

# Florida Health Care Transition Services Task Force for Youth and Young Adults with Disabilities

## Report and Recommendations *Implementation of Senate Bill 988*

### Ensuring Successful Transition from Pediatric to Adult Health Care

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Task Force  
January 1, 2009



## Acknowledgements

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This report is the result of many professionals and families – who collectively represent a wide range of agencies, disciplines, ages, and backgrounds - working together to improve the quality of life for young people with disabilities or special health care needs living in Florida. Thank you to everyone for their contributions, including Task Force and Workgroup members, the Healthy & Ready to Work National Resource Center, the Catalyst Center at Boston University, and the Florida Developmental Disabilities Council, Inc., for their generous support of the project. A special thanks to all the young people, families, and service providers who generously shared their stories with us, so those who read this report might better understand how policies and statistics are reflected in the real world experiences of youth and young adults with disabilities.

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## Executive Summary

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It is only recently that children and youth with disabilities and complex health conditions have survived to adulthood in relatively large numbers. In the 1970's, less than 30% of youth with spina bifida reached age 20. Today, more than 80% of those born with spina bifida reach adulthood.<sup>1</sup> There have been similar remarkable increases in survival for other serious diseases such as cancer, diabetes, sickle cell, muscular dystrophy, cystic fibrosis, and many other conditions. Though advances in technology and medical science have dramatically increased survival rates, youth with disabilities are much less likely than their non-disabled peers to finish high school, pursue postsecondary education, find a job, or live independently.<sup>2</sup>

Health care transition was defined 15 years ago as the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.<sup>3</sup> In recent years, there has been growing recognition that health care transition is a critical aspect of successful entry to adulthood; indeed, that it supports economic self-sufficiency, independence, and prevents school dropout and delinquency. As a result, there is increasing interest in services and supports for young people with disabilities and chronic health conditions that address all aspects of health and well-being, including promoting health, preventing secondary conditions, and preparing for entry to adult health care.<sup>4</sup>

The data demonstrate policy and practice do not reflect our current level of understanding about the importance of health care transition. According to the *2005/2006 National Survey of Children with Special Needs*, almost one in five adolescents with special health care needs ages 12-17 in the U.S. goes without needed health care services.<sup>5</sup> Only 41% receive the services they need for transition to adult health care, work, and independence. In Florida, the news is even worse: less than 34% receive needed transition services statewide, and only 16% of those in rural areas receive services. For the almost 500,000 youth and young adults with disabilities or special health care needs (YSHCN) ages 12-24 living in Florida, additional stresses from the many education, vocation, living and relationship transitions that occur during emerging adulthood can make the health care transition process particularly complex and difficult.<sup>5-7</sup>

While Florida has been at the forefront in recognizing the myriad challenges faced by youth as they age out of pediatric health care, there has been little investment in the development of a service system that meets the needs of these young Floridians. A call to action during the 2008 legislative session resulted in the passage of Senate Bill 988. SB 988 called for the establishment of a time-limited statewide Task Force to assess the need for health care transition services, to develop strategies to ensure successful transition from pediatric to adult health care systems, and to identify existing and potential funding sources.

On August 15, 2008, the Department of Health, Children's Medical Services (CMS), convened a 14-member Task Force comprised of key agency representatives and stakeholders. The Florida Developmental Disabilities Council provided support to the initiative by identifying 20 additional stakeholders to participate in the planning process, covering a portion of costs associated with the project, and providing a facilitator to help organize and manage activities for the full 35-member Workgroup. A series of teleconference calls were scheduled for three subcommittees – Financing and Structure, Services and Models of Care, and Education and Training – over three months. In addition, national and state-level subject experts participated in selected calls. The



teleconference calendar, background materials and literature, meeting minutes, and working documents were made available to Workgroup members via ongoing electronic communication and a dedicated project Web site, [www.healthcaretransition.org](http://www.healthcaretransition.org). A final meeting of the Task Force and Workgroup was held in Tallahassee on November 24, 2008.

While the legislatively appointed Task Force officially dissolves with the completion of this report, members will further develop the strategies outlined here. Using all information available to them, and with testimony from many young adults, families, and providers about their personal health care transition experiences, the Task Force made 16 recommendations to ensure successful transition from pediatric to adult health care in Florida. The recommendations are prioritized by anticipated level of resources required for implementation.

## Recommendations

*Strategies that can be accomplished with few additional resources are as follows:*

1. Continue via the Task Force and Workgroup to develop strategies identified in this report so a comprehensive action plan is ready to implement beginning June 2009.
2. Leverage CMS's infrastructure and federally mandated responsibility for health care transition planning to establish a state Office of Health Care Transition within CMS that guides, monitors, and supports local public/private transition coalitions, and is directed by a physician with experience in health care transition. Begin planning and development of localized service systems for YSHCN.
3. Organize local health care transition systems so services provided are based on evidence-based practice, the YSHCN's need for support, and resources that are available.
4. Develop a technical assistance guide to help YSHCN, families, and providers identify insurance coverage options available to YSHCN in Florida. Explore entities that can serve as financing resource assistance centers.
5. Offer health care transition training for professionals approved for Continuing Medical Education (CME) and/or Continuing Education Unit (CEU) credit at no cost to the individual.
6. Adapt and disseminate existing health care transition educational and training materials targeted to health care professionals, education professionals, YSHCN and families.
7. Pursue private and public grants to support the development and dissemination of new educational and training materials.
8. Utilize existing networks, associations, advocacy organizations, and agencies at the state and community levels to assist in dissemination of educational materials; identify and pool resources across agencies to support distribution.
9. Work with the Medicaid program and private insurers to develop policies relating to co-management of YSHCN.
10. Advocate for insurers to recognize the complexity of individual patients, and for payment to reflect the time and resources required for appropriate care.
11. Advocate for mandatory disability-related training for all health care professionals.



*Longer term strategies that require more significant financial support are:*

1. Implement the Family Opportunity Act and a Medicaid Buy-In option so transitioning youth and parents are able to work without loss of health care benefits.
2. Work with the Medicaid program to implement medical homes for YSHCN, including a demonstration using billing codes that address care coordination and other activities.
3. Extend CMS Network coverage for YSHCN to age 25 if not age 29.
4. Accept federal Medicaid matching funds for education and outreach to Medicaid-eligible adults who have Sickle Cell Disease.
5. Implement fully the proposed functions of the state Office of Health Care Transition and local transition coalitions by adequately funding a comprehensive, tiered system of care for YSHCN.



## Part I: Introduction

Taking responsibility for one's own health care is part of growing up and becoming independent. Adolescents and young adults, as developmentally able, need to understand their health condition, medication needs, and methods of paying for services. For the estimated 16% of youth with disabilities or special health care needs in Florida, these issues are especially important and challenging.<sup>5</sup> While advances in technology and medical science have dramatically increased survival rates, youth with disabilities are much less likely than their non-disabled peers to finish high school, pursue postsecondary education, find a job, or live independently.<sup>2</sup> A growing body of evidence suggests that persons with disabilities are particularly susceptible to secondary disabling conditions that can further impact their quality of life.<sup>4</sup>

According to recent U.S. Census figures, approximately 29 million young adults ages 18-24 live in the U.S. and 1.6 million live in Florida.<sup>6</sup> Even in the best of circumstances, this age is a complex and challenging period that recently has been termed "emerging adulthood."<sup>8</sup> Young people who have been dependent on parents throughout childhood start taking definitive steps to achieve financial, residential, and emotional independence. Developmental tasks include decision-making in the areas of marriage, vocation, education, child-bearing, religious practices and political values. Stresses encountered during earlier adolescence may persist, including pressure to use alcohol, tobacco, illicit drugs and engage in premarital sexual activity. This constellation of challenges may place the emerging adult at risk for a wide range of social, psychological and physical pathology, such as becoming a parent too soon, dropping out of school, or failing to find work.<sup>9</sup>

The challenges of transition to adulthood are especially difficult for adolescents and emerging adults with special health care needs. Chronic health conditions can impose extensive behavioral demands on the individual, including regular medication administration, therapies, or special diets. In early adulthood, frequent changes in living situations, educational routines, jobs, friendships, and romantic relationships are common. Any of these can undermine the routine and resolve needed to control certain medical conditions.<sup>7</sup> Developmental tasks during this time may be at odds with managing one's health issues. For example, establishing autonomy may result in the emerging adult not wanting to follow the advice of his/her physician or family.<sup>10</sup> Heightened concern for peer acceptance and the establishment of intimate relationships also are characteristic of this period, and young adults may be reluctant to admit to their significant other they have a health problem.<sup>11</sup> Moreover, a major developmental milestone during the stage of emerging adulthood is the ability to think abstractly.<sup>12</sup> Young adults may struggle with taking responsibility for the management of their health problems, or with understanding the consequences of poor adherence to medical advice. While abstract thinking may allow young people to better appreciate the need for adherence to medical advice, it may also result in their feeling overwhelmed and depressed about the future. Increased drinking, illicit drug use, or other high risk behavior can further impact adherence with health care appointments, laboratory studies, etc.<sup>12</sup>

As a result, there is increasing interest in services and supports for young people with disabilities and chronic health conditions that address all aspects of health and well-being, including promoting health, preventing secondary conditions, and preparing for entry to adult health care.<sup>4</sup> Blum et al. (1993) defined health care transition as the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems.<sup>3</sup> The American Academy of Pediatrics (AAP), American Academy of Family Physicians, American College of Physicians, and Society for Adolescent Medicine all have position papers concerning health care transition.<sup>13-15</sup> In addition, *Healthy People 2010* and *The Surgeon General's Call*

*to Action to Improve the Health and Wellness of Persons with Disabilities* identify goals to increase accessible health care and promote independence for all people with disabilities.<sup>4,16</sup>

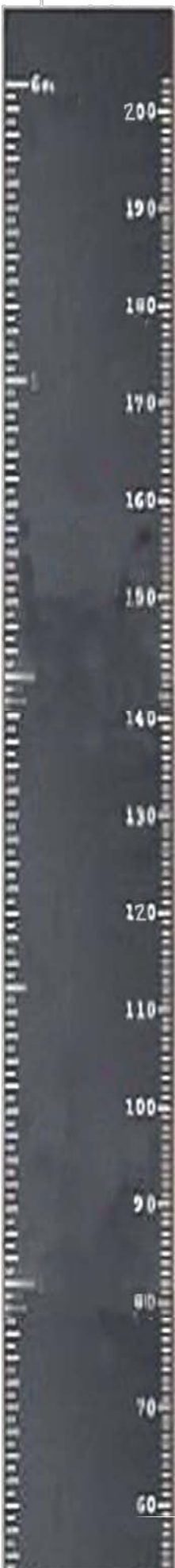
Florida has been at the forefront in recognizing the myriad challenges faced by youth as they age out of pediatric health care, and developing programs to address the needs of the emerging adult. These recent state initiatives highlight the significance of health care transition as young Floridians enter adulthood:

- Children’s Medical Services (CMS), Florida’s Title V program that serves income-eligible children from birth to 21 years with serious health conditions, has federally mandated responsibility to lead health care transition planning activities for these youth. CMS provides transition specialists in several regional offices and established a statewide Young Adult Advisory Board to help guide agency decision-making around transition.
- The Partners in Transition *Florida Strategic Plan on Transition* (2004) identified barriers and strategies to improve outcomes as youth transition from high school to adult life. The plan outlines several objectives concerning health care transition, such as ensuring access to mental, physical, and oral health care services; preparing young people for entry to the adult health care system; providing professional training; and incorporating health care goals and activities that support increased independence into Transition Individual Education Plans (IEP).
- The Florida Office on Disability & Health (FODH), established in 2007 at the University of Florida (UF) and funded by the Centers for Disease Control and Prevention (CDC), developed a strategic plan to support its mission of maximizing the health, well-being, and quality of life for all Floridians living with disability. One goal is to promote adequate benefits across age, education, and health transitions.
- The Florida Developmental Disabilities Council, Inc. (FDDC) *2006-2011 State Plan* includes strategies to ensure that health care transition needs are addressed early and at each life stage. FDDC sponsored a one-day Health Care Transition Summit in 2006 to explore ways to implement health care transition in communities, schools, and throughout the state.
- FDDC, in partnership with the University of South Florida (USF) and Hillsborough County Public Schools, funded the development of a school-based health care transition education program that provides a comprehensive curriculum for high school students with disabilities. Project results were used to help develop a disability curriculum that is now required for all third year medical students at USF College of Medicine. In addition, USF Pediatrics provides specialty transition clinics for CMS and HIV patients.
- The Health Care Transition Initiative at UF’s Institute for Child Health Policy (ICHP) utilized research data from their “Promising Practices in Health Care Transition” project to develop several high quality educational materials for adolescents and young adults, families, educators, and health care professionals.

