

SERVING PERSONS WITH DISABILITIES IN APPROPRIATE SETTINGS

THE NORTH CAROLINA PLAN

FINAL

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NC Department of Health and Human Services
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CHAPTER 1

OVERVIEW

Introduction

The United States Supreme Court's decision in the case of *Olmstead v. L.C.*, 119 S.Ct. 2176 (1999), has prompted a national reevaluation of the public system for serving persons with disabilities in appropriate settings. The *Olmstead* case, which involved a claim asserted against the State of Georgia, held that unjustified institutionalization of two individuals with mental disabilities constituted discrimination by the State in violation of the Americans with Disabilities Act (ADA). The Court's opinion endorsed the general ADA precept that persons with disabilities should receive services in the least restrictive environment appropriate to their needs. It also recognized, however, that states have an obligation to provide services for a wide range of disabilities, and that the least restrictive environment requirement might be subject to some limitations based on state resources.

Olmstead offered states a likely "safe harbor" defense to an ADA claim by having in place a "comprehensive, effectively working plan" for moving qualified disabled individuals to less restrictive settings. Most states, encouraged by federal agencies such as the Center for Medicare and Medicaid Services (CMS), are in the process of developing such plans.

North Carolina, through its Department of Health and Human Services (DHHS), undertook a planning process that reviewed past and current practices and lays the groundwork for continuing progress toward the goal of providing services to North Carolinians with disabilities in the least restrictive environment that is appropriate to their needs. The goal is not one that can be accomplished easily or instantly. It is one that has been a fundamental premise of state policy for at least the past decade. For North Carolina, therefore, *Olmstead* is a building block in implementing the most desirable human services programs.

This document summarizes the results and findings of the planning process and sets forth in a consolidated fashion North Carolina's plan to achieve greater integration of its citizens with disabilities into less restrictive settings. For convenience, and to reflect what has become common shorthand, this document and the associated programs may be referred to as the State's "*Olmstead* Plan." However, it is not circumscribed, nor is it necessarily mandated in all respects, by the *Olmstead* decision. Rather, it is a broader vision of implementing a philosophy of service approaches.

Fundamental Principles

The goal of the State of North Carolina, in administering publicly financed programs for individuals with disabilities, is to reasonably accommodate those persons with disabilities who are willing and able to be served in integrated community settings. The method proposed to meet that goal is to develop and adhere to a comprehensive written plan that will ensure timely review of and response to requests for community placement, an adequate supply of community services, and a short waiting list and timely movement off waiting lists for individuals seeking community placement.

This goal articulates North Carolina's existing commitment to serving its citizens. It also is consistent with the aims of federal partners, such as the Centers for Medicare and Medicaid Services (CMS), which has embraced a goal to "integrate people with disabilities into the social mainstream, promote equality of opportunity and maximize individual choice."¹

These are not new concepts for North Carolina. The State's human services agencies have embraced and, to varying degrees, implemented the movement toward expanded community-based services and reduced reliance on institutions for years. Some of this has been a result of changes in the accepted practices in the human service fields. Other changes have stemmed from North Carolina's vigorous advocacy community, in some cases through negotiation, in other cases through litigation.²

North Carolina's Achievements to Date

A number of examples illustrate that the principles expounded in *Olmstead* have been guiding North Carolina's human service efforts in recent years. While much remains to be done, a review of the current situation in this state must begin with an acknowledgement of the efforts that the State's administrators have put forth in the past.

The following points are illustrative of how implementation of the principle of least restrictive environment has taken hold:

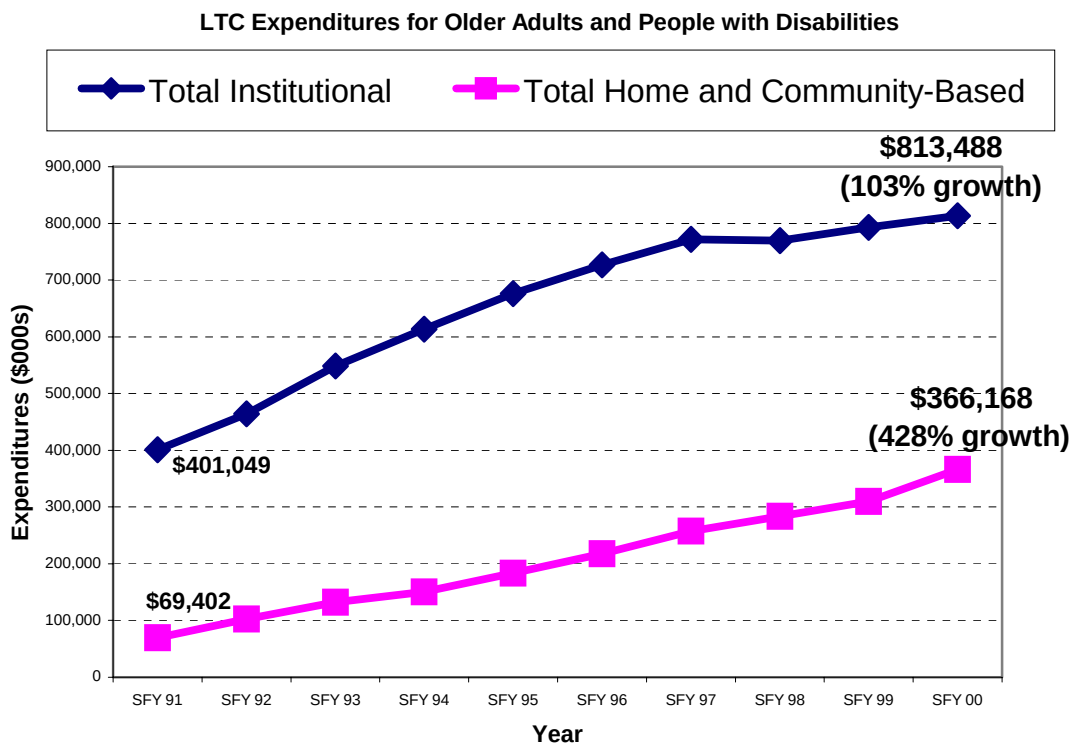
- The average daily census for the four State psychiatric hospitals has declined 28 percent from 2,593 (SFY 90) to 1,855 (SFY 99).
- The number of people served in the Division of Vocational Rehabilitation's Independent Living program in the last ten years has increased 351 percent, from 1,190 in (SFY 91) to 5,369 in (SFY 2000).
- North Carolina has reduced the residential census in the five Mental Retardation Centers by 4 percent per year in favor of small, family-like community settings and supported living. Fewer than 10 children under the age of 18 currently live in the Regional Centers.
- Over the last ten years (SFY 91-00) Medicaid-funded home and community-based service expenditures grew much faster than institutional spending for older adults and those with disabilities (non-MR/DD). For example, overall institutional costs (including nursing facilities and hospital long-term care beds) increased 103 percent, whereas home and community-based services (including CAP³, personal care services, home health, and home infusion therapy) increased 428 percent. Within the home and community-based services, CAP expenditures increased 483 percent and personal care expenditures for non-CAP eligible Medicaid clients increased 4,124 percent. The percent age of overall Medicaid long-term care spending for older adults and people with disabilities increased from 14.8 percent in (SFY 1991) to 31.0 percent in (SFY 00).

¹ Letter to State Medicaid Directors from Timothy M. Westmoreland and Thomas Perez, dated January 14, 2000, p. 1.

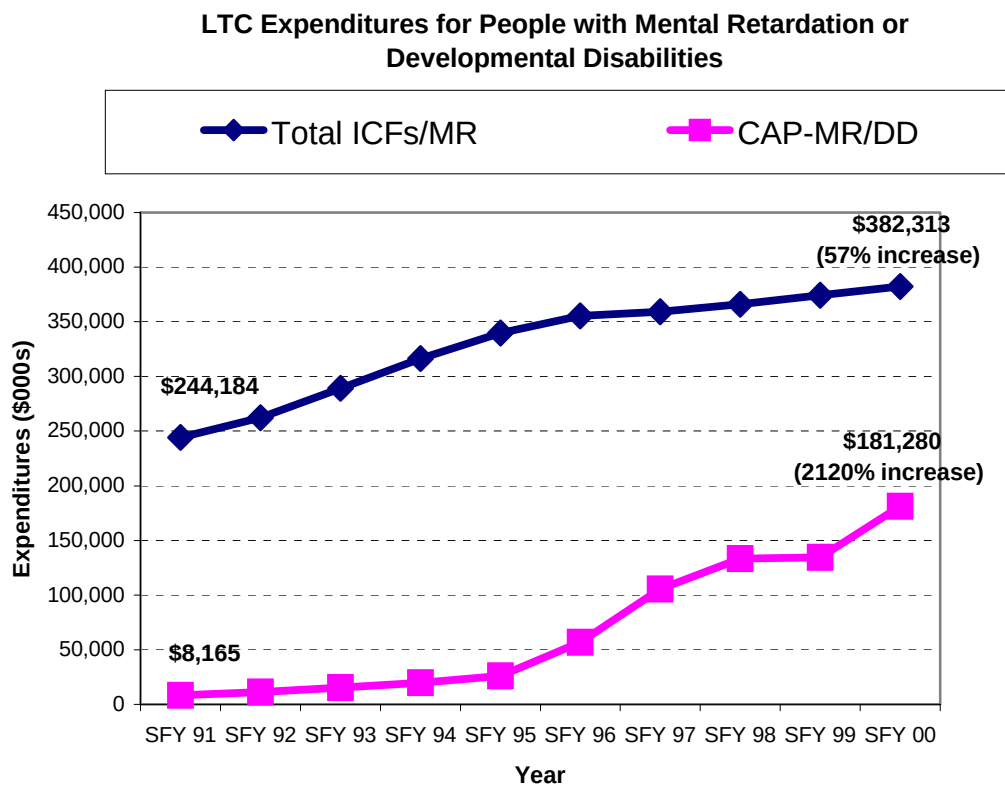
² See, e.g., *Thomas S. v. Flaherty*, 902 F.2d 250 (4th Cir.), cert. denied, 498 U.S. 951 (1990).

³ "CAP" is the Medicaid Community Alternatives Program. Various CAP programs provide funding for services and supports for various populations, such as CAP-MR/DD for children and adults with developmental disabilities and CAP-DA for adults with disabilities.

- Through a collaborative process between the State Division of Mental Health, Developmental Disabilities and Substance Abuse Services and four Regional Area Mental Health Planning Teams, a planning process was implemented to address two major goals: 1) identify and develop the array of services that people currently residing in State hospital beds identified for closure need to live in the community; and 2) develop or expand the capacity to serve those who otherwise would be admitted to a state psychiatric hospital. As of June 30, 2002, specific plans for each of the four Regions were completed and provide a blue print that details the kinds of treatment, services, and supports, the quantities required, and the costs associated with providing those services in each region of the state.
- Of the 27 individuals in the Wright Transitions Program at Dix Hospital at the time the hospital-based program was closed, nine individuals moved into independent or transitional housing and fourteen moved into supervised group settings such as group homes. Four individuals were not ready for discharge and were transferred to other units in the hospital to ensure they receive the services that will facilitate eventual discharge. In State Fiscal Year 2002, a total of \$671,000 in one-time bridge funding from the Mental Health Trust Funds and subsequent reallocation of funding up to \$1.8 million annually from the Dix Hospital budget, beginning in State Fiscal Year 2003, will follow these individuals into the community to be used by area programs to establish or expand a variety of services such as Assertive Community Treatment Teams, expanded psychosocial rehabilitation, case management, transportation, and supported housing. allocation of funding from the Dix Hospital budget. This represents the first time that institutional funds have followed clients from state hospitals into the community to provide needed community based services and supports.



- There was an even larger increase in the rate of growth for Medicaid-funded home- and community-based services for people with developmental disabilities. In the last ten years (SFY 91-00), the cost of services provided in ICFs-MR grew 57 percent, compared to the 2120 percent growth in the CAP-MR/DD expenditures. Further, even within the institutional spending, most of the growth was among smaller community-based ICFs-MR (135 percent) compared to State mental retardation centers (17 percent). The percentage of overall Medicaid long-term care spending for people with mental retardation or developmental disabilities increased from 3.2 percent in (SFY 1991) to 32.2 percent in (SFY 00).



Other information on current programs and status is contained in the detailed review of disability groups that follows in subsequent portions of this document.

Developing a Plan

The *Olmstead* court suggested that states develop a plan for moving persons with disabilities into a community setting. The following section analyzes the decision and its relation to North Carolina. Beyond the relatively narrow *Olmstead* purpose, DHHS determined to develop a plan and accompanying document that focused on the best way to meet the needs and desires of individuals receiving services and supports, consistent with the ability of the State to provide funding and oversight.

Several key decisions were made early in the process:

1. The community of individuals receiving services would be addressed by disability group rather than by services or providers. DHHS separately addressed the needs of individuals who are elderly and frail and people with acquired disabilities, people with severe and persistent mental illness or severe emotional disturbances, and people with developmental disabilities.
2. Specific need areas would be identified across disability groups, then procedures established within each group to meet the needs.
3. The planning process would include public meetings to involve consumers, providers, advocates and other interested North Carolinians. These meetings would serve at least two purposes: to solicit the input of attendees and to enlist the participants in advocating for needed action with decision-makers at all levels. Further public participation would be encouraged through various channels, including the Internet.
4. While the public input process was underway, agencies would survey their existing resources and needs to allow for a realistic evaluation of the present status of agency activities.
5. A cross-Departmental group of policy makers would oversee plan development, assisted by staff and outside expertise as necessary.
6. The planning group would produce an interim plan for dissemination on the Internet and to all those expressing an interest, inviting comment.
7. The “plan,” while written and published, would not be a static instrument, but rather a guide with provisions for periodic evaluation and adjustment.
8. The various agencies responsible for serving persons with disabilities would immediately focus on moving their locus of service provision to the least restrictive environment, with the expectation that subsequent plan development would support that effort. They also were to include this effort in planning activities, such as budget preparation.
9. The planning group established priorities for implementing DHHS efforts based on a variety of factors, such as present status, urgency of need, degree of modification of existing programs, number of affected individuals, cost, and need for outside actions, such as legislation.

Organization of this Document

The North Carolina plan for serving persons with disabilities in the most appropriate setting is set forth in the following sections of this document. The next section discusses the *Olmstead* decision itself, and certain aspects of its application to North Carolina. The following sections, one for each disability group, contain an overview of the current status of the group, describing the population in the State and addressing service needs and availability. These sections cover ten areas:

- 1) Overview
- 2) Description of specific programs serving people with disabilities
- 3) Assessment process for currently institutionalized and at-risk
- 4) Operation of waiting lists
- 5) Inventory of community-based services to assist people in moving back to the community
- 6) Assessing need for additional services
- 7) Identify housing alternatives to institutional placement
- 8) Adequacy of the workforce to provide services
- 9) Assuring and monitoring quality of care

10) Identify and expand the availability of safe, accessible, and affordable transportation resources

Next comes a summary of the public input received during the statewide public meeting process and other avenues. A fuller summary is attached as an appendix, and a compilation of the comments, edited solely to reduce duplications, is available on the DHHS website.

The last section of the document is the plan itself. It provides specific steps that the State will take to continue its efforts to ensure that persons with disabilities who are institutionalized or at-risk of institutionalization receives care in the most integrated setting appropriate to their needs and preferences. Specifically, the plan covers the following areas:

- Outreach to permit informed choice by candidates for community-based services;
- Assessment and identification of appropriate candidates for less restrictive placement;
- Development of service plans for transition to community placement;
- Waiting list improvement;
- Inventory existing community-based resources;
- Identification of needed community resources to support integration efforts; and
- Ongoing monitoring and quality assurance efforts.

Several caveats are in order. At the moment, this document is an interim plan, subject to revision after receiving comment from the interested community at large. Any interested individuals are invited to provide their input for consideration by sending it to DHHS via the Internet, by mail, or by direct contact with Department officials.

A “final” plan will be published after consideration of comments. However, this plan will never truly be “final,” because it will remain subject to review and revision based on progress in implementation, advances in treatment environments and techniques, and societal developments. In addition, practical considerations such as the economy and other demands at both the national and state levels will affect the State’s ability to respond to its requirements in all service areas. These factors may be positive or negative, but they must be included in a realistic operational system.

CHAPTER 2

OVERVIEW OF *OLMSTEAD* DECISION

In *Olmstead v. L.C.* the United States Supreme Court held that unjustified institutionalization of two individuals, who had mental disabilities violated the Americans with Disabilities Act. The decision is consistent with North Carolina's policy to provide services to its citizens with disabilities in the least restrictive environment appropriate to their needs. *Olmstead* reinforces this policy and has led to a general review of the process for moving persons with disabilities from institutions to community-based settings on both a national and state level.

The *Olmstead* Case Itself

Olmstead was a lawsuit brought by two Georgia women receiving treatment at the Georgia Regional Hospital, a state institution. Each of the plaintiffs was dually diagnosed with mental retardation and another mental disability. Each was voluntarily admitted to the state institution. After a period of time, each woman's treatment team concluded that she could be served in a community setting, however, both remained in the institution. (After the litigation commenced, each was placed in a community setting; however, the case continued.)

The plaintiffs brought suit in federal court. Among other claims, they asserted that their continuing institutionalization constituted discrimination by a public entity (the State of Georgia) in violation of the Americans with Disabilities Act (ADA). This was the only claim addressed by the United States Supreme Court.

The Court found that unjustified institutionalization could constitute unlawful discrimination under the ADA. Specifically, in an opinion by Justice Ginsberg, a six-Justice majority held that "under Title II of the ADA, states are required to provide community-based treatment of persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the treatment can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."

In her opinion, Justice Ginsberg cited two "evident judgments" in concluding that unjustified institutional isolation of persons with disabilities is a form of discrimination. First, institutional placement of individuals "who can handle and benefit from community settings perpetuates unwarranted assumptions" that these persons are incapable or unworthy of being in the community. Second, such confinement severely diminishes the daily life experiences of the individual, such as work, family, independence, and cultural enrichment.

The Court continued its history of relying on treatment professionals to determine whether a given individual meets the criteria for placement in a community setting, suggesting that courts normally should defer to reasonable professional conclusions. It emphasized, however, that it was not requiring states to impose community placement on an individual who did not desire it.

The Court did not make the states' obligation to avoid institutionalization absolute and immediate. It recognized the "States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand." It also recognized that the ADA does not require unlimited accommodations for persons with disabilities; rather, the ADA regulations refer to "reasonable accommodations."⁴ States may resist accommodations that would require a "fundamental alteration of the State's services and programs."⁵

The Court was unable to muster a majority of members to join in the section of the opinion that more fully outlines how the concepts of fundamental alteration and reasonable accommodation may be demonstrated in an ADA case against the state. Justice Ginsberg spoke on behalf of a four-Justice plurality when she articulated more specifics on the requirement. "Sensibly construed," she wrote, "the fundamental alteration component of the reasonable-modifications regulation would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities."⁶ No one had argued that the States would no longer require institutions: Some individuals are not prepared for community placement at particular times, some might require occasional short-term institutional care between longer periods in the community. For others, placement outside the institutional setting remains an issue of how to safely and successfully support individuals that have serious challenges, within a reasonable economic scale.

The plurality believed that the reasonable accommodation concept, therefore, includes a consideration of the overall resources of the state to provide for its populations of persons with mental disabilities. The states, therefore, must be given some leeway, so that they can maintain facilities and administer services fairly. In the most specific guidance available, Justice Ginsberg wrote: "If, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met."⁷

Applying *Olmstead* to North Carolina

Olmstead's basic policy declaration that individuals with disabilities should be served in the least restrictive setting appropriate to their needs is fully consistent with North Carolina's view. In addition, this State's experience with the *Thomas S.* litigation heightened the mental health and developmental disabilities communities' awareness of the need for continued efforts to realize this goal.

Like most states, North Carolina is faced with the reality of meeting the needs of its citizens in a host of areas with limited resources. As everywhere, services for individuals with disabilities compete for funding with services for education, transportation, public safety and all of the other responsibilities of the State. *Olmstead*, therefore, can and has served as a useful reminder to the State's policy makers of the needs of the disabled.

⁴ *Olmstead v. L.C.*, ____ U.S. ____, 119 S. Ct. 2176, ____ (1999).

⁵ Id. at 119 S.Ct. ____.

⁶ Id. at 119 S.Ct. ____.

