

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

August 15, 2008

Attendees

Joseph Chiaro, M.D., FAAP	Children's Medical Services / DOH
Phyllis Sloyer, RN, Ph.D., PAHM, FAAP	Children's Medical Services / DOH
Judy Rosenberg, RN, Ph.D.	USF Students with Disabilities Services
Lanetta B. Jordan, M.D., MPH	Sickle Cell Services, Memorial Regional Hospital
Linda Edwards, M.D.	UF Primary Internal Medicine Care Center
David Wood, M.D., MPH	UF Department of Pediatrics
Thomas Sullebarger, M.D.	Florida Cardiovascular Institute Heart Center
Laurie Woodward, M.D.	USF Department of Family Medicine
Jordan Knab, Ed.S.	USF FMHI
Jorge Sallent, M.D.	Pediatric Respiratory Center
Laurie Blades, MA, BCBA	Florida Department of Children and Families
Bambi Lockman	Department of Education
Becky Maguire, RN, MS	Agency for Persons with Disabilities
Eleanor Cofer	Children's Medical Services/DOH
Susan Corse Adams	Down Syndrome Association of Jacksonville
William Palmer	Division of Vocational Rehabilitation
John Reiss, Ph.D.	Institute for Child Health Policy at UF
Debbie Richards	FDDC
Robert Anderson	Department of Children and Families
Debra Dowds	FDDC
Janet Hess, MPH, CHES	Consultant/Early Childhood Council
<i>via conference call:</i>	
Cheryl King	The ARC of St. Lucie County, Inc.
Kathleen Core (for Mike Bolin)	Agency for Health Care Administration
Samantha Delusso (for Mike Bolin)	Agency for Health Care Administration
Patti Parisian, MPH, CHES	FSU College of Medicine / Sarasota
Kristi Chapman	Florida Independent Living Council, Inc.
Diane Straub, MD, MPH	USF Department of Pediatrics
Nancy Sawyer	Special Olympics of Florida

Dr. Joseph Chiaro, Deputy Secretary of Health for Children's Medical Services, Task Force Chair, called the Governor-appointed *Health Care Transition Services Task Force for Youth and Young Adults with Disabilities* to order at 1:05 p.m. Dr. Chiaro welcomed everyone and asked that they introduce themselves and what group they represented.

Dr. Chiaro then reviewed Legislation CS for SB 988 / HB 793 with the task force.

Dr. David Wood gave a brief description of the Florida Developmental Disabilities Council (FDDC) and their participation in the Transition Task Force. will fund some of the efforts put forth around the Transition Task Force. He also introduced Ms. Janet Hess who will act as the coordinator of the Transition Task Force.

Ms. Hess took a moment to familiarize the group with the meeting packet prior to Dr. Wood reviewing the PowerPoint presentation. Ms. Hess also referred the task force to the website (www.healthcaretransition.org) where all meeting information including minutes, committee work, etc. will be posted.

Dr. Chiaro requested a motion from the Health Care Transition Services Task Force to accept FDDC as co-working partners of the task force. Dr. Wood moved to accept the motion. Dr. Jorge Sallent seconded. The motion was accepted unanimously.

PowerPoint Presentation

Dr. Wood and Ms. Hess presented an overview of the project in a PowerPoint presentation, which included definitions the task force will be using:

- Disability: someone who has a physical or mental impairment that substantially limits one or more “major life activities”.
- CYSCHN: children and youth with special health care needs
- HCT: health care transition is the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered care to an adult oriented care system.”

Key points presented to task force:

Why now?

- Medical advances – increase in survival rates and disability risk
- Societal expectations – independence, self-sufficiency
- Legal requirements – age of majority
- Recognition that health impacts all other transitions
- Legislative and professional directives

Core national performance measures to be considered are:

- Families will participate in decision making and be satisfied with services
- CSHCN will receive coordinated, comprehensive care within a medical home
- Families will have adequate health insurance
- CSHCN will be screened early and continuously
- Services will be organized so that families can use them easily
- YSHCN will receive the services necessary to make transitions to all aspects of adult life, including health care, work and independence.

