

## **Health Care Transition for Youth with Special Health Care Needs (YSHCN)**

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## **Disclosures**

- None

## **Objectives**

- Describe the need for successful health care transitions for youth with special health care needs (YSHCN)
- Summarize the goals of transitional health care for YSHCN
- Discuss the challenges and barriers to successful transitions for YSHCN
- Suggest what physicians can do to improve the transition process for YSHCN

## **Who are Youth With Special Health Care Needs (YSHCN)?**

“Children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional conditions and who also require health-related services of a type and amount beyond that typically required by children”

## Medical Conditions of YSHCN

Allergies 53.0%	Seizure disorder 3.5%
Asthma 38.8%	Heart problems 3.5%
ADHD 29.8%	Blood problems 2.3%
Mood disorder 21.1%	Cerebral palsy 1.9%
Headaches 15.1%	Diabetes 1.6%
Intellectual Disability 11.4%	Down syndrome 1.0%
Autism 5.4%	Muscular dystrophy 0.3%
Joint problems 4.3%	Cystic fibrosis 0.3%

## YSHCN a Growing Population

- In 1950's, 20% of infants born with moderate or complex congenital heart disease survived their first year of life.
- Now, 80-90% of these children live to adulthood.
- In 1920, the mean age of death for a patient with Down Syndrome was 9 years old.
- In 2000, the mean age of death was 56.

## YSHCN a Growing Population

- 15% of children less than 18 years old have special health care needs
- 90% of these children will live into adulthood
- Each year 500,000 YSHCN will turn 18

## What is Health Care Transition?

“The purposeful, planned movement of youth with special health care needs from pediatric to adult care”

## Challenges of Transition

- Increased emergency department visits and hospitalizations
- Increased frequency of exacerbation of illness
- Gaps of care
- Lack of insurance
- Lack of housing
- Decreased employability
- Guardianship

## Health Benefits of Transition

- Screening for and treatment of adult conditions
- Provider experience with chronic adult conditions
- Access to adult inpatient and specialist services
- Informed and sensitive reproductive care
- Multidisciplinary support services to promote independence (housing, employment, transportation, guardianship)
- Facilitate long term planning and goals of care

## Goal of Transition

**“Maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.”**

*AAP, AAFP, ACP. Consensus statement of health care transition for young adults with special health care needs. Pediatrics 2002*

## 2002 Consensus Statement Goals for Transition to Adult Care

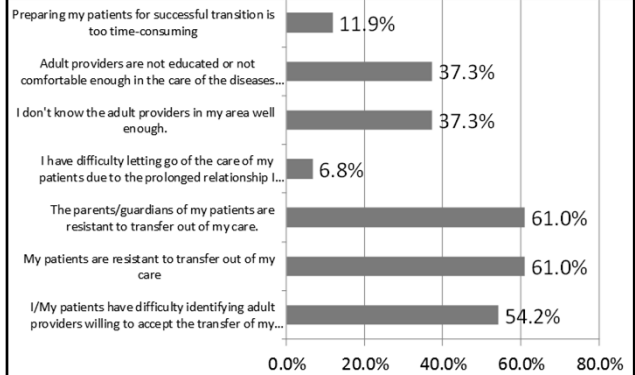
- Health care provider for current health care, care coordination, and future health care planning
- Up to date, portable, accessible medical summary
- Written health care transition plan by age 14
- Preventative care that follows guidelines
- Continuous, affordable, insurance coverage
- Core knowledge and skills about providing developmentally appropriate care should be training requirements for primary care residents and practitioners

## Current Status of Transition for YSHCN

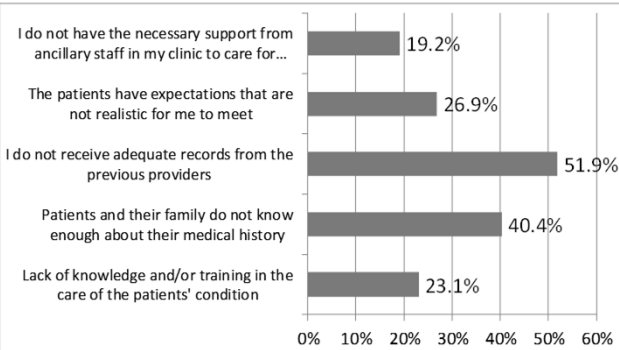
- Only 40% of YSHCN meet the national transitional core outcomes.
- Although most providers are encouraging YSHCN to assume responsibility for their own health, far fewer are discussing transfer to an adult provider and insurance continuity.

