

**South Carolina
Home and Community
Based Services
Task Force**

THE HONORABLE JOE WILDER, CHAIR



REPORT

SUBMITTED TO

Governor Jim Hodges

August 31, 2001

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South Carolina Home and Community-Based Services Task Force Report

I. INTRODUCTION

The decision in Olmstead v. L.C. provided South Carolina and many other states a unique opportunity to examine the status and progress of its services for persons with disabilities and to plan for an improved system that responds to the needs of its citizens with disabilities. The process broadened the dialogue among all stakeholders including state agencies, providers, consumers, families, advocates, and state government. This report summarizes the process, findings, and recommendations to be presented to Governor Jim Hodges.

The process has highlighted the continuing need to bring together agencies, service providers, caregivers, and people who need long-term care and assistance services to design programs that will work. The Task Force realizes that people with disabilities and their family members have vast practical knowledge of what it takes to enable persons with disabilities to function in the community, and the Task Force hopes that this effort will give persons with disabilities the power not only to direct their own lives but also to influence political decisions, so that everyone is able to live in the most integrated environment possible.

I. BACKGROUND

The Olmstead Decision

The case of Olmstead v. LC was brought by two women in Georgia whose disabilities included mental retardation and mental illness. At the time of the suit, they both were living in state-operated institutions despite the fact that their treatment professionals had determined that they could be appropriately served in the community. They claimed a right to receive care in an integrated setting based on Title II of the Americans with Disabilities Act of 1990 (ADA) which guarantees that states are to administer their services and programs “in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (28 CFR 35.130(d)).

In its ruling in June of 1999, the US Supreme Court stated that “Unjustified isolation . . . is properly regarded as discrimination based on disability.” “[H]istorically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem. . .” The Court, therefore, ruled that states must provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: (1) the state’s treatment professionals determine that such placement is appropriate; (2) the affected persons do not oppose such treatment; and (3) placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state supported disability services. The Court cautioned that nothing in the ADA condones the termination of institutional settings for persons unable to handle or benefit from community settings and that the state’s responsibility, once it provides community-based treatment to qualified persons with disabilities, is not boundless.

Under the ADA, states are obliged to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity” (28 CFR 35.130(b)(7)). Fundamental alteration of a program takes into account three factors: the cost of providing services to the individual in the most integrated setting appropriate; the resources available to the state; and how the provision of services affects the ability of the state to meet the needs of others with disabilities.

The Court suggested a state may be able to demonstrate it has met its "reasonable modifications" obligation if it shows that it has "a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings, and a waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated."

II. PURPOSE

The purpose of this effort is to respond to the Olmstead decision and to enable individuals with disabilities to live in the most integrated setting. In a letter dated January 14, 2000 from the U.S. Department of Health and Human Services, the directors of the Center for Medicaid and State Operations and Office for Civil Rights stated that the “recent Supreme Court decision in Olmstead v. LC” 119 S.Ct.2176, (1999), provides an important legal framework for our mutual efforts to enable individuals with disabilities to live in the most integrated setting appropriate to their needs. The Court’s decision clearly challenges us to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community based-services.” The letter further asserts that “no one should have to live in an institution or a nursing home if they can live in the community with the right support. Our goal is to integrate people with disabilities into the social mainstream, promote equality of opportunity and maximize individual choice.”

Governor’s Executive Order

In November 2000, Governor Jim Hodges issued Executive Order #2000-26 (See Appendix A) establishing the South Carolina Home and Community-Based Services Task Force. The Executive Order charged the Task Force to “develop a comprehensive, effectively, working plan as recommended by the United States Supreme Court in its recent decision in Olmstead v. LC.” Specifically, the Task Force was to:

1. Conduct a comprehensive review of all services and support systems available to persons with physical, mental or developmental disabilities in South Carolina. This review shall analyze the availability, application, and efficacy of existing community-based alternatives for persons with physical, mental, or developmental disabilities. The review shall focus on identifying affected populations, improving the flow of information about support services in the community, and removing barriers that impede opportunities for community inclusion.
2. The Task Force shall ensure the involvement of consumers, parents of consumers, advocates, providers and relevant agency representatives in developing the report.
3. Submit a comprehensive written report of findings to the Governor by [September 3, 2001]. This report will include specific recommendations on how South Carolina can improve its services for persons with physical, mental, or developmental disabilities by legislative, administrative, or agency action.
4. The plan shall contain a timeline for implementation.

The primary purpose of the Governor's Executive Order was to assemble a broad-based, representative group of stakeholders who were familiar with and committed to South Carolina's service delivery system and the people it serves, in order to develop a comprehensive plan in response to the Olmstead decision. In addition to responding to Governor Hodges' charge in his Executive Order, the Task Force, committed to improving services for individuals with disabilities, included recommendations that should be considered as the service delivery system moves into the future.

III. PROCESS

The South Carolina Home and Community Based Services Task Force is comprised of 33 members representing state agencies, service providers, consumers, families, advocates, and members of the SC Legislature. Appendix B provides a complete list of Task Force members. Paramount to the task was the involvement of key stakeholders in all stages of the process. In order to involve a broader group of stakeholders and to accomplish a thorough examination of services, the Task Force was divided into three workgroups that parallel the three state government organizational units that are the major providers of services to persons with disabilities in institutional and community settings. The Department of Disabilities and Special Needs (DDSN) serves persons with autism, brain injuries, spinal cord injuries and similar disabilities, and mental retardation and related disabilities. The Department of Mental Health (DMH) serves persons with mental illness, and the Department of Health and Human Services (DHHS) serves persons who are aged or have physical impairments and in most cases are also poor. Each workgroup was co-chaired by the agency's representative and a consumer, family member or advocate. Each of the Workgroups held formal meetings over a five month period, reviewed previous studies and data presented by the agencies, and conducted a survey and/or focus groups to gather input statewide regarding needs and recommendations.

The DDSN Workgroup was composed of approximately 30 members who represented the cross section of stakeholders referred to in the Governor's Executive Order. Appendix C provides a complete membership roster. This DDSN Workgroup conducted an opinion survey of consumers, family members, and those who were still on waiting lists. Approximately 900 surveys were completed. The survey questions also guided the discussion in most of the 12 focus groups that were held throughout the state involving 175 participants. The survey and a summary of the results may be found in Appendix C of the DDSN Workgroup Report.

The DHHS Workgroup included 30 members representing a broad array of agencies, providers, consumers, families, and advocates. Appendix D provides a complete membership roster. Five (5) focus group meetings were conducted including one in a nursing home and four with consumers living in the community. Minutes of the Workgroup meetings and records of the focus groups may be found in the DHHS Workgroup Report.

The DMH Workgroup included 23 members representing state agencies, providers, families, consumers and advocates. Appendix E provides a complete membership roster. This Workgroup reviewed previously conducted studies related to persons with mental illness and conducted 10 focus groups around the state. The studies they reviewed are referenced in their Report. The DMH Workgroup also included information from an interagency committee focused on children's issues.

In July – August 2001, the Task Force conducted four public hearings. On June 18th, South Carolina’s Educational Television station hosted a two-hour statewide teleconference using nine technical colleges as local viewing sites. Questions or comments could be made via telephone to a panel of Task Force members. Two-hour local public hearings were conducted in Columbia and Greenville on July 31st, and in Beaufort on August 9th. Approximately 200 people participated in the public hearing process. Additional public comments were made in writing. The public comment period was open for the entire month of July to enable as much consumer and provider input into this report as possible. The information gathered was incorporated into the final report before it was submitted to the Governor. A complete record of the public comment is provided in Appendix F.

IV. PRODUCT

Several products were developed as part of this process. Each of the three Workgroups produced a report of its work, findings and recommendations. Each of the Workgroup reports provides more detail and may be obtained from the state agency whose representative co-chaired the Workgroup. See Attachment G for contact information to obtain the workgroup reports. This document is a comprehensive report that integrates the three Workgroup reports with public comments and the full Task Force recommendations. This report serves as the beginning of South Carolina’s response to the Olmstead decision.

V. PRINCIPLES

Agreeing that all people with disabilities should have the widest possible range of options for their own lives, the following set of “core principles” were developed to guide the Task Force in reviewing the state’s existing services and in making recommendations for changes or additions:

Nurturing Human Potential. We should invest in a quality of life for all citizens that will maximize their ability to care for themselves and each other and to contribute their unique talents and experiences to the community.

Choice and Self-determination. Individuals should have a broad range of service options from which to choose, including the amount, kind, duration and location of services, to fit their individual needs and desires. Funding for services should follow the person.

Autonomy and Consumer-direction. Individuals should be in charge of their lives, with the power to decide which services they receive and the right to direct their own services if they choose.

Flexibility. The system should reduce red tape, streamline regulatory and legal restrictions and expand eligibility criteria, whenever possible, and package services and funding in a manner that serves the individual and public good.

Respect and Dignity. Services should be sensitive to the values, needs, and concerns of individuals and families, including cultural differences, family roles, and personal relationships so that all individuals are treated with dignity.

Integration. Individuals should not be limited to disability-specific services and should have opportunities to participate fully in the life of their communities, including recreation, housing, work, volunteer opportunities, commerce, transportation, religious services and political activities.

Empowerment. Individuals, families, and advocacy organizations should be enabled, educated, and organized to have a voice in the planning and delivery of services.

Equity. Necessary services should be available and accessible without regard to geographic location, race or ethnicity, gender, age, or socioeconomic status.

Availability. Comprehensive, integrated services should be available based on need. Quality of services and personnel should be uniform throughout the state enabling equal access to services needed.

Prevention. Services should be designed to respond quickly and appropriately to prevent worsening conditions such as family crisis, caregiver burn-out, job loss, isolation, exhaustion of resources, poverty, homelessness, institutionalization, malnutrition, abuse, neglect, medical decline, and functional loss.

Quality. The system should attract and retain high quality personnel by ensuring a living wage, benefits, and decent working conditions for hands-on service providers.

Health and Safety. People should be secure in their own lives. Individuals should be provided the resources, support and information they need to understand personal health and safety risks and make informed choices. They must not be exposed to neglect, abuse, or exploitation. They should have high quality health care. Ensuring the personal security and well being must not sacrifice the right of individuals to live everyday lives of their choosing in the community, exercise choice and pursue their dreams and aspirations.

Responsiveness. The design and delivery of services should accommodate change, evolve with experience, and remain open to innovation and new ideas.

Efficiency. Systems should be in place to prevent fraud and to ensure that the public investment provides the greatest possible benefit to those being served, supplementing rather than replacing existing resources.

Accountability. Quality, effectiveness, and satisfaction should be systematically measured, and effective mechanisms should be provided to deal with disputes and consumer complaints. The appeals process should be efficient and clearly explained to consumers and families.

Advocacy. Advocacy resources should be available to individuals and families to assist them in understanding their rights and the services available to them.

Cultural Competence. The system should be knowledgeable about cultural differences, values and their impact on service delivery, in order to train competent personnel and develop methods to ensure equal access to services and effective delivery of services.

II. CURRENT LONG-TERM CARE DELIVERY SYSTEM

The majority of long-term care services in South Carolina are funded and/or delivered through three state agencies: the Department of Health and Human Services (including the Bureau of Long-term Care Services and the Bureau of Aging Services), the Department of Disabilities and Special Needs and the Department of Mental Health. Although many other state agencies and local providers are essential elements of the community-based service system, most of the data included in this report were provided by these three major agencies.

A. BACKGROUND AND HISTORY

For the past three decades, and most significantly in the last decade, South Carolina has been transforming from an institutionally-based system of long-term care services to an expanded community-based system of care. As South Carolina has increased its community-based options, populations in all state-operated long-term institutional settings have been declining and the number of individuals served in the community has increased.

In 1979, the State developed one of the first national research and demonstration programs using Medicaid funding. This project, called Community Long-term Care (CLTC), began in three upstate counties and expanded statewide in 1983 through a waiver. Throughout the 1980s and 1990s, CLTC expanded its services and the number of consumers who could be enrolled. In 1988, a similar waiver program was developed for persons with HIV disease, and in 1994, a waiver was developed for persons who are dependent on mechanical ventilation.

