

2015 Florida Title V Needs Assessment Transition Resources

*Documents can be accessed from www.FloridaHATS.org

Strategic Plans/Advisory Recommendations

Statewide Task Force:

1. Florida Health Care Transition Services Task Force for Youth and Young Adults with Disabilities, 2009 Report and Recommendations, Implementation of Bill 988: [Ensuring Successful Transition from Pediatric to Adult Health Care](#)
** This report should be referenced in the CMSN Transition Brief, as it is the blueprint for the state HCT plan and FloridaHATS activities*
2. [Florida Strategic Plan for Health Care Transition](#) (one-page visual of strategies from 2009 report)
3. [Strategic Planning Guide for Health Care Transition Coalitions](#). This guide outlines the planning process used by coalitions (see below) as well as numerous data reports on YSHCN in Florida.

Regional Coalitions:

4. [HillsboroughHATS Action Plan](#) and [web page](#)
5. [Northeast FloridaHATS Action Plan](#) and [web page](#)
6. [PanhandleHATS Action Plan](#) and [web page](#)
7. [South FloridaHATS Action Plan](#) and [web page](#)

Medical Advisory Work Group ([web page](#)):

8. [5-23-14 Meeting Minutes](#)
9. [5-30-13 Meeting Minutes](#)
10. [5-19-12 Meeting Minutes](#)
11. [Florida Children's Hospitals Survey Results](#)

CMS Care Coordinators:

12. [Educational Material Needs Among CMS Staff](#) (survey results, 2013)
13. [HCT Training Needs Among CMS Staff](#) (survey results, 2013)

CMSN Budget Issue Proposals

**Summaries from last 2 years*

14. **2013-2014 BIP** (submitted by Mary Beth Vickers)

ISSUE NARRATIVE (NEED): THIS PROPOSAL SUPPORTS A SUCCESSFUL TRANSITION TO ADULT HEALTH CARE SERVICES FOR ADOLESCENTS AND YOUNG ADULTS WITH SERIOUS SPECIAL HEALTH CARE NEEDS AS THEY AGE OUT OF PEDIATRIC CARE. HEALTH CARE TRANSITION CONTINUES TO BE PROBLEMATIC FOR CMS ENROLLEES, THEIR FAMILIES, HEALTH CARE PROVIDERS, AND FLORIDA COMMUNITIES DUE TO LOSS OF CARE COORDINATION SERVICES, THE CHALLENGES OF FINDING AN ADULT HEALTH CARE PROVIDER, AND LOSS OF HEALTH CARE COVERAGE.

SUMMARY OF BUDGET REQUEST (SOLUTION): THERE IS A STATE EXPENDITURE IMPACT. THE DEPARTMENT OF HEALTH (DOH), CHILDREN'S MEDICAL SERVICES (CMS) PROPOSES TO USE FUNDS TO EXPAND A CURRENT CONTRACT WITH THE FLORIDA HEALTH AND TRANSITION SERVICES PROGRAM (FLORIDAHATS), AT THE UNIVERSITY OF SOUTH FLORIDA. FLORIDAHATS WILL IMPLEMENT THE PROPOSED ACTIVITIES IN A MINIMUM OF FIVE COUNTIES (HILLSBOROUGH, DUVAL, NASSAU, BAY, AND ESCAMBIA COUNTIES) THAT HAVE FORMED COMMUNITY COALITIONS THAT SUPPORT HEALTH CARE TRANSITION AND CURRENTLY COLLABORATE UNDER THE LEADERSHIP AND OVERSIGHT OF FLORIDAHATS. THE PROPOSED ACTIVITIES WILL SUPPORT CMS' EFFORTS TO DEVELOP AN EXPLICIT PROCESS WITH MEASURABLE OBJECTIVES THAT LOCAL CARE COORDINATORS CAN USE TO ENSURE THAT ADOLESCENTS AND YOUNG ADULTS WITH SERIOUS SPECIAL HEALTH CARE NEEDS SEAMLESSLY TRANSITION TO ADULT HEALTH CARE SETTINGS. FUNDS WILL BE DIRECTED TOWARD FLORIDAHATS TO EXPAND CURRENT SERVICES, AS DESCRIBED BELOW.

