

Health Care Transition Summit

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FINAL REPORT

*Prepared by:
Margaret Lynn Duggar & Associates, Inc.
1018 Thomasville Rd., Suite 110
Tallahassee, FL 32303
Telephone: (850) 222-0080
Email: mlduggar@mlduggar.com*

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** includes trivia from warm-up and original copies of post-concurrent worksheets*

PART ONE: FOLLOW-UP REPORT

Part One of the Final Report covers meeting details and outcomes.

I. Welcome and Charge for the Day

Health/Prevention Program Manager for the Florida Developmental Disabilities Council Charlene Seal welcomed participants, made general announcements and highlighted the day's proceedings. The main focus of the day would be to brainstorm action steps on ways to make health care transition (HCT) a major focus in Florida. She noted that HCT is often left out of healthcare. The purpose of the day was to fill in this gap so that children and adolescents with developmental disabilities would receive – and know how to coordinate – the best health care possible.

Ms. Seal then introduced Dr. John Reiss, Chief of Policy and Program Affairs at the Institute for Child Health Policy, Associate Professor at the Department of Epidemiology and Health Policy Research and Department of Pediatrics, University of Florida, and the lead speaker for the day. Dr. Reiss introduced and thanked key participants in the Health Care Transition Summit, and then focused on the charge for the day: to determine ways to implement consistent health care transition into communities, school districts and throughout the state to improve the health care transition for children and adolescents with developmental disabilities.

According to the State Plan on Transition, Health Care Goal 2 states:

Persons with developmental disabilities will have access to adequate health care choices during lifespan transitions (birth through childhood, childhood through young adult, and adult to old age.)

Health Care Objective 2.1 states:

By 2011, ensure that health care transition needs are addressed as early as possible and at each lifespan stage.

With these goals and objectives in mind, health care professionals and educators participating in the Health Care Transition Summit would spend the next six hours identifying priorities and strategies for collaborating in order to facilitate quality HCT for children and adolescents with developmental disabilities (see Appendix A). The following is a summary of the process implemented to achieve this cross-discipline collaboration during the summit:

(I, Welcome, Cont.)

- * Participants from both fields had the opportunity to learn about HCT from the “opposite” field’s perspective during the morning concurrent sessions. (Educators learned about HCT from the health care professional’s perspective and health care professionals learned about HCT from an educator’s perspective.)
- * The two groups convened to share compelling ideas, facts and concepts from their concurrent sessions, informally referred to as “Aha’s!” during the summit.
- * All participants learned of cutting edge resources related to HCT through the presentation of a website and sample curriculum, as well as through networking opportunities.
- * Participants had the opportunity to network over a casual professional lunch.
- * The last two hours of the Summit were dedicated to idea generation to determine practical solutions to the health care transition issue.

II. Guest Speaker Annie Wildeman

Dr. Reiss introduced Janet Hess, Consultant and Project Director for Kid Connection Network and the facilitator of the next item on the agenda – a Question and Answer dialogue with Annie Wildeman, a 20 year-old young woman with a developmental disability and experience with HCT. Ms. Hess stated that many people have perspectives on health care and health care transition, but the real experts are the young people and their families who go through the system and face its challenges. She then posed a series of questions to Ms. Wildeman about her HCT experiences. The following is a summary of the dialogue:

Q: Can you start by telling us a little about yourself?

A: My name is Anayansi Wildeman. I go to school at Alonso High School and I’m a senior; I am 20 years old and still going!

Q: Will you tell us a little bit about your family?

My mom Anayansi is here – she helps me out.

Q: What do you want to do after high school?

A: I want to be a radio broadcaster. I want to talk to people about their problems and help them out with their situations. After the newspaper article [the Tampa Tribune published an article on May 18 about Annie’s accomplishment in graduating from high school] I was offered a job as a consultant. I will have a special diploma – I know I’m a smart person, I know I have the brains but [the school system] sees that I have a disability and therefore they put me in the back [in special education.]

(II., Guest Speaker, Cont.)

Q: Tell us about some of your special health care needs and your medical condition.

I go to all kinds of doctors – eyes, ears, skin, bone, dentist – you name it, I’m there! It’s like they don’t know what to do with me [Annie described how she will go to one doctor and he/she will refer her to another doctor, who will refer her again, and so on.] It’s horrible, it really is.

Q: What could happen to help you, that might make you more independent and less dependent on your mom and other family members?