On a federal level, the passage of OBRA 1987 brought a number of significant nursing home reforms. South Carolina implemented the development of a Pre-admission Screening and Annual Resident Review (PASARR) system statewide to assure that persons with mental illness or mental retardation are not inappropriately placed in nursing facilities; implementation of a certified nurse aide testing, training and registry system; and development of a comprehensive resident assessment process for nursing facility residents.

In the last ten years, DDSN's four regional centers have gone from a bed or residential capacity of approximately 2,000 in 1990 to 1,100 in 2001. In the same period, persons served in the community nearly doubled from 12,000 to 23,000 (this includes all types of services, not just residential). These same trends are mirrored by the decrease in community Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR) group settings, and a dramatic increase in those consumers participating in the Medicaid Home and Community Based Waiver Programs for individuals who have mental retardation and related disabilities (MR/RD) or head and spinal cord injuries (HASCI).

The national movement in the mid-1960's and 1970's toward community mental health services resulted in DMH developing the initial components of a comprehensive, statewide network of Community Mental Health Centers that is now the centerpiece of the state's mental health system. In the mid-1980's, the average number of patients in all DMH facilities was approximately 3,200 with 1,200 in the two psychiatric long-term care facilities. In 1989, DMH created a Transition Leadership Council which developed the Toward Local Care (TLC) programs to transition individuals from the inpatient facilities to the community.

Since 1992 with the assistance of TLC and traditional placements, one long term psychiatric facility closed with a reduction of the census of two long-term facilities from 1,200 to 250 presently. With funds allocated by the state legislature and with the shifting of resources from inpatient to community, continued development has occurred to allow the creation or expansion of the TLC initiative. DMH has used a survey process to identify inpatient needs and requested proposals identifying models to serve these consumers from community mental health centers. This commitment to the process has exemplified system planning of state and local stakeholders and the programmatic implementation of assertive, individualized, team and consumer-driven services demanded by the latest research and the needs of individuals with severe and persistent mental illness.

As the South Carolina system of services has matured, the idea of institution versus community may have been an artificial distinction that needs to be reframed to the concept of in-home and out-of-home placement. Institutional services are but one of a series of options meant to match specific choices and needs with a corresponding level of expertise in care. Similarly, today there are widely different levels of community residential options than in the past. The key to out-of-home placement is the match of choice and need to expertise. It is less about a specific site of service than that the needed services are available, responsive, and that individuals and families are able to choose and control those services.

II. OVERVIEW OF CURRENT SERVICES

This section provides a brief overview of South Carolina's long-term care services provided through the three major state agencies that provide long term services. A detailed description of each agency's programs and services can be found in each respective Workgroup's report.

Department of Health and Human Services (DHHS)

The Bureau of Long Term Care Services is primarily responsible for the administration of Medicaid funded long term care options, both institutional and home and community-based services. Eligibility is determined and case management services are provided through 14 CLTC area offices, serving multiple counties.

The Aging Network consists of the State Office (Office of Senior and Long Term Care Services, Bureau of Senior Services), ten regional offices called Area Agencies on Aging (AAA), and local service providers. This network, created through the federal Older Americans Act, provides a broad continuum of home and community based services designed to assist older adults to maintain their independence and dignity.

In addition to the services provided through the local programs, the Bureau of Senior Services and the ten AAAs provide services to persons residing in long term care facilities. *The Long Term Care Ombudsman Program*, mandated both by federal and state law, protects the rights and quality of life of such persons by receiving and investigating complaints on behalf of residents. Complaints range from quality of life issues to serious abuse, neglect and exploitation. Approximately 4,000 complaints were investigated in the last federal fiscal year.

Department of Disabilities and Special Needs (DDSN)

DDSN has statutory responsibility to plan, develop, coordinate, and fund services for people with autism, brain injuries, spinal cord injuries and similar disabilities, and mental retardation and related disabilities. Not all individuals with these disabilities are eligible for services. Eligibility is based on severity of need and limitations on activities of daily living. In the case of mental retardation and related disabilities, age of onset must be prior to age 22. Statewide, DDSN provides services to most eligible people in their home communities through contracts with 39 local service provider agencies, called Disability and Special Needs (DSN) Boards. Each local DSN Board serves as the initial entry point and the single planning and service coordination point for all local services funded by DDSN.

DDSN uses a Person-Centered approach that gives South Carolinians with disabilities and their families more choice and control in the services and supports they receive. Consumers and families can use the resources allocated to them in ways that make sense to them. If consumers are not satisfied with their services, they may choose another provider with the DDSN funding available to them.

Historically, funding has gone to agencies in a lump sum to pay for programs. Services in that program were “bundled” by the agency, and consumers filled “slots” in programs that provided multiple services. When programs were funded in this way, consumers could decide to fill a slot or not attend that program. If they decided not to, the consumer and family had no money under their own control with which to go to another service provider. In the current system, the funding is assigned to the consumer (not the agency or program) and the consumer decides which provider or providers, within their funding band, will provide their services.

DDSN utilizes a multi-faceted approach to assure that quality services are being provided, whether in the community or in the regional centers. The principles of Continuous Quality Improvement guide DDSN in determining whether services and service providers are meeting expectations. The primary measure of quality and success is how the person with the disability and the family view the responsiveness of the system. DDSN has been working closely with The Council on Quality and Leadership in Supports for People with Disabilities (The Council) to further evolve its system of quality improvement, and to shift the focus of quality monitoring from process measures to outcome measures emphasizing personal outcome measures as defined by the primary consumer, and as a direct reflection of consumer satisfaction.

Department of Mental Health (DMH)

South Carolina is one of the few states in the nation in which all of the community mental health centers (CMHCs) and most of the psychiatric inpatient facilities in the state are directly run by the state department of mental health (DMH). DMH serves consumers with mental illness in all 46 counties through 17 comprehensive community mental health centers. Each CMHC serves multiple counties and is the point of intake for that geographic area. Each center is governed by a local administrative board that operates within DMH policies and guidelines.

Presently, DMH serves an active caseload of 56,817 consumers in its 17 community mental health centers and 1,706 patients in its seven in-patient facilities (five psychiatric facilities and two nursing care centers). In Fiscal Year 2000, the centers provided service to 92,331 consumers and

the inpatient facilities served 13,807 patients. DMH has approximately 5,500 employees and 7,000 volunteers.

It is important to note that the 1999-2000 Annual Statistical Report: Community Mental Health Centers shows that: the total number served in the CMHCs are increasing, adult caseloads are declining but child and adolescent caseloads are increasing, the majority of consumers are Medicaid eligible, and the vast majority of living arrangements are independent living or with family.

In all counties, there is hospital emergency room access to non-DMH psychiatric hospital services with varying levels of expertise in handling psychiatric emergencies. Community mental health centers investigate local private and public treatment approaches and options prior to offering a state treatment facility. The latest annual figures show that DMH staff participated in the diversion of 4,939 admissions to local hospitals. However, commitment laws mandate inpatient treatment if a person exhibits a danger to him or herself or others; and when local hospitals or treatment facilities cannot accommodate the individual, state treatment facilities are utilized.

Informal Supports

Even with the array of services in South Carolina, as in all states, most people who need support in daily life depend primarily on help from family and friends, usually without pay. Recent studies report 85% of all home care is provided by family and friends. Nearly one out of every four households (23% nationally) cares for persons fifty years old or older. Approximately 364,804 family caregivers of adults in South Carolina provide 339.6 million hours of caregiving per year (Peter Arno, Ph.D. and Margaret Memmott, March 1999 study for *Met Life*).

Approximately 72% of informal caregivers are female, shouldering the responsibility when a spouse, parent, adult child, or other relative becomes disabled. Traditionally, women cared for their children without pay or outside assistance. Increasingly, however, women work outside of the home. Often women are the sole or primary bread-winner for their families. Families of children who develop in predictable stages from infancy to independent adult can find appropriate services, such as day care, school, and mentoring programs. However, parallel supports often do not exist for children who do not fit the expected norms, such as children who continue to need daily assistance as they grow up, or who acquire disabilities and need assistance later in life.

The social benefit of the assistance provided by families and friends has not been sufficiently valued in our society. Although difficult to quantify, Arno et al (1999) estimates the value of unpaid caregiving for adults in South Carolina to be \$2.777 billion per year. Additionally, 270,000 children in South Carolina have one or more diagnosed special needs. Some of these families must provide care 24 hours a day, 7 days a week with no breaks.

The devastating costs also have not been sufficiently recognized. The daily commitment necessary to care for a loved one with severely disabling conditions can result in emotional, social and financial stresses and health problems for the informal caregivers, who may also be elderly. Due to accumulated physical and emotional stress, caregivers may become unable to meet needs. Some costs that cannot be measured in dollars include:

1. The caregiver has reduced opportunity to work, earn, and contribute to the economic welfare of the family and society. Unpaid care is a financial hardship to many families and contributes to the social problems associated with poverty.
2. People with disabilities lack choices in who provides assistance and have limited control over how services are given.
3. People with disabilities and their caregivers can feel trapped. Relationships are complicated by dependence, obligations, and power. People with disabilities may be forced into, or forced to stay in, unwanted or abusive relationships as the price for getting bathed, fed, etc.
4. The economic and emotional pressures of unpaid caregiving can lead to social isolation, burnout, neglect, and abuse.

Despite these pressures, many families and other informal networks do survive and provide a decent quality of life for people needing assistance. In today's economy, it is increasingly unreasonable to expect families and friends to "take care of their own," year after year, without support. Families change. Caregivers age, die, and become disabled. Economic pressures reduce the ability to donate labor.

The present system offers more choices for family caregivers and persons needing assistance through community based services. However, many remain unable to access the services needed to allow them to remain in the community. Premature or avoidable institutionalization may result when individuals have to remain on a waiting list for community-based services or when caps on services prevent the provision of the range of services needed for the individual to remain in the community. Additionally, families who do not meet the financial criteria for the Medicaid waiver program for community-based services may not be able to afford the full cost of private pay services. This may result in premature institutional placement as a private pay patient who rapidly depletes assets to pay for nursing home care and then depends upon Medicaid to pick up the cost of continuing placement.

Table 1. South Carolina's Home and Community-based Services

Program	Admin. Agency	Services	Population Served/ Number Served	Wait list	Budget
Medicaid Waiver Programs (All participants must meet Medicaid financial eligibility criteria and level of care.)					
Elderly and Disabled (E/D)	DHHS/CLTC	Case management, personal care, home-delivered meals, adult day health care, nursing services, environmental mod., institutional or CRCF respite, personal emergency response, diapers/underpads. Companion & attendant services are consumer/family-directed with 360 users as of April 2001.	18 or older with disability or elderly; meets nursing home level of care. <hr/> Fed. FY 99-00 – 14,487 served	3,341 (As of April 1, 2001)	\$76,043,628
HIV/AIDS	DHHS/CLTC	Case management, personal care, home-delivered meals, private duty nursing, foster care, environmental mods, two additional prescription drugs, diapers/underpads, nutritional supplements. Companion and attendant services offered as consumer or family-directed services.	All ages diagnosed HIV+ or who have AIDS and are at risk for hospitalization. <hr/> Fed. FY 99-00 – 1,073 served	None	\$2,585,582
Ventilator Dependent	DHHS/CLTC	Personal care, private duty nursing, additional prescription drugs, personal emergency response systems, environmental modifications, additional durable medical equipment and supplies.	21 or older, dependent on mechanical ventilation, nursing home level of care <hr/> CY 1999 – 32 served	None	\$658,852
Mental Retardation and Related Disabilities (MR/RD)	DDSN	Day habilitation, supported employment, residential hab., prevocational hab., homemaker services, environmental mod., respite, personal care aide, durable medical equip/assistive tech., prescription drugs, audiology, speech/language, adult companion serv., PT, OT, psych. services, nursing, adult dental, adult vision, vehicle mod.	All ages with mental retardation or related disabilities who meet ICF/MR level of care. <hr/> FY 00-01 – 4,300 served	None	\$115,700,000
Head and Spinal Cord Injury (HASCI)	DDSN	Respite, personal emergency response, nursing, psych. Services, communication services, PT, OT, attendant care, prescription drugs, specialized supplies/modifications, residential hab., day hab.,	Head, spinal cord injuries or similar disabilities who meet ICF/MR or nursing facility level of care.	203	\$9,400,000

