

**A Demonstration Model for  
School-Based Health Care Transition Education**

**Final Report**

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## Executive Summary

*A Demonstration Model for School-Based Health Care Transition Education* was designed to improve functional outcomes in adulthood for the approximately 11,500 adolescents and young adults with disabilities or other special needs in Hillsborough County, FL (Raffaele Mendez & Hess, 2003). In this project, adolescents and young adults with disabilities or special needs were defined as individuals from approximately 14 through 21 years who have a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required of adolescents and young adults generally.

Funded by the Florida Developmental Disabilities Council (FDDC), the project was intended to (a) prepare teens and young adults with disabilities or special health care needs to become successful adult health care consumers, and (b) educate families, caregivers, educators, and service providers about the steps that they can take to help youth successfully transition from pediatric to adult health care. An important consideration for FDDC was the potential to replicate the *Demonstration Model* in other communities throughout Florida.

Three primary intervention strategies were utilized in the *Demonstration Model*:

- Disseminate a health care transition information and resource guide to community-based providers and families of young people with disabilities, particularly families of high school students who receive special education services through the public school system,
- Provide classroom instruction, counseling, transition planning support, and printed materials on health care transition to high school special education students at selected school sites, and
- Provide district-wide training to educators on how to support students and families in the health care transition process, as well as intensive curriculum-specific training for special education teachers and support staff at school demonstration sites.

Evaluation of the *Demonstration Model* included a combination of quantitative and qualitative research techniques. Data were collected from students, high school staff, and families who participated in the project through performance tests, surveys, focus groups, and observation. Particular attention was given to assessing stakeholder experiences and satisfaction with the pilot in order to refine and improve specific program elements. Results from each program component are described below.

### Information and Resource Guide

The information and resource guide, which was printed in English, Spanish, Braille, and large print, was organized as a 10-step process towards successful health care transition and included several guidelines, checklists, and sample forms. It provided information about the differences between pediatric and adult health care, ways to pay for health care, finding adult providers, health-related skills that independent adults need to be able to perform, and ways to identify and access adult health care services. The accompanying resource section provided an extensive listing of national, state, and local agencies, facilities, service providers, and advocacy organizations that serve adults with disabilities or chronic health conditions.

A total of 10,000 copies were printed in English, and 1,000 were printed in Spanish. The guides were mailed to the parents/caregivers of all high school special education students in the Hillsborough County school district, or approximately 6,700 families. Additional distribution channels were used to reach community service providers, professional associations, health care facilities, advocacy centers, and family organizations. The guide can also be downloaded online at <http://usfpeds.hsc.usf.edu/adolescent>.

Extensive material pretesting was conducted separately during the planning phase for the project, so evaluation of the guide was limited to data collection from families of students who participated in the pilot curriculum. The majority of the 19 parents/guardians who responded to a family survey found the guide useful and easy to read. On a scale of 1 (very positive) to 5 (very negative), average ratings for usefulness and ease of understanding were 1.6 and 1.7, respectively. This compares to average ratings from 50 families and providers in the earlier pretest of 1.2 for usefulness and 1.8 for ease of understanding. Over 90% of family survey respondents were either “very satisfied” or “somewhat satisfied” with the guide.

### Student Curriculum

While the information and resource guide served as an educational tool for parents and providers, classroom instruction was intended to teach young people important health-related skills that they may not learn at home or in the community. Approximately 40 hours of instruction was packaged in an 8-unit module, covering topics such as the importance of self-determination and self-advocacy, rights and responsibilities at age 18, managing medication needs, communicating with health care providers, finding and using adult physicians, participating in health care decision-making, completing medical forms, health insurance, sexual health, staying safe, and constructing a personal Health Journal.

The pilot curriculum was implemented in 13 special education classes in five geographically and demographically diverse public high schools (grades 9-12). Of the 137 students who participated in the pilot, most received Specific Learning Disabilities (SLD), Educable Mentally Handicapped (EMH), or Physically Impaired (PI) services, and expected to earn a Special Diploma (rather than General Diploma) upon graduation. The module was implemented over 8 weeks as part of a Science, Health, or Life Management course.

A pre-test/post-test research design was used to assess change in student knowledge and skills resulting from classroom instruction. A written test was self-administered by students in class prior to start of the curriculum and following its completion.

Although the study design limits the degree to which a true causal effect can be established between classroom instruction and student performance, results from a comparative analysis show a statistically significant increase in student knowledge after participation in the curriculum. Among 82 SLD, EMH, and PI students who completed a 29-item achievement test both before and after the pilot, mean scores increased from 15.2 on the pre-test (56% correct) to 18.1 on the post-test (62% correct). There were also consistent gains in a broad range of skills and practices after program implementation. Students reported that they engaged more frequently in health-related activities that independent adults need to be able to perform, such as participating in health care decision-making, taking medication independently, keeping an emergency contact list, and understanding their health insurance coverage. On a scale of 1 (Never) to 4 (Always), the average score across 13 activities increased from 2.3 to 2.4.

While the degree of change might not appear meaningful in the real world, it is important to recognize that the assessment tool was limited in its ability to fully measure student performance. The students in this sample represent a wide range of abilities, and many struggle with reading and writing. Student variability is reflected in individual test change scores, which ranged from -9 (indicating a loss of 9 points from pre- to post-test) to 14 (indicating an increase of 14 points from pre- to post-test). Differences in exceptionalities were also reflected in post-test scores for frequency of performing health-related activities, which ranged from a mean score of 2.7 (“often”) among SLD students to a mean score of 2.2 (“sometimes”) among PI students. Given the diversity of the sample, change scores for the group as a whole do not reflect the considerably higher increases in knowledge and skills among many students.

Importantly, students, teachers, and families all agreed that the instructional module was highly relevant and valuable. Over 75% of parents/guardians who returned a family survey said that it is “very important” for their child to receive specialized instruction on how to manage his or her own health care. Students in focus groups said that the curriculum provided information that they did not receive elsewhere. They also said that it was important to receive the information in a classroom setting (as opposed to simply reading a book) because it provided them with the opportunity to ask their teachers and discuss items that they did not understand. Teachers were all very enthusiastic about the content and comprehensiveness of the module. Items that they were least satisfied with were: (a) the reading level was too high for some students, and (b) there was not enough time for many classes to adequately cover the material.

Evaluation data generated a number of recommendations for future implementation of the curriculum. The majority of teachers felt that the course should be required for all ESE students, particularly for those who expect to graduate with a special diploma or do not plan to continue with post-secondary education. Some students and teachers felt it should also be offered to the general population of high school students. Based on data from student performance tests, classroom observation, and focus groups, the curriculum seems to be most relevant for PI students. Because these teens typically have complex medical conditions, the information they receive in the curriculum, and the health journal that each student compiles, can be used immediately. While the curriculum material has important *future* implications for EMH and SLD students who may not currently experience serious medical issues, PI students arguably have the greatest potential to improve their present situation by applying health-related knowledge and self-management skills acquired in the course.

Students and teachers who participated in focus groups offered numerous additional recommendations to improve the curriculum, including: (a) develop a second version of the module for lower functioning students, (b) extend the implementation timeframe from 9 to 18 weeks, and (c) add more color pictures and hands-on activities.

### Educator Training

Educator training introduced important health care transition concepts to high school staff members, provided them with planning tools and strategies to support students and families in their educator roles, and identified health-related factors to be addressed in student Transition IEPs (i.e., Transition Individual Education Plan, a legally required document for all high school students who receive special education services). Overall, approximately 330 elementary and secondary school staff received training during district-wide departmental meetings: 130 secondary school special education personnel, 80 nurses, and 120 social workers.

A pre-test/post-test design was again used to assess change in educator knowledge, attitudes, and practices, as well as perceived barriers to health care transition support in SDHC. High school staff members completed an Educator Survey both prior to training and following the intervention period. Of 83 pre-surveys and 54 post-surveys completed, 27 matched sets were useable for comparative analysis.

Based on matched pre- and post-survey responses, a statistically significant increase in the post-test mean score for nine knowledge items suggests a positive program effect. Educators, on average, reported knowing “little” about most items prior to the training session. Post-training, they generally knew “something” about the same items. Importantly, knowledge items that increased the most from pre-to-post-survey were (a) writing health-related goals in Transition IEPs, (b) ways that pediatric and adult health care service systems are different, and (c) developing a health care plan. With almost 90% of post-survey respondents saying that it is “very important” to include health care goals in Transition IEPs, it appears that the majority of educators believe that the education system has considerable responsibility in helping to prepare students with disabilities for transition to adult health care.

Due to student privacy protections, evaluators were limited in their ability to quantify the number of students who have health-related goals in their Transition IEPs, or the number of Transition IEPs that were amended as a result of the pilot. The data indicate that, while there was a small overall increase in frequency of addressing health care issues during the Transition IEP process, there were no statistically significant changes in practice during the intervention period.

The apparent discrepancy between knowledge and practice with respect to Transition IEPs was also reflected in educator perceptions of barriers to the process. Post-survey respondents said that the two most significant barriers to addressing health care in Transition IEPs are (a) lack of a perceived mandate to include health-related issues, and (b) lack of knowledge about the health care transition process. While educators in the pilot project were sensitized to the issues surrounding health care transition, there are many other individuals that participate on Transition IEP teams who are likely less knowledgeable. Indeed, Transition IEP teams typically include representatives from community-based service agencies who may not be familiar with the importance of preparing for entry to the adult health care system.

The *Demonstration Model* appears to have effectively started the information diffusion process, but the data suggest that continued training and development of communication strategies are needed. Certainly, the relatively small number of educators who completed both pre- and post-surveys suggests that multiple, regularly scheduled trainings will be necessary in order to reach all current and new educators, and, ultimately, to impact practice.

### Other Recommendations

In addition to the recommendations outlined above, evaluation data indicate that the following supplemental components should be considered for future program implementation:

- Instructional/training module for parents,
- Training for community-based service providers, including physicians, and
- A sequential series of instructional modules for students that begins in middle school and continues through high school.

## Introduction

*A Demonstration Model for School-Based Health Care Transition Education* was designed to improve functional outcomes in adulthood for the approximately 11,500 adolescents and young adults with disabilities or other special needs in Hillsborough County, FL (Raffaele Mendez & Hess, 2003). In this project, adolescents and young adults with disabilities or special needs were defined as individuals from approximately 14 through 21 years who have a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required of adolescents and young adults generally.

Health care transition is the purposeful planned movement of adolescents and young adults with disabilities or other special health care needs from child-centered (pediatric) to adult-oriented health care systems (Blum et al., 1993). It includes seeking medical services from an adult-oriented practitioner, taking responsibility for one's own health care, and obtaining insurance to pay for health-related services. While many professionals now recognize health care transition as a critical aspect of successful entry into adulthood, a number of studies have identified significant barriers to effective transition.

This project, funded by the Florida Developmental Disabilities Council (FDDC), was intended to (a) prepare teens and young adults with disabilities or special health care needs to become successful adult health care consumers, and (b) educate families, caregivers, educators, and service providers about the steps that they can take to help youth successfully transition from pediatric to adult health care. An important consideration for FDDC was the potential to replicate the *Demonstration Model* in other communities throughout Florida.

Comprehensive program evaluation customarily assesses process, impact, and outcome indicators across multiple domains, including knowledge, behavior, health condition, environment, administration, and policy. However, examination of long-term outcome measures such as change in health status among young people with disabilities was beyond the scope of this project. Rather, this report summarizes findings from process and impact evaluation data collected before, during, and subsequent to the intervention, with a focus on recommendations to improve the program for future implementation.

## Background

While rapid advances in medical science have enabled more than 90% of children born with disabilities to reach adulthood, they are much less likely than their non-disabled peers to finish high school, pursue postsecondary education, find a job, or live independently (U.S. Department of Health and Human Services [USDHHS], 2001). As a result, caretakers and professionals have been increasingly interested in transition services that will improve functional outcomes for this population in adulthood (White, 1999). There is a growing body of evidence indicating that persons with disabilities are particularly susceptible to secondary conditions (i.e., medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences) that can further impact their quality of life (USDHHS, 2000). In light of this, it is particularly important to provide activities and services for young people with disabilities that address all aspects of health and well-being, including promoting health, preventing secondary conditions, preparing for adult living, removing environmental barriers, and providing access to the adult health care system.

The literature cites several commonly encountered barriers to successful transition from pediatric care to adult health care, including (a) the strong emotional attachments that families have with their pediatricians often make it difficult to leave pediatric medical homes, (b) limited knowledge among families and youth about the importance of health care transition and about the adult health care system, (c) lack of self-confidence and self-care skills among adolescents, (d) lack of training and support among community providers, (e) limited availability of adult care providers who are qualified and willing to serve young adults with disabilities, and (f) significant changes in public and private health care insurance policies once a child reaches age 18 or 21.