⁷ Id. at 119 S.Ct. ____.

The Scope of *Olmstead*

One of the fundamental issues faced by North Carolina is determining how broadly to apply the principles of *Olmstead*. The case itself dealt with individuals with mental disabilities, and the Court in its opinion was careful not to expand its holding beyond the case under consideration. The states, therefore, are left to their own analysis and exposition by subsequent courts, to determine the scope of their response. Federal agencies, advocates, consumers, and others have contributed to the analysis, and in some cases to the confusion, by offering their own views.

Some aspects seem clearer than others do. For example, while the Court limited its holding to those with mental disabilities, the rationale used by the Court, and the Americans with Disabilities Act itself, suggest that the strictures of the Act as described in *Olmstead* applies to all ADA disabilities meeting the other criteria, not just those associated with mental processes.

The conclusion that *Olmstead* is not limited to mental disabilities does not imply that all services to disabled persons must be offered in community settings. First, the Court itself felt that institutions are the appropriate setting for serving some disabled persons. The concurring Justices especially took pains to point out that the opinion was not a command to close institutions.

Next, *Olmstead* left open a number of issues that it did not need to address on the fact before it. Perhaps most fundamental was the nature of institutionalization for purposes of determining discrimination under the ADA. The plaintiffs in the case before the Court were individuals who were served in a setting that would meet the definition of “institution” under any standard, and they were long-term residents whose treatment teams had recommended community-based treatment. An open question is whether the same standards apply to a less restrictive setting and to short-term placements.

Because the term “institution” is used throughout the Supreme Court’s opinion, many have viewed the category of a given facility to be dispositive of whether *Olmstead* has any application to its residents. North Carolina has decided that this “bricks and mortar” approach, while it may be definitive for interpreting *Olmstead* on a given set of facts, misses the essence of the underlying policy. The focus should be on the appropriate setting for each individual participant in the State’s program, not on the label attached to a particular physical plant. Therefore, North Carolina’s plan will focus on assessing individuals to determine their needs and desires, then monitoring (or in some cases developing) each person’s movement through the service options to the least restrictive appropriate environment.

The analysis that North Carolina proposes for its review recognizes the basic premises underlying the Supreme Court’s opinion: that institutional placement of persons who can handle and benefit from community placement assumes that those persons are not worthy or capable of participating in community life, and that institutional confinement diminishes everyday life activities. To ensure that the State is not imposing this unwarranted segregation and isolation, each qualified individual will be assessed under essentially the following framework:

1. Is the State's involvement a service, program or activity offered by a public entity?
2. Is the individual a qualified individual with a disability?
3. Is the program one that could be offered in a less restrictive setting, but not offered to this individual?
4. Is the program in fact offered in a less restrictive setting?
5. If it is not offered in a less restrictive setting, could it be?
6. Does the State's failure to offer a less restrictive setting to this individual constitute unwarranted segregation and isolation?

This does not imply that all "institutions" must ultimately be closed and all services offered in the home. The Court recognized that some individuals are most appropriately served in institutional settings. Moreover, it noted that states did not need to make "fundamental alterations" in their programs to provide services in community settings. A fair reading of the opinion suggests that some services, for some persons, are not suited for community delivery. Open-heart surgery, for example, is performed in hospitals. In theory, mobile surgical suites, cardiac care units, and teams could be established to go into community settings and provide the necessary care. However, the cost would be prohibitive, and the inefficient use of available resources would preclude such an effort, given the marginal benefit to the patient.

Questions of the nature of institutions and scope of population also come into play in setting priorities. Real-world considerations, especially fiscal considerations and service availability, limit every state's ability to meet community placement goals immediately. Justice Ginsberg's plurality decision acknowledged these limitations by its suggestion of a plan demonstrating a waiting list moving at a reasonable pace. This concept avoids the specter of individuals leapfrogging the system by filing lawsuits, and recognizes that the varied and extensive responsibilities of the state to provide a range of services means that a given individual may have to wait a reasonable period of time before receiving services in a less restrictive environment.

The impact of the individual's desires is also somewhat unclear. The Court clearly stated that its finding of an ADA violation on the facts before it applied when the individual did not oppose placement in a less restrictive setting. It did not, however, address what happens if the individual does oppose moving to another setting. For a variety of reasons, some individuals (or their legal representatives) may prefer institutional placements over less restrictive alternatives. Their right to insist on such placement is not established (or refuted) by *Olmstead*. Another hard issue, one that must be resolved on a case-by-case basis, arises when the legal representative's wishes differ from those expressed by the individual.

The *Olmstead* decision continues the Court's practice of relying heavily on the judgment of treatment professionals for determinations within their professional expertise. One criterion to determine potential ADA violations were that the state's treatment professionals determine that community placement is appropriate. Questions about the appropriateness of professional judgment and treatment, therefore, are generally outside the scope of this plan.

Another unanswered question in the *Olmstead* decision is the position of those persons “at risk” for institutionalization. Some analysts, including HCFA, conclude explicitly or implicitly that the Supreme Court has ruled that the states will be subject to ADA liability if they do not implement programs to divert potential institutional placements. As a practical matter, deciding whether “at risk” people are within the purview of the *Olmstead* decision is unnecessary, because ignoring the at-risk population will tend to increase the population that clearly fall within *Olmstead*’s dictates. Moreover, if a person can avoid eventual inappropriate institutionalization by early diversion, then economy and better practice suggest that the effort be made.

In the approach taken by North Carolina, the precise parameters of the *Olmstead* decision are not especially relevant and need not be defined. As a policy matter, the State will continue its efforts to assure that all qualified participants in its programs, with or without disabilities, will be served in the least restrictive appropriate settings.

The Planning Process

The plurality opinion authored by Justice Ginsberg sought to give states guidance on implementing its decision. The opinion described what often is termed a “safe harbor” provision: a way for the states to have some assurance that they are in compliance with a requirement. Specifically, the plurality stated that the state would have deemed to have undertaken reasonable modifications to accommodate a plaintiff’s disability when it could show that it had in place “a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated . . .”.

Most states, including North Carolina, have accepted the Court’s invitation to develop such a plan. The plan concept also has been adopted by CMS, which has issued its own interpretations and suggestions. While not necessarily binding, the planning process has proven to be useful in demonstrating *Olmstead* compliance and in the broader objective of providing services in the least restrictive environment appropriate to individual needs.

North Carolina has taken advantage of this opportunity by formalizing an on-going, wide-ranging planning process. The Department of Health and Human Services formed an advisory group and a policy committee to guide the process. Two important components: surveying existing policies and practices, and soliciting input from the public, began in the spring of 2000. CMS has suggested, and Department leadership agreed, that public input from all sectors was vital to the plan. Accordingly, four public meetings were conducted, with participants asked to provide insight and opinions on various questions arising in the general area of service provision. The topics, and the responses, were not confined to the narrow parameters of *Olmstead*, but tended to encompass all aspects of service delivery from the perspectives of consumers, advocates and providers. Summaries of the public response have been provided to the State’s program directors and policy makers, so that they will receive the benefit of the process regardless of whether it technically falls within ADA considerations.

The next step was to create this document: a capsulization of North Carolina’s present and projected strategies for serving persons with disabilities in appropriate settings. One guiding principle throughout is that the process does not end with the production of a document labeled “the plan.” Indeed, the plan is intended to be an on-going, flexible approach that contains periodic evaluations and progress assessments. Changes are expected to meet changing circumstances. At any given time, therefore, the plan is appropriately viewed as a snapshot of the State’s efforts.

CHAPTER 3

FRAIL ELDERLY AND PEOPLE WITH ACQUIRED DISABILITIES⁸

Overview

Adults age 65 or older currently comprise almost 12 percent (996,239) of the State's population.⁹ By 2020, more than 15 percent of the State's population (1,652,288) are expected to be 65 years or older. The number of adults age 85 or older is expected to grow from 105,461 in 2000 to 189,908 in 2020, an increase of almost 43 percent in the proportion of the State's population age 85 or older.

Most older adults live independently at home or in the community. However, national estimates suggest that about 40 percent of persons who live to age 65 will use some nursing home care sometime in their lives.¹⁰ In 1990, approximately 23 percent of seniors living in the community needed assistance with at least one activity of daily living (ADL), such as meal preparation, bathing, or dressing.¹¹ The NC Institute of Medicine recently commissioned a study of the need for long-term care services among adults age 18 or older.¹² The study, which is an extrapolation of national data surveys to North Carolina, adjusted for North Carolina demographics, indicated that there are currently 79,800 adults living in the community with three or more ADL impairments. This is expected to grow to 98,400 people by 2010. There are currently 42,700 people living in nursing homes, State mental retardation centers or large ICFs-MR, and this number is expected to grow to 51,700 by 2010.

Table 1: Persons Aged 18+ with Long-Term Care Needs

<u>Level of Impairment and Care Setting</u>	<u>2000</u>	<u>2005</u>	<u>2010</u>	<u>Percent Change 2000-2010</u>
Community-Dwelling (includes Adult Care Home residents)		337,600	366,700	18.8%
<i>IADL impairments only</i>	123,600	134,400	143,500	16%
<i>1-2 ADL impairments</i>	105,400	114,800	124,800	18%
<i>3+ ADL impairments</i>	79,800	88,400	98,400	23%
Institutional residents	42,700	45,500	51,700	21.1%
Total Long-Term Care Need	351,500	383,100	418,400	19.0%

⁸ People with "acquired" disabilities are those who typically become disabled after childhood, for example, through illness, degenerative or chronic disease, or accident. This term is used to distinguish people who acquire disabilities later in life with those who have developmental disabilities that arise during childhood.

⁹ NC Office of Budget and Planning. July 2000 Population Estimates.

¹⁰ Feder, J., Komisar, H.L., Niefield, M., "Long-Term Care in the United States: An Overview," *Health Affairs* 2000, 19(3): 40-56.

¹¹ Activity of Daily Living (ADL) impairments relate to personal tasks such as bathing, dressing, toileting, transferring from bed to chair, personal grooming and eating. Instrumental Activities of Daily Living (IADL) impairments relate to tasks such as managing finances, doing light housework, transportation outside of the home, preparing meals, and using the telephone.

¹² Millennium Healthcare Solutions, Inc. Demand for Long-Term Care in North Carolina: Projections for 2000, 2005, and 2010. Final Report. Prepared for the North Carolina Institute of Medicine. Edison, New Jersey: December 8, 2000.

There is no exact count of the total number of people in North Carolina with disabilities of all ages, nor do we know the exact number of people with disabilities who need supportive services to maintain independent living. However, national data suggest that in 1996, 14.4 percent of people report some activity limitation due to chronic health conditions, 4.7 percent are unable to perform major activities, 5.3 percent are limited in the amount or kind of major activity they can perform, and 4.5 percent are limited in activities other than their major activity.¹³ In the 2000 Census, 298,213 (30.8 percent) of people age 65 and older in the community reported some level of physical disability, while 121,874 (12.6 percent) had a mental disability.¹⁴

According to the HIV/STD Prevention and Care Branch, within the NC Department of Health and Human Services, there were 12,780 people in this state known to have HIV disease on December 31, 1999.¹⁵ Infection with the human immunodeficiency virus (HIV) generally causes progressive damage to a person's organ and immune system and leads to a life threatening condition called AIDS (acquired immunodeficiency syndrome).¹⁶ However, not all people with HIV disease have been tested, thus the numbers of known people with HIV disease is likely to undercount the total number of people infected. Extrapolating from national data, the HIV/STD Prevention and Care Branch suggests that there are between 12,780 and 16,977 HIV infected people living in North Carolina. Through 1999, 231 children under age 13 were reported to have HIV infection. Treatment advances have helped delay the progression of HIV infection to AIDS, and the progression of AIDS to death. The HIV/STD Prevention and Care Branch estimates that there are approximately 4,000 people in the State living with AIDS. It is the people with AIDS, rather than those with HIV, who are most likely to require or be at-risk of institutionalization.

The State offers a number of programs for frail seniors and people with disabilities to serve them in home or community-based settings. The types of services that are available are based on a person's functional, cognitive and medical needs, and in some cases their financial eligibility for publicly funded services. Individuals who would otherwise need nursing facility services can receive home and community-based services through the Community Alternatives Program for Disabled Adults (CAP-DA). There are also special CAP programs for people with AIDS (CAP-AIDS) and for children who require 24 hour nursing care (CAP-C).

Individuals who do not meet the CAP eligibility requirements may qualify for some assistance with home and community-based services through the Home and Community Care Block Grant (HCCBG) if they are 60 or older or through the Social Services Block Grant (SSBG).¹⁷ Other people with disabilities may receive assistance through the In-Home State Funds (for adults younger than age 60) or through Ryan White funds (for people with HIV/AIDS). In addition, some older adults or people

¹³ "Major Activity" is defined as: for children under five -- playing; for persons 5 to 17 -- attending school; for persons 18 to 69 -- working or keeping house; for persons 70 and older -- ability to care for oneself and home (ADLs and IADLs). Adams, P.F., Hendershot, G.E., and Maranao, M.A., Current estimates from the National Health Interview Survey, 1996. National Center for Health Statistics. Vital Health Stat. 10(200), 1999.

¹⁴ 1990 Census Data for States, Metropolitan Areas, and Counties, and Model-Based Estimates of the Prevalence of Specific Disabilities for States and Counties: Table 3.

¹⁵ 2001 HIV Prevention & Community Planning. Epidemiologic Profile for North Carolina. HIV/STD Prevention and Care Branch. Epidemiology and Special Studies Unit. NC Department of Health and Human Services.

¹⁶ North Carolina HIV/STD Surveillance Report: Vol. 2000, No. 3. Epidemiology and Special Studies Unit. NC Department of Health and Human Services.

¹⁷ The amount of services available through the HCCBG or SSBG programs are not usually sufficient to meet the needs of someone who would qualify for nursing home level of services.

with disabilities who have the capacity to live at home and manage their lives may also receive services from the Independent Living Rehabilitation Program operated through the State's Division of Vocational Rehabilitation Services.

There are also programs available to help individuals with less severe disabilities to remain in their home or community. People who do not need nursing home facility level of care may qualify for services through Medicaid, Vocational Rehabilitation's Independent Living Program, HCCBG, SSBG, Division of Services for the Blind's Independent Living Program or the Adult Day Care Fund. For those who need a more structured living situation, the State operates a State-County Special Assistance program which helps pay for the costs of care in Adult Care Homes. In the 1999 legislature, the North Carolina General Assembly also established a pilot program to use SC/SA funds to support up to 400 individuals in their homes or in returning to their homes.

Description of Specific Programs

CAP/DA is a Medicaid program that covers the cost of case management, in-home aides, adult day health, respite and other services for people who are Medicaid-eligible who would otherwise need nursing facility level of care. This program has grown over the last six years with support from the "Aging at Home Program" through the Duke Center on Aging. Though it is an optional program for counties, all 100 counties have chosen to offer the program. In the calendar year 2001, 12,275 individuals received CAP/DA services. County commissioners decide if the county will offer the program, and select the local lead agency.¹⁸ The array of services provided under CAP/DA is in addition to the medical services normally covered through Medicaid. All individuals receiving services through CAP/DA funding are provided a case manager to arrange services for them. CAP/DA is available to adults of all ages who meet Medicaid nursing facility criteria; approximately 75 percent of the participants are 65 or older. To qualify for services under this program, a person must be Medicaid eligible and be able to be cared for in his or her private residence within the CAP cost limit. Each year, the Division of Medical Assistance provides an allocation to each county of how many individuals the county may serve during the year. The allocations are affected by each county's request, the number of individuals approved by HCFA in the CAP/DA waiver, and the State budget. Counties base their requests on the availability of local resources, including the availability of case managers and in-home aides.¹⁹ In calendar year 2001, 12,275 individuals received CAP/DA services.

The Division of Medical Assistance also offers a Community Alternatives Program for people with AIDS who would otherwise qualify for nursing home level care (CAP/AIDS). CAP/AIDS is a statewide program for individuals of all ages who are Medicaid-eligible. CAP/AIDS case management agencies may cross county lines and provide services to as many individuals as they have available staff resources. In addition to regular Medicaid covered services, CAP/AIDS provides coverage of case management, adult day health care, in-home services in excess of the regular Medicaid limits, waiver supplies, home mobility aids, personal emergency response systems, preparation and delivery of meals, and respite care (in-home and institutional). The CAP/AIDS program for calendar year 2001 served 43 people. In addition, approximately 179 people with AIDS reside in nursing homes.

Another CAP program targets children who are medically fragile. Children who are medically fragile are often cared for in a hospital or in a nursing home. However, the State also runs a community

¹⁸ Counties must pay a certain percentage of the costs of Medicaid services, currently 5.63% (SFY 2001).

¹⁹ In some counties, the CAP/DA lead agency is a county agency (DSS, health department, agency on aging).

alternative program for these children (CAP/C). These are children who have such complex medical conditions that they require 24-hour nursing or medical services. Children who meet these criteria include those born with severe birth defects, children with gastric feeding tubes or respirators, or those who were in serious accidents who would otherwise need to be cared for in a hospital or nursing home. The CAP/C program was designed to enable children who would otherwise need institutionalization to remain at home. Unlike most Medicaid programs, this program does not count the income or assets of the parent in determining the child's eligibility for services. In calendar year 2001, 478 children received CAP/C services.

Individuals eligible for Medicaid who do not qualify for nursing facility level of services required under the CAP programs may nonetheless still qualify for Medicaid home care services, including personal care services, home health services, home infusion therapies, hospice, private duty nursing and durable medical equipment. Medicaid will also pay for case management services through county Departments of Social Services for individuals whose condition puts them at risk of abuse, neglect, or exploitation. Traditional Medicaid coverage helps pay for medical care, medications, home health services, and personal care in-home aide services—but does not pay for adult day health care, institutional or group respite.. In addition, personal care services are limited to 60 hours per month.

The Home and Community Care Block Grant program, administered by the Division of Aging, helps pay for congregate and home delivered meals, in-home aides, adult day care or day health, housing and home improvement, respite care, home health, transportation, care management, and information and assistance. Services are available to adults age 60 or older. Funding is limited under the HCCBG program, so counties establish priorities on how the funds will be allocated. HCCBG services are targeted to minorities and persons with low income and socially isolated, with particular attention to low-income minority and people living in rural areas. Priority is generally given to older adults who are at risk of abuse, neglect or exploitation or who have functional impairments that limit their ability to carry out essential tasks and therefore put them at risk of placement in substitute care. As of 2001, the Division of Aging also began administering a new Family Caregiver Support Program through the 17 Area Agencies on Aging. Initiated under the 2000 Amendments to the Older Americans Act, the FCSP supports information and assistance; caregiver counseling, training and support groups; respite; and supplemental services. It is vital that adequate attention is given to supporting family caregivers who provide the majority of the long term care.

The Social Services Block Grant program offers similar services to those offered through the HCCBG program. SSBG funds can be used to pay for in-home aides, respite, adult day care and day health, case management, home delivered meals, transportation, home health, and housing and home improvement. In addition, SSBG funds help pay for adult protective services and guardianship through local Departments of Social Services. There is no age limit on who can be served with SSBG funds; however individuals must need assistance with at least one or more ADL or IADL. The priority system is similar to that used by the HCCBG program.

The State Adult Day Care Fund was established by the General Assembly for county departments of social services to purchase adult day care and adult day health services for elderly and disabled adults for the purpose of enabling them to remain in or return home. The appropriation for this Fund is capped which limits the number of people who can be served. The State In-Home Services Fund was established by the General Assembly for county departments of social services to provide services that enable adults who are elderly and disabled to remain in or return home. The funds are used primarily for in-home aide services but may also be used for housing and home improvement services, home-

delivered or congregate meals, and adult day care. The appropriation for this Fund is capped also limiting the number of people who can be served.

