Health Care Transition in the School Setting:

A Training Program for Educators

Course Script

Module 1. Introduction.

1.1 Welcome to the Health Care Transition Training for Educators, a course provided by Florida HATS. Thank you for participating in this training program, and for joining in this statewide effort to support students with chronic medical conditions and their families.

1.2 As an educator, you play a critical role in assuring that your students gain maximum benefit from their time in school. Your students with chronic medical conditions rely on you to develop the knowledge, skills and confidence to access the health services and related supports that they will need as adults.

1.3 This training program is about the students' transition from child-focused to adult oriented health care. Throughout this course you will meet individuals who have already completed this process. The course uses interactive tools for you to implement the recommendations in your school.

1.4 By the end of this course, you will be able to ...
Describe health care transition and its significance within the larger transition to adulthood
Identify the educator's role in health care transition
Partner effectively with health care providers
Name strategies to improve student health literacy, communication, and self-advocacy
Integrate health care transition into students' IEPs, 504 plans, and IHPs.

1.5 Ten modules make up this course.

1.6 Here are some important terms used throughout this course.
Youth with special health care needs is a phrase that is commonly used to describe children with on-going medical conditions.
Throughout this course, we use the phrases parents and caregivers interchangeably. Caregivers are the adults in your students' lives who have parental authority, such as legal guardians or foster parents.
The phrase "providers" refers to all healthcare providers – primary care, emergency, or specialty – be they doctors, nurses, social workers, or therapists.
The phrase adult medicine is a general term to encompass the primary and specialty practices that serve students beyond childhood.

1.7 The transition to adulthood is a broad process. This curriculum will focus on one aspect of that process: health care transition. This presentation will introduce you to the topic and key concepts used throughout the course.

1.8 In addition to the course's overall learning objectives, each presentation has its own.
By the end of this Module 1, you will be able to .....
Define health care transition
Explain its importance for students
And, describe its current state

1.9 When talking about health care transition, young people and their families often made the following point: health care transition is not a goal in and of itself.
Rather it is one step in the larger process of achieving their life goals.
Further, the process of health care transition supports their efforts at independence, further education, living independently in the community, and most importantly, "having a life".

1.10 Secondary transition refers to the process a student with a disability goes through as they move from high school to whatever comes next, including postsecondary education, employment and independent living.

1.11 As you will see throughout the course, many school-based transition services are inter-related with a successful health care transition.

1.12 In healthcare, transition is the purposeful planned movement of adolescents and young adults, with or without special health care needs, from child-centered to adult-oriented health care systems.

1.13 Health care transition encompasses preparation and planning for the move to adult health systems, transfer from pediatric to adult care, and engagement with the adult-oriented providers.
Preparation and planning are processes, begun by age 14, that occur over time. This allows for the student to gradually increase responsibility for managing their own health.
Transfer is the discrete event of changing to an adult medicine provider. This ideally happens between ages 18-21.
Fully transitioned patients are engaged in and receive on-going patient-centered adult care.

1.14 Many IEPs, 504 plans, and IHPs include health care skills, such as learning to take medication independently. Special education transition services and health care transition preparation frequently overlap.

1.15 For youth, the focus of health care transition is developing the skills to direct their own care. They must build a sense of control and responsibility for their own health, while preparing for additional rights they will gain at age 18.

1.16 Some students may never be able to make legal or medical decisions independently. Others may need a caregiver to complete physical tasks. Yet, these students will become adults – they are not exempt from transition. Preparing all students to direct and manage their care, to their fullest capacity, is critical. Making the transition from pediatric to adult oriented health care is especially important for youth with special health care needs.

1.17 Childhood providers play a critical role in facilitating successful health care transition.
Their challenge is to work in a coordinated fashion so that students receive continuous, developmentally appropriate, and responsive health care during key changes on the path to adulthood.

1.18 Through the health care Transition, families must facilitate growth and development in their child. The process of letting their child grow and letting their child go can be especially challenging for caregivers of children with complex conditions.

1.19 Successful health care transition is key to the overall transition. Without success in this area, all of the work toward vocational and independent living preparation is at risk.

1.20 The next section will further explore the importance of Health care transition for educators.

1.21 Consider a pediatrician's waiting room. Are there ducks on the wall? Little chairs, sized for the youngest patients? A pediatrician's office is surely a wonderful childhood environment – which re-enforces the reasons your oldest students might feel uncomfortable there.
The move to adult care promotes normal social and emotional development, supports a positive self-image and self-reliance; encourages independent living; and broadens the young person's system of interpersonal and social supports.

1.22 With improvements in medical technology, the life expectancy of children with special health care needs is well into adulthood and, in some conditions, equal to that of the general population.
About 500,000 individuals with special health needs turn 18 every year. The next 2 slides provide examples from specific conditions.

1.23 In the 1950s, few children with Cystic Fibrosis lived to see elementary school. Children born today with CF have a predicted mean life expectancy into the early 40s. As of 2012, more than 45% of the CF patient population is age 18 or older.

1.24 Life expectancy for people with Down Syndrome has increased dramatically in the last 30 years.
In addition, people with Down Syndrome experience accelerated aging in their 40s and 50s.
This increases the importance of their transition to adult medicine – a pediatrician is not equipped to provide geriatric care.

1.25 Perhaps you do not see many students with complex conditions, like CF or Down's Syndrome.
Think about other, more common conditions in your school. Students with comparatively simple conditions also must learn to manage medications, navigate insurance, and access specialty care.

1.26 Many students experience gaps in healthcare access, increases in symptoms, and decreases in independence IF their healthcare transition goes poorly.

1.27 Conversely, taking time to properly address the healthcare transition leads to positive overall transition outcomes.

1.28 Most students encounter multiple transfers and transitions between the ages of 18 and 26. Preparing for the healthcare transition should be a natural part of these changes.

1.29 Research shows that successful transition to work and independent living require, in part, the student's good health.
So addressing the issue of health care transition will contribute to their ability to fully participate in their community.

1.30 Throughout this course, you'll see slides, like this one, with interactive questions. Each interactive question slide will help you connect the material with your day-to-day work with students.
Take a moment to consider these questions:
What transition planning do you already complete with your students? How does health affect their overall transition to adulthood?
Writing down your response to these questions will help you prepare for this course's final activity.
The presentation will automatically resume in 1 minute.

1.31 We've seen the need for health care transition. Now let's look at evidence on the current state. Does it need improvement?

1.32 Discharge from pediatric care is frequently abrupt, without planning or preparation.
Rather than being based on a young person's readiness to negotiate the adult health care system, discharge is often precipitated by external factors. These include

hospital or insurance policies limiting pediatric care to children (typically under age 18 or 21).
In some cases, transition is prompted by displays of adult behaviors that pediatricians are not prepared for.
In these situations, transition takes the patient (and parents) by surprise, leaving them with a feeling that they've been 'kicked-out".

1.33 In the current state, healthcare transition outcomes commonly fall into the one of the following categories:
Everything Stays the Same
Mixed Transition
Full Transition
Dropping Out

1.34 Some students continue to receive both primary and specialty care from the same providers and facilities after they reach age 21, so their care seemingly stayed the same after they reached adulthood.
Frequently, individual providers have no formal policies about transferring students based on age.
When those policies are in place, pediatric providers continue to see their adult patients by requesting an "exception" or by simply ignoring age related policies.
How long is it acceptable to assume that 'everything stays the same'?
How would you react to a teacher who wanted to let a student continue attending school into their 40s or 50s?

1.35 Some youth transfer their primary care, but continue to see their pediatric specialist.
There is a known shortage of adult-oriented providers familiar with childhood onset conditions. This shortage causes difficulty in finding adult specialists who accept transitioning students. For example, many adult pulmonologists are not familiar with the care of individuals with cystic fibrosis.
Remember, youth with special health care needs are an emerging population in adult medicine. We will discuss this barrier to transition in greater detail later in the course

1.36 Key to a successful "full transition" is careful planning; the development of health care skills by the student; and good communication between all of the providers.

1.37 Some youth fall through the cracks. Dropping out from childhood care is most likely to occur upon discharge. Dropping out of adult medicine is more frequent if the student experiences an early barrier with new providers.
Many child-focused providers never find out if their former patients drop out of care. They are not aware of the size or significance of this problem.
In later modules, we will examine how to avoid this outcome.

1.38 You may only learn about problems with health care transition if your students experience a crisis related to accessing care.
Have you any of your students transitioned to adult care? Experienced an abrupt discharge from pediatric care?
If yes, what factors have led to their discharge? Did they know or understand the reasons?
Take a moment to consider these questions. The presentation will automatically resume in 1 minute.

1.39 Next we will examine health care transition barriers specific to educators, providers, students, and caregivers.

1.40 Many child-focused providers do not know **how** to broach the topic of transition, afraid of the patient's reaction. Other providers, sensing parents' fears of the unknown, don't know **when** to broach this topic. And if the pediatrician lacks a strong referral network in adult medicine, they may not want to begin the process at all.
Most importantly, the majority of providers have limited knowledge of school-based transition activities – leaving them unaware of the existing structure for students' transition preparation.

1.41 Many providers inadvertently create new barriers, trying to avoid the others. External factors often step in to create an abrupt transfer, such as during a medical crisis.
Additionally, providers develop a strong bond with their patients, especially those with complex conditions. Some pediatricians go so far as to explicitly promise not to discharge or transfer care. This makes an abrupt transition even more emotionally calamitous.
Some providers direct important communication solely to the caregiver, thus leaving the patient unprepared for adult medicine – where parents are typically not part of the visit.

1.42 Adult-oriented providers, such as internists or cardiologists, are less familiar with childhood onset conditions. They may mistakenly believe, for example, that only children can have ADHD or that people outgrow some childhood conditions. Some adults' doctors also say that they are unaccustomed to working with a patient's parent and are unfamiliar with education/voc programs.

1.43 Your students are probably not excited about reading their insurance paperwork, learning how to find an in-network provider, or going to the pharmacy on their own.
The main barrier for youth is the fact that health care is boring and complicated, yet vitally important.

1.44 Many families do not understand why their child cannot continue to receive care from childhood providers when they reach adulthood. They do not fully appreciate that pediatrics is a specialty, trained in the care of children and adolescents, but not of adults

Their fears – that the child will not properly manage their condition or that the new provider does not know enough about their child's condition is their main barrier.

1.45 Many educators are simply unaccustomed to explicitly addressing health care transition in special education plans.

Educators and health care providers both lack pathways to coordinate with each other in a meaningful way.

Finding ways to include them in existing routines – without increasing workload - is a main barrier.

1.46 Video clip

1.47 To be successful, health care transition must be a long-term planned process that attends to the medical, psychosocial, educational and vocational needs of the patient as they move through adolescence into adulthood.

In the next section, we will discuss the connections between the health care transition process and education.

1.48 Due to the growing need, health care transition is a national priority. Improvements in transition care are built into the Healthy People 2020 goals. The reality of transition is reflected in federal laws, like the Americans with Disabilities Act and the Individuals with Disabilities Education Act.

The National Center for Healthcare Transition Improvement, established by the US Department of Health and Human Services' Maternal and Child Health Board, provides resources to achieve these national goals.

1.49 Transition planning for youth with special health care needs includes the development of self-management and decision-making skills to foster active participation in maintaining his/her own health. It is a priority among educators' professional organizations and within federal law.

1.50 All of the different special education programs available to YSHCN focus on developing skills. Frequently, they also prepare students to transition from one phase of life to the next.

Even students who receive services for a short period of time gain knowledge or skills related to health care.

