

Young Adult Transitions

DD+

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November 2019

Objectives

1

Identify why transition planning is important

2

Identify tools to use to prepare young adults for transition

3

Identify top 5 can't miss tasks for preparation

Transition Barriers

- ▶ Gaps in Communication and/or consultation
 - ▶ Insufficient subspecialty/mental health providers
 - ▶ Irregular communication between adult/pediatric specialists
- ▶ Training limitations
 - ▶ Pediatric providers on adult conditions, Adult providers on pediatric conditions
- ▶ Care delivery, care coordination, and/or staff support gaps
 - ▶ Limited infrastructure
 - ▶ Bureaucracy overload
- ▶ Lack of patient knowledge and engagement
 - ▶ Poor adherence, unrealistic expectations of adult medical system
- ▶ Lack of comfort with adult care
 - ▶ Parents reluctance to relinquish responsibility/accept privacy

Only 15% of youth with and without special healthcare needs receive transition planning assistance from their healthcare providers. - National Survey of Children's Health, 2016

How do we do it?

► Gottransition.org

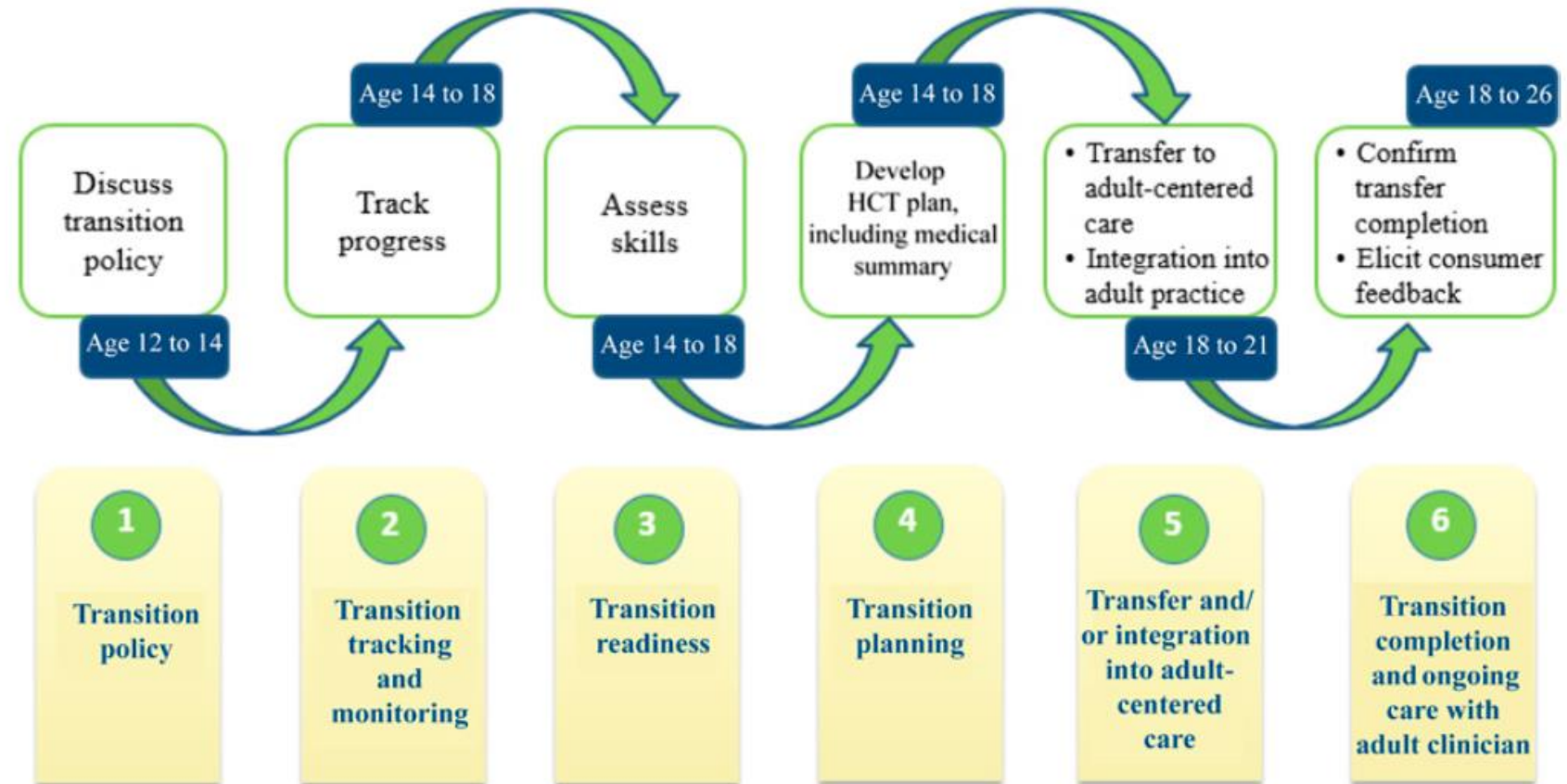


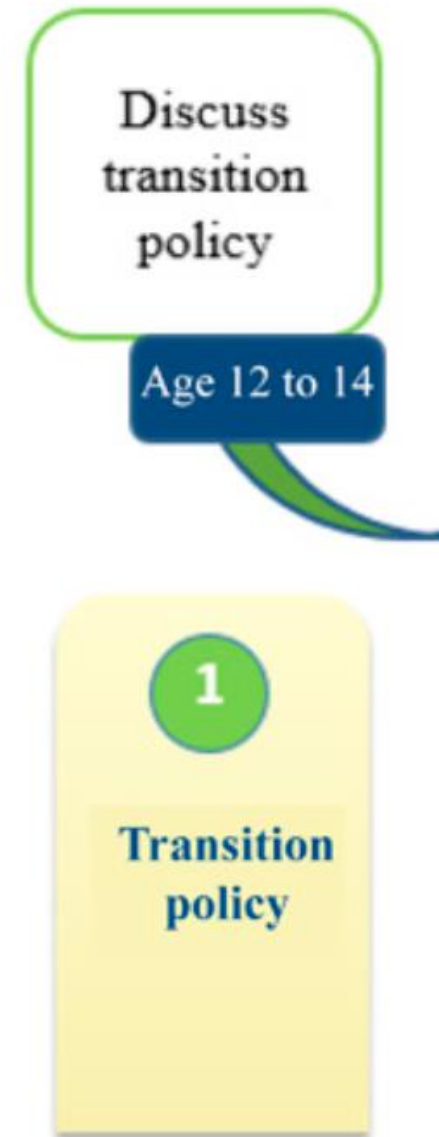
FIGURE 1
Timeline for introducing the Six Core Elements into pediatric practices.

Case 1

- ▶ Caleb is a 6yo with Cerebral Palsy whose parents recently moved to WNC from Alabama
- ▶ He requires help with most ADLs
- ▶ His parents are “on top of it” and he is receiving all appropriate services at school