*When I was at home, my mother took care of everything with my doctor. When I moved to Tampa (to go to college), she arranged for me to see a group of physicians if I experienced an exacerbation of symptoms. It is so time consuming. Negotiating appointments and arranging hospital admissions by myself has been difficult. I know so much more about my disease now than I did before. (But) because of my disease, I am at risk of losing my Bright Futures scholarship because I failed a class. I do not want to be owned by my disease.*

*Kelley, a 19 year old college student who has an autoimmune disorder*



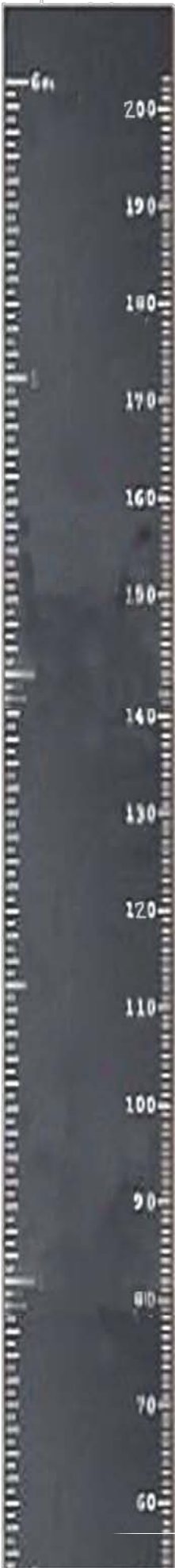
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- In 2004, using funding from the Institute for Child and Adolescent Research and Evaluation (ICARE), the Career Development and Transition (CDT) project at The Transition Center at UF in collaboration with ICHP conducted a survey of interagency teams in *Project CONNECT* sites to determine their knowledge of health care transition for students with disabilities. Findings resulted in training through the CDT project over a period of three years, development of health care transition self-determination classroom materials, and publication of two journal articles on the survey results and issues related to the Family Educational Rights and Privacy Act (FERPA) and Health Insurance Portability and Accountability Act (HIPAA) when teaching health care transition.
  - Jacksonville Health and Transition Services (JaxHATS), a nationally recognized health care transition program, provides a comprehensive medical home for youth and young adults with complex health conditions. Multidisciplinary staff provide primary medical care, coordinate specialty medical services, support educational and vocational goals, and help their patients develop individualized care plans to meet their long-term health care needs.
  - The newly formed Children and Youth Cabinet of Florida identified health care transition as an objective in its 2007 *Strategic Plan*: “Support the transitioning of adolescents into adult health care, especially those with special needs.”

Despite increased recognition that health care transition is a critical aspect of successful entry to adulthood – indeed, that it supports economic self-sufficiency, independence, and prevents negative outcomes such as school dropout and delinquency - there has been little investment in the development of a service system that meets the needs of these young Floridians. A call to action during the 2008 legislative session resulted in the passage of Senate Bill 988. SB 988 called for the establishment of a time-limited statewide Task Force to assess the need for health care transition services, to develop strategies to ensure successful transition from pediatric to adult health care systems, and to identify existing and potential funding sources. This report outlines recommendations from the Task Force for the development of an effective, evidence-based system of health care transition services in Florida.

### Statement of Need

It is indicative of the complexity of health care transition that youth and young adults with disabilities are not easily defined. Measures, indicators, and criteria that describe this population vary across systems and agencies. In the pediatric health care system, the federal Maternal and Child Health Bureau (MCHB) defines children and youth with special health care needs (CYSHCN) as children and adolescents who have a chronic physical, developmental, behavioral, or emotional condition and who require health and related services of a type and amount beyond that required of children and adolescents and generally.<sup>17</sup> By this definition, CYSHCN encompass all children and youth from birth through age 17 with disabilities and/or special health conditions.

As youth turn 18 and become young adults, they may be categorized in adult systems as persons with disabilities (PWD) or with disabling chronic conditions. While the term “disability” has multiple definitions, it generally refers to a physical or mental impairment that limits one or more life activities. In most adult systems, degree of disability is determined largely by capacity for gainful employment rather than by level of services required. Age criteria also vary: reports of health status generally define young adults as ages 18-24, while insurance utilization data often report coverage for young adults up to age 30. **For the purpose of this report, we use the term youth with special health care**



**needs (YSHCN) to encompass all youth and young adults with disabilities and/or chronic health conditions who are approximately 12 through 24 years old.** Based on 2000 U.S. Census figures, MCHB data and other sources, almost 500,000 YSHCN live in Florida.<sup>5,6</sup>

The data demonstrate policy and practice do not reflect our current level of understanding about the importance of health care transition. According to the *2005/2006 National Survey of Children with Special Needs*, almost one in five adolescents with special health care needs ages 12-17 in the U.S. goes without needed health care services. Only 41% receive the services they need for transition to adult health care, work, and independence. In Florida, the news is even worse: less than 34% receive needed transition services statewide, and only 16% of those in rural areas receive services.<sup>5</sup>

McManus et al. (2008) reported most pediatric practices do not routinely offer transition support services. Only a third of pediatricians said they make referrals to adult physicians for even some of their patients, and less than 15% provide transition educational materials to adolescents and their parents.<sup>18</sup> In addition, young adults with and without disabilities have the highest uninsurance rate of any age group in the U.S. A number of studies have demonstrated the majority of youth with disabilities are inadequately insured or experience gaps in insurance coverage during young adulthood, many for a substantial period of time.<sup>19</sup>

## **Barriers**

Barriers to health care transition are numerous and well documented.<sup>20-27</sup> Among the most frequently cited problems reported by health care providers, YSHCN, and families are:

- Lack of primary and specialty adult providers willing to take YSHCN due to low Medicaid reimbursement rates.
- Lack of training concerning childhood onset conditions among adult providers.
- General fragmentation in the adult health care system.
- Lack of reimbursement for time required by pediatric or adult primary care practices to provide transition services.
- Lack of knowledge among providers about how to support transitioning YSHCN.
- Lack of adequate insurance coverage among YSHCN due to loss of public and private insurance during young adulthood.
- Cessation of public programs for YSHCN at ages 18 or 21.
- Eligibility and access barriers to Supplemental Security Income (SSI) and Medicaid as an adult.
- Delays in the reauthorization process for adult SSI.
- Requisite two-year waiting period before qualifying for Medicare benefits.
- Limited employment opportunities for emerging adults that offer employer-based insurance.
- Absence of referral networks; lack of knowledge about community resources for YSHCN.
- Difficulty that youth and families have in leaving trusted pediatricians.
- Lack of self-efficacy, self-confidence, and self-advocacy among YSHCN due to development immaturity and/or stresses resulting from the many health, education, vocational, living, and relationship transitions that occur during emerging adulthood.



## Methodology

In accordance with guidelines outlined in SB 988, the Department of Health (DOH) convened a 14-member Task Force in August 2008. FDDC supported the project by identifying 20 additional stake-holders to participate in the planning process, covering a portion of costs associated with the initiative, and providing a Facilitator to help organize and manage activities for the full 35-member Workgroup.

Workgroup members were asked to join at least one of three subcommittees: 1) Financing and Structure, 2) Services and Models of Care, and 3) Education and Training. Subcommittee Chairs worked with the Facilitator to schedule a series of 4-5 teleconference calls, or “virtual” planning sessions, for each subcommittee over a three month period of time. In addition, national and state-level subject experts participated in selected calls. The teleconference schedule, background materials and relevant literature, meeting minutes, and working documents were made available to Workgroup members via ongoing electronic communication and a dedicated project Web site, [www.healthcaretransition.org](http://www.healthcaretransition.org). While the legislatively appointed Task Force officially dissolves with the completion of this report, members will further develop the recommendations and strategies outlined here. The Workgroup expects to finalize a comprehensive action plan in May 2009.

## Recommendation

- Continue via the Task Force and Workgroup to develop strategies identified in this report so a comprehensive action plan is ready to implement starting June 2009.



## Part II: Financing and Structure

The Financing and Structure Subcommittee focused on two primary issues: 1) obtaining and maintaining health insurance among YSHCN, and 2) compensation for the provision of health care services that are critical to the transition process.

### Health Insurance Options

Obtaining and maintaining health insurance is a major issue facing YSHCN as they leave high school. The Task Force found there is no single health insurance coverage option that covers a creditable health benefit package for YSHCN. Extent of disability, age, income, employment status, availability of family coverage through parents, pre-existing condition exclusions, costs of coverage, waiting periods, and scope of benefits all contribute to the lack of a uniform solution. For YSCHN who qualify for comprehensive benefits through CMS, coverage ends at age 21.

Even young adults *without* disabilities may endure years without secure insurance or lapses in coverage. Many jobs available to young workers ages 18-29 do not offer health insurance, or, if available, is so costly young adults decline the benefit. It is even worse for YSHCN. While the majority of young people without disabilities will eventually secure jobs with employers that offer comprehensive health benefits, YSHCN who are able to work are more likely to have part-time jobs that do not qualify them for employer-sponsored health plans, have pre-existing conditions that exclude them from private plans, or earn too little to pay for group or individual policies. Private insurance coverage for dependent, disabled adults via family plans may provide an option, but those plans are restricted by type of disability and income of the dependent adult.