Vocational Rehabilitation's Independent Living (IL) program provides services to help individuals with significant disabilities to live and function in their homes and communities. Some of the types of people served include people with spinal cord injury, multiple sclerosis, cerebral palsy, amputations, sensory impairments, brain injury, muscular dystrophy, spina bifida, diabetes, as well as older adults with functional impairments. The Independent Living program helps arrange services and supports needed to maintain independence, including independent living skills training, home and vehicle modifications, rehabilitation engineering, adaptive aids, prosthetics and orthotics, consumer-managed personal assistance systems, recreation therapy and leisure activities, communication/environmental control systems, and peer counseling and advocacy. To qualify for assistance, a person must have countable income and resources below state established thresholds,²⁰ have a severe disability that severely limits the ability to live independently, and have a good chance that services will improve the ability to live independently. While the program can serve older adults, about two-thirds of the program's past participants have been younger people (under age 65) with physical disabilities. Recently, however, the Independent Living Program has begun working with the Division of Medical Assistance to design a program to assess nursing facility residents for possible placement back into the community. When operational, the Independent Living program will play a central role in developing a system of services and supports to enable the person to transition successfully back to the community.

The Division of Services for the Blind also offers an Independent Living Program for persons with specific vision limitations as well as limitations in activities of daily living (ADL) or instrumental activities of daily living (IADL). The services that are part of this program are provided and/or arranged by the Social Workers for the Blind across the state to persons of all ages who are visually impaired. Basic skills training is provided in grooming, homemaking, personal skill development through group services. Adaptive aids are provided to the consumers (as funds permit and when no other resource is available) and the consumer is instructed in the use of these adaptive devices. During the 2000-2001 fiscal year, 5,749 consumers received Adjustment Services for the Blind. The Division also provides In Home Level I (Chore) service, which is a home management service for consumers who are self-directing and allows them to remain in their own home. For fiscal year 2000-2001, 555 consumers received this service.

North Carolina also provides financial assistance to help approximately 23,000 people with disabilities pay for the cost of adult care homes through the State-County Special Assistance Program (SC/SA). More than half (57 percent) of the current residents receiving SC/SA are 65 or older; the other 43 percent are adults with disabilities who are between the ages of 18 and 64. In 1995, the Research Triangle Institute conducted a study to examine the characteristics of residents in North Carolina's adult care homes.²¹ The study also showed that 41 percent of residents needed hands-on assistance in performing one or more activities of daily living, and nearly 20 percent needed help with three or more ADLs. Nearly two-thirds of the residents (64 percent) had moderate to severe cognitive impairments, with almost one-third (29 percent) exhibiting behavioral problems (wandering, verbally or physically abusive). The study found that residents in North Carolina adult care homes were

²⁰ The income and resource limits established by the NC General Assembly for the Independent Living program are similar (but not the same) as the Medicaid income and resource limits for the elderly and disabled. However, the Independent Living program allows individuals to exclude disability-related expenses in determining countable income. Because the rules are slightly more generous in the Independent Living program, it is able to serve some individuals who do not otherwise qualify for Medicaid.

²¹ Hawes C, Lux L, Wildfire J, et. al. Study of North Carolina Domiciliary Care Home Residents. Research Triangle Institute, Research Triangle Park, NC. Feb. 15, 1995.

significantly more impaired than residents of similar institutions in other states. To qualify for SC/SA, an individual must have functional limitations that require personal assistance and have income and resources below certain prescribed limits. In the past, SC/SA funds were only available to help people pay for the costs of adult care homes. To qualify for this program, individuals must have income less than 100 percent of the federal poverty guidelines, they must have limited assets, and they must have functional limitations that would meet the standards for care provided in adult care homes.

The North Carolina Department of Transportation (NCDOT) administers the State Elderly and Disabled Transportation Assistance Program (EDTAP) which is intended to supplement funds that are currently available to provide transportation services to persons who are elderly and to persons with disabilities. The EDTAP, originally enacted by legislation in the 1989 Session of the General Assembly, currently provides \$5.5 million annually in transportation operating assistance to the counties. Funds are distributed based on a formula allocation with no local match required. The Boards of County Commissioners sub-allocate the EDTAP funds to the local Community Transportation Systems and various human service agencies within the county.

The NCDOT also administers the State Rural General Public (RGP) transportation program, which is intended to provide transportation services to individuals who are not recipients of services from human service agencies. State RGP funds currently provide \$4.1 million in operating assistance to local Community Transportation Systems. State RGP funds may be used to provide up to ninety percent (90%) of the fully allocated cost of a trip. The ten percent (10%) match for a trip cost must be provided from fares, local funds, or any combination of both. State Adult Care, HCCBG, SSBG, Vocational Rehabilitation, and Title XIX funds are also used to support transportation services for the individuals who are elderly and frail and people with disabilities.

Assessment Process for Currently Institutionalized and At-risk

Depending on the setting of care and the population served, the State uses a variety of assessment instruments and processes to determine need for services and supports. For persons who require publicly funded nursing facility care or adult home care, a FL-2 form is used. The FL-2 form documents information about a person's medical condition, functional limitations and behavior problems. The FL-2 must be signed and dated by the attending physician. For nursing facility admissions, the FL-2 form is sent to the State for review by nurses who are responsible for determining if the person meets the medical criteria (as established by the Division of Medical Assistance) for admission to a nursing facility. Prior to the placement in a nursing facility, the individual must also be screened for mental illnesses, mental retardation or related conditions to make sure they are being placed in the appropriate setting. This screening is mandated by federal regulations and is called the PASARR process (Pre-Admission Screening and Annual Resident Review). DMA regularly reviews the assessments performed on nursing facility residents to determine if there have been significant changes in a person's needs or level of care. PASARR is not required for persons entering adult care homes.

Some people who meet the nursing facility level of care criteria may be appropriate for different CAP programs (described above). The CAP assessment process and services help keep people in their home environment rather than being placed in a nursing facility. DMA is currently working with the Division of Vocational Rehabilitation Independent Living Program to develop a transition program for those who are residing in the nursing facility and want to be integrated into the home or community setting.

The Division of Social Services uses another assessment tool for persons in need of adult protective services, in-home services or State-County Special Assistance and persons “at-risk” of institutionalization. The Division of Vocational Rehabilitation uses its own assessment tool for the Independent Living Program participants. The Division of Aging allows local Area Agencies on Aging to use their own assessment tools for home and community-based services. In an effort to get some consistency across the various human services programs, the State is in the process of developing a common set of assessment instruments. These new assessment instruments will be used to help identify the services people need and help develop service and support plans based on the individual needs. Regular reassessments will help identify changes in health conditions, functional status and cognitive abilities to assure that people are served in settings that are appropriate to their needs and are as integrated as possible.

Operation of Waiting Lists

County CAP/DA lead agencies may maintain waiting list for services, but are not required to do so. Currently, the State does not collect CAP/DA waiting list information from the counties, and has no information about how quickly people move off the waiting list for home and community-based services. DMA has not initiated an effort to standardize waiting list processes for CAP/DA. DMA conducted a survey of the local CAP/DA lead agencies in December 2001 regarding waiting lists for the program. The results of a survey indicate that only one county did not have some type of waiting list. There were 6,739 individuals on the lists-of that number, 1,026 or 15% were added since the CAP freeze effective October 1, 2001. Overall, there were 1,121 more individuals on the December 2001 lists than the December 2000 lists. Several respondents to the survey noted that the number waiting for CAP/DA is potentially greater as referrals for the program declined after the usual referral sources and the general public learned about the freeze.

CAP/C referrals are handled by DMA which assigns them to local case management agencies for assessment. At any given time, there may be delays in initiating assessments by several of the local case management agencies across the state. There is no waiting list for CAP/AIDS as all eligible individuals are served when they apply for the program. Each county keeps a CAP/C referral list of children waiting for CAP/C assessment. A master list is also kept at the state level.

Vocational Rehabilitation does maintain a statewide waiting list for Independent Living services. The waiting list is not automated, but is collected from local programs on a quarterly basis by the state office. Priority for services is given to individuals to avoid institutionalization. There were 1,128 people waiting for either general case services (such as home modification, vehicle modifications, adaptive aides, and equipment) or personal care services as of Sept. 30, 2000. In general, it takes four to five months from the time that the individual and the independent living staff develop a service plan to the time that the individual obtains services. However, the waiting list and length of time on the waiting list may expand as new people seek services, since the Independent Living program has already obligated all of its funding for this fiscal year for individuals who are or will be receiving services for their independent living goals.

The Division of Aging also has a waiting list for services funded through the Home and Community Care Block Grant. Not all of these individuals are “at-risk” of immediate institutionalization. The State’s waiting list documents up to three separate services for which a person is waiting. The services on the waiting list with the heaviest unmet need as of March 2003, are in-home

aide services (5,326 people), and home delivered meals (4,178). Approximately one-quarter (25 percent) of the service needs are met within four months; those remaining have been on the list an average of 15.1 months. While the State maintains a waiting list, the number of people listed on the statewide list may not reflect the total unmet need as some counties with long waiting lists or service shortages decide not to add new people to the list. In addition, older adults with needs often decline being added to a long waiting list because they need services immediately.

Local Departments of Social Services manage their own waiting lists; there is no statewide waiting list for home and community-based services funded through the Social Services Block Grant.

The Division of Services for the Blind manages a state-wide waiting list of persons who have requested and are eligible for In-Home Level I Services. This is a home management service in which the recipient must be self-directing and medically stable but yet is unable to carry out at least one or more tasks essential to the instrumental activities of daily living. This waiting list has been maintained due to funding limitations for the past three months as part of the data collected by the Agency's automation system. There were twenty-six persons who were on the waiting list as of 5/14/02 with fourteen identified as waiting due to insufficient agency fund, seven waiting due to their inability to locate a suitable provider and five waiting for other miscellaneous reasons. Their names are entered in the system by the Social Worker upon the determination of their eligibility. The waiting list is expected to expand in the next few months as expenditures are frozen.

Inventory of Community-Based Services to Assist People in Moving Back to the Community

State and local agencies have some capacity to identify community-based services to assist people in remaining or moving back to the community.

The North Carolina Division of Aging funded 44 local aging informational and assistance programs (I&A) in 2001-02. The funded I&A programs assisted over 78,000 older adults or their caregivers. The provision of I&A for older persons and their families is designed to: assess and evaluate an individual's needs; inform and educate about programs and services available; across the long-term care continuum; refer and/or directly connect the individual to appropriate resources; provide assistance to negotiate the service delivery system; work with long distance caregivers in identifying and locating needed services; advocate on behalf of individuals or a group to obtain change in the delivery or availability of services.

The Office of Citizen Services operates the CARE-LINE, the North Carolina Department of Health and Human Services' statewide Information and Referral Service. The Office of Citizen Services data base includes listings of government and non-profit agencies and support groups. Database agency information is updated daily. In addition, statistical reports are generated that capture a variety of information, including but not limited to types of inquiries received, geographic information and information and referrals given on every inquiry. The public may access the Office of Citizen Services via the US Post Office, e-mail (care.line@ncmail.net), and a statewide toll free number (1-800-662-

7030/within N.C. only and (919) 733-4261). The office is equipped with a TTY modem and has two bilingual staff available to handle inquiries from Spanish speaking persons.

In addition to the statewide information and referral databank, about 77 counties have developed resource databases. These databases were developed by local information and referral/assistance programs or Regional Area Agencies on Aging. The information includes both public and private agencies and providers that offer services and supports to older adults and is updated regularly. Many of these databases also include information about service providers for people with developmental disabilities or mental illness. These databases use the same software (IRis) as does CARE-LINE, and offer the possibility of being linked statewide. The Division of Aging is working with Division of Information Resource Management to conduct a study that will determine the feasibility of establishing a common Information and Referral service and database for all stakeholders involved. The main function of this Information and Referral service is to meet the needs of the elderly, families and children. It will maintain a comprehensive resource file of information about organizations that provide human services for the community and provide information about human services to people who need them ensuring that selected resources are accessible and geographically convenient to meet the person's needs. The project will begin in January 2003.

2-1-1 is the national abbreviated dialing code for free access to health and human services information and referral. 2-1-1 is an easy to remember and universally recognizable number that makes a critical connection between individuals and families in need and the appropriate community based organizations and government agencies. The number makes it possible for people in need to navigate the complex and ever-growing maze of human services' agencies and programs. The North Carolina Utilities Commission awarded the United Way of NC the 2-1-1 number on November 18, 1999, to be used for health and human service information and volunteer opportunities. The number provides 24 hour/7 days a week information and referral services. Today, North Carolina has four operational 2-1-1 centers that serve 13 counties. This accounts for almost 40% of North Carolina's population. Each call center maintains a comprehensive inventory of resources for each county it serves. Forty percent of North Carolinians currently have access to 2-1-1.

Assess Need for Additional Services

The North Carolina Institute of Medicine's Long-Term Care Task Force identified core services that should be available to everyone in need of long-term care.²³ These services should be available within each county or within a reasonable distance from the county, to ensure that people have access to needed services and supports. Many of these services that were identified are needed to help support individuals in their home or community. These include:

- information and assistance
- transportation
- housing and home repair and modification
- home delivered meals
- durable medical equipment and supplies
- medical alert or related services
- nursing services

NC Institute of Medicine. A Long-Term Care Plan for North Carolina. Interim Report by the North Carolina Institute of Medicine Long-Term Care Task Force to the North Carolina Department of Health and Human Services. June 30, 2000 at p. 16.

- adult day care/day health care
- attendant care
- in-home aide services
- home health
- respite services

The Long-Term Care Task Force tried to determine the availability of existing long-term care services. The State collects data on the use of publicly funded home and community-based services, but not on the extent of the unmet need for these services or the amount of services that are paid for through the private market. Nonetheless, these data do provide some information about the use of and geographic distribution of resources. Not surprisingly, the extent that these services are available and used varies widely throughout the state.

Table 2: Variations in Rates of In-Home Services Across North Carolina²⁴

<u>Services</u>	<u>High</u>	<u>Low</u>
Individuals receiving CAP-DA per 1,000 Medicaid eligible who are elderly and disabled.	200 (Avery)	8.39 (Johnston)
Individuals receiving Medicaid Personal Care Services per 1,000 Medicaid eligible individuals who are elderly and disabled	199.1 (Hertford)	0 (Polk)
Individuals receiving HCCBG funded Adult Day Care or Day Health per 1,000 adults age 60 or older	4.1 (Edgecombe)	0 (51 counties)
Individuals receiving SSBG or State Adult Day Care Fund funded Adult Day Care or Adult Day Health per 1,000 adults age 60 or older	4.4 (Graham)	0 (57 counties)
Individuals receiving HCCBG funded Home Delivered Meals per 1,000 adults age 60 or older	58.5 (McDowell)	0 (4 counties)
Individuals receiving HCCBG funded In-Home Aide services per 1,000 adults age 60 or older	51.5 (Tyrrell)	0 (Lee)
Individuals receiving SSBG funded In-Home Aide services per 1,000 adults age 60 or older	21.3 (Gates)	0 (15 counties)

The data not only shows that there is wide variation in the use of publicly funded home and community-based services across counties, but also that counties fund these services differently. Some counties rely more heavily on Medicaid to pay for in-home services; other counties rely more heavily on HCCBG/SSBG as the payment source.

County commissioners select a lead agency for the CAP-DA program and the HCCBG program. Part of the responsibility of these lead agencies is to assess the need for additional services at the local level. In 19 counties, the HCCBG and CAP/DA lead agent is the same organization/agency. Planning

²⁴ NC Institute of Medicine. A Long-Term Care Plan for North Carolina. Interim Report by the North Carolina Institute of Medicine Long-Term Care Task Force to the North Carolina Department of Health and Human Services. June 30, 2000. Appendix A.

in most communities is targeted on specific programs (for example, the CAP-DA or HCCBG program). There are only a few communities that have comprehensively examined the need for additional services to support individuals who are elderly and frail and people with disabilities to remain at home.

The North Carolina Institute of Medicine, in its Final Report dated January, 2001 recommended that the General Assembly encourage county commissioners to appoint comprehensive local planning teams to examine the need for long-term care services comprehensively.²⁵ To facilitate this local planning effort, the North Carolina Division of Aging, in conjunction with other state agencies, is developing a county data package which includes information on the number of people age 18 or older using publicly-funded long-term care services at the county level, and expenditures for these services. The Division of Aging collected this information from throughout DHHS in 2001 and is now compiling the data for publication and dissemination in 2003. The Division already provides counties each year with a similar data package for services to persons age 60 and older. In addition, the North Carolina Institute of Medicine contracted with Millennium Healthcare Solutions, Inc. to develop LTC needs projections at the county and/or regional level. This information was incorporated in the Final Report of the Institute of Medicine's Long-Term Care Plan for North Carolina. The State will also provide counties with technical assistance in how to use these data for planning purposes. Towards this end, the Division of Aging submitted a federal grant request to the US Office of the Assistant Secretary for Planning and Evaluation in May 2002 to pilot a Planning and Communications Network to Assist Families in their LTC Roles that, if funded would have helped two counties develop local long-term care planning processes, evaluate core LTC services, and develop strategic plans for LTC. Although the grant was not funded, the Division of Aging is working with the DHHS LTC Cabinet towards implementation of the project, which should also increase communications and cooperation between the state and local systems. The Aging Legislature Study Commission endorsed this proposal and there are bills in both the State Senate and House to fund a pilot of two counties or multi-county areas.

Identify and Expand the Availability of Local Transportation Resources

Transportation is often cited as one of the most significant barriers to community living and independence for individuals who are elderly and frail and people with disabilities. Having access to safe, reliable, affordable, and accessible transportation is more than just a simple community service need. It offers a lifeline to independence and mobility, which is often the difference between someone being able to remain in the community and premature institutionalization. Transportation barriers are not limited to individuals who are elderly and frail and people with acquired disabilities. Caregivers often face problems accessing needed transportation, especially when split shifts are needed.

The NCDOT and the NCDHHS have made great strides in coordinating, developing, and expanding employment transportation resources in conjunction with welfare reform efforts. Efforts such as car ownership programs, vanpools, carpools, expanded bus routes, extended hours of service, car maintenance assistance, volunteer programs, and many other specialized services have been established to eliminate barriers. The lessons learned from these initiatives will be useful in developing and implementing system infrastructure changes to meet the needs of the individuals who are elderly and frail and people with disabilities.

²⁵ NC Institute of Medicine. A Long-Term Care Plan for North Carolina. Interim Report by the North Carolina Institute of Medicine Long-Term Care Task Force to the North Carolina Department of Health and Human Services. June 30, 2000. Recommendation #10 at p. 20

North Carolina currently has 84 community transportation systems (single and multi-county) that serve all 100 counties. The State also has 16 urban transportation systems. Forty-one percent (41%) of all system-owned vehicles are equipped with lifts. All State funded Community Transportation Systems provide curb-to-curb services, and many provide door-to-door. Although these kinds of services are in place, they are woefully insufficient to fully address the transportation needs of individuals who are elderly and frail and people with congenital and acquired disabilities that require long-term supportive services.

Identify Housing Alternatives to Institutional Placement

The lack of affordable housing options is one of the primary barriers to successfully maintaining the individuals who are elderly and frail in home and community settings. With 13.8 percent of North Carolina's older adults living at or below the poverty level in 1999; finding and maintaining affordable housing is a critical need.²⁶ Yet there are currently only 673 subsidized housing projects for the elderly in North Carolina, offering 34,303 subsidized housing units.²⁷

Most housing subsidy programs are federal programs, over which the State has little control. With limited exceptions, the State does not subsidize residential costs, unless those costs are included as part of the costs of a medical institution (e.g., nursing facility, ICF's-MR, state psychiatric hospital, rehabilitation or acute-care hospital). The major exception is through the State-County/Special Assistance (SC/SA) program. SC/SA payments are used to support the residential costs of people who live in Adult Care Homes. The State recently began a pilot program to use SC/SA funds to support up to 400 people in their homes as an alternative to out-of-home placement. These funds can be used to help pay for residential costs or services, depending on the needs of the client.

The North Carolina Housing Finance Agency also offers three primary resources to assist in the production of affordable rental housing for low and moderate income households across North Carolina: federal low-income tax credits, State low-income housing tax credits, and below-market-rate loans. These rental production programs are awarded annually through the Multifamily Rental Development program.

While the State does not typically subsidize the costs of housing, limited state funding is available to help with the costs of home modifications to make existing housing accessible to people with disabilities. The Housing Trust Fund, administered by the North Carolina Housing Finance Agency, helps pay for home repairs through the Urgent Repair program in 52 counties. This program is designed to meet life safety issues in order to make a home livable. There are also programs in 39 counties to assist with minor home repairs and improvements of up to \$800 (per area of repair) through the Home and Community Care Block Grant program. More than 300 older adults are currently waiting for HCCBG-funded home repair services. The Division of Aging also sponsors a housing locator services and provides other housing information through the 17 area agencies on aging. The Division of Vocational Rehabilitation's Independent Living (IL) Program utilizes staff IL engineers and its service budget to assist IL counselors/case managers in implementing comprehensive independent living plans for consumers which include, among other services, environmental designees

²⁶ US Census Bureau. Poverty Status by State in 1999. People 65 or Older. Annual Demographic Survey, March Supplement. 2000.