		prevocational hab., and supported employment.	FY 00-01 – 423 served		
Program	Admin. Agency	Services	Population Served/ Number Served	Wait list	Budget
Medicaid State Plan services					
Home Health Services	DHHS through contracts with 85 providers	Intermittent skilled nursing, physical, speech and occupational therapies, home health aide, and medical supplies	Infants through adults who meet specific medical criteria. Homebound req. removed 3/01. <hr/> FY 99-00 avg 2,552 served each month	N/A	\$15,923,103
Hospice	DHHS, contracts with 38 providers	Optional state plan service that meets the medical, physical, psychosocial and spiritual needs of the patient; and the psychosocial needs of the family and caregiver.	Persons who are terminally ill <hr/> FY 99-00 – Avg 106 served each month	N/A	\$2,590,427
Children's Personal Care	DHHS	Personal care services	Children birth-21 st birthday who meet nursing home level of care <hr/> FY 99-00 – 437 served	N/A	\$1,596,760
Other services					
Optional State Supplement	DHHS, <hr/> DSS Elig	Assist with basic living needs not covered by SSI. Provides room and board in Community residential care facilities(CRCF)	Low income living in (CRCF) <hr/> As of 4/1/01 – 4,300	None	\$16,800,000 state dollars
Palmetto Senior Care	DHHS admin. Medicaid portion	Special community-based demonstration project in 2 counties that provides a package of services including all acute, preventive, social and long term care services. Centered around five adult day health centers.	Frail elderly (55 and older who meet nursing home level of care) <hr/> Currently 360 enrolled	None	\$865,800 --- \$2405/mth/per; Medicaid/ Medicare demo. waiver
Aging Network Services					
Area Agencies on Aging (10)	DHHS, Bureau of Senior Services	Transportation, home care, nutrition services and health promotion	Persons 60 and older, and in certain cases, persons under 60 (e.g, child being	1600 for meals; 1600 for home	Federal/state. Federal dollars have not increased

	(BSS)		cared for by 60+ year old FY 99-00, 29,000 served	care	in 10 years
Program	Admin. Agency	Services	Population Served/ Number Served	Wait list	Budget
Alzheimer's Resource Coord. Center	DHHS, BSS	Coordination of programs, information resource to persons and their caregivers	Persons with Alzheimer's and related disorders and their caregivers	N/A	
Family Caregiver Support Program	DHHS, Bureau of Senior Services	Multi-faceted and coordinated systems that provide information, assistance, counseling/support, respite and supplemental services	Caregivers for persons 60 or older; older caregivers of children with disabilities under age 19	N/A	\$1,400,000 Older Amer. Act. Begins in FY 01-02
Disabilities and Special Needs Services					
Disability and Special Needs (DSN) Boards (39 local providers)	DDSN through contracts	Services may include: prevention, STEPS family planning, public educ., early intervention, daycare, extended day services, genetic eval. & counseling, respite, family stipends, summer day camp, rehab. support, behavioral support, job coaching, job enclaves, supported employment, mobile work crews, center-based day services, supervised living, community training homes, service coordination	Persons of all ages with mental retardation (age of onset must be prior to age 18), related disabilities, autism, brain injuries, spinal cord injuries and similar disabilities (age of onset must be prior to age 22)	871 for day services 1531 for comm. resident services	\$265,000,000 (As of 6/30/01)
Mental Health Services					
Community Mental Health Centers (17 serve multiple counties to provide services statewide)	DMH	Comprehensive centers (main facility, clinics and outreach programs) usually provide: emergency & screening services, day treatment, consultation, education, prevention, inpatient services, child and adolescent services, elderly services, outpatient services, alcohol/drug abuse services, community support program, intensive case management, supported employment programs, living skills, outreach or Toward Local Care (TLC) programs	Adults in the community needing mental health services	N/A	\$102,051,041

Program	Admin. Agency	Services	Population Served/ Number Served	Wait list	Budget
Children's Services	DMH/ CMHC	Medication monitoring, individual, group and family therapy, clinical day programming, children's day treatment, intensive in-home services, school-based services, BabyNet services, case management. The availability of these services varies across the state.	Children and adolescents needing mental health services	N/A	\$53,801,610
Toward Local Care (TLC)	DMH	Case management team provides individual/group therapy, living skills, leisure and recreation, educational programming and vocational training. Medical/dental services and other community services available based on need. Built around three supported housing options: <ul style="list-style-type: none"> • Homeshare – adult foster care placement • Supervised community apartment complex • Group living arrangements 	Individuals transitioning from a residential mental health facility.	N/A	Included in total budget for CMHC
Housing and Homeless Program	DMH & housing partners	Approximately 1000 housing units across the state for quality, affordable housing options with supportive services. Step down residential option.	Persons who are mentally ill; persons who are homeless and mentally ill	N/A	Included in total budget for CMHC, plus grants

Table 2: South Carolina's Institutional Services

Program	Admin. Agency	Services	Population Served/ Number Served	Wait list	Budget
Medicaid Nursing Facilities (Currently 152 privately operated facilities participating in Medicaid)	DHHS/ BLTC admin. Medicaid	Intermediate, skilled or sub-acute 24-hour nursing care	Medicaid eligible persons whose mental or physical condition requires services above room and board level. FY 2000-01, Expected to serve 11,084	213 (As of 3/1/01)	\$346,720,111
Four (4) State-operated Long-term Regional Residential Centers	DDSN	24-hour residential care	Severe/more complex eligible conditions: autism, mental retard. /related disabilities FY 2001 bed capacity = 1,100		\$98,000,000
State-operated Psychiatric Facilities, Acute and Long Term Care	DMH	1. Acute psychiatric and substance abuse services 2. Acute psych.serv. 3. Acute psychiatric services 4. Inpatient substance abuse treatment	1. children/adults in 13 counties. Also serves deaf and hard of hearing statewide. Capacity 185/avg. 165 2. adults (33 counties). Cap 550/avg. 227 3. children/adults (forensic & not guilty by insanity). Capacity 298/avg. 226 4. 18 or older (chem. Dep. or mental illness/subs. abuse. Cap 150/avg. 132	N/A	\$108,105,270
Three (3) State Operated Psychiatric Nursing Home/ Intermediate Care Facilities	DMH	1. psych. & skilled nursing services 2. psych. and skilled nursing services 3. psychiatric and habilitative	1. persons with mental illness & phys. disabilities. Capacity 516/avg. 503 2. Veterans (mental illness & phys. dis.) require skilled care. Cap 220/avg 212 3. 18 or older (with mental retardation and mental illness). Cap 45/Closing	N/A	\$39,739,573
Private psych. Hospital res. (funded by DMH)	Private	Emergency psychiatric care	833 licensed beds statewide with 51% average utilization	N/A	\$2,133,794
Children's out of home therapeutic services	DMH	Moderate mgmt. rehab, supervised living, sex offender treatment, intense crisis care.	Children and adolescents.	N/A	\$10,240,475
Multi-agency Children's Res. Treatment Facilities	Private/ Contracts	Therapeutic residential behav. health treatment	Children and adolescents with severe behavior or mental health problems	Varies	\$33,440,857

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III. GAPS IN THE CURRENT SERVICE SYSTEM AND BARRIERS TO COMMUNITY INTEGRATION

South Carolina has made significant progress in the last few decades in providing community-based options. However, the system of services still has gaps. There remain barriers to community integration. This section identifies the major problems that need to be addressed to enhance the ability of our citizens to live where and how they choose.

1. Assessment and identification of affected populations. There is no single, comprehensive survey indicating the number of institutionalized individuals who may meet the conditions for community services as described in the Olmstead decision. Currently no data system exists to track persons affected by the decision, including persons living in community residences, regional centers, mental health facilities and nursing homes, as well as those not presently receiving services. There is a lack of tools and procedures to assess the needs of all individuals who may want to transition out of institutions or to avoid institutional placement.
2. At present only Medicaid-sponsored applicants for nursing facilities are assessed to determine if they meet the medical criteria for nursing home placement and therefore for long-term care. Partly because of a lack of information and partly because of a lack of a formal system for early access to services regardless of pay source, by the time individuals seek long term care, they are usually in crisis. Crisis makes it more difficult to maintain the community support system by adding formal services.
3. Lack of timely identification of people most vulnerable to unnecessary institutionalization impedes pre-crisis planning that could prevent institutionalization. The following, often overlapping, categories of people may be at particular risk:
 - a. DDSN's Critical Waiting List: Individuals in precarious life situations who are likely to go into crisis without careful planning and application of resources.
 - b. DDSN's Guarded List: Consumers who have manifested an increase in unstable behavior, mental health issues, or medical condition that places them at higher than average risk of institutionalization.
 - c. Persons with aging Caregivers: Those living with family caregivers who become less able to meet needs as they get older.
 - d. Aging Consumers: As people with disabilities age, some will develop complex health conditions or behavioral challenges.
 - e. Elderly: As individuals age, health and mental capacity may decline significantly.
 - f. Homeless people with disabilities.
 - g. Children with mental and/or behavioral disorders.
 - h. People with Severe Mental Illness (SMI)/Severe Emotional Disorder (SED) in corrections, jails, juvenile facilities, state contracted community residential care facilities (CRCFs) and residential treatment facilities.
 - i. Dually diagnosed individuals (e.g., mentally ill and substance abuse).
 - j. Children Leaving Public Schools: The gaps in services between exiting the school system and entering the adult services system may increase the risk of institutionalization.
 - k. Victims of abuse and neglect.

4. Screening through Medicaid's Early Periodic Screening, Diagnosis and Treatment (EPSDT) for all disabilities, particularly mental illness, in children is inadequate to ensure treatment that will prevent worsening disabilities and placement in more restrictive settings at increased cost.
5. There is insufficient service capacity to address the "at risk" population needs, including:
 - a. Availability of local acute care hospitals
 - b. Coordination of services for individuals with single and multiple disabilities
 - c. Services specifically designed for persons who are mentally ill/chemically addicted (MICA) or substance abusing/mentally ill (SAMI), including local short-term crisis stabilization, detoxification, and outpatient treatment.
 - d. Services to seniors
 - e. Education and training to staff to provide services to consumers in the various specialty areas of disability for identification and early intervention of "at risk" of institutionalization.
6. Many South Carolinians do not have the services and supports they need because they do not meet present eligibility criteria as established in law or by agency policy or procedure (e.g., age, diagnosis, level of severity, financial, or other reasons), although their functional needs are comparable to others who are currently receiving services. Examples of groups excluded are: spina bifida, ALS, arthritis, epilepsy, cerebral palsy, muscular dystrophy, multiple sclerosis, other progressive degenerative diseases and some individuals with brain injuries.
7. Lack of adequate crisis response, intensive community-based services, a continuum of educational services and wraparound services often results in placement of children in highly restrictive settings.
8. After a lengthy stay in an out-of-home placement, returning to the community typically becomes very difficult. The barriers include:
 - a. Lack of transition coordinators with knowledge of community resources.
 - b. Lack of consumer education necessary for informed choices, especially education tailored to the individual's particular situation, cognitive ability, learning style, and need for experiential opportunities to try out community integration.
 - c. Loss of personal resources, e.g. the individual no longer has a home, financial resources, close connections with family and friends, or a functioning community support system.
 - d. Decline in coping skills and functioning due to lack of use in the institution.
 - e. Family fears that the relative will be "dumped" or they will be forced into caregiving roles against their wills. Families may reasonably object to any process that seems to stir up false or unrealistic hopes.
 - f. Delay between time of discharge from nursing home and start of community services (e.g., home modifications, assistive technology, durable medical equipment, and case management).
 - g. State policies that do not allow a "bed-hold" for sufficient time for the individual to test movement back into the community. People may not attempt a move to the community for fear of losing their nursing home bed if return is not successful.
 - h. Lack of financial incentives for facilities to help residents return to the community.