A: A nurse in the house would be good for the both of us – this way I could do my thing, and my mom could do her thing. We’re together all the time and I’m not saying it’s bad, but it [would help ease occasional tension.] A help dog would be good, too. Instead of having to say, “Mom! I dropped this!” I could get the dog to pick it up. I don’t really like to bug [my mom] – I don’t like to bug anybody, really.

Q: What do you think would be helpful for other young people as they are transitioning into adulthood?

A: Well first off, try to help them find another doctor. That would help the [young adult] and their family, too. If they can find [a doctor for their adulthood years] then maybe, just maybe, things would be a whole lot better.

Ms. Wildeman then addressed the topic of how her faith plays a role in helping her to cope with her condition of *Osteogenesis Imperfecta*, or “OI.” She said, “When I pray, I don’t pray for myself, I pray for my friends and family; all I ask is for one more day – that’s all the miracle I need!”

The Question and Answer dialogue concluded with participants offering suggestions and responses to Ms. Wildeman. It was suggested that she investigate South East Eye Dogs and Canine Companions for Independence. Dr. Reiss commented that in his experience with adolescents with developmental disabilities, the young people are more concerned about their families and the strain their condition puts on them rather than on themselves: “What is needed is empathy, understanding and mutual support.”

III. Concurrent Sessions

A. Concurrent Session for Health Care Professionals

Warm-Up: Participants in this concurrent session began by introducing themselves, their agencies and the first thing that comes to mind when considering health care transition. Next, they pulled a fact about health care transition out of a Trivia Hat and read it to their small group. Aileen Millan drew a “wildcard” from the hat and received a gift certificate to Chili’s during the Networking Lunch awards ceremony.

Presentation: The objective of this presentation was to develop an understanding among health care professionals about HCT in the educational system in three areas:

- Education-based transition services
- Ways to include health care transition in planning
- Interagency collaboration and systems changes

These objectives were met by the following speakers in a presentation entitled *Education-Based Transition Services*:

Dr. Jeanne Repetto, Associate Professor, College of Education, University of Florida;

Sheila Gritz, Senior Training Specialist, Florida Self-Determination Initiative, The Transition Center at University of Florida; and

Joyce Lubbers, Project Connect Coordinator, The Transition Center at University of Florida

Dr. Repetto, Ms. Gritz and Ms. Lubbers reviewed the definition of health care transition from an educational perspective. The term encompasses the following concepts and qualities:

- * Change
- * Happens throughout life
- * Occurs across all areas of life
- * Happens to everyone
- * Requires support and planning

Next, they reviewed current transition requirements and services. IDEA 2004 requires addressing transition in a student’s Individualized Education Program (IEP) no later than age 16. SB Education Rule 6A-6.03028 requires that transition services be addressed by age 14.

Some aspects of transition services – a coordinated set of activities for a student with a disability – are that they:

- * are designed with an outcome-oriented process and based upon a student’s desired post-school outcomes
- * are based on the individual student’s needs.

Post school outcomes, generated by the student, range from post-secondary education and/or vocational training to integrated employment, independent living and community participation.

(IIIA, Concurrent Session for Educators, Cont.)

A major emphasis of this presentation was the presentation of a model Individualized Education Program and a transition curriculum, thus providing health care professionals with an understanding of “what’s going on in the educational arena” related to HCT. Thus, participants reviewed the main idea behind a transition IEP, according to the *Education-Based Transition Services* presentation. First, all students with disabilities who are age 14 or older should have a Transition IEP, which identifies the educational programs and services – in multiple domains – needed by the child to be successful on school and post-school adult life. It should contain a desired post-school outcome statement; a present-level of educational performance; measurable annual goals; benchmarks/short term objectives; agency responsibilities and linkages. A sample Transition IEP was provided to the group, which discussed how to integrate HCT into the school setting.

Speakers reviewed an effective curriculum for transition entitled *Standing Up for Me*, developed collaboratively by the Transition Center and the Institute for Child Health Policy, with support from the UF Institute for Child and Adolescent Research and Evaluation. *Standing Up for Me* is a set up supplemental lesson plans to teach students important aspects of HCT. A core principle of this curriculum is self-advocacy, or the empowerment of the student-patient to make his or her own HCT choices.

To conclude the presentation, speakers led the participants in a discussion of opportunities for collaboration at the state level and how Project CONNECT – a statewide initiative that focuses on improving interagency collaboration in Transition planning at the community level through the formation or revitalization of local community transition teams – is helping to meet this objective.