²⁷ NC Division of Community Assistance. Consolidated Housing Plan: 2000-2005. NC Department of Commerce. 2000 at p. 93.

and resulting modifications for homes that facilitate the consumer's IL goals. These three programs, combined, spend approximately \$5.9 million annual for home repairs or modifications; however, not all of these funds are spent on individuals who would otherwise be at risk of institutionalization.

Adequacy of the Workforce to Provide Services

Another major barrier that prevents individuals who are elderly and frail from living in a home or community setting is the dearth of available, qualified and trained staff who can provide assistance with the activities of daily living. The North Carolina Institute of Medicine, *Long-Term Care Plan for North Carolina*, recently noted that the lack of trained paraprofessionals to care for individuals who are persons who are frail and elderly and people with disabilities had reached crisis proportion in all service settings.²⁸ Nurse aides and other paraprofessionals play a critical role in the care of these persons and other people with disabilities in this state, by helping them with their most basic needs including bathing, dressing, eating and toileting. Yet, nursing facilities, adult care homes, and home care agencies have experienced a major problem recruiting and retaining qualified staff. Low wages, nonexistent or inadequate benefits, demanding work, inadequate recognition and appreciation, the lack of opportunity for meaningful input into the provision of care, all contribute to the difficulty that service providers have in recruiting qualified staff. There is also a shortage of home care nurses, and the problem is growing. This means fewer nurses for direct patient care and supervision of nurse aides.

There are a number of efforts being developed to try to recruit and retain nurse aides in caring for individuals who are elderly and frail and other people with disabilities. Some of these are being undertaken by the provider associations, others by the Department of Health and Human Services. The NC Institute of Medicine also recommended that the State implement a labor enhancement to try to improve the salaries and benefits of direct care staff. In addition, the community colleges and AHEC are in the process of designing new training curriculum to try to provide better training for nurse aides.

The 1999 General Assembly also took steps to improve the training of nurse aides, particularly for those that are responsible for administering medication in adult care homes. Beginning October 1, 2000, staff must pass a written exam (by a score of at least 90 percent) and have their clinical skills observed and validated by a pharmacist or registered nurse. Staff that administers medications must also complete 6 hours of continuing education annually. In addition, nurse aides and supervisors must complete an additional 5-hour training module on behavior interventions, and must have additional training on psychotropic drugs. A doctor, pharmacist or RN must review medication orders every 90 days.

Assure and Monitor Quality of Care

The State has a number of systems in place to assure and monitor quality of care: licensure or certification, surveys, complaint investigation, and Ombudsman programs. The 25 regional Long-Term Care Ombudsmen work with approximately 1,300 community advisory member volunteers to educate and advocate for residents' rights in nursing facilities and adult care homes. They routinely visit these facilities and promote the honoring of residents' rights. Ombudsmen can investigate complaints and advocate on behalf of individuals if requested to do so by a person or his or her legal representative.

²⁸ NC Institute of Medicine. A Long-Term Care Plan for North Carolina. Interim Report by the North Carolina Institute of Medicine Long-Term Care Task Force to the North Carolina Department of Health and Human Services. June 30, 2000 at p. 21.

Ombudsmen also advocate for systemic changes to improve the quality of care and the lives of individuals. The Division of Facility Services (DFS) has primary, but not exclusive, responsibility for ensuring the quality of home and community-based providers and residential facilities. DFS licenses nursing facilities, adult care homes, and home care and home health agencies. In addition to the initial licensure requirements, DFS conducts periodic surveys of nursing facilities, home care and home health providers to ensure that minimum standards of care are being met. DFS also investigates complaints.

Other agencies also help monitor the quality of care provided to individuals who are elderly and frail. Local Departments of Social Services have the statutory responsibility to investigate allegations of abuse, neglect or exploitation, which is critical to ensuring that family caregivers and facilities provide proper care. Local DSS staff also conducts routine monitoring of adult care facilities. The state DSS is responsible for monitoring the quality of DSS in-home aide programs and other services through its field staff.

The 26 regional Long-Term Care Ombudsmen work with more than 1,500 community advisory member volunteers to monitor care provided in nursing facilities and adult care homes. They routinely visit these facilities to monitor the quality of care being provided. In addition, Ombudsmen investigate complaints and can advocate on behalf of an individual resident if requested by that resident or his or her legal representative.

The Division of Aging, with the assistance of local DSS agencies, has responsibility to certify providers of adult day care and adult day health care. The DOA, with the assistance of regional Area Agencies on Aging and state DSS staff carry out certification of in-home aide service providers that offer home management services only. Area Agencies on Aging and state DSS staff also have responsibility for monitoring the quality of services under the HCCBG program.

In the CAP programs, the local case managers review the quality of care as an integral part of their responsibilities. In addition, DMA has a quality review operation that reviews a random sample of cases and conducts on-site reviews of each local CAP lead agency, including a review of services.

CHAPTER 4

PEOPLE WITH SEVERE AND PERSISTENT MENTAL ILLNESS OR SEVERE EMOTIONAL DISTURBANCES.

Overview

In 1998, approximately 321,820 adults in the State with serious mental illness,²⁹ and between 173,069 and 207,683 children under age 18 with serious emotional disturbances.³⁰ It is estimated that between 30 and 50 percent of these people also have a co-occurring substance abuse disorder.

The State offers care to adults with severe and persistent mental illness and to children and adolescents with severe emotional disturbances through the state psychiatric hospitals and special care units, area mental health, developmental disability, and substance abuse programs and schools for children with emotional disturbances. Some of the services are residential in nature, others are provided on an outpatient basis; some are for acute episodes, others are for more chronic conditions. In addition, the State helps pay for services provided by private providers through its Medicaid program and NC Health Choice. Other people with severe and persistent mental illness receive SC/SA to support their care in adult care homes.

Use of Mental Health Trust Fund

- Through a collaborative process between the State Division of Mental Health, Developmental Disabilities and Substance Abuse Services and four Regional Area Mental Health Planning Teams, a planning process was implemented to address two major goals: 1) identify and develop the array of services that people currently residing in State hospital beds identified for closure need to live in the community; and 2) develop or expand the capacity to serve those who otherwise would be admitted to a state psychiatric hospital. As of June 30, 2002, specific plans for each of the four Regions were completed and provide a blue print that details the kinds of treatment, services, and supports, the quantities required, and the costs associated with providing those services in each region of the state.
- Of the 27 individuals in the Wright Transitions Program at Dix Hospital at the time the hospital-based program was closed, nine individuals moved into independent or transitional housing and fourteen moved into supervised group settings such as group homes. Four individuals were not ready for discharge and were transferred to other units in the hospital to ensure they receive the services that will facilitate eventual discharge. In State Fiscal Year 2002, a total of \$671,000 in one-time bridge funding from the Mental Health Trust Funds and subsequent reallocation of funding up to \$1.8 million annually from the Dix Hospital budget, beginning in State Fiscal Year 2003, will follow these individuals into the community to be used by area programs to establish or expand a variety of services such as Assertive Community Treatment Teams, expanded psychosocial rehabilitation, case management, transportation, and supported housing. allocation of funding from the Dix Hospital budget. This represents the first time that

²⁹ Ibid.

³⁰ Comprehensive Child Health Plan: 2000-2005. Report to the North Carolina Department of Health and Human Services. Chapel Hill, NC: North Carolina Institute of Medicine, May 23, 2000 at p. 86.

institutional funds have followed clients from state hospitals into the community to provide needed community based services and supports.

Description of Specific Services

The State operates a different system of supports and services for people with severe and persistent mental illness than it does for the frail elderly or people with acquired disabilities. For example, the State offers publicly subsidized inpatient psychiatric services through the four state psychiatric hospitals: Cherry, Umstead, Dix and Broughton. There are also three schools for children with emotional disturbances: Wright School, Whitaker School, and Eastern Adolescent Treatment Program; and two facilities provide nursing home services to adults with Alzheimers, mental health or behavioral problems: Black Mountain and NC Special Care Center. The State also helps to subsidize outpatient and some residential services through area programs. Area programs provide individual and group therapy, case management, psychosocial rehabilitation, partial hospital/day treatment, and community based services. Residential or 24 hour services include supported housing, group homes, crisis stabilization, inpatient and residential treatment. Appropriate and adequate community based services assist individuals with mental illness to remain in their home and avoid the need for institutional placement.

Certain individuals with mental illness may be able to qualify for Medicaid coverage to help pay for the costs of care. Medicaid is typically limited to low-income individuals who are under the age of 21 or older than 65, pregnant, in families with dependent children, *or* disabled. To qualify, these individuals must also meet certain income and asset tests. Not all people who are poor qualify for Medicaid, however, because individuals between the ages of 21 and 64 who are without children and who are not considered disabled by the Social Security Administration cannot qualify, regardless of their poverty status. Medicaid provides coverage of inpatient, individual and group outpatient treatment, day treatment, client behavior intervention, admissions to general hospitals psychiatric units, and case management. Services provided by an area program must be ordered by a psychiatrist or PhD psychologist as part of an individualized treatment plan. Services can also be provided by a physician, psychologist, or clinical nurse specialist employed and supervised by a physician.

Children also are eligible for treatment provided in residential treatment centers. Some services are excluded from coverage under federal law. Medicaid cannot pay for the costs of care provided by “institutions for mental disease”³¹ (e.g., state or freestanding private psychiatric hospitals) for Medicaid-eligible persons between the ages of 21 and 64. Medicaid also excludes the room and board costs of residential treatment facilities, with the exception, Medicaid will cover all costs of a new residential treatment called Psychiatric Residential Treatment Facilities for children in which it covers both treatment costs and room and board. Medicaid limits the number of outpatient mental health visits it will cover for adults to 24/year, unless services are provided through area programs. Children’s mental health visits are not limited, although prior approval must be obtained for some services.

There is currently no community-alternatives program (CAP) for people with severe and persistent mental illness who are Medicaid-eligible. CAP waivers typically require that states show cost-neutrality in the Medicaid program. Because states do not cover the costs of care provided in public or private psychiatric facilities, states have little ability to show cost-neutrality through a CAP waiver

³¹ 42 USC 1396d(a)(1).

program (i.e., they could not offset new expenditures for community-based services with institutional savings to the Medicaid program). While North Carolina can not implement a CAP-program for people with severe and persistent mental illness under current federal law, the State does have considerable flexibility in its existing program to cover many of the services that would otherwise be offered in a CAP program. However, some services cannot be covered absent a CAP waiver, such as respite care or additional personal care services (beyond the specified limits).

Assessment Process for Currently Institutionalized and At-Risk

Assessment and treatment/habilitation plans are required for all persons admitted to State-operated institutions. The instruments used vary according to disability and age. The progress and status of the treatment/habilitation plans are reviewed periodically and modified as necessary.

Beginning April 2001, the State used a standardized assessment protocol to assess every resident of a state psychiatric institution and school for the emotionally disturbed to determine whether the person desires, and would be an appropriate candidate for reintegration back into the community. The State worked with the person, his or her family or legal representative, and the treatment professionals to determine what community supports and services would be necessary to support the person's transition back to the community. In May 2002, the Division completed assessments with everyone whom was in the facilities when the assessments were implemented. Assessments will be ongoing as individuals are admitted to the facilities. Future plans call for a similar process to be used for adults and children at high-risk for institutional admissions. The goal of this process is to determine whether a services and support plan can be developed in the community to divert people from unnecessary institutionalization.

The State is developing a new assessment protocol for people entering Adult Care Homes. In addition to the regular assessment process needed to determine level of services or for services and support planning purposes, the State will be including questions to identify people with mental illness or developmental disabilities that may need additional community supports and services.

Operation of Waiting Lists

Each area program maintains a waiting list for persons needing certain types of community based mental health and substance abuse services. These services are either of an urgent, or non-urgent nature. People are moved from these waiting lists as resources become available. These waiting lists are not collected at the state level. As part of the implementation of this Plan, a waiting list has been developed which includes projected community service and support needs for institutional individuals who have been assessed as potentially able to transition to the community.

Inventory of Community-Based Services to Assist People in Moving Back to the Community

Different inventories exist that collect data about community mental health services and providers through various databases. For example, area programs each maintain their own listing of community resources. The state Division of Facility Services maintains lists of licensed agencies, residential and institutional providers serving people with mental illnesses and emotional disturbances. Similarly, some of the sections within the Division of Mental Health, Developmental Disabilities and Substance Abuse services maintain their own inventory of available community-based services.

What the State lacks is a centralized inventory that includes all relevant public and private providers that offer mental health, developmental disability and substance abuse services. This centralized database should be linked with other community providers, such as medical and dental care, rehabilitation services, and in-home services that also provide services to people with mental illness.

Assess Need for Additional Services

A recent report commissioned by the NC State Auditor concluded that “many of the individuals currently residing in North Carolina’s four state [psychiatric] hospitals, in all levels of care, could be treated in community-based services if such services were available.”³² North Carolina has a higher rate of institutionalization than peer states. “At 32.3 beds per 100,000 persons in the general population, the bed capacity is 23 percent higher than the average in the peer group of comparable states. North Carolina’s rate of adult admissions, at 243 per 100,000, is second highest among peer group states.” The study concluded that over time, North Carolina’s hospital bed capacity could conservatively be reduced by 667 beds. However, community resources would have to be created to support individuals in the community.

The Auditor’s report identified services that are needed to support people with mental illness in a community-based setting. These include assessment services and acute care services including up to 15 days inpatient treatment. Alternative services should address crisis or acute mental health episodes as well as the ongoing services and supports needed to care for individuals with severe and persistent mental illness. On the acute care side, each catchment area should provide crisis stabilization beds and observation/holding beds. People with severe and persistent mental illness could need respite care, day treatment, intensive in-home services, therapeutic foster care, and outpatient therapy to enable them to live successfully in a home and community-based setting. Some individuals with more severe or complex problems may also need an Assertive Community Treatment Team (ACTT), residential support and other intensive services to enable them to successfully transition and remain in the community.

Identify and Expand the Availability of Local Transportation Resources

Transportation service providers often become frustrated with people with severe and persistent mental illnesses when they are late, slow, or fail to respond in the same manner as the general public, etc. The transportation service provider may not recognize, and sometimes appreciate or understand the barriers that this population faces. In most cases, this can be remedied by appropriate education and sensitivity training to bring about the needed understanding and appreciation.

Addressing consumer transportation needs is an essential element in all stages of program planning and service delivery. State and regional program consultants, as well as division leaders should be knowledgeable of State and local transportation resources. A greater emphasis should be placed on transportation planning. All too often, programs are planned at the State level without consideration of consumer transportation needs and local influences. Failure to address this vital component results in frustration for the consumer, and an inability for them to access needed services.

³² Office of the State Auditor. Study of State Psychiatric Hospitals and Area Mental Health Programs. Final Report. April 1, 2000.

Regional Non-Emergency Medical Transportation Services:

NC DOT is currently funding two multi-county non-emergency medical transportation demonstration projects, which are located in the mountain and piedmont areas of the state. The programs will expand transportation options for the local transportation systems, riders, human services agencies and medical providers. A regional coordinator position has been established in each of these areas to work with the local community transportation systems, medical facilities and human service agencies.

The purpose of these programs is to strengthen and improve regional transportation coordination efforts in an efficient, cost-effective and customer oriented manner while increasing the efficiency of the local transportation systems. A centralized telephone number will be established for transportation providers to use for scheduling out-of-county trips in the piedmont area. In the mountain area, a web site has been established to enable local transportation providers from each county to find out when and where trips are being scheduled. Based on this information, the county transportation systems contact each other to plan coordinated trips.

Medical providers (hospitals, doctors, clinics, etc.) are contacted and informed about the availability of out-of-county transportation routes and the need to schedule appointments accordingly(when possible). These coordination efforts have benefited the medical providers by reducing the number of missed appointments. It is believed that better coordination will also reduce operating costs and duplication of services. It will increase communication and the development of standardized routes and schedules.

Rural General Public Discretionary Projects

In SFY 2001-02, NCDOT received an increase of \$3million for the Rural General Public Program (RGP), making it a \$4.1 million program. In order to encourage the local transportation systems to expand and create services to serve the rural general public, NCDOT has provided \$1.6 million in discretionary RGP funds to support 38 projects statewide. Rural General Public funds may not be used to target isolated populations. It must be used to serve any member of the community that needs transportation. Additional RGP funding will support increased transportation services such as trips to shopping malls, recreational activities, grocery stores, banks, etc. for all populations, including persons who are elderly and have disabilities.

Identify Housing Alternatives to Institutional Placement

Individuals who need residential services and supported living situations sometimes receive services in Adult Care Homes. In 2000, approximately 23,000 people received State-County Special Assistance to help pay for the costs of Adult Care Homes. Extrapolating from an earlier study of Adult Care Home residents, nearly one-quarter of these individuals are likely to have a diagnosis of mental illness or to have used mental health services, including a past stay in a psychiatric hospital. Another 12 percent will have a mental retardation or developmental disability diagnosis and will have received mental health services. Almost three-quarters of all residents are likely to have behavioral problems, including wandering, being verbally or physically abusive, or resisting ADL assistance.

Often people with severe and persistent mental illness end up in Adult Care Homes because there are no other appropriate residential services in the community. About 10 percent of people with severe and persistent mental illness, or 9,900 adults, are in need of stable and affordable housing. The type of housing needed includes transitional housing to help move people out of institutions, subsidized housing in the private market and supervised group homes and residences (for individuals with the most serious disabilities or specialized treatment needs). Because many individuals with mental illness

rely on Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) as their income, they are in need of rental assistance subsidies to make housing affordable.³³ Yet, there are only 992 adults with severe and persistent mental illness who receive subsidized housing through HUD mental health funded units. The existing housing resources are woefully inadequate to address the housing needs of people with severe and persistent mental illness.

Adequacy of the Workforce to Provide Services

People with mental illness face the same problems finding well trained, motivated and adequately compensated staff to provide services as do other groups of people with disabilities. Access to trained mental health professionals is a particular problem in some communities. According to the NC Health Professional Database, the ratio of licensed mental health professionals varies from a low of no practicing providers per 1,000 people in Jones and Camden counties to a high of 3.63 mental health professionals per 1,000 people in Orange County.³⁴

Assure and Monitor Quality of Care

Oversight of the institutions, facilities and providers serving adults with severe and persistent mental illness or children/adolescents with serious emotional disturbances is split between the Division of Facility Services and Division of Mental Health, Developmental Disabilities and Substance Abuse Services. The Division of Facility Services has the responsibility for licensing ICF-MR, adult care homes and group homes for the mentally ill licensed that is assigned under 122C of the North Carolina General Statutes. The Division of Mental Health, Developmental Disabilities and Substance Abuse, through its area authorities, has the responsibility for accrediting and overseeing other community based services.

The North Carolina General Assembly recently enacted legislation to strengthen the oversight of facilities serving people with mental illness and developmental disabilities. In the 2000 session, the General Assembly passed legislation to impose administrative penalties on licensed facilities serving people with mental illness, developmental disabilities or substance abuse services for violations that harm the person's health or safety.³⁵ A new system was also created to oversee the use of restraints in facilities serving people with mental illness, developmental disabilities or substance abuse services.

³³ Division of Community Assistance, Department of Commerce. 2001-2005 N.C. Consolidated Plan. Sept. 19, 2000 at p. 89.

³⁴ The aggregated numbers of mental health professional include active non-federal, non-resident and resident physicians who have a primary specialty in psychiatry and psychiatry/child; psychologists and psychological associates with the primary specialty of clinical, community, counseling, developmental, educational, personality, physiological, rehabilitation, school or social; active RNs who have a major clinical practice or training in psychiatric/mental health; and active nurse practitioners with physician extender type of psychiatric mental health. The data are current as of October 1999, and have been supplied to the Cecil G. Sheps Center for Health Services Research, University of North Carolina, Chapel Hill from the respective licensing boards of these professions.

³⁵ Session Law 2000-55.

