TASK FORCE ON TRANSITIONS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES
February 23, 2009
10:00 – 3:00
NCIOM
Meeting Summary

WELCOME:
Adonis T. Brown
IL Consultant/Disability Peer Advocate
EnVisioned Independent Living

Dr. Silberman welcomed attendees and explained the information located in the handouts. Mr. Brown introduced the first group of speakers.

SUCCESSFUL TRANSITIONS: FAMILY PERSPECTIVE
Connie Hawkins
Executive Director
Exceptional Children's Assistance Center

In North Carolina there is not a central location or source of information for families of individuals with developmental disabilities to find information on the developmental disability services system, learn about the system, and use the system in the most efficient and effective way possible. Rather than going to family members of people with developmental disabilities, most information is directed to case managers.

In 2008, the Exceptional Children's Assistance Center had 85,000 contracts with families and gathered family opinions on the developmental disability service system. Family members believe the future is limited by the availablility of service and support options, by reforms that remove service and support options without creating others in their place, and by a lack of the family perspective in systemwide decisionmaking.

Mary LaCorte
Assistant Director
Exceptional Children's Assistance Center

Mrs. LaCorte represents the aging parents perspective. Mary Beth, her daughter, is a 33 year old young woman. She has very complex needs (due to deafness, blindness, and autism). However, her disability does not define her and there are many things that are meaningful to her.Mary Beth has made several transitions. Her transition from high school went relatively well, and though the Local Education Authority (LEA) was caring towards Mary Beth, it was focused on placing her in a residential setting. The LEA was also concentrated on placing her in what was available in the commmunity rather than determing placement based on what she needed. Her family was more focused on her health, happiness, relationships, and the quality and meaningfulness of her activities.

At 21, she transitioned into an Intermediate Care Facility for Mental Retardation (ICF-MR) group home. While the physical transition was easy, emotionally transitioning her life there was not. The rules of the system dictated how the transition took place, and Mary Beth had little to no personal input in the process. The home was designed to simply house individuals rather than support their interests and help them live more independently. Mary Beth moved back home after two months and was again able to make personal choices and have access to supports and services designed to help her live as independently as possible. As an aging couple, Mr. and Mrs. LaCorte recognize the need for a transition plan for Mary Beth for when they are no longer able to care for her. They will continue to interact with the system and want a plan that respects, understands, and supports Mary Beth as a unique individual.

Betsy MacMichael
State Director
First in Families of North Carolina

Ms. MacMichael represents the secondary transition. Her 16 year old daughter, Janie, attends Jordan High School, loves to read, struggles with math, and has cerbral palsy and spasticity. She has strong self-esteem, a decent sense of humor, and capacity to care about others, but lacks a sense of responsibility to contribute to her community and work in meaningful employment. She was just awarded a touch screen laptop by the Cerebral Palsy Foundation and is learning to use it in class and at home. As a parent, her feelings about transitioning vacilate on a regular basis, and she is uncertain. All the appropriate steps have been taken in preparation for this transition, but they have been taken one at a time rather than focusing on the large transition. Some examples of challenges in Janie's transitions have been that on her recent report card she received all As but her class rank is in the 200s out of 400 students, there have been several attempts to allocate an Assitive Techology device for her to take notes in class but no device has been allocated, and a whole semester was spent trying to aquire a urine sample so that she could go to sheltered workshop at Goodwill. Time is an important factor for many of the changes the Task Force is discussing.

Thea Gardner
Parent Representative

Ms. Gardner represents the transition from a developmental center. Her son, Robbie, left home at age 18 and moved to a private ICF-MR group home for six people. After one year, he moved to a five person group home. That too only lasted one year. When he exhibited an inapproriate behavior, the staff cleared the other residents out of the house, which was positive reinforcement for Robbie to continue his behavior. Robbie then moved to Murdoch developmental center for a year, There he was able to hold a job through their vocational program, and he learned about consequences to one's actions. He then transitioned to a two person group home. His transition was assisted a team including members from the center, a care provider, a case manager, and others. Robbie is happy in his new home. Coordination of all the partners made the transition successful. While Robbie had been in a home on the same property that was not successful, the involvement of all parties resulted in a successful living arrangement.

Ms. Hawkins concluded by explaining that the term transition is really a process as evidenced by the parents' presentations.

