

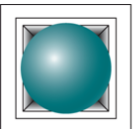
Making Health Care Transition Work for Youth with Autism: Youth and Parent Perspectives and National Resources

NIMH Webinar, December 13, 2019, 2:00-3:00 PM EST

Sarah Beth McLellan, Maternal and Child Health Bureau, Health Resources and Services Administration, HHS

Allysa and Lauren Ware, Family Voices

Peggy McManus, Got Transition®/The National Alliance to Advance Adolescent Health

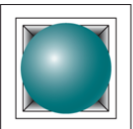


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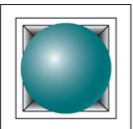
Disclosures

- The National Alliance to Advance Adolescent Health operates Got Transition[®], which is funded by the federal Maternal and Child Health Bureau (U1TMC31756).
- The presenters have no disclosures.



Presentation Overview

- Federal Maternal and Child Health Bureau's (MCHB's) portfolio of health care transition programs
- Real-life parent and daughter exchange about health care transition perspectives
- New and useful resources available for parents and youth at Got Transition, MCHB's national resource center





Health Care Transition and Children and Youth with Special Health Care Needs

Presentation for the National Institute for Mental Health

Sarah Beth McLellan, MPH
Public Health Analyst, Division of Services for CYSHCN
Maternal and Child Health Bureau (MCHB)

Vision: Healthy Communities, Healthy People



Health Resources and Services Administration (HRSA)

- Supports over 90 programs providing health care to people who are geographically isolated, economically or medically challenged
- Over 3,000 awardees, including community and faith-based organizations, colleges and universities, hospitals, state, local, and tribal governments, and private entities
- Serves tens of millions of people, including people living with HIV/AIDS, pregnant women, mothers and their families, and those otherwise unable to access quality health care



Maternal and Child Health Bureau: Who are we?

Our Mission:

To provide leadership, in partnership with key stakeholders, to improve the physical and mental health, safety and well-being of the maternal and child health (MCH) population which includes all of the nation's women, infants, children, adolescents, and their families, including fathers and children with special health care needs.



Division of Services for Children with Special Health Needs

- *Children and youth with special health needs are 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 or a type or amount beyond that required for children generally**
 - Over 18% of U.S. children under age 18 years have a SHCN
 - Only 14% of CSHCN receive care in a well-functioning system
 - Services needed from multiple systems—health care, public health, education, mental health, and social services



What are we trying to achieve?



- Optimal health and quality of life for all CYSHCN and their families
- Effective system of care for CYSHCN to achieve optimal outcomes
- Programs are centered around the child or youth with special health needs and their family

Our Driving Framework: Six Core Systems Outcomes



- Early and continuously screening



- Access to comprehensive and coordinated care through the medical home



- Community services are organized for easy use by families



- Families are partners in decision-making



- Adequate insurance/financing to pay for needed services



- Youth receive services needed to transition to adult health care

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Programmatic Focus on Health Care Transition

- **Got Transition**
- State Title V MCH Programs
- Leadership Education in Neurodevelopmental Disabilities (LEND)
- Epilepsy Programs
- Hemophilia Programs
- Sickle Cell Disease Programs



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Shared commitment to:

- Partnering with youth and families
- Collaborating with other entities—local, state, and federal level
- Using the evidence-base to reach project goals

Contact Information

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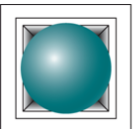