1.51 Beginning by age 14, IDEA requires that the IEP include a statement of transition service needs.

Transition services are a coordinated set of activities that promotes movement from school to post-school activities, including postsecondary education, vocational

training, employment, continuing and adult education, adult services, independent living or community participation.
Lack of attention to health needs and health management can jeopardize goals for learning, working, and living safely in the community.

1.52 Florida laws mirror IDEA. Transition services begin by age 14 or earlier and may not end until 22 for students with significant disabilities.

1.53 Young adults need to know how to manage their own health, access and pay for medical services.
Therefore, instruction that improves an adolescent's ability to take responsibility for their health needs and to work effectively with new health care professionals **are** included within the scope of transition services.

1.54 More than any other group, educators have the best resources to help students develop health care skills during transition.

1.55 Many secondary special education programs use the gradual release of responsibility framework. This emphasizes a "scaffolding" for skill development over time with plenty of opportunity for practice.
Whatever framework you use, individualized plans and services are the hallmark of special education skill development

1.56 In this section, we will discuss general guidelines to introduce this topic with students and parents.

1.57 The earlier the process begins, the more likely students are to take responsibility for their own care as a young adult. It is best to introduce this topic around age 12 and no later than age 14.

1.58 These 8 steps are the heart of the health care transition process. As you will see, there are many parallels with educational transition services. These eight steps will organize what to discuss with families and how to coordinate with health care providers.

1.59 This algorithm maps out the 8 steps of the Health care transition. It identifies specific tasks in the process, by age, with considerations for YSHCN.

1.60 This is the Florida Algorithm for youth and young adults with special healthcare needs, from FloridaHATS. It closely matches the national algorithm you just saw. The Florida Algorithm includes state specific considerations and tools. We will use this guide throughout the course to implement the 8 steps.

1.61 The Florida Algorithm provides age appropriate steps for all stages of adolescence. Use this framework as a guide to individualize your Health care transition discussions with youth and families.

1.62 Before closing this module, let's look at resources for your school.

1.63 The FloridaHATS website has the latest news and tools on transition. The toolbox offers practical resources for multiple audiences.

1.64 There are four regional coalitions within FloridaHATS:
Tampa-Hillsborough, Northeast Florida, the Panhandle Area, and South Florida
These regional coalitions can link you to local resources.

1.65 Children's Medical Services Managed Care Plan has nurses, social workers and other staff who can provide information to teachers, either one-on-one or in group trainings.
For those students who are enrolled in the Program, CMS Plan staff can facilitate communication between the child's health care providers and school staff
Later modules will provide further details on CMS services.

1.66 The National Center for Healthcare Transition Improvement's website is called 'Got Transition.' It provides national news on Transition research and events.
Got Transition dot org also provides a database of tools and resources. Filter the database by tools for youth, for families, for providers, or by state.

1.67 Throughout this course, you will see these key points from the introduction.

1.68 We've already discussed these key tools. Use the links from this course's toolkit to download or print copies for use during the course.

1.69 Now that you are familiar with the basics of health care transition, let's examine the relationship between transition and adolescent development in Module 2. You can pause the presentation for a quick break or continue directly on to the next module.

Module 2. Adolescent Development and Health Care Transition

2.1 Welcome to module two – Adolescent Development and Transition. This is the second of ten modules in the course ' Health Care Transition Training for Educators'.

2.2 This module provides information on adolescent development from the third edition of Bright Futures and evidence-based models of condition management. This module outlines health care transition stages that occur during adolescence and discusses uses of the gradual release of responsibility framework.

2.3 By the end of this module you will be able to:
Describe adolescent development stages
Define health care transition stages
And, identify youth with special health care needs and their developmental tasks

2.4 Health care transition is part of a developmental process. Independence in areas of life such as school, work, home and recreation are important for developing skills that make health care transition easier.

2.5 Consider the transitions that students prepare for: middle school to high school; graduation to post-secondary education; and school to work.
The health care transition takes place within the context of these life transitions.

2.6 Transition is an individualized process. Some of these suggestions will be better suited to younger or older children and not all strategies will be appropriate for everyone. Include these suggestions where appropriate in your transition services.

2.7 You may already be familiar with the key adolescent developmental tasks. In the next few slides we will review early, middle, and late adolescence.

2.8 All students at this age are self-conscious of and anxious about their appearance and body shape. With the move to middle school, old friendships often end. Making new friends can be difficult for teens who are different from the "typical." This can be a very difficult time for adolescents with chronic health conditions.

2.9 Key developmental tasks of middle adolescence are to become more independent and autonomous, to rely on one's own judgment, and to forge independent relationships.
It is typical for youth in middle adolescence to feel that their parents cannot really understand them; and to begin relying on friends for support and advice. This is also the time when many youth engage in risky behaviors and try new things.

2.10 Adolescents with typical cognitive development are becoming more capable of complex problem solving and decision making. This is an emerging skill. Youth need the opportunity to practice and learn how to consider multiple elements simultaneously, systematically, and exhaustively.

2.11 Late adolescence marks many transitions to adulthood. By the end of this stage the student attains all legal rights of adulthood. However, brain development continues until around age 25.

2.12 Successful health care transition is a long-term developmental process that is comprised of three stages: Envisioning a Future, Age of Responsibility and Age of Transition. The age of transition is divided into two phases Early and Late.
The age ranges for the stages serve as a point of reference – and will vary, based on the abilities of each individual student.

2.13 Envisioning a future is a critical first step in the long-term process of health care transition. This stage starts at the time of diagnosis and continues throughout early adolescence.
Envisioning a future recognizes that the child will become an adult and the importance of health care transition preparation.

2.14 During the age of responsibility, a child should receive steadily increasing levels of obligations for their own health care management, medical decisions, and household tasks.

2.15 During the age of transition's early phase, the adolescent and family gather information, start setting specific goals, and develop a written plan for achieving them. The young person assumes a more independent role in working with health care professionals and making medical decisions. Caregivers support the youth's increasing autonomy.

2.16 The "late stage" of health care transition begins when the adolescent turns 18, and gains new legal rights and responsibilities related to confidentiality, consent to treatment, and medical decisions.
In this phase, the young adult and their family must begin the process of transferring to adult medicine. Health insurance considerations arise throughout this phase.

2.17 Before we continue with our discussion on adolescent development and transition, this section will spend time defining the phrase "youth with special health care needs."
It provides additional information about who youth with special health care needs are and what types of conditions they have. You will also see how youth with special health care needs fit into the IDEA eligibility categories for special education and transition services.

2.18 The health care community defines Children and Youth with Special Health Care Needs as those "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

2.19 Defining youth with special health care needs focuses, first, on the different kinds of care included in the student's treatment plan.

2.20 After considering the content of the treatment plan, health care providers assess the condition's impact on the student, both in the intensity of their care and the way it changes day-to-day life.

2.21 Finally, medical providers consider the larger state of the student's health. If the patient has a treatment plan that provides special health care (like speech therapy, social emotional, or the others described earlier), due to their condition, for one year or more, then it would be appropriate to identify the patient as youth with special health care needs.
This definition excludes students who do not experience a health consequence, such as increased treatments. It also excludes patients who are recovering from a short-term illness/injury.

2.22 Unlike the health care community, educators use categorical areas to identify students who may qualify for special education services. These areas are categorized by the type of health condition/disability.

2.23 Consider these examples of students with chronic health conditions. Each one meets both the definition of youth with special health care needs and also eligibility criteria for an IHP, 504 plan, or IEP.

2.24 The US Department of Health and Human Services has a sub-agency to address the needs of children and families, called the Maternal and Child Health Bureau. This Bureau completes a regularly scheduled national survey of children with special health care needs. This survey works as a census to determine how many YSCHN live in the US; it also identifies common experiences among families with youth with special health care needs.

2.25 The most recent survey identified 73,716,714 children in the age range 0-17, nearly 20% of whom were YSHCN.
Another way of identifying the prevalence is to ask how many families include CYSHCN. 23% of households with children include at least one YSHCN.

2.26 Youth with special health care needs are equally likely to live in families at every income level.

2.27 When you hear the term "children with special health care needs, you might think about students who have chronic conditions that require continuous care (like diabetes), have a significant impact on functioning (like cerebral palsy or epilepsy) or are life altering, (like muscular dystrophy and cystic fibrosis).
More complex conditions are, however, quite rare, even among youth with special health care needs.

2.28 The National Survey data shows that most children who meet the youth with special health care needs definition are affected by more common and less severe conditions, like asthma, ADHD and migraine headaches.
Mental illnesses, chronic pain, and developmental delays are also quite common among youth with special health care needs.

2.29 Specific conditions which special educators see every day, like autism or seizure disorders, are fairly rare within the larger population of youth with special health care needs.

2.30 The data also show that one-quarter of youth with special health care needs are affected by three or more conditions. It is also noteworthy that over 12% of children are affected by a disorder that was not included on the National Survey's extensive list of conditions. This is because children are affected by more than 600 identified conditions, many of them very rare.

2.31 Because so many different chronic medical problems and disabilities effect children, it is unreasonable to expect educators to be knowledgeable about all of them.
One excellent source of basic information about childhood medical conditions is the "Medical Problems" section of the Kids Health web site, which was developed by the Nemours Foundation.

2.32 The next section examines specific needs of YSCHN during adolescent development.

2.33 Youth with chronic health conditions and disabilities will have a growing knowledge of the limitations that their health problems may have on their futures.

2.34 Throughout adolescence there is a greater importance of development for youth with special health care needs. They may face more barriers to fitting in and developing self-efficacy as they realize the effects of their specific chronic condition.

2.35 Early adolescence is the beginning of the process of "letting go" . It is critical that parents encourage their child to be more independent.
During middle adolescence, many teens also want more privacy. They may put up "please knock" or "do not enter" signs on their bedroom doors, as a way of establishing their own boundaries. Again, it's important to let caregivers know that this is a normal part of growing up.
This is also the time when adolescents establish some emotional distance from their parents, and want to spend more time with others their own age and gender.
Parents may feel hurt that their child no longer shares everything with them; yet, this is a normal and necessary part of adolescent development.
These tasks are even more important for YSCHN.

It is important to help youth develop positive health habits, self-care skills, and decision-making skills before they reach middle adolescent. Issues related to the adolescent's chronic health condition should not be the subject of parent-child power struggles.

2.36 This section describes practical strategies for addressing health care transition that are complementary to adolescent development.

2.37 As the child becomes a teen, the educator's tasks include supporting the adolescent's autonomy, promoting the teen's self-efficacy and, finally, facilitating the young adult's interdependence with their community.

2.38 Supporting optimal psychosocial development is a significant part of the educator's role. Good social skills significantly increase the probability that an adolescent will successfully transition to adulthood and compensate for limitations in cognitive and motor development. Children with chronic health conditions who develop and maintain friendships with peers are more likely to become independent and happy adults.

2.39 By age 18, young people should be able to
Answer all the doctor's questions
Know what questions to ask and
Be assertive and get the care they need

2.40 The gradual release of responsibility framework naturally parallels the health care transition stages.

2.41 How is health care transition similar to other transitions you prepare students for?
How does health care transition fit in with the IEP, 504, or IHP goals your students already create?
Jot down your responses to these questions. The slide will automatically advance in one minute.

2.42 The medical provider should also work with the student and family to prepare for the transition. Their activities should complement those in the IHP/IEP/504 plan.