A local study entitled *An Analysis of Community-Based Services and Supports for Children, Adolescents, and Young Adults with Special Needs in Hillsborough County* (Raffaele Mendez & Hess, 2003) provided corroborating evidence that lack of knowledge about health care transition and availability of adult primary care providers are critical gaps in Hillsborough County. Using the PRECEDE-PROCEED health promotion planning model and a social marketing framework, formative research and planning activities for a comprehensive health care transition education program began in early 2004 with funding from the American Academy of Pediatrics (AAP) CATCH Planning Funds.

Researchers in the AAP-funded project (Straub, Hess, Millrose, & Barrow, 2005) examined factors that influence health care transition among a broad spectrum of stakeholders in Hillsborough County. A significant finding was that families and health care providers give minimal attention to preparing youth for an increased level of responsibility in managing their own health care (as developmentally appropriate) such as learning about health insurance, improving communication skills, taking medication independently, and being able to describe their disability or medical condition. Researchers also identified a cross-cutting need among families and professionals for information and referral to local adult health care services, facilities, and resources.

*A Demonstration Model for School-Based Health Care Transition Education* was a direct result of these earlier Hillsborough County studies. It launched in November 2004 with \$30,000 in grant funds from FDDC. Primary collaborative partners in the intervention program were Florida Diagnostic & Learning Resources System (FDLRS), the School District of Hillsborough County (SDHC) Exceptional Student Education (ESE) Program, and the University of South Florida (USF) College of Medicine, Department of Pediatrics. Other partners that provided technical support and consultation included Healthy & Ready to Work (HRTW) National Center, The Transition Center at the University of Florida (UF), and the Institute for Child Health Policy (IHP) at UF. The fiscal agent for the project was Achieve Tampa Bay, Inc., an affiliate of United Cerebral Palsy. A project director provided program planning and management throughout the contract period, 11/1/04 to 10/31/05. See Appendix Attachments 1 and 2 for the project work plan and budget.

## **Program Description**

This section describes the three primary intervention strategies that were utilized in the *Demonstration Model*:

1. Disseminate a health care transition information and resource guide to community-based providers and families of young people with disabilities, particularly families of high school students who receive ESE services through SDHC,

2. Provide classroom instruction, counseling, transition planning support, and printed materials on health care transition to high school ESE students in selected classes, and
3. Provide district-wide training to educators on how to support students and families in the health care transition process, as well as intensive curriculum-specific training for ESE teachers and support staff in pilot class sites.

## Information and Resource Guide

The study of factors that influence health care transition in Hillsborough County (Straub et al., 2005) found that most families do not anticipate the importance and complexity of teaching their children health care management skills. Parents and caregivers may not consider the impact of those skills on a young person's potential to live and work independently. In addition, both families and professionals clearly identified a need for information about resources and services available to adults with disabilities or chronic health conditions.

To that end, Straub et al. (2005) developed and pretested a prototype information and resource guide among young adults, families, and service providers. Multiple resources were used to compile the guide, including existing educational materials and earlier focus group data. The guide provided information about changes that occur as youth move to the adult health care system, steps that can be taken to ensure a smooth transition process, and ways to identify and access adult-oriented health services and supports. Reaction to the material was very favorable among all study subjects. Respondents also suggested changes to improve the guide, particularly with respect to readability, understanding, usefulness, completeness, and accuracy. Material pretest results are provided in Appendix Attachment 4.

Pretest results were subsequently used in the *Demonstration Model* to refine and finalize an educational tool to assist parents, caregivers, and professionals in preparing young people for transition from pediatric to adult health care. The material was reviewed for content validity and accuracy in its final stages of development by technical advisors at USF College of Medicine, HRWT National Center, and ICHP at UF. The project director then worked with a local firm, In-Haus Graphic Design & Marketing, to produce an attractive, highly visual product entitled *Hillsborough County Information & Resource Guide: What's Health Got To Do with Transition? Moving from Pediatric to Adult Health Care*. Educational content was organized as a 10-step process towards successful health care transition, and includes several guidelines, checklists, and sample forms. The accompanying resource guide provides an extensive listing of national, state, and local agencies, facilities, service providers, and advocacy organizations that serve adults with disabilities or chronic health conditions.

The guide was produced in multiple print formats. An English version (10,000 quantity) was produced as two separate pieces: a 4-color, 20-page information booklet (7" x 8.5") accompanied by a smaller, 36-page resource guide (5.5" x 5.5") tucked inside the back cover of the booklet. A Spanish version (1,000 quantity) contains the same content but was produced as a single 32-page, 2-color booklet (7" x 8.5"). The guide was also produced in Braille and large print, and can be downloaded online at <http://usfpeds.hsc.usf.edu/adolescent>.

The English version was mailed in early March, 2005, to the parents/caregivers of all students in grades 9 through 12 who receive ESE services through SDHC (approximately 6,700 families). A cover letter printed in both English and Spanish introduced the guide, and provided directions for requesting copies of the Spanish version. Copies of the English version were also

mailed to study subjects who participated in the material pretest. Numerous other distribution channels were used to reach community service providers, professional association members, health care facilities, advocacy centers, and family organizations. To-date, approximately 2,500 additional copies of the English version and 200 copies of the Spanish version have been disseminated. The remaining guides are housed in the USF Department of Pediatrics, which also maintains and updates the guide on its Web site. Contact information to request additional copies is listed on the back cover of the guide and on the USF Web site.

## **Student Curriculum**

While the information and resource guide served as an educational tool for parents and providers, classroom instruction was intended to teach young people important health-related skills that they may not learn at home or in the community. Straub et al. (2005) found that high school ESE teachers and support staff in Hillsborough County were very receptive to the concept of integrating health care management skills and activities into a school-based program. Indeed, participants in focus groups provided tangible recommendations on how to structure a curriculum that engages both students and families.

Using the study data as a framework for planning, an advisory committee guided curriculum development. The committee was comprised of three high school ESE teachers, a transition specialist, a clinical social worker from the USF Adolescent and Young Adult Program, a doctoral student in USF College of Education, and the project director (total of seven committee members). An important aspect of the project is that the materials were developed in collaboration with experienced high school ESE teachers who were knowledgeable about practicalities and limitations within the classroom, text formats that ESE teachers and students generally prefer, SDHC curriculum guidelines, and Florida's Sunshine State standards.

Following an extensive literature review, the curriculum was assembled using elements from existing materials as well as original content. Advisory committee members and curriculum authors met several times from November 2004 to February 2005 to review and finalize the text. The module was reviewed for content validity and accuracy by several field experts, including two physician faculty members from USF College of Medicine, a school district nurse/prevention specialist, and an advisor from the Transition Center at UF. SDHC's ESE Curriculum Steering Committee then reviewed and approved the materials prior to implementation.

The curriculum was designed so that higher functioning ESE students in grades 9 through 12 would be able to read, understand key concepts, and complete assignments independently. Readability test scores were calculated at a 7th grade reading level. Topics covered in the 8-unit module include: the importance of self-determination and self-advocacy, rights and responsibilities at age 18, managing medication needs, communicating with health care providers, finding and using adult physicians, participating in health care decision-making, completing medical forms, health insurance, sexual health, staying safe, and constructing a personal Health Journal. Authors also began work on a unit addressing alcohol and drugs but later determined that there was not enough time in the allotted implementation period to cover an additional topic. Each unit has several standard components (e.g., vocabulary word list, crossword puzzle, unit activities) along with 2-5 lessons that introduce new content.

The pilot module was implemented in 13 ESE classes in five geographically and demographically diverse high schools from March through May 2005. Of the 137 students who

participated in the pilot, most received Specific Learning Disabilities (SLD), Educable Mentally Handicapped (EMH), or Physically Impaired (PI) services, and expected to earn a Special Diploma (rather than General Diploma) upon graduation. Other ESE categories represented in the sample were Language Impaired (LI), Traumatic Brain Injury (TBI), Emotionally Handicapped (EH), and Other Health Impaired (OHI). Most students in the pilot were relatively high functioning despite some cognitive impairment. The majority of classes combined students across different ages and grades, e.g., a 14 year-old and 20 year-old who both receive EMH services could be in the same class. Class sizes ranged from 6 to 20 students. PI classes were generally smaller in size, with EMH and SLD classes averaging 10-15 students each.

School and teacher participation in the pilot curriculum was completely voluntary. Teachers were informed that they would receive 18 in-service hours for completing all training, implementation, and evaluation activities associated with the pilot. Because fidelity of instruction would be critical to evaluating program effectiveness, the advisory committee attempted to recruit teachers who were recommended by ESE staff, were enthusiastic about the content, and agreed to adhere to strict implementation guidelines. In February 2005, pilot teachers attended a mandatory 6-hour training session coordinated through Florida Diagnostic Learning and Resources System (FDLRS) and SDHC. Classroom instruction began the last week of March 2005 and ran through the end of the school year. The launch of the curriculum was delayed until after FCATs were completed in order to avoid scheduling conflicts with the typically intensive FCAT preparation and testing period.

An estimated 40 hours of instruction was packaged in the 8-unit module. Teachers were advised to cover an average of one unit per week over eight weeks in order to complete the material. No additional time was built in for missed classes or review sessions. The last unit was dedicated to compiling individual Health Journals so that students would have them ready for their personal use after completing the course. Classroom materials were printed and distributed through FDLRS and SDHC. Each student received a copy of the text in a 1 ½" binder, along with a separate portfolio folder to use in assembling his or her personal Health Journal. Students were encouraged to keep all curriculum materials after completing the course. A separate teacher edition of the text included an instructional guide, answer key, and supplemental activities.

The module was embedded within Science, Health, and Life Management courses during the last 9-week grading period in the 2004-2005 school year. Unit quizzes and a comprehensive post-test were used to grade student performance and mastery of the material. Most classes in the pilot were scheduled 1 hour per day, 5 days per week (40 hours), although some were on a block schedule of 1.5 hours per day, 5 days per week (60 hours). The difference in total time allocated for the module ultimately impacted whether the class was able to fully complete all 8 units. Generally, students in PI classes had the most difficulty completing the units in the allotted timeframe, even those who were on the 1.5 hour block schedule. Teachers in higher functioning SLD classes on the block schedule were the only ones who reported having adequate time to cover all of the material.

Parents/guardians of students in the pilot classes were informed about curriculum content prior to its launch. Although all students were required to participate in the module, parents had the opportunity to provide negative consent for the unit on sexual health; that is, parents could choose to exclude their child from receiving information about sexual health.

Finally, while the focus of the curriculum was on acquisition of general health-related knowledge and skills, there were opportunities for students to use their personal health information in selected activities, such as preparation of Health Journal pages and sample medical forms. Parents and students were advised that the use of personal health information was completely voluntary and was not required to successfully complete the course. They were also assured that any personal health information disclosed during the course would be kept private and confidential. Teachers were asked to encourage parental involvement in these activities by having students complete Health Journal pages at home.

## **Educator Training**

Staff training was twofold: (1) general training on health care transition concepts for high school staff throughout the district, and (2) intensive training for ESE teachers and support staff participating in the pilot curriculum.

The purpose of district-wide general training was to introduce important health care transition concepts to high school educators; provide them with planning tools and strategies to support students and families in their educator roles; identify health-related factors to be addressed in Transition IEPs; and inform them about the *Demonstration Model*. Three groups were targeted for short training sessions in January and February 2005: (1) ESE support staff, which includes ESE specialists, transition specialists, and Parent Liaisons, (2) school social workers, and (3) school nurses. Initial plans included training for all high school ESE teachers (i.e., encompassing teachers *not* participating in the pilot curriculum) but had to be revised due to logistical difficulties in reaching such a large number of teachers in a short timeframe. Overall, approximately 330 school staff received training during district-wide departmental meetings: 130 secondary school ESE personnel (some ESE teachers), 80 nurses, and 120 social workers. Attendance at departmental meetings is generally mandatory for these staff members, so the figures represent a large percentage of the target population.

Each of the three general training sessions was positioned among several meeting agenda items and so had a limited time allotment. The presentations, which ranged from 30-60 minutes each, highlighted how educators can help students and families in their respective roles. For example, social workers can be particularly effective in helping students (including students who do not receive ESE services) identify and access adult-oriented resources in the community, nurses can encourage health-related self-management skills, and transition specialists can help identify relevant goals and activities for Transition IEPs. Copies of the health care transition information and resource guide were distributed, and a video entitled “Health Care Transitions: College and Beyond” (produced by the Institute for Child Health Policy at UF) was shown when time allowed.

As described earlier, pilot teachers attended a mandatory 6-hour session in February, 2005. School social workers, nurses, ESE specialists, transition specialists, and Parent Liaisons at school sites participating in the pilot were also invited to attend this session. A total of 20 staff members attended the 6-hour session: 11 ESE teachers, 1 ESE specialist, 2 transition specialists, 1 nurse, 2 social workers, and 3 Parent Liaisons. Everyone who participated was eligible to receive 6 in-service hours; for pilot teachers, the 6 hours were credited towards their total 18 in-service hours. The session included a presentation of the video, an in-depth review of the curriculum, and an informal discussion with an adolescent health expert, the Medical Director at the USF Young Adult and Adolescent Program.

