Module 2:
An Introduction to Transitioning Care for Young Adults with Epilepsy

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Objectives:

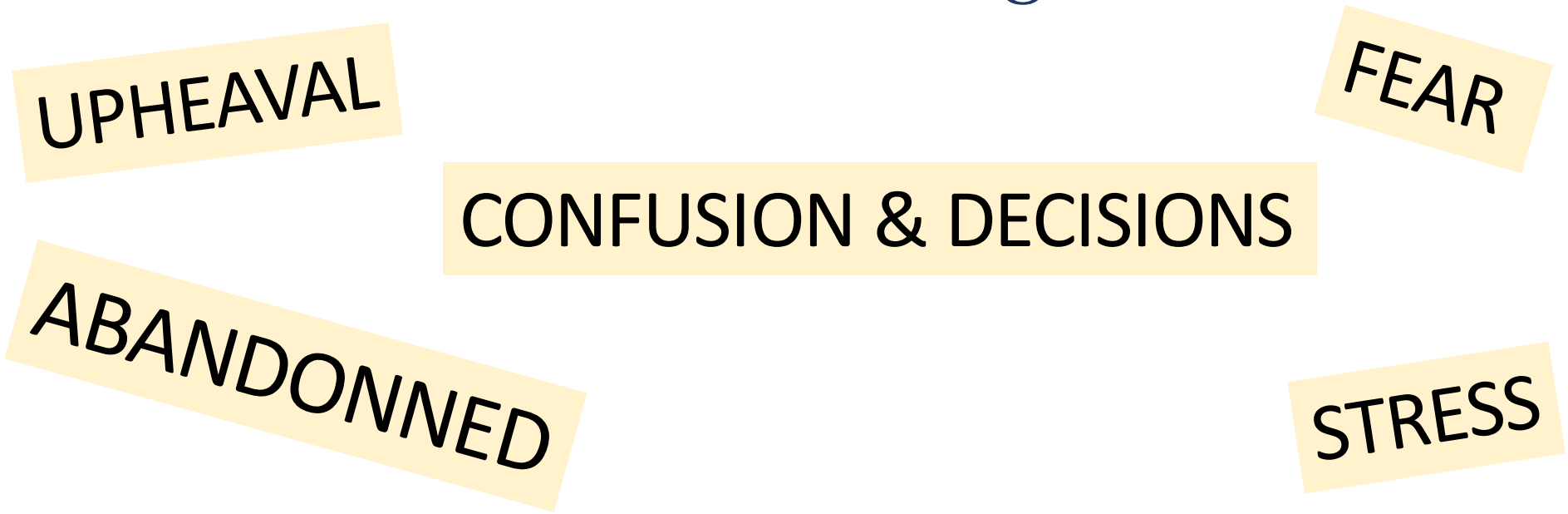
- Understand the difference between transitioning and transfer of care
- Become familiar with some of the challenges in transferring youth with epilepsy to adult-oriented care
- Become aware of the need for transitioning
- Awareness of the 6 core elements of Transition
- Introduction to Got Transition