- i. Inadequate interagency planning and coordination around children's needs, particularly for children who return to their homes.
9. There is no system of interim residential services for children who are ventilator dependent. No step down process from the hospital to home exists leaving many in the hospital because there is no where else to go.
10. There are insufficient intermediate care facilities (CARF Accredited) for traumatic brain injury survivors forcing many families to go out of state for services.
11. Waiting lists are of particular concern in the Olmstead decision. At present, there remain lists of people in the community who are awaiting services. Others in need of community services have not been identified or placed on a list. Because waiting lists are not maintained for all services, it is difficult to measure unmet needs and some individuals remain unable to access necessary assistance and support.
12. There is insufficient service capacity to address consumer needs. As increasing numbers of individuals leave institutional placements for the community, the demand for community services will increase.
 - a. Rural areas are particularly likely to have shortages of services, due to the lack of workers and the cost of transportation to the rural areas.
 - b. For individuals able to pay for their own services, there is no easy way to access these services.
 - c. Despite the passage of the Americans with Disabilities Act and other civil rights laws, goods, services, and accommodations offered to the general public often remain inaccessible to people with disabilities and the frail elderly. Lack of access to such mainstream services as housing, transportation, work, and recreation increases demands on the specialized disability-services system and increases the need for personal assistance and supports.
 - d. People with disabilities and older persons are disproportionately likely to be poor, and therefore, have difficulty finding affordable housing and services. Public benefits, including Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are often insufficient for independence.
 - e. Agencies have divided children into medical, educational, developmental, and emotional components rather than viewing the child as a whole, within the context of his/her family. Specific areas of concern include:
 - Lack of focus on the family;
 - Lack of accessible services statewide;
 - Lack of accountability for state agencies;
 - Inflexible/inadequate funding; and
 - Lack of coordination between agencies.
13. The current system in which service coordinators are employed by provider agencies, in some instances, fosters a more narrow understanding of services, creates a potential conflict of interest, and impedes coordination of services for individuals with single and multiple disabilities.

14. There are insufficient numbers of qualified professional staff in the community to work with children and adults with various disabilities. There is little empirical data to identify areas of greatest use, demand, and need. However, specific shortages exist in:
 - a. Nurses throughout the nation and in South Carolina.
 - b. Physicians and dentists both in terms of geography (rural and inner-city areas) and in terms of their training/expertise in working with children and adults with lifelong disabilities.
 - c. Occupational, physical, and speech therapists in some areas of the state.
 - d. Behavioral support personnel adequately trained in: appropriate functional assessments of behavior, development of behavior support plans (BSP), training for staff and families who implement BSP, counseling, psychiatric services for assessment and medication management, crisis stabilization, and community mental health services.
 - e. Supports statewide to allow children to take part in social, recreational, and vocational activities essential to their development.
 - f. Staff trained to assess, identify and work with children with co-occurring disorders.
 - g. Wraparound service workers statewide.
 - h. Trained school personnel to work with children with emotional/behavioral disorders.
 - i. Number of available local acute care hospital beds.

15. In the face of increasing demand, there is a shortage of direct care workers to assist and support people living in the community. Specific barriers to recruitment, retention, and training include:
 - a. Low wages and lack of benefits.
 - b. Insufficient training in various specialty areas of disability and lack of a statewide system of paraprofessional training for direct care and in-home workers that would provide a "career ladder" for career growth and development.
 - c. Medicaid rate increases for in-home services have not kept up with increases for nursing home reimbursement.
 - d. Regulatory restrictions create barriers to individuals who wish to recruit, select, train, and supervise their own personnel.

16. Many consumers and families do not have sufficient information about their choices, what services are available, how to access services, and their rights. Even when information is available at traditional health care settings such as doctors' offices and hospitals, it often is geared more toward institutional placement than community alternatives.

17. Although progress has been made in enhancing choice and funding consumer or family-directed service options, barriers continue to limit choice:
 - a. Lack of awareness of the choice and control that consumers and families do have and insufficient education on how services are funded. For example, many consumers and families need more understanding of how the multi-service DSN boards hold monies "in trust" for the consumer (with the obligation to use it to pay whatever agency actually provides the service) and provide multiple services that can be separated and selected one at a time by the informed consumer and family.
 - b. Lack of qualified service providers from which to choose. While current service providers meet many needs, the lack of many varied options prevents the exercise of true choice.

- c. The service delivery system generally does not allow consumers to recruit, select, train and supervise the people who work with them, including those who provide assistance of the most intimate nature. While some consumers, given the choice, might delegate part or all of their authority to an agency (including using an agency for some tasks and self-directed staff for other tasks), there is no true choice without other options.
 - d. The potential conflict of interest when service coordinators work for the same agency that provides direct services can limit the choices and information consumers have.
 - e. Current Medicaid home and community-based waivers and programs funded by the Older Americans Act do not fully utilize self-directed care options allowed by the federal Department of Health and Human Services.
 - f. The federal Center for Medicare and Medicaid Services still does not allow many forms of self-directed care, such as a true "cash and counseling" option in waiver programs. This option would allow care recipients to direct the spending of fixed amounts of service dollars and receive counseling as needed to assist their care planning.
 - g. Variation in people's capacity to choose is a common issue, with difficult legal and ethical implications. While it can never be presumed that an individual is incompetent to make his or her own choices, many people needing long term care are in fact incompetent or have significantly impaired mental capacities, and many of these have no formal guardian or other surrogate appointed.
 - h. Lack of use of the Health Care Power of Attorney and Patient Self-Determination Act to enable consumers to have advanced psychiatric directives.
18. Employment opportunities for people who need long-term services and supports are limited.
- a. There is an over-reliance on artificial work settings, such as sheltered workshops and not enough development of more integrated employment opportunities such as supported employment and other services to support real work settings.
 - b. Insufficient employment opportunities for people with disabilities, including recovering mental health consumers.
 - c. Consumers must negotiate government regulations to work, yet continue to receive benefits to afford treatment, medication and services.
 - d. There is inadequate attention to the vocational needs of youth with disabilities.
19. For those who do not work, there are insufficient meaningful day activities with variety such as: educational, vocational, volunteer work, day center activities, leisure and recreation.
20. There is insufficient capacity in rehabilitation programs, like clubhouses, to address the needs of mental health consumers in the community and of consumers leaving institutions.
21. Family/Caregiver and Other Natural Supports. The DDSN Olmstead Survey and the SHARE Consumer Survey are consistent with other studies in confirming that most people prefer to live at home with their families. This choice is also the most cost-effective alternative for the service system. However, many consumers lack adequate natural supports and many families/caregivers are unable to meet all needs.
- a. Family, friends, and other volunteers continue to provide the vast majority of services to persons needing assistance with activities of daily living. Traditionally, the prevailing view has been that families have an obligation to "take care of their own" rather than rely on more formal services. However, unpaid informal services are vulnerable to such forces

- as economic hardship, burnout, failed relationships, distance, crisis, lack of training, and death and disability of caregivers.
- b. Many consumers do not have a network of support, and do not have the knowledge or resources to develop this network on their own.
 - c. Negative stereotypes strain natural support systems. For example, an individual with mental illness may not tell the support system about their need for treatment for fear of being stigmatized.
 - d. Lack of support for families is a major reason that children are placed outside the home. Many parents report losing jobs because of the demands made on them to care for their children.
22. Respite is the need most frequently cited by families with children with disabilities. Often, what it takes to prevent families from "throwing in the towel" is an occasional break from the caregiving role. Respite is not a luxury, but an essential component in maintaining a person in the natural home, and is especially crucial for single primary caregivers. Barriers to respite include:
- a. Insufficient capacity of emergency, backup, and basic respite services, both in terms of trained, quality providers and the money to pay them.
 - b. Federal prohibitions from using Medicaid dollars to pay family members for respite services that restrict the family's ability to care for member with a disability.
23. Persons with disabilities cannot take full advantage of advances in assistive technology that can enhance gainful employment, communication, and independence in self-care, mobility and other areas. Manpower, information and financial resources are insufficient to:
- a. Educate consumers and families of new developments in this field;
 - b. Assess the needs to match the person with the proper assistive device;
 - c. Provide the funding streams to acquire the device;
 - d. Provide training in the use of the device; and
 - e. Repair and maintain the assistive devices.
24. Without adequate transportation, consumers may be living in a community, but remain isolated. This is not true community integration.
- a. Even in metropolitan areas, public transportation is not well developed in South Carolina. In rural areas, it is virtually non-existent. Most public transportation systems that do exist are not fully accessible to people with disabilities and do not comply with the Americans with Disabilities Act.
 - b. Medicaid funded transportation, per federal regulations, is restricted to medical services. It is often not available or accessible at the times needed.
 - c. Available options are limited even for persons able to afford to pay for transportation.
 - d. Curb-to-curb transportation does not meet the needs of many persons needing assistance and door-to-door transportation is even more difficult to arrange. Escort services are not generally included in transportation.
25. Inadequate housing and residential supports severely inhibit choice and the ability to transition to the community for all age groups and all disabilities. Specific barriers include:
- a. Lack of financial resources or special short-term assistance. Often people with disabilities have incomes limited to SSI and do not have the resources to pursue many choices in

- housing. For example, 76% of DMH adult consumers live below the poverty level and could afford no more than \$214/month for housing and utilities.
- b. Lack of appropriate or accessible housing (i.e., ramps, accessible bathrooms and accessible kitchens) can pose serious health and safety threats to individuals with disabilities moving into the community from institutional settings.
 - c. Insufficient supported housing and service programs to meet the demand to transition long-term or high recidivist consumers.
 - d. Housing programs that do exist, such as the Housing and Homeless Program, are not always available statewide. Every county has waiting lists for both conventional and Section 8 units.
 - e. Lack of alternative housing providers at the local level limits consumer options/choice.
 - f. Lack of coordination/partnership at the local level in funding decisions. The multiplicity of local governmental entities and funding impedes consumer input in decision-making process.
 - g. Lack of housing options for young people with disabilities to live together. Too often, they are placed in boarding homes or group homes with individuals who are much older.
 - h. Lack of adequate monitoring of boarding homes by DHEC to ensure quality.
26. Misinformation and negative public attitudes continue to be a significant barrier to building community resources and community integration particularly for consumers with mental illness or developmental disabilities. For the recommendations of the Governor's Task Force to be received positively, the public and the Legislature will need to become aware of:
- a. The background issues and legal precedents established by the Olmstead decision;
 - b. The needs of individuals with disabilities and their families;
 - c. The benefits to society when adequate services are provided and costly, unwanted institutionalization is prevented.
27. People with disabilities experience enormous stigma. The media often fuel this attitude by misrepresenting and sensationalizing the issues, for example feeding the unfounded public belief that people with mental illness are dangerous criminals. Agencies, consumers, and families experience the NIMBY (not in my backyard) attitude. Community opposition delays and complicates development of essential programs, including residential options.
28. Children with special needs, even more than adults, need to be supported and nurtured in a family home environment. As they undergo developmental stages, they are more malleable than adults, either for healthy or unhealthy influences. They are especially vulnerable during times of transition and change. Gaps and barriers specific to children with special needs include the following:
- a. Lack of system coordination that is child-focused rather than policy or agency focused which is supported and reinforced by current funding structure.
 - b. The educational system is the primary agency that interacts with all children and it is not a key player in the process.
 - c. Significant gaps for families who don't meet agency eligibility criteria.
 - d. Lack of appropriate service, residential and support options to maintain children in home community.
 - e. Inadequate and inflexible funding to provide community-based services (e.g., children in the mental health system do not qualify for existing Medicaid waivers).