## Evaluation Methods

Several broad questions guided process and impact evaluation activities. Due to the extensive amount of data that was collected in the materials pretest regarding the information and resource guide (during the AAP-funded research and planning phase), these evaluation activities focused primarily on the pilot curriculum and staff training. Evaluation research questions were:

1. To what extent did classroom instruction facilitate changes in knowledge and skills associated with health care transition among students?
2. To what extent did school-based training facilitate changes in knowledge, attitudes, and practice among educators?
3. What is the perceived value and relevance of the *Demonstration Model* among various stakeholder groups?
4. How can the *Demonstration Model* be improved for future implementation?

## Research Design

A combination of quantitative and qualitative research techniques were used to collect data from students, high school staff, and families who participated in the *Demonstration Model*. Particular attention was given to assessing stakeholder experiences and satisfaction with the pilot in order to refine and improve specific program elements. Listed below is a description of methods used in project evaluation. Evaluation instruments are provided in Appendix Attachment 3.

### Quantitative Methods

#### *Student Performance Test*

A pre-test/post-test research design was used to assess change in student knowledge and skills resulting from classroom instruction. A written test was self-administered by students in class prior to start of the curriculum and following its completion.

The student test contained three parts: (1) self-report of health-related skills and practices, (2) achievement of essential knowledge of content covered in the curriculum, and (3) general demographic data about the student. The self-assessment section was a 12-item Likert scale that was adapted from the *Ansell-Casey Life Skills Assessment* (Casey Family Programs, 2000). The achievement section was comprised of 29 questions that combined short answer, true/false, and matching items. Content-specific subsections measured knowledge of prescriptions, sexual health, types of physicians, general health care concepts, and health insurance. Demographic data collected from the student concerned gender, age, grade, race/ethnicity, living situation, and primary ESE category. Tests did not identify students by name; rather, they were coded to link pre- and post-test data and to protect student confidentiality.

Teachers were allowed to read test questions to students who were not able to read sufficiently by themselves. All students who participated in the curriculum were expected to complete both the pre- and post-test. However, it should be noted that graduating 12<sup>th</sup> grade students were released from their classes a week early, and so many of the older students were not able to complete the post-test. A total of 82 usable, matched pre- and post-tests ( $N=82$ ) were submitted by teachers to the project director, representing 60% of the 137 students who participated in the curriculum.

### *Educator Survey*

A pre-test/post-test design was also used to assess change in school staff knowledge, attitudes, and practices, as well as perceived barriers to health care transition support in SDHC. A large section of the survey specifically addressed the degree to which health care transition goals and activities are included in transition IEPs. The survey instrument was adapted from one in development by researchers at ICHP and The Transition Center for another transition-related program entitled *Standing Up for Me*, funded by the Florida Department of Education (FDOE) and UF Institute for Child and Adolescent Research and Evaluation (ICARE).

ESE high school teachers and support staff, nurses, and social workers who attended staff training sessions in January and February, 2005, were asked to complete a 2-page survey **prior** to the start of the session. Completed pre-intervention surveys were handed directly to the project director at the meetings. The same test was later administered to staff members at the start of the 2005-2006 school year in August 2005. ESE staff and school nurses completed the survey at their respective departmental meetings, and social workers received the survey electronically. Surveys did not link individuals by name; rather, respondents were asked to provide the last 4 digits of their Social Security number to link pre- and post-test data.

A total of 83 pre-intervention surveys were completed ( $N=83$ ). Of the 54 post-surveys that were completed, 27 were matched to pre-survey respondents ( $N=27$ ) and were useable for measuring change that resulted from the *Demonstration Project*.

### *Family Survey*

Parents/guardians were asked about their perceptions and satisfaction with the curriculum in a 2-page survey that was sent home with each student at the end of the module. The questionnaire, which was developed by the project director for the pilot, also addressed satisfaction with the information and resource guide that had been mailed to them earlier in the year. While the majority of questions were presented in a selected-response format, there were opportunities for families to add qualitative comments about their concerns or suggestions. A total of 19 family surveys ( $N=19$ ) were returned, representing a notably low response rate of approximately 15%.

## Qualitative Methods

### *Informal Communication*

Teachers participating in the curriculum pilot were encouraged to contact the project director throughout the implementation period with their questions and feedback. Several teachers communicated informally by telephone and email, identifying corrections and suggestions in real-time as they covered the material in class.

### *Classroom Observation*

The project director observed 3 classes ( $N=3$ ) for 45 minutes to 90 minutes each in mid-May, during the last phase of the module. A Likert scale was used in 2 PI classes (9 and 7 students, respectively) and 1 EMH class (5 students) to assess factors such as teacher enthusiasm, fidelity of instruction, and knowledge of the material, as well as student interest, understanding, participation in classroom discussion, and independent learning. The scale was developed by the project director specifically for the *Demonstration Model*.

## *Focus Groups*

A total of 3 focus groups ( $N=3$ ) were conducted by the project director and a co-moderator following completion of the module. An educator focus group, which lasted approximately two hours, was comprised of 5 teachers and 2 support staff from pilot curriculum sites (7 total). Two student focus groups, which lasted about one hour each, contained 6 and 9 students, respectively, for a total of 15 SLD students.

Participants provided information about perceived value and relevance of the curriculum material, items or activities that they liked the most and the least, and how it could be improved for future implementation. Focus groups responses were audio taped as well as recorded manually by the co-moderator. Due to conflicting end-of-year school activities, there was some difficulty scheduling a mutually beneficial meeting time for teachers. Teachers who were not able to attend the focus group were asked to submit written answers to the same questions posed to the group. Of the 12 teachers in the pilot, 10 completed this evaluation activity.

Adult study subjects in all evaluation activities were advised that participation was completely voluntary, as required by SDHC and the USF Institutional Review Board (IRB). A cover letter explaining program evaluation objectives, participant rights, and privacy safeguards was attached to family and staff surveys. Teachers who participated in focus groups and classroom observation provided written informed consent prior to implementation. The USF IRB determined that evaluation of *students* participating in the school-based pilot met Federal Exemption Criteria One (for research conducted in established or commonly accepted educational settings, involving normal educational practices), giving researchers sole responsibility for ensuring ethical research practices. As such, consent from students was not required for review of performance tests or classroom observation. However, written informed consent (for students 18 years old or older) or assent (for students less than 18 years old) was secured from all students who participated in focus groups, in accordance with the USF IRB. In addition, parents/guardians were given the opportunity to decline their child's participation in a focus group, classroom observation, or review of student tests if the student was less than 18 years old. As a result, 5 students were excluded from the evaluation study.

## **Instrument Reliability**

The student performance test and educator survey were assessed for reliability using Cronbach's alpha for internal consistency analysis. In particular, Cronbach's alpha values were calculated for the totality of both the pre- and post-test measures, as well as for items within subsections of the instruments. Subsection items were averaged to create a composite score, and then assessed for inconsistencies that might affect the reliability and meaningfulness of the scores.

## Student Performance Test

Table 1 (below) indicates that the overall Cronbach's alpha values for the entire pre- and post-test measure for students fell in the moderate to acceptable range of reliability (0.77 and 0.81, respectively). Values in this range suggest that scores from the pre- and post- assessments are likely to be reliable estimates of student skills and knowledge. It should be noted, however, that this calculation is based on a sample of  $N=23$ ; 60 cases were eliminated due to missing data on one or more of the items.

With regard to the section concerning self-reported health care skills and practices (which consisted of 12 items), Cronbach’s alpha values were again in the moderate to acceptable range of reliability (0.75 for pre and 0.82 for post), indicating that items from this section of the assessment tool might be reliably collapsed into a composite score. Alpha values from the section concerning essential knowledge (comprised of four content-specific subsections) indicate less reliability, suggesting that composite scores from these subsections might be less meaningful. Consequently, summary scores from subsections are reported only descriptively, but are not analyzed using any tests of significance.

Table 1. Cronbach’s alpha values for student pre- and post-test measures.

Assessment Item/Scale	Pre	Post
All Questions	0.77	0.81
Self-Reported Health Care Skills (items a-l)	0.75	0.82
Achievement of Essential Knowledge		
Prescriptions (items a-f)	0.55	0.47
Sexual Health/Types of Physicians (items a-e)	0.62	0.78
General Health Care Concepts (items a-n)	0.06	0.33
Health Insurance (items a-d)	0.51	0.63

### Educator Survey

Again, reliability of the educator instrument was assessed using Cronbach’s alpha for internal consistency analysis. Table 2 (below) indicates that the overall Cronbach’s alpha values demonstrate high levels of reliability in both the entire pre- and post- surveys (0.95 and 0.92, respectively). Values in this range suggest that scores from the pre- and post- assessments are likely to be reliable estimates of educators’ overall understanding of the issues surrounding health care transition (referred to here as HCT). It should be noted, however, that this calculation is based on a sample of  $N=63$  for pre- and  $N=21$  for post; many cases were eliminated due to missing data on one or more of the items.

With regard to topic-specific sections within the survey - Knowledge of HCT (9 items), Frequency of Specific HCT Goals in Transition IEPs (14 items), and Barriers to HCT (10 items) - all sections demonstrated high levels of reliability in both the pre- and post-administrations of the survey with reliability coefficients ranging from 0.86 to 0.96.

Table 2. Cronbach’s alpha values for educator pre- and post- surveys.

Assessment Item/Scale	Pre	Post
All Questions	0.95	0.92
Knowledge of HCT (items a-i)	0.90	0.92
Frequency of Specific HCT goals in Transition IEP (items a-m)	0.96	0.96
Barriers to HCT (items a-j)	0.93	0.86

### **Data Analysis Procedures**

Quantitative data (performance tests and surveys) were analyzed using descriptive, comparative, and correlational statistical procedures. Specifically, data from student performance tests and educator surveys were analyzed using SPSS™ Version 11.0.1 statistical software. Univariate tests were employed to calculate frequency distribution, mean, range, and standard

deviation for items in the student, educator, and family instruments. Bivariate procedures were used to (a) measure change, or difference in scores, between matched pre- and post-tests (one-way paired-sample t-test), and (b) examine the relationship between type of ESE service that students receive and the degree of change (one-way ANOVA). Alpha levels, or statistical significance levels, are reported for all bivariate measures.

Qualitative data analysis was performed by assessing participant responses across multiple dimensions. Focus group data and informal teacher feedback were reviewed for commonalities in responses, differences, degree of emotion, degree of specificity (detailed explanation), frequency (number of similar responses), and extensiveness (number of different people who had similar responses). Transcripts were coded and grouped by common themes. Similarly, classroom observation scores were assessed for degree of consistency or variation among teachers and classes with respect to curriculum implementation.

Finally, triangulation of quantitative and qualitative data from all sources served to corroborate evidence that supports the research findings and recommendations outlined in this report.

### **Limitations in Methodology**

There are several noteworthy limitations in research methodology. Although original plans called for non-intervention comparison groups to evaluate the impact of student curriculum and staff training, the logistics of implementing a quasi-experimental model during the contract period proved too cumbersome and costly. It was determined that, while it was important to explore change in individual knowledge, skills, and practice that can be attributed to the intervention, the focus of the evaluation should be on institutional change and improving various elements of the pilot project. Although a research design could not demonstrate true causal effects of the program, it was considered adequate for the purposes of this evaluation.

A related issue is recognition that an achievement test alone cannot provide a comprehensive assessment of performance among ESE students. These students characteristically encompass a wide range of cognitive abilities, often struggle with reading and/or writing, and require varying degrees of time and repetition to master new knowledge and skills. Even with this project's large, representative sample, a self-administered achievement test is limited in its ability to fully measure student performance, or to demonstrate outcomes that are generalizable to the ESE population as a whole. In addition, self-reported measures of health-related skills and practices raise questions concerning validity of student responses on the test. Again, given time and budget considerations, the performance test provided an acceptable if limited measure of program impact.

Self-reported measures of staff knowledge and practices pose similar questions of validity. And, although a large percentage of educators in the target population completed pre- and post-intervention surveys, a relatively small number of matched sets were useable to assess change. This was due, in part, to a delay in administering the post-survey until the start of the new school year. It is likely that staff turnover and new hires resulted in fewer individuals who had received training the previous year and were available to complete both surveys.

The low family survey response rate, while not surprising, suggests that the parent/caregiver sample was not sufficiently representative to generalize findings. Teachers report that, in general, parents of many high school ESE students are unresponsive to communication attempts from the school. And while the family letter and survey were sent home with all students in pilot classes, there are questions concerning the number of parents who actually received the questionnaire

Lastly, evaluation instruments used in the project were reviewed by project partners and advisors for validity prior to implementation, as noted above. However, formal procedures to establish each instrument’s level of validity were not conducted for the purpose of the pilot. Further, reliability tests were conducted post-hoc, that is, after implementation. It is recommended that, should these tools be utilized in a large scale study of the program, appropriate tests be administered prior to implementation to certify that they yield reliable and valid results.