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



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
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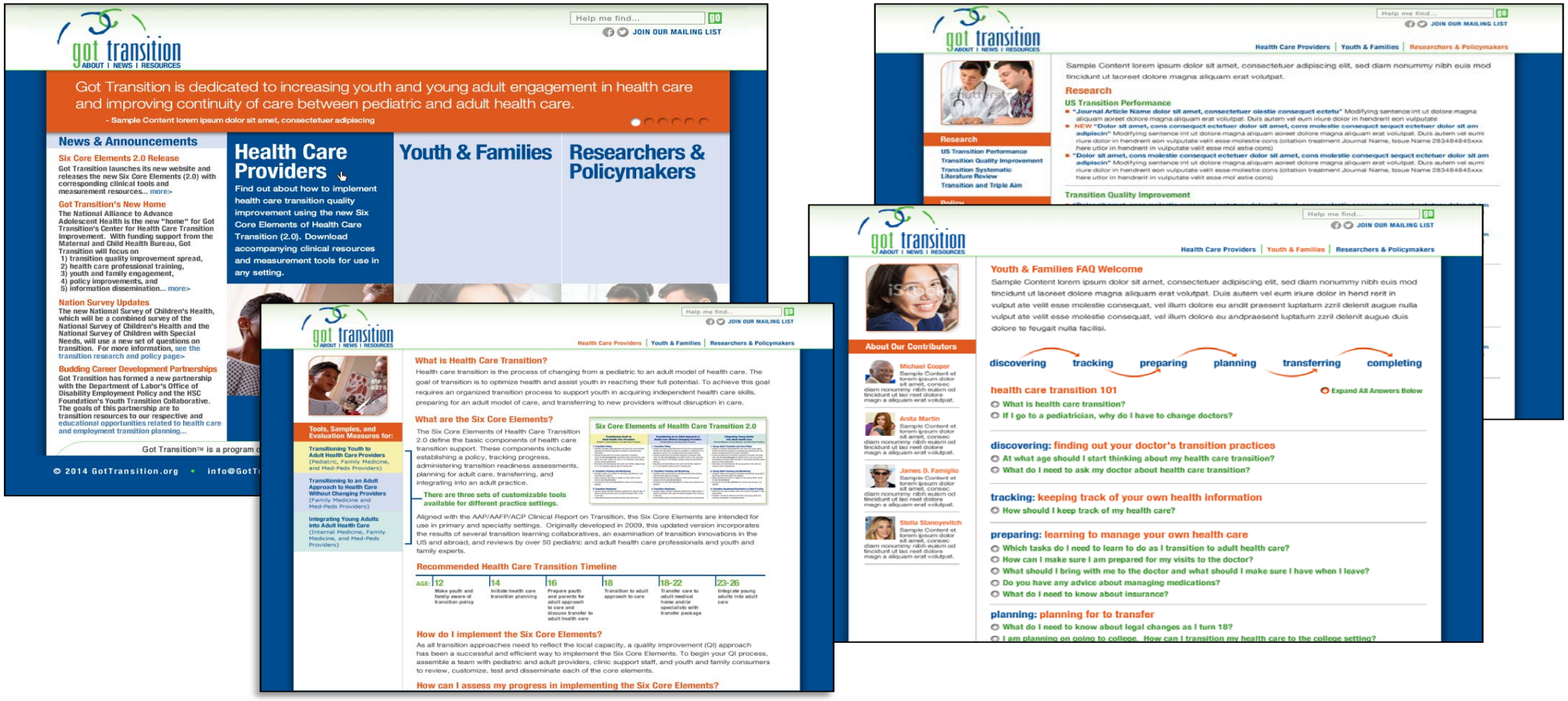
Website: www.gottransition.org



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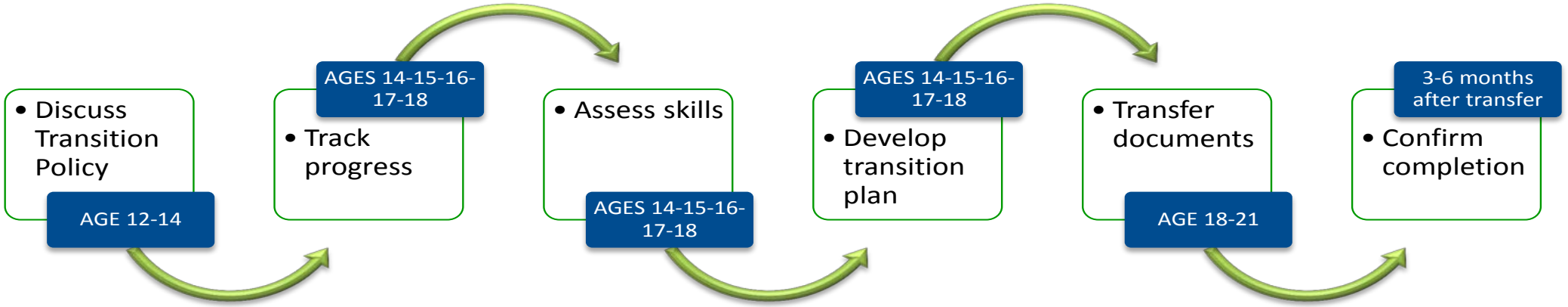
Transitioning to Adult-oriented Care

