

# Healthcare Transition for Youth with Special Healthcare Needs

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**Abstract:** *Because of medical advances in pediatric care, there are a growing number of individuals with childhood-onset chronic health conditions and disabilities who are aging out of pediatrics and are entering the adult health care system. Today, 90% of children with conditions which were previously fatal in childhood are surviving into adulthood. Changes are needed in the organization, financing and delivery of care to assure this growing population of young adults has access to the services they require. Pediatric providers need to put in place transition practices recommended by the American Academy of Pediatrics (AAP) and the approaches for managing complex conditions articulated in the Chronic Care Model. This includes developing and implementing written transition plans for all adolescent patients, supporting youth's acquisition of self-management skills, linking youth to community-based supports and making use of transition-related training and resource materials that have been developed for adolescents and their families. Changes are also needed to ensure that young adults have adequate health insurance coverage and health care professionals are appropriately compensated for direct care services, health care transition planning, and care coordination. The JaxHATS Program is a primary care based approach for promoting the successful transition of youth with significant health care needs from pediatrics to adult care.*

## Why is Transition an Issue?

It is estimated that about 10.2 million children and youth age 0 – 17 years in the U.S. have special health care needs. While this group constitutes about 14% of the childhood population, they account for 40% or more of medical expenditures for children, overall.<sup>1</sup> The proportion of children with special needs increases dramatically with age; about 9% of children under age 6 have special health needs, but this proportion almost doubles, to about 17 % for those aged 12-17 years.<sup>2</sup>

This large and growing number of young adults with special health care needs and disabilities is a result of advances in treatment, e.g., pharmacology, surgical techniques, and medical technology that have been made over the last three decades.<sup>3</sup> Today, 90% of children with conditions that were previously fatal in childhood are surviving into adulthood. However, while the number of adolescents and young adults (A/YA) with significant health care needs is growing, the current capability of our health care system to address the ongoing medical, mental health and social needs of this population is limited.<sup>4</sup>

Because the move to adult health care represents a critical change in the life course of young adults, sub-optimal transition experiences not only impede access to needed medical care, but can undermine their education and/or vocational

training, severely limiting their opportunities for a successful and productive adulthood.<sup>5</sup> It is critical that pediatric and adult-oriented physicians and other health care professionals work in partnership to effectively address the multiple barriers to a smooth and efficient transition of youth from pediatric to the adult health care system.

As is documented in the growing literature on health care transition, multiple patient, provider and system level factors contribute to the problem of providing uninterrupted high quality health care to A/YA with special health care needs. These factors include:

- The epidemiology and diversity of children and youth with special health care needs (CYSHCN)
- Limited implementation of transition models and guidelines
- Readiness of adolescents/young adults and their families for the move to adult medicine
- Differences in the structure and culture of pediatric and adult medicine
- The limited number of adult oriented providers who are interested in and trained to care for A/YA with childhood onset conditions
- The failure of private and public health insurance policy to provide coverage to young adults resulting in high rates of uninsured and under-insured young adults
- The limited support for transition related services and interagency collaboration<sup>6</sup>

## Epidemiology and Diversity of the Population

For the purposes of epidemiological research and policy development, CYSHCN are defined 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”.<sup>7</sup> The National Survey of Children with Special Health Care Needs (NS-CSHCN)<sup>8</sup> used a non-condition specific, functional and health services utilization based screening tool to identify children who met this definition of children with special health care needs (CSHCN). Approximately 17 % of youth age 12-17 years have special health needs. Each year approximately 500,000 individuals with chronic health conditions turn 18 and reach the legal definition of adulthood.

While these overall numbers are large, the number of youth with a certain health condition in a given geographic region who are approaching adulthood is relatively small because children and youth are affected by more than 200 chronic health conditions and disabilities.<sup>9</sup> With the exception of asthma, allergies, attention deficit disorder/attention deficit hyperactivity disorder(/), headache, and emotional problems, chronic childhood conditions are relatively rare. For example, of those children who meet the non-categorical

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definition of CYSHCN, 4% have joint problems, 4% have heart problems, 4% have a seizure disorder, 2% have blood problems, 2% have diabetes, 2% have cerebral palsy, 1% have Down syndrome, 0.3% have muscular dystrophy, and 0.3% have cystic fibrosis(CF).<sup>10</sup> In contrast, the vast majority of adults with chronic health needs are affected by a few major diseases and disabilities (e.g. cancer, cardiovascular disorders, stroke-related conditions, arthritis, orthopedic conditions, hearing and vision limitations), each of which occurs with high frequency.

