

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

Module 4 Transition Priorities Resource Companion Guide & Transcript

Main Content Speaker & Subject Matter Expert: Linda Hampton Starnes, FL Department of Health, Office of Children's Medical Service

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Photography & Media Specialist: Diane Wilkins Productions

Course Infrastructure and Technical Support: Florida Center for Integrated Media

TITLE: Transition Priorities

As a parent of two grown children who have very different rare conditions, varying abilities, and distinct medical complexities, I've experienced all the steps along the transition journey. Each step is important, each is connected, and each one helps young people move toward managing their own care—and their own life—to the best of their ability.

I'm going to mention a few topics this training hasn't yet addressed, but that are also very important transition priorities to talk about with patients and their families. The first is the need to plan for **emergencies**.

RESOURCE: [Emergency planning \(HHS.GOV\)](https://www.hhs.gov/emergency-preparedness-response-recovery/)

RESOURCE: [Emergency planning \(AAP.COM\)](https://www.aap.com/emergency-preparedness/)

RESOURCE: [Emergency planning \(Family Voices\)](https://www.familyvoices.org/emergency-preparedness/)

RESOURCE: [HHS Child and Adolescent Health Emergency Planning Toolkit](https://www.hhs.gov/emergency-preparedness-response-recovery/child-and-adolescent-health-emergency-planning-toolkit/)

In caring for patients with special health care needs, it's vital to ensure they have a **current portable medical summary** if they must go to the Emergency Department or in case of other urgent situations. This is similar to the full summary that will be needed when the actual transfer of care from pediatrics to adult services occurs.

RESOURCE: [Medical Home Portal: Care Notebook](https://www.medicare.gov/medicare-portal/care-notebook/)

Those with complex care conditions need to know how to explain their specific medical situation and advocate for the best care in difficult circumstances. A strong medical summary is a great support document. It should include information for medical emergency management specific to the person's diagnosis or condition. For example, individualized pain management information is crucial when a patient has an acute pain crisis episode due to sickle cell disease. The rarer the condition, the more important that current emergency management recommendations are available for first responders and Emergency Department personnel.

Preparedness also means ensuring patients and families know what to have on hand in medical ready-to-go situations, how to apply for special needs shelter status, and how to get extra medication during natural disasters and evacuations. It's critical that providers point families in the right direction to learn more and provide materials for them to use in the process of emergency planning and preparation for natural disasters, a home fire, or other unexpected situations.

RESOURCE: [Disaster Planning for CYSHCN \(Family Network on Disabilities\)](https://www.familynetworkondisabilities.org/disaster-planning-for-cyshcn/)

We can also encourage patients to learn about first aid. Suggest that families take a community first aid course together, or that their young person take a first aid course through a scouting or babysitting program, the county health department, **American Red Cross** or **American Heart Association**, or other organizations. Having first aid knowledge and self-care abilities for typical illnesses and injuries is one more step toward independent health management.

RESOURCE: [Centers for Disease Control and Prevention: CYSHCN in Emergencies](https://www.cdc.gov/emergencies/cyshcn/)

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RESOURCE: [American Red Cross: Florida Classes](#)

RESOURCE: [American Heart Association: Classes & Training](#)

Another part of preparing patients for an independent and healthy lifestyle is helping them learn about puberty, sexual health, and healthy relationships. Young people with intellectual and developmental disabilities often have fewer opportunities to learn about these topics due to myths, stereotypes, and misguided caution on the part of families and educators.

An even more compelling reason to ensure your adolescent and young adult patients learn about sexual health and healthy relationships is that sexual assault rates for those with intellectual and developmental disabilities is far higher than for non-disabled youth and young adults. It is estimated the vast majority of all people with developmental disabilities will experience sexual assault at some point in their life. Sadly, almost all of the abusers are known to their victims, often being caregivers or a family member.

People with intellectual disabilities are sexually assaulted at a rate far higher than that of people without disabilities, and it is estimated the vast majority of all people with developmental disabilities will experience sexual assault at some point in their life. Sadly, almost all of the abusers are known to their victims, often being caregivers or a family member.

However, regardless of the disability they live with, young people have feelings, sexual desires, and a need for intimacy and closeness. In order to behave in a sexually responsible manner and understand the concepts of healthy and appropriate relationships, youth and young adults need the opportunity to learn these particular skills. Adolescents with intellectual and developmental disabilities have: less understanding about healthy sexual relationships; a lack exposure to accurate and appropriate education; less opportunity for healthy, trusting peer relationships; and a high probability of being on the receiving end of unhealthy relationship interactions and bullying.

Ending the chance for abuse can start with accessible sexual education. All students need to learn the concepts of "my body is my own; I decide what is right for me" and sexual health care of my adult body.

RESOURCE: [Medical Home Portal: Sexuality & Children with Disabilities](#)

RESOURCE: [Advocates for Youth: Sexual Health Education for Young People with Disabilities](#)

RESOURCE: [Prevent Child Abuse America](#)

RESOURCE: [Child Welfare Information Gateway](#)

Also provide the same care that any youth needs during this time of transition preparation: ongoing encouragement of healthy nutrition, wellness activities, and emotional self-care. Take an interest in what they enjoy doing out in the community and ask questions about their talents and activities. Words of encouragement that reflect your hope for them to pursue high expectations and fun social activities go a long way!

RESOURCE: [Family Voices: Resources](#)

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In the same vein, support skill building in self-advocacy, self-determination, and self-efficacy related to health literacy and self-care management. Using health literacy methods such as “ask me three,” visual decision aids, and teach-back activities in the office setting will help foster these skills.

RESOURCE: [Got Transitions: Resources](#)

Finally—and perhaps just as important as any of the tips we've shared in this training—care for the whole family. Your patients with special health care needs—whether physical, developmental, cognitive, sensory, mental, or behavioral needs—will fare far better when the entire family receives ongoing support. In fact, research is looking more and more at family burn-out and the need for a resilience framework for family well-being.

RESOURCE: [Care Mapping](#)

[CARE MAP] Used with approval from Cristin Lind (cl@cristinlind.com).

When you consider the multiple layers of the health care system, as well as all the other child- and family-serving systems we must learn to navigate – as depicted in this one family's care map - it becomes clear that families need bridges across these systems and agencies. Well-informed and supported families can better support and care for their children and promote their smooth, safe, and successful transition from pediatric care to adult health services.

I implore you to ask questions and truly listen to your patients and their families:

- Provide care coordination services.
- Link families to needed health resources.
- Connect families to support groups, community-based or condition-specific organizations, and peer-to-peer supports.
- Consider all family members when providing resources. For example, share information about groups for dads, siblings, grand-families, kin-families, foster families, and military families.
- Share information on recreational and community activities that are warmly inclusive of all young people and all families.

And, finally, follow up to confirm that these connections are made and sustained.

The care coordination, supports, and resources you provide to families as they move through the transition years will have real value. They will strengthen your family- and patient-centered care, enhance patient and family satisfaction with your clinical services, and promote partnerships with families for improving health outcomes of youth and young adults with special or complex care needs. There may even be an increase in the job satisfaction for you and for your staff's experience!

Many thanks for all you do on behalf of all our children!

RESOURCES: [NASHP: National Standards for CYSHCN](#)

RESOURCES: [HRSA Maternal Child Health: CYSHCN](#)