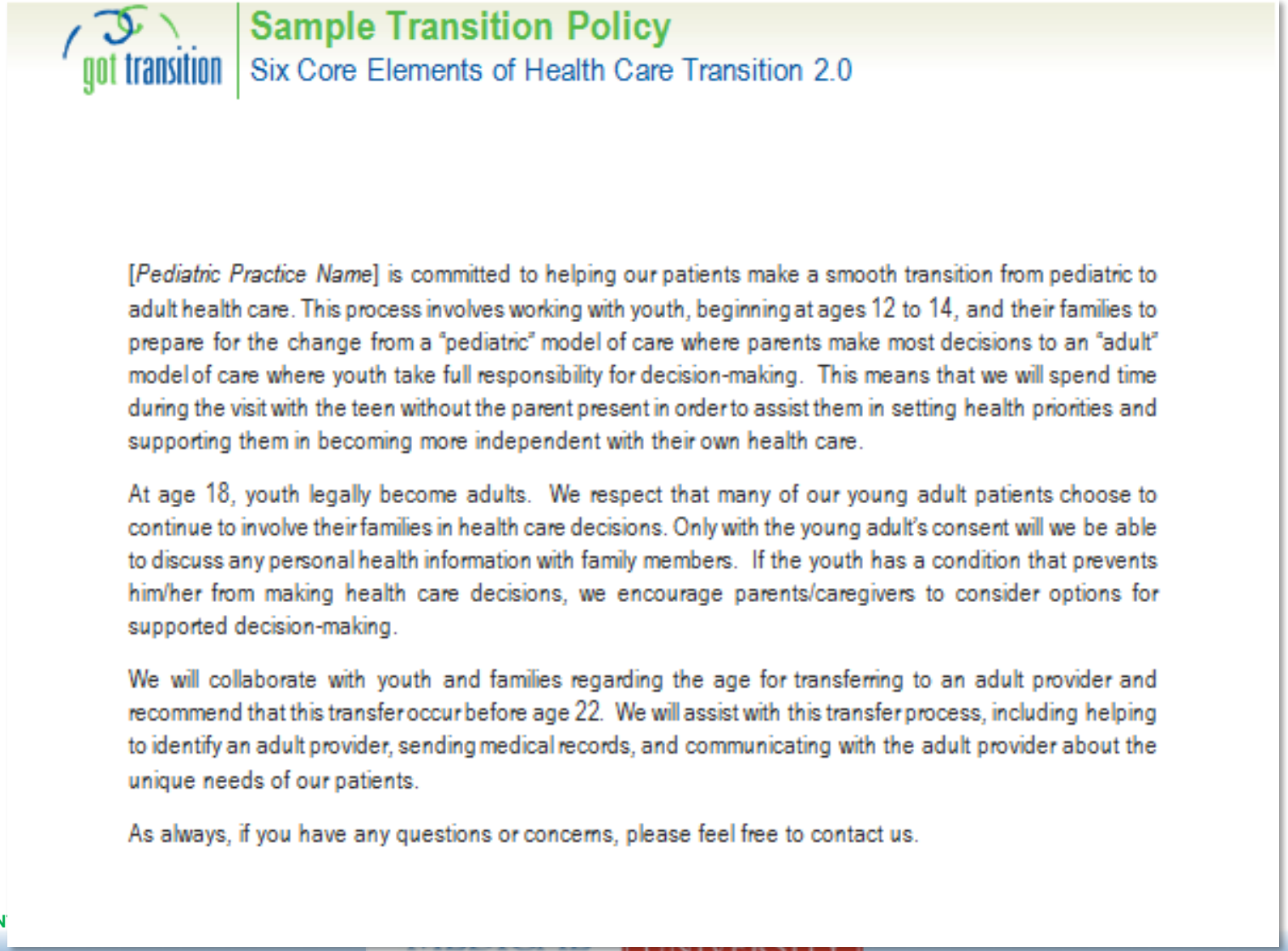
- Transitioning from a Pediatric to Adult Health Care Provider
- Transitioning to an Adult Approach to Health Care Without Changing Providers
  - Family physician
  - Med- peds
  - Child Neurologists

Six Core Elements of Transition 2.0



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

Transition Policy



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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