Data from the U.S. Census Bureau indicate people with disabilities are more likely to have public health insurance than people who do not have disabilities (22% versus 3% for individuals ages 22-24).<sup>28</sup> Although public insurance may be available to YSHCN, it is often subject to narrow eligibility requirements, limited benefits, and/or periodic review. After age 18, eligibility for SSI and Medicaid is determined in large part, again, by the individual's ability to work. Adults identified as severely disabled – meaning they are not able to earn significant income – may be eligible for Medicare through Social Security and/or for a Medicaid Waiver program. Mandated waiting periods, waiting lists, and administrative delays can create additional barriers. The net result is that the disability standard for adult health coverage is defined around *inability to work*, which keeps many YSHCN uninsured, underinsured, or restricted in income earnings to preserve public health benefits.<sup>29</sup>

The rules and regulations for public and private health insurance are complex and vary widely from state to state. Attached in Table 1 is a matrix that identifies the range of insurance options available to young adults ages 18-30 in Florida, along with income and asset guidelines for major publicly funded programs. Of note, under the new Cover

*I am the mother of a 17-year old young man with Williams Syndrome, autism, and cardiac and orthopedic problems. We live in Lee County. Other than his primary care physician, Kevin's doctors are all in Miami, St. Petersburg, Atlanta, and Boston. He's had close to 20 surgeries, none performed in Lee County. I have real fears about transitioning Kevin to the adult system. While there are few pediatric specialists that accept Medicaid, there are even fewer in the adult system. CMS staff work feverishly to get adult physicians, but almost none of them will accept Medicaid. Kevin also needs ongoing PT and OT to prevent him from being wheelchair bound, but Medicaid says that this is not medically necessary once he reaches age 18.*

*My understanding is that we will have to travel to Miami or Gainesville when he transitions. I am fortunate to have a car and be employed. However, since Kevin's birth, I have had to quit many jobs to care for him, and am painfully aware that my situation could destabilize at any time.*

*L. J., Kevin's mom*



Florida legislation introduced in 2008, additional/enhanced private insurance options will be available to Florida residents in early 2009. However, we expect Cover Florida plans will offer benefit packages too limited for most YSHCN and will include exclusions for pre-existing conditions, and that participation among YSHCN will be restricted.

The matrix points to a very complex network of coverage options not familiar or known to most people. Each option has its own unique set of exceptions or rules. The Task Force could not locate a single document that clearly identified all of the options or a single web-site, call center or help center that explains health care coverage options in Florida.

Finally, the matrix identifies options that are not available in Florida. Currently, 39 states offer a Medicaid Buy-In program that allows adults with disabilities who work but do not qualify for Medicaid because of income criteria to buy into Medicaid, thereby eliminating the risk of losing health coverage due to increased earnings. In addition, several states have adopted the Family Opportunity Act, a Medicaid buy-in option for families of CYSHCN that is part of the Deficit Reduction Act of 2005.

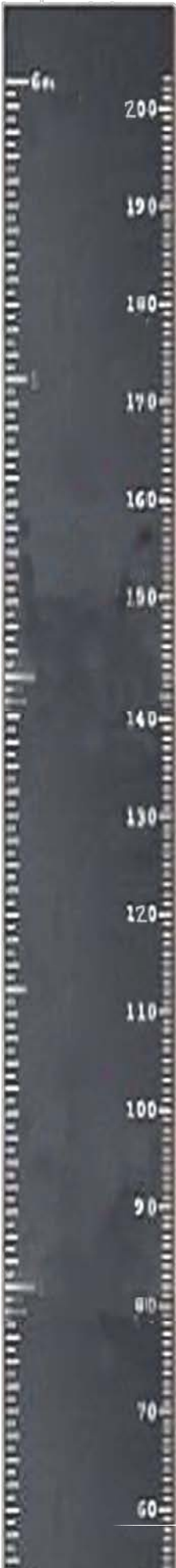
### **Compensation for Critical Services**

Besides the complexity of and lack of health insurance, issues relating to health care provider reimbursement are impediments to health care access. Providers are responsible for offering a "medical home" for YSHCN; however, payment strategies are not aligned with the concepts of a medical home. They do not recognize care coordination, shared management or prolonged service episodes. Current payment strategies in Florida do not uniformly or consistently include:

- Payment for non face-to-face consultations using a variety of technologies, including e-mail and telemedicine.
- Compensation for care coordination services, education, and outreach.
- Payment that adequately compensates physicians for additional consultation time needed to assess and manage care for persons with multiple or complex conditions.
- Recognition of co-management and multidisciplinary team approaches.

With respect to fee-for-service payments, the coding system is rooted in procedures. Work involving coordination and prolonged service episodes are poorly reimbursed, if at all. Currently, Florida's Medicaid MediPass system reimburses primary care providers at \$2 per member per month for care management, without respect to the complexity of the patient's needs. In addition, managed care contracts can require health care professionals to accept full risk capitation. White (2002) reported that there are no reliable predictive risk-adjusted methods for understanding the cost of medical home coordination for individuals with disabilities.<sup>30</sup>

Managed care organizations and other insurers often do not reimburse for Current Procedural Terminology (CPT) codes that are needed to adequately care for YSHCN, such as prolonged physician service without patient contact, team conferences, telephone calls, care plan oversight services, or preventive services with individual or group counseling. Of note, since 2004, federal Medicaid matching dollars have been available to states for education and outreach to Medicaid-eligible adults with Sickle Cell Disease (SCD), though few states have accepted the match to-date. Currently, Medicaid reimbursement is between 58.3% and 72.6% of the Medicare reimbursement. Medicaid is rarely accepted in the private adult health care system due to low reimbursements rates, and many providers limit the number of Medicare patients they serve due to inadequate compensation.



Evidence supports seamless health care transition service models that allow for co-management of YSHCN. That is, primary care providers (PCPs) may manage the YSHCN's general health care needs while simultaneously working with specialists who manage special health conditions. Or, pediatricians may work concurrently with internal medicine practitioners to co-manage the YSHCN's care until the latter is comfortable assuming primary responsibility for care. However, neither public nor private health insurers in Florida currently recognize the need for co-management during the transition process. McManus et al. (2008) identified a few examples in other states where shared arrangements or co-management exists. A study of such practices in Wisconsin demonstrated fewer tertiary hospital admissions and emergency room visits through the use of service agreements and co-management arrangements.<sup>31</sup>

Service agreements have been used by the *Epilepsy Collaboratives of the National Institute for Children's Healthcare Quality (NICHQ)*, the Veterans Administration, and others. They consist of 1) core clinical competencies which describe the conditions that can be handled, and the core services that will be provided by the PCP and the specialist; 2) referral agreements which include referral guidelines, work-up requirements, and preferred communication processes, including shared care plans; 3) access agreements which define waiting times for emergency and routine referrals, ongoing chronic care management, and questions, considerations, and evaluations; 4) graduation criteria for sending patients back to the referring physician; and 5) quality assurance agreements that identify standards of care, training and education processes, and measures to monitor care standards. Evaluation results show benefits for both primary care providers and specialists. PCPs are assured their patients will be seen promptly, and specialists are assured they will see only those patients requiring their services. Further, service agreements result in reductions in specialty demand, reduced waiting times for patients, and more timely feedback from the referral specialist.

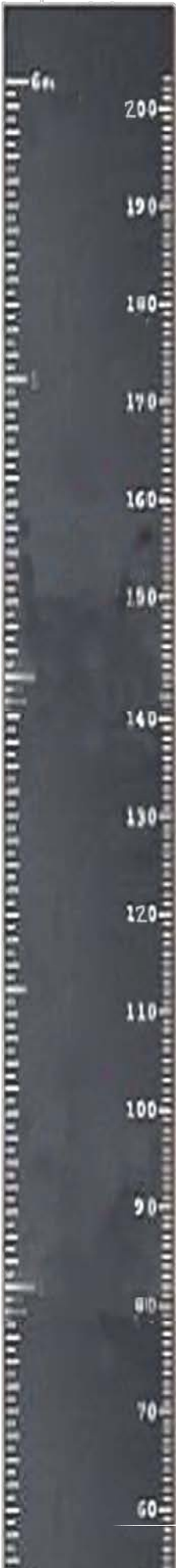
The AAP and MCHB have actively been engaged in promoting medical homes for all children, including CYSHCN. In addition, the National Committee on Quality Assurance, National Business Coalition on Health and major physician associations all support the medical home model. Several states, including Florida, have developed local medical home initiatives. However, CPT codes for care coordination and other services addressed above have not been used in these initiatives. A few states are currently involved in demonstrations with commercial insurers and Medicaid to compensate for care management. Colorado and Minnesota have medical home legislation and Minnesota's legislation specifically addresses compensation for the medical home based on a form of risk-adjustment.

The AAP has produced a cross-walk of CPT codes that may be used for elements of a medical home. This cross-walk is a valuable resource to use in negotiating fees with public and private insurers. It can also be used as the basis upon which to determine a global fee for medical home activities not rooted in clinical procedures.<sup>31</sup>

## **Recommendations**

*Strategies that can be accomplished with few additional resources are as follows:*

- Develop a technical assistance guide to help YSHCN, families, and providers identify insurance coverage options available to YSHCN in Florida. Explore entities that can serve as financing resource assistance centers.

- 
- Work with the Medicaid program and private insurers to develop policies relating to co-management of YSHCN.
  - Advocate for insurers to recognize the complexity of individual patients, and for payment to reflect the time and resources required for appropriate care.

*Longer term strategies that require more significant financial support are:*

- Implement the Family Opportunity Act and a Medicaid Buy-In option so transitioning youth and parents are able to work and contribute to their communities without loss of health care benefits.
- Work with the Medicaid program to implement medical homes for YSHCN, including a demonstration using CPT codes that address care coordination and other activities.
- Extend CMS Network coverage for YSHCN to age 25 if not 29.
- Accept federal Medicaid matching funds for education and outreach to Medicaid-eligible adults who have Sickle Cell Disease.

**Table 1: Health Care Insurance Benefit Options for Young Adults Ages 18-30 in Florida**

FINANCING OPTION	Limits		Eligibility Based on Employment Status	Eligibility Based on Disability/ Specific Health Condition	Pre-Existing Condition Exclusion/ Other Special Circumstances	Legislative Mandate	Requires Annual Certification	Monthly Premiums	Group	Individual	Comments
	Income	Age*									
<b>PRIVATE</b>											
Group Plan (through employer)	N	19-up	Y	N	Y	N	N	Y	Y	N	Typically requires 75% to full-time employment status
Individual Plan (single policy purchase)	N	19-up	N	N	Y	N	N	Y	N	Y	Can be expensive; high premiums for pre-existing
Adult Dependent Disabled Child via Family Plan	N-Family Y-Child	19-up	N	Y	N	Y FS 627.6041 FS 627.6615 FS641.31(29)	Y	Y	Y	N	Handicapped Children's statute; requires mental retardation or physical handicap, and less than 50% self-supporting
Adult Dependent - Student Status via Family Plan	N	19-25	N	N	N	Y FS 627.6562	Y	Y	Y	N	Must maintain full-time student status
Adult Dependent Child-Expanded Age via Family Plan	N	19-30	N	N	N	Y FS 627.6562	Y	Y	Y	N	Expansion thru Cover Florida
Student Insurance via Post Secondary School	N	Varies	N	N	Y	Y FS 627.6562	N	Y	N	N	Blanket Policy; limited benefits
Cover Florida	N	19-up	N	N	Y	Y - SB 2534	Y	Y	N	Y	Projected enrollment in 1/09
<b>PUBLIC</b>											
KidCare	Y	0-19	N	N	N	Y- Title XXI	Y	Y	N	Y	Comprehensive benefits, pay monthly premium; CMS to 21 yrs
Full Pay Healthy Kids and MediKids	Y	1-19	N	N	N	Y	Y	Y	N	Y	Cost-share option; families pay full cost of coverage
Medicaid (Child EPSDT)	Y	0-21	N	N	N	Y- Title XIX	Y	N	Y	N	Comprehensive benefits
Medicaid (Adult)	Y	21-65	N	N	N	Y	Y	N	Y	N	Adult benefits are limited
Medicaid & Medicare Dual Eligibility											Descriptions on next page
QMB	Y	18-65	N	Y	N	Y	Y	Y	Y	N	Qualified Medicare Beneficiaries
QMBs PLUS	Y	18-65	N	Y	N	Y	Y	Y	Y	N	QMBs with full Medicaid
SLMB	Y	18-65	N	Y	N	Y	Y	Y	Y	N	Specified Low-Income Medicare Beneficiaries
SLMB PLUS	Y	18-65	N	Y	N	Y	Y	Y	Y	N	SLMBs with full Medicaid
QDWI	Y	18-65	Y	Y	N	Y	Y	Y	Y	N	Qualified Disabled Workers
Medicare	Y	16-up	N	N	N	Y	N	Y	Y	N	Qualifies if parent has retired, or youth with SSDI has worked
TriCare/ ECHO (Extended Care Health Option for Military)	N-Sponsor Y-Child (ECHO)	17-up	Y	N	N	Y	N	Y	Y	N	Active duty, dependents < 23 yrs, retired; ECHO covers active duty dependents >23 yrs with physical or mental incapacity
Indian Health Services											Varies by tribe
Local Safety Net Plans	Y	19-up	Varies	N	Varies	N	Y	Varies	Y	N	Selected counties only
<b>OTHER PUBLIC OPTIONS</b>											
Medicaid Home & Community-Based Service Waivers											Description on next page
Adult Cystic Fibrosis	Y	18-up	N	Y	N	Y	N	N	Y	N	
Aged Disabled Adult	Y	18-60	N	Y	N	Y	N	N	Y	N	
DD Tier 1	Y	3-up	N	Y	N	Y	N	N	Y	N	Wait list
DD Tier 2	Y	3-up	N	Y	N	Y	N	N	Y	N	Wait list
DD Tier 3	Y	3-up	N	Y	N	Y	N	N	Y	N	Wait list
DD Tier 4	Y	3-up	N	Y	N	Y	N	N	Y	N	Wait list
Familial Dysautonomia	Y	3-up	N	Y	N	Y	N	N	Y	N	
Model Waiver	Y	0-21	N	Y	N	Y	N	N	Y	N	
TBI/Spinal Cord Injury	Y	18-up	N	Y	N	Y	N	N	Y	N	Wait list

