

Module 2:

An Introduction to Transitioning Care for Young Adults with Epilepsy



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Objectives:

- Understand the difference between transitioning and transfer of care
- Become familiar with some of the challenges in transferring youth with epilepsy to adult-oriented care
- Become aware of the need for transitioning
- Awareness of the 6 core elements of Transition
- Introduction to Got Transition

Transition

Vs.

Transfer

- A process that begins in early adolescence
- Prepare youth to become as independent as possible in understanding how to manage their illness and to navigate the healthcare system
- Plan with the patient, family, pediatric and adult health care teams to allow for a successful transition to adult-oriented care

- At its best, it is a formal hand-off of information from a pediatric care provider to an adult care provider when the patient reaches adulthood.
- At its worst is a referral to an adult care provider.

Patients and Parents Reaction to Transitioning

UPHEAVAL

FEAR

CONFUSION & DECISIONS

ABANDONNED

STRESS

Parents rate the stress of transitioning to the time that their child was first diagnosed with ID

GOOD TRANSITIONAL CARE

To provide UNINTERRUPTED care that
OPTIMIZES the patient's health
and MAXIMIZES quality of life

Need for Transition:

- 18 million young adults 18-21, approximately ¼ with chronic conditions
- Those 18-25 have the highest ER use and are likely to report no health care visits in last 12 months
- Most health providers feel they lack a systematic way to support youth and families in transitioning from pediatric to adult care

Why Transition Care????

- Rite of Passage
- Some pediatric hospitals/practices may not be accredited for > 22 yrs
- Practice may not be able to accommodate > 22 yrs
- Pediatric ward may not be able to care for patient
- Develop problems not usually treated by pediatricians

Some Challenges Transitioning Youth with Epilepsy

- Epilepsy has many causes, not a single disease
- Comorbid conditions –
 - Developmental and cognitive disabilities
 - Mental health
- Driving

Comfort of Providers Caring for Epilepsy Patients

Epilepsy +	Adult Neuro	Adult Epilepsy	Pedi Neuro	Pedi Epilepsy
Generalized Epilepsy no ID	93	100	94	100
Cortical Malformation	34	73	94	100
Epileptic Encephalopathy	11	53	82	91
Epilepsy w ID	16	53	-	-
Epilepsy w Autism	15	40	-	-

Borlot et al. Epilepsia 2014;55:1659-1666.



Transition Models from Pediatric to Adult Health Care: Innovative Strategies

Patience White, MD, MA, FAAP, FACP

Got Transition

Center for Health Care Transition Improvement



CENTER FOR HEALTH CARE TRANSITION IMPROVEMENT



Website: www.gottransition.org

got transition
ABOUT | NEWS | RESOURCES

Help me find... [GO] JOIN OUR MAILING LIST

Got Transition is dedicated to increasing youth and young adult engagement in health care and improving continuity of care between pediatric and adult health care.

News & Announcements

Six Core Elements 2.0 Release
Got Transition launches its new website and releases the new Six Core Elements (2.0) with corresponding clinical tools and measurement resources... [more>](#)

Got Transition's New Home
The National Alliance to Advance Adolescent Health is the new "home" for Got Transition's Center for Health Care Transition Improvement. With funding support from the Maternal and Child Health Bureau, Got Transition will focus on:
1) transition quality improvement spread,
2) health care professional training,
3) youth and family engagement,
4) policy improvements, and
5) information dissemination... [more>](#)

Nation Survey Updates
The new National Survey of Children's Health, which will be a combined survey of the National Survey of Children with Special Needs, will use a new set of questions on transition. For more information, see the transition research and policy pages.

Building Career Development Partnerships
Got Transition has formed a new partnership with the Department of Labor's Office of Disability Employment Policy and the HSC Foundation's Youth Transition Collaborative. The goals of this partnership are to transition resources to our respective and educational opportunities related to health care and employment transition planning...

Got Transition™ is a program of the

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Health Care Providers | Youth & Families | Researchers & Policymakers

Research

US Transition Performance
Transition Quality Improvement
Transition Systems
Literature Review
Transition and Triple Aim

Transition Quality Improvement

Sample Content lorem ipsum dolor sit amet, consectetur adipiscing elit, sed diam nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat.

Health Care Providers | **Youth & Families** | **Researchers & Policymakers**

Health Care Transition

What is Health Care Transition?
Health care transition is the process of changing from a pediatric to an adult model of health care. The goal of transition is to optimize health and assist youth in reaching their full potential. To achieve this goal requires an organized transition process to support youth in acquiring independent health care skills, preparing for an adult model of care, and transferring to new providers without disruption in care.

What are the Six Core Elements?
The Six Core Elements of Health Care Transition 2.0 define the basic components of health care transition support. These components include establishing a policy, tracking progress, administering transition readiness assessments, planning for adult care, transferring, and integrating into an adult practice.

There are three sets of customizable tools available for different practice settings.