Additional safeguards are provided in each of the state run psychiatric facilities by the facility Human Rights committee and client advocates. The Human Right committees are comprised of interested citizens who meet on a monthly basis and review, among other things, incidents of seclusion or restraint, complaints of individuals receiving services, allegations of abuse and other aspects of care. Additionally, the facilities employ client advocates whose job it is to protect the rights of individuals by investigating complaints and advising and training facility staff on human rights protections. Area programs must maintain a client rights committees to safeguard the interests of individuals.

CHAPTER 5

PEOPLE WITH DEVELOPMENTAL DISABILITIES

Overview

People with developmental disabilities are those who have a severe mental or physical impairment that manifested before the person attains age 22, is likely to continue indefinitely and results in substantial functional limitations in the persons ability to care for themselves, communicate, walk or move around, or live independently.³⁶

There are currently approximately 140,000 people with developmental disabilities in North Carolina. About one-fourth or 37,000 children and adults are being served through the area mental health, developmental disabilities and substance abuse programs (hereinafter “area programs”), the state mental retardation centers, private providers under contract with area programs, and community Intermediate Care Facilities for the Mentally Retarded (ICF-MR) homes. The majority of persons served by the DD service system in North Carolina have multiple disabilities.

Description of Specific Services

North Carolina has a unified system of services for people with developmental disabilities. Under state law, people with developmental disabilities obtain services through a “single portal.” The single portal of entry is through the area programs. Area programs help determine eligibility for DD services, as well as eligibility for other publicly funded programs. Area programs in coordination with the local Interagency Council (e.g., schools, vocational rehabilitation, services for blind, private providers, advocates, etc.) can help provide or arrange for residential services or day options such as active treatment, Community Rehabilitation Programs (sheltered workshops), supported employment, developmental day care or Adult Developmental Vocational Programs (ADVP). Area programs can also help arrange for other services and supports, including specialized therapies, behavioral intervention, respite services, transportation, assistive technology, and in-home supports, and can help hook people up with natural supports provided through churches, non-profits and volunteers. This is all based on a comprehensive person-centered plan developed from assessment results, needs and personal preferences.

Many people with developmental disabilities qualify for Medicaid. To qualify, a person must be younger than age 21, disabled (meeting Social Security disability standards) *or* older than 65, and must meet certain income and resource standards. Medicaid can help pay for necessary medical services, as well as personal care services. Medicaid also helps pay for ICF-MR care.

Individuals who would otherwise qualify for services in an ICF-MR may also qualify for services to enable them to remain in their home or in the community through the Community Alternative Program for children and adults with Mental Retardation or Developmental Disabilities (CAP-MR/DD). Qualified individuals work with a case manager to develop a treatment plan. Once approved, Medicaid will pay for authorized treatment and services up to a maximum of \$86,000/year. Recipients of CAP-MR/DD services are entitled to a full range of Medicaid covered medical services. In addition, Medicaid can also be used to pay for augmentative communication devices, case management services,

³⁶ NCGS 122C-3(12a).

community inclusion training, crisis stabilization, developmental day care, environmental accessibility adaptation, family training, personal care services, personal emergency response systems, respite care, vehicle adaptation, and other services, supplies and equipment. The State currently limits the number of people it serves through CAP-MR/DD by limiting the number of “slots.” This limitation is directly related to the amount of funding available to provide the state match for the Medicaid dollars. There are currently 6,581 slots in SFY 2001. Each Area program is required to maintain an active list of those waiting for service—some individuals may be getting some, but not all, of the services they need, others are receiving no services. Areas report this data to the state DD office every July and January. In July there were a total of 6,487 waiting for service.

In addition to Medicaid funded services and state funded services and supports provided through the area programs or state MHDDSAS system, some individuals with developmental disabilities may also receive services through the Independent Living program.

Assessment Process for Currently Institutionalized and At-Risk

North Carolina has a common assessment tool, the Support Needs Assessment Profile (NC SNAP) used by all of the area programs and MR Centers, to determine the acuity level of people with developmental disabilities. SNAP helps to assess a person’s level of need for assistance with daily living activities, health care or behavioral supports.

The Division of Mental Health, Developmental Disabilities and Substance Abuse services has initiated a process to assess each individual residing in a state and privately operated ICF-MR to determine their preference and supports needed to move back into the community. The process employs the results of the NC-SNAP, the individual’s comprehensive plan, input of the habilitation team, home area program, consumer and family input. Each person will be interviewed by an independent agent to discuss their options. Currently, 135 persons in the state mental retardation centers have expressed a preference to move into the community. Twenty-four individuals have moved into the community. The supports that are needed for 74 individuals have been identified by the mental retardation centers. The supports that are needed by the remaining 61 persons for their successful community integration are currently being identified.

Operation of Waiting Lists

Each area program maintains a waiting list for services for people with developmental disabilities. This waiting list is collected at the state level two times a year: January and July. As of 12/31/2001 there were 6,003 people waiting for services, and of this number, approximately 1,751 are potentially eligible for CAP-MR/DD funding.

Each area program determines a priority list for funding. The State has developed a list of those “at risk” for institutionalization. The estimated numbers of people with developmental disabilities who are “at-risk” of institutionalization for FY 2000-2001 include:

- Adults who have been identified as having a need for group living with intensive services or mental retardation center placement and children who have a need for residential treatment with intensive services and have a high acuity level on the SNAP assessment. Numbers of people identified: 750

- Children who are aging out of the at-risk (former Willie M) category in need of ICF-MR/DD level of care who have a high acuity level on the SNAP assessment. Numbers of people identified: 20.
- Children aging out of ICF-MR and specialized residential placements, regardless of the acuity level on the SNAP instrument. Numbers of people identified: 97.
- People who have shown a pattern of needing emergency respite, behavioral interventions or diagnostic admissions to the mental retardation centers. Numbers of people identified: 150.
- People with a diagnosis of mental retardation and mental illness that have gone through the MR/MI diversion process. In North Carolina, people with mental retardation are prohibited from admission to a public psychiatric hospital by state statute. These persons are diverted to community options. Numbers of people identified: 278.
- Adults with disabilities living at home with parents/primary caregivers that are age 60 and older, or in failing health. Numbers of people identified: 20.

Inventory of Community-Based Services to Assist People in Moving Back to the Community

Area programs maintain their own lists of providers and community resources for people with developmental disabilities. The State also maintains a listing of community resources, through the CARE-LINE; and the Division of Facility Services maintains listings of those providers licensed by the State. In addition, the DD Section of the Division of MHDDSAS has developed a “Provider Directory”.

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services in an effort to develop a unified method of service tracking and in the development and implementation of the State Plan has initiated the following practices. These practices will impact individuals identified within institutional and hospital settings, wishing to leave, and those identified as at risk for institutionalization living within community settings.

The integrated payment and reporting system (IPRS) was applied state-wide in July 2002. This system provides many significant new capabilities in the areas of utilization management and tracking and reporting services to consumers. In addition to billing and payment uses, the system provides the Division with IPRS end-users with a central consumer and provider database. The need for a state-wide database was identified in the initial draft of the 12/28/00 Plan, *Serving Persons with Disabilities in Appropriate Settings*.

Through the Division’s *State Strategic Business Plan* and the *Local Business Plan* not only are providers of services identified, but generic service and support providers within community settings are to be identified.³⁷

Assess Need for Additional Services

Many people with developmental disabilities need additional supports to enable them to live in a home or community setting. One of the largest unmet needs is for residential supports (see below). Residential services alone are insufficient to help people remain in the community. Supported work, specialized therapies, assistive technology, personal assistance, behavioral intervention and respite are among the other necessary services.

Identify and Expand the Availability of Local Transportation Resources

Consumer and consumer advocates for people with developmental disabilities are involved in State and local planning efforts. At the State level, the Human Service Transportation Council has strong representation from the NC Council on Developmental Disabilities, Division of Vocational Rehabilitation, Division of Aging, Division of Services for the Blind, Division of Mental Health, Developmental Disabilities and Substance Abuse and the Division of Medical Assistance. Consumer and consumer advocates may provide input to the Council's recommendations and decisions through Agency representatives and by actively participating in subcommittee meetings. The NCDOT recommends that every local Transportation Advisory Board (TAB) include representation from persons with disabilities and consumer advocates.

Conventional transit vehicles that have been properly adapted may be utilized to meet the needs of some selected individuals for whom paratransit services are the only option available. The need for paratransit services currently exceeds the available resources. Enhancing the conventional transit system to accommodate the needs of people with developmental disabilities may reduce the demand on paratransit services. Basic modifications can be made to improve the local transportation system's communication efforts (e.g., a telephone information service, printed materials being in alternate formats, accessible web pages, automatic visual and audible digital recording systems on vehicles, signage for individuals with visual impairments, flashing warning lights, etc.) to ensure access to individuals with disabilities. Transportation issues are also being addressed through the Local Business Plans of agencies providing management of the system of service provision for MH/DD/SA services.

Identify Housing Alternatives to Institutional Placement

In 1999, there were 6,126 persons with developmental disabilities who were on a waiting list for services and supports. This was an increase of 150 percent of people on the waiting list over the prior year. According to the Auditor's report, North Carolina had the 6th largest waiting list per capita in the United States in 1997.³⁸ The National Association of State DD Directors noted, however, that North Carolina is one of the few states with an active reliable DD wait list, so comparisons among the states were largely inaccurate. Many people have to wait for long periods of time—more than two years—before receiving some services that they need.

Paying for residential services is one of the largest state expenditures for people with developmental disabilities. Residential services include state-operated ICF-MR, private ICF-MR, other group living arrangements, family care homes, and supports provided to enable people to live in their homes. North Carolina houses about 36 percent more individuals with developmental disabilities in state or privately-operated ICF-MR than nationally—approximately 44 percent of these individuals are in the state's large mental retardation centers, while 55 percent are in the 336 privately operated ICF-MRs. Since 1993, N.C. has imposed a moratorium on the development of new ICF-MR homes.

In 1998, the proportion of people receiving residential services in smaller living arrangements (1-6 people) was about the same as the national average (58.7 percent). However, North Carolina was far more likely to rely on larger group facilities with more than 16 beds than the rest of the nation (34.9

³⁷ State Plan 2002: Blueprint for Change, Executive Summary, pages 72,73.

³⁸ Ibid citing a 1997 report issued by The Arc of the United States.

percent compared to 25.6 percent respectively). The State Auditor's report noted that North Carolina serves a greater proportion of people with developmental disabilities in large state-operated residential centers than does other states.³⁹ Nationally, between 1990 and 1998, the number of individuals served in large state-operated facilities dropped by 38 percent, compared to a reduction in North Carolina of only 18.8 percent.⁴⁰ It should be noted, however, that North Carolina has a higher percent age of persons who are profoundly and multi- disabled living in MRCs with an average length of stay of 15 years. There are less than 10 children living in state-operated Centers. North Carolina also has a legislatively approved plan that calls for carefully planned reduction of residential populations in the mental retardation centers by at least 4 percent per year.

Adequacy of the Workforce to Provide Services

Community programs have experienced the trend seen nationwide—inability to recruit and maintain a high quality, direct service work force. Studies have shown as high as an 85 percent turnover rate in communities as opposed to an 18 percent turnover rate in state operated MR Centers. This is becoming a crisis in our state. This must receive priority attention developing comprehensive training, pay tied to experience and training and career ladders for these essential staff.

Demand for direct care workers will only increase due to the aging of the population as well as advances in medicine and medical technology. Direct care workers provide most of the paid long-term care needed by individuals who are frail and have impairments. North Carolina is projected to need approximately 31,000 additional direct care workers between 1998 and 2008. Our state ranks 6th in the nation in terms of the projected number of additional direct care workers needed.

It is important to understand that shortages of direct care workers and high turnover rates are not solely the result of the cyclical nature of the economy. Direct care workers face physically demanding work. The job can often also be emotionally draining. Workers often care for persons with cognitive impairments and/or dementia that can result in difficult communications and/or disruptive behaviors. In addition, many persons cared for have chronic illnesses that lead to declining health and death resulting in workers experiencing grief and loss from relationships formed with individuals receiving supports, and families. Direct care jobs are typically low-wage jobs which often provide few, if any, benefits. Direct care workers often feel unappreciated by families, individuals receiving supports, employers and even the general public for the difficult job they do and their essential role in providing quality long-term care.

Indeed, low wages are a key barrier to recruiting and retaining a quality workforce. Direct care workers can often find jobs that are less demanding and provide better wages and benefits. North Carolina and other states are taking steps to stabilize and expand the direct care workforce. The North Carolina Long Term Care Institute of Medicine included a number of recommendations pertaining to both the professional and paraprofessional long term care workforce. North Carolina is already implementing a number of recommendations included in the report to address shortages of direct care workers. North Carolina is working to develop two new job categories to provide more career advancement opportunities, working to develop a statewide association for direct care workers to give more voice to their issues and more peer support for workers. In addition, like other states, North

³⁹ Office of the State Auditor. Study of State Psychiatric Hospitals and Area Mental Health Programs. Final Report. April 1, 2000.

⁴⁰ Ibid. Section III at p. 9.

Carolina is taking a number of steps to expand the potential pool of workers by expanding options for consumer directed care.

Within the MH/DD/SA Division a staff competency system has been designed to address challenges facing the workforce that provides supports and services for individuals and families within the state. This system does not replace or duplicate any of the existing licensing and certifications boards. It provides a framework for professionals and paraprofessionals that are not eligible for licensing/certification, to have their competence measured and documented. The intent of the staff competency based system is to create:

- A well trained, stable workforce at all levels
- A career ladder
- Clear justification for increasing the wages paid at all levels of staff, particularly direct support paraprofessionals who have the most interactions with consumers
- Better care for people with disabilities through more stable support and service systems
- Less staff turnover and reduction of associated costs of replacing and training new personnel
- Reduction in administrative costs through standardizing qualifications and competencies for professionals and paraprofessionals
- Improved professional ethics and standards
- Higher morale and more motivated employees
- Fewer service crises
- And higher service quality.

This need was identified in the initial draft of the 2000 document, *Serving Persons with Disabilities in Appropriate Settings: The North Carolina Plan*.⁴¹

North Carolina is also working to develop two new job categories to provide more career advancement opportunities, working to develop a statewide association for direct care workers to give more voice to their issues and more peer support for workers. In addition, like other states, North Carolina is taking a number of steps to expand the potential pool of workers by expanding options for consumer directed care.

Assure and Monitor Quality of Care

The Division of Facility Services has primary responsibility overseeing mental health, developmental disability and substance abuse facilities and agencies licensed under 122C of the North Carolina General Statutes. DFS licenses or certifies state institutional and residential facilities that house two or more adults or one or more children; as well as agencies that provide day services to individuals for three or more hours a day.⁴¹ For people with developmental disabilities, this includes ICF-MR, DD supervised living facilities, therapeutic homes, Adult Developmental Vocational Programs, sheltered workshops, and community respite facilities.

In addition to the initial licensure, the Division of Facility Services conducts regular inspections of these facilities. DFS's staff was recently expanded to provide more frequent inspections—the goal is to inspect every facility annually (or more often if problems are identified). State laws were recently strengthened to require reporting of the use of restraints, and to enable DFS to impose administrative penalties (in addition to stronger remedies) if health or safety of the individual receiving services and supports is threatened.

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⁴¹ State Plan 2002. Blueprint for Change, Staff Competencies, Education and Training, page 1.

⁴² 122C-3(14)b.

There are also oversight systems to protect individuals receiving services through the area programs and the state's mental retardation centers. The area programs have client's rights committees that help investigate complaints. Mental retardation centers have more extensive oversight mechanisms. The human rights committees support a staff of on-site advocates. On site reviews are conducted annually by consumers and family members to ensure the safety and quality of services provided to the individuals living in these institutions.

Within the Executive Summary of the State Plan 2002: Blueprint for Change, the Local Management Entity (LME), currently called the Area Authority, will also monitor qualified providers within the network. Local monitoring will focus on outcomes of the person and/or family, the quality of clinical and programmatic delivery and will not be considered a licensure inspection. LME's are responsible for establishing a consumer and family advisory committee (CFAC). Within the listing of roles and responsibilities the CFAC will also participate in monitoring service development and delivery. The addition of local monitoring and of CFAC's serve to strengthen the existing monitoring functions described within the first three paragraphs.

CHAPTER 6

PUBLIC INPUT

The Department has sought the input from various stakeholders in the development of this Plan. The Department has utilized several different mechanisms to obtain feedback from consumers and their families, advocates, providers of services, and local and state agency staff:

- 1) The Department held four public meetings across the State between August and October, 2000 to obtain public input on how to best provide services to individuals in the least restrictive setting. The meetings were held in Raleigh, Greenville, Charlotte, and Asheville. Individuals with disabilities, older adults, family members, treatment professionals, and providers of services and supports attended the meetings. In all, more than 900 people provided input into the development of the State's Plan.

These four public meetings provided the basis for the development of the Interim Plan Draft dated December 28, 2000. The Department held four additional public hearings between December, 2001 and January, 2002 in Raleigh, Greenville, Charlotte, and Asheville to obtain the public's views on the contents and proposals in the Interim Plan, and to offer an additional opportunity for public input into the finalization of the Olmstead Plan for the State. In all, approximately 300 people attended this second set of meetings and offered input into the Interim Plan.

- 2) The Division of Mental Health, Developmental Disabilities and Substance Abuse Services created an *Olmstead* Steering Committee to make recommendations to the full Department. This committee included 20 stakeholders representing different populations or agencies, along with still more individuals involved in the various subcommittees. This same Committee and subcommittees have reviewed the Interim Plan to provide additional comments as part of its on-going role of giving oversight to the Division's implementation of the Olmstead Plan.
- 3) The Department worked with the NC Institute of Medicine's Long-Term Care Task Force, which was charged by the NC General Assembly to develop a long-term care system that provides a continuum of care for older adults and disabled individuals and their families.
- 4) The Department has also appointed an Olmstead Planning group that is composed of the persons who have been designated in each division to be the Olmstead planning coordinator for that agency to meet and to provide constant updates to the Plan as such pertains to that division.

Finally, the Department has received comments throughout this process directly from interested parties through its *Olmstead* website, <http://www.dhhs.state.nc.us/docs/olmstead>, and directly through the CARE-LINE. All comments and suggestions have been considered in the development of the preliminary Interim Plan and in this Revised edition. The Department will continue to solicit the public's comments on the Plan in order to achieve its plan for a periodic update and revision to keep the Plan current.

Public Meetings

More than 1200 people have participated in a total of eight public meetings that have been held across the State. In the first round of hearings, participants were asked to work in small groups, addressing the following topic areas: 1) identifying individuals who could be cared for in the community or in a home setting; 2) services or resources needed to support people in the community or home; 3) regulatory or bureaucratic barriers that prevent or hinder an individual from being appropriately cared for in the community or home; and 4) quality, monitoring and reporting systems needed to oversee the quality of care provided in the community or home setting. Within each topic area, there was a series of discussion questions that participants were asked to address. A full summary of the comments from the public meeting is included in Appendix A. A full text of the recorded comments can be found on the internet at: <http://www.dhhs.state.nc.us/docs/olmsteaddiscussion.htm>.

In the second round of meetings that were held in the same towns as the first round, the participants were asked to give comments and testimonies relative to the published draft of the Interim Plan in order to assure that the Plan captured the things that the general public and consumer populations deemed important to the State's effort to implement the requirements of the Olmstead decision. A summary of the comments from these meetings is included in Appendix B.

Identifying People Who Could Appropriately be Cared for in the Community

The prevailing public comments from all sessions can be categorized into three main areas, those surrounding a person-center service system that is based on the persons right to self-determination, an improved and expanded system of less restrictive community-based services, and an orderly transitional planning from the more restrictive setting (i.e., treatment hospital, nursing home, regional center, etc.) to a less restrictive community-based program of service. Many people provided comments that the whole process should be person-centered, and based around the individual's stated preferences and desires. To the extent possible, people with disabilities should have the right to choose the type of service setting that is best for them. There was also strong support for involving the family or legal guardian, as appropriate, in the decision-making process, particularly when the individual is not capable of making an informed choice. The State should assess individuals who are institutionalized as well as those at risk of institutionalization to determine the individual's functional, cognitive, and medical needs. Assessments should be conducted periodically (some people suggested quarterly, others yearly) with regular reviews depending on the needs of the individual.

