, Suite 120
  - Denver, CO 80238
How are youth and adults faring in the pandemic?
Preliminary data suggests behavioral health challenges worsened

How would you rate your overall PHYSICAL health right now?
N = 245

- Excellent: 24.1%
- Good: 56.7%
- Fair: 15.5%
- Poor: 3.7%

How would you rate your overall MENTAL health right now?
N = 245

- Excellent: 4.5%
- Good: 40.7%
- Fair: 44.3%
- Poor: 10.6%
The importance of adult services

“Please tell us how your services/activities have CHANGED because of the COVID pandemic.”

Paid Work/Employment

- I continue to do this: 9%
- I continue to do this... But LESS: 7%
- I USED to do this... But now I CANNOT because of COVID: 21%
- I NEVER did this: 63%

Day Programming/Supports in the Community

- I continue to do this: 7%
- I USED to do this: 21%
- I NEVER did this: 31%
- 41%
Impact of the Pandemic on Behavioral Health of People with Intellectual and/or Developmental Disabilities

Share your Story!

Please take this survey to help us learn more about the mental health challenges and changes of people with intellectual and developmental disabilities during the Covid 19 pandemic.

To participate in the survey, use the QR Code below or follow the link:

Want to learn more about the survey?

Contact:
Jessica Solomon Sanders, MD
jessica.sanders@childrenscolorado.org

https://redcap.link/covidimpact
Questions?

Jessi Solomon Sanders, MD: jessica.sanders@childrenscolorado.org

RESOURCES:
• https://www.childneurologyfoundation.org/transitions/
• GotTransition.org
• IDDtoolkit.org