It is only recently that CSHCN with complex conditions have survived to adulthood in relatively large numbers. For example, in 1973 the average age of death for a child with CF was 7 years. Today the predicted median age of survival is 37 years and about half of all individuals with CF in the United States are age 18 or older.<sup>11</sup> In the 1970s less than one third of youth with spina bifida reached age 20. Today more than 80% of those born with spina bifida reach adulthood.<sup>12</sup> There are more adults than children alive today with cerebral palsy and congenital heart disease.<sup>13 14 15</sup> There have been similar dramatic increases in survival to adulthood for children with almost all other serious diseases such as cancer, diabetes, Down syndrome, muscular dystrophy, sickle cell disease, and other chronic conditions and disabilities. Medical advances have not only improved survival but have also lessened the impact of life threatening and other chronic conditions on children's cognitive and psychosocial development. Most young adults with childhood-onset chronic conditions have the physical, intellectual and emotional capacity and desire to live independently, work, and otherwise participate fully in community life.

### **Transition Models/Guidelines Implementation**

Over the last 20-30 years, the advances in medical science and treatment have not been matched by advances in the organization, financing and delivery of care that are needed to ensure that this growing population of young adults have access to the services they need. The transition of CYSHCN from pediatric to adult care was first recognized as an emerging health issue of national importance in 1989 by then Surgeon General C. Everett Koop, MD. At that time, Dr. Koop hosted a national conference for health care providers, families and youth and policymakers. The findings and recommendations for action developed at this meeting, recorded in the groundbreaking report "Growing Up and Getting Medical Care: Youth with Special Health Care Needs,"<sup>16</sup> recognize the importance of:

- Starting the transition process early
- Promoting the autonomy and self-management skills of adolescents
- Educating pediatricians about promising transition practices
- Building bridges between pediatric and adult medicine
- Providing adult-oriented physicians training in the management of childhood-onset conditions

While this report provided a solid foundation for action, minimal progress was made in the 1990s in implementing

recommendations and thereby, delivering needed services and supports to this growing, vulnerable population. Health care transition leaders convened a consensus conference in 2000 for the expressed purpose of drafting a policy statement that: 1) Could gain broad based support from pediatric and adult medical communities, and 2) Could be used to promote actions to ensure that all physicians who provide primary or subspecialty care to young people with special health care needs (SHCN) understand the rationale for transition from child-oriented to adult-oriented health care; have the knowledge and skills to facilitate that process; and know if, how, and when transfer of care is indicated.

The consensus statement, developed in 2000 identified the following six "critical first steps" to help ensure that physicians acquire needed knowledge and skills and that youth move successfully from pediatric to adult-oriented care:

1. Link all youth and young adults with SHCN to health care professionals who will address transition issues and assume responsibility for current health care, care coordination, and future health care planning (in order to ensure that as transitions occur, all young people have uninterrupted, comprehensive, and accessible care within their community)
2. Identify the core health care transition knowledge and skills needed by providers and make sure these competences are part of training and certification requirements for primary care residents and physicians in practice
3. Prepare and maintain a portable and accessible medical record (in order to provide a common knowledge base for collaboration among health care professionals)
4. Develop and maintain a written health care transition plan for all youth age 14 and older, which includes at a minimum, what services need to be provided, who will provide them, and how they will be financed
5. Ensure that adolescents and youth with special health care needs receive the primary and preventive care services that are standard for typical adolescents and young adults
6. Guarantee affordable, continuous health insurance coverage for all young people with SHCN; and make sure this insurance provides professionals with appropriate compensation for health care transition planning and care coordination for those who have complex medical conditions<sup>17</sup>

In 2001 this policy statement was formally endorsed by the AAP, the American College of Physicians-American Society of Internal Medicine and the American Academy of Family Physicians. It has served as a point of reference for transition related guidelines, policy statements, and related documents that have subsequently been developed for a number of childhood onset conditions including congenital heart disease, CF, diabetes, and for CYSHCN populations in Canada and England. Guidelines and policy statements have also been promulgated which put forth key considerations when discharging patients from pediatrics and transferring them to an adult provider or program.

