

Health Care Transition: Moving from a child to an adult model of care

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Internal Medicine - Pediatrics

Objectives:

- ▶ Define health care transition
- ▶ Discuss importance and barriers
- ▶ Review key aspects of the 2018 AAP/AAFP/ACP Clinical Report's evidence and practice recommendations
- ▶ Discuss 6 Core Elements of Transition

What is Health Care Transition?

- ▶ Process of changing from a pediatric to an adult model of health care
- ▶ Goals :
 - ▶ improve the ability of youth and young adults to manage their own health care and effectively use health services
 - ▶ Ensure there is an organized process in place that take the pediatric and adult practices, as well as youth and their families, through the 3 major steps of transition
 - ▶ Planning
 - ▶ Transfer
 - ▶ Integration

Why does it matter?

- ▶ Everybody has to do it
- ▶ There are increasing numbers of young people who have more complex health issues
- ▶ Correct utilization of health care
 - ▶ 18- 25 year-olds use the emergency room more than any other age group under the age of 75
- ▶ Studies show adverse effects associated with LACK of structured health care transition, in terms of medical complications, limitations in health and well-being, problems with adherence, discontinuity of care, higher ED and hospital use and higher costs of care

Why does it matter?

- ▶ The current evidence base on health care transition outcomes remains limited
- ▶ Most commonly reported quality of care outcomes:
 - ▶ Improvement in adherence to care
 - ▶ Improved perceived health status, quality of life and self-care skills
 - ▶ Increased adult visit attendance
 - ▶ Less time between the last pediatric visit and the initial adult visit

*few studies examined costs

Where do we stand?

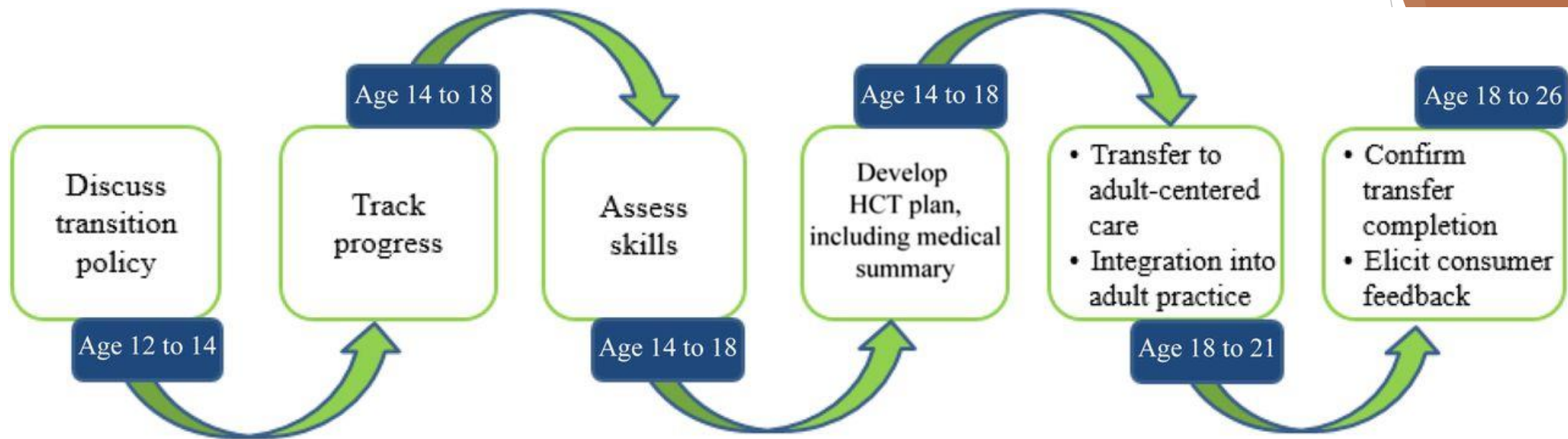
- ▶ National Survey of Children's Health, 2017-2018
 - ▶ ~19% of youth with special health care needs received transition planning guidance
 - ▶ ~14% without special needs received transition planning guidance

Barriers (youth, young adult and family)

