

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

**Education & Training Subcommittee
Teleconference Call
October 6, 2008**

ATTENDEES:

John Reiss, Ph.D., Subcommittee Chair, Institute for Child Health Policy at UF
Diane Straub, MD, MPH, Division of Adolescent Medicine, USF
Judy Rosenberg, RN, Ph.D., USF Students with Disabilities Services
Jordan Knab, Project 10, USF St. Petersburg
Bill Palmer, Division of Vocational Rehabilitation
Susan Corse Adams, Down Syndrome Association, Jacksonville
Kristi Chapman, Florida Independent Living Council
Susan Redmon, RN, MPH, Children's Medical Services
Patti Parisian, MPH, CHES, FSU College of Medicine
Susan Havercamp, Ph.D., Florida Center for Inclusive Communities, USF
Tom Rice (for Becky Maguire), Agency for Persons with Disabilities
Melinda Coulter, Agency for Persons with Disabilities
Frank Platt, Department of Children & Families
Catherine Heath, Department of Children & Families
Janet Hess, MPH, CHES, Project Facilitator, Early Childhood Council

CALL TO ORDER:

Dr. Reiss called the meeting to order at 11:05 AM.

DISCUSSION

- Teleconference minutes from September 5 and September 23 were reviewed and approved.
- Melinda Coulter from Agency for Persons with Disabilities discussed guardianship and related legal issues. She referenced a PowerPoint presentation and several handouts that were emailed to the group prior to the call. The following are key points in her presentation:
 - We should not jump directly to guardianship when discussing decision-making; in fact, many less restrictive options are available and should be considered first.
 - We need to ask whether we afford people with disabilities (elder, developmental, mental health conditions) with the same options that we afford ourselves. For example, do we allow individuals with cognitive disabilities to consult with others about where to live, or do we jump to conclusions about what is or isn't appropriate for groups of people?
 - It is important to view these options as ways to assist persons in decision-making, not as ways to make decisions for them. We want people to use their abilities to the fullest.
 - Even in the case of guardianship, the person still needs to be involved in decision making process. Decisions should be based on what they want, not what the guardian wants.
 - An individual with intellectual disabilities is not automatically incapable of making decisions; he/she just may need assistance. If that person takes a long time to make

decisions, we tend to get impatient and don't want to take the time to let them make their own decisions.

- Ms. Coulter discussed ways to provide assistance with medical decisions (i.e. consenting to medical procedures) from the least restrictive to the most restrictive options. These include making own decisions (least restrictive), Durable Power of Attorney, Health Care Surrogate, Living Will, Medical Proxy, Guardian Advocacy, and Guardianship (most restrictive).
 - Five Wishes is a legal document that provides a Living Will and Medical Durable Power of Attorney, and is valid in Florida. It is an excellent tool that should be considered by everyone; it costs \$1.
 - Many people (including professionals) are not aware of the Medical Proxy option, which does not go through the court system; it is self-designated. A Medical Proxy may be appointed to incapacitated individuals who have no advance directive, health care surrogate, or court appointed guardian or guardian advocate. It is recommended to be used only for emergency situations (e.g., individual is in pain or his/her capacity is questioned)
 - Guardianship is where the court removes an individual's rights. An alternative for people with developmental disabilities is Guardian Advocacy. Benefits are that the person is not considered "incapacitated" and retains some rights, and the process is less expensive.
 - Guardianship can be revoked at any point in time by the disabled person of interest.
 - Decision-making rights do not have to be all or nothing; it depends on the individual and their capacity or desires regarding particular types of decisions.
 - Young adults may make some poor decisions, but that does not necessarily mean that guardianship should be sought. First provide education and assistance in making better decisions.
- Ms. Coulter reiterated that, unless legally ruled otherwise, an individual is deemed capable of making his/her own medical decisions. Physicians do not have the authority to judge whether their patients can make competent medical decisions. The decision-maker is always the person of interest, unless he/she has given written permission to another person or the court has taken rights away. And unless permission is shown in writing, it DOESN'T EXIST (i.e., physicians and other healthcare providers cannot take someone's word for it).
- As an example, an 18-year old YSHCN at an office visit with his parents should first be asked by the physician whether he wants his parents involved in decision-making. Both families and providers need to be better educated about this issue.
- Dr. Reiss noted that it is important to actively involve youth in decision-making before they turn 18; have them provide "assent." This provides a way to transition to making decisions independently.
- The court process is often looked upon as an obstacle to keeping "parental rights" when, in fact, it is not a parental right to make your child's decisions once they reach adulthood.
- Ms. Hess noted that this subcommittee may want to recommend development of educational materials about health care decision-making that are targeted to health care providers.
- Catherine Heath from the Department of Children & Families spoke about issues concerning transitioning youth in foster care.

- Youth continue to have access to Medicaid until age 21.
- A significant problem is gaining access to medical records so that youth can make informed decisions. Youth may request their records at age 18, but records may not be complete or adequately informative.
- Case management and court oversight usually continues until at least age 19 for youth who receive developmental services.
- Ms. Heath referenced “Road to Independence” as a program that provides specific transitional support services for youth in foster care. It provides 90 days of wrap around services to help youth become independent. The court makes a determination at age 17 about services that will be provided at age 18. There is great variability in how well the program is implemented throughout Florida, e.g., resources differ among types of placements (e.g. foster home versus group home).
- A manual to help youth in foster care navigate the health care system is currently in development and will be available in 3-4 months. Title is “On my own, but not alone.”
- Ms. Heath’s contact information: 850-922-2425, Catherine_heath@dcf.state.fl.us
- Jordan Knab spoke about Project 10, FDOE’s only transition project, now housed at USF St. Petersburg. Mr. Knab noted that it is different from earlier projects in that is regionalized:
 - Regions consist of 5 areas across the state.
 - Local needs assessments will be conducted by early November. Regional field representatives will help determine needs based on capacities and resources available in each region. Mr. Knab was open to including health care transition questions on the needs assessment; Dr. Reiss will follow up in providing suggested questions to Mr. Knab.
 - Currently developing an extensive website with a section devoted to health care transition. Web site will offer podcasts and web trainings; at least some of the trainings will count towards CEUs. It is expected that, eventually, individual districts will use Project 10 to provide mandated training for their district employees.

ADJOURNMENT:

The meeting was adjourned at 12:40 PM.