\*NOTE: High end of age range generally indicates coverage through the end of the calendar year in which the individual reaches that age.



## CONSIDERATIONS

### PRIVATE OPTIONS

#### **COBRA**

Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) provides some employees and beneficiaries with the right to continue their coverage under a health benefit plan for a limited time after certain events, such as the loss of employment. Coverage may extend from 18 to 36 months.

#### **Court-Ordered Benefits**

Courts have the power to order divorcing parents to maintain their child's health insurance regardless of the cost. There is no age limitation if dependency is due to a mental or physical handicap that began prior to age 18.

#### **ERISA Plans**

Employee Retirement Income Security Act of 1974 (ERISA) provides some employer-sponsored health plans protection from state regulatory standards. ERISA plans generally are not required to comply with state-mandated benefits, but sometimes offer better benefit packages than other plans. ERISA plans currently cover approximately 50% of Florida employees.

#### **Self-Employed**

Self-Employed Health Insurance Deduction provides a tax break on insurance coverage for individuals who own their own business.

### PUBLIC OPTIONS

#### **Medicaid Home & Community-Based Service Waivers (HCBW)**

Waivers provide specific services over and above those received in the general Medicaid adult benefits package for persons who demonstrate need for a high level of care. Enrollment is typically capped; once enrollment reaches a specified number or dollar threshold, waiting lists are created. Starting in 2008, Developmental Disabilities (DD) Waivers encompass 4 tiers based on degree of need. There are currently 15 HCBWs in Florida. Some states offer an expansion of Medicaid benefits to low-income, childless adults ages 21-65 who are not disabled. This option, called a "non-categorical waiver," is not offered in Florida.

#### **Medicaid-Medicare Dual Eligibility**

##### **QMB Only - Qualified Medicare Beneficiaries without other Medicaid**

a) Entitled to Medicare Part A, have income of 100% Federal poverty level (FPL) or less, b) Resources that do not exceed twice the limit for SSI eligibility, c) Are not otherwise eligible for full Medicaid, and d) Medicaid pays their Medicare Part A premiums, Medicare Part B premiums, and, to the extent consistent with the Medicaid State plan, deductibles and coinsurance for Medicare services provided by Medicare providers.

##### **QMBs PLUS QMB with full Medicaid**

a) Entitled to Medicare Part A, have income of 100% FPL or less, b) Resources that do not exceed twice the limit for SSI eligibility, c) Are eligible for full Medicaid benefits, and d) Medicaid pays their Medicare Part A premiums, Medicare Part B premiums, and, to the extent consistent with the Medicaid State plan, Medicare deductibles and coinsurance, and provides full Medicaid benefits.

##### **SLMB - Specified Low-Income Medicare Beneficiaries (SLMBs) without other Medicaid**

a) Entitled to Medicare Part A, have income of greater than 100% FPL, but less than 120% FPL, b) Resources that do not exceed twice the limit for SSI eligibility, c) Are not otherwise eligible for Medicaid, and d) Medicaid pays their Medicare Part B premiums only.

##### **SLMB PLUS - SLMBs with full Medicaid**

a) Entitled to Medicare Part A, have income of greater than 100% FPL, but less than 120% FPL, b) Resources that do not exceed twice the limit for SSI eligibility, c) Are eligible for full Medicaid benefits, and d) Medicaid pays their Medicare Part B premiums and provides full Medicaid benefits.

##### **QDWI - Qualified Disabled and Working Individuals**

a) These individuals lost their Medicare Part A benefits due to their return to work, b) Eligible to purchase Medicare Part A benefits, have income of 200% FPL or less, c) Resources that do not exceed twice the limit for SSI eligibility, d) Not otherwise eligible for Medicaid, and e) Medicaid pays the Medicare Part A premiums only.

#### **Medically Needy**

Provides "share of cost" for individuals not eligible for Medicaid due to income but who incur a certain amount in medical expenses each month. Share of cost varies by household size and income; once the specified amount is incurred each month, Medicaid will pay medical expenses for the remainder of the month.

#### **Social Security Income (SSI)**

SSI beneficiaries automatically receive Medicaid benefits. SSI has stricter disability requirements for adults than it does for children; over 30% of children with disabilities who receive SSI benefits do not qualify for adult SSI benefits at age 18. Generally, eligibility for those under age 18 is determined by level of function, and for those over age 18, by employability.

#### **Ticket to Work**

Allows SSI beneficiaries to continue to work up to a specified income threshold and still receive Medicaid benefits.

#### **Catastrophic Coverage/ High Risk Pool**

The Florida Health Insurance Plan (FHIP) was created by the 2004 Legislature to provide coverage to persons unable to obtain health insurance due to their health status. However, FHIP is not funded to begin new enrollment and so is not an option until the Legislature provides a funding source.

## NOT AVAILABLE IN FLORIDA

#### **FAMILY OPPORTUNITY ACT (FOA)**

As part of the Deficit Reduction Act of 2005, states may allow families that do not qualify for Medicaid but have income less than 300% FPL to purchase Medicaid benefits for CYSHCN up to age 21. Disability requirements are similar to SSI standards.

#### **MEDICAID BUY-IN**

As part of the Ticket to Work and Work Incentives Act of 1999, states may expand Medicaid coverage to persons with disabilities ages 16 to 65 who work but do not qualify for Medicaid because of income criteria. Eligibility is based on SSI disability criteria.

### Part III: Services and Models of Care

The Services and Models of Care Subcommittee addressed ways to best organize and assess health care transition services in Florida. Factors that were explored include: 1) a framework of guiding principles, 2) magnitude of need among subpopulations of YSHCN, 3) organizational structure, 4) service models, and 5) performance measures.

#### Framework for a System of Care

Advances in medical science over the last 20-30 years have far outpaced advances in the financing, organization, and delivery of services that are needed to ensure that CYSHCN receive the health care they need. Recognizing that the key to improving care for CYSHCN lies in a systems approach to organizing and delivering services, the federal MCHB outlined six core outcomes in 2001:<sup>32</sup>

1. Families of CYSHCN will participate in decision-making at all levels, and be satisfied with the services they receive.
2. CYSHCN will receive coordinated, ongoing, comprehensive care within a medical home.
3. Families of CYSHCN will have adequate private and/or public insurance to pay for the services they need.
4. All children will be screened early and continuously for special health care needs.
5. Community-based systems will be organized so families can use them easily.
6. All YSHCN will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

In 2002, a "Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs," endorsed by the AAP and other national medical associations, outlined six critical first steps for successful health care transition.<sup>14</sup> More recently, Lotstein et al. (2008) provided a modified framework that identifies four core components.<sup>33</sup> Based on these data, the Task Force identified ten principles to guide Florida's system of care for YSHCN:


1. The structure and intensity of services are tailored to the physical, social and developmental needs of YSHCN and families, creating a tiered system of care that provides all YSHCN with the supports they need for successful transition.
2. Services are developed in partnership with YSHCN and families.
3. Services are easy to use, and accommodate the geographic and cultural diversity of YSHCN and families.
4. Services are organized within a medical home model, including a) a primary care physician to assure coordinated, uninterrupted, comprehensive, accessible care across pediatric and adult health systems, and b) access to age and disease-appropriate specialty care providers.
5. The provision of care coordination services meets the physical, social, and developmental needs of YSHCN and families, and includes, if needed, the development of an individualized health care transition care plan.

*My son Jeffrey is 6'2", 240 lbs, and 23 years old. He is autistic, mentally challenged, has obsessive compulsive behaviors, seizures, muscular weakness, severe eczema and allergies. His pediatrician oversees the care of five pediatric specialists. What (adult) primary care doctor is prepared to deal with his complex medical needs? What specialists am I going to see?*

*When Jeffrey was 21, he became ill and his pediatrician was out of town. The other partners in the practice refused to see Jeffrey because of his age, even though he has the development of an 8 year old. We ended up spending 10 hours in the emergency room, and then they wanted to put him in a hospital room with a 60-year old man. Jeffrey is still traumatized by the event.*

*Jeffrey has a sister Lisa, who also is 23 and has similar challenges PLUS gynecological problems. I belong to several parent groups and we all struggle!*

*S.C., Jeffrey's & Lisa's mom*

- 
6. YSHCN are continuously screened to provide preventive care and detect other conditions.
  7. Services are integrated and provided in collaboration with other community-based organizations and systems, e.g., education, vocational rehabilitation, mental health, child welfare, juvenile justice, independent living, etc.
  8. YSHCN have access to affordable, adequate and continuous health insurance.
  9. Services promote the development of disease self-management skills, healthy sexuality and understanding of preventive health care.
  10. YSHCN have access to age-appropriate educational and vocational opportunities that support economic self-sufficiency and independence.

### **Magnitude of Need**

It is only recently that children and youth with complex health conditions have survived to adulthood in relatively large numbers. In the 1970's, less than 30% of youth with spina bifida reached age 20. Today, more than 80% of those born with spina bifida reach adulthood.<sup>1</sup> There have been similar dramatic increases in survival for other serious diseases such as cancer, diabetes, sickle cell, muscular dystrophy, cystic fibrosis, and many other conditions. As such, most YSHCN with childhood onset chronic conditions strive for normalcy and opportunities: some want to get a job following high school while others want to go to college, and many expect to marry and have children.