Outcome: Participants concluded the concurrent session by offering to the facilitator the top compelling ideas and concepts from the presentation (“Ahas!”) and filling out a worksheet on which they could offer ideas, suggestions or questions that were not raised during the discussion. For a compilation of the top compelling concepts, ideas and facts from this concurrent session, as determined by the health care professional participants, refer to section 3C. For a compilation of participants’ post-concurrent session ideas, questions and suggestions, as captured on the handout, please refer to Appendix B.

B. Concurrent Session for Educators

Warm-Up: Participants in this concurrent session began by breaking into 3 small groups of approximately 6 people in each group. They introduced themselves, their agency and the first thing that comes to mind when considering health care transition. Next they pulled a fact about health care transition out of a Trivia Hat and read it to their small group. Susan Reed from Children's Medical Services in Orlando drew a "wildcard" from the hat and received a gift certificate to Chili's during the Networking Lunch awards ceremony.

Presentation: Attendees next heard a presentation by Dr. John Reiss and Dr. Robert Gibson, Research Associate at the Institute for Child Health Policy of the University of Florida, on health care transition entitled *Health Care Transition 101 (for Educators)*. The following is a summary of the highlights from the presentation and the discussion it generated. Summary notes of the presentation are in regular text; participant comments are notated with *italics*.

Dr. Reiss and Dr. Gibson began by giving an overview of the ideas they wished to address:

- What is Health Care Transition?
- Who needs HCT services and support?
- Why is HCT a new-emerging issue;
- Why HCT is difficult to implement;
- What are some promising practices in the field of HCT?
- What are the issues and opportunities for partnership?

From a health care professional's perspective, HCT is defined as:

The purposeful and planned movement of adolescents and young adults with chronic physical and medical conditions from a child-centered to adult oriented health care system.

Participants learned that Health Care Transition, as defined above, is difficult to implement because of four reasons:

- 1) the present health care system
- 2) physician knowledge, experience, and values
- 3) the lack of health and education linkages
- 4) the lack of models, evidence and mandates

To address these four concerns, participants first reviewed the ways that health care systems have changed over the past 30 years. It has shifted from a paradigm of institutional-based care of defects in the 1970's to a hospital and community based care of children by professionals in the 1980s to a present-day concept of community based care for children and families through professional-family partnerships. These concepts generated the following comments:

(IIIB. Concurrent Session for Educators, cont.)

We need a medical doctor that will meet the needs of adolescents with developmental disabilities. The challenge is finding resources and providers that the child feels comfortable with.

Health Care Transition is a curriculum and education issue, too. We need purposeful and planned HCT.

Those who need HCT are children and youth who need to be prepared for the transfer to adult care. For those with disabilities and chronic health conditions, a smooth transfer is especially critical.

Some health care professionals are afraid of people with disabilities.

The young person with the developmental disability is the expert in care and teaching.

You cannot deal with people with developmental disabilities in 15-minute blocks.

A lot of families are concerned about diagnosis and whether they could apply learning and daily living skills to healthcare.

Some nurses are involved in IEP meetings and we are making sure that there are frequent bathroom breaks, snacks and allowances to visit the school nurse without permission.

There is a definite need for this process to come into schools.

The environment in which a physician works is an important part of the systems change that is needed – a universal design is needed. Too often a child with a developmental disability is referred to as “handicapped” or “disabled” rather than as a person with a disability or a person with a handicap.

Dr. Gibson noted that typically, health care needs are not addressed in IEPs. The “check out time” from pediatrics is the time at which “transfer” takes place, a kind of transition. Another kind of health care transition is when individuals change from one primary or specialty care provider to another. Two promising practices that Dr. Reiss presented concerned youth and family education and preparation. The idea is to “help youth acquire knowledge and skills needed to interact independently and effectively with the adult health care system.” It also supports families during the “let go” and “let grow” process – a process that individuals must experience as they transition from adolescence to young adulthood. Other promising practices that Dr. Reiss and Dr. Gibson presented included: providing opportunities for skill development in real-life settings and the “holistic approach,” that addresses “health, work, play, love and in(ter)dependence.”

(IIIB. Concurrent Session for Educators, cont.)