THERE ARE AN ESTIMATED 450,000 ADOLESCENTS AND YOUNG ADULTS IN FLORIDA BETWEEN THE AGES OF 12 THROUGH 26 YEARS WHO HAVE DISABILITIES OR OTHER SPECIAL HEALTH CARE NEEDS. DURING EVERY PHASE OF THEIR LIFESPAN, THESE INDIVIDUALS USE HEALTH CARE SERVICES AT MUCH HIGHER RATES THAN THE GENERAL POPULATION. EACH YEAR, ALMOST 50,000 YOUNG FLORIDIANS WITH CHILDHOOD CHRONIC AND SERIOUS CONDITIONS BECOME ADULTS. NATIONAL DATA SHOWS THAT OVER 85% OF THESE ADOLESCENTS AND YOUNG ADULTS WHO GROW UP WITH CHRONIC AND SERIOUS HEALTH CONDITIONS NOW HAVE LIFE SPANS THAT EQUAL THAT OF THEIR HEALTHY PEERS DUE TO ADVANCES IN MEDICAL CARE. WHILE MEDICAL CARE HAS ALLOWED THESE CHILDREN TO SURVIVE THE PEDIATRIC YEARS, OUR CURRENT HEALTH CARE SYSTEM DOES NOT ADEQUATELY SUPPORT THEM INTO ADULTHOOD. OFTEN THESE ADOLESCENTS AND YOUNG ADULTS LOSE SOME OR ALL OF THEIR HEALTH CARE SERVICES AND SUPPORTS WHEN THEY TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE. AS A RESULT, THEIR CARE IS INTERRUPTED AND THEIR HEALTH MAY BE AFFECTED. THESE INTERRUPTIONS OR GAPS IN CARE CAN OCCUR DUE TO MANY CHALLENGES. THESE CHALLENGES INCLUDE AN INABILITY TO FIND AN ADULT PRIMARY CARE PHYSICIAN OR SPECIALIST WHO IS KNOWLEDGEABLE ABOUT THEIR DISEASE, SINCE PREVIOUSLY, THESE CHILDREN OFTEN DID NOT REACH ADULTHOOD; LOSS OF CARE COORDINATION TO HELP THEM NAVIGATE A COMPLEX HEALTH CARE SYSTEM; AND LOSS OF HEALTH CARE COVERAGE, SINCE THEY MAY NO LONGER BE ELIGIBLE FOR MEDICAID OR OTHER SUBSIDIZED COVERAGE AND NOT BE ABLE TO PURCHASE PRIVATE COVERAGE BECAUSE OF A PRE-EXISTING CONDITION OR COST. THESE CHALLENGES PUT THESE ADOLESCENTS AND YOUNG ADULTS AT-RISK FOR MULTIPLE ACUTE HEALTH CRISES OR DEATH DUE TO THEIR PRIMARY CONDITION, DEVELOPMENT OF SECONDARY DISABLING CONDITIONS, AS WELL AS INCREASED COSTS TO THE INDIVIDUAL, HEALTH CARE SYSTEMS, AND THEIR COMMUNITIES. MOREOVER, INTERRUPTIONS IN MEDICALLY NECESSARY HEALTH CARE SERVICES AND THE OCCURRENCE OF HEALTH CRISES CAN ALSO INTERRUPT THEIR EDUCATION, CONTRIBUTE TO SCHOOL DROPOUT, AND REDUCE THEIR POTENTIAL PRODUCTIVITY AS ADULTS.