According to the *2005/2006 National Survey of Children with Special Health Care Needs*, approximately 16% of youth ages 12-17 in Florida have a special health care need.<sup>5</sup> An estimated 5% of youth require a high level of transition support due to the complexity of their condition, and a little over 1% meet eligibility criteria for SSI (i.e., signifying a severe disability).<sup>34</sup> Based on these data along with data from the U.S. Census 2006 *American Community Survey*, *National Health Interview Survey*, and research conducted by Ireys et al. (2004), there are an estimated 471,799 YSHCN ages 12-24 in Florida with one or more special needs. Among this population, approximately 150,000 have a complex disabling condition that requires an intense level of transition support, and over 35,000 qualify for SSI.<sup>5,6,34,35</sup>

The Task Force identified several other subpopulations of YSHCN that appear to be particularly vulnerable for poor short-term and/or long-term health outcomes:

- YSHCN in the child welfare system (over 7,000 YSHCN ages 15-17 in out-of-home care)
- YSHCN in the juvenile justice system
- YSHCN with mental health conditions
- YSHCN living in rural areas with limited access to specialized services
- YSHCN from non-English speaking families
- YSHCN in college, many separated from their families and medical homes for the first time. Postsecondary institutions in Florida (state universities, community colleges) report that they provide accommodations for almost 13,000 students with disabilities or special needs.

**Table 2. Youth and Young Adults Ages 12-24 in Florida**

<b>Florida Youth and Young Adults Ages 12-24</b>	<b>Population Estimates</b>
All	3,005,092
<b>With one or more special health care needs</b>	<b>471,799</b>
With disabling condition requiring high level of transition support	150,255
With severe disability / receives SSI benefits (1.6% < age 18; 1.12% for ages 18-24)	36,061
With one or more special health care needs and attends college	12,794

Sources: 2005/2006 National Survey of Children with Special Health Care Needs; U.S. Census 2006 American Community Survey ; National Health Interview Survey; Ireys et al.; Florida post-secondary institution reports

### **Organizational Structure**

While there is an abundance of research that explores transition issues and barriers, evidence of good practice is not as well established. A recent report from the HRTW Transitions Model Project provides a summary of seven effective yet diverse approaches from practices around the country, and includes Florida's JaxHATS as a profiled program.<sup>36</sup> Though the seven practices vary widely, they illustrate the importance of tailoring programs to individual needs, concerns and issues of the young people they serve. Paramount to each approach is a commitment to providing a medical home where services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-competent.

In addition to the JaxHATS program, CMS currently provides transition support to almost 26,000 Florida YSHCN ages 12-21 through their 17 network offices statewide. Key recommendations from the Task Force are to:

- 1) Leverage CMS's federally mandated transition planning responsibility and its existing infrastructure to create a statewide Office of Health Care Transition within CMS that provides guidance, support, and oversight of local transition systems of care for YSHCN
- 2) Use CMS regional offices to support the development of local systems by organizing local public/private transition coalitions that design and implement a service delivery model that fits the unique needs and resources of the community, and includes both pediatric and adult providers.

The role of the State Office will be to:

- Provide leadership under the direction of a physician with expertise in transitioning YSHCN from pediatric to adult health care.
- Provide technical assistance to local planning coalitions in 17 CMS areas, including creating a database of adult primary and specialty care providers who will serve YSHCN.
- Establish a clearinghouse of best practices and toolbox of resources; develop and disseminate education and training materials to both physicians and consumers.
- Establish an advisory committee that includes YSHCN, families, and representatives from key state agencies and professional associations.
- Develop a clear mission, vision, goals and objectives for a state health care transition plan.
- Support interagency collaboration and service coordination.
- Develop performance measures for both state and local systems; conduct state-level evaluation of system structures, processes, impact, and outcomes.



- Develop policies and procedures for tracking, monitoring and reporting on YSHCN throughout the transition process.
- Host transition conferences for YSHCN, families and providers.
- Provide training for adult primary and specialty care providers in childhood onset conditions such as congenital heart disease, cerebral palsy and other developmental disabilities, genetic diseases, childhood cancers, pediatric transplants, etc.
- Promote the adoption of telehealth, e-health, personal health records, and electronic medical systems to support health care transition.
- Promote high quality transition service models appropriate for urban, suburban and rural areas of the state.
- Identify underserved populations in the transition age range and initiate programs to address service gaps.
- Secure adequate resources to create and sustain a robust, comprehensive system of care at the state and local levels.

The role of each local transition coalition will be to:

- Establish a local planning and oversight committee that includes YSHCN, families, pediatric and adult physicians, hospitals, academic medical facilities, and other key stakeholders in the areas of education, vocational rehabilitation, mental health, independent living, etc.
- Conduct a needs assessment that a) identifies prevalence and spectrum of conditions among YSHCN in the catchment area, b) documents number and type of services required by YSHCN, and c) secures participation and input from a diverse group of regional stakeholders.
- Develop a clear mission, vision, goals and objectives for a local health care transition plan.
- Establish policies, procedures, and budget guidelines for service delivery; address issues such as establishing clear guidelines for hospital policy and physician credentialing when serving YSHCN.
- Implement a Continuous Quality Improvement (CQI) program to regularly update/improve operations; conduct local-level evaluation of system structures, processes, impact, and outcomes.
- Develop policies and procedures for tracking and monitoring YSHCN through the transition process; develop program “exit” criteria.
- Develop strategies for active participation among primary and specialty care providers in both pediatric and adult systems; promote collaboration and coordination between the two systems.
- Provide training for adult primary and specialty care providers in childhood onset conditions such as congenital heart disease, cerebral palsy and other developmental disabilities, genetic diseases, childhood cancers, pediatric transplants, etc.
- Raise awareness of health care transition; advocate for policy change and funding support.

### **Service Delivery**

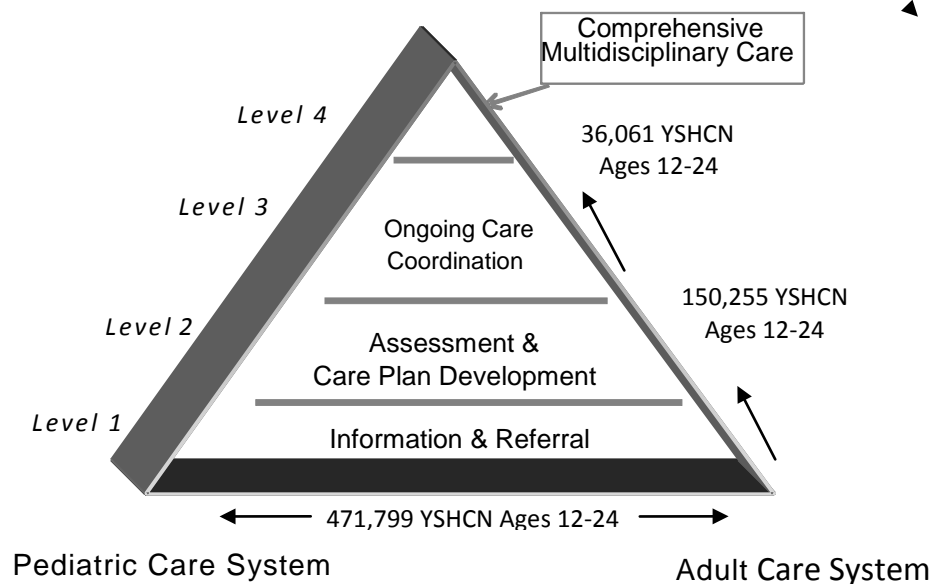
Local systems will be organized within a hierarchy of services based on the YSHCN’s need for transition support and the resources that are available. Services will span both pediatric and adult systems, offering maximum flexibility for individual patients, practices, and communities. YSHCN will first be assessed for level of need, and then triaged into one of four service levels. Level 1 includes basic support that is available to

all YSHCN; the three subsequent levels reflect an increasing and cumulative level of service provision for YSHCN with more complex conditions. Recommended service components and model programs for each level are outlined below.

- *Level 1 provides:*
  - Information to YSCHN and their families about the availability of adult physicians, resources, and insurance options; patient-centered health care tools, including a medical summary form, emergency contact list, and transfer of care form.
  - For YSHCN who have strong support networks and less complex conditions.
  - Model: School-Based Health Centers/Clinics (secondary and post-secondary)
- *Level 2 provides all services in Level 1 plus:*
  - Nurse specialist conducts an assessment with input from other professionals, as needed.
  - Development of an individualized care plan that serves as a blueprint for transition supports.
  - May include consultation with a medical-legal partner regarding employment, health insurance, independent living, decision-making options, housing, etc.
  - Model: Center for Youth and Adults with Conditions of Childhood, Indianapolis, IN
- *Level 3 provides all services in Levels 1 and 2 plus:*
  - Nurse specialist provides ongoing care coordination.
  - May include palliative and/or hospice care.
  - Models: Sickle Cell Transition Program, Memorial Hospital, Hollywood, FL; HIV/AIDS Transition Program, Miami, FL; Rainbow Center, Jacksonville, FL; CMS transition programs
- *Level 4 provides all services in Levels 1, 2, and 3 plus:*
  - Enrollment in a multidisciplinary, comprehensive medical home with ongoing primary care.
  - Active referral and consultation with adult specialists.
  - Intensive counseling to improve self-management of health conditions.
  - Model: JaxHATS, Jacksonville, FL

**Table 3. Proposed Health Care Transition Model of Care in Florida**

*Health Care Transition Model of Care Across Pediatric and Adult Care Systems*





## Performance Measures

The State Office will develop performance measures based on MCHB core outcomes for CYSHCN, CMS health care transition indicators for YSHCN, and other key process, impact, and outcome measures at the state, community, organizational, and individual levels. Examples are listed below.

- Core measures and indicators:
  - Percent of YSHCN with health insurance that adequately meets their needs
  - Percent of YSHCN with a personal doctor or nurse
  - Percent of YSHCN who receive health care transition education
  - Percent of YSHCN whose primary care provider facilitates transition to adult providers
  - Percent of YSHCN whose health care provider talks about how their health care needs might change as they get older
  - Percent of YSHCN for whom a plan is developed to address their changing needs
- State, community and organizational measures:
  - Number of staff per YSHCN
  - Cost per YSHCN
  - Response time for an assistance request
  - Level of satisfaction with services
  - Number of preventable hospitalizations and emergency room visits

## Recommendations

*Strategies that can be accomplished with few additional resources are:*

- Leverage the infrastructure of CMS and its federally mandated responsibility for health care transition planning to establish a statewide Office of Health Care Transition within the agency that guides, monitors, and supports local public/private transition coalitions, and is directed by a physician with health care transition experience. Begin planning and development of localized service systems for YSHCN.

- Organize local systems so that services provided are based on evidence-based practice, the YSHCN's need for transition support, and resources that are available.

*The following strategy will require a larger financial investment:*

- Implement fully the proposed functions and responsibilities of the state Office of Health Care Transition and local transition coalitions by allocating adequate funding to develop and maintain a comprehensive, tiered system of care for YSHCN.

*We admitted a 23 year old African American woman to Tampa General with a huge atrial septal defect with severe pulmonary hypertension and cyanosis. She decompensated after a recent pregnancy, and lost the baby. Fortunately, our surgeons were able to patch the ASD, and she is doing reasonably well post op, but she was a very high risk case.*

*She had not been seen by a cardiologist for seven years, since she was 16. If she had a proper transition, she could have been operated on under much safer conditions, and she might have carried her pregnancy successfully.*

*T.S., Cardiologist*



## Part IV: Education and Training

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The Education and Training Subcommittee considered a number of factors in exploring education and training related to health care transition. Key target audiences were identified first, as follows:

- Health care professionals
- Education professionals
- YSHCN and their families

Each audience segment was then assessed more specifically with respect to 1) content areas for the audience, 2) materials and resources that are currently available, 3) content and format of new materials to be developed, and 4) strategies and mechanisms through which needed education and training could be delivered. In general, there has been much progress over the last five years in the development of high quality educational materials. Table 4 (attached) lists educational and training materials related to health care transition that are currently utilized or available in Florida, as well as other resources that may be useful for future planning.