Comments/Discussion: The discussion that followed involved perspectives from family members in the audience, barriers and obstacles to successful transitions, and ongoing initiatives to help with transitions in North Carolina. A participant explained that there are separate challenges for single parents, including job loss and difficulty training the new staff about her child. Another participant explained that there are unofficial groups of parents who have found each other for social and other supports. A participant explained that his daughter moved into a six person ICF-MR group home, which has great respect and flexibility for the people who live there. The issue of transition is being focused on by the ARC of NC, which is conducting 14 community education forums across the state to discuss the difficulties of transitions. Other topics included beginning transition in elementary school, highlighting successful programs and practices, and the need for a catalog of residential options.

SUCCESSFUL TRANSITIONS: COMMUNITY PERSPECTIVE
Cindy Ehlers, MS, LPC, CBIS
Assistant Area Director of Clinical Operations
East Carolina Behavioral Health LME

Ms. Ehlers is the clinical director of an LME and the mother of 19 year old son with developmental disabilities who lives at home. He uses a feeding tube and non-verbal communication, is incontinent and has used services from the CAP-MR/DD waiver for 14 years. Since he was five years old, she has been told that he should live in a group home, may not meet the next milestone, and should move him for her own comfort. She has professional experience in a lot of different community based settings.

East Carolina Behavioral Health (ECBH) is the consumer-driven Local Management Entity (LME) for nine counties in the eastern region of the state. The majority of the communities are rural. ECBH coordinates care for people with mental health, intellectual and developmental disabilities, and substance abuse disorders and manages public dollars for citizens of these counties to ensure appropriate services are available.

A recent gap and needs analysis showed that 125 people from the area live in Caswell developmental center (one-fourth of all residents). At the time most people moved in, there were no community resources to meet their needs. For some people, the center remains their home, but many want to move to the community. The ECBH initiative is to design a transition that provides access to services and supports needed in the community.. The new program will develop 16 guaranteed placements (as long as the tenants do not break the law) and provide wrap-around services and subsidized rent. Flexible funding is needed for individual and unique supports. The partnership with providers includes the Arc of North Carolina and Nurses Plus. The Arc of North Carolina will provide various roles including advocacy, fiscal responsibility, and guardianship. Nurses Plus will provide direct care staff to people in the community.
The direct care staff of the initiative participate in team meetings, visit the family, and get to know the needs of the person and their family before the person moves to the community. Self determination and advocacy play a large role. The move to the community is not the same for

every person, andit is important to understand the perspectives of both the individual and the family. In addtion, there are important tools needed for staff to help in the transitions including in-depth knowledge of the system, services, funding, limitations, and ingenuity.

Christopher is a 15 year old young man with developmental disabilities who serves as a successful example of transitioning back to the community. His explosive behavior and physicial violence against his mother and grandmother caused him to be admitted to the Caswell developmental center for respite care. He was then moved to the Dewey unit, for dually diagnosed individuals, for a longer stay. During his stay, his mother was allowed to visit only on an approved schedule, he was not allowed any home visits, and he was placed on a restrictive diet that did not allow food from home. When he was ready to leave, the treatment team wanted him to stay or go to a group home and his mother wanted him to come back home. To facilitate his transition home, there was a process to get to know his situation completely including self-direction, advocacy, and staff training and supervision. There was ongoing communication with his team and family before, during, and after his transition was complete. For the first three months, a staff member lived with Christopher and his family and gathered information on his behaviors and needs. There were some interventions to help his mother stop rewarding bad behavior. Christopher is now living at home and attending public school. He no longer has overnight awake staff, but there is backup available within 10 minutes from his home.

Comments/Discussion: Ms. Ehlers, on behalf of ECBH, recommended that North Carolina pursue a Medicaid Section 1115 waiver. The waiver would be a pilot demonstration, wherean LME would manage all the public funding for residential services for developmental disabilities including dvelopmental centers, ICFs-MR facilites, and other services in the area. The discussion that followed focused on staff recruitment, self-direction, consumer driven services, purchased guardianship, single stream funding, and the unique program provided through ECBH.

REVIEW AND DISCUSSION OF POTENTIAL RECOMMENDATIONS:

The Task Force discussed the potential recommendations including the following topics:

- Health information technology.
- Additional positions within the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services.
- Assessment tools for individuals with I?DD.
- Flexible funding for services and supports.
- The need for a glossary of terms used for developmental disabilities.
- Training for providers on the DD system.
- Case management.
- Shared and alternative family living.
- Licensing requirements (residential, provider agencies, and workers).
- Occupational Course of Study.
- Assistive Technology.
- Foster care.
- Vocational Rehabilitation.
- Community and family outreach.
- Future planning.

- Review evidence of what works in other states for transitions into more integrated community settings.
- The need for partnership and collaboration.
- Pay for performance/performance based contracts for LMEs and providers.

The next meeting will be held Monday March 16, 2009.