- f. Inadequate resources devoted to children's services result in many gaps.
29. South Carolina's Nurse Practice Act restricts choice of providers and inhibits community integration for many consumers needing support with medication administration and other unskilled and skilled procedures such as routine tube feeding, routine catheter care, and bowel programs. Nurse delegation, as allowed under current law, has not been widely used to provide for the skilled needs of long term care recipients in the community, leading to higher costs and lower availability of services.
 30. While attempts have been made, South Carolina still does not have mechanisms in place easily to share or coordinate information across agencies as needed to improve services and accountability. Infrastructure issues between and among agencies related to varying computer systems, databases, and tracking of consumers, are barriers to improving standardization and consistency across agencies.
 31. Sufficient resources have not been applied to ensure comprehensive quality assurance, to include a foundation of health, safety, financial stability and integrity, and respect for individual rights and preferences. There is not general agreement on how to measure outcomes nor how to address consumer satisfaction, safety, and choice. For example, because uniform measures of success of mental health programs are just beginning and not widely used, it is difficult to evaluate program effectiveness and allocate resources.
 32. There is no independent complaint resolution process for persons receiving long-term care services in the community.
 33. The Long-term Care Ombudsman Program has not been given adequate resources to timely and appropriately investigate complaints in nursing homes.
 34. Because agencies that provide in-home workers are not subject to licensure, there is no oversight apart from that provided by DHHS Medicaid and aging efforts and no way for consumers to get information about legitimate agencies.
 35. Lack of information on services, how to access them, and the choice and control that consumers and families have results in potentially eligible persons not receiving services. Accurate and updated data is essential for identifying and documenting the need for further service development. This is consistent with the responsibility for planning of state agencies.
 36. Funding issues continue to limit access to services and choice.
 - a. South Carolina Medicaid funding for Long Term Care through its five waivers and nursing home coverage is based on the medical diagnosis and the location of care rather than focusing on the need for long term care services. The type and amount of services, and the time waiting for services are all dependent, to some degree, upon which of these options is available and chosen by long term care recipients, rather than by their needs:
 - Some waiver programs have no waiting lists while others require waiting for up to several months.
 - Some waiver programs offer more service options due both to Center for Medicare and Medicaid Services cost effectiveness requirements and to state funding levels.

- Funding for Medicaid nursing home coverage and waiver services are in separate budget lines, leading to possibly funding the location of service rather than the need.
- b. Although DDSN has implemented a "money follows the consumer" policy within its institutional consumer population who want to move to the community, implementation of this policy is not uniform in the service delivery system; and in general, institutional and community services are separate categories in the state budget.
37. South Carolina's Medicaid State Plan does not include all possible service options or eligibility categories allowed in federal regulations. While South Carolina provides many elective services, the following services and coverage groups are not included:
- a. Personal care services and private duty nursing (in-home as well as in other settings), are available to children; adults may receive these services only through certain Medicaid waiver programs.
 - b. South Carolina does not include the Medically Needy Program. This option extends Medicaid eligibility to individuals who have more income than allowed under the usual eligibility standards, but who have incurred medical expenses that are equal to or greater than the difference between their income and the usual eligibility standards.
 - c. While DHHS has added the Working Disabled eligibility option, there were only 80 recipients enrolled in this category as of March 1, 2001. In addition, South Carolina has not applied for the grant under the Ticket to Work and Work Incentives Improvement Act (TWIA) to cover working individuals who have specific impairments that are likely to lead to disability.
 - d. Medicaid waivers do not currently include all allowable services.
38. While there has been a considerable lessening in the restrictions of federal rules, there are still a number of ways in which these regulations are biased toward institutional care or otherwise limit choices.
- a. States are required to provide nursing home care but must get a special waiver for comparable in-home care services. Along with increasing administrative efforts for home based care, this means that home and community-based services are more at risk in times of budget problems than nursing home care since the State is not required to provide waiver services.
 - b. Federal prohibitions on the payment of Medicaid dollars directly to family members for the services they provide to a family member with a disability impact the family's ability to provide the needed care over an extended period of time.
 - c. Collection of functional assessment data is required by the federal government as part of the Minimum Data Set (MDS). However, state Medicaid agencies do not have access to the data that could be used for planning and de-institutionalization efforts.
 - d. Medicare provides very little funding for in-home services, often with a requirement that the individual be categorized as home-bound. Medicare also provides little nursing home coverage and no pharmacy coverage.
 - e. Federal regulations for applying for waiver opportunities excludes state psychiatric facilities for persons 18-64 years of age due to the Institute on Medical Disease (IMD) category and the inability to demonstrate cost neutrality.
39. There is a lack of a continuum of long-term care options from living independently to total institutionalization. This includes both in-home services and residential options. While the

issue of quality of care in institutions is beyond the scope of this report, the Task Force has identified the following problems that should be addressed:

- a. The choices and experiences available to people who live in institutions are often limited.
- b. Difficulty recruiting and retaining direct care staff causes costly turnover and lowers the quality of services.
- c. Younger persons with disabilities (and the frail elderly) have few opportunities to live together and share services and resources.
- d. Inadequate accessible housing in residential centers for more medically involved consumers impedes mobility, care and the ability of family to spend time with the consumer. Older buildings were not designed to accommodate consumers with bulky wheelchairs and medical equipment.
- e. Children in institutional settings, including residential treatment facilities and juvenile justice facilities, lack appropriate educational, social, and recreational activities.
- f. Commitment laws, treatment provided in antiquated buildings, and lack of funding other than state mental health dollars impede efforts to control admissions of persons with mental illness.

IV. RECOMMENDATIONS

Considering the Governor's charge and the ADA's integration mandate, the Home and Community Based Services Task Force developed a vision for a continuum of care in South Carolina that recognizes the importance of choice and the value of all parts of the continuum.

I. ASSESSING NEEDS OF CHILDREN, ADULTS, ELDERLY

To supplement the assessment process carried out by the agencies, the Task Force recommends establishing an independent assessment process to offer people opportunities to live in a home or community based setting. Once a clear explanation of home and community-based services is presented, the first step in the actual assessment process should be choice: where, how, and with whom do you want to live? The next step should be needs: what will it take to make that choice possible? The question "Where and how do you want to live?" must be asked in context, explaining "If you had the option of getting help in some other setting, including a home of your own, what would you use?" Specific recommendations for both agency and independent assessments follow.

1. Agency Assessment Process

- a. All agencies providing long-term care services should incorporate Olmstead/community integration issues into their routine evaluation and planning with consumers including habilitation plans, care/service plans, person-centered plans, etc.
- b. All persons living in institutions should be assessed for their desire for community placement on at least an annual basis. This assessment should be repeated whenever the consumer or family desires. This will include assistance for persons who have communication barriers related to their disability, cultural background or primary language. The consumer's choice to continue to receive services in an institutional setting or to consider moving to the community needs to be incorporated as part of each individual's annual/routine evaluation/planning meeting. Efforts will be made to involve in this process other people chosen by the consumer such as a "circle of friends" or other

informal supports. **TIMELINE:** This will continue to be completed as part of each individual's annual program plan.

- c. The Minimum Data Set (MDS) questionnaire, which was established federally, is conducted within facilities soon after admission and at regular intervals thereafter. A "choice" question should be incorporated in the MDS process. The state should add a requirement that residents be asked during the process if they would prefer to live somewhere else. This would be an easy way to make a routine inquiry, which may identify some people who would prefer home or community based services. If the inquiry proves to be useful, South Carolina could advocate that the Center on Medicare and Medicaid Services apply it nationwide at which time it could be incorporated into the software package.
- d. DDSN will develop a "community living" curriculum designed to better inform consumers living in institutions and families on the options available to them in the community. This curriculum will include experiential learning and "real life" discussion with consumers who live in the community. **TIMELINE:** 6 months
- e. All agencies should include continual consumer education, information and training on options as part of the assessment process.

2. Independent Assessment Process

- a. As part of the state's efforts to identify persons affected by the Olmstead decision and new consumers entering the service system, an independent assessment process is recommended. Although each population may have special needs, it is recommended that an assessment process focusing on consumer needs and strengths across agencies and disabilities be developed. Instead of viewing the consumer through the lens of agency criteria, the assessment will identify consumer desires and needs as evidenced by presenting and underlining issues that have emerged; and the desired and needed treatment, services, and supports.
- b. South Carolina should develop an assessment process and assessment plan that includes participation of stakeholders. Consumers, family members, advocates, public and private service providers and all affected state agencies should have at least one representative at the planning table. The following public services are essential for persons with a disability and should be involved in the development of this process: transportation, education, vocational rehabilitation, employment, alcohol and drug, housing, health (medical, mental and physical), and finance. This body would develop the plan and protocols for identification and assessment.

II. THOSE CURRENTLY IN INSTITUTIONAL SETTINGS

Those who want to move from institutions to the community need to be able to do so. South Carolina should ensure that persons with disabilities living in state-operated institutions or privately operated nursing homes who have a desire to move to the community have alternatives suited to their desires and needs, including health, safety, and community integration.

1. Transitioning to the Community

- a. All persons living in institutions who have indicated their desire to move to a community setting should move to the community within one year. The community options should be suited to their needs including health, safety and community integration.
- b. There needs to be a clear and accountable structure for the placement process into the community. For DDSN consumers, Regional Transition Coordinators (RTCs) who are knowledgeable about community services and supports, should be designated for those moving to community options. The Transition Coordinator should work with the individual and the family to identify which specific services/supports are needed to support the person in their new home. They should also identify what services are currently not available in the community that the person requires. This information should be relayed to the appropriate regional office and used to update the “Unmet Needs List” to assist in planning for the development of additional service/ support capacity. TIMELINE: Within 1 month of placement decision
- c. A “transitioning to the community” orientation program should be prepared to help Regional Transition Coordinators educate consumers and their families who have decided to move into the community and are in the process of making service/support decisions. TIMELINE: 6 months
- d. DDSN should maintain a sufficient bed reserve capacity at institutions (or another appropriate community options) to allow the readmission of people for up to 90 days whose community placement is not successful. TIMELINE: On-going
- e. DDSN should continue to plan and budget for startup costs associated with people moving from home or from institutions to the community. TIMELINE: On-going
- f. DHHS should apply for the federally funded Nursing Home Transition Grant that is intended to aid states in identifying nursing home residents interested in returning to the community and developing services and programs to assist in this return. Even without this grant, planning efforts should be developed to ensure assistance to individuals wishing to return to the community.
- g. Develop a process for identifying, assessing and setting up services. This process should be developed in conjunction with the application for the federally funded Nursing Home Transition Grant. This process should include housing and transportation options as well as in-home services.
- h. Incorporate recent federal changes to the Medicaid program. The federal Center for Medicaid and Medicare Services now give states greater flexibility in coordinating in-home services before discharge from an institution. These include home modifications and service coordination. The Medicaid program in South Carolina should adopt those changes and incorporate them in its waiver management practices.
- i. DMH should seek funding to address the current needs identified in the latest surveys of consumers in DMH hospitals who meet TLC criteria. DMH projects an additional 40 Homeshare beds, 18 Supervised Apartment beds and 366 group residential beds are needed as well as the full service package of supports including but not limited to crisis intervention/stabilization, clubhouse, supported employment, entitlement assistance, individual/group/family/marital counseling. Medical and dental services as well as other community services are required.
- j. DMH should continue to transition consumers to the community through its successful TLC process and community development opportunities. DMH should target consumers in the hospital and expand its efforts by 20% annually.

- k. Strengthen transitional planning for children to include family and natural support system members as well as representatives from all agencies involved in providing services, including educational and vocational services. The impact of the child's return home on the rest of the family should be taken into account and the transition plan should enumerate resources needed to support other family members.
- l. During times of transition for children, the agency transferring services to another agency should be held accountable for the services until the transition is complete.
- m. Coordinate efforts between the Department of Juvenile Justice and Department of Corrections and the appropriate service providing agency to ensure that the transition needs of individuals with disabilities who are incarcerated are addressed.
- n. Conduct a study on the need for and strategies for developing interim residential facilities for children who are ventilator dependent and need to transition from the hospital to home.