- ▶ Fear of new health care system
 - ▶ *Not wanting to leave their pediatric clinician
 - ▶ Anxiety about how to relinquish control around managing youth condition
 - ▶ Anxiety about not knowing the adult health care system (ex finding a physician, finding parking, making appointments)
 - ▶ Changing and/or different therapies recommended in adult health care
 - ▶ Fear of not being listened to
- ▶ Inadequate Planning
 - ▶ Inadequate preparation and support on the transition process
 - ▶ Not having seen clinician alone
 - ▶ Young adults less interested in health
- ▶ System Difficulties
 - ▶ Lack of communication/coordination and transfer of medical records
 - ▶ Limited availability of adult primary and specialty providers
 - ▶ Loss of insurance coverage among young adults and cost of care barriers

Barriers (Adult and Pediatric clinician)

- ▶ Communication and/or consultation gaps
 - ▶ *Lack of communication, coordination, and guidelines
 - ▶ Lack of medical records and follow up recommendations
 - ▶ Gap in consultation with pediatric clinicians
- ▶ Training limitations
 - ▶ Lack of knowledge/training in pediatric-onset conditions
- ▶ Care delivery, care coordination, and/or stable support gaps
 - ▶ Lack of mental health and supportive services
 - ▶ Unfamiliar with local and regional resources for young adults with chronic conditions
 - ▶ Lack of coverage for young adults
- ▶ Lack of patient knowledge and engagement
 - ▶ Young adults lack of knowledge about disease treatment, medications, medical hx
 - ▶ Dependency on parents or guardians
- ▶ Lack of comfort with adult care
 - ▶ Unrealistic youth, young adult and family expectations of time and attention
 - ▶ Parents reluctance to relinquish responsibility
 - ▶ Parents unaware of changes in privacy issues



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

Six Core Elements of Health Care Transition

1. Transition Policy
2. Transition Tracking and Monitoring
3. Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transfer Completion

*NOT a model of care but a structured PROCESS that can be customized for use in a busy practice and applied to many different types of transition of care models and setting

Practice or provider	#1 Transition and/or care policy	#2 Tracking and monitoring	#3 Transition readiness and/or orientation to adult practice	#4 Transition planning and/or integration into adult approach to care or practice	#5 Transfer of care and/or initial visit	#6 Transition completion or ongoing care
Pediatric^a	Create and discuss with youth and/or family	Track progress of youth and/or family transition preparation and transfer	Conduct transition readiness assessments	Develop transition plan, including needed readiness assessment skills and medical summary, prepare youth for adult approach to care, and communicate with new clinician	Transfer of care with information and communication including residual pediatric clinician's responsibility	Obtain feedback on the transition process and confirm young adult has been seen by the new clinician
Adult^a	Create and discuss with young adult and guardian, if needed	Track progress of young adult's integration into adult care	Share and discuss welcome and FAQs with young adult and guardian, if needed	Communicate with previous clinician, ensure receipt of transfer package	Review transfer package, address young adult's needs and concerns at initial visit, update self-care assessment and medical summary	Confirm transfer completion with previous clinician, provide ongoing care with self-care skill building and link to needed specialists

1. Transition Policy

- ▶ Develop a policy/statement
- ▶ Share and discuss with youth and family beginning at age 12-14
- ▶ What is included
 - ▶ Include a transition time frame
 - ▶ an explanation of the practice's transition approach (What will your practice offer youth and families to assist them in transition?)
 - ▶ explain the legal changes that take place at age 18



Sample Transition Policy

Six Core Elements of Health Care Transition 2.0

[*Pediatric Practice Name*] is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a “pediatric” model of care where parents make most decisions to an “adult” model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parent present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult’s consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 22. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.

1. Young Adult Transition and Care policy

- ▶ Develop a transition policy/statement that describes the practice's approach to accepting and partnering with new young adults, including privacy and consent information.



Sample Young Adult Transition and Care Policy

Six Core Elements of Health Care Transition 2.0

[Adult Practice Name] welcomes young adults, including those with special health care needs, to our practice. We aim to provide high quality, comprehensive, and confidential health care to meet young adults' unique needs.

Our practice places the young adult, ages 18 and older, in the center of his/her own health care, with the health care provider as a partner in supporting your health goals. This means that adult providers do not discuss any aspects of your care with anyone else unless you specifically ask that we do. We understand that some young adults involve family and close friends in their health care decisions and would like their provider to share information with those close to them. To allow others to be involved in your health care decisions requires that a signed consent form be completed, which is available at the clinic. For young adults unable to provide consent, we will need legal documentation about decision-making arrangements.

