

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

Services and Models of Care Delivery Subcommittee
Teleconference Call
February 11, 2009

ATTENDEES:

David Wood, MD, MPH, UF Department of Pediatrics; Subcommittee Chair
Janet Hess, MPH, CHES, Project Facilitator, Early Childhood Council
Eleanor Cofer, RN, Children's Medical Services
Linda Edwards, MD, UF Primary Internal Medicine Care Center
Cheryl King, ARC of St. Lucie
Judy Rosenberg, RN, PhD, USF Students with Disabilities Services
Susan Redmon, RN, MPH, Children's Medical Services/DOH
Gerald (Jay) Hemness, JD, Center for Guardian Advocacy
Nancy Sawyer, Special Olympics of Florida
Susan Corse Adams, Down Syndrome Association of Jacksonville
Jorge Sallent, MD, Pediatric Pulmonologist
Martha Kronk, Shriners Hospitals for Children/USF
Kirk Hall, Vocational Rehabilitation
Diane Straub, MD, MPH, USF Department of Pediatrics
Lanetta Jordan, MD, MPH, Sickle Cell Services, Memorial Regional Hospital
Janice Dunlap for Robert Anderson, Department of Children and Families

CALL TO ORDER:

Dr. Wood called the meeting to order at 8:07am.

DISCUSSION

- Dr. Wood and Ms. Hess provided an update on the legislative report:
 - Dr. Chiaro met with the Governor's staff and reported they were very supportive and impressed with the report. They liked how the recommendations were stratified based on level of resources required. They encouraged DOH to move forward on a number of issues, though the most costly recommendations will need to wait (e.g., extending the age of CMS to 25 or 29, full funding of the transition system).
 - Some legislators are interested in introducing a bill during the 2009 session outlining recommendations that can be implemented using existing resources. This action would support DOH in setting up a state Office of Health Care Transition within CMS, along with several other key activities. We are currently developing language for the bill.
 - Ms. Hess sent out an action alert about Medicaid Buy-In (Senate Bill 0348 sponsored by Senator Crist), which is one of our recommendations. This option has been proposed in earlier years but cost issues have been difficult to overcome. The focus now is to get the bill on the Health Regulation Committee agenda; the session starts in March. It is appropriate for both providers and families to contact their district representatives and Senator Gaetz, Committee Chair, to advocate for the bill.
 - Dr. Wood is tentatively scheduled to present on the report sometime in May to the Florida Children and Youth Cabinet.

- We are still waiting for hard copies of the report that CMS is printing. Task Force members will each receive a copy, and there will be a press release.
 - A question was raised about the Governor's Commission on Disability. The report has been forwarded to them, and Dr. Wood would like to get it on their agenda for a presentation.
 - FDDC has allocated additional funds to continue supporting the work of the Task Force in the development of a statewide, coordinated system of health care transition services.
- Dr. Jordan, who participates in a planning committee for Healthy People 2020, suggested that the possibility of incorporating specific health care transition objectives in HP 2020, i.e., identifying a set of measureable indicators for youth and young adults with disabilities. Subcommittee members were very enthusiastic about the idea, and would like to pursue the recommendation. Dr. Jordan will keep the committee abreast on development of the indicators.
 - Dr. Wood reiterated that the goal of this subcommittee is to put more detail into the recommendations in our report, including projected cost for state-level infrastructure and local-level coalitions. Another task might be to develop a template for organizing community coalitions. For example, how do you conduct a needs assessment or gap analysis of your local system? How do you pull people together? We could create planning guide for communities to use in planning for and organizing health care transition services, similar to work that has been done in the field of mental health (TIP system, developed at FMHI).
 - Given CMS's role in organizing the state-level office, Ms. Redmon asked about the vision for local coalitions: Who will coordinate and facilitate regional groups? How do you identify the key organizations/partners, and get them started? Dr. Wood responded that parent and youth groups should be key players. Ms. Corse Adams concurred, and suggested inviting Charlotte Temple from ASK in Jacksonville to join the Task Force; she feels Ms. Temple could be instrumental in mobilizing family groups for this purpose. The planning guide could help address these kinds of activities.
 - Ms. Redmon commented that Project 10 is currently hiring 5 regional transition specialists to cover the state and provide training for schools. As discussed in earlier subcommittee calls, the group feels Project 10 staff should be key partners in local coalitions. Dr. Wood encouraged everyone to think about any other systems or groups that should be included at the local level. Ms. Hess will ask Jordan Knab to join the next call to discuss both Project 10 and the TIP model.
 - Because there are few studies on young adult populations, Dr. Wood suggested we start to systematically build a body of evidence on conditions such as Spina Bifida, Cystic Fibrosis, Down Syndrome, etc. As outlined in the report, the state office could collect and disseminate existing data in a user-friendly format; these resources will be particularly useful for professional training purposes. Anyone who has existing data is encouraged to forward the information to Ms. Hess, who will post it on the web site. Dr. Jordan will forward a document concerning Sickle Cell Disease issues across the lifespan.

ADJOURNMENT

Meeting was adjourned at 9:05 am. The next meeting was scheduled for March 4, but was later changed to Wednesday, March 18, at 8 AM. The group agreed to schedule Wed morning calls every 3 weeks. Ms Hess will check with other Task Force members to see if there is a preference to rotate days.