Participants also learned about the three stages of health care transition:

- 1) envisioning a future
- 2) the age of responsibility
- 3) the age of transition

Each stage was discussed in detail, followed by a discussion of resources available to help facilitate and implement each stage. One such resource is a new website available to young adults with developmental disabilities, *Envision My Future: A Young Person's Guide to Health Care Transition*, located in PDF format at http://hctransitions.ichp.ufl.edu/pdfs/envisioning_my_future_gray.pdf. This resource was developed for kids and their families as a training website in transition. Another website located at www.cms-kids.com describes the Children's Medical Services (CMS) program that provides children with special health care needs with a family centered, managed system of care. Finally, <http://hctransitions.ichp.ufl.edu/> provides links to several HCT resources, including access to a list serve on HCT.

Outcome: Participants concluded the concurrent session by offering to the facilitator the top compelling fact, ideas and concepts from the presentation (“Ahas!”) and filling out a worksheet where they could offer ideas, suggestions or questions that were not raised during the discussion. For a compilation of the top compelling concepts, ideas and facts from this concurrent session, as determined by the educator participants, refer to section 3C. For a compilation of participants’ post-concurrent session ideas, questions and suggestions, as captured on a handout provided by the facilitator, please refer to Appendix C.

C. Whole Group: Concurrent Session Summary Reports

The following is a compilation of the compelling ideas and facts (“Aha’s!”) noted by participants in the 10:00 a.m. Concurrent Sessions:

Health Care Professionals	Educators
1. <i>Standing Up for Me</i> (curriculum) is an empowering, standardized method for educating and forming self-advocates.	1. Primary Care and transition go hand in hand.
2. Positive responses from teachers are needed [for students with developmental disabilities] to their HCT needs.	2. Communication between all parties involved in an adolescents’ health care transition is critical.
3. The transition process starts at age 14 or earlier. “Womb to tomb” care is needed.	3. We need to work on integrating healthcare into IEPs and 504s/daily living recommendations.
4. Project <u>CONNECT</u> focuses on collaboration; people can volunteer to help this effort (State Department of Education to review approval)	4. We need to answer the question: “How do we know it [HCT] is working?”
5. Medical professional involvement is needed in the IEP process.	5. Parents, teachers, physicians and the students themselves need support and information
	6. Legal aid referrals are available (colleges and law schools; law students work with individuals)
	7. We need to nurture students and adolescents with disabilities into being self-advocates.
	8. Funding!

IV. HCT Resources: Website, Networking and Curriculum

A. Website

Dr. Reiss and Dr. Gibson presented a structured orientation to the Florida Developmental Disabilities Council Health Care Transition training website located at <http://hctransitions.ichp.ufl.edu/ddcouncil>. The website features an introduction to HCT and then four chapters on the consumer perspective; school, vocational, and legal systems; promising practices for HCT; and developing HCT plans. It was noted that this content is of value to both to educators and health care professionals, but is geared toward an audience of parents and older youth.

The audience can go through the training course at their own pace, viewing the 4-5 slide show presentations offered in every chapter as their schedule allows. Each slide show presentation is approximately 15 minutes long and has an accompanying audio track. Other website features include video clips, written documents and a resource section. Participants questioned whether the website was developed with ADA needs in mind. Dr. Reiss said that it does meet all of the ADA requirements, and that it passed the ADA Clearinghouse in Tallahassee.

B. Networking

Summit participants took a break at 12:15 PM for a networking lunch. During this time, professionals from across Florida, practicing in either the field of education or the field of health care, had the opportunity to network with each other. The lunch also allowed Summit participants time to complete a “Networking Scavenger Hunt” handed out at the registration table that morning. The scavenger hunt was designed as an icebreaker as well as a fun way for the participants to discover interesting facts about each other, especially as related to HCT.

The atmosphere at the 2006 Health Care Transition Summit was congenial, and many participants later commented that this time was very valuable to them in forging connections that they otherwise would not have made; they also said that the summit provided them with new contacts to utilize as a resource in the area of health care transition (see Appendix D).

C. Curriculum

Dr. Reiss introduced Janet Hess, MPH, CHES, Consultant and Project Director, Kid Connection Network, who presented a health care transition curriculum entitled *What's Health Got to Do with Transition? A Multi-Level Health Care Transition Education Program*. The presentation consisted of three main sections: she began by giving an overview of HCT and the school setting; then she discussed *A Demonstration Model for School-Based Health Care Transition Education*; finally, she highlighted opportunities for replication of the curriculum presented.

(IVC., Curriculum, Cont.)