We ask that new patients transferring to our practice obtain from their previous provider(s) a medical summary or medical record and send it to us before the first appointment. We make every effort to coordinate the transfer of care with previous providers, including communicating with pediatric providers and assisting with transfer of specialty care, as needed. Having your medical information in advance helps to ensure greater continuity of care and a better experience for you.

Your health is important to us, and we look forward to having you as a new patient. If you have any questions or concerns, please feel free to contact us.

2. Transition Tracking and Monitoring

- ▶ Establishing a mechanism to track progress of each youth
 - ▶ Ex) individual flow sheet within the chart can be used to track individual patient progress with the Six Core Element
- ▶ The long-term goal is to track health care transition progress among all youth ages 12 and older, with and without chronic conditions.
- ▶ For adult providers: Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry.



Sample Individual Transition Flow Sheet

Six Core Elements of Health Care Transition 2.0

Patient Name: _____

Date of Birth: _____

Primary Diagnosis: _____

Transition Complexity: _____
Low, moderate, or high

Transition Policy

-Practice policy on transition discussed/shared with youth and parent caregiver _____
Date

Transition Readiness Assessment

-Conducted transition readiness assessment _____
Date Date Date

-Included transition goals and prioritized actions in plan of care _____
Date Date Date

Medical Summary and Emergency Plan

-Updated and Shared medical summary and emergency plan _____
Date Date Date

Adult Model of Care

-Decision-making changes, privacy, and consent in adult care discussed with youth and parent/caregiver (if needed, discussed plans for supported decision-making) _____
Date

-Timing of transfer discussed with youth and parent/caregiver _____
Date

-Selected Adult Provider

Name	Clinic	Phone	Fax	First Appointment Completed
_____	_____	_____	_____	_____

Transfer of Care

-Prepared transfer package including:

- Transfer letter, including effective of date of transfer of care to adult provider
- Final transition readiness assessment
- Plan of care, including goals and actions
- Updated medical summary and emergency care plan
- Legal documents, if needed
- Condition fact sheet, if needed
- Additional provider records, if needed

-Sent transfer package _____
Date

-Communicated with adult provider about transfer _____
Date

-Elicited feedback from young adult after transfer from pediatric care _____
Date



Sample Individual Transition Flow Sheet

Six Core Elements of Health Care Transition 2.0

Patient Name: _____

Date of Birth: _____

Primary Diagnosis: _____

Transition Complexity: _____
Low, moderate or high

Welcome and Orientation

-Contacted young adult before the first visit to welcome and answer questions _____
Date

-Transfer package received from pediatric provider _____
Date

- Transfer letter
- Final transition readiness assessment
- Plan of care, including transition goals and pending actions
- Updated medical summary and emergency care plan
- Guardianship or health proxy documents, if needed
- Condition fact sheet, if needed
- Additional provider records, if needed

-Orientation material shared with young adult _____
Date

-Practice policy on transition discussed/shared with young adult _____
Date

Adult Model of Care

-Clarified adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication _____
Date

-If needed and not previously addressed, discussed legal options for supported decision-making _____
Date

Self-Care Assessment

-Conducted self-care assessment _____
Date Date Date

-Included self-care goals and prioritized actions in plan of care _____
Date Date Date

Medical Summary and Emergency Care Plan

-Updated and shared medical summary and emergency care plan _____
Date Date Date

Transfer Completion

-Communicated with pediatric provider confirming transfer or care and arranging for consultation, if needed _____
Date

-Elicited feedback from young adult about transition and experience with care _____
Date