2.43 Self-efficacy is defined as the belief in one's own capabilities to organize and execute a course of action that will achieve specific goals. Promoting self-efficacy involves helping adolescents to gain the knowledge and skills they need to be successful; to make good decisions; and to have confidence in themselves

2.44 Fishful Thinking is a website sponsored by the National Association of School Psychologists. It includes tip sheets and strategies for building students' sense of self-efficacy. Their tools are useful for many different professions.

2.45 It is much easier for youth to prepare for health care transition gradually than to do so abruptly. This process takes time.

2.46 Video clip

2.47 Planning for health care transition also involves a discussion of other transitions such as from high school to work or higher education. Talking about these future events illustrates the connection between health and achieving future life goals.

2.48 Educators play a key role in teaching families and youth what issues need to be addressed, providing health care transition-related information, coordinating resources, identifying priorities, and developing a plan to address these priorities.

2.49 During this early stage, parents should begin to "coach" their children to answer one or more questions at medical visit; and so that they are comfortable asking questions about treatments, medications, and the future course of their conditions. In addition, parents should also be encouraged to give their child choices whenever possible. For example allowing the child to choose what clothes to wear to school provides them practice in making decisions and also gives them a sense of control.

2.50 Ask families to envision a future for their child. Of course the future is uncertain and plans may change over the course of the child's development. However, envisioning a future makes it more likely that families and ultimately young adults will think about the future and make plans accordingly. These plans should include securing and paying for health care during adulthood.

2.51 It is critical that parents, and, ultimately, students themselves, ask these future-oriented question. While there might not be clear answers to these questions, the process of asking the questions will orient everyone to the future. Once parents' have envisioned their child working or living independently, it will be natural for them to provide opportunities that will move them toward these goals. Independence in self-care, including health-promoting activities, is a building block of living independently and being employed.

2.52 Middle adolescents should have responsibilities such as chores around the house and expectations for the completion of school assignments. At the same time they need opportunities to develop independence in the areas of finance and interacting with other adults. Involvement in community and activities with friends are also important during this time.

2.53 During the age of responsibility, the student needs opportunities to take an increasing level of accountability for daily self-care and general health care.

This stage is especially challenging for parents or caregivers of children with complex conditions, who have been very involved in the care of their child for many years.

2.54 Examples of taking responsibility for one's own health care include: telling parents when the supply of medications is low, so more can be ordered, and calling doctors to make or change an appointment, with supervision from parents. During this stage, the caregiver's challenge is to move from the role of "doer" to that of "coach".

2.55 The Canadian Hospital for Sick Children provides guidance for parents of youth with special health care needs on supporting their child's growing self-efficacy.

2.56 People with disabilities are at much higher risk of sexual victimization than people without disabilities. This is true for women and for men. People with intellectual or developmental disabilities are especially vulnerable. Conversely, students with intellectual or developmental disabilities may need education to recognize when their own sexual advances are unwanted or inappropriate. It is critical to address these topics during middle adolescence, despite reluctance. Do not assume that another provider will prepare the student or family for this aspect of adolescent development.

2.57 This resource offers guidance for educators to appropriately discuss sexual health and developmental disabilities with students, parents, and caregivers.

2.58 Encourage youth and families to think about what skills they will need to be successful in the next phase of life. Can the young adult live independently, begin post-secondary education, maintain employment, and navigate life in the community?

2.59 Educators play a key role in helping families and youth to understand what issues need to be addressed, providing health care transition-related information, identifying resources; and supporting them to determine priorities and develop a plan to address them.

2.60 In the late phase, the young adult and their family need to begin the process of identifying adult primary and/or specialty care physicians and transferring care. Educators can also help young adults to understand that "interdependence" is a sign of maturity, that they can and should make good use of all available resources, support and guidance as they establish a life of their own

2.61 Before closing this module we will review the resources for use in your transition services

2.62 The American Academy of Pediatrics' website offers many tools for implementing the third edition of Bright Futures.

2.63 These tools use the gradual release framework to create age-appropriate scaffolding for students at each stage of adolescence.

2.64 All students should be given an increasing level of responsibility for their own health care, in keeping with their physical and cognitive limitations and strengths.

2.65 Use the links from this course's toolkit to access the tools from this course.

2.66 The relationship between adolescent development and health care transition stages plays an important role in the next module, working with the health care community.
You can pause the presentation for a quick break or continue directly on to the next module.

Module 3. Working with the Health Care Community.

3.1 Welcome to the module Working with the Health Care Community. This is the third of ten presentations in the course "Health Care Transition Training for Educators."

3.2 One of the basic goals of this training program is to provide information that facilitates a partnership between educators and health care providers.
By the end of this module you will be able to:
Partner with health care providers
On behalf of specific students and
On behalf of the broader population of youth with special health care needs in your school
Coordinate care during health care transition
And, discuss health care transition with families & students

3.3 The first section will describe differences between healthcare and education, as well as commonalities between the two communities.

3.4 Before continuing with this section, consider the differences in approach between educational and medical interventions.

3.5 Take a look at how each field defines and identifies students with additional needs. What differences and similarities do you notice?

3.6 In the medical community, care coordination involves determining where to send the patient next, what patient information to send with referrals, and how to manage accountability among all providers.
Health care professionals notice failures in coordination particularly when the patient has a poor health outcome after falling through the cracks. That might mean

directing the patient to the "wrong" door, a poor handoff, or inadequate information exchanges.

In schools, service coordination involves promoting seamless delivery among multiple agencies, using similar goals & tasks as health care coordinators. Educators also notice failures in coordination when students experience a poor outcome after falling through the cracks.

In both worlds, successful transition is predicated on effective care or service coordination.

3.7 Infusing health care transition related activities into the school setting, through IHPs, IEPs, and 504 Plans, has several advantages for students.
Skills used in health care transition are similar to the skills in the special education Transition Plan.

3.8 Health care professionals understand that children develop at different rates and have different kinds of skills. They want to help children to acquire new skills over time.
Schools are a practical, comfortable, natural learning environment, where a number of different individuals may be available to support the adolescent.
Partnering with providers during health care transition leads to stronger results, rather duplicated efforts, in your shared activities.

3.9 The following section provides a brief review of the ways in which health care needs and medical treatments may affect learning.

3.10 Recall from module 2 that YSCHN are defined as children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.
They have a wide range of conditions, from allergies to diabetes to muscular dystrophy to intellectual disabilities.
Nearly 20% of children in the US are YSHCN.

3.11 Compare the definition of youth with special health care needs and the categorical areas for special education services.
Clearly, there is overlap, as one-third of youth with special health care needs also receive special education. Unfortunately, the majority do not have educational services in place.
Data from the National Survey of Children's Health indicate that in Florida about 37% of youth with special health care needs receive special education, while the majority do not.

3.12 Conversely, those students who do not meet the definition of youth with special health care needs are also unlikely to receive special education.

What can we learn from this? These data suggest that health care providers and educators come to the same conclusions when they assess students who do not require extra assistance.

However, many students struggle with chronic health conditions and meet the definition of youth with special health care needs, yet are not identified for special education services.

Let's see how health conditions affect youth with special health care needs' learning.

3.13 Nearly half of youth with special health care needs missed four or more school days due to their illness.

3.14 If we focus only on youth with special health care needs who missed the most school days, then we see that one quarter of the students experienced a functional limitation virtually every day.

3.15 More than one-quarter of youth with special health care needs in Florida have repeated at least one grade, which is greater than the national rate.

3.16 In contrast, less than 13% of non-youth with special health care needs in Florida have repeated at least one grade

Thus, youth with special health care needs in Florida are more than twice as likely to repeat s grade than students without a special health care need.

3.17 In summary, Data clearly show that, while the term "child with special health care needs" is not one that is used in the school systems, they are an academically "high risk" population.

About 1/3 of the children who receive special education services in Florida appear to meet the MCHB definition of youth with special health care needs.

3.18 When they are at school, youth with special health care needs may have difficulty with attention, concentration, and endurance, because of their condition or their medical treatments.

Thus, from an educational perspective, it may be useful to think about youth with special health care needs as students who have "diverse learning needs".

3.19 Anyone who has had a brush with the medical system knows that it can be quite challenging to understand a diagnosis, communicate with doctors, make medical decisions, follow a treatment regimen, deal with insurance and pay for medical services. People with chronic conditions and disabilities must develop health care competencies to meet the challenges of the day.

3.20 Remember, skill development is a step-by-step process that involves planning and follow-up. It is best for students to receive gradually increasing levels of responsibility over time, while they have support from family, school, and child-focused providers.

3.21 The health care community recognizes that educators are key partners in the effort to provide youth with the services they need to transition successfully to all aspects of adulthood.

3.22 Educators already serve as the lynch pin in the larger transition to adulthood and in skill development.
There is no other institution or profession that does more to prepare youth with special health care needs to achieve their greatest level of individual independence. The schools also have the lead responsibility in addressing school to work issues, and supporting the move to post secondary education or training

3.23 America relies on you to teach students essential skills, such as reading for comprehension; basic math; communication; critical-thinking, planning and decision making.
Without such a foundation, medical providers cannot expect youth to play a progressively active role in their own health care.

3.24 Child-focused health care professionals are encouraged to inform their patients about the need to prepare for changes in health care, but are not required to do so. In contrast, schools are legally obligated to include transition goals in IEPs and to create a plan for addressing these goals.

3.25 When we say that providers are encouraged to address transition, we mean that their professional organizations – the American Academy of Pediatrics, the American College of Physicians, and the American Academy of Family Physicians – have released joint policy statements, clinical guidelines, ethical practices, licensure provisions, and evidence-based tools to steer providers toward delivering excellent care during the health care transition.

3.26 The consensus statement also discusses why planning for the move to adult care is so important. It identifies critical first steps that to ensure that their patients successfully transition to the adult-oriented health care system
Childhood-focused providers are responsible for tasks that prepare your students for a successful transition prior to the care transfer.
Adult-oriented providers are responsible for tasks that maintain continuous, coordinated care after the transfer is complete.

3.27 The following section discusses the evidence for health care transition practices and provides data on how the hc community is doing without your help.

3.28 The national child health survey of all families in the US identified adolescents nationwide. Researchers asked parents whether doctors had discussed the shift to adult providers; the child's changing needs as he or she approached adulthood; coming changes to insurance coverage in adulthood; and whether the child was encouraged to take responsibility for his or her health. Survey results showed that this outcome was achieved for only 41 percent of adolescents in the US.

3.29 Data from Florida indicate only one-third of adolescents received key health care transition related services.
In rural areas it dropped to only 16% of youth.

3.30 It is important to understand that while the Health Care Transition consensus statement reflects important clinical guidelines, these recommended activities are not yet included in any Federal legislation.

3.31 Compare that to schools, where IDEA regulations define and mandate transition services.
Educators are student's only source for clearly identified and guaranteed transition preparation.

3.32 Let's face it -reaching out to a new group of professionals may be a challenge. In the next few slides, we'll identify potential barriers.

3.33 Barriers for partnering with health care providers, as an educator, may center on the barriers everyone encounters when adjusting routine tasks at work.

3.34 Medical providers, educators, students, and their caregivers all will be concerned about uncertainty in this, as well with existing time constraints. Including a new group of providers may also raise concerns about role clarity within the special education team.

3.35 While these barriers arise from natural concerns, partnering with the health care community will actually address more barriers than it raises.

3.36 What would you want a pediatrician to know about a student's IHP, IEP or 504 plan?
What could the participation of a nurse or physician assistant add to your students' transition plans?
What barriers to a student's successful transition could a medical provider help prevent/address?
When you finish writing down your responses to these questions, the slide will advance in 60 seconds.