McManus Margaret et al Pediatrics. 2013

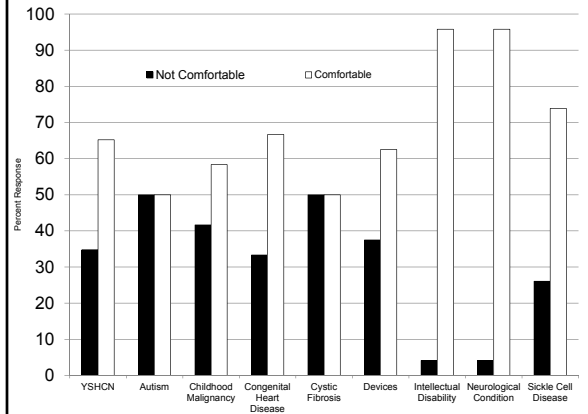
## Barriers to Successful Transitions: Pediatric Perspective



## Barriers to Successful Transitions: Adult Provider Perspective



## Comfort Level of Adult Health Care Provider by Chronic Disease Condition



### **Expectations of Physicians who Care for YSCHN**

- Understand the rationale for transition from child-oriented to adult-oriented health care
- Have the knowledge and skills to facilitate that process
- Understand how and when transfer of care is indicated

### **Six Core Elements of Transition**

1. Transition Policy
2. Transition Tracking and Monitoring
3. Orientation to Adult Practice
4. Integration into Adult Practice
5. Transfer of Care/Initial Visit
6. Transfer Completion/Ongoing Care

[www.gottransition.org](http://www.gottransition.org)

### **1. Transition and Care Policy**

- Develop a statement that describes the practice's approach to accepting new young adults, including privacy and consent information.
- Educate staff about the practice's approach.
- Post policy and discuss with young adults at first visit and regularly as part of ongoing care.

### **2. Tracking and Monitoring**

- Establish process for identifying transitioning patients until age 26 and enter their data into a registry.
- Track young adults' completion of the Six Core Elements incorporating them into the clinical care process, using EHR if possible.

### **3. Orientation to Adult Practice**

- Identify adult providers interested in caring for young adults.
- Establish a process to orient new young adults into practice.
- Provide information about the practice and offer a "get-acquainted" appointment.

### **4. Integration into Adult Practice**

- Communicate pediatric provider(s).
- Ensure receipt of transfer package.
- Make pre-visit reminder call identifying any special needs.
- Provide linkages to information on insurance, self-care management, and community supports.

### **5. Transfer of Care/Initial Visit**

- Review transfer package.
- Address patient concerns about transfer.
- Conduct self-care assessment (transition readiness assessment).
- Review patient's health priorities.
- Update portable medical summary and emergency care plan.

### **6. Transfer Completion/Ongoing Care**

- Communicate with pediatric practice confirming transfer and consult as needed.
- Connect patient with adult specialists and other support services.
- Continue with ongoing care management.
- Elicit feedback to assess experience.
- Build collaborative partnerships with pediatric primary and specialty care providers.

## **Timeline for Health Care Transition**

- **Age 12:** Make youth and family aware of transition policy
- **Age 14:** Initiate health care transition planning
- **Age 16:** Prepare youth and parents for adult model of care and discuss transfer
- **Age 18:** Transition to adult model of care
- **Age 18-22:** Transfer care to adult medical home and/or specialists with transfer package
- **Age 23-26:** Integrate young adults into adult care

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## **A Case-based Approach to Transitions of Care from Pediatric to Adult-based Care Settings**

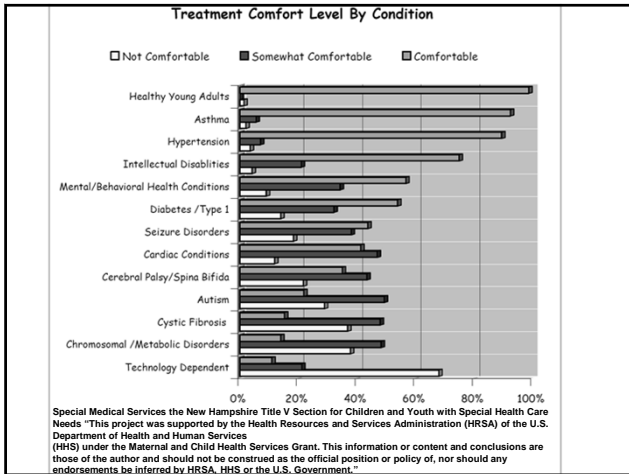
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## **Disclosures**