This consensus statement helped to raise awareness about health care transition in the pediatric and adult health care communities and to promote action. Over the last decade, a variety of health care transition (HCT) related materials and

resources have been developed, and a broad range of HCT programs and projects have been implemented. Numerous HCT conferences and workshops have been held. However, the dissemination of recommended HCT practices into the larger practicing community has proceeded slowly. There have not been major changes in public and private health insurance policies, leaving this population vulnerable to gaps in health insurance.<sup>18 19</sup> As a result, a minority of youth with SHCN now receive needed HCT services and supports.<sup>20</sup>

The 2001 National Survey of Children with Special Health Care Needs gathered data from parents about how often key HCT services were provided to youth aged 13-17 by health care providers. Parents of only one-half of the study group reported that their child's physician had talked about changing medical needs in adulthood. Of those, only 59% (or 29.5% of the total sample) reported having developed a plan to address these needs and only 42% (or 21% of the total sample) indicated that a physician had discussed shifting their child's care to an adult-oriented provider. Overall, only about 15% of the sample received all three of these critical services. Younger teens and non-Hispanic African American children were less likely to have discussed changing providers. Results from a number of other smaller scale and condition-specific studies confirm the findings from the 2001 NS-CSHCN that a relatively small proportion of youth receive key HCT services and supports.

For many adolescents, the discharge from pediatrics is abrupt and entry into the adult health care system is haphazard. Experts and guidelines recommend that the timing of the transfer to adult care should be based on a young person's readiness and ability to negotiate the adult health care system<sup>21</sup>; and should take place when the individual is medically stable. However in practice, the timing of transfer appears to be based primarily on age. Many pediatricians, especially those who are community-based providers, have a policy to discharge their patients when they reach a certain age (typically age 21) or when they graduate from college. Many child health services and programs have maximum age eligibility policies, as defined in legislation, charters, and by-laws or other operating procedures. This includes the 21 year upper age limit for Florida's Children's Medical Services Program, and the 18 year old age limit for Shriners Hospitals (Shriners Hospitals, 2005) and Nemours Children's Clinic.

Hospitals that serve both adults and children have policies that exclude inpatients over a certain age, e.g., age 18, from the pediatric floors of the hospital. Such inpatient age policies appear to be driven by a number of considerations, including staff training and expertise, the availability of medical equipment for patients of a certain size, the perceived appropriateness of the care setting, and policies limiting physician privileges. Youth may also be precipitously discharged out of pediatric care when they display "adult behaviors", such as becoming pregnant, abusing illegal substances, challenging authority, becoming sexually active, or being adjudicated to the juvenile justice system.<sup>22 23</sup>

## Readiness and the Transition

Research and anecdotal information indicates that many young adults and their families are reluctant to leave pediatric doctors, especially when these professionals have provided care to the child for many years. This reticence appears to be associated with the emotional bond that develops between patients/families and providers; concerns about the capacity of the adult system to provide high quality care and supports; and the capability of the young person to negotiate the adult system independently.<sup>24</sup> However, other research indicates that many youth see the move from pediatric to adult care a natural part of growing up and are relatively comfortable with the move, especially when they feel prepared for this change.<sup>25 26</sup>

Adult oriented health care providers expect their patients to be autonomous and able to negotiate the health care system with little or no help from their physicians. In order to be ready to receive care from the adult health care system, young adults must be capable of accomplishing a broad range of tasks and activities that include:

- Making appointments and showing up on time for medical visits
- Providing a medical history
- Giving detailed information about their current symptoms
- Actively participating in medical decision making
- Following through on referrals
- Having prescriptions filled and taking medications as directed
- Adhering to the physician's course of treatment
- Having health insurance or otherwise being able to pay for needed care<sup>27 28</sup>

## What Can Be Done?

In order for a young person to be truly ready for the adult health care system, preparation must start in childhood. Parents should be given the expectation that their child with special health care needs will grow into adulthood and, unless cognitively impaired, will eventually have to assume full responsibility for their own health care. Pediatric providers should serve as a guide and role model for parents by giving the child responsibilities for their own care and actively involving them in decision making, as developmentally appropriate. By involving the child early in their own care and instilling positive health habits, some of the problems with adherence often associated with adolescents may be ameliorated.

