Florida's Youth 2 Adult Transition (FLY2AT) Training Course for Professionals

Module 1 HealthCare Transition Resource Companion Guide & Transcript

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The Benefits of Using a Structured Approach to Healthcare Transition.

TITLE: Benefit #1: Customizable & Patient-Centered Process

Dr. Rita Nathawad: **The Six Core Elements** is not a model of care, but a structured process that can be customized for a variety of practice types, including primary care and specialty settings. Its goal is optimal transition from pediatric to adult care for all youth. We know it is critical to consider the unique needs of each patient and family. By using the Six Core Elements, healthcare providers can tailor transition services to the complexity of the health condition, social determinants of health, and psychosocial needs of the patient and family.

The Six Core Elements supports a holistic approach, where the full burden of transition counselling does not need to fall solely on the medical provider. Other members of the clinical team, including medical assistants, nurses, social workers, and support staff, may be trained to serve as valuable resources for implementing health care transition services. It is often helpful for practices to review patient flow through the clinic and determine where and with whom transition support and counselling is best integrated.
RESOURCE: Got Transition® - Six Core Elements of Health Care Transition™

TITLE: Benefit #2: Positive Care Outcomes

A structured approach to the development and implementation of **health care transition services benefits the patient, the family, and the provider**.

For patients, studies have demonstrated increased skills and knowledge regarding medical condition and self-care; improved adherence to management plans, including taking medications and attending scheduled appointments; and increased self-advocacy skills in visits with adult providers.

Families report decreased stress, and patients and families report less lag time between the final pediatric visit and the initial adult visits and fewer gaps in care during the transfer phase of transition. Patient and family quality of life is also enhanced through advanced planning for educational, vocational, insurance, and other support needs as the patient moves to adult services.
RESOURCE: Got Transition® - Youth & Young Adults; Got Transition® - Parents & Caregivers

Providers and pediatric care teams also benefit. Studies show provider wellness is enhanced when patients have positive outcomes. Transition and transfer planning offer the potential for increased satisfaction about the care that was provided. Health care transition planning gives us confidence that our patient will still be well cared for when they are no longer part of our own practice.

TITLE: Benefit #3: Cost Savings

Gaps in care and loss of their care team when patients move to adult services can be quite costly for the health care system. Without access to well-equipped adult primary care or specialty services, patients

experience increased morbidity and mortality during the transfer period and increased emergency department and urgent care center visits. For example, patients living with sickle cell disease have been shown to have worse outcomes during transition and transfer periods due to lack of care team access. Disease monitoring metrics such as hemoglobin A1C in patients living with diabetes have also been shown to worsen during the transition and transfer period. In addition, studies of patients after kidney and liver transplant show an increased risk of rejection when close medical monitoring is lost during the transition and transfer period.

TITLE: Overcoming Barriers to Success

Uncertainty about Availability of Medical Services and Specialists

Vital system supports such as care coordination, care planning, and social services that are found in many pediatric clinical settings may be less available in adult clinical settings. Concerns for patients with a medical complexity can be compounded because medically necessary care often includes costly services that may not be available through adult health insurance plans.

TIP: START EARLY WITH ACTIVE PREPARATION

I recommend *early* transition planning, especially for youth with special health care needs. Transition planning is most helpful when the clinic incorporates active preparation, outreach, and support for self-advocacy—as well as partnerships with family members; medical, mental health, and behavioral health providers; and community supports to bridge service gaps. Partnerships are critical in health care transition work. It is critically important to identify and make connections with providers in your area that have special interest in patients with specific conditions or perhaps a background in palliative care or the care of individuals with disabilities. Cultivate these relationships and support these partners in becoming champions for your patients on the adult side.

