

**TASK FORCE ON TRANSITIONS FOR PEOPLE
WITH DEVELOPMENTAL DISABILITIES**

December 17, 2008

10:00 – 3:00

NCIOM

Meeting Summary



Topic: Transitions from Aging Parents

ATTENDEES:

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

Interested Persons/Staff: Julia Bick, Wayne Dawson, Denise Harb, Angela Harper, Suzanne Harris, Freda Lee, Neal Mahan, Shawn Parker, Kenny Stallings, Kimberly Alexander-Bratcher, Mark Holmes, Jesse Lichstein, Thalia Shirley-Fuller, Pam Silberman

WELCOME AND INTRODUCTIONS:

Leza Wainwright

Co-Director

*Division of Mental Health, Developmental Disabilities
and Substance Abuse Services*

Ms. Wainwright welcomed the participants and asked them to introduce themselves.

OVERVIEW OF AGING ISSUES:

Genny Pugh

Executive Director

Turning Point Services

Lifestyles choices and health promotion are very important factors in aging—even more than genetics. Like the rest of the US population the population of people with developmental disabilities is aging. The typical lifespan of a person with developmental disabilities has increased significantly to an average age of 70 years old. There are 526,000 people with developmental disabilities over the age of 60, and this number is expected to double by 2030. There are 479,000 people with developmental disabilities living at home with parents aged 60 and over. Fewer than 50% of parents have made plans with and for their aging son or daughter with developmental disabilities.

People with developmental disabilities experience many of the normal changes associated with aging, yet they experience them sooner than the general population. For example,

individuals with Down syndrome can experience aging up to 20 years earlier than what is expected in normal aging. In addition, individuals with developmental disabilities may also experience complications of aging due to sedentary lifestyles, difficulty in expressing changes in health status, and the risk for dementia. Person Centered Plans should take these factors into account so that individuals with developmental disabilities can age in the manner and setting that they wish. Focusing on the relationship between physical activity, cognitive functioning, and general health is necessary for people with developmental disabilities to age successfully.

Aging in place (i.e. remaining in a living setting) is the desire of many people both with and without developmental disabilities. However, for a person with developmental disabilities, aging in place presents some challenges: the need for significant supports for people with functional decline or dementia, decreasing capabilities of caregivers coinciding with increasing needs of the individual with developmental disabilities, and establishment of two generation elderly families. It is possible for a person with developmental disabilities to remain in at home or in a residential facility, but it requires the staff and support team to be dedicated to this goal.

In addition, individuals with developmental disabilities deserve the right and opportunity to acknowledge the end of life, affirm its value, and grieve the loss of a friend. Supports in end of life issues should accompany the aging process in individuals with developmental disabilities.

North Carolina is currently experiencing challenges in identifying unserved and underserved individuals, changing the approach to services, creating later life supports, improving health care, educating health care providers, empowering consumers, identifying dementia, creating dementia capable services, identifying gaps in legal/financial arrangements, and educating providers and consumers.

Comments/Discussion: The discussion that followed focused on addressing the challenges in North Carolina. Topics included better diagnostic tests for dementia, depression, and Alzheimer's disease; flexible funding for aging in place; long term care insurance availability; partnerships with the Divisions of Aging and Mental Health, Developmental Disabilities, and Substance Abuse Services; funding for employment programs; senior services; reinstatement of a waiting list; and the relevance of statewide family support services.

SERVICES TO SUPPORT COMMUNITY LIVING:

Rose Burnette

Waiver Manager

Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

North Carolina Department of Health and Human Services

Many people with developmental disabilities are served by the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS), which provides both Medicaid and non-Medicaid, state-funded services. Services depend

on the individual's needs as determined in the person centered planning process, and are individualized to each person. The services funded by Medicaid include targeted case management, community based, private Intermediate Care Facilities for people with Mental Retardation (ICFs-MR), state operated ICFs-MR (i.e. developmental centers), and community based services such as the Community Alternatives Program for Individuals with Mental Retardation or other Developmental Disabilities (CAP-MR/DD).

Targeted case management provides assessments of needed services and supports for individuals with developmental disabilities as well as planning to identify a course of action to respond to the assessed needs (i.e. the Person-Centered Plan). Case managers aid in completing the Person Centered Plan by connecting individuals to services and supports, and monitoring services and supports to make sure they delivered as indicated in the Person Centered Plan.

The Community Alternatives Program for Individuals with Mental Retardation or other Developmental Disabilities (CAP-MR/DD) offers specific services that promote community living and avoid large, congregate care settings. These waiver services compliment and/or supplement services available through the Medicaid state plan and other state, local and federal programs. Individuals considered for CAP-MR/DD funding must meet the same level of care that is provided in an ICF-MR facility. The waiver must also be a cost effective alternative to living in an ICF-MR facility. The specific services designed for individuals living in their own home or family's home include home and community supports (HCS), personal care services, and residential supports. The services designed for where people work and day activities include supported employment, day supports, adult day health, individual/caregiver training and education, and specialized consultative services. Crisis services and crisis respite services provide additional staff for the individual, as needed, during an acute crisis situation to support the individual to continue to participate in his daily routine and/or residential setting without interruption. Behavioral consultation is intended to assist the individual in acquiring and maintaining the skills necessary to live in their communities and avoid placement in large congregate care settings. CAP-MR/DD services that provide additional supports include augmentative communication, home modifications, specialized equipment and supplies, transportation, vehicle adaptations, and the personal emergency response system (an electronic device to assist individuals with securing help in an emergency).