3.37 Now that we've reviewed potential barriers, let's discuss resources and strategies that address them.

3.38 When holding plan meetings with students and their families, include providers beyond the initial evaluation.
You might start by identifying a natural partner, such as the student's CMS nurse, the pediatrician office's care coordinator, or a social worker at the specialist's office.
Try contacting the person who sends you the special education evaluation documents; provide them with a copy of the student's transition goals.

3.39 CMS Plan Nurse Coordinators receive special training in health care transition, provide program enrollees and their families with transition materials, and develop a health care transition plan with all enrollees.

CMS Plan staff often have a long-term working relationship with the student and family. They also have more frequent contact with the student's primary and specialty care providers.

For students in the CMS Plan program, including their nurse coordinator in the school's transition planning process is a natural bridge between you and the health care community.

3.40 Find out if your student's health care providers have broached the topic of health care transition. If not, spend time educating them about the issues that need to be address and identify useful health care transition resources.

If yes, the provider may be eager to support the school-based transition plan and partner with you.

Either way, encourage families to work directly with their health care providers to identify health care transition priorities and develop a plan to address these priorities.

Incorporate these health care transition goals and activities into school-based transition plans.

3.41 Use your existing resources and models to frame discussions with parents on health care transition within the framework they already understand.

3.42 Before closing this module we will review resources for use in your school.

3.43 CMS has 15 Area-Offices and additional locations throughout the state of Florida.

CMS Program staff receive training in the Federal and state rules and regulations for both health care and education, such as FERPA and HIPPA.

They are interested and available to partner with educators to support students with disabilities and chronic health conditions.

3.44 The CMS Plan serves children with special health care needs who are enrolled in the program. Enrollees must meet financial and clinical eligibility requirements. Children may be found clinically eligible in one of two ways:

Based on the responses to a parent-based survey, which determines if the student is a CYSHCN.

Or, based on their doctor's confirmation of diagnoses & functional limitations.

3.45 The National Center for Transition has many tools to partner with care coordinators and other health care providers during transition.

3.46 The Florida Transition Task Force Report, entitled *"Ensuring Successful Transition from Pediatric to Adult Health Care"* is available on the Florida Health and

Transition Services website. It provides detailed information on health care transition needs across the state.

3.47 FloridaHATS offers a complementary version of the this training course for health care providers.

3.48 As you go through this training, remember the differences in "transition" between the health care community and educators. Keep in mind that health care transition is essential to the success of your existing transition services. Health care providers are a natural source of partnership in your efforts.

3.49 Use the links from this course's toolkit to access the tools from this course.

3.50 The next module covers important health insurance information that affects many aspects of the transition to adulthood.
You can pause here for a break or continue on to the next module.

Module 4. Health Insurance and Transition

4.1 Welcome to the module "Health Insurance and Transition." This is the fourth of ten modules in this course

4.2 Eligibility and application requirements change frequently. Always direct students and caregivers to insurers for updated information.

4.3 By the end of this module, you will be able to:
Describe common options for health insurance coverage for transition age students
Refer students and families to insurance resources
Add insurance related activities to transition plans

4.4 Addressing insurance during transition is critical for the student's health.

4.5 Prior to the Affordable Care Act, transition included financially or medically catastrophic gaps in health care.
Consider the immediate and the long-term effects of losing prescription coverage for students with cystic fibrosis, diabetes, or muscular dystrophy.
How many days or months without treatment are acceptable?
Today, if students plan ahead, losing coverage is avoidable.

4.6 This section describes Medicaid, highlighting differences between coverage for children and for adults.

4.7 KidCare is the State of Florida's program for children. Florida Healthy Kids, Medicaid, and Children's Medical Services Plan are all part of KidCare. These related programs have specific eligibility requirements for their services.

4.8 KidCare benefits include well-child visits, shots, hospital stays, dental coverage, vision services, prescriptions, and mental health services. Additional benefits vary by program.

4.9 Students age out of coverage at their 19th or 21st birthday, depending on which program provides the their KidCare coverage.
The student must then apply for new coverage – whether through Medicaid or through other insurers.

4.10 Students moving from children's to adult's Medicaid will find many differences between the two programs.
For example, medical eligibility is higher for adults than for children.
Conversely, students who did not meet financial eligibility for KidCare may qualify for Medicaid.

4.11 Typically adults are eligible for Medicaid if they are: permanently disabled, ineligible for Medicare and meet financial requirements.
There are several specific programs under which adults may qualify for Medicaid beyond these parameters. The next few slides will examine some of these programs.

4.12 Adults who are eligible for SSI are automatically eligible for Medicaid coverage. The Social Security Administration manages this coverage.
The student need not file a separate Medicaid application, unless they require Medicaid waiver services from the state – such as for home-based healthcare services.

4.13 Students who age out of foster care under responsibility of the State of Florida and with Medicaid may continue their coverage until age 26. There is no income limit or medical requirements for this coverage.

4.14 Home and Community Based Services (HCBS) Waivers are Medicaid programs that provide services in the home for persons who would otherwise require care in a hospital or nursing facility. Without waiver services delivered in the community, some young adults will not be able to live at home or receive needed supports in the workplace.

4.15 Waivers provide specific services over and above those in the general Medicaid adult benefits package and are targeted to persons who demonstrate the need for a high level of care. Enrollment is typically capped; once enrollment reaches a specified number or dollar threshold, waiting lists are created.

4.16 The Agency for Persons with Disabilities Waiver provides Home and Community-Based Services for people with specific intellectual or developmental disabilities.
Each individual who is determined eligible for services is assigned a Support Coordinator. Once on the waiver, their support coordinator meets with the student

regularly to assess, develop, and monitor an individualized Support Plan. The support plan, much like a transition plan, includes goals for services, health, and safety.

Much like the other waivers, it is extremely important to apply despite the wait list. Those on the waitlist receive limited services until they enter the waiver program. If a student begins receiving services in childhood, include their APD Support Coordinator for creating and implementing the health care transition plan.

4.17 Young adults have multiple options to maintain coverage through their parents' insurance.

4.18 Adult children can remain on or later re-join a parent's plan until age 26, even if they are otherwise independent.
This rule applies to parents' employment benefits and to individual plans, such as those purchased on healthcare dot gov.

4.19 44 states, including Florida, have laws that mandate insurers continue coverage of children with disabilities after age 26.
To qualify for continuation of coverage, a physician must certify that the student is incapable of self-sustaining employment due to intellectual or physical disability. The student must also be chiefly dependent on the policyholder for support and maintenance.

4.20 Examples of students who may be eligible include:
Those who receive SSI or SSDI benefits
Those who require total supervisory, physical assistance, or custodial care; or students for whom treatment, rehabilitation, educational training or occupational accommodation has not and will not result in an ability to support themselves.

4.21 The Marketplace Plans are those created through the Affordable Care Act. A marketplace is a site to purchase individual coverage.

4.22 Students can sign up for health insurance during open enrollment periods, at the end of the year, or upon major life changes, such as marriage or a change in income.

4.23 The State of Florida elected not to create a state-based marketplace. Therefore, health care dot gov is the only source of marketplace plans for Floridians.

4.24 The next few slides describe additional options to obtain health care coverage.

4.25 If available, students may elect to use their own employment-based insurance prior to age 26. That is, they are not required to remain on their parents' insurance if they are working and their employer offers benefits.

In the event that the student loses access to their own employment-based coverage (or to their parents'), they may elect to extend those benefits by purchasing COBRA continuation of health insurance.

4.26 Students with chronic conditions may be eligible for other public insurance programs, including Medicare. Even if a student does not qualify for Medicaid, they may qualify for other state programs, such as Medically Needy Coverage or Discount Drug programs.

4.27 Insurance is a dense and potentially overwhelming topic. This section identifies ways to include insurance in transition plans.

4.28 Students and parents have varying levels of familiarity with health insurance rules and requirements.
Educate students about the importance of maintaining coverage and guide them to reliable resources.

4.29 Inform students with disabilities of key provisions within the ACA that protect their coverage.

4.30 Just The Facts: The 411 on Health Insurance for Young Adults Ages 18-30 in Florida helps students navigate health insurance. It has sections for different insurance needs, such as 'private health insurance,' 'public health insurance,' and 'no health insurance.'
Provide the guide to students as a transition plan activity.

4.31 Health care dot gov provides a website for students to find local assistance with signing up for health insurance.
The site is searchable by state or by zip code.
Add 'contact navigators' to the transition plan to coincide with student's age out of pediatric coverage.

4.32 Consider age appropriate steps for health insurance at each stage of transition.
Examples of such activities include carrying their own insurance card, reading an explanation of benefits summary, reviewing the current health insurance plan, locating key information about new coverage, and identifying important dates.

4.33 Encourage parents to contact their employer or insurance company to maintain their child's private coverage.

4.34 Students can complete the adult Medicaid application on-line or by mailing in a paper application.
Use transition assessment and planning tools to include filing a Medicaid application at age 19 or 21.

4.35 The waiting lists for Florida Medicaid Waivers can be quite long, sometimes years.
Don't discourage the student from applying because of the waiting lists – this is the only way to access waiver programs.
To apply for a waiver, the student should contact the operating agency and/or submit a Medicaid application.
This is an extremely important transition plan activity for students who will require in-home care, nursing home care, or workplace supports

4.36 Remember, you have important resources to help you include health insurance coverage in the student's IHP/IEP/504 plan.
If the student has CMS or APD services, include their nurse coordinator in your activities.
Health care providers, include the office's care coordinator, are an excellent resource to help students learn how to use health insurance.

4.37 List three places you will refer students and caregivers to when they have insurance questions.
These might include a specific person in your school or their health care provider's hospital system; a specific program; or a website.
This slide will automatically advance in 1 minute, giving you time to answers to the questions on this screen.

4.38 Before closing this module, let's look at tools to support these strategies in your school.

4.39 Within the Medicaid website, this page provides contact information for local and regional offices.

4.40 This site provides the newest and the most relevant articles on the Affordable Care Act for young adults.

4.41 The Florida Division of Consumer Services has a website dedicated to state protections and programs for purchasing health insurance.

4.42 The Exceptional Parent website offers a succinct summary of how the Affordable Care Act affects students with developmental and intellectual disabilities.

4.43 These are additional resources for obtaining public coverage.

4.44 Transitioning youth have more options than even for maintaining coverage. Finding out specific information for their individualized coverage needs is a dense, but important topic. Encourage students and families to be persistent with insurers.

4.45 Follow the links to the tools discussed in this module.

4.46 You can pause the presentation for a quick break or continue directly on to the next module.

Module 5. Legal and Financial Aspects of Transition

5.1 Let's begin the Module 'Legal and Financial Aspects of Transition.' This is the fifth of ten modules in the course.

5.2 By the end of this module, you will be able to:
List legal rights & responsibilities conferred at age 18
Describe programs that address legal & financial needs
And, address legal & financial considerations in transition plans

5.3 Reviewing coming rights and responsibilities reinforces the need to prepare for the coming transition.

5.4 When an adolescent turns age 18, he or she gains their legal rights as an adult.

5.5 The 18 year old also gains new responsibilities. These include obligations to the government, such as for jury duty, and to financial agreements, such as debt repayment.

5.6 All rights previously accorded to parents under IDEA transfer to the student upon their 18th birthday.

5.7 Students also gain medical rights immediately and automatically on their 18th birthday.

5.8 Parents have no right to make medical decisions on behalf of their adult child. Health care professionals cannot provide medical information to parents without prior written authorization from the patient.
HIPPA imposes severe penalties for inappropriate sharing of personal health information.