Individuals and their families need better information about what resources already exist and how to access these services. Many noted that it was impossible to make informed choices because they did not know the various options that might be available to them. The public suggested several different ways to better inform consumers and families about long-term care options. These suggestions can be divided into three groupings: providing information directly to consumers and their families through the media, public forums, door-to-door canvassing, and the internet; using intermediaries to convey the information including advocacy groups, treatment professionals, health care providers, social workers and case managers, churches, law enforcement, and civic leaders; and developing community information and assistance programs which can help individuals identify needed resources.

Services or Resources Needed to Support People in the Community

Overwhelmingly, the public talked about the need to develop additional community resources to prevent institutionalization. Certain key resources were mentioned repeatedly in all the sessions, including:

- Advocacy services: including case advocates, Ombuds programs, community advisory committees and human rights protection
- Assistive technology
- Basic skills training
- Case management and mentoring personnel
- Communication services for people with communication barriers: including people with visual or hearing impairments or non-English speakers
- Crisis intervention services: including crisis beds or respite services
- Crisis intervention services: Assertive Community Treatment Teams ACTT/PACT services, High Risk Intervention (HRI) and Client Behavioral Intervention (CBI) services for people with mental illness
- Day activities: age-appropriate day activities including club houses, social programs, adult day care or day health, education, or recreation
- Employment Services: greater availability of job coaches, Community Rehabilitation Programs (sheltered workshops), supported employment services, community work and training programs
- Family support: including respite care
- Guardianship
- Housing: an array of affordable and accessible residential settings/housing with qualified personnel, and located in areas that are considered safe
- Housing: specialized group homes for people with mental illness or developmental disabilities that have the appropriate supports and support services
- Housing: home modifications to make housing more accessible and affordable
- Independent living services to assist with community-based living
- Information and assistance: to help consumers, families and professionals find the needed services and supports
- Mental health services: including wider availability of trained mental health professionals and psychosocial counseling
- Peer support and mentoring services
- Personal care services provided by better-trained direct care staff
- Services for individuals with substance abuse problems: including detox centers, halfway house and residential treatment
- Specialized services: including services for multiply diagnosed individuals or those with special health needs
- Transitional services to help people move from an institutional to community setting or from a group home to independent living, and to help some children in State custody transition into independent living situations when they turn 18
- Transportation services that support community living and work opportunities

Many commented during both sets of meetings that services need to be in place in the community before transitioning people from institutional settings to community-based care. Resources should be available throughout the State in order to eliminate or reduce county variation in availability of services. The State also needs to remove regulatory barriers to home and community-based care, such as the current institutional bias in public funding for services. Current laws and program funding make it easier for people to qualify for services in an institution than in the home or community setting.

Overall, people expressed concerns with the current availability of providers and the quality of the staff that are in provider programs. Most often these concerns addressed the quality of care provided by direct service staff such as certified nurse aides, although the staff of other provider programs were also mentioned. A number of people commented on the need to provide better training for direct service providers, including training that is matched to the people they are serving. Several people talked about the need to reduce staff turnover through higher pay, better benefits, advancement opportunities, and recognizing the value of the work provided by direct service providers. Others suggested that the State provide training and pay for the families to be the primary caregivers.

While most people focused on providing care to individuals in the least restrictive, community or home setting; there were a number of individuals who expressed concern that Olmstead may lead to the inappropriate de-institutionalization of a loved one. Several people raised the concern that the services and supports available in the community were not as comprehensive as those available in the institution, and that the funding available to serve people in the community would not be the same as it is serving the same individual in an institution. This was raised a number of times in the second round of meetings with comments that asked that some parity must be assured in the quality of services and staff at the institution and community levels.

Regulatory or Bureaucratic Barriers that Hinder Individuals from Being Appropriately Cared for in the Community or Home

Aside from a general lack of services in the community, the participants brought up other issues that hinder their ability to obtain needed services for a family member. First, several people talked about how fragmented the system is and how difficult it is to obtain timely information about available services and supports. On the positive side, some mentioned that the single portal system set up for people with developmental disabilities through area MHDDAS programs has helped to reduce fragmentation.

Others talked about the need to expand the availability and flexibility of all public programs. Several people talked about the need to make the funding more flexible, for example, by creating individualized budgets that the individual could control. Several people raised concerns about the disincentives implicit in some program rules to their going to work or becoming more independent. For example, getting a job may cause people with developmental or physical disabilities to lose their Medicaid eligibility rendering them unable to obtain or afford private health coverage.

In general, people who had tried to use the State's appeal processes to obtain needed services had mostly negative experiences. Some people talked about the difficulty individuals have in understanding the appeals process, and that the process is often confusing, even for other professionals. Others complained that the appeals process was not consistent within the various agencies of the Department, and that it took too long to resolve issues. The public talked about the need to develop an appeals process that is clearly defined and easy to understand, accessible at the local level, and act in an expeditious manner. Consumers and their advocates need to be informed of the process up-front on their rights to and how to access the appeals process.

This problem was discussed with even greater emphasis during the second set of meetings. In these, the testimony addressed the consumer's concern that filing a complaint could lead to a cessation of services entirely, or lead to some other form of retribution by the provider. It was strongly recommended that the appeals process not be under the same line of supervision as the provider of

service, and that all applicants for services have the appeals process explained to them during the intake process.

Quality, Monitoring and Reporting

Information, choice, and individual/family involvement were seen as key to the development of a treatment plan and ensuring quality. People talked about the need to obtain information about available providers and community resources, and the right to check out the providers before deciding on a treatment plan. They wanted information about the service providers, including staffing patterns, staff satisfaction, how long they had been in business, credentials, licensure, and the results of state monitoring reports. It was felt that the only way informed choice and the right to self-determination could be achieved would have to come from the consumer knowing the full range of options that were available.

A number of other suggestions were raised about ways to ensure quality in community and home-based settings. First, people talked about the need to involve consumers in the quality oversight mechanism—by finding out their needs, wishes and desires; giving them greater choice of services (perhaps through vouchers and an understanding of available options); establishing a consumer hotline or other methods to obtain consumer feedback; and developing better appeals process that is not controlled by the service provider. The need for an improved and independent appeals agent and process that was easily accessible to all was stressed at the second set of meetings. Family members should also be brought more into the service satisfaction monitoring systems. Consumers, family members and guardians should be surveyed to assess acceptable standards of quality in services and their satisfaction with what they received.

In addition to the consumers and family, people suggested structural oversight mechanisms. Some suggested requiring providers and facilities to have quality assurance programs and standards. Others talked about the need to improve the governmental regulatory system.

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

The Steering Committee has met six times over the course of the initial year of this planning to provide input to the Division about how it could best provide services and supports to people with disabilities in the most integrated setting appropriate to their needs. The Committee had three active subcommittees: 1) client assessment; 2) fiscal and human resources; and 3) monitoring and reporting. This Committee has been instrumental in developing the plan and providing continued oversight for the Olmstead implementation in State hospitals and centers.

Assessment

The Steering Committee recommended the use of various assessment tools to identify institutional or at-risk people who might be appropriate candidates to obtain care in a home or community-based setting. These assessment tools include: NC SNAP for people with developmental disabilities, LOCUS for adults with mental illness, and CALOCUS for children who have a mental illness. In addition, the client assessment subcommittee developed a recommended timeline to ensure that people who are currently institutionalized as well as those at-risk of institutionalization be initially assessed, and then at least annually thereafter.

Fiscal and Human Resources

The Committee identified possible funding sources that should be explored to expand the existing availability of home and community-based services. For example, the Committee recommended expanding the number of people served through the Medicaid CAP-MR/DD program, modifying the existing CAP-DA waiver to enhance the mental health component, and exploring the development or expansion of Medicaid waivers for other targeted populations, such as the traumatic brain injury (TBI) group. The Committee also recommended the use of Medicaid Disproportionate Share Hospital (DSH) funds to use as one-time bridge funds for the development of community-based services.

In addition to identifying potential sources of funds, the Committee suggested use of expanded State appropriations. Some of the suggestions include:

- expanding services for people without other sources of insurance,
- increasing funding for certain effective medications that are available to people while they are institutionalized, but unavailable once they leave the institution;
- developing a revolving loan fund to help people make required security deposits or pay for the first month's rent; and
- establishing a funds reserve that can be used to leverage loans or as a match for housing grants.

The Committee also emphasized the need to ensure that providers are adequately trained and paid to provide quality services to individuals who leave institutions for communities.

Monitoring, Reporting and Quality Assurance

The Committee made recommendations to simplify the current appeals process to make it easier for consumers and their families to use and to ensure more timely resolutions for disputes. Individuals should be advised of their right to appeal. The Committee also suggested a process to educate consumers, families, professionals, and the public about the new system of services and supports that are in place to provide care for people in the most integrated setting that is appropriate to their needs and preferences. In addition, the Committee suggested that the State develop a system for individual tracking and monitoring. This system would examine the capacity of the State to meet individual's service needs, the movement of individuals who are institutionalized through the transition process, the outcomes, the cost of services, and the overall performance of the system.

NC Institute of Medicine's Long-Term Care Task Force

In 1999, the North Carolina General Assembly directed the NC Department of Health and Human Services (DHHS) to develop a long-term care system that provides a continuum of care for older adults and people with disabilities and their families. The Department was directed to develop this system in conjunction with other stakeholders. The Department asked the North Carolina Institute of Medicine (NCIOM) to convene a statewide task force to assist DHHS in the development of this plan. The task force was chaired by Robert A. Ingram, Chairman of GlaxoWellcome, Inc. and David H. Bruton, M.D., DHHS Secretary, and 49 additional members that included representatives of the North Carolina General Assembly, county commissioners, local governments, long-term care providers and industry associations, consumer advocacy groups and businesses. The Task Force began meeting in

November 1999 and met 11 additional times through December 2000. In addition, two Work Groups were appointed which also met on numerous occasions in addition.

The Task Force's guiding principle was to develop a long-term care system "to support older and disabled persons needing long-term care, and their families, in making their own choices with regard to living arrangements and long-term care services that will result in appropriate, high quality, cost-effective care that is provided in the least restrictive setting."

The Task Force made recommendations in eight different areas: 1) DHHS organizational issues; 2) how consumers enter the long-term care system; 3) assuring availability of services; 4) ensuring the quality of services; 5) workforce issues; 6) financing options; 7) data and data system requirements; and 8) pilot and demonstration projects. A copy of the Interim Report dated June 30, 2000 is available on-line at: <http://www.nciom.org/ltclayout.pdf>.⁴³

Several of the recommendations of the Task Force have direct relevance to the development of this Plan. These include, but are not limited to:

- 1) The Secretary should create a new Long-Term Care/*Olmstead* Cabinet and Office of Long-Term Care to guide the overall work of the Department and the various Divisions in the implementation of the long-term care and *Olmstead* plans for the State.
- 2) The Department should develop a uniform portal of entry for long-term care services. The uniform portal would include common information and assistance, screening, level of services and care planning assessment tools. These new assessment tools would be based on the RAI-family of instruments. The level of services assessment tool will provide information to individuals about the range of long-term care services that may be appropriate based on their functional, cognitive, mental health and health care needs.
- 3) Every North Carolinian should have access to certain core long-term care services. These core services include many services needed to support people in their homes or community, including: adult day care/day health, durable medical equipment and supplies, home delivered meals, home health and care management, housing and home repair and modification, information and assistance, in-home aide services, medical alert or related services, nursing services, respite care, and transportation. Support must also be provided to caregivers to enable them to continue to provide informal support to their loved ones.
- 4) Several recommendations were made to assist in the recruiting and retention of qualified direct care staff. For example, the Task Force recommended that the Department develop new training curricula and career ladders. In addition, the Task Force recommended that the General Assembly fund a labor enhancement fund that would be used for enhanced wage benefits or payment of shift differentials.
- 5) The Task Force recommended that the General Assembly increase appropriations to expand the availability of Medicaid CAP services as well as other home and community-based services for non-Medicaid eligible individuals.

⁴³ A copy of the final report will be available on-line at www.nciom.org sometime in January 2001.

CHAPTER 7

THE "OLMSTEAD PLAN"

ENSURING THAT PEOPLE WITH DISABILITIES RECEIVE CARE IN THE MOST INTEGRATED SETTING APPROPRIATE TO THEIR NEEDS AND PREFERENCES

The intent of the Department's "Olmstead Plan" is to ensure that all people with disabilities who are institutionalized or at-risk of institutionalization receives services and supports in the most integrated setting appropriate to their needs. After a comprehensive review of existing programs and services in the State, the suggestions and comments from the eight public meetings that were conducted by the Department, and the planning from the Division of Mental Health, Developmental Disabilities and Substance Abuse's *Olmstead* Steering Committee, the Department focused on seven areas that are critical to the development of a comprehensive, effectively working plan to implement the Olmstead requirements:

- 1) outreach to inform potential candidates for community-based services about their options and choices,
- 2) the assessment and identification of appropriate candidates for community placement;
- 3) the development of service plans for community transition,
- 4) the operation of waiting lists,
- 5) the inventory of existing community-based resources and supports,
- 6) the identification of needed community resources to support community integration efforts; and
- 7) the ongoing monitoring and quality assurance efforts.

Informed Choice

Critical to the success of this undertaking is the need to inform individuals, their families and/or legal guardians, local service providers and treatment professionals about the State's plan to provide people with disabilities with greater options to be served in integrated settings. This educational effort will take many forms:

- During the Spring, 2001, the Department widely distributed the initial draft of the Interim Draft Plan to educate affected individuals, the caregivers, and the public at large, about the State's renewed commitment to ensure that people receive needed services in the least restrictive setting that is appropriate to their needs. Summaries of the Plan have been distributed to interested individuals, advocacy organizations, professional associations, institutions, as well as State and local agencies. In addition, the Plan was made available on the Internet.
- As part of the identification process that is described in the following Section, each resident has been asked if they wish to be considered for assessment for transition back into the community. The resident and his or her family or guardian, as appropriate, was given information about potential community-based services to help them to make informed choices about leaving the institution, and in the development of an appropriate community care plan. Individuals were provided information about the assessment process, the availability of community resources and services, the timeframe involved in developing a transition plan, the waiting list policy, and the appeals and grievance process.

- Similar information will be provided to individuals receiving state-subsidized services that are “at-risk” of institutionalization, in order to divert people from unnecessary institutionalization.
- In addition, the Department is expanding the current CARE-LINE system and makes it accessible to the public via the Internet. This new On-Line CARE-LINE is expected to be opened for use by July 1, 2002. The CARE-LINE system maintains and provides an inventory of community-based services that could support individuals in a home or community-based setting. The information is currently available through a toll-free telephone number, and will soon be available through the Internet.

Assessment and Identification of Appropriate Candidates for Community Placement

The Department will assess all potentially qualified people with disabilities who are residing in institutional, in a group living setting, or who are at risk of out of home placement. The priority for assessments is:

- People residing in state psychiatric institutions, mental retardation centers, community-based ICFs-MR, and nursing homes; and secondly,
- Anyone who specifically requests an assessment for community-based services, including at-risk individuals.

While the specific tools may vary across disability/age groups, the types of information collected and the process used will be similar. In general, the State will work closely with the treatment professionals or other appropriate personnel to identify individuals who could appropriately be cared for or served in the community. The assessment protocol will consider information from a range of sources, including but not limited to interviews of individuals, interviews of families or the person’s legal guardian (as appropriate), staff, and other medical, treatment or habilitation records. The assessments will examine the person’s functional, medical and psychosocial needs, as well as the individual’s strengths and skills in community living. Individuals will be reassessed on a regular basis, at least annually, but more often if the person experiences a significant change in functional or health status. Specifically, the procedure that will be used for each disability group is described in the following:

Older Adults or People with Acquired Disabilities

The Division of Medical Assistance has been in the process of implementing a nursing facility transition program. The first part of this effort was to develop a brochure, called ***Going Home***, for nursing facility residents and their families. This brochure would have outlined the community-based resources available to them should they leave the nursing facility. This effort was abandoned after its production was attempted due to the inability to design a meaningful brochure of reasonable size that would provide the information needed to help the transition. In lieu of the brochure, a poster on Olmstead, community services outside a nursing facility, and transitional planning has been sent to all nursing facilities.

Next, the State has identified potential candidates for community placement from the current nursing facility residents. Nursing facility residents will continue to be reviewed to determine each resident’s potential for discharge to the community. Regional Ombudsmen and Nursing Home

Community Advisory Committee members visit nursing facilities on a regular basis and communicate with residents and with staff. During these visits, the ombudsmen and committee members will have the opportunity to listen and communicate with residents who may express an interest in living in their own home or community setting. Once a resident expresses a clear desire to be assessed for transfer into a more integrated setting, the Regional Ombudsman and/or Nursing Home Community Advisory Committee member will notify the facility social worker who will be responsible for contacting and making a referral to the local Division of Vocational Rehabilitation Independent Living Office for further evaluation. Family members and/or nursing facility staff can also identify people who may be appropriate candidates for community placement and make their own referral to the Independent Living Office.

After being referred, the Division of Vocational Rehabilitation Independent Living program counselors will assess the resident to determine if the person is an appropriate candidate for transition. Candidates will be seen as soon as possible after referral, and eligibility will be determined at least within 60 days. After eligibility is determined, an Individualized Independent Living Plan will be developed jointly with the resident and family, as appropriate. Identification of financial resources, including comparable benefits will also be part of the Plan development. The independent living plan that is developed, will identify specific goals and services that are needed for residents to achieve their IL goals for the successful transition to community living. After the plan is agreed upon, service delivery will be initiated. Such services may include identification of needed community supports, including affordable and/or accessible housing, adaptive equipment (environmental controls, mobility devices, etc.), accessible transportation, assistants for the consumer-managed personal assistant service, and informal support networks of people.

At-Risk Individuals

The Department will continue the process of designing a uniform assessment tool that can be used to screen any individual who is seeking public funding for certain kinds of long-term care services (including nursing home, assisted living or in-home care). This assessment tool will be based on the RAI family of instruments and will be able to assess a person's functional, cognitive, health, and psychosocial needs, as well as his or her system of informal supports and environment. The goal was to have these assessments instruments in use across long-term care settings early this calendar year, but this has had to be modified due to other priorities. When it gets into use, information from the assessment tool will be gathered from client interviews, and will be supplemented by information from the treatment professionals and other caregivers to discern whether the applicant could be appropriately cared for in the community. In the meantime the VR/IL program will utilize its independent living evaluation instrument to assess referrals from these sources.

People with Developmental Disabilities

The State will initially conduct assessments of all individuals residing in mental retardation centers or community-based ICFs-MR who have expressed a desire to live in a more integrated community setting and whose parent/guardians and habilitation teams support this move. The assessments will be based on NC Support Needs Assessment Profile (NCSNAP), in conjunction with the development of a person-centered plan and individual interview. These initial assessments began in July 2001 and will be completed by June 30, 2002 for residents in the state mental retardation centers, and will begin July 2002 for people in community ICFs-MR.

In the second stage, the Department will assess individuals residing in community ICFs-MR as well as those at-risk of imminent institutionalization. This includes:

- Individuals who went through the mental retardation/mental illness (MR/MI) diversion process who are at risk of imminent hospitalization;
- Individuals residing in community ICFs-MR;
- Children aging out of children's ICFs/MR and specialized residential centers;
- Children aging out of "Willie M" and in need of ICF/MR level of care with a NC SNAP score of 3 or higher;
- Individuals with a pattern of emergency respite, diagnostic admission to mental retardation centers and failure in community placement;
- Adults with disabilities in need of ICF-MR level of care who are living at home with caregivers who are age 60 and older or in failing health; and
- Anyone else who specifically requests an assessment for community-placement.

Each new client entering an institution and those in the area programs that meet the definition of at-risk shall be assessed using this protocol as soon as possible after admission to the mental retardation center or entry into an area developmental disability single portal process. The assessment process begins immediately for those who enter the single portal, but must be completed within 30 days. For individuals who are admitted to state mental retardation centers, the assessment must occur no later than 60 workdays after admission. Once assessed, individuals will be reassessed on an annual basis, or more frequently if change occurs.

People with Mental Illness

The Department began its systematic assessment process with a 10 percent random sample of all individuals in state psychiatric institutions, child residential schools and Wilson Special Care Center. After completing the 10 percent sample, all remaining persons in the affected facilities were assessed. The Department used the Level of Care Utilization System (LOCUS) for adults with mental illness disorders (including adults with a comorbidity of substance abuse) and the Children and Adolescent Level of Care Utilization System (CALOCUS) instrument. The Department began with a 10 percent statistically significant random sample of all individuals in April 2001.. The entire population was assessed by May, 2002. During the initial phase of Olmstead assessments in mental health facilities, 545 adults and 17 children and adolescents were assessed to be potentially able to transition to the community.