TITLE: BARRIER: Lack of Clinician Communication

One of the most common reasons adult providers are hesitant to take on new complex patients is a lack of information about the patient when they first present. So, I strongly encourage the development of a **health summary document** that is updated throughout the course of patient care. This will allow for easy sharing of relevant information with new providers. I typically send a summary note and also offer my phone number for a warm telephone call hand-off if the provider prefers. I also let the adult provider know that myself and our team are available to provide any support or resources needed after the patient establishes with them. The ability to share information through electronic medical records may also facilitate information sharing and easy sending of transfer notes and summaries to new care team members. **National Academy for State Health Policy**

RESOURCE: Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs | Lucile Packard Foundation for Children's Health (lpfch.org)

RESOURCE: NASHP - The National Academy for State Health Policy

Similarly, providers can also use a "**Shared Plan of Care**." The use of a shared plan of care is discussed in a publication of the same name from the **National Center for Medical Home Implementation and the National Academy for State Health Policy**. This tool, when developed in partnership with patients and families, allows us to compile a single, comprehensive, integrated, and shared plan of care that is inclusive of strengths, relationships, and outcomes, to support coordination of care and communication between providers.
RESOURCE: Shared Plan of Care2.pdf (aap.org)
RESOURCE: Tools and Resources for Medical Home Implementation (aap.org)
RESOURCE: NASHP - The National Academy for State Health Policy

TITLE: TIP: Start Transition Early & When Patient's Health is Stable
I have to re-emphasize: It is *critical* to start the conversation early. Consider early care mapping to set goals and understand what services exist in the pediatric side that will be needed on the adult side. **Care mapping** allows the patient and family to visualize all of the services and needs they have that will need to be translated into the adult health care side. Engage the patient based on their developmental and cognitive capacity to slowly take over self-management as appropriate. This requires partnership, open communication, and collaboration among patient, family members, other caregivers, and providers to ensure the goals are in line with patient needs.
RESOURCE: Boston Childrens Hospital: Care Mapping
RESOURCE: FCRC Family & Community Resource Centre: Care Mapping
RESOURCE: Complex Child" Care Mapping for Children with Complex Conditions or Disabilities.

TITLE: TIP: Include Self-Advocacy Skills & Community Partnerships
We need to empower youth and caregivers to communicate about their comfort level in self-management and set realistic goals. Youth and caregiver voices are a vital part of the discussion when planning adult services and care needs. Pediatric and adult services both have the goal of optimizing patient health and well-being, but the expectations put on the patient may be very different. Youth must understand their rights as a patient and learn to ask questions during medical visits. Offices should create a safe, judgment-free zone for patients to learn and practice health care self-management skills over time.

Health care teams should be well informed about community resources and policy changes affecting youth with special health care needs and educate patients and families on this topic. Practices should build a network of community partners where they may refer patients and families when needed. A collaborative approach between medical, social, and educational/vocational services will best serve the patient and family.

TITLE: Uncertainty Regarding Insurances - Florida Medicaid
Another important step in health care transition is identifying current health insurance coverage limitations, which will be covered in Module 3. This includes confirming at what age current coverages

will end and identifying health care coverage the youth and family intend to secure *before* current coverage ends. For example, Medicaid eligibility requirements change at adulthood, and some youth with chronic conditions may have limited options for coverage. It's critical to initiate this review of current healthcare coverage *early*, as eligibility determinations for continuity of services may change during transition. Some patients may be eligible for **long-term-care waivers**, which may begin as early as age 18, but must be applied for at least six months before that patient's 21st birthday to avoid a gap in services. Long-term-care waivers will also be discussed in Module 3. Young adults covered through their caregiver's private insurance plan may remain on the plan to age 26 as well.

Gaps in health insurance can lead to a decline in health status and poor outcomes. Pre-planning to determine what options exist for those who will lose coverage is crucial. Pre-planning also allows for early referrals to case workers, case managers, social workers, and public benefit attorneys, if needed.

RESOURCE: AHCA: Federal Waivers
RESOURCE: NASHP State Approaches to Reimbursing Family Caregivers of CYSHCN through Medicaid.
RESOURCE: Medicaid: Section 1115 Demonstrations: State Waivers List

Thank you for your interest in using a structured, patient-centered approach to health care transition. Please complete the Module 1 Questionnaire, and then proceed to Module 2, which covers Education and Employment Transition.

REFERENCES:

Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. Pediatrics. 2018;142(5):e20182587: Reference: www.aappublications.org/news

ADDITIONAL RESOURCES:

Florida-centric publication provides resources for pre-planning and navigating health insurance: https://fcaap.org/posts/news/the-florida-pediatrician-winter-2019/

Medical Home National Initiatives (aap.org): https://www.aap.org/en/practice-management/medical-home/medical-home-national-and-state-initiatives/medical-home-national-initiatives/