5.9 The Florida Bar Association provides a pamphlet for young adults about their new legal rights and responsibilities. It is available in full on their website to view or to download as a PDF.

5.10 The next three sections present ways to address legal and financial considerations. The first program is Florida's Department of Vocational Rehabilitation Program, or VR.

5.11 VR's Mission is "to help people with disabilities find and maintain employment and enhance their independence." They administer several programs to achieve this goal.

5.12 VR's School-to-Work Transition Program offers a number of activities that prepare students for training and/or work after they leave high school.

5.13 Anyone can refer a student for VR services by calling the numbers on the screen.
Students without an IEP may be eligible for VR services.
Complete the referral at age 16.

5.14 Florida VR operates under a prioritization methodology called the Order of Selection.
Federal rules require that when a program cannot serve every eligible individual who applies, due to resource constraints, it must prioritize services to individuals with the most significant barriers to employment.
Even if there is a waiting list at the time of application, it is important to apply.
People are released from the waiting list according to their application date; the sooner applied, the sooner received

5.15 The Florida HATs Transition 2 Go fact sheet on VR provides a one-page summary of this module's Vocational Rehab section.
It also includes links to various VR programs' applications and eligibility information. Provide the student with this tool as part of their transition plan.

5.16 The issue of decision-making capacity is a complicated one. Acknowledge the emotional difficulty that families face during such proceedings. This section of the presentation provides concrete information for the informal and formal supported decision-making options.

5.17 Decision making consists of these three key abilities.

5.18 Each of the following activities demonstrate the three key abilities required to make a decision:
Completing an application for a high interest credit card, asking a friend to help you move, or starting a new prescription without reading about the side effects

5.19 Recall from Module 2 that complex problem-solving and decision-making capacity emerge during middle adolescence.

5.20 As an educator, you are familiar with many theories of cognitive development, such as Piaget's Stages.
Common to many of these theories is that decision-making capacity develops gradually, over the years.
Signs of increasing capacity include: understanding cause and effect, forming goals, and using rational thought.
The capacity grows throughout adolescence and into early adulthood.

5.21 Like all of the other skills discussed in the course, decision-making skills can be taught using the gradual release of responsibility model.
All students would benefit from modeling, explicit demonstration, and supervised practice when it comes to making legal and financial decisions.

5.22 There are a range of decision-making supports available, based on students' abilities & needs.
Four types of supports will be discussed: creating an informal support network, designating a health care surrogate, guardianship, and guardian advocacy.

5.23 For some students, informal supports may be sufficient.
Consider using a network of family, friends, and social services providers. This network provides guidance and advice as the student navigates complex decisions.
The student retains all medical, financial, and legal rights & responsibilities. Therefore, privacy laws still apply.

5.24 Consider the wide variety of informal support options.
This range offers a greater change of individualized supports that maximize the student's existing abilities and allow for more development with age.

5.25 Other students may require more formalized decision-making support.
A Health Care Surrogate Designation is a document in which the student identifies another adult to make their medical decisions.
Many physicians prefer a designation of health care surrogate over guardianship because the document is limited to one aspect of life.

5.26 A health care surrogate has no authority to act until such time as the attending physician determines the individual lacks the capacity to make informed health care decisions. This may be a temporary or an on-going state.
Upon receipt of the document, physicians must comply with the Health Care Surrogate instructions.
Medical providers may request a second opinion to confirm the patient's capacity to make decisions.

5.27 Guide students to identify key aspects in the health care surrogate process.
These include: who will serve as the surrogate; under what circumstances surrogacy will be in effect; where the student will store documentation; when new providers will be informed of surrogacy; and how surrogate will be notified of medical emergencies.

5.28 Have any of your students completed the process to assign a health care surrogate?
How aware of the process were you?
Take a moment to consider these questions. The presentation will automatically resume in 1 minute.

5.29 Guardianship is a legal, rather than medical, determination that an adult is unable to make decisions independently. Guardianship includes identification of the guardian and the parameters of their responsibility.

5.30 Many people describe guardianship as a "civil death." In the US, wards have fewer rights than prisoners.
Perhaps the best way to understand the circumstances of an adult who has a guardian is to imagine the rights of an adult woman in the 1600s and 1700s. While guardianship is an important protection for people who truly lack decision-making capacity, the full weight of this designation cannot be understated.

5.31 Guardians gain the right to make all legal, financial, and medical decisions for their ward.

5.32 Guardianship is not a temporary state. Once in place it is virtually always maintained for the lifetime. Consider what your student will be like in middle age. No matter how else they change over their lifetime, they will still be incompetent in the eyes of the law.

5.33 These are the basic steps of the guardianship process. Note that anyone can file an application. It is not limited to parents or family members

5.34 During guardianship proceedings the judge determines competence and need for guardianship. The physician's role is to communicate assessment results, medical opinion, and supporting records.
The physician assesses the student's ability to: comprehend that a decision must be made, make a plan based on their decision, and execute the plan.

5.35 If school staff files the petition, they may be called to testify. Regardless of who files, school documents may be subpoenaed. Be prepared to demonstrate alternatives to guardianship that have been attempted and why they are not sufficient.

5.36 Potential guardians fill out their own application to serve in this capacity and submits it to the court. The application process includes criminal and financial background checks.
Frequently, the appointed guardian is a parent, childhood caregiver, sibling, or other family member. A trusted friend can also serve in this role.
If there is no individual in the ward's life to serve as guardian, then a public agency or state guardian will be assigned.

5.37 People with developmental or intellectual disabilities have an additional option – Guardian advocacy. To use this option the student's disability MUST begin before age 18 and impair his or her decision-making abilities.
5.38 Like guardianship, this process includes filing a petition with probate court, notice to the student, and a hearing.

The main difference is that this process does not include declaring the ward legally incompetent.

Guardian advocacy is specifically designated for people with intellectual or developmental disabilities. Unlike full guardianship, the court automatically appoints an attorney with expertise in special needs law to represent the student's interests. This process also offers more opportunities to waive fees.

5.38 The Florida HATs Transition 2 Go fact sheet on guardianship provides a one-page summary of this module's guardianship section. It also includes links to legal resources and service providers. Use this tool to introduce the topic with parents and caregivers or in the student's Transition Plan.

5.39 There are many facets to financial support and independence during transition. The next few slides introduce programs through the Social Security Administration

5.40 SSI is a need-based program for children and adults with disabilities. Its benefits include monthly income and Medicaid coverage.

People who may be eligible for SSI include:

Children under 18 whose parents meet the SSI income guidelines

Adults who meet medical requirements, but do not meet SSDI work history requirements

Adults who meet the medical requirements for SSI and receive an SSDI benefit payment that is less than the SSI payment in their home state

5.41 SSDI is a need-based program for disabled adults. Its benefits include monthly income and Medicare coverage.

Typically, SSDI pays benefits to workers who became disabled as adults. Workers pay into the program with every pay check.

The SSDI program also pays benefits to adults who have a disability that began before they became 22 years old. Their benefits are paid on the parent's Social Security earnings record.

5.42 Children and adults with the same condition face different medical requirements.

Unlike SSDI for children, when adults file for SSDI they must prove that they could not complete essential tasks for ANY job.

If the student already receives SSI, then SSA reviews their medical condition when they turns 18.

Conversely, if the student was ineligible for child benefits due to parents' income, then they may become eligible after their 18th birthday

5.43 This booklet provides information on obtaining and maintaining Social Security benefits for children.

Pages 10 – 15 specifically focus on the required steps for applying for benefits when the student transitions to adulthood.

5.44 Applications for Social Security disability benefits are filed with social security. Applications for benefits under the Medically Needy program are made at a local office of the Department of Children and Families.
For both programs the application is forwarded to the Division of Disability Determinations to review medical eligibility.
The claim is then returned to either the Social Security Administration or the Department of Children and Families for a final determination of eligibility.

5.45 Disability Determination Services will likely interview parents and review documentation. Parents may provide
Information on medical condition
Dates of medical appointments, hospitalizations,
releases of information to specific providers,
Copies of medical reports or information from their own records
Determination Services or Social Security may independently contact health care providers, teachers, day care providers, or other family members. They may also request school and medical records. Their goal is to gather information about how the student's disability affects their activities of daily living.

5.46 Like guardianship, the physician's role is NOT to make determination, but to provide medical opinion, assessment, and records.
A diagnosis alone is not enough information to verify the student's functional capacity.
Determination Services, Social Security, or the family may request documentation from their providers that demonstrates how specific symptoms affect day-to-day tasks.

5.47 It is important to know that students, their guardians, disability determination services, or social security may request evidence to verify the disability claim. This may include IEP/IHP/504 records, academic performance records, or testimony from school staff.
Keep in mind that this process uses a deficit model and requires not only a diagnosis, but functional limitations. Discussions using a strengths-based approach would be mis-leading in this context.

5.48 The final stage of adolescent development is interdependence. This is true for ALL students. For some students, this will include personal care attendants to carry out physical tasks. For others it will include a health care surrogate or guardian who supervises medical care. For many it will include the support of their parents, caregivers, siblings, and friends.

5.49 Recall the eight steps of the Transition Process. Addressing legal and financial considerations is a key part of the final three steps in the transition process.
5.51 Recall that, under IDEA, transition services must begin by age 14, but they may begin sooner based on individual needs. Students who may need decision-making support may begin as early as age 12.

Rows 3 and 4 in the Florida Algorithm outline specific program requirements and steps to take at specific ages.

5.50 Address legal and financial considerations as part of the IHP/IEP/504 plan. Include discussions on confidentiality, consent, decision-making capacity, and social service programs for adults.
Like all transition plan areas, add age appropriate items to the plan and gradually build toward the 18th birthday and beyond.

5.51 Here are important items to discuss with students and families.

5.52 At what age will you introduce decision-making or social security with students and families?
How will you prepare parents and students for these changes?
Take a moment to consider these questions. The presentation will automatically resume in 1 minute.

5.53 If you are concerned about a student's decision-making capacity, then the first step is to try cultivating this skill!
Use simple decisions – such as choosing the day's clothing – to assess the three key abilities or as a springboard to progressively more complex decisions.

5.54 Parents need accurate information to explore all options and make the best possible decision. Encourage parents to discuss these issues with their child, to the greatest extent possible.

5.55 Some educators avoid discussions of decision-making capacity, assuming someone else will address it.
Others add guardianship to IEPs automatically, due to concerns for educational rights that students with intellectual disabilities will gain at age 18.
Many educators raise the issue, but focus on the parents' concerns and fail to provide complete information about the long-term impact of removing the student's rights.

5.56 For students with limited decision-making capacity, try less formal supports before there are legal responsibilities attached.
Remind the student and family that practice is the key to success.
Include steps for developing and maintaining such a network in the health care transition plan.

5.57 Include goals to develop decision-making capacity around age 12. Begin testing informal supports by age 16.
Remember, this capacity continues to emerge and becomes most prominent by age 17.
If these attempts do not work out, make sure to document what was tried, for how long, and if/how the outcome demonstrates lack of decision-making capacity.

5.58 For those students who will need it, Include guardianship steps as part of the health care transition process at age 17. This allows time for the family to find legal advice, gather documentation, and complete the process before the student's 18th birthday.

5.59 Addressing legal and financial considerations in the IHP, IEP, or 504 plan is an important step in the transition to adulthood. But, you don't have to go it alone! This is an area that naturally lends itself to partnering with the health care community – Centers for Independent Living, Medical providers, care coordinators, and program specific case workers are supports for you, as well as good referral sources for students.