Sample Transition Registry

Six Core Elements of Health Care Transition 2.0

Transition Registry 1/21/2014							
DOB	Age	Name	Primary Diagnosis	Transition Complexity*	Date Last Seen	Next Scheduled Appointment (Date or Blank)	Date of first appointment with adult provider (Date or Blank)
	Red if over 18					Highlighted if no appt	Highlighted if not done by 22
3/4/1995	18 Y	Mary Smith	seizure disorder	3	12/13/2013	1/30/2014	
9/2/1996	17 Y	Billy Jones	asthma	1	6/23/2013	12/22/2014	
12/25/1997	16 Y	Susan Cue	congenital heart disease	1	7/6/2013	8/6/2014	
1/17/1993	21 Y	Terrence Train	JRA	2	8/16/2013		6/7/2014
6/17/2002	11 Y	Devin Carn	asthma	2	6/19/2013	12/21/2014	
4/18/1996	17 Y	David Crockett	well	1	12/22/2012		
4/2/1998	15 Y	Tom Sawyer	ADHD	2	6/19/2013	12/19/2014	
1/3/1990	24 Y	Jen Lawrence	cerebral palsy	3	1/14/2014	2/20/2014	
2/14/1999	14 Y	Sasha Jones	well	1	4/16/2012		
2/3/1994	19 Y	Enrique Montoya	well	1	5/13/2013		

*Complexity Scoring
 1= Low Complexity
 2= Moderate Complexity
 3= High Complexity

Transition Registry 1/21/2014								
Name	Policy Shared with Youth/Family (Yes or Blank)	Readiness Assessment Administered (Date or Blank)	Plan of Care Updated and Shared with Youth/Family (Date or Blank)	Medical Summary and Emergency Care Plan Updated and Shared with Youth/Family (Date or Blank)	Adult Provider Identified (Yes or Blank)	Transfer Package Sent to Adult Provider (Yes or Blank)	Communicated with Adult Provider (Yes or Blank)	Elicited Feedback about Transition from Youth and Family (Yes or Blank)
	Highlighted if not shared by 12	Highlighted if not done by 14	Highlighted if not done by 14	Highlighted if not done by 16	Highlighted if not done by 22	Highlighted if not done by 22	Highlighted if not done by 22	Highlighted if not done by 22
Mary Smith	Yes	8/13/2013	8/13/2013	8/13/2013	Yes			
Billy Jones	Yes	6/23/2013	6/23/2013	6/23/2013				
Susan Cue	Yes	7/6/2013	7/6/2013					
Terrence Train	Yes	8/16/2013	8/16/2013	8/16/2013	Yes	Yes	Yes	Yes
Devin Carn								
David Crockett	Yes	12/22/2012	12/22/2012	12/22/2012				
Tom Sawyer								
Jen Lawrence	Yes	9/14/2013	9/14/2013	9/14/2013	Yes	Yes		
Sasha Jones								
Enrique Montoya	Yes	5/13/2013	5/13/2013	5/13/2013				

3. Transition Readiness

- ▶ Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self care
- ▶ Jointly develop goals and prioritized actions with youth
- ▶ Transition readiness assessment should begin at age 14 and continue through adolescence and young adulthood, as needed.



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:

Name:

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 22?

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

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

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

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

Using Health Care

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



Sample Transition Readiness Assessment for Parents/Caregivers

Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what your child already knows about his or her health and the areas that you think he/she needs to learn more about. After you complete the form, compare your answers with the form your child has complete. Your answers may be different. We will help you work on some steps to increase your child's health care skills.

Date:

Name:

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 for your child to prepare for/change to an adult doctor before age 22?										
0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
How confident do you feel about your child's ability to prepare for/change to an adult doctor?										
0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

My Health *Please check the box that applies to your child right now.*

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

Using Health Care

My child knows or can find his/her doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child makes his/her own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, my child thinks about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a way to get to his/her doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows to show up 15 minutes before the visit to check in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows where to go to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a file at home for his/her medical information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a copy of his/her current plan of care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to get referrals to other providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows where his/her pharmacy is and how to refill his/her medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows where to get blood work or x-rays if his/her doctor orders them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a plan to keep his/her health insurance after ages 18 or older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child and I have discussed his/her ability to make his/her own health care decisions at age 18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child and I have discussed a plan for supported decision-making, if needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Transition Readiness/Orientation to Adult Practice

- ▶ Establish a process to welcome and orient new young adults into practice, including a description of available services.
- ▶ Provide youth-friendly online or written information about the practice and offer a "get-acquainted" appointment, if feasible.



Sample Welcome and Orientation of New Young Adults

Six Core Elements of Health Care Transition 2.0

[Adult Practice Name] is pleased to welcome you into our practice. Our practice places young adults in the center of their own health care. This means that our providers do not discuss your care with anyone else unless you ask that we do. We understand that some young adults involve family and close friends in their health care decisions. To allow others to be involved in your health care decisions you will need to complete a signed consent. These forms are available at the clinic. For young adults unable to provide consent, we will need legal documentation about decision-making arrangements.