### Health Care Professionals

Health care professionals who need transition-related education include those in practice as well as those in training. This group encompasses medical students; physicians with a M.D. or D.O. degree who are practicing/training in the areas of pediatrics, family medicine, general internal medicine, psychiatry, and specialty disciplines (both pediatric and adult); and nurses, social workers, therapists, mental health counselors, and child life professionals who provide care to YSHCN in in-patient and out-patient settings.

Educational content for health care professionals in pediatric medicine should focus on best practices develop by the AAP and Society of Adolescent Medicine (SAM): starting the transition process early; promoting self-management skills and autonomy in YSHCN; facilitating transfer to identified adult providers; and providing adult providers with a medical summary. Educational content for physicians and nurses in adult medicine should address medical management of childhood onset conditions in young adults (which has not otherwise been addressed in their training); information about psychosocial development of YSHCN; strategies for addressing the psychological and support needs of YSHCN; CPT coding and insurance reimbursement; and best practices in the care of individuals with disabilities and functional impairments.

A variety of materials that speak to the health care transition process were identified. However, there are fewer existing resources related to the medical management of young adults with childhood onset conditions. Strategies for addressing the educational and training needs of health care professionals already in practice include:

- Make professionals aware of the issue of health care transition and how to access transition-related materials and trainings.
- Adapt or develop transition-related training materials, including web-based training approved for CMEs/CEUs at no cost to providers, legal guidelines regarding medical decision-making, information about Vocational Rehabilitation (VR) programs, and physical accessibility.
- Offer training through Florida's Area Health Education Centers (AHECs), Medical School/Hospital Grand Rounds, conferences, medical associations and other venues.



- Utilize the Office of Professional Licensure to disseminate transition-related training information when health care professionals apply for/renew their license.
- Explore the feasibility of requiring physicians, nurses, and other health care professionals who are licensed in Florida to complete training related to the care of persons with disabilities.
- Engage a physician champion for outreach to health care professionals.

Strategies for the educational needs of those being trained in health care professions include:

- Adapt or develop health care transition training materials for programs that train individuals to work in health care and related settings as physicians, nurses, social workers, counselors, therapists and child life professionals; include medical schools and physician residency programs.
- Identify all such programs, disseminate, and periodically follow-up to determine if/how these materials are incorporated into the training program curricula.
- Advocate for all medical schools in Florida to require disability-related training; promote the USF disability curriculum as a model program.

*This week I visited Sam, a 33 year-old patient with severe cerebral palsy. While he is nonverbal, he communicates. And while it may seem that he is incomprehensible, if you pay close attention you can quickly pick up on what he is "saying" through his vocalizations. His disability is severe, but he has an impressive record for health, more than I have seen in many patients without disabilities.*

*Sam's mother spends most of her days caring for him. Through this visit, not only did I see Sam's mental and physical disabilities, but I learned about the amazing amount of strength that a mother has when she is caring for a child. She was able to form an interdisciplinary team... he's had fewer problems recently because of the integration of the team involved in his care.*

*The amazing amount of information that (I) gathered in these 2 hours was unbelievable. This has been one of the most valuable experiences of medical school.*

*3<sup>rd</sup> year medical student at USF*

## Education Professionals

Education professionals working in middle and high schools who need health care transition training include general education teachers, Exceptional Student Education (ESE) teachers, guidance counselors, school psychologists, social workers, school nurses, and others who provide services to students with IEPs or 504 plans.

Professionals in postsecondary settings who need training include guidance and mental health counselors as well as staff in Offices for Students with Disabilities. This group also includes counselors from the Division of Vocational Rehabilitation (DVR) and those in training to fill educator positions.

Content for education professionals in secondary schools should include information about the knowledge and skills that YSHCN need to more actively participate in self-care and health care decision-making, and how these skills are related to key academic and life management skills that are part of the school curricula. In addition, training should include strategies and mechanisms for incorporating health care transition goals and activities into Transition IEPs, 504 plans, and/or curricula, thereby ensuring that students have the knowledge and skills to access health care services, supports and accommodations in their community and as they enroll in postsecondary education and training programs. Community-based agencies who are involved in the YSHCN's health care transition process (such as mental health providers) should also participate in IEP meetings. Activities that may be included in Transition IEPs and/or integrated into curricula are:

- Career and technical (vocational) training that does not conflict with the health needs of the YSHCN
- Self-determination and self-advocacy
- Modifications to physical education programs
- Classroom seating, such as avoiding being next to windows because of allergies or noise
- Health care management skills, self-care, and knowledge of health insurance
- Special dietary needs
- Understanding own needs and required accommodations
- Accessibility, such as entrances, school activity areas, transportation, emergency evacuation
- Medication, medical supplies and equipment
- Non-paid community-based vocational education, Volunteer experiences, paid employment, and recreational activities to develop work and social skills

A variety of educational and training materials for educators in middle and high school settings were identified, though there are fewer existing resources for those who work in postsecondary settings. Strategies to address the needs of working professionals include:

- Make educators aware of the issue of health care transition and how to access transition-related materials and trainings.
- Adapt or develop transition-related training materials, including web-based training approved for continuing education credit at no cost to the individual and materials for postsecondary professionals; enlist existing networks for material dissemination.
- Offer training through the Florida Department of Education (FDOE), conferences, workshops, and other venues.
- Utilize the Florida Bureau of Teacher Certification and other related licensure agencies to disseminate transition-related training information when professionals apply for/renew their certificate or license.
- Explore the feasibility of requiring selected professionals who are certified through the Florida Bureau and other licensure agencies to complete training related to health care transition, i.e., knowledge and skills needed to access adult-oriented health care in the community; participate in health care decision-making, etc.

Strategies for those being trained as education professionals include adapting/developing and disseminating materials to programs that train teachers, counselors, school nurses, and social workers; and assessing the extent to which they are incorporated into the program curricula.

### **YSHCN and Families**

Educational content for YSHCN should include information about how to actively participate in self-care and health care decision-making; sexuality and reproductive health; self-determination; how to obtain and maintain health insurance; how to access and make good use of health and related services and supports; and how to maintain optimal health in order to gain maximum benefit from education and work, and to fully participate in community life. Educational content for families includes information about how to support YSHCN through the transition to adulthood, including education, work, health care, and independent living. For parents whose children have limited

decision-making capacity, educational content should include information about guardianship and other mechanisms to assist and support a dependent adult child.

Numerous educational and training materials for YSHCN and their families have been developed in recent years with support from CMS, FDDC, and others. Strategies for addressing the health care transition-related educational and training needs of YSHCN, families, and their social support networks include:

- Make YSHCN, families, and community-based providers aware of the importance of planning for health care transition and how to access transition-related materials and training through CMS, FDDC, ICHP, USF, and other organizations.
- Distribute existing materials more broadly by printing additional hard copies, CDs, and DVDs; develop disability-accessible, non-English, and web-based formats; disseminate through schools, health care providers, public libraries, community-based organizations, and the internet.
- Adapt or develop health care transition training, and train trainers who can implement workshops for YSHCN and families at the state and community levels. Include training on how to educate/inform physicians about specific conditions or diseases.
- Establish YSHCN peer mentoring programs in schools and community-based organizations.
- Explore the feasibility of engaging a YSHCN spokesperson for statewide outreach activities, e.g., identify a young ambassador to deliver the health care transition message.

*Most low income families are so busy with work that addressing the issues of their special needs child is very hard. My mother-in-law, who speaks very limited English, works full time and overtime, pretty much 7 days a week. Her 18-year old son, Cesar, has schizophrenia and depression, and wants to work. But she can't even afford his doctor visits, so has no option but to deny Cesar the opportunity to work so that he doesn't lose his SSI and Medicaid. She doesn't know who to turn to with all of these issues. If there was information available in Spanish for her to read and use, it would make the whole process a lot easier.*

M.V.

## Recommendations

*The following strategies can be accomplished with limited additional resources:*

- Adapt, develop and disseminate health care transition educational and training materials targeted to health care professionals, education professionals, YSHCN and their families.
- Pursue private and public grants to support the development and dissemination of new educational and training materials.
- Utilize existing networks, associations, advocacy organizations, and agencies at the state and community levels to assist in dissemination of educational material; identify and pool resources across agencies to support distribution.
- Offer transition-related training for professionals approved for CME/CEU credit at no cost to the individual.
- Advocate for mandatory disability-related training for all health care professionals.

Finally, while the Task Force did not identify specific strategies to inform funders, policy-makers, and other stakeholders about the issues surrounding health care transition, members recognize the importance of reaching these key decision-makers. To that end, we hope this report will serve as a platform for education and subsequent action.