2. Quality Institutional Care.

- a. In an effort to enhance the quality and richness of life for those consumers who decide not to consider moving into community-based residential options, changes should be initiated (and/or continued) that should increase the range of choices and experiences available to residents in such areas as food, clothing, personalized spaces, day activities, employment, and recreation. TIMELINE: 1 year
- b. Examine residential centers to determine the best ways to improve accessibility for consumers with bulky medical equipment to facilitate quality care and quality family time.
- c. Increase funding for Eden Alternative initiatives in nursing homes. Special financial incentives should be continued so as to encourage further development of the Eden Alternative philosophy. The *Eden Alternative*TM seeks to eliminate the plagues of the long term care institution: loneliness, helplessness, and boredom. The ten (10) principles of the "Edenizing" nursing home are found in Appendix A of the DHHS Workgroup Report.
- d. Specialized units or wings of nursing homes should be targeted toward younger persons with disabilities who choose this option.
- e. Recruit, train and retain qualified direct care staff, including certified nursing assistants, by ensuring a living wage, benefits, and decent working conditions.
- f. Cross-train staff to ensure competency to work with children with co-occurring disorders.
- g. Consumer satisfaction (both child and parents) should be measured on a regular basis to monitor quality of care.

III. THOSE AT RISK OF BEING INSTITUTIONALIZED

- 1. Assessments in the community should be aimed at offering choices to prevent unwanted institutionalization and linked to a care/service plan.
- 2. All persons involved in the long term care process, including DDSN, DMH, and CLTC staff, DSS eligibility workers, nursing home social workers and hospital discharge planners should be trained to provide clear explanations of home and community-based services prior to obtaining a person's choice of location of services. An explanation of the consumer's rights and responsibilities and assumption of risks should also be done at this time.
- 3. Once a newly referred person is determined to be eligible for DDSN services, they should be assessed as to their potential risk for unnecessary institutionalization. TIMELINE: Within 1 month of eligibility determination

4. A process that designates local, regional, and state office roles and responsibilities should monitor all persons who are now at risk of being unnecessarily institutionalized. TIMELINE: 6 months; then On-going
5. For all consumers deemed to be at risk of unnecessary institutionalization, a community- based pre-crisis plan should be developed. TIMELINE: Within 6 months
6. A comprehensive, statewide Crisis Intervention & Support System should be developed in order to prevent unnecessary institutionalization, which includes community- based crisis respite beds. Details of what this system should include for DDSN and DMH can be found in their respective workgroup reports. TIMELINE: Plan- 6 months; Full implementation- 2 years
7. Special training should be made available to service coordinators in averting, minimizing and managing crises in the community. TIMELINE: 1 year
8. DHHS should assess all persons seeking nursing home placement, regardless of their funding source, prior to nursing home admission. As part of this assessment, consumers should be made aware of community alternatives and their medical and functional status as well as financing options including Medicaid eligibility criteria. While no applicant will be denied the right to enter a nursing home using his or her private funds, this assessment will ensure an informed choice is made.
9. Residential Care Facility (RCF) regulations should be amended to include levels of need so as to provide for varying degrees of independence.
10. Medicaid's EPSDT should be expanded to include a behavioral assessment in the screening to facilitate earlier identification of children with these disabilities and provision of appropriate and early services.

IV. WAITING LISTS

1. Waiting lists should be developed, maintained and monitored, including the length of time a person has been waiting for services. TIMELINE: 6 months
2. An "Unmet Needs List" should be developed and/or continued to include: a) services needed by people on a waiting list, and b) additional services needed by people who are currently receiving some services. This list should be used to allocate resources and develop additional services and supports. TIMELINE: 9 months

V. DATA SYSTEMS AND COLLECTION

1. An Interdepartmental Task Force should be convened to study the feasibility of adopting common hardware and software in order to facilitate consumer information sharing. TIMELINE: Commence 3 months
2. Databases should be maintained for consumers who are at risk for unnecessary institutionalization (e.g. consumers with aged caregivers, consumers who are reaching their

elder years, critical waiting list, guarded list, people with challenging behaviors). TIMELINE: Within 6 months; then On-going

3. A centralized database should be developed to track persons directly affected by the Olmstead decision across DHHS, DDSN, and DMH and other appropriate agencies, and to track the state's progress towards implementing all recommendations in the Governor's Task Force Plan. TIMELINE: 6 months
4. Information about the progress of implementation should be published to all stakeholders in a timely fashion.

VI. QUALITY ASSURANCE/OUTCOMES

1. The health and safety of those consumers who use facility- or agency-based services should continue to be monitored through a system of licensure. TIMELINE: Annually
2. Risk Management Committees should be established that would review data on all critical incidents; allegations of abuse, neglect and exploitation; medication errors, emergency and programmatic use of restraints; and "unexpected" deaths. TIMELINE: 3 months
3. Quality should be defined and measured in terms of the personal goals, outcomes and satisfaction of the individual consumer. Personal Outcomes measure the progress made toward improving the quality of life of the person with the disability and the quality of service provided by the organization, from the consumer's vantage point. Personal Outcomes serve as important information for individual planning, organizational self-assessment, and directing staff development. According to the work of "The Council on Quality Supports and Leadership," there are 25 Personal Outcomes that are measured. These are presented on Page 22 of the DDSN Workgroup Report. Consumer satisfaction with present services should be monitored through an organized system of surveys, group meetings, and personal interviews. TIMELINE: 1 year
4. Develop follow-up quality review and monitoring for individuals who move to the community. Monitoring of the overall quality and stability of service providers should be accomplished through an organized system of on-site visits, observations, record reviews, and interviews. Ensure continued communication between the individual and his or her providers of basic services. TIMELINE: 6 months
5. Develop a complaint system for in-home care, similar to the Ombudsman Program, to afford a simple and independent way to voice complaints about care.
6. Review DSS's Adult Protection Services program, particularly the Omnibus Adult Protection Act and the Probate Code, to determine its keeping with the concepts of autonomy as espoused in the Olmstead decision.
7. Ensure that rights are protected even in emergencies. Make sure individuals are free to report serious problems, including abuse and neglect, without fear that revealing weakness will result in their institutionalization. An emergency or failure of systems does not justify denial of civil rights. Agencies that deal with such issues must respect the right of competent adults to

assume risks and even to stay in dangerous situations. While individuals should be offered alternatives, such services cannot be forced without proof of legal incompetence. If a person is living with an abuser, the perpetrator, and not the victim, should be forced from the home.

8. Separate service plan development for service provision from monitoring to avoid potential conflict of interest.
9. DHHS should develop a Stakeholder Board. Advocates, people with disabilities, aging providers, and DHHS staff should be included in this board to provide input to DHHS in the implementation of its plan to improve home and community services. The board should meet at least quarterly to discuss the plan's progress and to provide feedback during the maintenance of these services.
10. A multi-agency/consumer/family/provider team should be established to: monitor the system, develop a mechanism for monitoring, and identify a schedule of monitoring and reporting to ensure compliance with the goals and mission of home and community-based services, and to report findings directly to the Director of the Department of Mental Health.

VII. COMMUNITY SERVICES & SUPPORTS ISSUES

1. General Issues

- a. Assessment of community resources needs to occur simultaneously with consumer assessments. A multi-system, multi-disability data collection instrument would identify duplication and gaps in services, location and types of services available and needed such as mental health, medical, vocational, educational, transportation, dental, and social/leisure needs to assist with community tenure. The assessment should identify the capacity of community services and lack of supports for children, adults, and elderly. The flexibility of service provision should be assessed to assist with the paradigm shift from program/agency centered to consumer-centered focus. **TIMELINE:** The assessment of needs and gaps analysis should be completed in one year. Planning and problem resolution in closing gaps by developing services should begin in the following year.
- b. It is highly recommended that the concept of a multi-system team of state agencies, private providers, consumers, families, and interested stakeholders continue in developing community infrastructure to address the individualized needs of consumers using the philosophy of service integration by identifying service needs across multi-disability areas.

2. Service Coordination

- a. Service coordination should be person-centered and consumer-controlled. People should have real choices and options. It is imperative that people receive information and support in making important decision about their services. The service coordinator is a vital resource in not only coordinating services, but providing information and empowering the consumer and family to have control in decisions affecting their lives. South Carolina should offer a variety of options:
 - Establish a service coordination option that is independent of the service providers. This option eliminates the potential/actual conflict of interest between service coordinators and service providers and ensures that the coordinators are accountable to

- the consumer and family. The system of independent service coordination should include multiple providers to ensure choice for the consumers. TIMELINE: 18 months
- Offer agency or facility-based service coordination.
 - Develop team coordination. Transition should be the joint responsibility of the present service provider and the future provider(s), e.g., public school works with vocational rehabilitation as an individual is aging out of the school system.
 - Self-directed service coordination where the individual is fully responsible for identifying his or her own needs, defining the services and supports that are needed, and accessing them. Training should be offered to these consumers in how to be their own advocate, how to identify and access services, how to give a medical history, how to maintain personal medical history, when to call 911.
- b. Training must be provided to all service coordinators to ensure they have the knowledge and skills to educate and assist the consumers and families effectively. This training should be provided prior to providing services to consumers and families to ensure service coordinators have at a minimum:
- knowledge of the broad array of services within and beyond their own agency and how to access those services
 - knowledge of the various disabilities/medical conditions of the consumers they serve
 - skills in the area of managing potential/actual crises in the community
 - ability to coordinate implementation of the individual service plan
 - understanding of their role in facilitating the transition of a consumer from institutional to community living as well as supporting the person in the community to be sure needs are properly identified and addressed
- c. Address recruitment and retention issues such as adequate pay, professional competencies, manageable workloads and training to develop and maintain quality personnel.

3. Direct Care (and In-home Care) Worker Recruitment, Retention, and Training

- a. Direct service providers should have a living wage, workers' compensation coverage, and benefits, to make it possible to recruit and retain quality personnel. Workers should be protected from abuses such as extensive unpaid travel time.
- b. Reimbursement rates for publicly funded in-home services should be examined. Rates should be adequate for competitive pay and benefits for direct care workers. If rates are not competitive, they should be increased. A cost of living adjustment should be made annually to keep these rates at a competitive level.
- c. Acknowledge the value of direct care and personal assistance workers. Efforts should be made to recognize the contributions of personal assistance workers and increase the prestige of their positions.
- d. Allow consumers and families more control over recruitment of providers. This would improve accessibility of in-home providers statewide.
- e. Allow the use of self-employed attendants. Self-directed care using self-employed attendants should be utilized to address shortages in the work force and to increase the individual's personal autonomy. This is particularly the case in rural areas where transportation problems can make in-home care very difficult to find.
- f. Support licensure of home health agencies through the currently proposed legislation (S.0324). This legislation should be passed.

- g. Analyze the current Medicaid State Plan and Medicaid Waivers, with the involvement of consumers, families and providers, in order to determine what additional changes need to be made to increase the availability of both direct care and professional staff services in the community, and to establish realistic funding levels. TIMELINE: 1 year
- h. Develop and implement additional strategies to overcome the barriers to direct service staff recruitment and retention. TIMELINE: 1 year
- i. Additional work force issues associated with building/expanding a community system to support people leaving the institution should be considered as the service delivery system prepares to meet the demands of the Olmstead decision.
 - How do consumers develop friendships and circles of support in the community? Direct service workers need to be prepared to assist in this effort as “bridge builders” for the consumer into fuller community involvement.
 - Staff must believe in the capabilities and potential of the consumer.
 - Increase opportunities for service provider skill development through on-going training so that they feel more confident working with people with lifelong disabilities.
 - Allow flexible working schedules and the use of part-time staff in order to facilitate direct care staff recruitment.
 - Apply the recommendations from DDSN and other agencies’ Workforce Development Committees.
 - Ensure that the workforce is diverse and reflective of South Carolina.