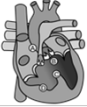
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## **Outline**

- **Case-based discussion of transition-specific challenges**
  - **Transition readiness assessment**
  - **Transition planning**
  - **Available tools and resources**
  - **Special populations:**
    - **Intellectual disability/autism**
    - **Rare genetic conditions**



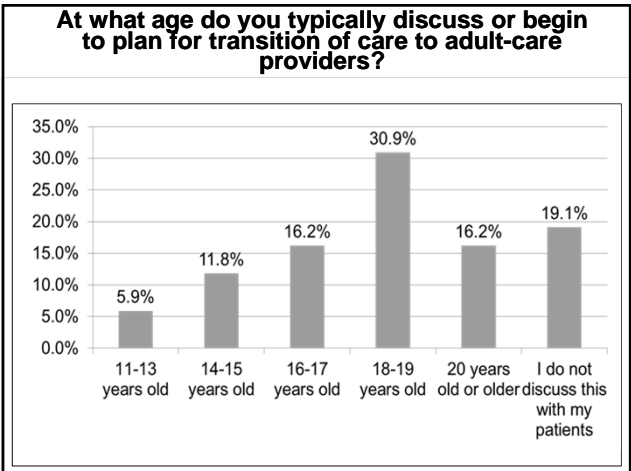
## Case 1



- You are seeing a 16 year old female for a well child check. She has a history of Tetralogy of Fallot s/p repair as a young child. She sees her pediatric cardiologist for yearly visits. Her most recent echocardiogram shows some developing tricuspid regurgitation, but she remains asymptomatic at this time. She is sexually active and takes oral contraceptive pills. She does well in school and is planning to attend college.

## Case 1

- What should you be doing to help her prepare for transition to adult-based care?
  - Anticipatory Guidance
  - Assess Transition Readiness
  - Transition Planning





## Anticipatory Guidance

- Age 12: Make youth and family aware of transition policy
- Age 14: Initiate health care transition planning
- Age 16: Prepare youth and parents for adult model of care and discuss transfer
- Age 18: Transition to adult model of care
- Age 18-22: Transfer care to adult medical providers

## Assess Transition Readiness

Patient Name: \_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_ Today's Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ (MM/DD/YYYY)

Transition Readiness Assessment Questionnaire 5.0

Directions: Please check the box that best describes your skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

	No, I do not know how	No, but I want to learn	Yes, I am learning to do this	Yes, I started doing this	Yes, I always do this when I need to
	1	2	3	4	5
<b>Managing Medications</b>					
1. Do you fill a prescription if you need to?					<input checked="" type="checkbox"/>
2. Do you know what to do if you are having a bad reaction to your medication?					<input checked="" type="checkbox"/>
3. Do you take medications correctly and on your own?					<input checked="" type="checkbox"/>
4. Do you monitor medications before they run out?		<input checked="" type="checkbox"/>			
<b>Appointment Keeping</b>					
5. Do you call the doctor's office to make an appointment?					<input checked="" type="checkbox"/>
6. Do you follow-up on any referral for tests or check-ups or tests?					<input checked="" type="checkbox"/>
7. Do you arrange for your ride to medical appointments?					<input checked="" type="checkbox"/>
8. Do you call the doctor about unusual changes in your health (for example, allergic reactions)?		<input checked="" type="checkbox"/>			
9. Do you apply for health insurance if you lose your current coverage?		<input checked="" type="checkbox"/>			
10. Do you know what your health insurance covers?		<input checked="" type="checkbox"/>			
11. Do you manage your money & budget household expenses (for example, use checking/savings card)?					<input checked="" type="checkbox"/>
<b>Keeping Health Issues</b>					
12. Do you fill out the medical history form, including a list of your allergies?					<input checked="" type="checkbox"/>
13. Do you keep a calendar or list of medical and other appointments?					<input checked="" type="checkbox"/>
14. Do you make a list of questions before the doctor's visit?					<input checked="" type="checkbox"/>
15. Do you get financial help with school or work?					<input checked="" type="checkbox"/>
<b>Talking with Providers</b>					
16. Do you tell the doctor or nurse what you are feeling?					<input checked="" type="checkbox"/>
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					<input checked="" type="checkbox"/>
<b>Managing Daily Activities</b>					
18. Do you help plan or prepare meals/food?					<input checked="" type="checkbox"/>
19. Do you keep home-room clean or clean-up after meals?					<input checked="" type="checkbox"/>
20. Do you use neighborhood stores and services (for example, Grocery stores and pharmacy stores)?					<input checked="" type="checkbox"/>

Courtesy of David Wood, MD, MPH

© Wood, Sawicki, Retse & Livingston, 2012

## Transition Planning

- Portable Medical Summary
- Discuss timing of transfer
  - Primary care
  - Specialists
- Insurance
- Transportation
- Other condition-specific needs



## Medical Passport

- Small, portable record carried on the person at all times
- Some medical apps could serve the same purpose.