THE DEPARTMENT OF HEALTH, CHILDREN'S MEDICAL SERVICES IS PROPOSING TO DEVELOP AN EXPLICIT PROCESS WITH MEASURABLE OBJECTIVES THAT LOCAL CARE COORDINATORS CAN USE TO ENSURE THAT ADOLESCENTS AND YOUNG ADULTS WITH SERIOUS SPECIAL HEALTH CARE NEEDS SEAMLESSLY TRANSITION TO ADULT HEALTH CARE SETTINGS. FUNDS WILL BE DIRECTED TOWARD FLORIDAHATS TO EXPAND CURRENT SERVICES INCLUDING:

- a) **CONDUCT A TELEPHONE SURVEY OF A REPRESENTATIVE SAMPLE OF NO LESS THAN 600 CMS ENROLLEES, AGES 14 THROUGH 20 YEARS, AND THEIR FAMILIES, IN A MINIMUM OF FIVE COUNTIES (HILLSBOROUGH, DUVAL, NASSAU, BAY, AND ESCAMBIA COUNTIES) THAT HAVE A COMMUNITY HEALTH AND TRANSITION SERVICES (HATS) COALITION DEVELOPED WITH THE LEADERSHIP AND OVERSIGHT OF FLORIDAHATS (HILLSBOROUGHHATS, JAXHATS, AND PANHANDLEHATS) . USING A VALIDATED INSTRUMENT AND STANDARD SURVEY AND QUALITATIVE METHODS, THIS SURVEY WILL ASSESS THE OPTIMAL AGES FOR PROVIDING TRANSITION INFORMATION AND SUPPORT BASED ON THE COGNITIVE FUNCTIONING OF THE ADOLESCENTS AND YOUNG ADULTS, FAMILY AND SOCIAL SUPPORTS, AND SEVERITY OF ILLNESS. (\$125,000.00)**
- b) **DEVELOP AND PILOT TEST STANDARDIZED HEALTH CARE TRANSITION INTERVENTIONS WITH CMS ENROLLEES AND THEIR FAMILIES. THESE HEALTH CARE TRANSITION INTERVENTIONS WILL HELP SELECTED ENROLLEES LEARN HOW TO BETTER NAVIGATE THE HEALTH CARE SYSTEM AND ADVOCATE FOR THEIR NEEDS IN ORDER TO ACHIEVE A SUCCESSFUL HEALTH CARE TRANSITION. FLORIDAHATS WILL ENSURE THAT CMS CARE COORDINATORS FULLY UNDERSTAND AND USE BEST PRACTICES FOR HELPING ADOLESCENTS AND YOUNG ADULTS TRANSITION TO AN ADULT HEALTH CARE SYSTEM. (\$100,000.00)**
- c) **BASED ON THE FINDINGS OF THE SURVEY AND THE RESULTS OF THEIR EFFORTS IN WORKING WITH CARE COORDINATORS, FLORIDAHATS WILL DEVELOP RECOMMENDATIONS AND IMPLEMENTATION STRATEGIES TO IMPROVE CMS HEALTH CARE TRANSITION OUTCOMES STATEWIDE. (\$25,000.00)**

MEASURABLE OBJECTIVES FOR THIS PROGRAM WILL INCLUDE:

- **IDENTIFICATION OF TRANSITION READINESS FOR NO LESS THAN 600 CMS ENROLLEES, AGES 14 THROUGH 20 YEARS, IN A MINIMUM OF FIVE COUNTIES**
- **DEVELOPMENT OF STANDARDIZED, EVIDENCE-BASED BEST PRACTICES THAT SUPPORT CMS CARE COORDINATOR EFFORTS TO ENSURE THAT HEALTH CARE TRANSITION SERVICES FOR ADOLESCENTS AND YOUNG ADULTS WHO HAVE SERIOUS SPECIAL HEALTH CARE NEEDS RESULT IN COST-EFFECTIVE AND SUCCESSFUL HEALTH CARE TRANSITION OUTCOMES**
- **IDENTIFICATION OF A HEALTH CARE TRANSITION PROCESSES, WITH PARTICIPATION FROM LOCAL HEALTH CARE PROVIDERS AND COMMUNITY STAKEHOLDERS, THAT STRENGTHENS COMMUNITY-BASED SYSTEMS OF CARE FOR HEALTH CARE TRANSITION**

15. **2012-2013 BIP** (submitted by Phyllis Sloyer)