**Table 4: Health Care Transition and Related Materials in Florida**

PROGRAMS AND MATERIALS	Target Audience	Content	Format	Length	Current Distribution	Language	Access	Source	Comments
<b>DEVELOPED/UTILIZED IN FLORIDA</b>									
Welcome to Health Care Transition	YSHCN, families	HCT	Web-based module		Internet	English, Spanish	<a href="http://hctransitions.ichp.edu/ddcouncil">http://hctransitions.ichp.edu/ddcouncil</a>	ICHP, FDDC	
Envisioning My Future	YSHCN	HCT	Print	24 pages	CMS clients	English, Spanish, Creole	<a href="http://hctransitions.ichp.edu/resources.html">http://hctransitions.ichp.edu/resources.html</a>	ICHP, CMS	
CMS Transition Workbooks (3 versions)	CMS clients 12-21 yrs	HCT	Print	24 pages	CMS clients	English, Spanish, Creole	<a href="http://hctransitions.ichp.edu/resources.html">http://hctransitions.ichp.edu/resources.html</a>	ICHP, CMS	
Now That You're in High School	YSHCN - High School	HCT	Print, Web-based in 2009	30 pages	CMS clients	English, Spanish in development	<a href="http://hctransitions.ichp.edu/resources.html">http://hctransitions.ichp.edu/resources.html</a>	ICHP, CMS	Recommend dissemination through FDOE and other networks
Since You're Not a Kid Anymore	YSHCN- Middle School	HCT	Print, Web-based in 2009	30 pages	CMS clients	English, Spanish in development	<a href="http://hctransitions.ichp.edu/resources.html">http://hctransitions.ichp.edu/resources.html</a>	ICHP, CMS	Recommend dissemination through FDOE and other networks
This is Health Care Transition	YSHCN, families	HCT	Streaming video, DVD	30 minutes	CMS clients	English, Spanish	<a href="http://hctransitions.ichp.edu/resources.html">http://hctransitions.ichp.edu/resources.html</a>	ICHP, CMS	Recommend dissemination through FDOE and networks
What's Health Got to Do with Transition? (Classroom Curriculum)	ESE High School Students	HCT	Print	170 pages (40 hrs)	Classes in Hillsborough	English, Braille	<a href="http://usfpeds.hsc.usf.edu/divisions/ad-med/resources/index.htm">http://usfpeds.hsc.usf.edu/divisions/ad-med/resources/index.htm</a>	USF, FDDC, HCPS	Recommend dissemination through FDOE
Hillsborough County Information & Resource Guide	YSHCN, families	HCT	Print	40 pages	10,000 in Hillsborough	English, Spanish, Braille	<a href="http://usfpeds.hsc.usf.edu/divisions/ad-med/resources/index.htm">http://usfpeds.hsc.usf.edu/divisions/ad-med/resources/index.htm</a>	USF, FDDC, HCPS	Reprinting 3,000 copies
Talking With Your Doctor	YSHCN	HCT	Streaming video, DVD	18 minutes	Internet	English	<a href="http://video.ichp.ufl.edu/twyd.php">Http://video.ichp.ufl.edu/twyd.php</a>	ICHP, CMS	
4-1-1 on Disability Disclosure: A Workbook for Youth with Disabilities	YSHCN	Disclosure, Confidentiality	Print	100 pages	Public high schools	English	<a href="http://www.ncwd-youth.info/assets/guides/411/411_Disability_Disclosure_complete.pdf">http://www.ncwd-youth.info/assets/guides/411/411_Disability_Disclosure_complete.pdf</a>	NCWD for Youth	FDOE plans to re-disseminate in 2009
A Guide for School to Work Transition	ESE High School Students	Transition to Employment	Print	Pamphlet	Public high schools	English, Spanish, Creole	<a href="http://rehabworks.org/">http://rehabworks.org/</a>	DVR/FDOE	
A Checklist for Students with Disabilities Transitioning to Adult Life	ESE High School Students	Transition to Employment	Print	Pamphlet	Public high schools	English, Spanish, Creole	<a href="http://rehabworks.org/">http://rehabworks.org/</a>	DVR/FDOE	
Frequently Asked Questions for Youth in Foster Care Transitioning to Adulthood	Youth in Foster Care	Independent Living	Print	20 pages	DCF clients	English	<a href="http://amajn.com/c_fcf/04_reports/ILFAQ-2cFinal10_2.pdf">http://amajn.com/c_fcf/04_reports/ILFAQ-2cFinal10_2.pdf</a>	Florida's Children First	
Youth@Work: Talking Safety Florida	High School Students	Occupational Safety	Print	186 pages		English, Spanish	<a href="http://www.cdc.gov/niosh/talkingsafety/states/fl/">http://www.cdc.gov/niosh/talkingsafety/states/fl/</a>	NIOSH, CDC	
Planning Ahead Guide	Persons with DD, families	Self-determination	Print	100 pages		English	<a href="http://fddc.org/sites/default/files/file/publications/PlanningAheadFinal.pdf">http://fddc.org/sites/default/files/file/publications/PlanningAheadFinal.pdf</a>	FDDC	Estate planning, guardianship
TIP System: Transition to Independence Process	Youth-EBD, providers	Transition to Adulthood	Print, Web-based			English	<a href="http://tip.fmhi.usf.edu/">http://tip.fmhi.usf.edu/</a>	FDOE, FMHI/USF	
Sexuality Across the Lifespan (2 versions)	Caregivers for ID/DD, Educators	Sexuality	Print	114 pages		English, Spanish	<a href="http://www.albany.edu/aging/IDD/docs.htm">http://www.albany.edu/aging/IDD/docs.htm</a>	FDDC, University at Albany	
Public Education Health Courses	GE Students Grades 9-12	General Health	Print	Text books	Public high schools	English	<a href="http://data.fldoe.org/crsCode/default.cfm?level=912&amp;%20category=Health">http://data.fldoe.org/crsCode/default.cfm?level=912&amp;%20category=Health</a>	FDOE	Range of health topics
Public Education Health Courses	GE Students Grades 6-8	General Health	Print	Text books	Public middle schools	English	<a href="http://data.fldoe.org/crsCode/default.cfm?level=68&amp;%20category=Health">http://data.fldoe.org/crsCode/default.cfm?level=68&amp;%20category=Health</a>	FDOE	Range of health topics
Public Education Health Courses	ESE Students Grades 6-12	General Health	Print	Text books	Public schools	English	<a href="http://www.fldoe.org/ESE/corguide.asp">http://www.fldoe.org/ESE/corguide.asp</a>	FDOE	Focus on independent living



PROGRAMS AND MATERIALS	Target Audience	Content	Format	Length	Current Distribution	Language	Access	Source	Comments
Five Wishes (legal document)	U.S. Residents	Health care decision-making	Print	12 pages	Internet	English, Spanish	<a href="http://www.agingwithdignity.org/5wishes.html">http://www.agingwithdignity.org/5wishes.html</a>	Aging With Dignity	Valid in Florida; must pay for document
Disability History and Awareness: Florida Resource Guide	Florida Residents	Disability	Print	74 pages		English	<a href="http://www.fldoe.org/ESE/pdf/DisabilityHistoryandAwarenessWeeks.pdf">http://www.fldoe.org/ESE/pdf/DisabilityHistoryandAwarenessWeeks.pdf</a>	FDOE	Overview of Disability in Florida
Health Care Transition	CMS Care Coordinators	HCT	Web-based module		CMS staff	English	<a href="http://elearning.mchtraini ng.net/course/category.php?id=21">http://elearning.mchtraini ng.net/course/category.php?id=21</a>	ICHP, CMS, MCHB	Recommend adapting for other providers
Care of Patients with Disabilities	Medical Students	Disabilities	Didactic, experiential	30 hours	USF medical students	English	<a href="http://usfpeds.hsc.usf.edu/divisions/ad-med/resources/index.htm">http://usfpeds.hsc.usf.edu/divisions/ad-med/resources/index.htm</a>	USF, FODH	Currently being evaluated through FODH
Medical Homes: Transitions Module	Physicians	HCT	Print	90 minutes		English	<a href="http://www.medicalhomeinfo.org/training/materials.html">http://www.medicalhomeinfo.org/training/materials.html</a>	AAP	
<b>IN DEVELOPMENT IN FLORIDA</b>									
Now That You're an Adult	YSHCN post high school	HCT	Print, web-based	30 pages	CMS clients	English, Spanish	Print to be completed 12/08; web-based in '09	ICHP, CMS	Include info about college; distribute thru universities
Healthcare Access for Persons with Disabilities	Healthcare practitioners	Disabilities	Web-based module	1 hour	Internet	English	Available in 2/09 through Gulfcoast North AHEC	FLCIC/USF FODH	CME/CEU credit; focus on sensory, physical disabilities
Standing Up for Me/HCT Supplement (Classroom Curriculum)	ESE students	HCT	Print		Public Schools	English	Will be available through FDOE	ICHP, UF, FDOE	
<b>OTHER RESOURCES</b>									
Healthy & Ready to Work National Center	YSHCN, families, providers	HCT	Web site			English	<a href="http://www.hrtw.org">http://www.hrtw.org</a>	MCHB	Repository of tools, data, guidance
Transition to Adult Health Care: Training Guide in Two Parts	YSHCN, families	HCT	Print	85 pages		English	<a href="http://www.waisman.wisc.edu/hrtw/Adult_Teen.pdf">www.waisman.wisc.edu/hrtw/Adult_Teen.pdf</a>	Waisman Center, WI	
Rhode Island Adolescent Healthcare Transition Program	YSHCN, families, providers	HCT	Print	Various tools	RI	English	<a href="http://www.health.ri.gov/family/specialneeds/transition">www.health.ri.gov/family/specialneeds/transition</a>	RI Dept. of Health	
Washington Adolescent Health Transition Project	YSHCN, families, providers	HCT	Print	Various tools	WA	English	<a href="http://depts.washington.edu/healthtr">http://depts.washington.edu/healthtr</a>	University of WA	
Carolina Health and Transition Project CHAT (3 versions)	YSHCN, families, physicians	HCT	Print	50 pages each	NC	English	Distributed through Mountain Area Health Education Center	NC Dept. of Health	Pilot curriculum developed in partnership with family medicine physicians
Building Capacity Among Pediatric Residents to Promote Health Advocacy Among Persons with DD	Pediatric Practitioners	CYSHCN and DD	Print, CD	2.5 hours	University of Illinois, Chicago	English		UIC, AAP	Comprehensive curriculum that can be adapted across disciplines
Patients with Intellectual Disability (4 modules)	Healthcare practitioners	DD	DVD	2 hours each		English	In process of approval for CME / CEU credit	Special Olympics	Modules on medicine, psychiatry, dental, and vision health
It's My Life: Framework for Youth Transitioning from Foster Care to Successful Adulthood	Professionals	Independent Living	Print	97 pages		English	<a href="http://www.casey.org/Resources/Publications/ItsmyLifeFramework.htm">www.casey.org/Resources/Publications/ItsmyLifeFramework.htm</a>	Casey Family Programs	
Staying Safe at Work (Classroom Curriculum)	Youth, adults with DD	Occupational Safety	Print	4 hours		English	Available through UC Berkeley	NIOSH, CDC, UC	Brochure includes contact information; \$25 per copy
Casey Life Skills	Youth ages 8-18	Independent Living	Web-based	Various modules		English, French, Spanish	<a href="http://www.caseylifefskills.org/index.htm">www.caseylifefskills.org/index.htm</a>	Casey Family Programs	Includes youth in foster care
Mental Health in Developmental Disabilities	Clinicians, providers	Mental health, DD	Web-based	Various modules		English	<a href="http://www.cequick.com/nadd/default.asp">www.cequick.com/nadd/default.asp</a>	NADD	Dual diagnosis certification program in development
Strengthening Transition Partnerships: Building Federal TA Center Capacity	Providers	Transition	Print	16 pages		English	<a href="http://ctserc.org/transitionresourceidir.pdf">http://ctserc.org/transitionresourceidir.pdf</a>	USDOE/OSEP	National resource directory

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## Glossary

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AAP	American Academy of Pediatrics
AHCA	Agency for Health Care Administration
AHEC	Area Health Education Center
ALF	Assisted Living Facility
ALW	Assisted Living Workgroup
APD	Agency for Persons with Disabilities
CDC	Centers for Disease Control and Prevention, DHHS
CE(U)	Continuing Education (Unit)
CF	Cystic Fibrosis
CME	Continuing Medical Education
CMS	Children’s Medical Services, Florida Department of Health
CNS	Consolidated Need Standard
COM	College of Medicine, USF
CQI	Continuous Quality Improvement
CPT	Current Procedural Terminology
CYSHCN	Children and Youth with Special Health Care Needs
DCF	Department of Children and Families
DD	Developmental Disabilities
DHHS	U.S. Department of Health and Human Services
DMRT	District Medical Review Team
DOH	Florida Department of Health
DVR	Division of Vocational Rehabilitation, FDOE
EBD	Emotional or Behavioral Disorders
ERISA	Employee Retirement Income Security Act of 1974
ESE	Exceptional Student Education (special education in Florida)
FBR	Federal Benefit Rate
FDDC	Florida Developmental Disabilities Council, Inc.
FDOE	Florida Department of Education
FLCIC	Florida Center for Inclusive Communities at FMHI, USF
FLOIR	Florida Office of Insurance Regulation
FMHI	Louis de la Parte Florida Mental Health Institute, USF
FODH	Florida Office on Health and Disabilities, UF
FPL	Federal Poverty Level
FSU	Florida State University
GE	General Education (standard curriculum)
HCBS	Home and Community-Based Services
HCDA	Home Care for Disabled Adults