In the second phase, which began in September 2002, the Department will continue to assess individuals who are admitted to state operated mental health facilities. Annual reviews and updates will be completed with individuals who were previously assessed, but remain hospitalized. Future phases will include individuals who are at risk to hospitalization including:

- Adults who have had three or more institutionalizations in the past year;
- Adults who have had one or more admissions to an institution for more than two consecutive months in the past year;
- Children with three or more institutionalizations in the past year;
- Children with one or more admissions to an institution for more than two consecutive months in the past year;

- Children who have been accepted for admission to state-run residential units, but who are on the waiting list; and
- Anyone else who specifically requests an assessment for community-placement.

When those who are at risk of institutionalization are assessed, each new person entering an institution who meets the criteria for at risk, and those in the area programs who meet the definition of at-risk, shall be assessed using this protocol as soon as possible after admission, and no later than five work days post-admission for mental health clients. If a client is discharged from a state institution prior to the completion of this assessment process, institution staff shall send the appropriate area program as much information as they have gathered under the assessment process. The assessment will be updated as appropriate for individuals who are readmitted to an institution within 45 days of the completion of the assessment. In addition, once assessed, individuals will be reassessed on an annual basis, or more frequently if change occurs, for as long as the person continues to receive publicly supported services or supports.

Service and Support Planning

Once appropriate candidates for community-based services have been identified, the State will work with the individual, his or her family, and the treatment professionals in developing an individualized plan. The person's needs, choices and preferences will underlie the development of each individual's plan. This is similar to the process already in place in many programs. While the person's choices will be strongly considered in the development of the care plan, each individual is not guaranteed to receive all requested services and supports. The development of a plan will be driven both by what is appropriate and necessary to support an individual in the community, as well as a consideration of any potential legal restrictions, and limits and fair distribution of system resources.

Waiting Lists

As noted in Chapters 3-5, the Department maintains waiting lists that capture qualified individuals waiting for home and community based services and supports in some of the State's programs. Currently, the information that is collected is not always maintained at the state level, and, in most cases, the State has little way to disaggregate the data to determine unduplicated counts of individuals waiting for services.

To address this problem, the Department is developing a plan to begin collecting this data in a centralized, consistent method. The Department will develop a unified waiting list procedure that will capture data about the number of qualified people seeking community-based services, and the length of time people spend on the waiting list before services are provided. The State's plan has two phases: 1) immediate data collection under current methodology; and, 2) the development of an electronic automated waiting list. The State's existing systems will be integrated into this database once it is completed.

Short term: By the end of the current State fiscal year, the Division of Information Resource Management within the Department will assess current capabilities in the different Divisions to help develop a unified policy for the maintenance and collection of waiting list information by local and State agencies. The list will identify qualified individuals who have been identified as appropriate candidates for community placement. This list shall be maintained separately for individuals who are

currently institutionalized, and for those who are currently in the community, but at-risk of institutionalization. Data will also be collected about how long it takes from the time the person first seeks services, to the time that services are provided.

Long-term plan: The Department's longer-term goals are to develop an electronic automated waiting list. This database will include all the individuals who have been assessed and identified as appropriate candidates for community-based services. The State will explore the possibility of developing a unified client base (to the extent allowed by federal laws), so that the State can maintain an unduplicated count of all qualified individuals seeking home and community-based services. The State's goal is to begin implementing an automated database that can collect assessment data and waiting lists by July 1, 2003.

Inventory of Existing Resources

The State and many local communities maintain numerous databases that include information on community resources—agencies, providers and organizations that provide home and community-based services needed to support people with disabilities in the community. For example, at the local level, 50 counties have automated resource directories that are used as part of the information and referral system for older adults. They may be operated by a variety of local agencies, including United Way, hospitals, Area Agencies on Aging or local aging providers. These databases include information about public and private agencies and providers that offer services to older adults, and some include information about service providers for people with developmental disabilities or mental illness. Many of these databases use similar software; have the capacity to be searched on-line; include contact information about the agencies as well as a description of what services the agency provides and the types of clients served; and are regularly updated.

At the state level, the most comprehensive database of local agencies and providers is maintained through the Department of Health and Human Services' Office of Citizen Services. The office operates a statewide Information and Referral Service called the CARE-LINE and a Department Ombudsman Program. Both services rely heavily on the office database, which includes information on more than 10,000 government and nonprofit agencies across North Carolina. By July 1, 2002, the "On-Line CARE-LINE" will be available to the public. The "On-Line CARE-LINE" will enable the public to access information regarding government and nonprofit agencies Statewide via the Internet. The public may obtain basic information regarding the type of services provided and clients served by the agencies. The database is limited to government and nonprofit agencies, and therefore it will not provide a complete listing of all providers. Most of the service agencies within the Department maintain a Web-site that provides information on the agency and its services. Private for-profit nursing homes and adult care homes are not included.

The Department's Division of Facility Services maintains a comprehensive listing of all licensed health care facilities and agencies, and the Divisions of Medical Assistance, Social Services, Aging, Vocational Rehabilitation, and Mental Health, Developmental Disabilities and Substance Abuse Services have data on providers who participate in their programs. These databases are not included in the CARE-LINE database, although many providers may be listed in several of them.

The Department is currently working on a plan to consolidate the information from all these databases and make them accessible to the public. The NC Division of Aging is leading a Departmental interagency planning effort to develop a statewide automated information and assistance

referral system for the collection, storage and dissemination of data for the aging population. In addition, the Department is developing a Department-level provider system that will contain core information about all providers that serve DHHS clients. This information will also be added to the statewide-automated information and assistance system, once developed. The Department plans on having this statewide-automated information and assistance system developed no later than July 1, 2002.

Identification of Needed Community Resources

The Department has identified some resources that are needed to support people in the most integrated setting. The first focus will be to expand existing services and programs rather than create fundamental alternations of the service delivery system for people with disabilities. The Department recognizes the need for additional funds to expand the number of people served through the various Community Alternative Placement programs, to support the transition of people to community settings, and to provide services to at-risk individuals. The Department also recognizes the need for some fundamental changes in policy and funding strategies. Specific functions that will require greater funding include:

- Evaluate people who are currently institutionalized or at risk of institutionalization
- Transition people from state mental retardation centers, large community ICFs-MR, psychiatric hospitals, and residential treatment centers into appropriate community-settings
- Transition people from nursing home to community settings
- Expand the number of people served through the CAP-DA program
- Expand the number of people served through the CAP-MR/DD program
- Expand the number of children who are medically fragile served through the CAP-C program
- Expand the number of people served in the CAP-HIV/AIDs program
- Increase the number of individuals age 60 or older who are at-risk of institutionalization who receive in-home services through the HCCBG program
- Increase the numbers of disabled adults age 18-59 who are at-risk of institutionalization who receive in-home services through the State In-Home funds

One of the major problems that has been identified in the public meetings, and in the Division of Mental Health, Developmental Disabilities and Substance Abuse Services Steering Committee, and the NC Institute of Medicine's Long-Term Care Task Force is the lack of trained, qualified direct care or paraprofessional staff. Service providers have difficulty recruiting and retaining these staff. The Department has identified policies that could help recruit and retain trained, qualified direct care staff. These policies include:

- Enhance wages of direct care staff with strategies such as increasing the Medicaid personal care service hourly rate for direct care services. This enhancement must be used for wages, benefits, and payment of shift differentials (e.g., nights/weekends). Providers would be required to submit additional cost data to ensure accountability for use of these funds as intended.
- Develop a continuing education and professional development initiative that would include direct care staff. Funding in the first year would be used to develop an educational program and to begin implementation of financial incentives in support of continuing education and professional development for direct care workers, such as bonuses, tuition, and other financial assistance. Subsequent year funding would continue incentive implementation.

- Develop a career ladder and associated curricula requirements and job category qualifications for direct care workers. The purpose of the career ladder is to provide a career path for aide workers that recognizes the attainment of additional skills and broadens the pool of potential workers by providing additional job opportunities. The Department would work with the North Carolina Board of Nursing, the Center for Nursing, the Community College system, long-term care provider organizations, and other appropriate organizations to consider the need to re-engineer current job categories of aide workers to meet the current and future needs of individuals receiving long-term care services and supports.
- Ongoing data collection efforts related to North Carolina's direct care workforce. The analysis should include information on demographics, turnover and retention rates, wages/benefits, comparison of active versus inactive Nurse Aide registrants and other direct care workers with regard to job stability and wages.

The Department has implemented a Department-level Cabinet to address *Olmstead* and long-term care issues. The Cabinet's membership is made-up from all the Directors of Divisions that address long-term care or *Olmstead* policy issues. The Cabinet, which meets on a monthly basis, is chaired by the Secretary of the Department or the Secretary's designee.

In addition to the Cabinet, the Department has also created an Office of Long-Term Care/*Olmstead* planning to coordinate the work of the Cabinet, collect and analyze *Olmstead* and long-term care data, identify emerging policy issues, work with the stakeholders and the general public, and help coordinate evaluation efforts in this area. One of the responsibilities of the Office will be to use the information from the waiting lists, the individualized care plans, and the inventory of available community resources to identify other potential service gaps, including those for housing and specialized services.

The lack of decent, safe and affordable community housing options has been identified by DHHS Divisions and throughout the *Olmstead* public hearing process as a common barrier to community living for all *Olmstead* affected populations. Income, not age or disability, is often the common barrier to accessing community housing resources for these populations. According to North Carolina's 2001-2005 Consolidated plan, 19.5 % of the state's elderly live below the Federal poverty level. Over 100,000 non-elderly blind and disabled receive SSI income at 75% of the Federal poverty rate. Unable to compete in the private market, these populations are dependent on subsidized housing, at a time when the stock of subsidized housing available to them is shrinking.

In high growth areas like North Carolina competition for housing units has decreased the housing stock available to the persons with disabilities and long-term illness. Many Public Housing Authorities have closed Section 8 waiting lists. Though the recent economic downturn has "softened" the rental market and more landlords are interested in working with the program, in many markets it remains difficult to find decent housing that will accept the rental assistance. Units have been lost in the conversion of public housing to mixed income projects, the loss of the Federal preference for persons with disabilities, and elderly only admission policies. The elderly and persons with mobility impairments must often leave their homes for want of home accessibility modifications. In addition, because lower income individuals and families are harder to serve and need the long term commitment of rental assistance, current income targeting in the majority of housing production resources does not include extremely low income populations.

Recognizing that addressing this need would require a sustained and systematic response, the Department of Health and Human Services has taken the first steps by creating a Department wide

housing initiative. Located within the Secretary's office, reporting to the Assistant Secretary of Long Term Care, the new Department Housing Coordinator will be working both within Department and with outside agencies. The intention of this initiative is to coordinate the Department's housing activity: to reduce the fragmentation of housing efforts being pursued by the various Divisions, to increase the knowledge base of DHHS staff about the affordable housing system, and to improve the capacity of both State and local agencies to maximize existing housing resources and to influence housing policy on the local, state and federal level for the benefit of DHHS constituents.

Throughout the Department, Olmstead has given new impetus to existing Division housing activities. In the 2002 Low Income Housing Tax Credit allocation process the NC Housing Finance Agency (HFA) has joined with DHHS in an effort to expand the availability of affordable rental units to persons with disabilities and other special needs. Significant bonus points were offered to developers who partnered with local lead agencies in submitting Targeting Plans for DHHS review that include mechanisms for making Tax Credit units affordable and available to persons whose extremely low incomes would otherwise make them ineligible for this housing. One hundred twenty eight units of high quality rental housing will be developed for persons with disabilities and/or homeless populations as a result of the 2002 process. Both DHHS and HFA are committed to expanding and improving upon this process in future years.

The newly created DHHS Housing Work Group, with representatives from the various Divisions, has already begun the process of coordinating housing activity within the Department and will be responsible for the review of Low Income Housing Tax Credit Targeting plans this year.

The Division of Vocational Rehabilitation is working closely with the housing development arm of Volunteers for America in the pre-development phase for two multi-unit independent apartment communities with specialized design features and services for persons with serious mobility impairments.

The Division of Mental Health, Developmental Disabilities and Substance Abuse Services is operationalizing the portion of the Mental Health Trust Fund earmarked for supported housing development in partnership with the non-profit housing intermediary, Housing Works. The Trust Fund dollars will support a number of initiatives including: establishing a loan/grant fund to provide gap financing for community supportive housing developments, a small fund to support home modifications, and a pool of funding to be used to leverage other sources to develop replicable financial models for small scale group homes and community residences for persons with the most serious disabilities or specialized treatment needs.

The Division of Services for the Deaf and The Hard of Hearing has concern about accessible communication and appropriate language use. We know that accessible communication and appropriate language use substantially enhances the outcomes of all human service programs for providers and consumers alike. Establishing a communication plan with an individual or group not only assures effective communications, but it better assures equal access to information upon which the Department's policy on informed choice and self-determination are based.

A communication plan for individuals who are deaf, hard of hearing, deaf-blind, and late-deafened will be within the policies of the Department and within the framework of the American's with Disabilities Act (ADA). The Plan is intended to allow a more meaningful involvement and opportunity to have a more substantive input into all aspects of planning, design, implementation, monitoring, and evaluation of their services and supports.

The Division of Services for the Deaf and The Hard of Hearing has provided leadership and administrative support for formalizing a working group "Affordable Housing for Deaf/HH/Deaf-Blind and Friends" comprised of advocates and community members who are exploring relationships with affordable housing developers, particularly to address the housing needs of the deaf, hard of hearing or deaf and blind elderly.

This is not an exhaustive list of the housing activity within DHHS, as throughout the various Divisions the lack of affordable, decent and stable housing has been increasingly identified as a common barrier to the effectiveness of the programming and services that the Department provides. Increasing the supply of affordable community housing opportunities for persons with disabilities and long-term illnesses will require building improved and sustainable connections between the community service and support systems and the affordable housing system. Future activities will include:

- Expanding and improving upon DHHS participation in the Low Income Housing Tax Credit program.
- Developing data on unmet need across the housing spectrum.
- Creating an inventory existing and potential funding resources, both for bricks and mortar development, rehabilitation and accessibility modifications to meet these needs, identifying sources, uses and barriers to their use.
- Collectively engaging the affordable housing industry, HUD, Local Public Housing /Section 8 Authorities, NC Housing Finance Agency, the Department of Commerce's Division of Community Assistance, USDA Rural Development, Department of Veteran's Affairs, private developers, and public and private housing providers to better address the supportive housing needs of the persons with disabilities and long-term illness.
- Partnering with the Center for Universal Design, Fair Housing enforcement agencies, HUD and the NC Housing Finance Agency to both educate consumers and housing providers about Fair Housing rights and responsibilities and to assure that new construction is carried out according to Fair Housing accessibility requirements and principals of Universal Design.

The NC Institute of Medicine's Long-Term Care Task Force recommended development of comprehensive local planning effort to identify local services gaps and encourage the development of more home and community-based services.⁴⁴ In addition, Section 22.1 of the Studies Act of 2001 [S.L.2001-491 (S166)] asked the Division on Aging to study whether counties should designate local agencies to organize local long-term care (LTC) planning processes. In response to these directives, the Division on Aging is developing "A Communications and Planning Network to Support Families in Long-Term Care", which will connect State and local interests committed to local LTC planning and reform. The Network will consist of three major groups: the local planning team, a State team, and the LTC Cabinet. It is anticipated that up to two counties or multi-county areas will be selected to initially participate and voluntarily agree, with endorsement of their county commissioners, to work for at least one year to develop local planning processes consistent with IOM Recommendation 16. It is important to note that the planning focus and participants will cover all aspects and populations of long-term care. Each local planning team will have a lead agent(s) named by the County Commissioners to guide and support their work. The State team will consist of representatives from all relevant DHHS divisions, consumers, and other stakeholders, and will be responsible for general technical assistance,

⁴⁴ A Long-Term Care Plan for North Carolina: Interim Report to the North Carolina Department of Health and Human Services. Chapel Hill, NC: North Carolina Institute of Medicine, June 30, 2000. Recommendation # 10.

policy guidance, and the consideration of all aspects of a comprehensive LTC system. The LTC Cabinet will provide common outcomes for the planning teams, overall policy direction, and general evaluation of the Network.

The local planning teams will begin by completing LTC core service (IOM Recommendation 11) evaluation for their community, with assistance from the State Team. The core service evaluation will assist the planning teams in determining the availability, adequacy, effectiveness, efficiency, and equity of core services for their consumers. Based on this evaluation, planning teams will develop specific improvement strategies that are required to achieve a comprehensive LTC system. Local planning teams and the State Team will periodically meet to discuss barriers to planning and core service development, receive training on specific issues and concepts, and to develop approaches to resolving common development problems. It is anticipated that local teams will be selected and initiate planning by early 2003. The concepts learned through these initial projects will be used to assist other communities in assessing their LTC systems and services.

One of the primary needs that have been identified is those surrounding transportation. Increased awareness of public transportation resources by marketing the services of community transportation systems to all population, particularly the elderly frail and people with disabilities.

A Department-level Human Services Transportation position will be created to coordinate the development of uniform policies, definitions, and reporting procedures for all DHHS programs that provide transportation services. An action plan will be developed to eliminate transportation barriers and to expand transportation resources to the elderly and persons with disabilities.

Ongoing Monitoring and Quality Assurance Efforts

Ongoing monitoring of the system and the care provided to specific individuals is critical to the success of the plan. The Department has developed a plan to ensure ongoing monitoring and oversight, both at the systemic level and also on the individual level.

Systemic: People who use the services and supports will have a voice in determining the quality of those services and supports. The Department will conduct regular customer satisfaction surveys to determine whether the people who are being served are satisfied with the care they are receiving.

The Department will also use the assessment and waiting list data to monitor the system of care for people with disabilities. The Department will collect statewide information about the number of people assessed, the number of institutional and at-risk individuals who desire community-based services, their level of functional, cognitive, developmental and health care needs, the length of time spent on the waiting list, and the availability of community-based services.

In addition to regular consumer surveys and the collection of assessment and waiting list data, the Department will work with the newly created Long-Term Care Forum and the Division of Mental Health, Developmental Disabilities and Substance Abuse Services' Steering Committee to obtain regular feedback about the operation of the plan. These groups will include various stakeholders, including consumers and family members, advocates, providers, facility and professional staff, and local and state agency staff. The stakeholders will be asked to provide input into the timeliness of response, whether the appropriate people were involved in the assessment and care planning process,

the stability of the client-staff relationships, availability and appropriateness of services, interagency communication and coordination, and the adequacy of monitoring and evaluative efforts.

Individual: Success in achieving personal outcomes will be measured on a regular basis to determine whether the appropriate issues are being addressed and whether the appropriate services and supports are being provided. As one measure, the Department will examine the periodic assessment data to identify changes in functional, health or psychosocial status. These data can help identify any potential problem or quality of care issues, and should trigger changes in the individual's plan.

Individuals also have a right to seek review if they disagree with the initial determination of eligibility for community-placement or if they disagree with treatment decisions. These rights already exist under existing programs⁴⁵ and under the Americans with Disabilities Act.⁴⁶ During the public meetings, several people commented on the difficulty of using the existing appeals and review process. Therefore, the State will conduct a review of existing appeals processes to determine if there are ways to streamline and simplify the process, ensure that decisions are made in a timely fashion, and educate consumers about their appeals rights. Individuals will be apprised of these rights during the initial and periodic assessments, during the development of the individual care plan, and whenever the client expresses a concern about service options.

⁴⁵ Different programs offer different review or appeal remedies to individuals that think they have been "aggrieved" by the agencies' actions. For example, individuals have a right to appeal Medicaid eligibility determinations (including eligibility for CAP services) under NCGS 108A-79. Area programs are required to have grievance policies for services provided to individuals with mental health, developmental disabilities or substance abuse problems. These review requirements are found in 10 NCAC 14V.0201(a)(18), and 10 NCAC 14V.0504 (human rights committees). Nursing home and adult care home residents have a right to appeal discharge notices and changes of level of care determinations, either directly or through representatives, under NCGS 131E-117(12) and NCGS 131D-21(11). The Independent Living program appeal rights are outlined under 34 CFR 36148 and 10 NCAC 20B.0212-0222 and 0225. The appeal provisions for individuals seeking services through the Home and Community Care Block Grant are found in 10 NCAC 22.0103(b)(5). Appeal provisions for the Social Services Block Grant are set out in the Family Services Manual, Vol. VI, Chapter II, Section 8080-8090.