## Evaluation Results

Results from data collection activities are reported below. Quantitative data from student performance tests, staff surveys, and family surveys are listed first, followed by qualitative findings from informal feedback, classroom observation, and focus groups.

### Quantitative Data

#### Student Performance Tests

Data collected from student performance tests are reported in three sections: demographic composition of the sample, self-reported skills and practices, achievement of essential knowledge.

#### *Demographic Composition*

The composition of students who completed both pre- and post-intervention performance tests is summarized in Table 3 below.

Table 3. Demographic summary data from student pre- and post- tests.

	<i>N</i> =82		All SDHC ESE Students In Grades 9-12
	Frequency	Percent	Percent
<b>Gender</b>			
Male	46	56.8	67.6
Female	35	43.2	32.4
<b>Grade</b>			
9 <sup>th</sup>	28	34.1	36.4
10 <sup>th</sup>	25	30.5	26.1
11 <sup>th</sup>	19	23.2	19.3
12 <sup>th</sup>	10	12.2	18.2
<b>Race/Ethnicity</b>			
White or Caucasian	35	42.7	50.6
Black or African American	24	29.3	29.5
Hispanic or Latino	19	23.2	17.5
Other	3	3.7	2.4
Multiracial	1	1.2	
<b>ESE Program</b>			
Educable Mentally Handicapped (EMH)	25	31.3	
Physically Impaired (PI)	22	27.5	
Specific Learning Disabilities (SLD)	21	26.3	
Other Health Impaired (OHI)	1	1.3	
Traumatic Brain Injury (TBI)	1	1.3	
Other	1	1.3	
Don't know	9	11.3	

\* Lack of student response to certain questions resulted in frequencies that are less than 82 for some items.

In addition, the average age of students in the sample was 16.3 years. The great majority lived with their birth parents, although several lived with adoptive parents, foster parents, relatives, or in group homes. Importantly, the sample appears sufficiently representative of the larger population of ESE high school students in Hillsborough County with respect to gender, race/ethnicity, and grade level (SDHC, 2003; Raffaele Mendez & Hess, 2003).

### **Skills**

Results from the self-reported health-related skills and practices are reported below in Tables 4 and 5.

Table 4. Percent of student responses to items regarding health-related skills and practices.

<i>N</i> =82	Pre-Test (%)				Post-Test (%)			
	Never	Sometimes	Often	Always	Never	Sometimes	Often	Always
Schedules own appointments	69.1	22.2	3.7	4.9	68.8	20.0	5.0	6.3
Understands condition/disability	5.4	33.8	5.4	55.4	4.1	37.0	6.8	52.1
Can explain condition/disability	18.2	39.0	15.6	27.3	10.5	44.7	15.8	28.9
Talks to doctor without help	28.4	35.8	16.0	19.8	22.1	41.6	10.4	26.0
Keeps emergency contact list	32.1	17.3	8.6	42.0	22.8	15.2	7.6	54.4
Uses health insurance card	44.6	13.5	13.5	28.4	43.7	23.9	7.0	25.4
Participates in decision-making	48.7	25.0	7.9	18.4	33.8	28.6	18.2	19.5
Fills out medical forms	57.1	29.9	5.2	7.8	54.3	22.9	8.6	14.3
Can describe prescriptions/dosage	30.8	33.8	13.8	21.5	30.0	28.3	5.0	36.7
Takes medication independently	33.9	19.6	7.1	39.3	18.3	31.7	11.7	38.3
Understands insurance coverage	45.3	25.3	10.7	18.7	31.9	31.9	13.9	22.2
Has place in home for medical info	29.1	8.9	8.9	53.2	15.4	9.0	12.8	62.8

Summary data shows that degree of change in skills during the implementation period varied across items. Participation in health care decision making, independence with medication, keeping an emergency contact list and medical information, and understanding health insurance coverage appear to be the areas of greatest improvement.

Table 5. Summary data by student exceptionality for all items concerning health-related skills and practices.

Key: *Never*=1, *Sometimes*=2, *Often*=3, *Always*=4

<i>N</i> =82	Pre-Test		Post-Test	
	Mean	SD	Mean	SD
All Students	2.3	.61	2.4	.62
SLD students	2.4	.75	2.7	.63
EMH students	2.3	.60	2.4	.62
PI students	2.0	.52	2.2	.59

Mean scores show PI students to be slightly less independent in health-related skills and practices, although there appears to be similar levels of improvement across all exceptionalities following the intervention.

### **Knowledge**

Summary data from the achievement portion of the test are reported in Table 6. Four subsections contained topic-specific questions that were covered in the curriculum: prescriptions, sexual health and types of physicians, general health care concepts, and health insurance.

Table 6. Summary data of student knowledge by topic.

<i>N</i> =82	Maximum Score	Pre-Test		Post-Test	
		Mean	SD	Mean	SD
All Knowledge Questions	29.0	15.2	4.2	18.1	4.7
Prescriptions (items a-f)	6.0	3.9	1.7	4.5	1.4
Sexual Health/Types of Physicians (items a-e)	5.0	2.4	1.6	3.0	1.7
General Health Care Concepts (items a-n)	14.0	7.4	1.9	8.5	2.1
Health Insurance (items a-d)	4.0	1.6	1.1	2.0	1.2

Means of overall pre- and post-test scores were compared to determine if students' health care knowledge had significantly increased after participating in the pilot curriculum. The mean pre-test score was 15.2, which represented 56% items correct out of 29 total items. Post-test scores were similarly variable and reflected a broad range of performance with a mean of 18.1, which represented 62% items correct out of 29 total items. A one-way paired-samples t-test revealed a small but significant increase in students' overall test scores ( $t(1, 81) = -6.025, p < .001$ ).

Change scores were also calculated to measure the difference between individual student pre- and post-test scores. Change scores varied considerably among students, ranging from -9 (indicating a loss of 9 points from pre- to post-test) to 14 (indicating an increase of 14 points from pre- to post-test), but the mean change score across all students was less dramatic ( $M = 2.85, SD = 4.289$ ). A one-way ANOVA revealed no significant differences in change scores among exceptionalities, i.e., degree of change between pre- and post-test scores were generally consistent among SLD, EMH, and PI students.

### Staff Surveys

Data collected from educator surveys are reported in two parts: (a) composition of the sample, and (b) data concerning general knowledge of health care transition, transition IEPs, and barriers to facilitating health care transition in the school setting.

### ***Composition of Sample***

Listed in Table 7 below is occupational composition of the full pre-survey sample ( $N = 83$ ) well as the pre-post matched survey sample ( $N = 27$ ). As mentioned earlier, the number of respondents who completed both surveys was limited because post-survey administration was delayed until start of the 2005-2006 school year.

Table 7. Occupational make-up of educator pre-survey sample and subgroup of pre-post matched participants.

	Pre-Survey ( <i>N</i> =83)		Pre- Post Matched Survey ( <i>N</i> =27)	
	Frequency	Percent	Frequency	Percent
Social Worker	20	24.1	2	7.4
ESE Specialist	19	22.9	8	29.6
Nurse	16	19.3	6	22.3
ESE Teacher	15	18.1	8	29.6
Other	8	9.6	2	7.4
Transition Specialist	4	4.8	1	3.7
School Administrator	1	1.2	0	0

The matched pre-post participants were descriptively compared to those of the entire pre-survey sample to determine if the 27 matched participants were a reasonably representative sample. The pre-post matched group consisted of a variety of ESE educational professionals, with representation from each occupational category in the pre-survey sample except school administrator. Of note, the pre-post matched group consisted of fewer social workers (24% of the overall pre-survey group versus 11% of the pre-post matched group) and more ESE teachers (18% of the overall pre-test group versus 29% of the pre-post matched group). Composite score means from the pre-post matched group were also compared to those of the overall pre-survey sample. They were fairly consistent, though means of the matched group were slightly higher than the overall sample. In general, these informal analyses suggest that the pre-post matched group is a reasonably representative sample of the overall pre-survey group.

### ***Knowledge and Barriers***

Tables 8 through 11 summarize educator responses to questions concerning their knowledge of health care transition, perceptions about including health-related goals in Transition IEPs, barriers in the school setting. It should be noted that many social workers and nurses typically do not attend transition IEP meetings, and so are not necessarily knowledgeable about goal and activities that are written in transition plans. Consequently, those staff members frequently answered that they didn't know or simply did not answer the items concerning transition IEPs.

In addition to summary data outlined below, the 27 participants who completed both a pre- and post-survey were compared on composite scores in each of the three subsections. A series of three paired-samples t-tests were conducted to determine if scores had increased significantly from pre- to post-administrations. A Bonferroni adjustment was used to account for the use of three significance tests upon the same data set; p-values reported here were multiplied by three to prevent spurious positive results.

Table 8. Summary data concerning educator knowledge of health care transition.

*Key: Never heard of it=1, Know very little about it=2, Know something about it=3, Know a great deal about it=4*

	Pre-Survey (N=83)		Post-Survey (N=27)	
	Mean	SD	Mean	SD
All questions (a-i)	2.3	.6	2.9	.5
a. Difference between pediatric and adult health care systems	2.2	.7	3.0	.7
b. Health insurance eligibility changes after age 18	2.2	.7	2.9	.7
c. Introducing and practicing age-appropriate health-related skills	2.5	.8	3.1	.6
d. Guardianship and other health care decision-making alternatives	2.4	.7	2.9	.6
e. Finding appropriate adult physicians	2.5	.8	3.0	.6
f. Communicating effectively with health care providers	2.6	.7	3.0	.6
g. Developing a medical summary or care plan	2.1	.9	2.9	.7
h. Writing health-related IEP goals	1.9	.8	2.7	.7
i. Accessing adult health services in the community	2.2	.8	2.9	.7

Prior to training sessions, educators appeared to know “little” about most items associated with health care transition prior. Post-training, they generally knew “something” about the same items. Importantly, the item that educators knew least about in the pre-survey, writing health-related IEP goals, reflected the largest gain in knowledge subsequent to the intervention. The 27 matched pre-post composite scores increased from a pre-survey mean of 2.31 ( $SD=.633$ ) to a post-survey mean of 2.94 ( $SD=.508$ ), which was statistically significant ( $t(1,26) = -6.996, p < .001$ ).

Table 9: Summary data concerning importance of including health-related goals in Transition IEPs.

Key: Don't know/no opinion=0, Not important=1, Somewhat important=2, Very important=3

	Pre-Survey (N=82)		Post-Survey (N=27)	
	Mean	SD	Mean	SD
Importance of health-related goals in Transition IEPs	2.6	.9	2.8	.6

Clearly, the great majority of educators believe that it is important to include health-related goals in Transition IEPs, with almost 90% of post-survey respondents saying that it was “very important.”

Table 10. Summary data concerning frequency of including health-related skills in Transition IEPs.

Key: Don't Know=0, Never=1, Rarely=2, Sometimes=3, Often=4, Always=5

	Pre-Survey (N=82)		Post-Survey (N=27)	
	Mean	SD	Mean	SD
All questions (a-m)	2.3	1.3	2.7	1.2
a. Self-determination and goal setting	2.7	1.7	3.4	1.4
b. Independence with self-care	3.0	1.8	3.4	1.6
c. Interpersonal communication skills/assertiveness	3.1	1.8	3.3	1.6
d. Use of transportation system or services	2.5	1.7	3.0	1.4
e. Identify and access community agencies	2.7	1.7	3.1	1.5
f. Overall general health, including sex education	1.8	1.4	2.4	1.4
g. Knowledge of own health condition/disability, medications	2.5	1.7	2.9	1.6
h. Knowledge of relationship between disability and future goals	2.4	1.7	2.7	1.6
i. Take medications independently	2.1	1.5	2.4	1.6
j. Knowledge of when and how to access urgent medical care	1.7	1.4	2.1	1.7
k. Maintaining a personal health record	1.5	1.3	2.1	1.4
l. Knowledge of own insurance plan and coverage	1.4	1.2	1.9	1.3
m. Complete medical forms and communicate with providers	1.6	1.4	2.0	1.4

The data indicates that some items are included in Transition IEPS much more frequently than others, ranging from goals for independence with self-care that are addressed fairly frequently, to goals for knowing about health insurance coverage that are addressed very rarely. A small increase was identified between the matched pre- and post-survey mean composite scores (from a pre-survey mean of 2.47 ( $SD=1.30$ ) to a post-survey mean of 2.69 ( $SD=1.23$ )), although the difference is not statistically significant.

Some educators wrote comments in this section of the survey to explain their responses. Several individuals noted that basic health-related goals (e.g., activities of daily living such as self-care) are regularly included in Transition IEPS for low functioning students with severe disabilities, but other types of health care transition goals are not likely to be addressed unless the student has a significant medical condition. A couple of respondents also indicated that parents often consider health information confidential, and do not want their child's health issues addressed in his or her transition IEP.

Table 11. Summary data concerning barriers to including health-related goals in Transition IEPs.