State funded services are available to individuals who are ineligible for Medicaid and therefore not eligible for CAP-MR/DD, individuals who receive Medicaid but do not meet the ICF-MR level of care (and so not eligible for CAP-MR/DD), and individuals who are CAP-MR/DD recipients but need additional help to pay for things the waiver does not cover, such as room and board in a group home. The state funds help pay for I/DD targeted case management (for individuals not eligible for Medicaid), comprehensive clinical assessments, respite care, personal care services, supported employment, long-term vocational support, adult day vocational programs, and developmental therapy. In many ways, these services are similar to what is offered to other individuals with I/DD through the CAP-MR/DD program.

Comments/Discussion: The discussion that followed focused on the need for improvements in the system as a whole, including long term support and follow up, collaboration with partner agencies, unintended consequences of services, definitions of alternative family living situation, income eligibility requirements, licensing requirements, and availability of services.

HOUSING OPTIONS:

Angela Harper

Housing Specialist

*Division of Mental Health, Developmental Disabilities, and Substance Abuse Services
North Carolina Department of Health and Human Services*

The best practice housing model for persons with developmental disabilities focuses on self-determination and self-control with key elements of independence, accessibility, affordability, and responsibility. It enables people to successfully select, acquire and maintain safe, decent, and affordable housing with access to a variety of individualized, flexible support services. The benefits include independent private living space, permanent housing that is not time limited, the opportunity for housing stability, a standard lease for the tenant, and the ability to establish and maintain connections within the community.

The Housing Specialist addresses housing needs of individuals, served by DMHDDAS, for the purpose of supporting the development of housing resources and residential options. The Housing Specialist also focuses on establishing and strengthening access to community based support services for consumers within the public system by coordinating statewide meetings of Local Management Entities' (LMEs) Housing Specialists and assists them in developing and maintaining collaborative relationships with community service providers, low-income housing developers, public and private housing agencies, consultants, local, regional, & state advocacy groups, local and regional governments, and faith-based organizations for the purpose of developing housing resources and residential options. The LME Housing Specialists' role is to expand housing opportunities, which requires an investment of time and relationship building; developing connections with housing providers, both public and private, to maximize access to existing affordable housing units; and educating consumers, families and service providers about accessing and maintaining affordable housing, about the NC Landlord-Tenant and Fair Housing laws, and about negotiating reasonable accommodations.

There are a variety of organizations and programs available to help find appropriate housing for individuals with developmental disabilities. The Arc of North Carolina's Opening Doors Initiative increases the range of housing options available to meet each individual's aspiration to live independently in the community with appropriate in-home supports through Regional Housing Resource Coordinators and a variety of residential settings.

Group homes for adults or supervised living in a 24-hour facility which provides residential services to individuals in a home environment, with the primary purpose being the care and the habilitation of adults whose primary diagnosis is a developmental disability. Specialized community residential centers for individuals with developmental disabilities also called Intermediate Care Facilities for People with Mental Retardation (ICF-MR) are designed for individuals with no other option for successful community living. Self-determined housing includes supported apartments, housing choice/section 8 vouchers, public housing, low income housing tax credit apartments (LIHTC), NC LIHTC targeting program, key program assistance, and the Housing 400 Initiative. The self-determined options vary from set aside housing units to assistance and tax credits.

Comments/Discussion: The discussion that followed focused on the intense needs in the state. There are 109,000 nonelderly Supplemental Security Income recipients in NC and these housing options have a 92% occupancy rate. Other topics included the differences between rehabilitation (making a home accessible) and home modification (changes after living in a home for some time and adjusting to needs), loan application process, current requirements for families to convert units back to their original state after modifications have been made if they move out, fair housing laws, and the growing number of families now in foreclosure.

DISCUSSION AND COMMENTS FROM THE TASK FORCE:

The participants discussed recommendations related to the presentations. Some of the topics included:

- Long Term Care insurance and future planning.
- A variety of housing issues based on the intensity of an individual's needs.
- Benefits of group housing and socialization.
- Converting family members to care providers, outreach and information for families and professionals, and general health promotion and disease prevention.
- % People with MR/IDD and where they live: 4.08% adult care homes, 18.73% family care homes.
- Support of \$1400-1600/month for individuals in own apartment/home/parent home.
- DMHDSAS concept of care in a residential treatment center.
- Quality and intensity of care.
- The Olmstead Act.
- Special assistance and flexible cash subsidies to families.
- Aging in place and aging parents.
- Managing disability from birth and how to stay healthy.
- Emergency funds to support families providing care at home.
- Development of a waiting list for better knowledge of family needs for services and supports, prioritization in the system, and increases in capacity.
- –Partners such as the Division of Aging and the faith community.
- The full spectrum of options for individuals and families.

- Case manager competency.
- Regional management and variation and the need for statewide programs.