ISSUE NARRATIVE (NEED): THIS PROPOSAL SUPPORTS THE SUCCESSFUL TRANSITION OF ADOLESCENTS AND YOUNG ADULTS WITH SPECIAL HEALTH CARE NEEDS AS THEY AGE OUT OF PEDIATRIC CARE AND INTO ADULT HEALTH SERVICES. IT PROMOTES STABILITY FOR THEIR HEALTH AND ENSURES THEY CONTINUE TO RECEIVE COST EFFECTIVE AND ACCOUNTABLE MEDICAL CARE AFTER THE AGE OF 21. THE STATE RECEIVES A RETURN ON ITS INVESTMENT AS THESE YOUNG MEN AND WOMEN BECOME PRODUCTIVE ADULTS WITHIN THEIR COMMUNITIES. IT CREATES PART IV OF FLORIDA STATUTE 391 IMPLEMENTING A PROGRAM OF SERVICES RELATED TO THE TRANSITIONING OF ADOLESCENTS AND YOUNG ADULTS, WHO HAVE SPECIAL HEALTH CARE NEEDS, FROM PEDIATRIC CARE TO ADULT SYSTEMS OF HEALTH CARE.

SUMMARY OF BUDGET REQUEST (SOLUTION): THERE IS NO STATE EXPENDITURE IMPACT. EXISTING FTES ARE ALREADY IN PLACE. DOH/CMS PROPOSES TO USE EXISTING FUNDS TO ESTABLISH THE OVERSIGHT OF THE FLORIDA HEALTH AND TRANSITION SERVICES PROGRAM (FLORIDAHATS) WITHIN CMS AS WELL AS ESTABLISH COMMUNITY-BASED COALITIONS WITH CMS AREA OFFICES AND OTHER INTERESTED STAKEHOLDERS TO DEVELOP UP TO EIGHT LOCAL TRANSITION SERVICE PLANNING PROGRAMS.

THERE ARE AN ESTIMATED 450,000 ADOLESCENTS AND YOUNG ADULTS IN FLORIDA BETWEEN THE AGES OF 12 THROUGH 26 YEARS WHO HAVE DISABILITIES OR OTHER SPECIAL HEALTH CARE NEEDS AND USE HEALTH CARE SERVICES ACROSS THEIR LIFESPAN AT MUCH HIGHER RATES THAN THE GENERAL POPULATION. EACH YEAR, ALMOST 50,000 YOUNG FLORIDIANS WITH CHILDHOOD ONSET CONDITIONS BECOME ADULTS. NATIONAL DATA SHOWS THAT OVER 85% OF THESE ADOLESCENTS AND YOUNG ADULTS WHO GROW UP WITH CHRONIC HEALTH CONDITIONS ARE NOW EXPERIENCING LIFE SPANS THAT EQUAL THAT OF THEIR HEALTHY PEERS. ADVANCES IN MEDICAL CARE HAVE ALLOWED THIS POPULATION TO SURVIVE, BUT OUR CURRENT HEALTH CARE SYSTEM DOES NOT ADEQUATELY SUPPORT THEM INTO ADULthood. OFTEN THIS POPULATION EXPERIENCES AN INTERRUPTION IN THE PROVISION OF HEALTH SERVICES AS THEY TRANSITION FROM PEDIATRIC TO ADULT HEALTH CARE. CHALLENGES THEY FACE DURING THIS INTERRUPTION OF SERVICES INCLUDE INABILITY TO FIND A PRIMARY CARE PHYSICIAN OR SPECIALIST FOR ADULTS WHO IS KNOWLEDGEABLE ABOUT THEIR DIAGNOSIS, LACK OF ASSISTANCE IN SYSTEMS NAVIGATION AND CARE COORDINATION, AND LOSS OF HEALTH CARE COVERAGE. THESE CHALLENGES PUT THEM AT RISK FOR ACUTE EPISODES OR DEATH DUE TO THEIR PRIMARY CONDITION, DEVELOPMENT OF SECONDARY DISABLING CONDITIONS, AND INCREASED COSTS TO THE INDIVIDUAL, HEALTH CARE SYSTEMS, AND THEIR COMMUNITIES. MOREOVER, INTERRUPTION IN APPROPRIATE HEALTH CARE CAN LEAD TO INTERRUPTION IN THEIR EDUCATION AND EVENTUAL SCHOOL DROP OUT, REDUCING THEIR POTENTIAL PRODUCTIVITY AS ADULTS.