5.60 Before closing this module, we will review the resources for use in your school.

5.61 The National Center for Supported Decision-making is a key resource for any student who may lack capacity. Their toolkit offers information for educators, students, and caregivers, with a focus on transition-aged youth.

5.62 Disability Rights, Florida offers many resources to educate students and families on guardianship and other legal considerations.

5.63 The Department of Vocational Rehab website on Ticket-to-Work provides information on how to participate in the program, who is eligible, how to maintain Medicaid and Medicare coverage while using Ticket-to-Work, and a fact sheet on the program.

5.64 The Social Security's Plan for Achieving Self-Support program website gives information on benefits, how to participate, and eligibility.

5.65 S S A dot gov slash disability s s i
Provides the news and information on the program. students can use the website to complete the application, check the status of their application, or manage their benefits.

5.66 The Florida Developmental Disabilities Council provides a comprehensive guide to housing resources.

5.67 The Florida Commission for the Transportation Disadvantaged has a goal to ensure the coordination of transportation Florida's most vulnerable people. Their website provides resources for people with disabilities.

5.68 When addressing legal and financial considerations, there is a wide range of supports and options for the student. Use the transition plan to complete specific requirements and start early!

5.69 Follow the links to download or print copies of tools for financial services.

5.70 Use the links from this course's toolkit to access the decision-making tools from this course.

5.71 You are now more than half way through the course. Good job!
You can pause the presentation to take a break or automatically continue to the next module.

Module 6: Assessing Health Care Transition Readiness

6.1 Welcome to the module "Assessing healthcare transition Readiness." This is the sixth of ten presentations in the course.

6.2 By the end of this module you will be able to:
Discuss the importance of healthcare transition readiness assessment
Administer assessment tools
And, integrate health care transition assessment worksheets into IHP/IEP/504 evaluations

6.3 Assessing healthcare transition readiness incorporates concepts discussed in the previous five modules, including the healthcare transition stages and the areas of transition discussed in the previous modules.

6.4 Assessing healthcare transition readiness lays the foundation for skill development.

6.5 A young person's knowledge about their disability is paramount to independently managing their condition. Also important is knowledge of good health habits such as diet, exercise and sexual health.
Finally, students must learn to identify important changes in their health and determine how to respond when they are in crisis.

6.6 Video clip

6.7 This section introduces student assessment tools.

6.8 The healthcare transition Readiness Assessment Questionnaire (or the TRAQ) and the healthcare transition Planning Guide worksheets are the recommended assessment tools. They both have separate sections for students and for caregivers. The TRAQ and the Planning Guides integrate with and support special education evaluation tools.

6.9 TRAQ is a validated, student-centered questionnaire to assess youths' health care self-management knowledge and skills.. It is self-administered and takes less

than 5 minutes for youth to complete. TRAQ is available in an Excel file to input, score and aggregate results, or in PDF

6.10 Take a moment to review the response options on the TRAQ. These provide a range of ability levels, from no knowledge to complete skill mastery.

6.11 The TRAQ consists of 20 questions that assess the student's skills within 5 categories. It is important to emphasize with the student that the document, as a whole, is meant for ages 12 -21. Some activities will be age appropriate for the student and others will not.

6.12 Including the TRAQ with annual IHP/IEP/504 planning for families is an easy way to introduce health care transition assessment.

6.13 In keeping with the Gradual Release of Responsibility framework, the student is the TRAQ's target audience. Emphasize that there is no right or wrong answer – the assessment simply takes a picture of the student's current habits.

6.14 The three Planning Guides are age-specific, separated by the three healthcare transition Stages. They include assessment worksheets for students and for parents to complete at home.
The worksheets present an opportunity for students and their families to engage in dialogue about healthcare transition, and to think more comprehensively about needs and future plans.

6.15 "Thinking about the Future" asks a series of yes/no questions and has check boxes. This information provides youth and families with a context for health care transition. Questions are grouped under the headings of school and work, living arrangements and planning.
Pages 23 – 27 of the Guide provide worksheets on health care independence using the seven areas of health care transition.

6.16 Envisioning a future is a critical first step in the long-term process of healthcare transition. The first Planning Guide asks a number of questions to start this process

6.17 Planning Guide 2 follows a similar format to the first guide, with added emphasis on the youth's new responsibilities and their self-efficacy.

6.18 The first two Planning Guides for Youth have only 2 sets of student worksheets "Thinking about Your Future" and "Health Care Independence."
Parents complete the other two sets of worksheets.

6.19 In the final guide, the healthcare transition Plan Worksheet is part of the student's, rather than parents', activities. This reinforces the idea that young adults now have the lead role in directing their care.

6.20 Assessing health care transition readiness complements the Present Levels of Academic Achievement and Functional Performance assessment. It is especially relevant to the domains of communication, independent functioning, and social emotional behavior.

6.21 Health care transition readiness assessment correlates to the 504 evaluations, especially the sections on major life activities, health information, manifestation determination, and mitigating measures.

6.22 The next few slides discuss using TRAQ and the Planning Guides with parents or caregivers.

6.23 Parents' and caregivers' input is important during assessment.
The TRAQ provides them with a separate set of directions.
Emphasize that the parent should not complete the student's form for him or her.
Ask parents to fill out a separate form using their instruction set. Then compare to the students' responses.

6.24 The first two Planning Guides have 3 sets of parent worksheets "Thinking about Your Child's Future," "Parents' health care transition activities," and "Transition Plan Family Worksheet".

6.25 The questions in the worksheet for parents correspond to those in the worksheet for youth. For example, "my child will finish high school" on pp. 5 matches "I plan to finish high school" on page 19 of the youth worksheets.

6.26 This section appears in all three guides. It assess the caregiver's transition preparation activities with the student.

6.27 Children with significant physical limitations will not have a goal to 'complete independently.' Their ability to direct others – for example, a personal attendant – is the more appropriate goal. Therefore, both options are presented in the caregiver worksheets for the Age of Responsibility.

6.28 Even at the Age of Transition, the Planning Guide provides questions for the parent to answer about themselves. The questions address key activities that support their child's independence, including those for Early Transition related to insurance, SSI, and Vocational Rehabilitation services.

6.29 The next few slides discuss how to introduce and administer assessment tools with your students.

6.30 Recall the eight steps of the Transition Process.
The first two steps describe assessment concepts. They are key to all subsequent transition activities.

6.31 When introducing the assessment tools to students, build off of your initial healthcare transition conversation. Each student should start with assessment tools for stage 1, regardless of their age.

6.32 Including health care transition readiness assessment in your "scaffolding" conversations will help make it a natural part of your regular activities.

6.33 Recall that, especially in the area of decision-making, it may be appropriate for individual students to begin transition preparation before age 14.
The Florida Algorithm for youth with special health care needs highlights healthcare transition readiness assessment beginning at age 12.
Middle school teachers might use health care transition concepts as part of activities for the transition to high school.

6.34 The FloridaHATS toolkit includes TRAQ as PDF, with a separate scoring guide. Earlier slides provided examples of that format.
The toolkit also offers an alternate format of the TRAQ as an Excel file to input, score and aggregate results, seen here.

6.35 Students' and parents' responses to the health care transition assessment tools will lead to better preparation for IHP/IEP/504 meetings.
Use their responses to create the transition services plan or to evaluate progress on the previous year's goals.

6.36 The Planning Guides are lengthy. To avoid overwhelming the student or the parent, advise them to break the worksheets into smaller portions.

6.37 Students and parents should complete their worksheets independently, outside of IHP/IEP/504 meetings. These worksheets support the in-person TRAQ assessment.
Module 7 will discuss how to use the healthcare transition Plan worksheets.

6.38 The guides are organized developmentally. With all students, start at the first healthcare transition guide, building with the student's abilities year-by-year.
If a child is unable to use the Planning Guide, support parents' worksheet completion. Include the student in this process to their fullest capability.

6.39 There are multiple ways to integrate health care transition assessment with IHP/IEP/504 evaluations.

6.40 Joe is a 19 year old young man with a severe seizure disorder and some intellectual disabilities. His health depends on how well he remembers to take his medications and on following his doctor's advice to get enough sleep and abstain from alcohol.
He currently lives at home with his mother. She provides daily reminders for medications and sets up his pillbox every week. She also provides him with

reminders about sleep every evening and about alcohol any time he leaves the house with his friends.

Joe will graduate from high school at the end of this school year. His transition goals are to become a chef and to move into his own apartment. He is meeting his IEP transition plan focuses on employment, postsecondary education and community living. Over the last year he has attended community college to complete a course on food preparation. At the end of the semester, he hopes to become a sous-chef through a work study program. His mother found an apartment for him that is near a community service provider and has agreed to fill out Joe's lease application. However, as graduation approaches, Joe's mother is increasingly concerned that Joe is not prepared to manage his seizure disorder without her supervision. She has concerns that his health will suffer and that there could be long-term consequences of ignoring the doctor's advice. Joe and his mother now frequently argue about whether she should delay the apartment application for a year or two.

6.41 Using the TRAQ, Joe's transition coordinator realizes that he answers many of the questions with, "No, but I would like to learn."

Based on their work for independent living and employment goals, the transition coordinator believes that Joe is capable of completing many health care transition activities himself.

Most of his mother's concerns could be addressed, with modeling and practice, by transferring responsibility for health care activities from Mom to Joe.

The transition coordinator wants to discuss this with someone at his doctor's office when she sends the IEP evaluation form.

6.42 Jane is a 16 year old student with Type 1 diabetes. Her health depends on maintaining a stable blood glucose level. She has had an insulin pump since age 13. Jane lives with her parents and younger sister. At school she participates in marching band and she takes AP classes to prepare for college. Her marching band instructor is certified as Trained Diabetes Personnel and her 504 plan includes notifying teachers of Jane's Diabetes Medical Management Plan.

Jane's mother has been "in charge" of the insulin pump for the last three years. Her mom also provides reminders about nutrition and physical activity, accompanies the marching band to away games, provides Jane with snacks before longer trips, and makes all of the pharmacy runs for supplies/medications

Jane is preparing to take the SATs this year and hopes to go to college in California. Her parents are afraid that Jane is not prepared to take care of her diabetes and that she will wind up in the emergency room. They think California is too far away for someone with Type 1 diabetes.

6.43 Jane's resource specialist realizes that fears about diabetes could jeopardize Jane's goals. The specialist provides Jane's family with planning guide as part of her junior year 504 re-evaluation.

When the family completes the Planning Guides, they realize that Jane doesn't know what is in her Diabetes Medical Management Plan or how to adjust her insulin pump after exercise.

6.44 What would be the best year to begin health care transition assessment with Joe and his mother?
How about with Jane and her parents?
Jot down your answers to these questions. The slide will automatically advance in one minute.

6.45 Before closing this module, we will examine additional resources.

6.46 Medical evaluations and other documents in IHP/IEP/504 planning are a natural way to include providers in health care transition assessment.

6.47 In 2014, The National Center for Health Care Transition Improvement released a new Transition Readiness Assessment tool, similar to the TRAQ, that matches each domain of their Six Core Elements.

6.48 The Waisman Center offers additional resources for integrating health and IEPs.

6.49 The Florida Department of Education offers example IEPs and implementation guides for 504 planning.

6.50 Health care transition assessment integrates with and supports existing special education evaluations.
Use these tools to your benefit when preparing for the student's transition plan.

6.51 Use the links from this course's toolkit to access the tools from this course.

6.52 The next module demonstrates how to use assessment results to address students' gaps in knowledge or skills.
You can pause here for a break or continue to the next module.

