Summary: Transition from Pediatric to Adult Care

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1. Transition is different from transfer

- a. Transition is a long process that involves preparation steps before leaving pediatric care, a move to an adult provider (if necessary) and some time getting integrated into adult care.
- b. Transfer is the name we give to the move to adult care.
- c. Because transition involves both the preparation to get ready for adult care and some time integrating into adult care, both pediatric and adult providers play a role.
- 2. For medical care, the general framework for addressing transition in the clinical setting is called the Six Core Elements of Transition.
 - a. This was developed by Got Transition[®], a program of The National Alliance to Advance Adolescent Health, supported by Health Resources and Services Administration (HRSA) and Maternal and Child Health Bureau (MCHB).
 - b. They were also endorsed in the transition guidelines developed by the American Academy of Pediatrics (AAP), the American College of Physicians (ACP), and the American Academy of Family Physicians (AAFP), published in 2018.
 - c. Many of the published studies to improve transition in medical settings has used all or part of this framework as the foundation for the intervention.

3. The Six Core Elements are:

- a. Transition Policy to be introduced between 12 years old and 14 years old.
 - i. This introduction can be brief but removes some of the shock of talking about transfer too late.
 - ii. Should be introduced at a time of calm.
- b. Transition tracking and monitoring from 14 years old until transfer
 - i. Clinics should be aware of how each adolescent patient is moving through the recommended preparation steps for transition and tracking this to help patients who are behind and using completion of the steps as a guide for determining transfer.
- c. Transition readiness from 14 years old until transfer
 - i. Adolescents should have a readiness assessment completed periodically (at least once a year) to monitor their readiness.
 - ii. This is one of the elements that should be tracked in part (b)
- d. Transition planning from 14 years old until transfer
 - i. Includes helping patients assume more responsibility for their care, such as getting refills and scheduling appointments.
 - ii. Also includes giving patients/families time to identify a preferred adult provider.
 - iii. Should include getting a care summary ready, like keeping the problem list and medication list up-to-date.

- e. Transfer to an adult provider generally expected between 18 years old and 21 years old
 - i. Pediatric provider roles: 1) Assist with scheduling with an adult provider, 2) Prepare a brief care summary for the patient to take to the new provider, 3) Remain available to the patient/family and the adult care team for questions.
 - ii. Key Care Summary Components for Primary care:
 - 1. Up-to-date problem list
 - 2. Accurate medication list
 - 3. Allergies and serious intolerances
 - 4. Vaccines
 - iii. Care summary components to consider for mental health
 - 1. Recent diagnostic or monitoring results [such as the last 2-3 Patient Health Questionnaire (PHQ-9) scores or recent IQ testing]
 - 2. Other members of the care team (if known), such as the patient's counselor
 - iv. Adult provider roles: 1) Review any materials sent by the pediatric provider or patient/ family in advance, 2) Consider having a "welcome packet" for new young adult patients (and perhaps all new patients) with information like how to schedule appointments, how to call the on-call provider, how to call for refills, etc.), 3) Consider scheduling new young adult patients in the early or late visits of a clinic session to allow them to have more time.
- f. Integration into Adult Care from the first adult appointment until about age 26 years old
 - i. May involve some back-and-forth between pediatric and adult care for a period of time
 - ii. Adult providers should be prepared to provide developmentally appropriate care for young adults, including being patient with questions, recognizing that full adult decision-making ability is not reached until 25-30 years of age, and supporting young adults if they bring parents/caregivers to appointments.
 - iii. Adult providers should give the young adult time alone regularly, and especially during the first visit.
 - iv. Adult providers should acknowledge the lived experience of the young adult and their caregiver with respect to their medical history, especially if the patient has a diagnosis with which the provider is less familiar.

4. Transition considerations more specific to mental health care

- a. Having clear roles for care providers for students who are away at college (ex. Is campus health going to be refilling medications or not? Does the patient need/have a pharmacy at school?)
- b. Transferring during a time of stability so as not to further exacerbate a mental health crisis
- c. Making accommodations for those with new-onset conditions, particular serious mental illnesses like schizophrenia

5. Transition considerations more specific to those with developmental disabilities

- a. Discuss Individualized Education Plan (IEP) transition planning through school as part of transition planning and tracking during the adolescent years
- b. Addressing guardianship / supported-decision making (ideally before transfer)
- c. Assessing for resource needs, such as navigating changes in insurance and the Social Security Disability Insurance (SSDI) program
- d. Making sure family has considered back-up caregiving if the main caregiver is unavailable

Resources

- Moving Into Adulthood Resource Center (aacap.org) Resources for young people and their families as they make the move to adulthood, both healthcare-related and covering other topics. Specifically from the American Academy of Child and Adolescent Psychiatrists; last updated in 2019.
- Got Transition[®] Resources for young people, their parents and caregivers, and clinicians who care for adolescents and young adults and want to address transition more consistently in their practice. Site for materials related to the Six Core Elements and how to implement them. Seeks to be a repository for all patients and the providers who care for them, so not specifically focused on mental health care. Does give some consideration regarding developmental disabilities. Updated regularly.
- ► <u>The Transitions to Adulthood Center for Research</u> | <u>Transitions ACR (umassmed.edu)</u> Rocused on the education-to-work transition for youth with mental health conditions.
- Types of Guardianship Disability Rights Florida Reviews guardianship and guardianship alternatives and is specific to Florida, which is helpful because states vary in how they address certain guardianship issues.
- Aunt Bertha (<u>https://www.findhelp.org/</u>) Provides a number of resources for people with all sorts of social needs; for transition, contains links to the county board of developmental disabilities and offices of vocational rehabilitation.
- Florida Education Transition Resources (<u>https://fcsua.org/K_transition.php</u>) Reviews the requirements and recommendations for transition planning in the education system and links to some other Florida-specific and national resources to support the move from education to the work force for adolescents with disabilities.