4. Education & Advocacy

- a. Continue to financially support the educational efforts by consumer advocacy groups and other organizations that provide information and advocacy to consumers and their families.
- b. Consumers need to have more opportunities for education in self-advocacy. The types of training and public education that should be available to consumers, community providers, and the general public in order to assure a successful transition from institutional to community-based living includes:
 - Continue to build support regarding the importance of the “circle of support” concept.
 - Use the expertise of all staff/friends/family members in assisting people who want to move from one community placement to another (i.e. community residential home to independent living with self-directed services).
 - Use parents/family members and peers as trainers in the transition process and institutional staff for follow-up consultations in the community when needed.
 - Educate communities about people with lifelong disabilities. Use real stories and people. This may be accomplished in part by establishing a “Speaker’s Bureau” staffed by consumers, family members, and advocates that would be available to civic organizations, churches, neighborhood associations, etc. to inform the public regarding the special needs and lives of people with lifelong disabilities.
 - Expand training to consumers/families about person-centeredness, rights, choices, etc.
 - Assist all consumers who desire to begin building a natural support system (e.g., circle of support); help consumers if needed in selecting members.
- c. Work with other stakeholders to develop an organized program for monitoring the safety and quality of community living options using parents, neighbors, advocates, constituent organizations, etc. TIMELINE: 1 year

- d. Additionally, consumers deserve the dignity to risk and try new things. Implied in this is also the freedom on occasion to fail. The following areas need to be considered as the service delivery system moves forward:
- Allow consumers to take reasonable risks. When a person returns to an institution from the community, an analysis should be done with the consumer, the community staff and the institution staff to determine why the person returned to the institution and what services/supports need to be in place when they return to the community.
 - Monitoring by outside entities of community placements should be done (i.e., families, consumers, citizens in the community, Protection & Advocacy, constituent organizations, civic organizations, peers, etc.). It is recommended that this system be formalized in order to assure that no consumer is left without the benefit of such a program.
 - Consumers need to have the opportunity for a private interview when giving feedback to monitoring entities about their services or supports. Also, trained consumers should conduct these interviews to provide the opportunity for consumer to consumer feedback about services.
 - Advocacy organizations need to be engaged in helping build the knowledge base of consumers and their families.

5. Employment

Greater emphasis needs to be placed on supported employment programs and services that can move a person along the independence continuum as far as they desire. Portions of this continuum may include Vocational Rehabilitation, enclaves, mobile work crews, supported employment, and independent employment.

- a. DDSN should request new funding to increase the number of community day program and/or supported employment placements available to consumers by 300 for each of the next two years in order to both reduce community waiting lists and accommodate for regional center consumers who desire to move to the community. TIMELINE: Next 2 years
- b. DDSN should prepare a Request for Proposals to expand the supported employment and “real work” opportunities available to consumers throughout the state, thus reducing reliance on the sheltered workshop model. TIMELINE: 1 year
- c. Formally evaluate disability specific and mainstream employment-related agencies such as Vocational Rehabilitation, Commission for the Blind, Job Service, vocational education, and post-secondary education as to their effectiveness in serving people with long-term care needs.
- d. Increase job coaches in every mental health care center by 50%.
- e. Increase job opportunities for mental health consumers throughout the state by 25%.
- f. Ensure accurate tracking of consumer employment is maintained on the DMH data system.
- g. Ensure that consumers have access to training, support, and advocacy to make use of the Social Security Work Incentives.

6. Day Activities

- a. DDSN should request new funding to increase the number of community day programs and/or supported employment placements available to consumers by 300 for each of the next two years in order to both reduce community waiting lists and accommodate regional center consumers who desire to move to the community. TIMELINE: Next 2 years

- b. Ensure that community recreation opportunities are accessible to people with disabilities and seniors. Ensure that consumers have access to services, supports, and assistive technology necessary to locate, travel to, and participate in the recreation and leisure activities of their choice.
- c. Implement the recommendations that are identified in the assessment of need and ensure that there are sufficient day treatment and vocational development programs available to meet the needs of mental health consumers currently in the community and consumers leaving institutions.

7. Family/Caregiver and Other Natural Supports

- a. DDSN should continue to provide information and education to consumers and their families on “essential lifestyle planning,” circles of support, choice, rights, self-advocacy, and other person-centered techniques. TIMELINE: On-going
- b. DDSN should gather more information from other states and provide financial resources to support a “Speaking for Ourselves” self-advocacy program in South Carolina. TIMELINE: 1 year
- c. Prepare additional information on service and support funding to better inform consumers and families of how monies flow and the choice and control they have in selecting and paying for services. TIMELINE: 6 months
- d. Despite this current lack of federal Medicaid match, it is still in the best interests of both the state and the affected family to use state dollars to assist families to directly meet the needs of their member with disabilities whenever possible. DDSN should request additional funding to increase services to family caregivers for the next two years. TIMELINE: Next 2 years
- e. Investigate how best to increase the monies available directly to families who support their member with disabilities in the home (e.g. “family vouchers” with state dollars; “micro boards” made up of family providers; amending the federal prohibition on monies going directly to family caregivers). TIMELINE: 1 year
- f. Financial resources should be directed to those organizations that provide consumers and families with information/education on rights, choices, and person-centered planning. TIMELINE: 6 months
- g. Develop skills in service coordinators to work with caregivers and consumers in developing contingency plans for other forms of care that can be used as caregivers age.
- h. Family members who give up other opportunities should receive reimbursement for the care they provide. This will benefit both the recipient and giver of care.
- i. Ensure that individuals and families have knowledge of and access to services currently available for caregivers, and thus reduce the stress and demands on all parties. These services include: in-home and institutional respite, adult day health care, companion and sitter services.
- j. Counseling and peer groups should be available for both caregivers and care recipients.
- k. Develop a centralized information & referral system to make information about services accessible to families and consumers. Enhance on-line information and referral systems. One method of doing this is the “211” system of phone assistance.
- l. Apply for the federal Real Choice Systems Change grant to support efforts to increase supports and flexible options across agencies and disabilities for consumers, families and other needed system changes. Even if the grant is not funded pursue these needed changes.

- m. DHHS should arrange for training for both consumers and caregivers, such training to be tailored to individual needs and desires. Caregiver training should include assistance with activities of daily living (e.g., bathing, dressing, toileting, etc.), recognition of medical problems and coping mechanisms for dealing with the stress associated with being a caregiver. Training for consumers should include recognizing and articulating their needs, supervising and directing services, selecting assistants, and dealing with problems.

8. Respite

- a. An assessment of the respite needs of all family caregivers should be undertaken. This assessment should identify the type and frequency of respite most helpful to the family. It should also identify the barriers to the development of more qualified respite providers.
TIMELINE: 6 months
- b. More funds need to be available for family members to purchase respite services. Each family that provides home support for an eligible family member needs to have access to a number of days of respite services each year to be used as the family desires. Ensure funding and standard flexibility that will allow families to access natural support systems for respite and will allow the family to receive regular and frequent respite services
- c. Ensure that respite, back-up, and emergency services are available.
 - Develop capacity in Home Health and other professional service agencies to provide on-call assistance and back-up when regular caregivers are unavailable.
 - Provide funding flexibility to individuals to make their own back-up arrangements, e.g., by allowing individuals to advance pay and/or to maintain a personal registry of aides not locked to a fixed schedule.
- d. Support efforts of the South Carolina Respite Coalition to identify and develop respite resources, training and funding strategies.

9. Assistive Technology

- a. Develop systems and resources for assistive devices (e.g. an Assistive Device Resource Center) that would be responsible for keeping abreast of new developments in the field; providing assessments to match people with devices; assisting with procurement and funding; training consumers and families on use of the device; and providing resources for maintenance and repair of assistive devices. TIMELINE: 1 year
- b. Make assistive technology available to individuals in hospitals or other facilities so they can learn how to use it before moving to the community.
- c. Maximize Medicaid and other funding for devices that can increase independence and/or decrease the need for recurring services.

10. Transportation

- a. Improve Medicaid transportation service to include door to door and escort provisions for those in need.
- b. Investigate Center for Medicare and Medicaid Services policies to determine if and how non-medical transportation can be provided.
- c. Inform consumers about non-Medicaid transportation so that they are aware of the options.
- d. In areas with public transportation:
 - Ensure that public transit systems are fully accessible and compliant with ADA mandates. This should apply to both fixed-route systems and paratransit services.
 - Seek federal funding and create mandates and incentives for accessible taxis.

- Enforce mandates with litigation and advocacy.
- e. In areas without public transportation:
 - Develop innovative transportation systems.
 - Develop lower cost, more flexible options such as direct payments to people with wheelchair-equipped vans who would be willing to provide transportation.
 - Reimburse friends and families who provide transportation with labor and mileage.
- f. South Carolina needs to improve consumer access to transportation, but not develop a program that would further isolate consumers from natural supports. The state should undertake a statewide study of the adequacy of the non-medical transportation services available to consumers. Results of this study will aid in planning and implementing additional needed improvements. TIMELINE: 1 year

11. Housing/Residential Supports

The home is the core of stability around which the rest of our lives revolve. It is a place of safety, a place of comfort, and a place to express individuality through furnishings, etc. A person can be himself or herself at home. Choices in housing should not be restricted to “institution or community,” but the philosophy of choice should reach to those individuals already living in the community who want to move to less restrictive settings. The key here, as in other areas of this report, is personal choice with real options being available. The state should promote a variety of housing/residential options:

- a. DDSN should request new funding to increase the number of community housing options available by 300 for each of the next two years in order to both reduce community waiting lists and accommodate for regional center consumers who desire to move to the community. TIMELINE: Next 2 years
- b. DDSN should identify barriers to competition in housing at the local level. Once identified, remove those barriers.
- c. Work with state, federal and private agencies/corporations to identify existing and additional funding sources to support consumers in the housing options of their choice. Advocate for funding priority from state, federal and private agencies for the development of quality affordable housing specifically for persons with disabilities. TIMELINE: 9 months
- d. Create innovative funding arrangements (e.g., pooling resources of individuals) to enable people with disabilities (young or old) to live together in their own homes.
- e. DMH Housing Development and Access Coordinator positions should be fully dedicated and funded and the number of new independent housing developed should increase by a minimum of 50 units each year statewide.
- f. DMH should increase residential opportunities by 20 beds statewide each year.
- g. Advocate for additional rental assistance to help consumers secure affordable, independent housing of their choice.
- h. Establish DMH tracking system for consumers’ utilization of conventional public housing, tenant- and project-based Section 8 housing.
- i. Establish and maintain a DMH consumer waiting list for safe, affordable, and quality housing to monitor consumer access.
- j. To the maximum extent possible, develop service delivery opportunities for seniors and people with disabilities to obtain services where they live rather than locate consumers based on location of services.

- k. Remove barriers to and provide support for home ownership as an important means of security and control.
- l. Work with state and local public housing authorities to access Section 8 vouchers for home mortgage and to waive certain other restrictions that may prevent people with disabilities from becoming homeowners.
- m. Encourage local governmental entities to include consumers and other stakeholders in the decision-making process when determining housing needs and how federal housing dollars will be spent. One way might be to establish a housing and service consortium that would include state Medicaid officials.
- n. Include local housing experts on the Home and Community Based Services Task Force to address funding for community housing initiatives during the implementation of this plan. Review the report from the Governor's Task Force on Affordable Housing.
- o. Expand funding and assistance for home modifications and assistive technology in the home to enable individuals to function as independently as possible as needs change time.
- p. Fully enforce the Federal Fair Housing Act to ensure access to private multi-family housing and prevent discrimination based on disability. One provision of this act requires zoning laws to modify the definition of "family" to include people with disabilities in congregate or cooperative living arrangements, whether a traditional group home or an informal alliance of people who choose to live together and pool resources.
- q. Modify the state building code to conform to the Fair Housing Act, Americans with Disabilities Act Accessibility Guidelines and "visitability" standards, so that most new houses would be readily modifiable when needed for disability access.
- r. Make assistance and support available to individuals in making housing choices and accessing resources. Such services could include peer counseling, help with house-hunting, financial and benefits counseling, and home safety.