Participants learned that HCT is important in the schools because “skills used in transition are similar to other expectations of independence; school provides a practical and comfortable learning environment; the school setting provides an opportunity to reach a large percentage of students with disabilities; and the school setting provides opportunities to coordinate with the IEP process.” Next, Ms. Hess gave a close analysis of *A Demonstration Model for School-Based Health Care Transition Education*, a comprehensive health care transition project implemented in the Hillsborough County School District in Tampa in 2005, funded by the Florida Developmental Disabilities Council, Inc. (FDDC). Its core strategies are:

- 1) to disseminate HCT information and a Resource guide to families and providers
- 2) to train school district staff to include HCT goals and activities in IEPs
- 3) to pilot a curriculum in selected high school classes

To achieve the first objective, *What's Health Got to Do with Transition?* booklets were printed, which contained the core HCT information and resources. Ten thousand copies were printed in English; 1,000 in Spanish and more are available as needed in Braille and large print; approximately 6,700 high school students received the booklet in the mail. To achieve the second objective, presentations were made to 332 secondary school staff at district wide departmental meetings in order to introduce HCT concepts and how to include HCT on the IEP. Teachers also received intense training on a HCT curriculum, piloted among 137 students, 13 classes and 5 schools in order to meet the third objective of the project.

The HCT curriculum is the core of the HCT project. Targeted to high school students with SLD, EMH or PI (Specific Learning Disabilities, Educable Mentally Handicapped and Physically Impaired) between the ages of 14 and 22, it is designed for science, health and life management classes. It features a comprehensive teacher's guide with an answer key and activities, pre and post student tests, field trip and guest speaker opportunities, and a take home Health Journal. Based on the results of the curriculum evaluation, the curriculum generated a “high level of interest, perceived relevance, and satisfaction among students, teachers and families.” The evaluation also concluded that, among students exposed to the curriculum, “a statistically significant increase in knowledge among students and consistent but small gains in frequency of performing health-related skills” had taken place.

Ms. Hess concluded her presentation with recommendations based on the curriculum and opportunities to replicate the program piloted in Hillsborough County. Students exposed to this curriculum appreciated the basic information it provides on “teen topics” such as sex, alcohol and drugs (the Sexual Health and Substance Abuse units overlap with regular Health classes). After Ms. Hess's presentation, Tampa-area teacher Diana Pollard and her student Mario spoke about the positive impact the curriculum had on both of their experiences with health care transition.

V. Whole Group Collaboration

The remainder of the Health Care Transition Summit was dedicated to identifying solutions to integrate health care transition programs into schools and agencies throughout the state. This was achieved by the following Q&A process:

A. Brainstorming

Dr. Reiss began the afternoon session by reminding participants of the overall FDDC mission and of the Goals/Objectives associated with Health Care Transition. He highlighted the complex delivery system in Florida that is currently in place to carry out the above mission and goals/objectives as related to HCT. Dr. Reiss noted that the complexity of the delivery system results from complicated solutions developed independently by many different entities. Both health care professionals and educators were convened to resolve this difficulty by collectively identifying practical solutions to integrate HCT programs into the schools, communities and throughout the state. To begin, participants engaged in a brainstorming activity to compile information that they had learned about health care transition during the day.

After listing their **discoveries and knowledge**, Dr. Reiss led participants in a discussion of the opportunities that Health Care Professionals have to **positively impact** educators & education and vice versa, in order to improve HCT for children and adolescents with developmental disabilities, and to ensure collaborative and consistent HCT programs in the schools & communities (Part 2, Tables 1 & 2)

The brainstorming period concluded with a discussion of three critical areas of focus for health care transition for the adolescent as well as for parents and providers: **communication, education and collaboration**. Participants discussed the ways that important steps we can take to ensure that children and teens know how to communicate with their doctors, make appointments, and make informed health decisions. Then they considered how to ensure that parents and caregivers are learning about changes in health care needs, services and insurance as youth transition into adulthood. Lastly, they examined how ways to facilitate collaboration between youth, family, doctors and providers so that they are all working together to plan for a child's/adolescent's needed skills and services. (Part 2, Table 3)

Once the above ideas had been captured, participants considered "How can we make it happen?" by examining the **barriers and resources** – the current landscape of health care transition – that would either facilitate or impede the implementation steps. (Part 2, Table 4)

B. Ranking and Blueprinting

After the discussion period, participants received ten sticker “dots” in red and green. They were asked to use 5 red dots to rank the education strategies that they recommend FDDC undertake as necessary priorities. Some participants felt that particular strategies were so critical that they placed all five dots next to that strategy. Similarly, participants used 5 green dots to rank the health care strategies.