Key: Don't Know=0, Not a barrier=1, Moderate barrier=2, Significant barrier=3

	Pre-Survey (N=82)		Post-Survey (N=27)	
	Mean	SD	Mean	SD
All questions (a-j)	1.6	1.0	1.9	.7
a. Lack of knowledge about health care transition process	2.0	1.2	2.2	.9
b. Perception that health issues are a low priority for Transition IEPs	1.8	1.2	1.9	.9
c. Lack of perceived mandate to include health-related issues	1.7	1.3	2.2	1.0
d. School district policies and procedures	1.1	1.1	1.5	1.0
e. Lack of tools/examples	1.8	1.2	1.9	.8
f. Lack of time	1.5	1.1	1.9	.8
g. Lack of funding	1.5	1.3	1.8	1.0
h. Family does not perceive importance	1.3	1.2	1.7	1.0
i. School does not perceive importance	1.3	1.1	1.5	1.0
j. Student does not perceive importance	1.5	1.2	2.0	1.0

The change in pre- and post-survey scores is interesting in that educators rated barriers to including health care transition goals in Transition IEPs as more “significant” after program implementation. Notably, lack of knowledge about the process was perceived as the greatest barrier in both pre- and post-surveys. One possible explanation is that staff training generated increased awareness of the issues and barriers, resulting in higher post-intervention scores. In the comparative analysis of matched pre- and post-surveys, a small increase was identified (from a pre-test mean of 1.70 ( $SD=.941$ ) to a post-test mean of 1.87 ( $SD=.726$ )), but was not statistically significant.

### Family Surveys

Of the 19 parents/guardians who completed a family survey, 58% reported that their child who participated in the curriculum was Caucasian. Other racial/ethnic groups represented in the sample were Hispanic (16%), African American (11%), and Other (11%). Approximately 42% of families indicated that their child received EMH services; the next largest exceptionality reported was PI. Average age among the children of respondents was 16.8 years, and gender was evenly split between male and female.

As mentioned earlier, a low survey response rate and small sample size limits the degree to which the family data can be generalized to the population at large. Nevertheless, the information is useful within the context of this evaluation. Over 75% of parents/guardians felt that it is “very important” for their child to receive specialized instruction on how to manage his or her own health care, and were either “very satisfied” or “somewhat satisfied” with the pilot curriculum. Approximately 2/3 of parents in the sample assisted their child in filling out forms for his or her personal Health Journal. Two respondents suggested that the curriculum text, and specifically the information on sexual health, should be modified so that students with developmental disabilities can more easily read and understand the material.

The majority of families found the information and resource guide easy to read and helpful. On a scale of 1 (very positive) to 5 (very negative), average ratings for usefulness and ease of understanding were 1.6 and 1.7, respectively. Over 90% of respondents were either “very satisfied” or “somewhat satisfied” with the guide. It should be noted that a couple of families reported that they had not received a copy of the guide. Since it was mailed to all families of ESE students, it is likely that the guide was sent to an incorrect address, or the parent either did not notice it or did not remember receiving it in the mail.

## Qualitative Data

### Informal Communication

Teachers in pilot classes provided feedback electronically throughout implementation concerning their progress with the module, feedback from students, and suggested changes to the text. Comments communicated to the project director reflected a high degree of satisfaction with curriculum content among both teachers and students:

- *“My students are very excited about the material. They actually are ready to go before the bell. It’s wonderful!!”*
- *“Everything is going great!! Both the students and I are really enjoying it.”*
- *“ Things are still going strong! I really cannot get over how much my kids love it!!”*
- *“ They (my students)... seem to be willing to talk about their own experiences.”*
- *“ I enjoy the interaction with the students. They really ask a lot of questions.”*

A particularly interesting note from one teacher:

- *“Some (of my students) have said, ‘Are you trying to scare us?’ My response was, ‘No, just educate you.’ ”*

Concerns that teachers expressed were: difficulty that many students had with vocabulary words, lack of time to review the material at the end of each unit, amount of time to cover particular units, student boredom with crossword puzzles in every unit, and length of certain assignments. Issues raised in email communications were also covered in subsequent teacher and student focus groups. An especially valuable aspect of real-time feedback was the detailed attention that teachers gave to proofing the text and suggesting format changes.

### Classroom Observation

Summary data from the classroom observation scale that was used to assess the dynamics of teacher-student interactions in 3 classes (1 EMH and 2 PI classes) are listed in Table 12 below:

Table 12: Summary of classroom observation ratings.

<i>The following items were rated from 1 (a lot) to 5 (none)</i>	<b>N=3 Mean Score</b>
Teacher knowledge of topic	1.2
Teacher fidelity of instruction	1.2
Teacher enthusiasm	1.5
Student participation in discussion	1.5
Student interest in topic	1.8
Student degree of understanding	2.3
Student level of independence in completing assignment	3.2

There were notable differences in functional abilities among EMH and PI students who were observed. Many PI students, who typically have both physical and cognitive impairment, were accompanied by personal classroom aides. Curriculum text was read aloud in all classes: the teacher read the text to lower functioning PI students, while EMH students and higher

functioning PI students took turns reading the material as the rest of the class followed along. Teachers in all classes encouraged student discussion and questions as the material was covered, and highlighted particularly important information. Among the 3 classes, high functioning PI students appeared to have the greatest degree of interest and enthusiasm about the topics covered, an observation corroborated by anecdotal reports from teachers who participated in the pilot.

### Focus Groups

Results from student and teacher focus groups are reported together in three themes that align with questions addressed to participants: importance of the curriculum, assessment of curriculum features, and value of personal health journals. Several recommendations for program improvement resulted from focus groups, and are discussed further in the “Conclusions and Recommendations” section of this report.

#### ***Importance of the Curriculum***

Students and teachers overwhelmingly agreed that the curriculum was highly relevant and important for students. The majority of teachers felt that the course should be required for all ESE students, particularly for those who expect to graduate with a special diploma or do not plan to continue with post-secondary education. Some students and teachers felt it should also be offered to the general population of high school students. Several students commented that it was important to receive the information in a classroom setting (as opposed to simply reading a book) because it provided them with the opportunity to ask their teachers and discuss items that they didn't understand.

- *“The entire curriculum was fantastic because all of my students have health-related issues.” (PI teacher)*
- *“My kids loved being able to take the curriculum home and follow up with their parents, especially because many parents don't know this information.” (teacher)*
- *“It's a good course. Parents don't tell you everything. It helps you get prepared.” (student)*
- *“It's a hassle when you're 18 and you have to learn it on your own. This (course) can help you now to prepare for the future.” (student)*
- *“(We) don't get that much (information) in the doctor's office.” (student)*
- *“Getting this information in class is important.” (student)*
- *“It's important to have teachers explaining things because most of us can't read that good.” (student)*
- *“This curriculum gives students real-world information to guide them with decisions they will be faced with.” (teacher)*

#### ***Assessment of Curriculum Features***

Students and teachers were asked about specific aspects of the curriculum that they liked and did not like. A number of program recommendations were subsequently formulated from participant responses to this question.

- Readability. Consensus among teachers was that the reading level was appropriate for higher functioning students in the pilot, but was difficult for many. All teachers read the text aloud, or had students take turns reading the text aloud as a class activity. In addition, comprehension was particularly difficult for ESOL students who speak little or no English. While teachers felt that the vocabulary words were very challenging for their students, they acknowledged that it was important for students to become familiar with medical terms that they will encounter as adults. Most teachers said that, given more time to cover each unit, students should be able to better understand and retain the information.

- *“Some of the vocabulary words were difficult.” (student)*
- *“Our teacher explained vocabulary words we didn’t know. We read chapters together in class.” (student)*
- *“I felt rushed. I didn’t have enough time for vocabulary words.” (teacher)*

- Interest. The majority of participants said the material covered in the curriculum was very interesting to students. Not surprisingly, degree of interest varied by topic, and students appeared most interested in the unit on sexual health. One teacher reported that a male student thanked her for the information because “now we can actually understand the girls we’re dating.” A PI teacher said that her students were somewhat apprehensive about the information on sexual health because many had not been exposed to it before, but they all wanted to learn. Students also seemed to enjoy the unit on personal safety and first aid.

The unit on insurance appeared to be the least interesting to students. In addition, students reported that they grew tired of crossword puzzles in every unit, and would prefer variety in those activities (e.g., word search, scrambled words). There was clear consensus among students and teachers that overall interest could be greatly enhanced by adding (a) color pictures, and (b) more hands-on activities (e.g., field trips into the community, guest speakers, videos, more role playing exercises, using actual prescription bottles and insurance cards in the classroom). Teachers noted that visual material can also serve to increase comprehension among lower functioning students.

- *“I liked learning about reproductive health, AIDS, and other STDs.” (student)*
- *“Insurance was boring, but was the most relevant unit.” (teacher)*
- *“The insurance unit was great because my students will probably live in supported situations, but they think everything is free.” (teacher)*
- *“The unit on STDs turned out to be my favorite.” (teacher)*

- Completeness. Several students and teachers reported that students felt there should be more material concerning alcohol and drugs in the module, particularly with respect to their impact on judgment and behavior (e.g., drinking and driving). Interestingly, curriculum authors initially planned to include that information, but later determined there was not enough time to cover an extra unit during the pilot’s limited timeframe. Several teachers felt that there should be more emphasis on the importance of mental health, including what young people need to do to be mentally healthy and how to access mental health services. They also recommended that the material concerning abuse be expanded to distinguish between different types of abuse and varying perceptions of abuse.

One teacher, concerned about her students' unrealistic expectations of leaving the family home at age 17 or 18, suggested that a step-by-step guide to independent living would be invaluable for demonstrating the actual costs and responsibilities required to live independently. Finally, teachers agreed that information about how to access community resources should accompany the resource guide that is attached to the curriculum.

- *“This was the first time that someone openly allowed them to ask questions about it (drugs and alcohol).” (teacher)*
- *“I’d like more information on the consequences of major drugs, and doing them over and over.” (student)*
- *“They (students) need to know about emotional health and self-esteem, and where to go for mental health services.” (teacher)*

### ***Value of Health Journals***

The majority of teachers felt that creating a personal health journal was a valuable component of the curriculum, but several expressed concern with the logistics of having students complete personal health forms while maintaining student privacy. Participants indicated that some parents were a barrier to the activity because they felt it was intrusive and did not want to risk sharing confidential information with non-family members, or they were not willing to give that information to their children. Teachers speculated that, for some families, providing important health information to their child with a disability represents giving up some degree of control over the child. Moreover, many students expect that their parents will always be available to fill out forms for them. In other situations, teachers reported that parents themselves did not understand how to fill out health forms and so could not provide assistance to their child.

Student response to the value of creating a personal health journal was mixed. Some said that they thought it was important and planned to use their journal, while others did not think that they would need and/or use it. It is worth noting that student focus groups were comprised entirely of SLD students, many of whom do not currently experience significant health problems. One could hypothesize that PI students (most of whom have complex health conditions) might respond differently to the same question.

- *“It may be helpful if you get in an accident and couldn’t talk.” (student)*
- *“I don’t think I’ll ever use it.” (student)*
- *“Some parents are not willing to put that information into their child’s hands.” (teacher)*
- *“It (health journal) has value, but it may be a long way down the road for my students.” (teacher)*
- *“There needs to be a parent education piece to this activity.” (teacher)*

### **Conclusions and Recommendations**

The purpose of *A Demonstration Model for School-Based Health Care Transition Education* was to help prepare teens and young adults with disabilities or special health care needs to become successful adult health care consumers, and to educate families, caregivers, educators, and service providers about the steps that they can take to help youth successfully transition from pediatric to adult health care. The strategies used to accomplish this were:

(a) disseminate a health care transition information and resource guide to service providers and families of young people with disabilities, (b) provide classroom instruction to high school ESE students, and (c) provide district-wide training to educators on how to support students and families in the health care transition process. This section returns to the original research questions that guided process and impact evaluation, and provides answers from the data collected.

### **1. To what extent did classroom instruction facilitate changes in knowledge and skills associated with health care transition among students?**

The research design of the pilot limits the degree to which a true causal effect can be established between classroom instruction and student performance. Nevertheless, the data show a statistically significant increase in student knowledge after participation in the curriculum. Among 82 SLD, EMH, and PI students who completed a 29-item achievement test both before and after the pilot, mean scores increased from 15.2 on the pre-test (56% correct) to 18.1 on the post-test (62% correct). In addition, there were consistent gains in a broad range of skills and practices after program implementation. Students reported that they engaged more frequently in health-related activities that independent adults need to be able to perform, such as participating in health care decision-making, taking medication independently, keeping an emergency contact list, and understanding their health insurance coverage. On a scale of 1 (Never) to 4 (Always), the average score across 13 activities increased from 2.3 to 2.4.

While the degree of change might not appear particularly meaningful, it is important to recognize that the assessment tool was limited in its ability to fully measure student performance. The ESE students in this sample represent a wide range of abilities, and many struggle with reading and writing. Student variability is reflected in individual test change scores, which ranged from -9 (indicating a loss of 9 points from pre- to post-test) to 14 (indicating an increase of 14 points from pre- to post-test). Differences in exceptionalities were also reflected in post-test scores for frequency of performing health-related activities, which ranged from a mean score of 2.7 (“often”) among SLD students to a mean score of 2.2 (“sometimes”) among PI students. Given the diversity of the sample, change scores for the group as a whole do not reflect the considerably higher increases in knowledge and skills among many students.