Name	John Doe
DOB	2/2/1992
Diagnosis	Autism
Other Dx	OCD, ADHD, Cognitive Disability
Operations	tonsillectomy
Meds	Risperdal 0.2 mg daily Aldomet XR 20 mg daily Clonidine 0.1 mg QHS
All	GIF/CF
Drug allergies	none
ADL	I need help getting in and out of the tub. I can dress myself, but need help with buttons and zippers. I am independent in using the bathroom. I need some supervision when eating. I wander at night. Transportation I need someone with me when walking outside.
Communicate	It can take a while to put my thoughts into words. Sometimes I have difficulty responding to people. It is easier for me to understand pictures. extremely uncomfortable around people I don't know. I prefer to meet new people one at a time.
Behaviour	When I am upset I prefer to be left alone. Large changes upset me. Changes that upset me include: A change in routine.
Coverage	Medicaid
1 <sup>st</sup> provider	Christopher Hank's MD
Pharm	Walgreens 111-222-3333
Decisions	I have a substitute decision maker(see ICF below)
ICE	Jane Doe (mother) 333-222-1111
Date Created	4/29/2014 www.sickkids.ca/myhealthpassport

www.sickkids.ca/myhealthpassport

### Portable Medical Summary

Sample Medical Summary and Emergency Care Plan  
Six Core Elements of Health Care Transition 2.0

This document should be shared with and signed by youth and families/caregivers.

<b>Form Completed By:</b>	
<b>Child Information:</b>	<b>Relationship:</b>
Name:	Professional Language:
DOB:	Relationship:
Parent (caregiver):	Address:
Cell #:	Home #:
E-Mail:	Best Way to Reach:
Health Insurance Plan:	Text Phone Email Group and ID #:
<b>Emergency Care Plan:</b>	
Emergency Contact:	Relationship:
Preferred Emergency Care Location:	Phone:
Estimated Ongoing/Recurring Problems:	Suggested Tests:
	Treatment Considerations:
<b>Special Concerns for Transition:</b>	
<b>Allergies and Procedures to be Avoided:</b>	Reactions:
<b>To be avoided:</b>	Why?
<input type="checkbox"/> Medications	
<input type="checkbox"/> Medical Procedures	
<input type="checkbox"/> Diagnostics	
<input type="checkbox"/> Procedures	
<input type="checkbox"/> Primary Diagnosis	Details and Recommendations:
<input type="checkbox"/> Secondary Diagnosis	
<input type="checkbox"/> Behavioral	
<input type="checkbox"/> Communication	
<input type="checkbox"/> Feeding & Swallowing	
<input type="checkbox"/> Hearing/Vision	
<input type="checkbox"/> Learning	
<input type="checkbox"/> Physical/Neurodevelopmental	
<input type="checkbox"/> Physical Disabilities	
<input type="checkbox"/> Respiratory	
<input type="checkbox"/> Sensory	
<input type="checkbox"/> Sleep	
<input type="checkbox"/> Speech/Language	
<input type="checkbox"/> Other	

© 2014 Transition Tools for Health Care Transition Assessment (TCTHA) for Youth™, a program of The National Alliance to Advance Autism Research and Treatment (NAAART), www.naaart.org

Source: [www.gottransition.org](http://www.gottransition.org)

## Case 2

- You are seeing a 17 year old male with Autism and Intellectual Disability. He has limited verbal communication. He has a history of challenging behaviors and seizures and is on multiple medications for this. He struggles with medical visits, particularly if he has to spend time in a busy waiting room. It took many visits until he would allow you to fully examine him. He is dependent on family and staff for most of his activities of daily living.