Aligned with the AAP/AAFP/ACAP Clinical Report on Transition, the Six Core Elements are intended for use in primary and specialty settings. Originally developed in 2009, this updated version incorporates the results of several transition learning collaboratives, an examination of transition innovations in the US and abroad, and reviews by over 50 pediatric and adult health care professionals and youth and family experts.

Recommended Health Care Transition Timeline

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

How do I implement the Six Core Elements?
As all transition approaches need to reflect the local capacity, a quality improvement (QI) approach has been a successful and efficient way to implement the Six Core Elements. To begin your QI process, assemble a team with pediatric and adult providers, clinic support staff, and youth and family consumers to review, customize, test and disseminate each of the core elements.

How can I assess my progress in implementing the Six Core Elements?

Discovering: finding out your doctor's transition practices

- At what age should I start thinking about my health care transition?
- What do I need to ask my doctor about health care transition?

Tracking: keeping track of your own health information

- How should I keep track of my health care?

Preparing: learning to manage your own health care

- Which tasks do I need to learn to do as I transition to adult health care?
- How can I make sure I am prepared for my visits to the doctor?
- What should I bring with me to the doctor and what should I make sure I have when I leave?
- Do you have any advice about managing medications?
- What do I need to know about insurance?

Planning: planning for to transfer

- What do I need to know about legal changes as I turn 18?
- I am planning on going to college. How can I transition my health care to the college setting?

got transition?

CENTER FOR HEALTH CARE TRANSITION IMPROVEMENT

BOSTON MEDICAL CENTER

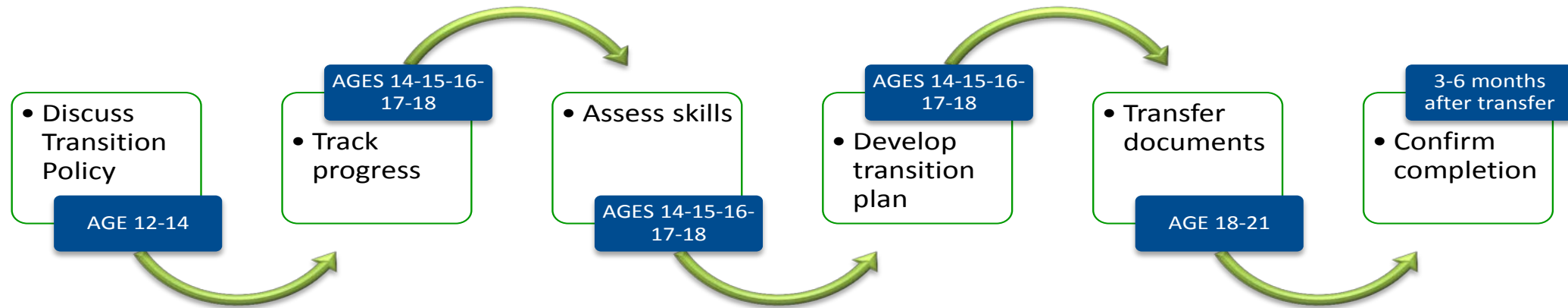
BOSTON UNIVERSITY

EXCEPTIONAL CARE. WITHOUT EXCEPTION.

Transitioning to Adult-oriented Care

- Transitioning from a Pediatric to Adult Health Care Provider
- Transitioning to an Adult Approach to Health Care Without Changing Providers
 - Family physician
 - Med- peds
 - Child Neurologists

Six Core Elements of Transition 2.0



Transition Policy



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.

Transition Tracking

- Establish criteria and process for identifying transitioning youth and enter their data into a registry.
- Utilize individual flow sheet or registry to track youth's transition progress with the Six Core Elements.
- Incorporate the Six Core Elements into clinical care process, using HER when possible

Transition Readiness

- Literacy level (Grade 5.7)
- Validated questions on importance and confidence
- Youth/Young adults and caregivers appreciate reviewing/learning what general skills are needed to be successful in an adult practice

 **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)
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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"/>

Transition Planning With Youth And Families

- Develop with Youth and Family a Care Plan that Includes Transitioning Goals
- Determine What Supports May be Needed When Transitioning to Adult-oriented Care
 - Review supported decision making
 - Identify communication needs
- Share Care Plan with Youth, Family, and Providers of Care

Transfer of Care

Your practice responsibility when transferring to a new adult provider

Transfer letter to the new adult provider with:

- Appropriate documentation
- Statement that the youth's care is covered by your practice until first visit
- Offer to be a consultant as needed



- Readiness assessment
- Medical summary and emergency care plan
- Plan of care & decision support documents
- Condition fact sheet, if needed

Transfer Completion

- Determine if patient integrated well into adult practice
- Ask patient/family for feedback
- Offer to remain on as a consultant

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References

Borlot, F., Tellez-Zenteno, J. F., Allen, A., Ali, A., Snead, O. C., & Andrade, D. M. (2014). Epilepsy transition: Challenges of caring for adults with childhood-onset seizures. *Epilepsia*, 55(10), 1659-1666.