Module 7. Health Care Skill Development

7.1 Module 7, Health Care Skill Development, will build off the previous presentation on Assessing Transition Readiness.

7.2 By the end of this module, you will be able to:
List specific steps for making a health care transition plan with students
Discuss the Florida HATs tools with students, parents, & colleagues
And, identify activities and tasks for students' Transition Plans.

7.3 The student's goal during health care transition preparation is to gain the knowledge and skills to manage their health care independently. The educators' and parents' shared goal is to support the students with planning, tools, and coaching.

7.4 Self-management expectations instill in students a sense of responsibility and ownership of personal health.

7.5 In addition to the health management skills that everyone must learn, youth with special health care needs have important, condition specific skills to master.

7.6 Video clip

7.7 The next section will discuss how to use health care skills development to complement educational and vocational goals in IEPs,504s, and IHPs.

7.8 Recall the eight steps of the Transition Process.
The first two steps pertain to assessment. The remaining six steps are integral items to address in the Transition Plan.

7.9 IDEA defines transition services as "a coordinated set of activities for a child, designed within a results-oriented process that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities."

7.10 Major life activities addressed in Section 504 have an impact on both the health care transition and the overall transition to adulthood.
Accessing health care is both a functional skill and a critical component of independent living. Services that improve an adolescent's ability to manage their own health care must be part of 504 plans.

7.11 The IHP itself is a plan to address health needs. Many schools use the IHP to develop health skills, such as medication management.
Consider specific health care transition activities, based on ages & stages, when identifying which skills to address in the IHP.

7.12 Use the TRAQ results to determine which skills the child has yet to attain. Discuss the results with the student and parent to identify their priorities among these skills.

7.13 What does the student need to develop a particular skill? The Planning Guide worksheets support this step and identify individual student needs.
These might include modeling, coaching or practice.

7.14 The Transition Plan is the fourth worksheet in the Transition Planning Guides, with dedicated areas to write out the Transition Plan matched to assessment worksheet categories.
Recall that for early and middle adolescence, the Transition Plan is a parent worksheet. For late adolescence, the Transition Plan moves to the student worksheets.

7.15 Plans will vary for individuals, but should be task-based.
Establish a timeline that builds gradual independence in all of the student's medical tasks.
If the Planning Guide reveals that the student has many areas that require goals, choose the most important 2 or 3 areas rather than making a goal for every area.

7.16 Health care skills development fits in with the IEP Transition Plan in the following sections:
Education/training, employment, independent living, programs & services

7.17 In a 504 plan, health care skills fit in with the accommodation plan on page 1 and with the plan & placement section on page 3.

7.18 Insert health care transition skills development goals into the other goals you include in the plan.

7.19 Later in this presentation we will discuss student tools & activities for use while carrying out the plan.

7.20 Working with the student's primary care providers, specialists, CMS nurse, and other healthcare providers will increase the student's skills in multiple areas.

7.21 Follow-up with the student and family as you would for any other IEP/IHP/504 activities.
Complete re-assessments annually with each new plan to encourage the student's progress through the health care transition stages. Celebrate newly mastered skills and make new goals for the coming year.

7.22 How do steps 1-5 match the IEP process? The Section 504 process? IHPs?
Take a moment to consider these questions. The presentation will automatically resume in 1 minute.

7.23 Now that you are familiar with all of the available tools, let's identify potential activities and tasks for students' Transition Plans.

7.24 In this section we will focus on activities for steps 3-7 in the Transition Process.

7.25 Addressing health care transition in your work reinforces your message that the adolescent is increasingly autonomous, and has the responsibility for monitoring and managing her/his health in "real world" settings, such as the workplace.
Skills used in health care transition, including planning, self-determination, and communication are similar to the skills that you cultivate with the students for work, independence, future education and other aspects of community living.
Further, schools are a practical, comfortable, natural learning environment, where a number of different individuals are available to support the adolescent.

7.26 Explaining the necessity of routine medical tests is one potential activity for the student's health care transition plan. This skill supports communication with multiple providers or insurance companies.

7.27 Students who will ultimately manage personal attendants for daily tasks should rehearse directing others, such as school aides. This develops the student's ability to describe their needs and provide correct instructions.
The Center for Independent Living in your area is an excellent resource for training.

7.28 Medication management is a very important skill set for self-management. Different skills from this set are appropriate for different health care transition stages. These activities also transfer to other areas of transition.

7.29 It is important for students who use medical equipment to become responsible for its use, care, maintenance and ordering. This activity could eventually include obtaining insurance approval for new equipment.

7.30 Interacting with health care providers is a specialized social skill to practice and master prior to the student's care transfer.
Adding different tasks for the student's one-on-one time with the PCP into the health care transition plan encourages the student to practice different aspects of managing a doctor's visit throughout their health care transition stages.

7.31 One way to record medical information and simultaneously instill responsibility is to have students keep a medical journal. Medical journals and templates are available from a variety of commercial and non commercial sources.
It is also simple to make a medical journal with a three ring binder and dividing tabs.

7.32 The 2 page Health Care Transition Summary from Florida HATs is one example of a medical journal.

7.33 Students may prefer e-summaries to a paper medical journal. Electronic tools allow for increased independence and privacy during middle and late adolescence. Potential tools include patient portals in the physician's electronic medical record; simple functions in the student's cell phone (such as their contact list, the note page, the alarm, and reminders); or downloadable applications.
This is one area that may allow teenagers to quickly master specific tasks within the overall activity and gain confidence.

7.34 My Medical keeps track of test results, stores medical histories, and monitors chronic conditions. It works with iPhones, iPads, and Android phones. My Med Schedule sends e-mails or text reminders when it is time to take medications or get a refill. Originally designed for post-transplant patients, it does not require a smart phone.

7.35 Think of the tasks you use in transition plans that address employment or independent living: making phone calls to follow-up on job interviews, requesting reasonable accommodations from an employer, or filling out employment forms. Each of these activities is a transferable skill with an analogue in health care: calling a pharmacy to re-fill a prescription, describing health history to a new provider, or filling out insurance forms at a doctor's appointment.

7.36 How do these skills compare to those you typically include in transition plans? Take a moment to consider these questions. The presentation will automatically resume in 1 minute.

7.37 The Florida HATs student self-management booklets are excellent tools to foster independent skills that are also developmentally appropriate.

7.38 Like the Planning Guides, there are three Self-Management booklets, separated by the Transition Stages.
Each booklet provides age appropriate preparation activities for youth to complete independently.

7.39 The first booklet, *Since You're Not a Kid Anymore*, emphasizes the link between health care skills and independence. By highlighting growth from elementary school to middle school, this guide encourages the student to think about the future.
This booklet targets students in middle school.

7.40 The second Patient Self-Management Booklet re-enforces the youth's self-efficacy during middle adolescence.

7.41 The last booklet has a slightly different format to highlight the major life changes that begin at age 18.

7.42 Each booklet provides material for youth with special health care needs, a section with health care terms and definitions, and ideas for staying healthy. The Self-Management Booklets focus on the youth's increasing responsibility throughout the health care transition stages.

7.43 Booklet activities encourage the student to prepare for a situation before it arises. The material instills confidence that the student will master new skills.

7.44 My Health Care is a free instructional resource for transition-age students with intellectual or developmental disabilities. It focuses on improved communication with health care providers, the use of adaptive tools, and development of self-advocacy skills. It encompasses approximately 22 hours of classroom instruction, incorporating modeling, games and role play activities throughout the course.
An Instructor's Guide and training video provide step-by-step guidance that corresponds to learner materials. It also offers guidance in integrating Florida Access Points for English Language Arts and Health Education in teaching and

learning. The instructor's guide includes formative assessment rubrics to aid learning among students at every performance level.

7.45 The curriculum uses the "GLADD," teaching model for students with ID/DD. GLADD serves as a reminder about important skills to use when communicating with health care providers and others:
Give information
Listen and learn
Ask questions
Decide on a plan
Do your part in following through on the plan

7.46 *What's Health Got To Do with Transition* is another curriculum sponsored by the Florida Developmental Disabilities Council, developed in partnership with the School District of Hillsborough County.

7.47 *What's Health Care Got to Do with Transition* addresses a broad range of issues concerning movement from child systems to adult systems.
It is appropriate for both ESE and general education students in grades 9-12. It addresses self-advocacy, decision-making and self-management skills, rights and responsibilities when turning 18, staying safe physically and emotionally, and maintaining sexual health. It contains 40 hours of instruction, structured in 8 units with practice activities, homework assignments and tests.

7.48 Remember Joe, from the last presentation? He is the 19 year old student with seizure disorder and some intellectual disabilities. His mother provides most of the day-to-day condition management, which leads her to believe Joe's IEP goals, and independent living, are unachievable
What health care transition goals could go into Joe's IEP to ensure independence?
Perhaps in early adolescence Joe could have learned to set up medication reminders and his weekly pillbox.
In middle adolescence he could have met with his doctor to discuss the effects of alcohol on his seizures and prepared for social situations that might include alcohol.
At the age of transition, Joe could have selected a mentor to guide him through financial decisions so that he could have selected his own apartment.
These are just a few ways that the health care transition could have integrated with his IEP through the years.

7.49 How about Jane, from Module 6? Recall that she is a 16 year old student, with diabetes, who hopes to attend college in California. Her parents are afraid she will not be able to manage her health and want her to stay home.
What health care transition activities could be part of her 504 plan?
Jane could have started learning about her insulin pump the first year she had it - when she was 13 – and gradually taken over its maintenance.
Managing snacks and physical activity could have been a 504 activity in middle adolescence.

Now that she is 16, one goal might be to attend an out-of-town marching band competition without her parents.

7.50 Here are additional resources for student skills building.

7.51 My healthcare is the curriculum for students with ID/DD.

7.52 The Institute for Child Health Policy has developed a variety of health care transition booklets, guides, videos and other resource materials.

7.53 The Florida Department of Education offers a number of services and resources for addressing the secondary transition in IEPs.

7.54 The Florida Centers for Independent Living website offers an interactive map to locate nearby offices. Search using the map or by the county list.

7.55 Project 10 assists Florida schools in improving secondary transition services to students with disabilities and their post-school outcomes.

7.56 The Illinois Transition Care Project created a presentation for students, parents, and caregivers entitled 'Health Goals and IEPs." It is an in-depth presentation on working with the IEP team on building health care skills through the educational transition plan.

7.57 Create a transition plan with students to address 1 -3 skills. Tailor the plan's tools and activities to individual student needs. Update the plan and its activities annually, when you complete re-assessment.

7.58 Use the links from this course's toolkit to access the tools from this course.

7.59 This module's activities are relevant throughout the transition process. In the next module, we will focus on bringing these skills together to manage a key task: The care transfer.

Module 8: The Care Transfer

8.1 Welcome to 'The Care Transfer' module. This is the eighth of ten presentations in the course.

8.2 By the end of this module you will be able to:
Describe characteristics of adults' health care to students and families
Identify care transfer activities for IHP/IEP/504 plans
Support students during the care transfer
And, list strategies to coordinate services with medical providers during the transfer

8.3 Adjusting to the differences between children's and adults' medical care is a major challenge for students and parents.

8.4 The term culture shock describes the discomfort experienced when moving to a very different environment. For example, from a rural village to a large city or to a new country.
It is normal to feel uncomfortable in a new, strange environment, where old ways of doing things may not work.
The care transfer is akin to culture shock.
Prepare the student for some confusion and discomfort, while emphasizing their ability to learn new customs.