A more structured approach to preparing an A/YA for the transfer to adult care should begin in early adolescence. Results from a 2006 survey conducted by the Institute for Child Health Policy for Florida's Children's Medical Services Program (unpublished), identified four physician activities that were rated as especially helpful by families and youth. These are:

- The provider talking with the A/YA and their family about the health care needs that the A/YA will have when he/she is an adult
- The provider informing the A/YA and family about the recommended age for transfer to adult care

- The provider meeting alone with A/YA for at least some of a medical visit
- The provider encouraging the A/YA to take more responsibility for his/her health care

Florida's Children's Medical Services (CMS) Program has also developed a set of resource materials that can be used by health care providers with their adolescent/young adult patients and their families to guide and support health care transition related interventions. The CMS Health Care Transition Planning Workbooks were developed to assist families and youth to assess their status on health care transition related behaviors, activities, knowledge, and then to develop HCT related priorities and plans.

There are three age-related workbooks (age 12-14; age 15-17; and age 18+). The workbooks are similar to one another except that the behavioral expectations increase with age. In the first part of each workbook young people and their families respond to questions around future schooling, employment and living arrangements. In the second part "Health Care Independence", youth and families are asked to rate the level of independence in activities related to seven aspects of health care transition: 1) basic knowledge about the chronic condition; 2) health care behaviors; 3) medications, medical tests, equipment and supplies; 4) physician visits; 5) health care transition; 6) transition to adulthood (work, independent living); and 7) knowledge of health systems. Physicians can use these workbooks with their patients and families to identify transition related goals as well as steps that will help the young person achieve a greater level of independence on important transition related tasks and activities. These workbooks are available in both English and Spanish, and can be downloaded and printed by families or providers from the CMS Web site, (<http://www.doh.state.fl.us/alternatesites/cms-kids/cmsntransition.htm>) and the Institute for Child Health Policy's Health Care Transitions (ICHP-HCT) web site, (<http://hctransitions.ichp.ufl.edu>).

A related resource is the CMS booklet "Envisioning My Future". This 24-page guide is written for teens/young adults and families and has a separate section for youth in three different ages (12-14; 15-17 and 18+). Each section includes information to help youth be more in charge of their own health care, tips for parents, and a checklist of transition skills and activities, such as maintaining health insurance coverage. The guide also includes a list of transition related resources. This booklet is available in both English and Spanish and can be downloaded and printed by families or providers from the CMS and the ICHP-HCT Web site. Physicians can use this booklet to help youth and families understand why planning for the transfer to adult care is important and what they can do to prepare.

CMS has also developed two colorful booklets specifically for teens: "Since You're Not A Kid Anymore - It's Time To Be More In Charge Of Your Health Care" for teens in middle school and "Now That You're In High School - It's Time To Be More In Charge Of Your Health Care." These two 30-page health care transition guides include information and

activities designed to help teens with SHCN take a more active role in their own health care. These booklets are given to all adolescents enrolled in the CMS program and are available for download from the CMS and ICHP-HCT Web sites. Pediatricians can use these booklets to introduce the topic of transition to their adolescent patients and to address in more detail some questions that are raised in the booklet, such as how health care needs may change in adulthood, how A/YAs can take more responsibility for their own health care, and at what age A/YAs should transfer to adult care.

In addition, CMS has developed two educational videos that can be used by pediatric providers to inform and educate youth and their families. "This is Health Care Transition" is a 29 minute video that shows how families and health care providers can work together to help youth develop the knowledge and skills they need to be more independent in their health care and achieve their life goals. This video can be used to introduce families to the topic of transition, and to help families identify questions and concerns that they need to bring up with their pediatrician.

"Talking with Your Doctor and Other Health Care Providers" is an 18 minute video that is designed to teach A/YAs how to communicate more effectively with health care providers so that professionals understand A/YAs concerns, answer A/YAs' questions and give information and supports that A/YAs need to be more in charge of their own health. The video also shows A/YAs how to prepare and give health care providers the information they need to give them the best possible medical care. Pediatricians can use this video and its GLADD (Give information, Listen/Learn, Ask, Decide, Do) approach to structure the medical encounter, and help A/YAs play a more active role during health care visits. Both of these videos can be viewed and downloaded from video section of the ICHP-HCT web site (<http://video.ichp.ufl.edu/>) and are available from ICHP as DVDs.

With support from the Florida Developmental Disabilities Counsel, the Institute for Child Health Policy developed a web-based health care transition training program for youth with disabilities and chronic health conditions, and their families. This training program addresses a range of topics related to transition, including ways to maintain health insurance coverage; how to include health self care in individualized educational plans (IEPs) and 504 plans; guardianship; differences between pediatric and adult health care; and strategies for helping youth to be more involved and responsible for their own care. This course is available on the ICHP-HCT web site at [http://hctransitions.ichp.ufl.edu/ddcouncil/training\\_home.php](http://hctransitions.ichp.ufl.edu/ddcouncil/training_home.php).

