

Meeting Minutes
Statewide Health Care Transition Services Task Force
For Youth and Young Adults with Disabilities

Task Force Meeting
November 24, 2008

ATTENDEES:

Joseph J. Chiaro, M.D., FAAP, Children's Medical Services, FDOH; Task Force Chair
David Wood, M.D., MPH, UF Department of Pediatrics
Becky Maguire, RN, MS, Agency for Persons with Disabilities
William Palmer, Department of Education, Division of Vocational Rehabilitation
Bambi Lockman, Department of Education
Robert Anderson, Department of Children and Families
John Reiss, Ph.D., Institute for Child Health Policy at UF
Phyllis J. Sloyer, RN, Ph.D., PAHM, FAAP, Children's Medical Services, FDOH
Kristi Chapman, Florida Independent Living Council
Laurie Woodard, M.D., USF Department of Family Medicine
Tom Sullebarger, M.D., Cardiologist, Florida Cardiovascular Institute Heart Center
Patti Parisian, MPH, CHES, FSU College of Medicine @ Sarasota
Laurie Blades, MA, BCBA, Florida Department of Children and Families
Judy Rosenberg, RN, Ph.D., USF Students with Disabilities Services
Debbie Richards, Florida Developmental Disabilities Council, Inc.
Susan Redmon, RN, MPH, Children's Medical Services, FDOH
Eleanor Cofer, RN, Children's Medical Services, FDOH
Kirk Hall, Department of Education, Division of Vocational Rehabilitation
Jordan Knab, Project 10, USF at St. Petersburg
Janet Hess, MPH, CHES, Project Facilitator, Early Childhood Council

Teleconference:

Cheryl King, ARC of St. Lucie
Mary Beth Senkewicz, Florida Office of Insurance Regulation
Lanetta Jordan, M.D., MPH, Sickle Cell Services, Memorial Regional Hospital
Jorge Sallent, M.D., Pediatric Pulmonologist, Pediatric Respiratory Center

CALL TO ORDER:

Dr. Chiaro called the meeting to order at 1:10 pm.

APPROVAL OF MEETING MINUTES FOR LAST TASK FORCE MEETING

Minutes from the first Task Force meeting on August 15, 2008, were unanimously approved.

DISCUSSION

- Dr. Chiaro asked each of the Subcommittee Chairs to summarize their findings and recommendations, which are outlined below. Following some discussion about the definition of youth and young adults with disabilities, Task Force members agreed to use a definition that encompasses all adolescents and young adults ages 12-24 with disabilities and/or chronic health conditions.
 - Finance & Structure:
 - Dr. Sloyer reported that this section identifies difficulties associated with health insurance coverage for YSHCN. The Subcommittee found a wide array of options that are very complex and difficult to understand with respect to eligibility requirements, benefits, income limitations, exclusions, payment, etc.

- A matrix was developed to show what is/is not available in Florida. It includes some new options in the private sector: 1) extension to age 30 for adult disabled dependents, and 2) Cover Florida, which will be useful to some YSHCN but will have limited benefits. An option that Florida has explored but has not yet adopted is a Medicaid Buy-In program, which allows people who have disabilities and work to buy into the Medicaid program. Although there are significant costs associated with instituting this option, it is included in our recommended strategies.
 - The report also addresses the need for co-management, that is, financial reimbursement for both a pediatrician and an internist during the time of transition from the pediatric community to the adult health care community. To date, there are very few insurers that pay for co-management.
 - Another relevant issue is insurers paying for increased time needed to care for individuals with disabilities/chronic health conditions, including support for non-face to face consultations, etc. Dr. Jordan noted that states have the option to receive federal Medicaid matching funds for education and outreach to Medicaid-eligible adults with Sickle Cell Disease (SCD). While this option would create a fiscal impact, the Task Force agreed that we should recommend expanding the Medicaid adult benefit package to secure federal matching dollars. It offers an incentive to physicians for providing SCD education and outreach, and could serve as a model for other adult chronic diseases and conditions.
 - The recommendation to develop a technical guide and provide assistance to YSHCN about insurance options could be accomplished with few additional resources.
 - A question arose from the Task Force about insurance options for individuals who are not disabled but have chronic health conditions such as diabetes or asthma, particularly those who lose Medicaid benefits and need to find other coverage. Ms. Senkewicz confirmed that, as long as continuous health care coverage is maintained (lapse no longer than 63 days), the pre-existing condition clause could be reduced or eliminated in the Cover Florida program.
- Services and Models of Care:
 - Dr. Wood described a framework for health care transition services in Florida that is flexible and can be adapted to local needs and service systems.
 - Two levels of care are recommended: local coalitions and a State Office of Health Care Transition. Each region will have a public/private organizational structure that will support transition locally, while the state office will serve as a clearinghouse and provide technical assistance. Recommendations at both levels emphasize provider training. Funding will be required to support the recommended structure, but a dollar figure was not identified in the report.
 - Recommendations from other Task Force members included:
 - Address the issue of hospital rules and credentialing, e.g., children's hospitals versus adult hospitals.
 - Differentiate between strategies that can be implemented in the short term with few additional resources, and those that require significant funding.
 - Identify other transition programs in Florida that can serve as models and describe how they provide services, e.g., Dr. Jordan's sickle cell

- programs, CF centers, HIV clinics, CMS transition clinics, children's hospitals (Joe DiMaggio).
 - Create a database of adult providers, which can be initiated through the current CMS database system and with additional information provided by condition-specific organizations (e.g., hydrocephalus).
 - Education & Training:
 - Dr. Reiss reported that the subcommittee identified 3 key audiences that could benefit from transition education: healthcare professionals, education professionals, and YSHCN and their families.
 - There are a significant number of materials already developed; the challenge is how to make better use of those materials, how to infuse the importance of transition into ongoing practice, and how to better utilize and integrate existing systems.
 - Ms. Lockman noted that the *Standing Up for Me* Health Care Transition supplement is almost ready for dissemination; the resource section is the only piece missing. The Hillsborough County curriculum will require some additional attention once revised Sunshine State standards have been finalized. Ms. Lockman plans to redistribute the *4-1-1 on Disability Disclosure*. She also asked to delete the reference to FDLRS in the report.
 - Recommendations from other Task Force members included:
 - Identify HCT strategies that can be included in IEPs or 504 Plans
 - Indicate that community-based providers involved in the health care transition process (such as DCF mental health providers) should participate in IEP meetings along with school-based staff and VR.
 - Identify physician champions to help promote HCT practice
- Other recommendations for the final report included:
 - Add information about federal policies that are barriers to transition, such as the 2-year wait for Medicare.
 - Emphasize that the state Title V agency (CMS) has federally mandated responsibility for planning around health care transition for YSHCN.
 - Prioritize strategies that require few additional resources and that can be implemented in the short term, such as utilizing the existing CMS infrastructure to create a database of adult providers, organize local coalitions within the 17 area offices, develop a technical guide for insurance options, etc.
- Changes to drafts from each subcommittee are due to Ms. Hess by December 1; Ms. Hess will forward the final draft to Task Force members for review on December 5.

Adjournment

Meeting was adjourned at 4:10 pm.