8.5 Pediatrics uses a developmental orientation, with a focus on assisting children to acquire new skills over time.
Providers often use a supportive approach to families and patients, which is non-judgmental. Adult-oriented providers might describe this as a paternalistic approach.
Office staff tends to be warm, optimistic and interpersonally oriented.
This approach accommodates the family's competing priorities - school obligations, extra-curricular activities, siblings' needs, parents work responsibilities, and so forth.

8.6 Adult medicine focuses on the diagnosis or disease, rather than on the whole person.
Adult medicine uses a specialist – consultation model to treat chronic conditions.
Providers share findings and recommendations in a written format more frequently than by phone or in a face-to-face conversation.
Adult medicine facilities are much more business-like and formal.
The approach is less accommodating to the preferences and priorities of the patient.

8.7 As discussed in module 2, pediatric care uses the Shared Management Model.
In this family-oriented model parents are the experts in the child's chronic condition.

8.8 Adult medicine regards the patient as autonomous.
Providers do not view the patient or the family as an expert in their own health condition. They may take umbrage at being "schooled" on the patient's needs.
During medical visits, patients are seen alone. Practice staff members expect them to make decisions and function independently.

8.9 Pediatric providers rely on parents' observations about the child's development, changes in their health status, response to medications, and so forth.
The Provider is responsible for active advocacy and oversight.
Children with complex medical needs often receive care through condition-specific clinics.

8.10 Adult-oriented providers conduct tests or procedures to diagnose a new condition. They rely less on the observations of the patient or caregiver, especially with new patients.
Patients, rather than Providers, have primary responsible for oversight and advocacy, such as requesting a specialist forward test results to the PCP or getting prior approvals from insurance.
Primary care providers typically refer patients with complex needs to multiple specialists. The patient sees these providers, sequentially, over time, on different days and in different locations. Condition specific clinics are less common.

8.11 Pediatric clinics and practices have an established multidisciplinary model, with easily accessible care coordination, services, and supports
Nurses and other staff provide medical care AND psychosocial support.

8.12 Staff roles and responsibilities are more differentiated in adult medicine. Nurses & other staff address ONLY medical issues. They refer to social work for non-medical needs or for psychosocial support. It is also important to note that care coordination, supports, and services staff are less accessible in adult medicine.

8.13 When pediatricians use the word "transition" they usually mean transferring care from one place to another place. They also use it as short hand for the transition to adult-oriented care.

8.14 Adult-oriented providers use the phrase "transition" to refer to a transfer in the care location. They are generally unfamiliar with the use of the phrase in the context of transition to adulthood.

8.15 Despite the barriers, the transfer remains crucial for continuous, accessible medical care.

8.16 Many children's hospitals and facilities have policies regarding the maximum age of patients. For example, Nemours Children's clinics cannot serve individuals over the age of 21.
Insurance reimbursement, professional guidelines, and licensure laws may also require a care transfer between the ages of 18 and 22.

8.17 Many students and parents see the transfer as a loss.
This is especially true for students with complex conditions. Over the years their pediatrician may have provided: a life-altering diagnosis; emergency care; referral for an important surgery; or a new treatment.

8.18 Despite the challenges, there are many benefits to working with Adult-oriented Providers.
Unlike childhood providers, they are experts in the health of adults. From vital signs to prescription dosages, adult oriented providers anticipate natural changes in health that come with aging.

They frequently have difficult conversations with patients and caregiver family members – about guardianship, SSDI, community-based services, and nursing homes. The key is that they usually do this with their elderly patients and not with their youngest patients.

Finally, Adult-oriented Providers are accustomed to learning about new conditions. They are fully capable of learning to treat your students.

8.19 Some students learn about transition on what becomes their last visit.
This type of abrupt discharge and transfer frequently leads to an interruption in care.

8.20 Let the student know that it is OK to find a new provider if the first referral is not a good fit. Dropping out of care is not the next option.

8.21 Educators may only find out about care transfers if they create a crisis for the family.
Has this happened to your students? If so, how did you become aware of the issue? Take a moment to consider these questions. The presentation will automatically resume in 1 minute.

8.22 Educators see students much more frequently than health care providers. If a patient "drops out" of medical care, school staff may find out before a new doctor does.

8.23 Recall the eight steps of the Transition Process.
The final steps in this process focus on the successful movement to new adult providers, to adulthood, and to a new health care system.

8.24 Video clip

8.25 Good transition planning is the best way to pre-empt or address barriers associated with a care transfer.

8.26 Medical providers can have a huge impact on the overall transition to adulthood, in ways both positive and negative.

8.27 The National Center for Healthcare Transition Improvement provides six core elements of transition, based on the practice setting.
Encourage the family to find out what types of primary care providers they see – pediatrician, family medicine, and meds-peds are all different fields in medicine that treat children. Internal medicine, family medicine, and meds-peds treat adults. Knowing their doctor's field will help plan for the timing of the transfer.

8.28 Many Pediatric practices write a practice transition policy that proactively outlines their process.
Such policies support transition and avoid interruptions in care.

Encourage students and parents to find out if their providers have such a policy in place.

8.29 If the pediatrician does not have a transition policy, it will create barriers related to the care transfer,
If they do have a policy in place, it will help your transition plan development and prepare the student for the transfer.

8.30 Opening communication between providers, educators, students and families can avoid duplications in transition plans and help everyone work toward the same goals, on the same timeline.

8.31 This section provides strategies to prepare student for the transfer and tasks to include in their IHP/504/IEP.

8.32 Families tend to forget how things went when they started with their current providers. This is understandable, since some children have been receiving care from their pediatricians for their entire lives.
Just as they learned to negotiate the pediatric health care system, they will also develop the new knowledge, skills, and experience for the adult health care system.
Talking about these past experiences may help youth and families appreciate that building trust and respect takes time.

8.33 During the transfer the student is the decision-maker, with full responsibility for oversight and self-advocacy.

8.34 Remind the parent of the Shared Management Model and clarify their role during the transfer. The Path to Independence, first discussed earlier in the course, remains a useful tool throughout this transition stage.

8.35 Use the care transfer as a marker that the student is ready for independent completion of tasks.
The transfer is an opportunity for the student to use the top of their abilities.

8.36 The care transfer to a new doctor should not coincide with other important or difficult changes during late adolescence.

8.37 Students who are starting college may not be thinking of finding a new doctor as part of their move.
However, even simple chronic conditions, like asthma or ADHD, need advance planning to manage.

8.38 Engaging medical providers in the school-based plan is a natural time to enlist them in care transfer process.

8.39 Include specific items for YSHCN based on the student's needs and the new provider's familiarity with the condition.

8.40 Health care providers should discuss the fields of primary and specialty medicine with the student, help locate new providers, and clarify the new provider's field, especially when making multiple referrals.

8.41 Prepare the student for making initial contact with the new provider's office and doing research before the first appointment.

8.42 Students should make a list of questions for the initial visit.

8.43 What is one task for the care transfer that would fit into an IHP/IEP/504 plan? Take a moment to consider these questions. The presentation will automatically resume in 1 minute.

8.44 Before closing this module, let's look at resources for your school.

8.45 The ultimate goal of transition preparation is a smooth transfer to adult medicine that provides continuous and accessible care for the student.

8.46 Use the links from this course's toolkit to access the tools from this course.

8.47 The next module reviews key points and resources from the entire course. You can pause here for a break or continue automatically into the next presentation.

Module 9: Conclusion

9.1 Welcome to the course's conclusion. This is the ninth of ten modules.

9.2 This module reviews the course's key points and tools and discusses next steps to address the health care transition in your school

9.3 This course began with a description of the health care transition and its importance.

9.4 Successful transition to adulthood depends on a successful health care transition.

9.5 The course highlighted specific needs of YSCHN throughout the health care transition.

9.6 Throughout the course, we identified key strategies and concepts for working with parents and caregivers during transition.

9.7 Module 2 illustrated how transition and adolescent development progress together.

9.8 Module 3 focused on the differences in "transition" between the health care community and educators. Keep in mind that health care transition is essential to the success of your existing transition services.

9.9 Module 4 presented information and tools for students to maintain continuous coverage during transition.

9.10 Module 5 identified legal and financial considerations during transition, including decision-making support, vocational rehab, and social security.

9.11 Module 6 focused on assessing health care transition readiness and health care skills.
Health care transition assessment integrates with and supports existing special education evaluations.
Use these tools to your benefit when preparing for the student's transition plan.

9.12 In module 7 we covered the development of health care skills by creating a transition plan with students to address 1 -3 skills.

9.13 Module 8 provided information on the care transfer.

9.14 This section reviews resources from the course and provides links to the tools from each module.

9.15 Bookmark the FloridaHATS website for quick access to the latest news and tools on transition.

9.16 Here are links to specific Florida HATs tools used in the course.

9.17 Got transition dot org is the official website of the national Center for Health Care Transition Improvement. This slide contains all of their tools referenced during the course.

9.18 Resources on adolescent development include tools for the 3rd Edition of Bright Futures, tools to develop the student's self-efficacy, and a guide to discussing sexual health with students who have developmental disabilities.

9.19 While there are many differences between education and health care, these tools will help partner with your natural allies from the medical community.

9.20 Tools for maintaining insurance during transition include the Florida HATs insurance guide for students, resources on the Affordable Care Act, from Medicaid, and for private insurance.

9.21 Addressing financial considerations during transition focused on resources from Vocational Rehab and Social Security.

9.22 Module 5 also gave resources for students who will need decision-making support after turning 18.

9.23 Use these tools to assess students' health care transition readiness.

9.24 To integrate health care skill development into the IEP/504/IHP, use these tools.

9.25 Use these tools to support the student during their transfer to new, adult-oriented providers.

9.26 Access the tools listed on this slide in the course toolkit.
Links to the tools listed on this slide are also accessible via the FloridaHATS website.

9.27 The following slides describe statewide efforts to improve transition care.

9.28 Join us in improving care for transitioning students.
Connect students and families to the wide range of educational materials and resources available on the FloridaHATS web site.
Sign up for the mailing list to keep updated on important transition issues. Through the mailing list, you'll learn about upcoming events, including webinars on a variety of transition-related topics.
If you live in one of the regions that have formed a transition coalition, consider joining with others to improve your local system of care.
Maybe most importantly, become a transition champion by working within your own agency, institution or professional association to educate and advocate for policies that support improved transitional care.

9.29 The next module provides the off-line continuing education activity

Module 10. Continuing Education Activity

10.1 This module is the tenth, and final, presentation in the course. These practice activities provide an opportunity for you to think critically about concepts presented in earlier modules and apply them in two sample scenarios.

10.2 Recall the first example student, Joe.

10.3 Thinking back on the course, how would you prepare for the next IEP? How would you assess Joe's current health care skill level?
How has health affected Joe's previous IEP progress? What health related concerns are apparent for the future?

10.4 How would you integrate health care transition readiness assessment into Joe's IEP preparation?
Who will provide the assessment tools to Joe and his mother?
When will he complete the TRAQ?
Which health care providers should be involved in his health care transition preparation? How will you communicate with them?

10.5 What are two health goals that you could incorporate into his next IEP?

10.6 Document the health care transition goals you've created for Joe on a blank IEP form.

10.7 Next, let's discuss Jane's 504 plan.

10.8 Thinking back on the course, how would you prepare for the next 504 plan?
How would you assess Jane's current health care skill level?
How has health affected Jane's previous activities? What health related concerns are apparent for the future?

10.9 When will you assess Jane's health care skill level?
Who will complete the assessments with Jane & her parents?
How could you partner with her health care providers?

10.10 What is one health care transition activity that belongs in this year's 504 plan?

10.11 Document the health care transition activities you've created for Jane on a blank 504 form.