

TASK FORCE ON TRANSITIONS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

October 1, 2008

10:00-3:00

NC IOM

Meeting Summary

ATTENDEES:

Task Force /Steering Committee: James Bodfish, Adonis Brown, Leza Wainwright, Robert Atwater, William Bingham, Almon Carr, Connie Cochran, Carol Donin, Beverly Earle, Jean Farmer-Butterfield, Daniel Fox, Susan Hartley, Joan Johnson, Jill Keel, Scott Keller, Annette Lauber, Matty Lazo-Chadderton, Vivian Leon, Karen Luken, Betsey MacMichael, Michael Maybee, Marian McLawhorn, Maureen Morrell, Alexander Myers, Susan Parish, Dwight Pearson, Genny Pugh, I. Azell Reeves, Daniel Rice, Dave Richard, Holly Riddle, Ellen Russell, Michael Sanderson, Karen Stallings, Jim Swain, Peggy Terhune

Interested Persons: Ging Fernandez, Kenny Stallings, Shealy Thompson

Staff: Kimberly Alexander-Bratcher, Mark Holmes, Jesse Lichstein, Thalia Shirley-Fuller, Pam Silberman, David Jones

WELCOME AND INTRODUCTIONS

Leza Wainwright

Co-Director, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

Ms. Wainwright welcomed participants to the meeting and asked everyone to introduce themselves.

OVERVIEW OF THE TASK FORCE CHARGE AND NC IOM PROCESS

Mark Holmes, PhD

Vice President, North Carolina Institute of Medicine

The North Carolina Institute of Medicine (NC IOM) is a quasi-state agency whose purpose is to be concerned with the health of the North Carolina people by monitoring and studying health matters, responding authoritatively when found advisable, and responding to requests from outside sources for analysis and advice when this will aid in forming a basis for health policy decisions. The NC IOM creates broad-based task forces to study health issues facing the state and compiles task force/study group reports to be circulated.

The North Carolina General Assembly has charged the NC IOM to convene a panel to study and report on the transition for persons with developmental disabilities from one life setting to another and to report findings and recommendations to the General Assembly no later than March 1, 2009. The report and recommendations should focus on: the transition for adolescents leaving high school, including adolescents in foster care; transition for persons with

developmental disabilities who live with aging parents; and transition from the developmental centers to other settings.

OVERVIEW OF THE ISSUE: A NATIONAL PICTURE OF DEVELOPMENTAL DISABILITIES

Susan Parish, PhD, MSW

Assistant Professor, School of Social Work, University of North Carolina at Chapel Hill

The developmental disability (DD) service system is made up of many parts, including residential, vocational, educational, and health services, case management, and family supports. Medicaid is the largest source of funding for DD services, with the vast majority of funding going to residential services. Most people with DD in the United States live with a family member, and the demand for long-term residential care far exceeds the supply.

The developmental disability (DD) service system has three main constraints: poverty and deprivation in the DD population, the states' fiscal restraints, and unmet needs for care. Families of children with disabilities are more likely to live in poverty than other families and are more likely to experience deprivation in food, housing, and health care. As state recessionary patterns continue, the ongoing state Medicaid commitments will continue to strain state budgets. In addition, federal assistance in the future may be reduced as federal priorities shift to the bail-out and budget shortfalls.

There are three pertinent transitions for individuals with DD. One transition is from institutional care to other care settings. Since 1970 there has been a move towards deinstitutionalization of care, stimulated by lawsuits, enforcement of regulations, and state recessions. In addition, operating dual systems of care, with both community and institutional care, is very expensive. Ten states have closed all institutions. North Carolina still has a system of institutional care, though has downsized its public institutions by 3% annually since 1998. The end of caregiving is another important transition for individuals with DD. Over half of family caregivers are over the age of 45, and people with DD are beginning to outlive their parent caregivers, many without plans for care following the loss of a caregiver. In addition, women's increased employment and greater family mobility can mean fewer family members are available to care for family members with DD. The third transition is the transition to adulthood, with the goal of employment, independence, and full community participation. Drop-out rates for youth with DD is high, though declining, and can be a predictor of life-long need for care. In addition, employment rates are very low for youth with DD, which can lead to the inability for youth with DD to leave their parents' home, low rates of community participation, and poverty.