⁴⁶ For example, 10 NCAC Subchapter 1M contains administrative procedures for processing ADA complaints against one of the Divisions in the Department. *Olmstead* itself was a claim asserted under the ADA.

APPENDIX A

SUMMARY OF COMMENTS FROM THE PUBLIC HEARING

I. Identifying individuals who could be cared for in the community or in a home setting

What is the best way to identify people who might desire and be capable of moving from an institution to the community or home setting?

Foremost, the State should try to find out what the individual prefers. To the extent possible, people with disabilities should have the right to choose what type of setting is best for them. There was also strong support for involving the family or legal guardian in the decision making process, particularly when the individual is not capable of making an informed choice. Many people commented that the whole process should be person-centered, and based around the individual's stated preferences and desires. People talked about the need to provide better information to affected consumers and their families to help them make informed choices. The information should include information about services available in the community, as well as the experiences of others who have tried to move from an institutional setting to a home- or community-based setting.

In addition to working directly with the consumer and his or her family or guardian, people suggested working with providers or caregivers to identify people who could appropriately be cared for in the community. The State should also initiate an aggressive outreach campaign to educate community leaders (including people in the faith community) about new options for caring for people in their home or community setting. They, in turn, can help provide this information to families that could benefit from or would want to consider such community/resources.

The State should assess individuals who are institutionalized as well as those at-risk of institutionalization to determine the individual's functional, cognitive, and medical needs. The assessment can be used to identify people who would be appropriate candidates for community placement, as well as help ensure that community supports are matched to the person's need.

What processes should be in place to prevent institutionalization or reduce institutionalization for people who desire to stay in their home or community setting.

Individuals and their families need better information about what resources already exist and how to access these services. The current system is intimidating for some people; making it difficult for them to access community-based services. Part of the bureaucratic barriers could be reduced if local agencies communicated more effectively, and worked collectively to address the needs of at-risk individuals in the community.

Some people also suggested that the State institute pre-admission screening and ongoing assessments, to identify people who might be at-risk of institutionalization. The State may be able to avoid unnecessary institutionalization by identifying those individuals who could be appropriately cared for at-home, and by providing the needed services and supports to enable them to remain at home. Again, members of the public reiterated that principles of self-determination should drive the process.

What is the best way to inform families about the range of long-term care services available in their community that may prevent a person from being institutionalized (if the consumer does not desire an institutional setting)?

The public suggested several different ways to inform families about long-term care options. They roughly broke down into three groupings: providing information directly to consumers and their families through the media, public forums, door to door canvassing, and the internet; using intermediaries to convey the information including advocacy groups, treatment professionals, health care providers, social workers and case managers, churches, law enforcement, and civic leaders; and developing community information and assistance programs which can help individuals identify needed resources. This latter approach may include single portals of entry (for example, the area MHDDSAS programs serve as the single portal for services for people with developmental disabilities), 211 human service agency telephone hotlines, information and assistance/referral agencies or family resource centers.

Several people commented on the need to train the service providers about the range of services that are available in the community. One suggestion was to establish interagency councils to enable agencies to share information; another suggested co-locating workers in different agencies. The information should be consistent across agencies, and to the extent possible, across county lines. Information about other available resources should be available when individuals apply for public programs even if that agency does not actually provide the services directly.

What types of professionals should conduct the assessments to determine whether a person could appropriately be cared for in the community? How often should assessments be done?

The public identified a number of treatment professionals that should be involved in the assessment process, including medical personnel, social workers, psychiatric professionals, caseworkers, independent living counselors, and/or other professionals depending on the person's needs. Sometimes, individuals with special health needs may need a specialist involved in the assessment. Ideally, an interdisciplinary team of professionals should conduct the assessment. The assessors should be trained, and should be non-biased. Families should also be brought into the assessment process. The assessment should be person-centered; the plan that is developed from the assessment should be based around the consumer's own goals and desires.

Assessments should be conducted periodically (some people suggested quarterly, others yearly) with regular reviews depending on the needs of the individual. Some members of the public wanted access to the assessment instruments so that they could help identify the types of services that may be appropriate for their family members; others did not want access to the instruments but to the results of the assessments that were conducted.

II. Services/Resources Needed to Support People in the Community or Home

What services need to be available so people can be served in the community or home setting rather than an institution? Do you have concerns about the available resources in your community?

Overwhelmingly, the public talked about the need to develop additional community resources to prevent institutionalization. Certain key resources were mentioned repeatedly, including:

- Advocacy services: including case advocates, Ombuds programs, community advisory committees and human rights protection
- Assistive technology
- Basic skills training
- Case management
- Communication services for people with communication barriers: including people with visual or hearing impairments or non-English speakers
- Crisis intervention services: including crisis beds or respite services
- Crisis intervention services: Assertive Community Treatment Teams ACTT/PACT services, High Risk Intervention (HRI) and Client Behavioral Intervention (CBI) services for people with mental illness
- Day activities: age appropriate day activities including club houses, social programs, adult day care or day health, education, or recreation
- Employment Services: greater availability of job coaches, sheltered workshop and supported employment
- Family support: including respite care
- Guardianship
- Housing: an array of affordable and accessible residential settings/housing with qualified personnel
- Housing: specialized group homes for people with mental illness or developmental disabilities
- Housing: home modifications to make housing more accessible
- Independent living services
- Information and assistance: to help consumers, families and professionals find the needed services and supports
- Mental health services: including wider availability of trained mental health professionals and psychosocial counseling
- Peer support services
- Personal care services provided by better-trained direct care staff
- Services for individuals with substance abuse problems: including detox centers, halfway house and residential treatment
- Specialized services: including services for multiply diagnosed individuals or those with special health needs
- Transitional services to help people move from an institutional to community setting or from a group home to independent living, and to help some children in state custody transition into independent living situations when they turn 18
- Transportation

Services need to be in place in the community before transitioning people from institutional settings to home and community-based care. Resources should be available throughout the state in order to eliminate or reduce county variation in availability of services. People were particularly concerned with the lack of resources in rural communities, and the need to have resources available in their local communities so individuals could reside close to the family. The same array of services currently available in the institutions need to be assured in the community including primary care, psychological services, dental services, occupational therapy, physical therapy, psychosocial rehabilitation.

Training and support should also be given to the family, to help them care for the individual at home. Some suggested paying family members for their services, while others focused on the need for better training, respite and other family supports.

The State also needs to remove regulatory barriers to home and community based care, such as the current institutional bias in public funding. Current laws make it easier for people to qualify for services in an institution than in the home or community setting. A concern was also raised that there was no economic incentive for area programs to serve people in the community (and pay for services out of limited area program funds), when they could transfer people to state institutions and not have to pay for the costs of care. Many people commented that people should not need to be institutionalized to receive services. One suggested mechanism would be to create or expand the Medicaid Community Alternatives Placement program to provide additional services and supports to individuals who would otherwise need institutionalization. The State should design similar programs for individuals not currently being covered by such programs, such as individuals with mental illness or with less severe disabilities. Another suggestion was to make special assistance more flexible, to allow people to use the financial support to provide services at home instead of adult care homes.

Several people mentioned that consumers should have more control over the funding. Monies should follow the individual so that the consumer and his or her family could decide on the needed services and hire the caregivers. Funding should follow the individual from agency to agency, and if needed, from county to county. Services should be individualized; rather than trying to fit the person to the service, the services should be provided to meet the individual consumer's needs. To do that, categorical funding restrictions should be removed so that there is more flexibility in the use of funds. Some people thought the state should establish a voucher system, to enable the affected individual to purchase needed services.

While most people focused on providing care to individuals in the least restrictive, community or home setting; there were a number of individuals who were concerned that Olmstead may lead to the inappropriate de-institutionalization of a loved one. Several people raised the concern that the services and supports available in the community were not as comprehensive as those available in the institution, and that the funding available to serve people in the community would not be the same as it is serving the same individual in an institution. Some expressed concern that the community is not accepting of people with disabilities, and that it would be easier to exploit people with disabilities in a community setting than in an institution. Others expressed the concern that the Olmstead ruling may lead to the closing of institutions or that others who need institutional services would not be permitted to access institutional services. Others were afraid that if a loved one tried to move to the community, and it failed, that they would have a hard time being able to get back into the institution.

Several people raised specific issues about the availability of service to serve children with developmental disabilities or severe emotional disturbance. People were concerned about the adequacy of funding for children and adolescents in area MHDDSAS program; and also about the capacity of local schools to address the needs of children with disabilities, especially those that have accompanying behavioral problems.

What is the best way to ensure that your family member is receiving appropriate services?

The public comments generally broke down into two broad groupings—those focused at examining care at the individual level; and those aimed at ensuring that systems were in place to ensure the adequacy of care provided to everyone.

Individual-focused comments: Many people made suggestions aimed at ensuring the quality of care provided to specific individuals with disabilities. Several suggestions focused on getting the consumer more involved in directing their own care, as well as involved in local planning processes and oversight committees. To be effective, consumers need to be trained to become better self-advocates. The training should include information on their rights in institution and community settings, appropriate and available services and supports, and how to become better advocates for obtaining needed resources or resolving problems. Others suggested developing or expanding existing leadership programs for people with disabilities so that consumers can be involved more actively in local planning processes or human rights committees.

Similar comments were made focused on family members. Many people suggested that family members should get more involved in examining treatment options and in monitoring the quality and availability of services. At least one person raised the concern that “confidentiality” protections were being used to exclude family members from the care planning process. Family members also need training to become better advocates and to understand the rights of their loved ones.

Systems focused comments: Other people focused on the need to establish systems that can help ensure that consumers receive appropriate services. Several people suggested that the State establish an Ombuds program to monitor services provided in the community and to advocate on behalf of individuals with disabilities. This would be similar to the system in place for older adults and people with disabilities who reside in nursing homes or adult care homes. Others suggested that the State establish better regulatory oversight, to ensure that individuals are receiving high quality oversight and to identify gaps in community services. Several people talked about the need to establish appeals and grievance systems that are easy to use and understand. Another suggestion was that the State conduct customer satisfaction surveys to help identify potential problem areas.

What training would you like to have available to assist you in caring for your loved one?

The public offered several suggestions for training that would help them in caring for their loved ones. Several people talked about the need for training about clients’ rights as well as assertiveness training and communications skills so that they could become better advocates on behalf of their loved ones. They also wanted basic advocacy training so that they could help influence the public policy process including the allocation of limited resources. Some other people commented on the needs to obtain training about behavioral or medical issues—including a better understanding of their loved one’s diagnosis, treatment plan and systems of services. They wanted the skills needed to become more active partners in the care planning process. Others talked about the need for skills training about how to address the behavioral and functional needs of the person with disabilities, including in-home training when needed. Other people talked about the need to establish support networks to help provide emotional support and skills for family members.

What needs to be done to educate community leaders and the general public about the need for community-based services?

Many people talked about the need to work directly with community leaders, to give them a better understanding of the needs and capabilities of people with disabilities. Community leaders should be invited to visit agencies and facilities serving these consumers, so that they have a better understanding of people with developmental disabilities, mental illness, physical disabilities and cognitive impairments.

Some people suggested that another way to educate the public and community leaders is to start the educational efforts with providers, schools, agencies and churches. The State should offer provider forums and should help train police how to work with people with disabilities. Several people suggested the need to begin the education effort in the schools, teaching the school administrators and staff, teachers, and the other students about the capabilities of and needs of people with disabilities.

Consistently, the public talked about the need to focus on success stories, and using the media in this community education effort. Many people expressed the desire to publicize the positives of community integration of people with disabilities. The goal of these efforts would be to reduce the negative images or lack of understanding that some community members have about people with different types of disabilities. Some suggested taking advantage of events like the Special Olympics to gain public acceptance. Others talked about reducing community fear by showing the public of plans to address emergencies or unexpected occurrences. Communities should also establish speakers' bureaus of people who can talk about the needs of people with disabilities.

Do you have any concerns about the qualifications of the staff that are providing services to your family member? If so, do you have any suggestions about how to ensure that there are sufficient numbers of trained and qualified staff?

Overall, people expressed concerns with the current availability of providers and the quality of the staff. Several people mentioned the need to ensure that the same quality of staff that is available in the institutions should be available in the community.

Several people focused their comments on the quality of specific types of providers. Most often these concerns addressed the quality of care provided by direct service staff such as certified nurse aides, although other providers were also mentioned. Several people commented on the need to provide better training for direct service providers, including training matched to the people they are serving. Staffs that dispense medications in adult care homes or group homes should be required to have higher qualifications and additional training. The State should work with the community college system in designing entry level and continuing education training, and should provide tuition remission to recruit potential caregivers. Others talked about the need to establish staff certification or credentialing requirements. A suggestion was also made to require continuing education for all staff. Several people talked about the need to reduce staff turnover through higher pay, better benefits, advancement opportunities, and recognizing the value of the work provided by direct service providers. Others suggested that the State provide training and pay for the families to be the caregivers.

Concerns were also raised about the quality of care and appropriateness of placement of people with disabilities in adult care homes. Some talked about the need to monitor community providers and residential facilities, including adult care homes and group homes.

III. Regulatory or Bureaucratic Barriers

Do current laws and policies help or hinder you in obtaining needed services for your family member? What policies or practices have helped you? What policies or practices have made it difficult to obtain needed services?

Aside from a general lack of services in the community, the public brought up other issues that hinder their ability to obtain needed services for a family member. First, several people talked about how fragmented the system is and how difficult it is to obtain timely information about available services and supports. On the positive side, some mentioned that the single portal system set up for people with developmental disabilities through area MHDDSAS programs has helped reduce fragmentation. Another related issue was bureaucratic barriers—for example, one person commented that it took six months to complete the paperwork at area mental health centers to obtain needed services. Another issue raised was the lack of accountability; there should be someone in charge that can fix problems when something is wrong.

Others talked about the need to expand the availability and flexibility of public programs. Several people talked about the need to make the funding more flexible, for example, by creating individualized budgets that the individual could control. Several people raised concerns about the disincentives implicit in some program rules to becoming more independent. For example, getting a job may cause people with developmental or physical disabilities to lose their Medicaid eligibility. Others talked about the Medicare home health rules that deny services to individuals who can leave their home with the help of home health workers; but who would otherwise be homebound. People also talked about the need to expand Medicaid eligibility and to remove any eligibility rules which made it easier to qualify for institutional or residential care than for care at home or the community. One example, is that Medicaid will protect the income and assets of a person living at home if their spouse enters a nursing home; but there is no similar “spousal protection” for people in the Special Assistance program if their loved one enters an adult care home. Others suggested expanding the CAP-MR/DD and CAP-DA slots, and to set up similar programs for people with other or milder disabilities.

What has your experience been in applying for public programs to assist you in caring for your family member? Do you have any suggestions on how to improve the application process?

The most consistent response was the difficulty finding information. Some people thought that agency workers intentionally limited information or access because of the number of people already on the waiting list or the overall lack of services. Several people suggested that the State establish a uniform or single portal of entry or “one-stop shopping,” so those individuals would know where to go to obtain needed information. People complained about the need to file multiple applications across agencies and advocated for a single application that could be used across programs. Others talked about the problems of having to be re-certified so frequently; and suggested limiting re-certification to once a year. Concerns were raised about the lack of coordination across agencies serving the same people. People need case managers to help them walk through the maze of services. Other people raised concerns about the lack of compassion among some of the agency staff—the whole process can be “humiliating.” To address this issue, some suggested better training and education for the staff as well as consistent caseload standards across the state. People also raised the issues of the lack of services for middle-income individuals.

Have you tried to appeal the denial of eligibility or services? If so, what has your experience been? Do you have any suggestions for how to improve the appeals process?

Most people who talked about their experiences with appeals had negative experiences. Some people talked about the difficulty understanding the process—the process is confusing, even for the professionals. It should be easier to file appeals (perhaps through a toll-free phone number). Others complained that the process is not consistent and it takes too long to resolve problems. The time delay can cause problem for people needing services. A concern was also raised that the State did not respond to some complaints. Only one person talked about satisfaction with an appeal they were involved in.

We would like to obtain ongoing feedback from the public about how to improve public programs. What is the best way to seek ongoing input from the public in the development of public policies?

Several comments were made about ways to involve the public in the development of public policy. First, it is important to involve the stakeholders from the beginning not just asking them after the policy has been developed. Consumer should serve on public agency committees on a regular basis. The State should have regular forums for citizen input; one suggestion was standing committees to hear consumers' issues and report this information back to the appropriate agency or provider. The State should also survey consumers to obtain information about their satisfaction with services and their experiences with the public system.

Information about public policies should be distributed widely. There should be regular communication through the media and through the Internet. Information should be conveyed in multi-media forms to reach people with different types of disabilities. Information should also be made available to the public through providers, libraries, and school systems.

IV. Quality, Monitoring and Reporting

What is the best way to ensure quality in community and home-based settings?

A number of suggestions were raised about ways to ensure quality in community and home-based settings. First, people talked about the need to involve consumers in the quality oversight mechanism—by finding out their needs, wishes and desires; giving them greater choice of services (perhaps through vouchers); establishing a consumer hotline or other methods to obtain consumer feedback; and developing better appeals process. Family members should also be brought into the monitoring system. Consumers, family members and guardians should be surveyed to find out what are acceptable standards of quality.

In addition to the consumers and family, people suggested structural oversight mechanisms. Some suggested requiring providers and facilities to have quality assurance programs and standards. Others talked about the need to improve the governmental regulatory system, to include more frequent visits to providers or facilities, ensure qualified staff are involved in monitoring, and to ensure that regulators use objective non-politicized standards in evaluating quality of care. One person suggested that the State develop a rating system to encourage providers to offer more than the minimum level of care—similar to the 5-star rating system used for child care providers. Another suggestion was that community-based services be accredited.

Others suggested involving independent advocates or independent case managers (independent of the service providers) who could monitor the quality of services provided to their clients. Again, the public talked about the need to improve the quality of direct care staff through increased financial compensation.

What do you think is the most important aspects of care and quality of life that we should monitor as we move people out of institutions and into home and community settings. What are appropriate outcome goals for people in the community? In institutions?

A number of people talked about the need to set individualized quality standards based on what the individual wants and needs. Ask the person what they value as most important. Quality of care and outcome standards should be based around the individual's needs and desire, not based on the setting of care. The focus should be on the consumer's quality of life. The State should examine safety issues, whether the person has an opportunity for meaningful relationships and to live near family and friends, and whether he or she has an opportunity to grow and be as independent as possible.

Other people talked about the need for human rights standards for community placements. There should be consequences for violations of quality standards, with immediate attention to severe infractions.

What information would be useful to you in choosing care providers or in designing a treatment plan for your family? What is the best way to communicate this information to you?

Information, choice, and individual/family involvement were seen as key to the development of a treatment plan and ensuring quality. People talked about the need to obtain information about available providers and community resources, and the right to check out the providers before deciding on a treatment plan. They wanted information about the service providers, including staffing patterns, staff satisfaction, how long they were in business, credentials, licensure, and the results of state monitoring reports. Some suggested the development of a standardized report card for public and private providers. People also wanted information about consumer satisfaction with services, and wanted the ability to visit these providers at any time to inspect the services ("open-door" policy). Others suggested the need to obtain information about service providers from other families through family support groups.

What kind of appeals process should we have in place to ensure that your family member is receiving appropriate services and public subsidies?

The public talked about the need to develop an appeals process that is clearly defined and easy to understand, accessible at the local level, and expeditious. Stakeholders should be involved in developing the appeals process. There needs to be consistency in the administration of appeals across the state. Consumers and their advocates need to be informed of the process. Several people also talked about the need to involve outside advocates, such as an Ombudsman, legal aid, or an outside advocate available to represent the consumer in the process; although at least one person talked about the need to have an informal process not involving the courts or lawyers.

How can we involve consumers in the monitoring and oversight process?

People talked about the need to involve consumers and family members directly in the oversight process. The State can include consumers into human rights/advisory committees or boards, give the consumer more control over hiring and firing staff, and seek their input through questionnaires, and public meetings.