THE DEPARTMENT OF HEALTH, CHILDREN'S MEDICAL SERVICES (CMS), PROPOSES DEVELOPING AT LEAST EIGHT COMMUNITY-BASED COALITIONS THROUGHOUT FLORIDA THAT ARE MADE UP OF LOCAL STAKEHOLDERS WHO WILL COLLABORATE TO DEVELOP SYSTEMS OF COMPREHENSIVE, COORDINATED, AND CULTURALLY SENSITIVE HEALTH CARE FOR ADOLESCENTS AND YOUNG ADULTS WITH SPECIAL HEALTH CARE NEEDS WITHIN THOSE COMMUNITIES. THESE SYSTEMS OF CARE WILL RECOGNIZE DIFFERENT MODELS THAT ACCOMMODATE THE GEOGRAPHIC AND CULTURAL DIVERSITY IN THE STATE AND ARE ADAPTED TO THE LOCAL NEEDS OF COMMUNITIES AND LOCAL HEALTH SERVICES DELIVERY SYSTEMS. THE MODELS SHOULD PROMOTE THE INTEGRATION OF HEALTH CARE TRANSITION SERVICES WITH OTHER TRANSITION PROGRAMS SUCH AS EDUCATION, VOCATIONAL REHABILITATION, AND INDEPENDENT LIVING FOR ADOLESCENTS AND YOUNG ADULTS WITH SPECIAL HEALTH CARE NEEDS WHO ARE 12 THROUGH 26 YEARS OF AGE.

THE DEPARTMENT OF HEALTH WILL WORK IN PARTNERSHIP WITH THE AGENCY FOR HEALTH CARE ADMINISTRATION, THE OFFICE OF INSURANCE REGULATION, OTHER STATE AGENCIES AND ORGANIZATIONS, COMMUNITY-BASED PEDIATRIC AND ADULT HEALTH CARE PROVIDERS, MAJOR HEALTH CARE ORGANIZATIONS, ACADEMIC MEDICAL SETTINGS, AND OTHER INTERESTED STAKEHOLDERS TO PROMOTE ACCOUNTABILITY FOR THE HEALTH CARE OF ADOLESCENTS AND YOUNG ADULTS AS THEY TRANSITION INTO ADULT HEALTH SERVICES. THIS PROPOSAL WILL FOCUS ON THE CONSISTENT AND PRODUCTIVE PARTICIPATION BY THESE ADOLESCENTS AND YOUNG ADULTS IN POST-SECONDARY EDUCATION, EMPLOYMENT, AND COMMUNITY LIFE IN FLORIDA. ANTICIPATED IMPACT OF THIS PROPOSAL INCLUDES POTENTIAL FOR MORE PRODUCTIVE AND HEALTHIER CITIZENS WHO ARE SUCCESSFUL AS THE FUTURE WORK FORCE OF FLORIDA AS WELL AS A MEASURABLE COST SAVINGS FROM DECREASED EMERGENCY DEPARTMENT VISITS AND HOSPITALIZATIONS. THE PROPOSAL PROVIDES A RETURN ON INVESTMENT MADE BY THE STATE BY RECOGNIZING THE POTENTIAL FUTURE ECONOMIC AND SOCIAL CONTRIBUTIONS AND VALUE OF THIS POPULATION AS THEY BECOME ADULTS.

CMS CURRENTLY PROVIDES CARE COORDINATION FOR CHILDREN, ADOLESCENTS, AND YOUNG ADULTS WITH SPECIAL HEALTH CARE NEEDS FROM BIRTH TO 21 YEARS OF AGE. IN ORDER TO CONTINUE THE PROVISION OF CARE COORDINATION THROUGH 26 YEARS OF AGE, CMS PROPOSES A POLICY CHANGE. THE APPROVAL OF PART IV OF CHAPTER 391, FLORIDA STATUTES, WILL PROVIDE THIS STRATEGIC AND COMPREHENSIVE APPROACH TO THE DEVELOPMENT AND IMPLEMENTATION OF EFFECTIVE HEALTH CARE TRANSITION PROGRAMS FOR ADOLESCENTS AND YOUNG ADULTS WITH SPECIAL HEALTH CARE NEEDS.