A second issue to consider is that this evaluation focuses on short-term impact only. Should the program be replicated, evaluators may want to explore long-term impact of the curriculum on student knowledge and skills, i.e., do students retain knowledge and sustain newly acquired skills over time?

### **2. To what extent did school-based training facilitate changes in knowledge, attitudes, and practice among educators?**

Again, the research design limits the degree to which a causal effect can be established between training and changes in educator knowledge or practice. However, based on 27 matched pre- and post-survey responses, a statistically significant increase in the post-test mean score for nine knowledge items suggests a positive program effect. Educators, on average, reported knowing “little” about most items prior to the training session. Post-training, they generally knew “something” about the same items. Importantly, knowledge items that increased the most from pre-to-post-survey were (a) writing health-related goals in Transition IEPs, (b) ways that

pediatric and adult health care service systems are different, and (c) developing a health care plan. With almost 90% of post-survey respondents saying that it is “very important” to include health care goals in Transition IEPs, it appears that most educators believe that the education system has considerable responsibility for helping to prepare students with disabilities for transition to adult health care.

Due to student privacy protections, evaluators were limited in their ability to quantify the number of students who have health-related goals in their Transition IEPs, or the number of Transition IEPs that were amended as a result of the pilot. The data indicate that, while there was a small overall increase in frequency of addressing health care issues during the Transition IEP process, there were no statistically significant changes in practice during the intervention period.

The apparent discrepancy between knowledge and practice with respect to Transition IEPs might be best explained within the framework of diffusion theory. Rogers’ *Diffusion of Innovations* (as cited in Oldenburg & Parcel, 2002) offers a theoretical framework for how new information and practices, or “innovations,” are communicated and ultimately adopted by a population. Post-survey respondents said that the two most significant barriers to addressing health care in Transition IEPs are (a) lack of a perceived mandate to include health-related issues, and (b) lack of knowledge about the health care transition process. While educators in the pilot project were sensitized to the issues surrounding health care transition, there are many other individuals that participate on Transition IEP teams who are likely less knowledgeable. Indeed, Transition IEP teams typically include representatives from community-based service agencies who may not be familiar with the importance of preparing for entry to the adult health care system.

The pilot appears to have effectively started the diffusion process, but the data suggest that continued training and development of communication strategies are needed. Certainly, the relatively small number of educators who completed both pre- and post-surveys (i.e., staff who attended mandatory departmental meetings in both Spring 2005 and Fall 2006) suggests that multiple, regularly scheduled trainings will be necessary in order to reach all current and new educators, and, ultimately, to impact practice.

### **3. What is the perceived value and relevance of the *Demonstration Model* among various stakeholder groups?**

There was a clear consensus among stakeholders who participated in the evaluation that the *Demonstration Model* was highly relevant and valuable. Response to each of the three project components is summarized below.

#### Information and Resource Guide

Because an extensive amount of data concerning the information and resource guide was collected during the AAP-funded material pretest (see Appendix Attachment 4), additional evaluation data was collected only from families of students who participated in the pilot curriculum, all of whom should have received a mailed copy of the guide.

As with the earlier material pretest, the majority of the 19 family survey respondents found the guide useful and easy to read. On a scale of 1 (very positive) to 5 (very negative), average ratings for usefulness and ease of understanding were 1.6 and 1.7, respectively. This compares to average ratings in the earlier pretest of 1.2 for usefulness and 1.8 for ease of

understanding. Over 90% of family survey respondents were either “very satisfied” or “somewhat satisfied” with the guide. It should be noted that there was considerable concern during material development that the reading level might be too high for some individuals. The challenge was to present some fairly complex information in a way that was easy to understand yet did not compromise content integrity. While readability continues to be a concern, the text was simplified as much as possible prior to printing the guide.

An important objective for this component of the *Demonstration Model* was to maximize usage by offering the information in multiple formats and channels. Approximately 200 copies of the Spanish version have been requested and distributed to-date, which suggests a reasonably high level of interest among the Spanish-speaking community. In addition to online accessibility, the guide is available in Braille and large print.

Informal feedback from families and professionals provides further evidence of the guide’s usefulness. The guide received recognition from administrators in the Florida Department of Health, Children’s Medical Services, who used the Hillsborough County guide as model to develop a similar statewide publication entitled *Envisioning My Future* (Gibson & Reiss, 2005).

### Student Curriculum

Students, teachers, and families all said that the instructional module was very important and relevant. Data collected from family surveys, focus groups, and informal communication indicate that the curriculum provides students with critical skills and knowledge that they often do not receive at home or within the community. Over 75% of parents/guardians who returned a family survey said that it is “very important” for their child to receive specialized instruction on how to manage his or her own health care. Students in focus groups said that it was important to receive the information in a classroom setting (as opposed to simply reading a book) because it provided them with the opportunity to ask their teachers and discuss items that they did not understand. Teachers were extremely enthusiastic about the content of the module as well as the comprehensiveness of the teacher’s guide, curriculum format, and accompanying materials.

The majority of teachers felt that the course should be required for all ESE students, particularly for those who expect to graduate with a special diploma or do not plan to continue with post-secondary education. Some students and teachers felt it should also be offered to the general population of high school students. Importantly, based on data from student performance tests, classroom observation, and focus groups, the curriculum seems to be most relevant for PI students. Because these teens typically have complex medical conditions, the information they receive in the curriculum, and the health journal that each compiles, can be used immediately. While the curriculum material has important *future* implications for EMH and SLD students who may not currently experience serious medical issues, PI students arguably have the greatest potential to improve their present situation by applying health-related knowledge and self-management skills acquired in the course.

### Educator Training

Teachers in the focus group, all of whom participated in the intensive, 6-hour curriculum training session, said that the level of training for pilot teachers was appropriate. As noted earlier, respondents to the Educator Survey identified lack of information about health care transition as

a significant barrier to helping students in the process. Clearly, continued training and education are a critical first step to effect change in practice.

The relevance and value of provider training, in general, is reflected in the impact of the *Demonstration Model* on the development of a related program at the USF College of Medicine. Findings from the AAP-funded research project (Straub et al., 2005) used in planning the *Demonstration Model* were presented to physician faculty at USF in early 2005. In particular, researchers pointed to the lack of physicians who are knowledgeable about disabilities (especially childhood onset conditions) and are willing to assume responsibility for the care of young adults with disabilities or chronic illness. That is, there is an enormous lack of qualified adult health care practitioners for young people with disabilities to transition to. Moreover, very few medical schools provide training that specifically addresses the care of persons with disabilities despite the fact that approximately 1 in 5 people in the U.S. have a disability (USDHHS, 2000). Subsequent to that discussion, USF launched in Summer 2005 an innovative disability curriculum that is now required for all third year medical students.

#### **4. How can the *Demonstration Model* be improved for future implementation?**

Evaluation data generated a number of recommendations for future implementation of the program. Many of the suggestions came directly from teachers and students who participated in the curriculum and subsequent focus groups. In light of FDDC's interest in replicating the *Demonstration Model* in other Florida school districts, these recommendations provide a framework for improving and expanding the program within Hillsborough County and throughout the state.

- a. Develop a second version of the curriculum for students who read at the 3<sup>rd</sup> or 4<sup>th</sup> grade level. The current version, which is a 7<sup>th</sup> grade reading level, is appropriate for many higher functioning ESE students but difficult for lower functioning students.
- b. Consider the development of a third version of the curriculum for general education high school students. Many teachers felt that the material is relevant for all students, including those without disabilities.
- c. Expand the pilot to reach more students. Consider making the module a required course for all high school ESE students. Students who should receive the curriculum are listed in order of priority:
  - PI students
  - ESE students on a special-diploma track
  - All ESE students
  - Students who are not planning to continue with postsecondary education
  - All students
- d. Increase the implementation period to run from 9 to 18 weeks (one or two 9-week grading periods) depending on the pace of students in the class. Allow enough time for a unit review prior to each unit test.

- e. Add a unit on alcohol and drugs, and the dangers of high-risk behaviors. Add an activity on identifying and accessing appropriate community resources. Integrate additional mental health content into the curriculum, including how to access mental health services. Expand the abuse material to distinguish between different types of abuse and varying perceptions of abuse.
- f. Add words to the vocabulary list that are frequently used on medical forms, such as “occupation,” “spouse,” “primary” and “secondary” insurance, etc.
- g. Add color pictures, multi-sensory activities, and more hands-on/interactive assignments to the module. Alternate crossword puzzles with word searches, scrambled words, etc. Invite guest speakers when possible.
- h. Modify health journal assignments so that the class completes each journal activity as a group using a fictitious person as an example. Send blank copies of journal pages home with students, have them fill in their own health information with their parents’ assistance or oversight, and keep the forms at home for their personal health journal. By completely omitting student specific information in the classroom, the curriculum is better aligned with federal and state privacy guidelines (e.g., FERPA, HIPAA)
- i. Develop an accompanying instructional/training module for parents. Encourage ESE support staff (transition specialists, ESE specialists, parent liaisons, nurses, social workers) to proactively inform and engage parent participation in the training.
- j. Provide multiple, regularly scheduled trainings each year for high school ESE staff, nurses, and social workers.
- k. Develop a comprehensive training program concerning health care transition for community-based service providers, including physicians.
- l. Initiate a discussion with the FDOE about program replication in other school districts in the state. It is important to coordinate replication efforts with FDOE’s plans to expand *Standing Up for Me*, a statewide transition-related curriculum that may provide a companion piece on health care transition.
- m. In the long term, consider the development of a sequential series of modules that begins in middle school (7<sup>th</sup> or 8<sup>th</sup> grade) and continues through high school. This would provide opportunities for content to be expanded as well as reinforced as students’ progress through each grade.

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## Attachment 2

### Program Funding Budget

	Budget Plan	Actual Expenditures
<b>EXPENDITURES:</b>		
<b>Contractual Services</b>		
Project Management	5,000	4,746
Curriculum Development	1,000	1,000
Translation	400	700
Graphic Design	3,500	4,000
Technical Assistance	In-Kind	In-Kind
<b>Subtotal Contractual Services</b>	<b>9,900</b>	<b>10,446</b>
<b>Other Operating Costs</b>		
Training Materials	2,500	In-Kind
Production / Printing	13,550	16,140
Operating/Office Supplies	1,000	664
ADA Compliance	300	In-Kind
<b>Subtotal Other Operating Costs</b>	<b>17,350</b>	<b>16,804</b>
<b>Total Direct Expenditures</b>	<b>27,250</b>	<b>27,250</b>
<b>Overhead/Indirect Cost (10% )</b>	<b>2,720</b>	<b>2,720</b>
<b>TOTAL FDDC BUDGET</b>	<b>29,970</b>	<b>29,970</b>

<b>FDDC Expenditures</b>	<b>29,970</b>	<b>29,970</b>
<b>In-Kind Support</b>	<b>16,400</b>	<b>17,328</b>
<b>TOTAL PROGRAM COST</b>	<b>46,370</b>	<b>47,298</b>

## **Attachment 3**

### **Evaluation Instruments**

- A. Student Performance Test (Pre/Post)
- B. School Staff Survey (Pre/Post)
- C. Family Letter and Survey
- D. Student Focus Group Questions
- E. Teacher Focus Group Questions
- F. Classroom Observation Scale

## Assessment of Student Knowledge, Attitudes, and Skills Pre/Post Intervention Questionnaire

1. Please write the **last 4 digits** of your student number: \_\_\_\_\_
2. Read each statement below. Circle a number from 1 to 5 that describes how **OFTEN** you do each item.

- 1 = Never  
 2 = Sometimes  
 3 = Often  
 4 = Always  
 5 = This doesn't apply me

	Never	Sometimes	Often	Always	Doesn't Apply
a. I schedule my own doctor's appointments.	1	2	3	4	5
b. I understand my disability, medical condition, or special needs.	1	2	3	4	5
c. I can explain to other people about my disability, medical condition, or special needs.	1	2	3	4	5
d. I talk to my doctor without help from an adult.	1	2	3	4	5
e. I keep a list of emergency telephone numbers.	1	2	3	4	5
f. I use my health insurance card.	1	2	3	4	5
g. I participate in making decisions about my health care, such as choosing a doctor I like.	1	2	3	4	5
h. I fill out medical forms in the doctor's office.	1	2	3	4	5
i. I can describe my medications and dosages.	1	2	3	4	5
j. I take my medication without being reminded by an adult.	1	2	3	4	5
k. I understand my health insurance coverage. I know what is required for referrals, prescriptions, etc.	1	2	3	4	5
l. I have a place in my home where I keep important medical information.	1	2	3	4	5

3. John's doctor prescribed an antibiotic for his sore throat and cough. Read the prescription label for John's medication and answer the questions below.