Facilitators counted those health care and education strategies that received the most dots and compiled a single flip chart sheet of the top 5 ranked items from each category (education and health care) for a total of ten strategies. Discussion of the ten top-ranking strategies followed, according to which items are that can happen now, and which items are critical.

VII. Conclusion

The session concluded with a request that attendees fill out a Session Evaluation and Customer Satisfaction Survey (See Appendix D for results).

Facilitators observed that the Health Care Transition Summit met the objectives and outcomes as recommended by FDDC and as noted in Page 8 of the process agenda (See Appendix F). The following summarizes these outcomes:

A. Outcomes of Morning Session

Based on the facilitator’s observations of the 9:30 AM – 12:15 portion of the agenda, participants engaged in the following activities:

1. Strengthened their familiarity with FDDC’s State Plan, particularly its Health Care Transition Goal & Objective.
2. Gained an understanding, from an individual’s perspective, the challenges and opportunities that the current health care transition landscape offers.
3. Networked with key players in health care transition from both the educational and health care fields.
4. Engaged in rich discussion on what health care transition is and how it is currently implemented in schools and the community.
5. Built consensus by sharing knowledge on critical and compelling health care transition theories, ideas, websites & resources, research and curriculum.

B. Outcomes of Afternoon Session

Based on the facilitator's observations of the 1:00 PM – 4:00 PM portion of the agenda, participants engaged in the following activities:

1. Were exposed to, and responded to, a model health care transition curriculum.
2. Made observations about the current complex delivery system and practical solutions to integrate health care transition programs.
3. Generated implementation steps to improve the health care transition for children and adolescents with developmental disabilities by discussing:
 - A) **Curriculum** on Health Care Transition
 - B) **Communication** skills for children/teens to communicate with doctors, schedule appointments and make informed health care decisions
 - C) **Collaboration** of youth, family, doctors, and caregivers
 - D) **Knowledge** of health care services and insurance
4. Prioritized the implementation steps (for an improved, collaborative health care transition program) by assigning objectives and strategies to create a blueprint of recommendations for future use by FDDC.

PART TWO: SUMMARY EVALUATION REPORT

Part Two includes recommendations and observations made by the Provider.

I. Compilation and Analysis of Responses from Whole Group Collaboration

The following is an outline of the questions and topics posed to summit participants (A-D), followed by (E) a compilation and analysis of their responses in table format. See Part One for a summary of the process implemented to generate participant input.

A. Discoveries and Knowledge

Dr. Reiss asked participants:

- i. ***“What do you know from your field about health care transition and what did you learn from the “opposite group” (from the educators if you are a health care professional and from the health care professionals if you are an educator)?”***

Facilitators recorded responses on Flip Chart 1: Health Care Professionals & Health Care on a sheet entitled “Discoveries & Knowledge” and Flip Chart 2: Educators & Education on a sheet with the same title.

B. Implementation

Next, Dr. Reiss focused the group’s attention on “what can be done” – those activities that can be readily implemented – based on the discoveries and knowledge that were recorded. He asked:

“In order to improve HCT for children & adolescents with developmental disabilities, and in order to ensure collaborative & consistent HCT programs in the schools& communities,

- i. ***What are the opportunities that health care professionals have to positively impact educators/ education?”***
- ii. ***What are the opportunities that educators have to positively impact health care professionals/health care?”***

C. Communication, Education and Collaboration

The next series of questions focused on how to communicate, educate and collaborate about HCT, based on the recommended strategies generated from Implementation Question B. The facilitator led the remaining portion of the Question and Answer Session by asking:

- i. ***“What are the most important steps we can take to ensure that children and teens know how to communicate with their doctors, make appointments, and make informed health decisions? “***
- ii. ***“How can we ensure that parents and caregivers are learning about changes in Health Care needs, services, and insurance as youth transition into adulthood?”***
- iii. ***“How can we ensure that youth, family, doctors, and providers are working together to plan for a child’s/adolescent’s needed skills & services?”***

D. Current Landscape

The last portion of the Question and Answer Session focused on an examination of the current landscape of health care transition. Participants were asked:

- i. ***“What are the barriers and resources that must be considered when making these opportunities happen?”***

E. Compilation and Analysis of Responses

The following tables summarize the responses to the above questions:

TABLE 1

A. Discoveries and Knowledge

What do you know from your field about health care transition and what did you learn from the “opposite group” (from the educators if you are a health care professional and from the health care professionals if you are an educator)?