At our practice, you have the right to:

- Be treated in a caring way
- Make your own decisions
- Talk to your health care provider alone
- Have things explained in a way that you understand
- Have access to your medical information

In turn, you are responsible for:

- Keeping appointments and cancelling appointments in advance
- Telling us about your current symptoms and health history to help us treat you
- Following treatment plans that you develop with your health provider
- Asking questions about your care
- Knowing what your insurance covers

Below is a list of frequently asked questions and answers about our practice. If you have a question that is not listed below, feel free to ask any of our staff. We look forward to having you in our practice.

Q: What services does the practice provide (including preventive, acute and chronic illness care, and, if offered, sexual health, mental/behavioral health, wellness programs, and other specialty care)?

A:

Q: Are services confidential?

A:

Q: Where is the office located (including map and nearest public transportation)?

A:

Q: What providers are available to care for young adults?

A:

Q: What are the office hours (including walk-in options, if available)?

A:

Q: Are there after-hours call-in options?

A:

Q: How do I schedule, reschedule, or cancel an appointment?

A:

Q: What insurance is accepted?

A:

Q: How much do visits cost?

A:

Q: What should I bring for my first appointment?

A:

Q: What resources are available to assist me to learn about wellness and self-care (e.g., nutrition and fitness classes, support groups, special apps or websites, local community resources)?

A:

4. Transition Planning

- ▶ Develop and regularly update the plan of care, including readiness assessment findings, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.
- ▶ Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information.
- ▶ Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.
- ▶ Plan with youth/parent/caregiver for optimal timing of transfer. If both primary and subspecialty care are involved, discuss optimal timing for each.
- ▶ Obtain consent from youth/guardian for release of medical information.
- ▶ Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care.



Sample Medical Summary and Emergency Care Plan

Six Core Elements of Health Care Transition 2.0

This document should be shared with and carried by youth and families/caregivers.		
Date Completed:	Date Revised:	
Form completed by:		
Contact Information		
Name:	Nickname:	
DOB:	Preferred Language:	
Parent (Caregiver):	Relationship:	
Address:		
Cell #:	Home #:	Best Time to Reach:
E-Mail:	Best Way to Reach: Text Phone Email	
Health Insurance/Plan:	Group and ID #:	
Emergency Care Plan		
Emergency Contact:	Relationship:	Phone:
Preferred Emergency Care Location:		
Common Emergent Presenting Problems	Suggested Tests	Treatment Considerations
Special Concerns for Disaster:		
Allergies and Procedures to be Avoided		
Allergies	Reactions	
To be avoided	Why?	
<input type="checkbox"/> Medical Procedures:		
<input type="checkbox"/> Medications:		
Diagnoses and Current Problems		
Problem	Details and Recommendations	
<input type="checkbox"/> Primary Diagnosis		
<input type="checkbox"/> Secondary Diagnosis		
<input type="checkbox"/> Behavioral		
<input type="checkbox"/> Communication		
<input type="checkbox"/> Feed & Swallowing		
<input type="checkbox"/> Hearing/Vision		
<input type="checkbox"/> Learning		
<input type="checkbox"/> Orthopedic/Musculoskeletal		
<input type="checkbox"/> Physical Anomalies		
<input type="checkbox"/> Respiratory		
<input type="checkbox"/> Sensory		
<input type="checkbox"/> Stamina/Fatigue		
<input type="checkbox"/> Other		

Summary of Spina Bifida for Health Care Professionals

Spina Bifida (SB) is a neural tube defect in which there is failure of the neural tube to close very early in pregnancy, resulting in a spinal cord defect usually visible at birth. The most common form of SB in which there is an open lesion is myelomeningocele (MM), but other types of SB exist, including occult dysraphism where lipomas may be present. The MM subtype is associated with varying degrees of lower extremity paralysis and sensory loss, hydrocephalus, Chiari II malformation, syringomyelia, tethered cord, bowel and bladder dysfunction, and some learning disabilities. Conditions such as hydrocephalus, Chiari II, and syringomyelia, are not generally seen in those with lipomas and other forms of occult dysraphism. SB is generally not felt to be a progressive condition, and any deterioration in adulthood should prompt a search for a treatable condition.