EXISTING FTEs ARE IN PLACE TO IMPLEMENT THIS PROPOSED LEGISLATION. THERE ARE NO SERVICE PROGRAM COSTS, LOCAL GOVERNMENT REVENUE OR EXPENDITURES, OR LOCAL REVENUE IMPACTS. CMS WILL USE EXISTING FUNDS TO ESTABLISH THE OVERSIGHT OF THIS PROGRAM. FLORIDA HEALTH AND TRANSITION SERVICES PROGRAM (FLORIDAHATS) IS AN EXISTING PROGRAM WITHIN CMS WHICH WILL WORK UNDER THE DIRECTION OF CMS TO FULFILL THE REQUIREMENTS OF THE PROPOSED LEGISLATION.

MEASURABLE OUTCOMES FOR THIS PROGRAM WILL INCLUDE:

- **DEVELOPMENT OF A PLANNING AND IMPLEMENTATION PROCESS AND THE NECESSARY GUIDES FOR USE BY COMMUNITY PROVIDERS AND ORGANIZATIONS IN BUILDING COORDINATED SYSTEMS OF SERVICES FOR THE TARGET POPULATION**
- **DEVELOPMENT AND DISSEMINATION OF RESOURCE GUIDES THAT OUTLINE THE VARIOUS PUBLIC AND PRIVATE HEALTH CARE FINANCING OPTIONS, INCLUDING COMMERCIAL INSURANCE, AND THEIR RESPECTIVE HEALTH CARE BENEFITS**
- **COORDINATION WITH TRAINING INSTITUTIONS, INCLUDING MEDICAL CENTERS, TO COMPILE AND MAKE AVAILABLE EXISTING TRAINING FOR HEALTH CARE PROVIDERS ON THE PRINCIPLES, OBJECTIVES, AND METHODS OF SUCCESSFULLY LINKING THE TARGET POPULATION TO ADULT HEALTH CARE PROVIDERS**
- **MAINTAIN AND UPDATE WEB-BASED MATERIALS RELATED TO HEALTH CARE TRANSITION THAT CAN BE USED BY THE TARGET POPULATION, FAMILIES, PROVIDERS, AND OTHERS INVOLVED IN HEALTH CARE TRANSITION**
- **COLLECT AND DISSEMINATE INFORMATION CONCERNING EVIDENCE-BASED AND BEST PRACTICES IN SPECIFIC CLINICAL AREAS FOR HEALTH CARE TRANSITION SERVICES FOR ADOLESCENTS AND YOUNG ADULTS WHO HAVE CHRONIC SPECIAL HEALTH CARE NEEDS OR DISABILITIES**

- **PROVIDE TECHNICAL ASSISTANCE TO COMMUNITIES, PROVIDERS, AND ORGANIZATIONS INVOLVED IN THE DEVELOPMENT AND IMPLEMENTATION OF SYSTEMS OF SERVICES FOR THE TARGET POPULATION**
- **DEVELOP AND DISSEMINATE QUALITY IMPROVEMENT AND EVALUATION COMPONENTS FOR HEALTH CARE TRANSITION PROGRAMS, INCLUDING A COMMON OR COMPARABLE SET OF PERFORMANCE MEASURES FOR ALL ENTITIES THAT PROVIDE HEALTH CARE TRANSITION SERVICES FOR THE TARGET POPULATION**
- **COLLABORATE WITH A NETWORK OF SPECIALISTS IN THE FIELDS OF ADOLESCENT MEDICINE AND HEALTH CARE TRANSITION TO PROVIDE TECHNICAL ASSISTANCE AND RECOMMENDATIONS REGARDING BEST PRACTICES AND HEALTH CARE TRANSITION POLICY GUIDANCE**