Educators	Health Care Professionals
<p>1. The level of parents’ education, for all socio-economic and educational backgrounds is a factor in successful health care transition; a parent guide is needed.</p> <p>2. The Project Connect Team is a valuable resource providing collaboration and student input (reference www.thetransitioncenter.org for more details).</p> <p>3. Two to five transition specialists in each school is an excellent idea.</p>	<p>1. The school curriculum and the availability of materials were both discoveries from today’s summit.</p> <p>2. CMS can identify a transition specialist (to provide a resource for the offices – both school and physician offices)</p> <p>3. The link between the Project Connect team and consumer Advocates is a positive ongoing activity.</p>

TABLE 2

B. Implementation

In order to improve HCT for children & adolescents with developmental disabilities, and in order to ensure collaborative & consistent HCT programs in the schools & communities:

Strategies for Health Care to Impact Education

i. What are the opportunities that health care professionals have to positively impact educators/ education?

- Stay in touch with school nurses
- Social workers can partner with teachers, parents, etc.
- Educate school systems on CMS via presentations at schools and at CMS
- Coordinate a memorandum of agreement (MOA) between Department of Education, Department of Health, Juvenile Justice and other entities that commits signers to collaboration, especially on health
- Encourage and promote pediatricians' interest in school activities
- Facilitate health literacy/communication between HMOs, Medicaid and the role of parental responsibility
- Promote (medical) Resident Education and curriculum that included HCT, especially for medical schools with pediatrics programs; allow for input from parents into the program and curriculum planning

Impact of Education on Healthcare

ii. What are the opportunities that educators have to positively impact health care professionals/health care?

- Give health care contact information to both schools and physicians; build relationships and put information where professionals can access it
- Encourage teachers to make references to CMS
- Address the fact that some teachers are intimidated by contacting healthcare professionals and/or by legal issues questions as related to HCT
- Utilize family support networks to get the HCT information out
- Health care professionals should be available for the IEP and request a copy of it
- Partner; both health care professionals and educators are working toward the same goal and can achieve the best interest of the consumer as a result of partnering
- Cross train professionals (involved in HCT)

(Table 2, Impact on Education, cont.)

- Launch a statewide (medical) residency education program re: health care transition
- Implement Third-Year medical student classes on serving people with disabilities; Offer this subject as specialty area/specialization available to medical students
- Emphasize physician education (or all health care professionals) especially as related to communication with patients who have developmental disabilities

(Table 2, Impact on Health Care, cont.)

- Promote the expectation among physicians that the family helps with planning for HCT
- Start a Pediatrician/Teacher Team to have discussion with Managed Care entities about the student-patient's needs
Start a system at schools that puts CMS as a contact for teachers
- Get the patient-student more involved in their own HCT planning (more involved children are more compliant)
- Advocate student independence to increase later quality of life
- Start transition early (11-12 years old) and get the parents to attend the IEP meetings

TABLE 3

C. Communication , Education and Collaboration

i. Communication

What are the most important steps we can take to ensure that children and teens know how to communicate with their doctors, make appointments, and make informed health decisions?

- Listen to the consumer/child (this includes everyone – doctors, teachers, parents, caregivers, etc.)
- Direct questions to the consumer/child (a 12 year-old is cognitively able to have questions directed to them)
- Involve children/consumer in the conversation on health
- Encourage parents to learn from the students' curriculum (youth teach parents)
- Communicate at all levels and stages of the HCT process
- Provide alternative formats to share information

ii. Education

How can we ensure that parents and caregivers are learning about changes in Health Care needs, services, and insurance as youth transition into adulthood?

- Plan for Health Literacy education in the schools for both students and parents
- College courses (for medicine, nursing education, and other medically-related courses) do not clearly define health care transition in the course descriptions and HCT is not clearly identified in the curriculum

(Table 3, Education, cont.)

- Share information that would facilitate pediatrician's comfort with referring the student-patient to another physician for adult care)
- The consumer needs a place to transition to, so emphasize the training of third-year medical students in this area
- Facilitate teachers' communication with physicians to eliminate the barrier of the discomfort some educators experience when communicating with physicians
- Use CMS as a contact for teachers

iii. Collaboration

How can we ensure that youth, family, doctors, and providers are working together to plan for a child's/adolescent's needed skills & services?