Got Transition

Peggy McManus

Co-Director, Got Transition

President, The National Alliance to Advance Adolescent Health

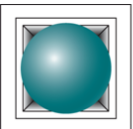
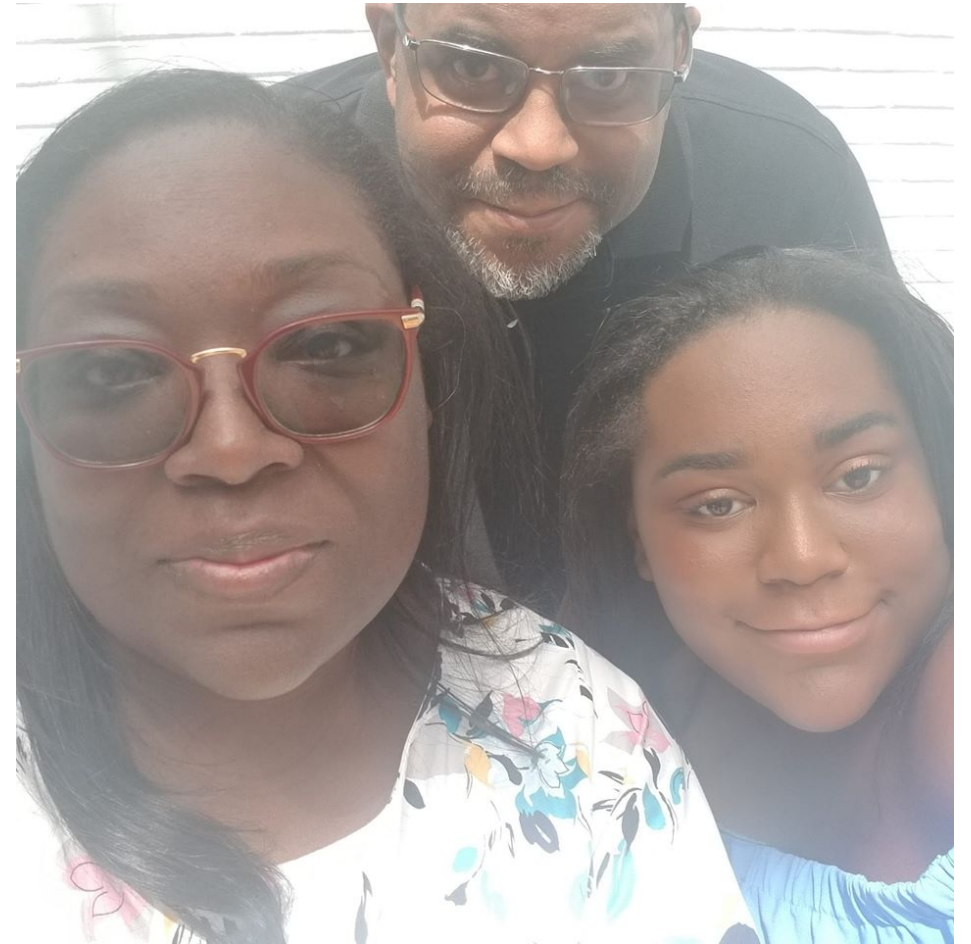


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Parent and Daughter Introduction

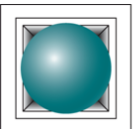
- Allysa Ware, MSW (soon to be PhD)
 - Program Manager, Family Voices
 - Parent consultant, Got Transition
- Lauren Ware, high school student
 - Flutist (soon to be Music Performance major)
 - Lover of cats
 - Passionate about politics



Real-Life Exchange on Health Care Transition

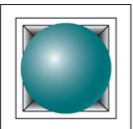
Allysa and Lauren will begin a conversation discussing the following questions:

1. At what age should parents and youth start talking and thinking about health care transition?
2. What information do you feel like you need to know to confidently handle your own health care?
3. How often does your doctor speak directly to you and offer to talk to you by yourself?



Real-Life Exchange on Health Care Transition (Continued)

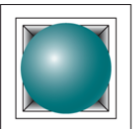
4. What information and guidance from your doctor would be helpful in planning for health care transition?
5. Have you received help from your doctor about transition?
6. What are some of your concerns about changing from family-centered pediatric care to patient-centered adult care?
7. What suggestions would you offer your pediatric doctor to make this change easier?