HCPS	Hillsborough County Public Schools
HCT	Health Care Transition
HRTW	Healthy & Ready to Work National Resource Center
ICHP	Institute for Child Health Policy at UF
ICP	Institutional Care Program
IEP	Individual Education Plan
JaxHATS	Jacksonville Health and Transition Services
LIS	Low Income Subsidy
LTC	Long Term Care
MCHB	Maternal and Child Health Bureau
MEDS-AD	Medicaid Program for certain Aged or Disabled Individuals
MMMIA	Minimum Monthly Maintenance Income Allowance (amount the “well spouse” is entitled to receive)
NADD	National Association for the Dually Diagnosed
NCWD	National Collaborative on Workforce and Disability for Youth
NIOSH	National Institute for Occupational Safety and Health, CDC
OSEP	Office of Special Education Programs, USDOE
OSS	Optional State Supplementation ( cash payments)
PACE	Program of All Inclusive Care for the Elderly
PCP	Primary Care Provider
PEPW	Presumptive Eligibility for Pregnant Women
PNA	Personal Need Allowance
PW	Pregnant Women
PWD	Persons with Disabilities
QMB	Qualified Medicare Beneficiary
QWDI	Qualified Disabled and Working Individual
SAM	Society of Adolescent Medicine
SCD	Sickle Cell Disease
SGA	Substantial Gainful Activity
SLMB	Specified Low-Income Medicare Beneficiary
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Social Security Income
TA	Technical Assistance
TWIIA	Ticket to Work and Work Incentives Improvement Act
UF	University of Florida at Gainesville
USDOE	U.S. Department of Education
USF	University of South Florida
VR	Vocational Rehabilitation
YSHCN	Youth with Special Health Care Needs

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## Appendix 1: Family Medicaid Income Eligibility Guidelines

Family-Related Medicaid Income & Asset Limit Chart									
Family Size	MEDS for Children & Pregnant Women (PW) Income Limits				Family Medicaid (1931) & Medically Needy		Asset Limits		
	100% Ages 6-18	133% Ages 1-5	185% PEPW PW	200% Ages <1	CNS	Income Level	MEDS	Family Medicaid (1931)	Medically Needy
1	867	1,153	1,604	1,734	867	180	NONE	2,000	5,000
2	1,167	1,552	2,159	2,334	1,167	241	NONE	2,000	6,000
3	1,467	1,951	2,714	2,934	1,467	303	NONE	2,000	6,000
4	1,767	2,350	3,269	3,534	1,767	364	NONE	2,000	6,500
5	2,067	2,749	3,824	4,134	2,067	426	NONE	2,000	7,000
6	2,367	3,148	4,379	4,734	2,367	487	NONE	2,000	7,500
7	2,667	3,547	4,934	5,334	2,667	549	NONE	2,000	8,000
8	2,967	3,946	5,489	5,934	2,967	610	NONE	2,000	8,500
9	3,267	4,345	6,044	6,534	3,267	671	NONE	2,000	9,000
10	3,567	4,744	6,599	7,134	3,567	733	NONE	2,000	9,500
11	3,867	5,143	7,154	7,734	3,867	795	NONE	2,000	10,000
12	4,167	5,542	7,709	8,334	4,167	857	NONE	2,000	10,500
13	4,467	5,941	8,264	8,934	4,467	919	NONE	2,000	11,000
14	4,767	6,340	8,819	9,534	4,767	981	NONE	2,000	11,500
15	5,067	6,739	9,374	10,134	5,067	1,043	NONE	2,000	12,000
16	5,367	7,138	9,929	10,734	5,367	1,105	NONE	2,000	12,500
17	5,667	7,537	10,484	11,334	5,667	1,167	NONE	2,000	13,000
18	5,967	7,936	11,039	11,934	5,967	1,229	NONE	2,000	13,500
19	6,267	8,335	11,594	12,534	6,267	1,291	NONE	2,000	14,000
20	6,567	8,734	12,149	13,134	6,567	1,353	NONE	2,000	14,500
21	6,867	9,133	12,704	13,734	6,867	1,415	NONE	2,000	15,000
22	7,167	9,532	13,259	14,334	7,167	1,477	NONE	2,000	15,500
23	7,467	9,931	13,814	14,934	7,467	1,539	NONE	2,000	16,000
24	7,767	10,330	14,369	15,534	7,767	1,601	NONE	2,000	16,500
Additional Person	+300	+399	+555	+600	+300	+62	NONE	SAME	+500
Effective Date	March 2008	March 2008	March 2008	March 2008	March 2008	April 1992			April 1992

Source: Florida Department of Children and Families, [www.dcf.state.fl.us/ess/FamilyMedChart.pdf](http://www.dcf.state.fl.us/ess/FamilyMedChart.pdf)



## Appendix 2: SSI Income and Asset Guidelines

SSI-Related Programs -- Financial Eligibility Standards: July 2008						
Program and Type of Coverage	INCOME LIMIT		ASSET LIMIT		Diversion/ Maintenance Need Standard	
	Individual	Couple	Individual	Couple		
<b>PROGRAMS MANAGED BY SOCIAL SECURITY</b>					Child Allocation: \$319 (difference between Couple and Single FBR) SGA for DMRT: \$940 Student Earned Income Disregard: \$1550 per month; \$6240 annual cap <b>ICP ICP/Hospice, ALW, LTC, CF and PACE</b> Community Spouse Allowances: Maximum Income Allowance: \$2610 MMMIA: \$1750 Excess Shelter: \$525 Family Members Allowance: (MMMIA minus income) divided by 3 Other Dependents: Use CNS chart <b>Maximum Resource Allowance:</b> Community Spouse: \$104,400 <b>Community Hospice Spouse Allowance</b> Spouse only: use FBR W/ Dependents (or dependents only) use CNS	
<b>PROGRAMS FOR PEOPLE 65+ OR DISABLED (Community Medicaid Programs)</b>						
*MEDS-AD Full Community Medicaid (88% FPL)	\$763	\$1027	\$5000	\$6000		
*Medically Needy No Income Limit. Full Community Medicaid when Share of Cost is met.	Subtract \$180 from gross income	Subtract \$241 from gross income				
<b>PROGRAMS FOR PEOPLE with MEDICARE (Medicare Part B Premium \$96.40; Part A free for most)</b>						
*OMB Pays Medicare premium, coinsurance & deductibles only (100% FPL)	\$867	\$1167	\$5000	\$6000		
*SLMB Pays Medicare premium only (120% FPL)	\$1040	\$1400				
*Q11 Pays Medicare premium only (135% FPL)	\$1170	\$1575				
*WD (QDWI) Working Disabled Program; only Pays Medicare premium; Must have lost SSDI due to employment (200% FPL)	\$1734	\$2334				
<b>PROGRAMS BASED ON INSTITUTIONAL POLICY- Possible Patient Responsibility and Income Trust</b>					Individual PNA+	Couple PNA+
Institutional Care (ICP) Pays Nursing Home room, board & care (and Pays Medicare premium, coinsurance & deductibles)	\$1911	\$3822	\$2000	\$3000	\$35	\$70
Hospice Pays for Hospice services related terminal illness (and Pays Medicare premium, coinsurance & deductibles)	\$1911	\$3822	\$5000 if MEDS-AD eligible	\$6000 if MEDS-AD eligible	FPL-\$867 (ICP= \$35)	FPL-\$1167 (ICP = \$70)
HCBS Home and Community Based Services (Waivers) (and Pays Medicare premium, coinsurance & deductibles)	\$1911	\$3822	\$2000	\$3000	ALW only: \$715.40 PACE/LTC in ALF :R&B + \$174 PACE/LTC at home: \$1911 PACE/LTC in NH: \$35 Cystic Fibrosis: \$1911	ALW only: \$1430.80 PACE/LTC in ALF:R&B + \$348 PACE/LTC at home: \$3822 PACE/LTC in NH: \$70 Cystic Fibrosis: \$3822
<b>STATE FUNDED PROGRAMS</b>					Individual PNA+	Couple PNA+
OSS Redesign (Optional State Supplementation) Assists with paying room & board at Adult Living Facilities (ALF) State rate = \$661.40 single / \$1322.80 couple Maximum payment = \$78.40 single / \$156.80 couple	\$715.40	\$1430.80	\$2000	\$3000	\$54	\$108
OSS Traditional (Optional State Supplementation) Assists with paying room & board at Adult Living Facilities (ALF) State rate = \$822 single / \$1644 couple Maximum payment = \$239 single / \$478 couple	\$822	\$1644				
HCDA (Home Care For Disabled Adults) Pays small stipend to caregivers of disabled	\$1911	\$3822			+ PNA = Personal Need Allowance	

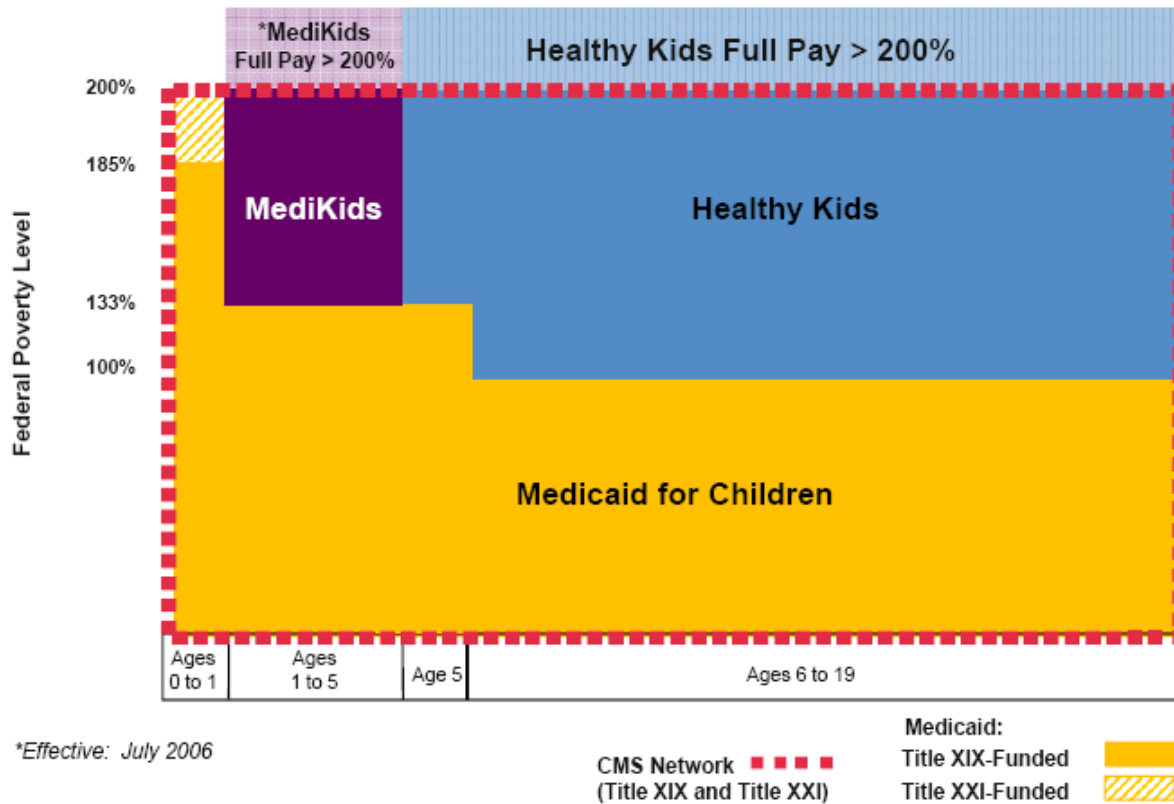
\* A \$20 General Income Disregard is granted in these programs. \$20 will be subtracted from the total of all income not based on need before comparing the income to the income limit. \* In addition to the \$20 General Income Disregard, \$65 is subtracted from the total of all earned income, and 1/2 of the remainder is subtracted before comparing the income to the income limit.

+ An additional \$1500 in assets is allowed for each individual for burial purposes.

Source: Florida Department of Children and Families, Bureau of Economic Self-Sufficiency Services (2008)

Appendix 3: KidCare Income Eligibility Guidelines

# Florida KidCare Eligibility



Source: Florida KidCare, [www.floridakidcare.org/resources.html](http://www.floridakidcare.org/resources.html)