Health care transitions for young adults with special health care needs to be considered are:

- Identify primary care provider
- Identify core knowledge and skills
- Knowledge of condition, prioritize health issues
- Maintain an up-to-date medical summary that is portable and accessible
- Apply preventive screening guidelines
- Ensure affordable, continuous health insurance coverage

State Initiatives in Florida:

- Health Care Transitions Initiative at the Institute for Children Policy, University of Florida
- Children's Medical Services
 - Transition specialists for YSHCN up to age 21
 - Transition programs in several CMS offices statewide
 - Young Adult Advisory Board
 - State level MCHB core performance measures
- University of South Florida
 - Demonstration model for school based health care transition education
 - College of Medicine disability curriculum
- FDDC
 - State Plan
 - Partners in Transition: Florida Strategic Plan on Transition
 - HCT Web-based training modules
 - Health Care Transition Summit (2006)
- Florida Office on Disability and Health
- JaxHATS

Key issues to be considered by sub-committees:

- Professional culture and traditions
- Changing role of youth
- Capacity and training: availability and quality of adult providers who are trained in pediatric onset conditions and willing to take primary responsibility for care
- Communication
 - Among providers
 - Between adult provider and youth
 - Information about resources and adult services
- Service fragmentation
 - Lack of systematic transfer of records and co-management of care during transition
 - Minimal case management in adult practices
 - Linkages to community-based adult services
- Health care financing
 - Adequate health insurance after age 18
 - * Aging out of health care plans/services (private insurance, state Title V, SCHIP)
 - * Benefits in temporary jobs often limited, unavailable, or high premiums
 - * Desire to work and be independent may jeopardize dependent status needed to remain on health plan
 - * Increased salary may lower/eliminate SSI payments
- Provide knowledge of reimbursement guidelines
- Other systemic barriers
 - Employment opportunities
 - Transportation
 - Limited assistance for adults with disabilities
 - * Fewer publicly funded programs
 - * Stricter eligibility criteria
 - * Increased financial burden
 - * Termination of childhood support systems

Framework for Health Care Transition:

- Ongoing access to age and disease appropriate primary and specialty care providers
- Access to uninterrupted, affordable health insurance
- Development of disease self-management skills
- Access to age appropriate educational and vocational opportunities to allow economic self-sufficiency

Work Plan Proposal

The following timeline was proposed in order to meet the statutorily required deadline for the strategic plan:

August 18 – November 30, 2008

- identify findings and develop goals/objectives in subcommittee teleconference calls

December 1 – 31, 2008

- Review draft report at 2nd meeting in early December
- Submit final report by January 1, 2009

It was agreed that the task force and developmental disabilities workgroup would continue through May 2009 and develop specific action steps based on the plan. The bulk of the work will be conducted through conference calls.

The group agreed to form three subcommittees in order to address the requirements in law. Members were asked to join at least one subcommittee. The subcommittees and members (i.e., members present at this meeting) are listed below. It was suggested that members not present at this meeting communicate their subcommittee preference(s) to Ms. Hess.

Subcommittees:

Financing & Structure

Dr. Phyllis Sloyer - Chair
Dr. Joseph Chiaro
Dr. Lanetta Jordan
Dr. Jorge Sallent
Debbie Richards

Services & Models of Delivery

Dr. David Wood – Chair
Dr. Judy Rosenberg
Dr. Linda Edwards
Susan Corse Adams
Dr. Jorge Sallent
Eleanor Cofer
Robert Anderson
Dr. Tom Sullebarger
Becky Maguire

Dr. John Reiss
Dr. Laurie Woodard
Laurie Blades

Education & Training

Dr. John Reiss - Chair
Jordan Knab
Bambi Lockman
William Palmer
Laurie Blades
Dr. Laurie Woodard
Susan Corse Adams
Dr. Judy Rosenberg
Dr. Linda Edwards
Becky Maguire

It was recommended that each subcommittee hold at least two to three conference calls from August to November. Members were encouraged to invite subject experts and constituents who are not on the Task Force (particularly YSHCN and their families) to participate in these calls. Subcommittee meeting minutes and work material will be posted on the web site so that they are available for review by all task force members.

After subcommittees were selected, each took time to nominate a chair, coordinate a meeting/conference call date and discuss key issues they would like to address. It was agreed that Ms. Hess would work with the three chairs to communicate subcommittee member lists, conference call schedules and work plans to the task force.

Ms. Hess asked the task force to complete a FDDC event satisfaction survey prior to adjournment.

Dr. Reiss moved adjournment. Dr. Phyllis Sloyer seconded. Unanimous approval, meeting adjourned at 4:20 p.m.