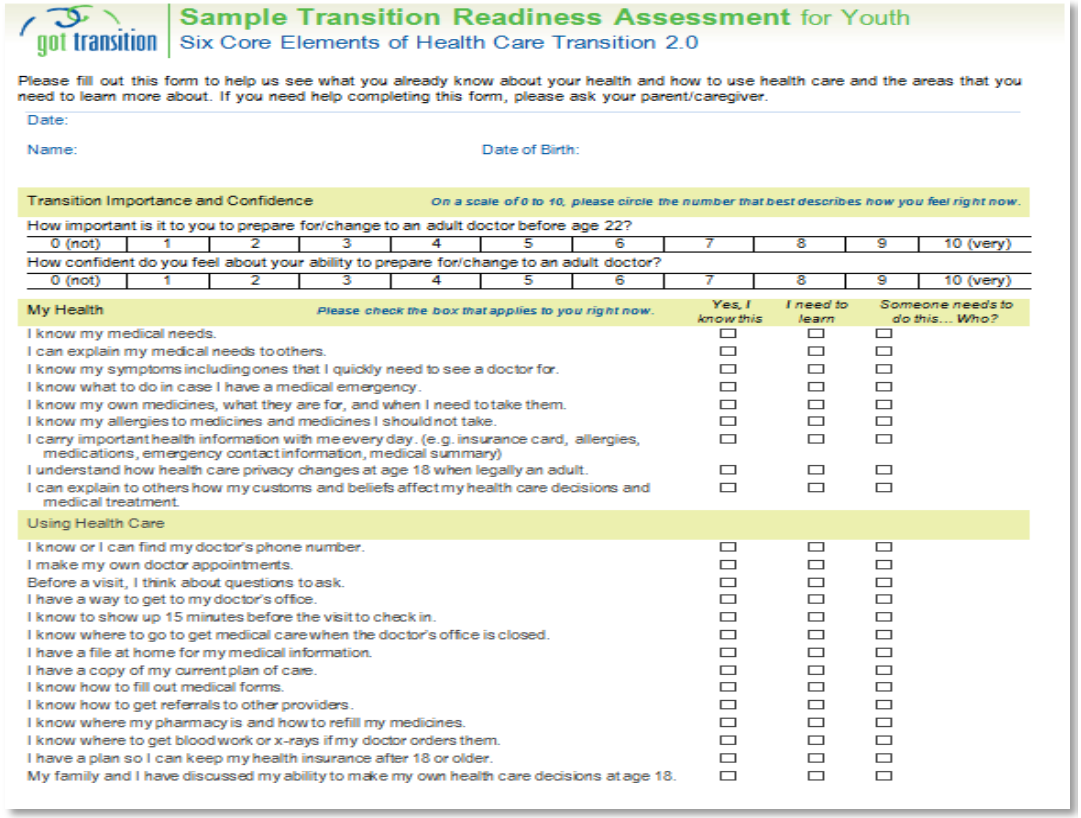
- Establish criteria and process for identifying transitioning youth and enter their data into a registry.

- 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



got transition | **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.	☐	☐	☐
I can explain my medical needs to others.	☐	☐	☐
I know my symptoms including ones that I quickly need to see a doctor for.	☐	☐	☐
I know what to do in case I have a medical emergency.	☐	☐	☐
I know my own medicines, what they are for, and when I need to take them.	☐	☐	☐
I know my allergies to medicines and medicines I should not take.	☐	☐	☐
I carry important health information with me every day. (e.g. insurance card, allergies, medications, emergency contact information, medical summary)	☐	☐	☐
I understand how health care privacy changes at age 18 when legally an adult.	☐	☐	☐
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	☐	☐	☐
Using Health Care			
I know or I can find my doctor's phone number.	☐	☐	☐
I make my own doctor appointments.	☐	☐	☐
Before a visit, I think about questions to ask.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know to show up 15 minutes before the visit to check in.	☐	☐	☐
I know where to go to get medical care when the doctor's office is closed.	☐	☐	☐
I have a file at home for my medical information.	☐	☐	☐
I have a copy of my current plan of care.	☐	☐	☐
I know how to fill out medical forms.	☐	☐	☐
I know how to get referrals to other providers.	☐	☐	☐
I know where my pharmacy is and how to refill my medicines.	☐	☐	☐
I know where to get blood work or x-rays if my doctor orders them.	☐	☐	☐
I have a plan so I can keep my health insurance after 18 or older.	☐	☐	☐
My family and I have discussed my ability to make my own health care decisions at age 18.	☐	☐	☐

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.