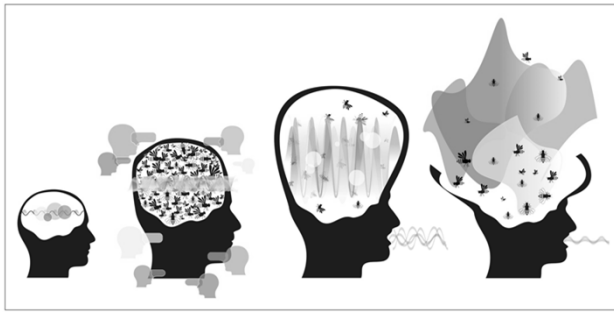
## Case 2

- What is different about transition planning in this patient compared to the 1<sup>st</sup> case we discussed?

## Case 2

- Guardianship
- Long-term planning
- Behavioral challenges: how do they affect the visit
- Condition-specific medical needs
  - e.g. Down syndrome

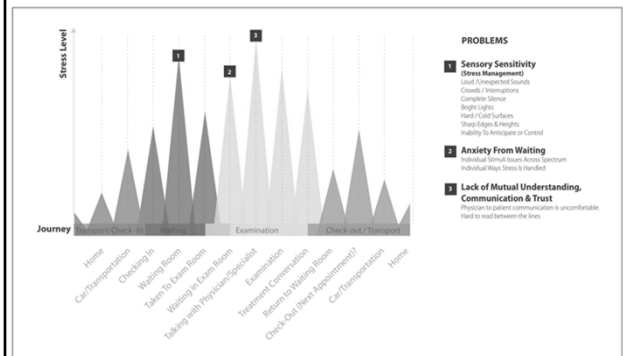
## Accommodations for patients with developmental disabilities



Erika Braun. Reshaping the Participatory Design Process for Wicked Problems. The Ohio State University. Expected Publication 2010.

Used with permission from Erika Braun

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## Case 3

- A 21 yo male college student with spina bifida presents to your office to establish care with a new PCP. He is accompanied by his mother. He has limited lower-extremity function and is wheelchair bound, performs self-catheterization of his bladder, and has a VP shunt.

## Case 3 continued

- As you take a history, his mother answers every question before he can answer, even when you ask about his future goals or how college is going.
- She provides you a list of medications and catheter supplies that need refills.
- At the end of the visit, you realize the only thing your patient has said to you is “hello” when he shook your hand.

## Internists and transitioning patients

- Survey of 67 randomly selected Internists:
  - *“Please list concerns you have about accepting the care of medically complex patients as they transition from child-centered care to adult-centered medical care.”*
- 3 items cited by greater than 5 participants:
  - 1. Difficulty obtaining records
  - 2. Lack of training in pediatric onset and congenital disorders.
  - 3. Parents often being reluctant to relinquish responsibility for healthcare/decision-making to young adult patients

Peter NG et al. *Pediatrics* 2009; 123(2): 417-423

## Adult-care Providers

- Tips to encourage parents to “let go”
  - Ask them to leave the room for part of the encounter
  - Talk directly to the patient
  - Use TRAQ or similar assessment to help re-frame the conversation
  - Give the patient “homework”
    - Learn medication
    - Write questions for next visit

## Case 4

- A 23 yo Female presents to your office to establish care.
  - Her medical history is only significant for Pseudoxanthoma elasticum (PXE), which she tells you is a genetic connective tissue disorder that can cause heart problems, blindness, GI bleeds, and blood vessel calcification.
  - Currently, her only manifestation is a rash on her neck and axilla which she has had for years.
  - She has not seen a doctor in about 5 years because she left home for college and has been busy with that

## Case 4 continued

- She was diagnosed as a teenager by a dermatologist who did a skin biopsy.
- She saw a cardiologist 5 years ago and had an echocardiogram which was normal.
- She saw an ophthalmologist 5 years ago and was told she had some “orange peel” in her eyes.
- She wants to know what she should be doing to prevent complications and remain healthy.
- She also recently found out she is pregnant and wants to know if her child will be affected.

## **Patients with rare medical conditions**

- **Genetic conditions:**
  - GeneReviews: [www.genetests.org](http://www.genetests.org)
  - Condition specific organizations: [www.pxe.org](http://www.pxe.org)
  - Genetic counselors
- Highlights the need for a portable medical summary with a “future-planning” mindset
- Pediatric providers can be a good resource.

## **Conclusions**

- **Before transfer:**
  - Start young
  - Assess current knowledge/skills
  - Make a transition plan
  - Develop a portable medical summary
- **At the time of transfer:**
  - Stagger timing of transfers of different providers
  - Allow time for “failure”
  - The transition period does not end at the time of transfer