Discussion:

Discussion focused on the desire to examine work settings, guardianship, and financial supports.

SYSTEM OF SUPPORTS AND SERVICES: TRANSITIONING INDIVIDUALS FROM STATE OPERATED DEVELOPMENTAL CENTERS TO THE COMMUNITY

Carol Donin

Team Leader, Developmental Centers, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

State operated facilities serve as a public safety net for individuals with developmental disabilities (DD) whose clinical treatment needs exceed the level of care available in the community. There are three developmental centers in North Carolina, one in each region of the state: J. Iverson Riddle (West), Murdoch (Central), and Caswell (East) Developmental Centers. They provide Intermediate Care Facility for Mental Retardation (ICF-MR) level of care as well as respite care and other specialty programs.

Admissions to the developmental centers are typically for significant behavioral challenges or complex medical needs when the level of acuity exceeds community resources. Discharge planning involves comprehensive transition planning, and services and supports must be arranged prior to and be ready at discharge.

There are several current and proposed initiatives to help with downsizing efforts. The 2005 Appropriations Bill requires budgets of developmental centers to be reduced and positions eliminated as the net census is reduced. Medicaid savings are transferred from the ICF-MR budget to the Medicaid budget for community services for people with DD. A new Community Alternatives Program for persons with mental retardation and developmental disabilities (CAP-MR/DD) waiver has been proposed as a means of supporting individuals transitioning from developmental centers. A new Systematic Therapeutic Assessment, Respite, and Treatment (START) Model has been proposed as a way to provide community based crisis intervention and prevention services. And an ICF-MR Bed Transfer has been proposed.

There are many challenges and barriers to successfully transitioning individuals with DD from state institutions including lack of services in the community, issues related to case management, and individuals in developmental centers are often deemed lower priority by Local Management Entities for limited community funding. To succeed in transitions the state needs leadership, funding sources, investments in community service systems, and the involvement of those most affected.

Discussion:

Discussion focused on small residential care settings, reimbursement, licensing of homes with two or more individuals with DD, and the need for education at the community level.

WHAT'S HAPPENING IN NC? DATA REVIEW

Shealy Thompson, PhD

Community Policy Management, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

Over 100,000 people in North Carolina have a developmental disability (DD). Public services and support systems for these individuals are state developmental centers, intermediate care facilities (ICF-MR), CAP-MR/DD Waiver Services, and state-funded habilitation supports.

Currently a little over 1,500 persons live in state developmental centers; two-thirds of these individuals are aged 45 and over. The majority of individuals being admitted are moving from ICF-MR group homes, supervised living, state psychiatric hospitals, and their natural family. In 2007-2008, 27 people have moved to community settings. There are 330 ICF-MR facilities, with

over 2,500 beds, in North Carolina. However, North Carolina averages using community services for only 37% of adults and 19% of children. As of SFY 2008 CAP-MR/DD waiver services had over 10,000 enrollees, and were serving around 9,800 people. The number of persons receiving CAP-MR/DD waiver services has increased by 7% since 2006, when the waiver services began. Around 78% of expenditures for CAP-MR/DD services were for services where people live (i.e. home and residential supports). Over 18,000 individuals in North Carolina are receiving state-funded habilitation supports for either mental retardation or developmental disabilities.

The Division of Mental Health uses several data sources: Integrated Payment and Reporting System, Medicaid Service Claims, Healthcare Enterprise Accounts Receivable Tracking System, Client Data Warehouse, National Core Indicators Surveys, Statewide System Performance Report, Community Systems Progress Report, and Consumer Adverse Events.

Discussion:

Discussion focused on disaggregation of race and ethnicity in the data, foster care data systems, and alternative data sources and datasets.

LARGE GROUP DISCUSSION

Discussion focused on state by state comparisons of deinstitutionalization, comparison of peer resources, networks of support for aging parents, and the need for workforce recruitment and retention. Funding, transition supports, and the need to increase capacity and support for the developmental disability system.