New and Useful Health Care Transition Resources

Got Transition (www.gottransition.org)

- ❑ Serves as a clearinghouse of resources on transition for health professionals, youth and families, and researchers and policymakers
- ❑ Develops and disseminates practice resources (eg, Six Core Elements of HCT), tip sheets (eg, coding and reimbursement, medical home), and research and quality improvement reports (eg, on evidence for HCT, quality improvement studies)
- ❑ Provides education and technical assistance to state public health programs and others to guide evidence-based HCT approaches.



Resources for Improving the Transition Process

- Working with youth around transition readiness skills

Pediatric to Adult Care Transitions Tools | Self-Care Assessment for Young Adults with Intellectual/Developmental Disabilities

This document should be completed by young adults (aged 18-25 years old) with intellectual or developmental disabilities in order to assess their ability to engage in self-care with regards to their health. If a young adult's intellectual or developmental disabilities prevent him or her from independently filling out this document, the young adult's caregiver should fill out the caregiver version of this Self-Care assessment form instead.

Please fill out this form to help us see what you already know about your health and using health care and areas that you need to learn more about. If you need help completing this form, please let us know.

Date:

Name:

Date of Birth:

Legal Choices for Making Health Care Decisions

- I can make my own health care choices.
- I need some help with making health care choices (Name: _____ Consent: _____).
- I have a legal guardian (Name: _____).
- I need a referral to community services for legal help with health care decisions and guardianship.

Personal Care

- I care for my all my needs.
- I care for my own needs with help.
- I am unable to provide self-care, but can direct others.
- I require total personal care assistance.

Transition and Self-Care 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 take care of your own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
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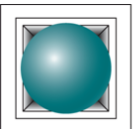
How confident do you feel about your ability to take care of your own health care?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
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My Health

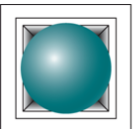
Please check the box that applies to you right now.

	Yes, I know this.	I need to learn.	Someone needs to do this... Who?
I know my medical needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can tell other people what my medical needs are.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do if I have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know the medicines I take and what they are for, and when I need to take them without someone reminding me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what medicines I should not take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what I am allergic to, including medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can name 2-3 people who can help with my health goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain to people how my beliefs affect my care choices.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



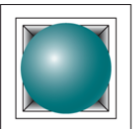
More Resources

- Preparing a medical summary and emergency care plan
 - American College of Physicians:
 - Transition Readiness Assessment:
www.acponline.org/sites/default/files/documents/clinical_information/high_value_care/clinician_resources/pediatric_adult_care_transitions/gim_dd/idd_transitions_tools.pdf
 - Medical Summary and Emergency Care Plan:
www.acponline.org/sites/default/files/documents/clinical_information/high_value_care/clinician_resources/pediatric_adult_care_transitions/gim_dd/idd_medical_summary_for_young_adults.docx



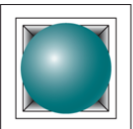
Tip Sheets for Youth and Family Members

- Questions to Ask Your Doctor about Transitioning to Adult Health Care
 - gottransition.org/resourceGet.cfm?id=440
- Questions to Ask Your Child's Doctor about Transitioning to Adult Health Care
 - gottransition.org/resourceGet.cfm?id=441
- Integrating Young Adults with Autism Spectrum Disorder into Your Practice: Tips for Adult Health Care Clinicians
 - gottransition.org/resourceGet.cfm?id=518
- Planning to Move from Pediatric to Adult Care?
 - gottransition.org/resourceGet.cfm?id=5
- Turning 18: What it Means for Your Health
 - gottransition.org/resourceGet.cfm?id=446



More Resources

- 2018 AAP/AAFP/ACP Clinical Report on Health Care Transition: Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home
 - pediatrics.aappublications.org/content/142/5/e20182587
- Young Adult Transition Quiz: “Are you ready to transition to adult health care?”
 - English: gottransition.org/youthfamilies/HCTquiz.cfm
 - Spanish: gottransition.org/youthfamilies/HCTquizES.cfm



Thank You and Questions



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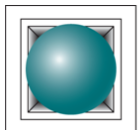


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