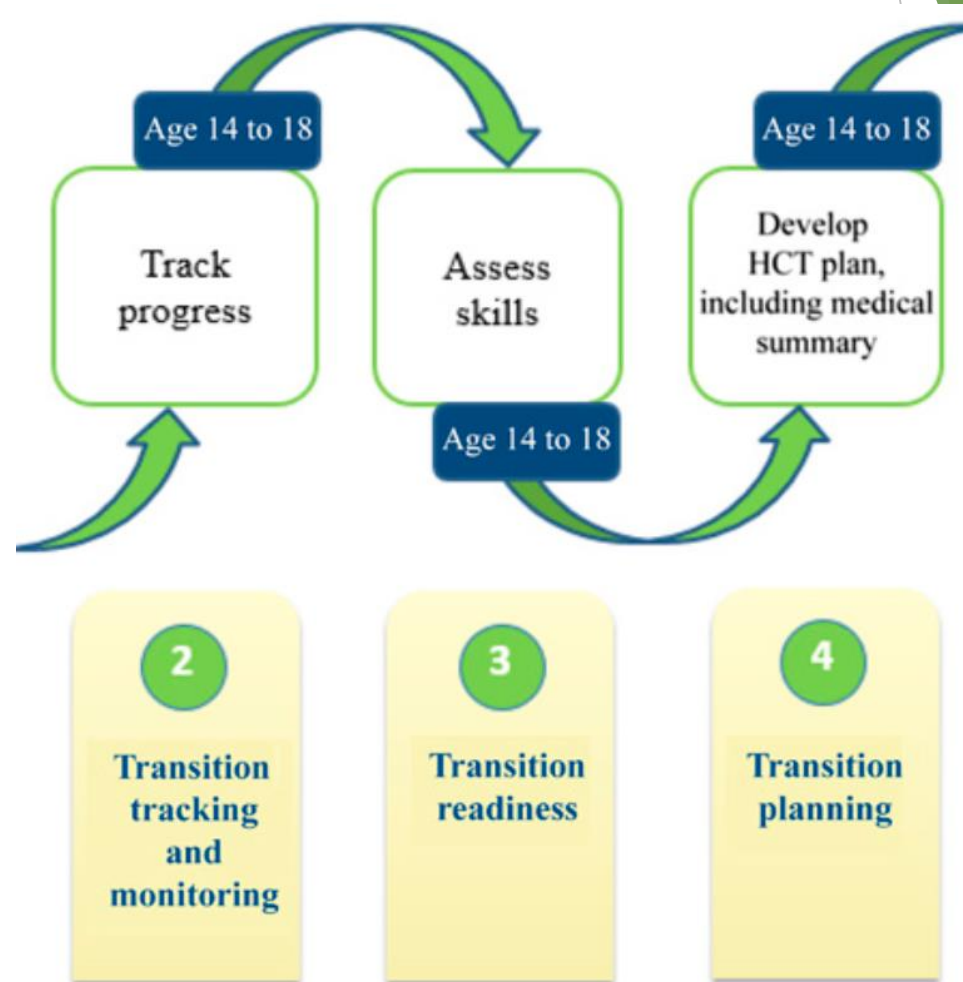
Case 2

- ▶ Katie is a 13yo with Down Syndrome who is here for her WCC
- ▶ Do you have a transition policy?
- ▶ Sample:
<https://www.gottransition.org/resourceGet.cfm?id=221>
- ▶ How can you track?
- ▶ <https://www.gottransition.org/resourceGet.cfm?id=222>



Case 2

- ▶ Casey is a 16yo patient with autism who is coming in for a Special Olympics physical
- ▶ What might your priorities be?



Case 2 cont

- ▶ Discuss and Assess Transition Readiness:
- ▶ <https://www.gottransition.org/resourceGet.cfm?id=225>
- ▶ Identifying special medical needs
 - ▶ What specialists?
 - ▶ Do they have dentist?
 - ▶ VERY LIMITED options for sedation dentistry as adult
- ▶ Start discussing guardianship if appropriate
 - ▶ Need current psych eval (within three years)
 - ▶ Partial guardianship is option
- ▶ Financial Planning
 - ▶ ABLE Account, Special Needs Trust
- ▶ Update transition plan
 - ▶ Identify available adult providers and age for transition
 - ▶ Medical Summary

Guardianship

Guardianship is a legal relationship in which one individual is given the authority by the court to make decisions on behalf of another individual who is unable to make and/or communicate decisions on their own.

Not all vulnerable adults need guardianship.

Guardianship can take away people's right to make the most basic decisions for themselves—such as where they will live and what they will do in the course of a day. Before pursuing guardianship, consider less restrictive alternatives.

Medical Summary

- ▶ My Health Report:
http://flfcic.fmhi.usf.edu/docs/FCIC_My_Health_Report_Fillable.pdf
- ▶ My Health Passport (English, Spanish, Chinese):
- ▶ http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf
- ▶ Transition Care Summary
- ▶ <https://www.gottransition.org/resourceGet.cfm?id=227>

Health Maintenance in IDD

- ↵ Still follow USPSTF guidelines
- ↵ Canadian Consensus Guidelines (2018)
- ↵ HealthWatch Tables
 - ↪ Down Syndrome
 - ↪ Fragile X
 - ↪ Prader Willi
 - ↪ Smith Magenis
 - ↪ 22q11 deletion syndromes
 - ↪ Fetal Alcohol Spectrum Disorder
 - ↪ Autism Spectrum Disorder
 - ↪ Angelman Syndrome
- ↵ Sexual history and education important
 - ↪ Don't presume abstinence
 - ↪ High rate of LGBTQ

Top 5 Tasks for Preparation

1. Develop and share transition policy
2. Assist in appropriate service applications
3. Guardianship, if appropriate
4. Help identify appropriate specialists.
5. Make transition health summary