These materials can serve as an aid in providing youth and families with anticipatory guidance about the eventual transfer to adult services and help pediatricians to structure and focus their transition related services and supports. Pediatric providers should formally introduce the topic of transition when a patient reaches adolescence, and preparation for the eventual transfer to adult care should be integrated into the

ongoing plan of care. In addition to informing the A/YA and family about the recommended age for transfer to adult care, providers should talk about the health care needs that the adolescent will have when she/he is an adult; spend an increasing amount of time alone with the patient as she/he gets older; and give the adolescent an ever increasing level of responsibility for their own care, in keeping with the cognitive/developmental status of the patient. While it does require additional time and effort, the AAP Consensus Statement on Transition indicates that providers should also develop and maintain a written health care transition plan for all youth age 14 and older, which includes at a minimum, what services need to be provided, who will provide them, and how they will be financed.<sup>17</sup>

As a young person approaches the time of discharge from pediatrics, the AAP Consensus Statement proposes that providers should also prepare and maintain a portable and accessible medical record or medical summary that can be used by the new adult provider as the basis for their plan of care.<sup>17</sup> Because many pediatric conditions are relatively rare and adult primary and specialty care providers may not be familiar with the most recent advances in the management of some childhood-onset conditions, this summary should include key references to the current literature as well as information about the screening and preventive health services that are recommended for adults with the patient's condition(s).

Pediatric primary care providers should also make specific referrals to adult primary care providers, and encourage the young person to establish a working relationship with an adult oriented primary care provider (family physician or general internist) who can provide continuity when the patient is discharged from pediatric care. Similarly, pediatric specialists should implement a "staged discharge" from their care by doing the following: 1) identify adult specialty providers with whom they can develop a referral relationship; 2) facilitate referrals of patients (and families) to adult specialty care providers before they leave the pediatric specialty provider's care; 3) provide a medical summary of the youths' health care and medical history with recommendations for care to the adult providers; 4) be available to the adult specialty providers for consultation or interaction over specific aspects of care that they may want input on; and 5) follow-up with both the youth and the adult provider to make sure the hand-off was successful.

### **Chronic Care Model**

The Chronic Care Model provides an organizational approach to integrated care for people with chronic disease that is sufficiently robust to address both the health care system challenges during transition and the developmental needs of the emerging adult.<sup>29 30</sup> Wagner identified the following elements as the most critical to provide effective chronic disease management:

- Well-developed processes and incentives for making changes in the care delivery system

- Assure behaviorally sophisticated self-management support that gives priority to increasing patients' confidence and skills so that they can be the ultimate manager of their illness
- Reorganize team function and practice systems, e.g., appointments and follow-up, to meet the needs of chronically ill patients
- Develop and implement evidence-based guidelines and support those guidelines through provider education, reminders, and increased interaction between generalists and specialists
- Enhance information systems to facilitate the development of disease registries, tracking systems, and reminders and to give feedback on performance

A number of studies have demonstrated that the Chronic Care Model (compared to regular primary care) can improve processes of care and health outcomes for persons with chronic health problems.<sup>31 32</sup> However, no studies have attempted to adapt the Chronic Care Model to the special developmental challenges and health system barriers that complicate the health care transition for youth and emerging adults with special health care needs.

### **JaxHATS Program**

In spring of 2005, a community needs assessment in Jacksonville was conducted to determine areas of unmet need among children and youth with special health care needs. The needs assessment identified the fact that youth with chronic medical problems often left pediatric care and did not successfully transition to adult care. Out of that planning process the Jacksonville Health And Transition Services (JaxHATS, [www.jaxhats.ufl.edu](http://www.jaxhats.ufl.edu)) program was developed. JaxHATS is organized around the Chronic Care Model applied to youth during health care transition. JaxHATS currently serves 300 youth, ages 16-26, with a wide range of chronic health problems, including 30 youth with type 1 diabetes and 40 youth with cerebral palsy. The co-Medical Directors of JaxHATS are David Wood, MD, MPH, a general pediatrician, and Linda Edwards, MD, Chief of General Internal Medicine at UF, College of Medicine-Jacksonville. The JaxHATS team has developed an excellent working relationship with the adult providers within UF & Shands. The program is supported with a contract from the Florida Title V agency (Children's Medical Services) and is promoted as a model of care throughout Florida.