Most individuals with MM have hydrocephalus, which is most commonly treated with a ventriculoperitoneal shunt. Shunt malfunction is a common problem in patients with MM and can present with a wide range of symptoms including headache, nausea, vomiting, blurred vision, as well as subtle symptoms like deterioration in sensorimotor function, changes in bladder function, back pain, or changes in school performance, cognition, or memory. In most cases of shunt malfunction, the ventricles will appear enlarged on CT compared with a baseline CT done when the patient is asymptomatic; however, up to 15% of patients with MM can have a shunt malfunction with no significant change in ventricular size. Therefore if symptoms of shunt malfunction are present, consultation with an experienced neurosurgeon is recommended regardless of CT findings. Most cases of shunt malfunction will require shunt revision, although in rare cases, shunt malfunction may be caused by constipation which puts pressure on the distal end of the shunt.

The Chiari II malformation is seen in almost all patients with MM, although only 10-15% become symptomatic, and the majority of these present during infancy. In the Chiari II malformation, the cerebellar tonsils, vermis and brainstem descend through the foramen magnum to a variable degree. Surgical intervention may become necessary for symptomatic patients with swallowing difficulties, breathing difficulties or stridor, severe sleep apnea, increasing sensorimotor dysfunction, headache and/or neck pain. These symptoms should prompt a referral to a neurosurgeon. The most common cause of Chiari symptoms in adults is a shunt malfunction; rarely symptoms may require decompression surgery. Associated syringomyelia - an accumulation of cerebrospinal fluid within the spinal cord - may often be present with the Chiari malformation but requires treatment only 15-35% of the time, usually due to back or limb pain, or sensorimotor loss.

Tethered cord occurs when the spinal cord becomes progressively stretched due to its attachment to the distal end of the spinal canal. Tethering is a universal radiographic finding but symptoms from spinal cord tethering - referred to as tethered cord syndrome - occurs in only about 1/3 of patients, and even less frequently in adults. Tethered cord syndrome is manifested by worsening scoliosis, back or leg pain, sensorimotor changes, spasticity, and worsening bladder or bowel function, and may require neurosurgical evaluation and untethering of the spinal cord.

Neurogenic bladder dysfunction occurs in over 90% of patients with SB and can be manifested across a spectrum ranging from small, hyperreflexic bladders to large, flaccid bladders. The goals of urologic management are preservation of renal function, reduction in urinary tract infection, and attainment of continence, if so desired by the patients. Elevated bladder pressures due to hyperreflexic or poorly compliant bladders can result in renal damage and, eventually, failure. Anticholinergic medications, such as oxybutynin, are used in many patients to keep bladder pressure low and are combined with bladder catheterization to attain continence. Some patients have had bladder augmentation surgery to improve bladder volumes and/or reduce pressures, and some have an abdominal wall or umbilical stoma (Mitrofanoff) through which to catheterize the bladder avoiding the urethra. Some also require bladder neck surgery to attain continence. Approximately two-thirds of all patients self-catheterize to empty their bladders, so bacteriuria is often present but does not necessarily indicate infection nor require treatment. Symptoms of infection (abdominal pain, fever, malaise, or urinary changes such as increasing incontinence) suggest a bladder infection and require treatment, but it is not recommended to check urine in asymptomatic patients or treat bacteriuria alone. Individuals with thoracic level SB may lack the usual signs of dysuria or flank pain. Patients with MM are at increased risk for bladder and renal stones, as well

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4. Transition Planning/Integration into Adult Practice

- ▶ Communicate with pediatric provider(s) and arrange for consultation assistance, if needed.
- ▶ Prior to first visit, ensure receipt of transfer package
- ▶ Make pre-visit appointment reminder call welcoming new young adult and identifying any special needs and preferences.

5. Transfer of Care

- ▶ Confirm date of first adult provider appointment.
- ▶ Transfer young adult when his/her condition is **stable**.
- ▶ Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.
- ▶ Prepare letter with transfer package, send to adult practice, and confirm adult practice's receipt of transfer package.
- ▶ Confirm with adult provider the pediatric provider's responsibility for care until young adult is seen in adult setting.