Rx 3820819-03411	Bob's Pharmacy	Phone 813-927-0651
John Smith 1243 North St Boston MA	Dr. Anthony Carter	
Take 1 Capsule every six hours for 10 days.		
VIBRAMYCIN 500 MG Capsules QTY 42		
Refills - Dr. Authorization Required		Discard After 10/03/05
Directions: Medicine must be taken with food. Do not take on an empty stomach.		
WARNING: NOT TO BE TAKEN WITH DAIRY PRODUCTS.		

- a. If John takes his first dose at 11 AM, at what time should he take his second dose? \_\_\_\_\_
- b. If John starts feeling better before he is finished with his prescription, he is planning to stop taking the medicine and save it to use if he gets sick another time. Is this a good plan? \_\_\_\_\_
- c. Why or why isn't this a good plan? \_\_\_\_\_  
\_\_\_\_\_
- d. John feels the start of a bad migraine headache. He didn't tell the pharmacist or doctor who prescribed the antibiotic about the migraine medicine that he keeps at home. He isn't sure whether it's safe to mix the migraine medicine and the antibiotic. What should John do?  
\_\_\_\_\_
- e. John drinks a lot of milk, usually a glass at every meal. What does the prescription say about drinking milk with this antibiotic? \_\_\_\_\_
- f. As it turns out, John is still not feeling better after he finishes his prescription. He asks his pharmacist for a refill. What is the prescription number? \_\_\_\_\_
- g. What will the pharmacist say or do when John asks for a refill on this prescription?  
\_\_\_\_\_

4. Fill in the blank with the correct word or letter from the word bank.

<b>Word Bank:</b>	
A. Specialist	D. Pediatrician
B. Genital Herpes	E. Chlamydia
C. Primary Care Physician	

- a. A \_\_\_\_\_ is a doctor who provides regular medical check-ups and treats common health problems.
- b. \_\_\_\_\_ is a sexually transmitted disease that has no cure.
- c. A doctor who provides medical care for children (only) is called a \_\_\_\_\_.
- d. \_\_\_\_\_ is a sexually transmitted disease that is curable if discovered early and treated with antibiotics.
- e. A doctor who treats only certain disorders or diseases is called a \_\_\_\_\_.

5. Write True (T) or False (F).

- \_\_\_\_\_ a. Doctors do not typically ask their patients about medical problems that the patient's family members have experienced.
- \_\_\_\_\_ b. A young parent is legally responsible for providing child support starting at age 21.
- \_\_\_\_\_ c. A person who is constantly angry or worried has a health problem.
- \_\_\_\_\_ d. The amount of money that a person receives from a public assistance program such as Medicaid is determined by the amount of money he/she earns in a paid job.
- \_\_\_\_\_ e. Preventable injury is the leading cause of death among teens.
- \_\_\_\_\_ f. There are several methods that have proven 100% effective in preventing pregnancy and sexually transmitted diseases.
- \_\_\_\_\_ g. Guardianship is when an adult who might need help in making important decisions asks someone like a family member or friend for advice.
- \_\_\_\_\_ h. An 18 year-old is legally responsible for making all of his/her own medical decisions.
- \_\_\_\_\_ i. HIV blood tests are included in routine physicals at the doctor's office.
- \_\_\_\_\_ j. Friends can help protect you from bullying and sexual abuse.
- \_\_\_\_\_ k. A Health Care Summary can be used when visiting a new doctor or in an emergency.
- \_\_\_\_\_ l. Sexual health means being able to have a baby.
- \_\_\_\_\_ m. Employers are not required to offer medical and dental insurance to all of their employees.
- \_\_\_\_\_ n. Pediatricians can provide the services and medical tests that adults need to stay healthy.

6. This chart lists two health insurance plans, **Plan A** (HMO) and **Plan B** (PPO), that are offered to the employees of Company XYZ. Answer the questions below the chart about the monthly premium for four individuals/families that are eligible for coverage in the company plans.

	<b>PLAN A – HMO</b>	<b>PLAN B – PPO</b>
<b>Premium cost</b>	\$75 per month for the employee \$50 per month for a spouse \$25 per month per child under age 21 Children age 21 and over not covered	\$50 per month for the employee \$35 per month for a spouse \$15 per month per child under age 21 Children age 21 and over not covered
<b>Doctors</b>	Chosen by insurance company	Any doctor you choose
<b>Covered costs for doctor visits and hospital stays</b>	Covers 100% of doctor visits, including physicals. No charge for hospital stays if you go to a hospital selected by the insurance company.	You pay the first \$200 per year of any medical expenses. Then insurance pays 80% of all other costs.
<b>Prescription benefit</b>	\$10 co-pay for each prescription	\$10 co-pay for each prescription

- a. A single male employee pays \_\_\_\_\_ per month in Plan B.
- b. A female employee, her husband, and their 3-year old child pay \_\_\_\_\_ per month in Plan A.
- c. A female employee (divorced) and her two children ages 13 and 22 pay \_\_\_\_\_ per month in Plan A.
- d. Which plan has the least expensive premium for a male employee and his wife? \_\_\_\_\_

**The rest of the questions are about YOU.** Please **circle** one answer for each question.

7. I am:

- a. Male
- b. Female

8. I am in:

- a. 9th Grade
- b. 10th Grade
- c. 11th Grade
- d. 12th Grade

9. I am \_\_\_\_\_ years old.

10. My race or ethnicity is:

- a. Black or African American
- b. Hispanic or Latino
- c. White or Caucasian
- d. Asian or Pacific Islander
- e. Multiracial
- f. Other \_\_\_\_\_

11. I live with:

- a. my birth parents(s)
- b. my adoptive parent (s)
- c. my foster parent(s)
- d. relatives
- e. in a group home or facility
- f. Other \_\_\_\_\_

12. I receive services from the following Exceptional Student Education (ESE) program:

(check only one answer)

- a. \_\_\_\_\_ SLD – Specific Learning Disabilities
- b. \_\_\_\_\_ EMH – Educable Mentally Handicapped
- c. \_\_\_\_\_ PI – Physically Impaired
- d. \_\_\_\_\_ OHI – Other Health Impaired
- e. \_\_\_\_\_ TBI – Traumatic Brain Injury
- f. \_\_\_\_\_ LI – Language Impaired
- g. \_\_\_\_\_ Other (please list): \_\_\_\_\_
- h. \_\_\_\_\_ I don't know

## Health Care Transition Survey

This survey is part of a Demonstration Model for Health Care Transition Education funded by the Florida Developmental Disabilities Council, Inc. (FDDC) and conducted in partnership with the School District of Hillsborough County (SDHC), Florida Diagnostic and Learning Resource System (FDLRS), and the University of South Florida (USF). Survey questions were developed in collaboration with the University of Florida's Transition Center and Institute for Child Health Policy.

**For the purpose of this survey, health care transition is defined as a purposeful, planned process that supports youth and young adults with chronic health conditions and disabilities to move from child-centered (pediatric) to adult-oriented health-care providers, programs, and facilities.**

You are being asked to complete the survey because you work with secondary school students who receive services from the Exceptional Student Education (ESE) Program in Hillsborough County. You will also be asked to complete a subsequent questionnaire later in the school year.

The survey is designed to 1) collect information about knowledge, attitudes, and practices of school district personnel with respect to health care transition, 2) identify barriers to addressing health-related transition issues in schools, 3) assess health care transition information and training needs of school district personnel, and 4) evaluate the effectiveness of educational materials currently being distributed to ESE high school students and staff in Hillsborough County. The results from the surveys will be used by project partners to improve ways of addressing health-related transition issues in schools and to promote collaboration between educational and health care programs and services.

There are 8 questions on this survey. It is expected that the total completion time will be about 5-10 minutes. If you choose to participate, please complete the attached survey and return it to Janet Hess before you leave today's meeting. You may also fax your survey to her attention at (813) 681-7089.

Your participation is completely **voluntary**. By returning the survey, you are agreeing that you consent to participate. If you choose not to participate, or if you withdraw, it will not affect your relationship with SDHC, FDLRS, USF, or any other party. There is **minimal risk** to you to participate. Your privacy and research records will be kept **confidential**. Authorized research personnel, the USF Institutional Review Board and its staff and other individuals acting on behalf of USF, and the U.S. Department of Health and Human Services may inspect the records from this research project, but your individual responses will not be shared with anyone else. To protect the confidentiality of your responses, you will be asked for the last 4 digits (only) of your Social Security Number.

The results of this survey may be published. However, the data obtained from you will be combined with data from other people in the publication. The published results will not include your name or any other information that would personally identify you. If you have any questions about the study, please contact Janet Hess at (813) 653-3279. If you have questions about your rights as a person who is taking part in the research study, you may contact a member of the Division of Research Compliance of the University of South Florida at (813) 974-5638.

**Thank you for taking the time to participate in this important project!**



FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL, INC.

These materials were commissioned, funded, and sponsored by the Florida Developmental Disabilities Council, Incorporated, and produced through funding provided by the U.S. Department of Health and Human Services, Administration for Developmental Disabilities.

**START HERE. Please answer all questions on the front and back of the page.**

- 1) Please provide the *last 4 digits* of your Social Security Number: \_\_\_ \_\_\_ \_\_\_ \_\_\_
- 2) Which position best describes your role in the school district? (*circle one answer*)
- School Administrator
  - Social Worker
  - Nurse
  - ESE Teacher
  - Transition Specialist
  - ESE Specialist
  - Guidance Counselor
  - Other: (Please specify) \_\_\_\_\_

**These questions concern your knowledge, attitudes, and practices in health care transition.**

*For the purposes of this survey, health care transition is defined as a purposeful planned process that supports adolescents and young adults with chronic health conditions and disabilities to move from child-centered (pediatric) to adult-oriented health-care providers, programs, and facilities.*

- 3) Listed below are specific issues associated with health care transition. *Please rate your knowledge of each item.*

<b>Circle one number for each topic.</b>	I have <b>no knowledge</b> about this issue.	I know <b>very little</b> about this issue.	I know <b>something</b> about this issue.	I know a <b>great deal</b> about this issue.
a. Ways in which pediatric health care systems differ from adult service systems	1	2	3	4
b. Changes in eligibility for health insurance that may occur when a young adult reaches age 18, 21, or 23	1	2	3	4
c. Introducing and practicing health-related skills at appropriate ages/developmental stages (e.g., describing condition/disability, taking medicine independently, scheduling appointments, etc.)	1	2	3	4
d. Guardianship, Health Care Surrogates, and other health care decision-making alternatives	1	2	3	4
e. Finding appropriate adult physicians	1	2	3	4
f. Communicating effectively with providers	1	2	3	4
g. Developing a medical summary or care plan	1	2	3	4
h. Writing health-related goals in Transition IEPs	1	2	3	4
i. Accessing adult health services and facilities in the community	1	2	3	4

- 4) Overall, which statement best describes your knowledge of health care transition? (*circle one*)
- I have never heard of health care transition before taking this survey.
  - I know very little about health care transition.
  - I know something about health care transition.
  - I know a great deal about health care transition.

5) How important is it to include health-related goals, issues, tasks and concerns in the Transition IEP of students with chronic health conditions and disabilities? (*circle one*)

- a. Not important  
b. Somewhat important  
c. Very important  
d. Don't know/no opinion

6) The following is a list of specific goals, tasks, and issues that might be included in a Transition IEP. *Based on your experience, please rate how often each of the following is addressed in the Transition IEPs of students who may need assistance in these areas.*

<b>Circle one number for each item.</b>	Never	Rarely	Sometimes (50% of time)	Often	Almost always	Don't know
a. Self-determination and goal setting	1	2	3	4	5	6
b. Independence with self care (e.g., dressing, feeding, toileting)	1	2	3	4	5	6
c. Interpersonal communication skills/assertiveness	1	2	3	4	5	6
d. Use of transportation system or services	1	2	3	4	5	6
e. Identify and access agencies other than school system that can help achieve educational and vocational goals	1	2	3	4	5	6
f. Overall general health, including sex education, family planning	1	2	3	4	5	6
g. Knowledge of health condition/disability, medications, therapies	1	2	3	4	5	6
h. Knowledge of relationship between health condition/disability and future educational and vocational goals	1	2	3	4	5	6
i. Follow medication schedule, take medications independently	1	2	3	4	5	6
j. Knowledge of when and how to access urgent medical care	1	2	3	4	5	6
k. Maintaining a personal health record	1	2	3	4	5	6
l. Knowledge of insurance coverage, how to use plan's benefits	1	2	3	4	5	6
m. Complete health forms, communicate effectively with providers	1	2	3	4	5	6

7) Overall, how often are health-related issues currently addressed in Transition IEPs, based on your experience ? (*circle one*)

- a. Never  
b. Rarely  
c. Sometimes (50% of time)  
d. Often  
e. Almost always  
f. Don't know/doesn't apply

8) To what degree do the following factors stand in the way of including health related goals, issues, tasks, and concerns in Transition IEPs?