- Don't assume it (HCT) will happen on its own
- Utilize electronic media to facilitate communication among all parties involved in HCT (i.e. video conference an IEP meeting so physician can attend)
- Educate students that they have the right to invite who they want to the IEP
- Follow up with the agencies that the consumer is using
- Distribute HCT Fact Sheets to parents with Frequently Asked Questions

TABLE 4

D. Current Landscape

What are the barriers and resources that must be considered when making these opportunities happen?

Barriers	Resources
<ul style="list-style-type: none">● Funding needs to increase● The education level of parents about HCT● Communication● Transportation (getting to IEP meetings and doctors' offices)● Time conflicts (not flexible to working parents)● Competing initiatives● Language, legal status and culture	<ul style="list-style-type: none">● Advocacy Groups● Statewide expertise for sharing HCT information (See Appendix A, List of Attendees for a list of agencies with information on – and an interest in – HCT)

II. Ranking

Next, participants ranked the implementation steps that they perceived as the most critical to health care transition in Florida. They did so by placing dots beside those opportunities that they recommend FDDC undertakes as necessary priorities from among those listed above (Item IA-D, Tables 1-4)

TABLE 5

<u>Top-Ranked Priorities</u>	
Educators	Health Care
<p>1. HMO's, Medicaid, Health Literacy and parent responsibility</p> <p><i>Facilitate health literacy/communication between HMOs, Medicaid and the role of parental responsibility</i></p> <p>2. (Tie) A) Resident Education and Curriculum, specialization</p> <p><i>Promote (medical) Resident Education and curriculum that included HCT, especially for medical schools with pediatrics programs; allow for input from parents into the program and curriculum planning</i></p> <p>B) Educate schools on CMS and vice versa</p> <p><i>Educate school systems on CMS via presentations at schools and at CMS</i></p> <p>3. Parent Education</p> <p><i>Plan for Health Literacy education in the schools for both students parents; Encourage parents to learn from the students' curriculum (youth teach parents)</i></p>	<p>1. Promote the expectation among physicians that the family helps with planning for HCT</p> <p>2. Cross training of professionals involved in HCT</p> <p>3. Get the child/consumer more involved in the conversation on health care transition and in their own HCT planning</p>

(Table 5, Educator Priorities, cont.)

4. Physician Education

College courses (for medicine, nursing education, and other medically-related courses) do not clearly define health care transition in the course descriptions and HCT is not clearly identified in the curriculum; Share information that would facilitate pediatrician's comfort with referring the student-patient to another physician for adult care)

5. Coordinate partnerships between Social Workers and teachers, parents, physicians, etc.

(Table 5, Health Care Priorities, cont.)

4. CMS can identify transition specialists

5. Tie health literacy to students and parents; make school curriculum and other materials available to all

III. BLUEPRINT

Based on the results of the ranking, MLD&A recommends the following action steps, prioritized according to participants recommendations on: A) Which strategies are critical (must happen in order for a successful statewide, collaborative system of health care transition)? B) Which strategies can happen now (the resources, timing, and momentum are in place and make the actions possible)?

TABLE 6

<p align="center"><u>Critical Strategies</u> Which strategies are critical (must happen in order for a successful statewide, collaborative system of health care transition)?</p>	<p align="center"><u>Strategies That Can Happen Now</u> Which strategies can happen now (the resources, timing, and momentum exist now, and make the actions possible)?</p>
<p align="center">Cross training of professionals involved in HCT</p>	<p align="center">Facilitate health literacy/communication between HMOs, Medicaid and the role of parental responsibility</p>
<p align="center">Promote the expectation among physicians that the family helps with planning for HCT</p>	<p align="center">Educate parents on HCT</p>
<p align="center">Tie health literacy to students and parents; make school curriculum and other materials available to all</p>	<p align="center">Coordinate partnerships between Social Workers and teachers, parents, physicians, etc.</p>
<p align="center">Plan for Resident Education, Curriculum and a HCT Specialization field for medical students</p>	<p align="center">Get the child/consumer more involved in the conversation on health care transition and in their own HCT planning</p>
<p align="center">Educate school systems on CMS and vice versa</p>	<p align="center">CMS can identify transition specialists</p>
<p align="center">Plan for and implement Physician Education in the area of HCT</p>	<p align="center">Tie health literacy to students and parents; make school curriculum and other materials available to all</p>