Sample Transfer of Care Checklist

Six Core Elements of Health Care Transition 2.0

Patient Name: _____

Date of Birth: _____

Primary Diagnosis: _____

Transition Complexity: _____

Low, moderate, or high

-Prepared transfer package including:

- Transfer letter, including effective of date of transfer of care to adult provider
- Final transition readiness assessment
- Plan of care, including transition goals and pending actions
- Updated medical summary and emergency care plan
- Guardianship or health proxy documents, if needed
- Condition fact sheet, if needed
- Additional provider records, if needed

-Sent transfer package _____

Date

-Communicated with adult provider about transfer _____

Date



Sample Transfer Letter

Six Core Elements of Health Care Transition 2.0

Dear Adult Provider,

Name is an age year-old patient of our pediatric practice who will be transferring to your care on date of this year. His or her primary chronic condition is condition, and his or her secondary conditions are conditions. Name's related medications and specialists are outlined in the enclosed transfer package that includes his or her medical summary and emergency care plan, plan of care, and transition readiness assessment. Name acts as his or her own guardian, and is insured under insurance plan until age age.

I have had name as a patient since age and am very familiar with his or her health condition, medical history, and specialists. I would be happy to provide any consultation assistance to you during the initial phases of name's transition to adult health care. Please do not hesitate to contact me by phone or email if you have further questions.

Thank you very much for your willingness to assume the care of this young man or woman.

Sincerely,

5. Transfer of Care/Initial Visit

- ▶ Prepare for initial visit by reviewing transfer package
- ▶ Address any concerns that young adult has about transferring. Clarify approach to adult care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication.
- ▶ Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss the young adult's needs and goals in self-care.
- ▶ Review young adult's health priorities as part of their plan of care.
- ▶ Update medical summary and emergency care plan.



Sample Self-Care Assessment for Young Adults

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, 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:

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 manage your own health care?

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

How confident do you feel about your ability to manage your own health care?

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

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 explain my medical needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my symptoms including ones that I quickly need to see a doctor for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know what to do in case I have a medical emergency.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my own medicines, what they are for, and when I need to take them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know my allergies to medicines and the medicines I should not take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Using Health Care

I know or I can find my doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I make my own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, I think about questions to ask.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a way to get to my doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know I need to show up 15 minutes before the visit to check in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to go to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a file at home for my medical information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know how to get referrals to other providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where my pharmacy is and how to refill my medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I know where to get blood work or x-rays done if my doctor orders them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I understand how health care privacy changes at age 18 when legally an adult.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have a plan so I can keep my health insurance after 18 or older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Transfer Completion

- ▶ Contact young adult 3 to 6 months after last pediatric visit to confirm transfer of responsibilities to adult practice and elicit feedback on experience with transition process.
- ▶ Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed.
- ▶ Build ongoing and collaborative partnerships with adult primary and specialty care providers.

6. Transfer Completion/Ongoing Care

- ▶ Communicate with pediatric practice confirming transfer into adult practice and consult with pediatric provider(s), as needed.
- ▶ Assist young adult to connect with adult specialists and other support services, as needed.
- ▶ Continue with ongoing care management tailored to each young adult.
- ▶ Elicit feedback from young adult to assess experience with adult health care.
- ▶ Build ongoing and collaborative partnerships with pediatric primary and specialty care providers.

Special Considerations

- ▶ All youth and young adults need a safe health care transition
- ▶ However, youth with complex medical conditions, developmental and/or intellectual disabilities and/or behavioral health conditions and social complexity post additional challenges
- ▶ Flexibility to the process may be needed
 - ▶ Regarding age
 - ▶ Delayed/staggered transfer to specialist
 - ▶ Greater care coordination support
 - ▶ Pediatric consultation
 - ▶ Need for non-health support systems such as education, living resources, employment

Six Core Elements: Roles of Youth and Families

	1. Discovering	2. Tracking	3. Preparing	4. Planning	5. Transferring	6. Completing
Youth/Family	Learn about your providers approach to transition	Know your own health information	Learn to manage your own health care	Get ready for adult health care	Make the change to an adult provider	Provide feedback

Resources

- ▶ <https://www.gottransition.org/index.cfm>
- ▶ <https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative/condition-specific-tools>
- ▶ Pediacast CME : Transitioning Pediatric Patients to Adult Health Care
- ▶ *Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home*, Pediatrics November 2018
- ▶ *Care of Adults with Chronic Childhood Conditions: A practical Guide*

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Questions ?