<b>Circle one number for each item.</b>	Not a barrier	A moderate barrier	A significant barrier	Don't Know
a. Lack of awareness/knowledge about the health care transition process	1	2	3	4
b. Perception that health issues are a low priority for Transition IEPs	1	2	3	4
c. Lack of a perceived mandate to include health-related issues	1	2	3	4
d. School district policies and procedures	1	2	3	4
e. Lack of tools/examples	1	2	3	4
f. Lack of time	1	2	3	4
g. Lack of funding	1	2	3	4
h. Family does not perceive importance of including health-related issues	1	2	3	4
i. School does not perceive importance of including health-related issues	1	2	3	4
j. Student does not perceive importance of including health-related issues	1	2	3	4

**Thank you for completing our survey! Your time and effort are truly appreciated.**



FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL, INC.  
This material is commissioned, funded, and sponsored by the Florida Developmental Disabilities Council, Incorporated, and produced through funding provided by the U.S. Department of Health and Human Services.

School District of Hillsborough County

FLORIDA DIAGNOSTIC & LEARNING  
RESOURCE SYSTEM

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May 2, 2005

Dear Parent or Guardian:

We hope you have had a chance to talk to your child about his or her participation this spring in the new instructional module on health care transition entitled *What's Health Got to Do with Transition?* We're excited about the opportunity to help students prepare to transition from pediatric to adult-oriented health care, become stronger self-advocates, and be more independent in managing their own health care.

You might remember from earlier correspondence that the curriculum is an 8-week course that began in late March and will continue through the end of the school year. It is part of a pilot project funded by the Florida Developmental Disabilities Council (FDDC) and conducted in partnership with the School District of Hillsborough County (SDHC), Florida Diagnostic Learning and Resource System (FDLRS), and the University of South Florida (USF). Your child is enrolled in one of 13 classes in Hillsborough County that were selected to participate in the instructional module. Approximately 175 high school ESE students from 5 different schools are currently receiving the pilot curriculum.

Researchers from USF would like to evaluate the program by (1) assessing your child's progress and interest in the curriculum, and (2) assessing your satisfaction with the pilot program. Outlined below is a description of the evaluation process for each.

**Students:** In order to measure the effectiveness of the program, researchers will assess each student's progress in meeting the curriculum's learning objectives. This part of the study will not require any additional time from students. Researchers will review and analyze data from two tests completed by each student, one before the curriculum started and one after it is completed. The tests measure knowledge and skills that students demonstrate with respect to health care transition. They also ask for some general information, such as age, grade, gender, race/ ethnicity, and ESE program. Students are not identified by name on the tests. Rather, code numbers are used to protect student confidentiality. All data will be combined so that individual students are not identified in the study.

In addition, a researcher may visit your child's class for general observation purposes, or the class may be selected to participate in a focus group. If his or her class is chosen for a focus group, it will be conducted during a regular class period and will last approximately 45 minutes. The purpose of the focus group is to find out what students like and don't like about the curriculum, which information is most valuable to them, and how they think the course can be improved for future students. A moderator will ask a series of questions, and students will have a discussion about the course. The moderator will take notes on what is said during the discussion; the session will also be tape recorded so that student comments are documented correctly. Student names will not be linked to any specific comments that are offered.

If you approve of your child's participation in these activities, you do not need to respond to this letter. If you do *not* wish for your child to participate, please sign and return the bottom portion of the letter to your child's teacher by **Friday, May 6**.

**Parents/Guardians:** Researchers also want to know how parents and guardians feel about the pilot program. Attached is a short survey that asks a few questions about your child's participation in the new curriculum. It also asks some questions about the health care transition information and resource guide that you recently received in the mail. Our goal is to make this program as helpful as possible in preparing your child for transition to adult-oriented health care.

There are 16 questions on the survey, and it is expected to take you about 5-10 minutes to answer the questions. You will not be identified by name on the survey. Instead, your survey will be assigned a code number to protect confidentiality. If you choose to participate, **please complete the survey and return it to your child's teacher by Monday, May 16.** If you would like help in completing the survey, or would prefer to answer the questions by telephone, you may contact the Project Director, Janet Hess, at (813) 653-3279. You may also fax or mail the survey directly to her (see contact information below). By returning the survey, you are agreeing that you consent to participate.

Participation in these evaluation activities is completely *voluntary* for both you and/or your child. If you choose not to participate, or if you withdraw, it will not affect your relationship with SDHC, FDLRS, USF, or any other party. There will be no grade penalty for students who choose not to participate in the study. There is *minimal risk* to for you and/or your child to participate. Your privacy and research records will be kept *confidential*. Authorized research personnel, the USF Institutional Review Board and its staff and other individuals acting on behalf of USF, and the U.S. Department of Health and Human Services may inspect the records from this research project, but your individual responses will not be shared with anyone else. All records will be kept in a locked storage cabinet by researchers for 3 years, and then will be destroyed by shredding.

The results of the evaluation may be published. However, data obtained from you and/or your child will be combined with data from other people in the study. The published results will not include your name or any other information that would personally identify you or your child. If you have any questions about the study, please contact Janet Hess. If you have questions about your rights as a person who is taking part in the research study, you may contact a member of the Division of Research Compliance of the University of South Florida at (813) 974-5638.

We really appreciate your time and help in making this program as valuable as possible to you and your child. Your participation can make a difference!

Sincerely,

Janet Hess, MPH, CHES  
Project Director and Co-Principal Investigator

Contact: [hessj@tampabay.rr.com](mailto:hessj@tampabay.rr.com)  
Phone (813) 653-3279 Fax (813) 681-7089  
4942 Willow Ridge Terrace  
Valrico, FL 33594

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**If you grant permission for your child to participate in evaluation activities it is NOT necessary to return this.** However, if you **DO NOT** wish for your child to participate in evaluation activities, please check (✓) the appropriate item(s) below, sign, and return this portion of the letter to your child's teacher by **Friday, May 6.**

I certify that I am the parent or guardian of \_\_\_\_\_ and **DO NOT** give permission for him/her to participate in the following evaluation activities:

\_\_\_\_\_*Review of student tests*    \_\_\_\_\_*Observation of class*    \_\_\_\_\_*Participation in a focus group*

Parent/Guardian Signature \_\_\_\_\_ Date \_\_\_\_\_

Teacher's Name \_\_\_\_\_ School \_\_\_\_\_





## Student Focus Group Questions

1. Let's first talk about the content of the curriculum. Do you think students need to receive instruction about health care transition? Why or why not?
2. Think about how you might use this information in your life. What do you think is the most important information in the course? What do you think is the least important information in the course?
3. Now let's talk about the way the lessons are designed. That may include how easy or hard it is to read the material, the length of time you spent on each unit, the way the test questions are written, and the activities in each unit.

What do you like most about the lessons and activities? What do you like least about the lessons and activities? How could they be improved for other students who take the course?

4. Let's talk specifically about developing your Health Journal. How important do you think a Health Journal is? Do you plan to use it? Why or why not?
5. Do you have any other suggestions about how to make the course more interesting or more helpful to students?

## Teacher Focus Group Questions

**Set up flip chart that lists the following items: readability, ease of understanding, complexity, relevance, completeness, interest level, enjoyment, accuracy. Have participants refer to the list when assessing the curriculum in its entirety as well as its component units.**

1. Let's talk first about the curriculum as a whole. What did you like most about the curriculum? What did you like least?
2. The flip chart has a list of items/attributes that we're going to use in discussing the curriculum. Think about these items in terms of your personal thoughts as well as feedback that you received from students. As we go down the list, I want you to tell us how satisfied you were with each. If you weren't satisfied, tell us why, and whether you have suggestions on how it might be improved.

### **Notes for moderator:**

- ♦ Readability - which classes is it appropriate for? how many versions should there be? at what reading levels?
  - ♦ Ease of understanding - difficulty in understanding concepts?
  - ♦ Structure – level of interest in content, activities? too repetitive?
  - ♦ Complexity – adequate timeframe to complete the curriculum? 1-2 weeks to cover each unit? 50-minute vs 90-minute blocks?
  - ♦ Completeness – more on mental health? add unit on risky behavior (alcohol, drugs)?
3. Now let's discuss each unit individually. For each one, please share with us any corrections, issues, and/or concerns, as well as your suggestions for improvement. Again, please refer to the list of items on the flipchart.

### **Notes for moderator:**

- ♦ Begin with Teacher's Guide, and move through Units 1 – 8
  - ♦ Did students fill out Health Journal forms/activities in class or at home? How much assistance did they need?
  - ♦ Were parents/families engaged in helping with Health Journal activities?
  - ♦ Did students or parents express privacy concerns?
4. What would you recommend that the school district do in the future with respect to implementing the curriculum?
  5. Are there any other comments you would like to make about the curriculum, or anything else you would do to improve the course for future teachers and students?

### Classroom Observation Scale

	A lot	-----	None	
Student participation in discussion	1	2	3	4 5
Student interest in topic	1	2	3	4 5
Student degree of understanding of topic	1	2	3	4 5
Student level of independence in completing assignments	1	2	3	4 5
Teacher fidelity of instruction w/respect to curriculum materials	1	2	3	4 5
Teacher enthusiasm	1	2	3	4 5
Teacher knowledge of topic	1	2	3	4 5

Date of observation: \_\_\_\_\_

Number of students in class: \_\_\_\_\_

Number of males: \_\_\_\_\_

Number of females: \_\_\_\_\_

Type of ESE service that students in class receive: \_\_\_\_\_

Number/types of student questions: \_\_\_\_\_

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## Attachment 4

### Materials Pretest Results

Educational materials were pretested among young adults, families, and service providers who participated in focus groups sponsored by the AAP CATCH Planning Funds (Straub et al, 2005). Surveys with accompanying information guides were mailed to 23 young adults/families and 103 providers, for a total of 126 surveys mailed. Completed surveys were returned by 8 young adults/families and 42 providers comprised of 6 physicians, 2 ARNPs, 19 RNs, 7 educators, and 8 other community-based providers (N=50). With two provider mailings returned undeliverable, this represents a 35% and 42% response rate for families and providers, respectively.

The *Family and Young Adult Survey* contained a total of 10 questions and the *Service Provider Survey* contained 12 questions. Overall reaction to the information guide among respondents was very favorable. With few exceptions, families and providers had similar responses when asked about various attributes of the guide and its contents. Service providers were asked to rate some elements both for themselves *and* for families (e.g., how helpful is the information to you? how helpful is the information likely to be to families?). Interestingly, the response in which families and professionals differed the most was their assessment of how easy the guide is for families to understand (i.e., complexity, clarity of text). On average, families rated it *very easy to easy*, and professionals rated it *moderately easy* to understand. See attached the attached chart for more detailed summary data.

The survey also provided opportunities for respondents to make suggestions for improvement and to add qualitative comments. The issue of potential difficulty that some families might have in understanding the text was reflected again in comments from several service providers. Other suggestions included adding a Table of Contents, having a detachable resource listings section, developing a separate guide for persons with significant developmental disabilities, adding subspecialty physicians, making the guide shorter, and adding notes pages and worksheets for families to use.

Although sample sizes were too small to generalize the data to the population at large, the sample data were extremely valuable for pretesting purposes. Many of the suggested changes were eventually incorporated into the guide, including simplifying the text as much as possible, adding a Table of Contents, and creating a detachable resource guide. The addition of attractive images to the product design should improve levels of interest and enjoyment in reading the material. The final version of the guide can be viewed at <http://usfpeds.hsc.usf.edu/adolescent>.

## Materials Pretest Summary Data

<u>Items</u>	<u>Families/Young Adults</u> (N = 8)	<u>Providers</u> (N = 42)
<i>Respondents were asked to rate the following from 1 (very positive) to 5 (very negative):</i>		
	<i>Mean Score</i>	<i>Mean Score</i>
<b>Completeness of content</b>	1.5	1.4
<b>Easy for families to understand</b>	1.4	2.2
<b>Overall helpfulness to families</b>	1.0	1.0
<b>Enjoyable to read</b>	1.8	--
<i>Respondents were asked to rate the following as very (1), somewhat (2), or not useful (3):</i>		
<b>Usefulness to families (by topic)</b>		
<b>Planning for change</b>	1.3	1.2
<b>Understanding adult vs pediatric systems</b>	1.4	1.1
<b>Paying for health care/insurance</b>	1.1	1.0
<b>Age 18 in legal terms</b>	1.3	1.1
<b>Practicing health-related skills</b>	1.4	1.2
<b>Using adult providers</b>	1.3	1.0
<b>Communicating effectively</b>	1.3	1.2
<b>Developing a medical summary</b>	1.3	1.1
<b>Seeking support from schools</b>	1.4	1.1
<b>Identifying community resources</b>	1.1	1.0
<i>Respondents were asked to answer Yes (1), No (2), or I don't know (3):</i>		
<b>Resource listings were complete</b>	63% Yes 25% No 13% DK	85% Yes 10% No 5% DK
<b>Resource listings were accurate</b>	100% Yes	85% Yes 15% DK