### **JaxHATS Model**

As has been presented in this article, there are multiple and complex barriers to successful health care transition for YSHCN. To address and overcome these barriers at the local level, a comprehensive program is needed. The JaxHATS team adapted the Chronic Care Model into an Integrated Chronic Care Model for Health Care Transition (ICCMHCT) program to the transition process as a way to both support youth and families during transition, as well as to actively influence the pediatric and adult health care system to make them more responsive to the needs of YSHCN. The model emphasizes the word "integrated" because it integrates care between multiple disciplines and across pediatric and adult

health care systems, including actively bridging communication and care between pediatric and adult specialty providers, and pediatric and adult primary care providers and pediatric and adult health and social service providers.

The JaxHATS team is multidisciplinary and includes a pediatric and adult primary care physician, nurse care coordinator and medical social worker. This team has become familiar with and regularly communicates with both the adult and pediatric systems of care and child and adult community based services. The JaxHATS program works closely with Children's Medical Services and Florida's Title V program to ensure that all eligible youth under 21 years of age are enrolled in CMS and to provide access for JaxHATS enrolled patients to services and supports available through CMS.

These disciplines work together to address the following needs of youth with chronic health problems going through transition:

1. To assess the need for and provide comprehensive, continuous and coordinated primary medical care
2. To coordinate and refer to appropriate specialty medical care (both pediatric and adult specialty care, depending upon the specific needs of the youth and the specific transition policies of the specialty providers)
3. To support the youth and their families for increasing disease self management. This support is tailored to the developmental level of the youth and/or their support network
4. To support the youth in increased independence in the use of the health care system
5. To assess the need and referral to educational, vocational and independent living support services. The youth's educational, vocational and independent living goals are part of the JaxHATS transition health care plan

Visits in the JaxHATS program occur at the JaxHATS clinic which is located at the Adult Ambulatory Care Center at UF & Shands in Jacksonville, FL. The JaxHATS program includes the following elements:

1. Regularly scheduled patient visits with the primary care team for chronic care management that include:
  - a. Assessment of disease self management
  - b. Negotiation of self-management goals between the primary care provider and the youth to be reviewed at every visit
2. Regular visits (at least 4 during the first 12 months) with the Nurse Coordinator and Social Worker to support increased independence in the use of the adult health care system and to support educational, vocational and independent living goals
3. Referral to and monitoring of regular visits with adult specialists
4. Use of an electronic medical record shared by the primary care providers and adult specialists to coordinate care and monitor care
5. Regular assessment of the youth's readiness to transition fully to adult health care services using the Transition Readiness Assessment Questionnaire (TRAQ 3.0), a questionnaire developed by the JaxHATS team. Once a youth demonstrates competence in the key behaviors needed for success in the adult health care system, he/she is discharged from JaxHATS to adult primary care

## Summary

As a result of medical advances in pediatric care, there are a growing number of individuals with childhood-onset chronic health conditions and disabilities who are aging out of pediatrics and are entering the adult health care system. Changes are needed in the organization, financing and delivery of care to assure this growing population of young adults access to the services they need. Pediatric providers need to put in place transition practices recommended by the AAP and the approaches for managing complex conditions articulated in the Chronic Care Model. This includes developing and implementing written transition plans for all adolescent patients, supporting youth's acquisition of self-management skills, linking youth to community-based supports and making use of transition-related training and resource materials that have been developed for adolescents and their families.

The JaxHATS Program is a primary care based approach for promoting the successful transition of youth with significant health care needs from pediatrics to adult care. Changes are also needed to ensure that young adults have adequate health insurance coverage and health care professionals are appropriately compensated for direct care services, health care transition planning, and care coordination.

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## Becoming an adult. Always a challenge.

For teens and young adults with disabilities and chronic health conditions, learning to take charge of their health and health care during this challenging time is critical to their living productive and satisfying lives. However, finding appropriate health care, stable insurance and other community supports may undermine their best efforts.

### *JaxHATS*

makes this transition easier by aiding youth and their families in this critical period of life. Jacksonville Health and Transition Services, a University of Florida College of Medicine program at Shands Jacksonville, provides primary care – and much more – to youth ages 14 to 25 to help them gain the knowledge and skills necessary to become healthy and achieve their long-term goals.

JaxHATS' interdisciplinary professional team, composed of physicians, nurse coordinator and social worker, also provides information and referrals regarding health insurance, specialty health care and other community services.

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