12. Autonomy

- a. Review Medicaid waivers and Older Americans Act (OAA) funded services to ensure that self-directed care is utilized to the limits allowed by current federal regulations.
- b. Explore flexible funding options that support consumer and family independence and decision-making. Develop a "cash and counseling" demonstration.
- c. Enable individuals the capacity to choose. Assessments and services must be designed to accommodate a wide range of abilities and situations, and to afford each individual, including individuals with impaired mental capacities, the greatest possible opportunity to make choices for themselves. For a child or an adult with a formal surrogate (e.g., legal guardian), that surrogate must be consulted. Formal and informal service providers should be trained to respect individual choices and to reject stereotypical views such as "because an individual needs long term care, that person is unable to act as a competent adult."
- d. DMH should collect data on consumers who have developed an advanced psychiatric directive and further educate consumers about how to exercise that option in establishing control over treatment methods.
- e. DHHS should develop comprehensive personal assistance and support services for people in need of long term care, recognizing that the following elements are critical to making these services effective:
 - Consumer direction: Because of the intimate nature of care that is provided, people with severe difficulties should have a greater opportunity to self-direct personal

assistance. As a matter of choice, every individual should have the right to self-direct personal assistance as follows:

- Recruiting and selecting assistants
- Training assistants
- Directing what services are performed, when, and how
- Terminating assistants

Some consumers will prefer to delegate some or all of these functions to a care provider (e.g., assisted living or group home staff or home care agency). Others will want to direct their own care. For individuals who choose to self-direct (select and manage their own assistants rather than using the traditional agency or service model) under Medicaid or Medicare, DHHS should, as appropriate, authorize at least one fiscal agent to serve as employer of record for payroll purposes. The consumer would assume the legal risk of injury to person or property. This option will also be offered to people who cannot direct their own care but who have a trusted person able and willing to direct services on their behalfs, such as the parent of a minor child living at home, the duly authorized adult child living with a senior with dementia.

- Flexibility. Personal assistance and supports are intended to assist the individual in doing what he or she cannot do without assistance. Thus, the services should be defined by the individual, based on day-to-day needs and choices. While some definition of duties will be needed, the system should afford maximum flexibility. Flexibility in care plans and schedules should be maximized.
- Availability of Quality Personnel
 - Home health agencies and other professional providers must be carefully monitored for screening, training, and quality assurance. Consumers must have safe and effective mechanisms to register complaints. Sanctions should be imposed against agencies that persist in failing to honor service contracts or deliver quality services. Individuals should have prompt and effective remedies if injured or forced to spend out-of-pocket because of agency failures.
 - People self-directing services should have the flexibility of hiring unlicensed and uncertified personnel to carry out their directions. Such flexibility will expand the personnel pool by allowing individuals to recruit and retain quality personnel.
 - People self-directing services should have access to funding at the reimbursement rates to agency providers, less actual costs incurred by a fiscal intermediary, to ensure that most of the funding goes to hands-on services.
 - Current regulatory restrictions that prohibit reimbursement of family caregivers should be relaxed to allow individuals this choice and to make it economically viable for the family.
 - Services and supports should be defined broadly enough to allow individuals free choice in the care of their bodies, the management of their homes, their relationships and associations, their work and how they spend their time.

13. Increasing Consumer and Family Choice, and Control

- a. Increase the number of service and support providers throughout the state in order to provide consumers and families with more choice and control. TIMELINE: 1 year
- b. Create and make available a listing of qualified providers, identifying the types of services and the location in the state where they would provide them. TIMELINE: 4 months

- c. Make consumers and families aware of all service options. Consumers and families should be involved in all service planning and monitoring activities and should be involved in choosing service providers. This policy should be implemented in all service agencies.
- d. Hold ongoing discussions with the Center for Medicare and Medicaid Services to determine how they interpret current regulations and what options are available to states. As federal regulations become more flexible, changes should be made at the state level.
- e. Minimize risk and maximize personal choice. Much of the danger and abuse that occurs in both institutional and community settings results from the individual's isolation, powerlessness, and lack of control. When individuals are capable of understanding risks, the system should offer information and choices. There is every reason to think that if we give individuals and families the resources and supports they need, they will do the best possible job of ensuring safety.

H. OTHER SIGNIFICANT ISSUES

1. Public Awareness & Support

- a. Each agency should prepare a brief pamphlet on the Olmstead decision and its implications for South Carolina to inform the general public of these issues. TIMELINE: 3 months
- b. Continue to educate the public about the facts of mental illness through DMH's public relations campaign and through partnering with advocacy groups.
- c. Educate the public about disabilities, the needs of consumers and families and the abilities of individuals with disabilities. Promote the benefits of investments in community-based services and the long-term economic impact of those initial investments.

2. Information/Identification of Eligible Unserved

- a. Ensure the public's access to information about public and private service resources by licensing of agencies (not individuals) and distributing registers, enhancing information and referral services, web sites listing available services and registries.
- b. Authorize cross-departmental studies with reports and public hearings on the following topics: cross departmental information sharing on eligible service recipients; cross departmental service and responsibility sharing for multiply eligible service recipients; and cross departmental planning to provide for a continuum of care as service recipients age. TIMELINE: 1 year

3. Children with Special Needs

The following recommendations are made in addition to the recommendations related to children's services throughout this report:

- a. Develop and implement policies, procedures, and systems that outline and provide continuous, integrated services to children with special needs from the time of identification of the disability (e.g. referral of infants (by pediatricians) to early intervention and pre-school services, to school age day program (and where necessary, residential) to transition from school to adult services. TIMELINE: 1 year
- b. Develop and implement, or refine, policies and procedures that would mandate coordinated care for children across agencies. Serious consideration should be given to utilizing existing structures such as the Interagency System of Care for Emotionally Disturbed Children (ISCEDC) teams to regularly staff children in institutional settings or at risk for placement in institutional settings.

4. Amend the Nurse Practice Act

- a. Amend the Nurse Practice Act in order to implement a Medication Administration Technician Certification, as well as to authorize the delegation of other specific routine procedures to specially trained direct care staff. TIMELINE: 1 year
- b. Create an exception from the definition of nursing for self-directed (supervised by the consumer or family) attendant services provided in the community.
- c. Collaborate with the Board of Nursing to implement recommendations that were developed in 1997 by the Long Term Care Committee of the Human Services Coordinating Council to address the following as related to the delegation of tasks:
 - Encourage schools of nursing to include data on delegation in their curricula.
 - Provide a brochure about delegation to be mailed to currently licensed nurses.
 - Provide materials on delegation to employers of unlicensed assistive personnel.
 - Develop a training component on skilled nursing tasks.These recommendations should be implemented for those who choose to use nurse-delegated services.

5. Currently Ineligible Groups

- a. Identify gaps in needed services for individuals who are not presently eligible under existing programs (e.g., progressive degenerative diseases, some brain injury), and develop additional services for those persons.
- b. Conduct a study to determine the impact (i.e., numbers of people involved, costs and funding request) of using functional limitations rather than diagnosis or other medical category as the eligibility for specific services, waiver programs, etc.
- c. There should be no caps on the number of people served and no provision that services may be denied because it would be less costly to confine the individual in an institution.

6. Funding Services

- a. Monitor waiting lists to justify increases in funding.
- b. Agencies, advocates, and family members should engage in a coordinated effort to educate legislators and policymakers about the relative costs of institutional care and community-based care as well as the efficacy of care in these settings. This should include economic analysis demonstrating the potential long-term cost savings following short-term cost increases as community services are developed to provide the infrastructure necessary for successful transition.
- c. Laws should be added to enhance tax incentives for long-term care insurance. This type of insurance allows individuals to plan ahead for long-term care needs. Educational efforts need to be made so that individuals are aware of the availability of and benefits of long-term care insurance.
- d. Long Term Care insurance and medical insurance currently available in the market should be reviewed for institutional bias and opportunities found to increase consumer control and community integration and to prevent unwanted and unneeded institutionalization. Based on this review, work with private insurance carriers of medical and long term care insurance to support community alternatives equal to acute care and to include parity for mental health services.

Medicaid Funding for Long Term Care

- e. A phased approach should be developed to coordinate services and service levels across waiver programs. This approach should have the goal of equalizing service packages and waiting lists (should they exist) so that home and community-based waiver services are based upon need rather than condition. This approach will require coordination on the state level and approval from the federal level.
- f. Coordinate and merge the availability and funding for nursing home and waiver services. Recognizing that nursing homes will continue to play an important role in the continuum of care, and that there is a cost to maintain facilities and staff, a phased approach should be developed to coordinate and merge the availability and funding for nursing home and waiver services. The goal of the approach should be to develop a system which integrates funding streams so that long term care applicants are able to have the money follow them rather than reside with the nursing home or waiver program.
- g. Eliminate waiting lists. Medicaid funding should be allocated so as to fully fund the long term care system, with the goal of providing long term care services without a waiting list regardless of the location of the care.
- h. Advocate for sufficient funding to serve individuals wherever they choose to live. Funding should follow the individual, not be attached to beds.
- i. Advocate for increased reimbursement limits to providers to ensure Medicaid coverage is sufficient to promote a continuum of care. Increased limits would encourage more providers to accept Medicaid.
- j. Institutional providers should have the opportunity, and be encouraged, to adapt to a new service delivery environment.

Expand South Carolina's Medicaid Options

- k. Include personal care services and private duty nursing services as options in the Medicaid state plan.
- l. Include the Medically Needy eligibility category option in the Medicaid state plan.
- m. South Carolina should apply for a grant under The Work Incentive Improvement Act (TWIIA) that provides funds for health care services to certain people who are disabled.
- n. Fully implement TWIIA to allow Social Security recipients to retain Medicaid and other vital benefits when they obtain employment.
- o. Investigate and incorporate all appropriate options for expansion of Medicaid services and coverage. DHHS should continue to investigate all options for expansion in Medicaid services and coverage groups, to include, but not be limited to, such options as comprehensive rehabilitation for brain injury and spinal cord injury consumers.
- p. Initiate an outreach effort to increase the number of Medicaid recipients enrolled in the Working Disabled eligibility category.
- q. Promote professional education in disabilities and the aging process for all medical/health professionals (e.g., physicians, dentists) so they will serve all populations effectively.
- r. Ensure that medical providers comply with the nondiscrimination and accessibility provisions of the Americans with Disabilities Act.
- s. Revise Medicaid regulations to accomplish specific recommendations in this report.
- t. Maximize use of Medicaid outreach funds. Because 75% of people with long term care needs typically become Medicaid eligible after exhausting resources, Medicaid outreach

funds can go a long way to funding other assessments for those persons who are currently accessing nursing homes with private-pay funds.

- u. DMH should increase the pace for the process of transitioning patients from its facilities. It should also examine ways to restructure the current inpatient system. The possible closing of an ICF/MR facility and combining service across other inpatient facilities are being pursued. A percentage of the savings expected from closing of wards and restructuring the inpatient system will be allocated for home and community based activities to DMH Transition Council for oversight of implementation of enhanced community programming.
- v. DMH should negotiate the buying of existing, but vacant, waiver slots from DDSN to assist with the mentally retarded/mentally ill population. This action would increase community capacity, but would not generate reoccurring revenue for cost shifting purposes.
- w. Pursue block grant funding and explore additional grant funds for activities related to Olmstead, community reintegration, and crisis diversion.
- x. Pursue the development of a home and community-based waiver for children, elderly, and individuals with mental retardation/mental illness.

7. Federal Regulations and Practices

Federal regulations need to be more flexible as they pertain to the elderly and persons with disabilities. South Carolina should support the following changes in federal regulations/laws:

- a. Make home and community-based services a required service under Medicaid so that they have the same standing in federal Medicaid policy as does institutional care.
- b. States should have access to MDS data that will enable them to be able to identify nursing home recipients desiring to return to the community and assess their needs.
- c. Remove the home-bound restriction as a requirement of receiving in-home services under Medicare. Federal legislation is now pending.
- d. South Carolina should support amendments in the Social Security Act to:
 - Raise or eliminate the level at which an individual is presumed to be capable of substantial gainful employment and thus ineligible for benefits.
 - Increase financial security for poor people with disabilities, e.g., by increasing resource limits for SSI and Medicaid.
- e. Review federal regulations and laws to identify those that prohibit authorization of innovative community and home care services.
- f. Pursue policy change in Medicaid waiver criteria to include acute care and long term care consumers, 18-64 years of age, in state IMD psychiatric facilities. This would free up state funds and increase ability to obtain federal funds.

8. Oversight and Plan Modification

- a. The Task Force should meet semi-annually at the call of the Chair to monitor agencies' progress and refine the plan. All affected agencies and other public entities should cooperate fully with this periodic analysis and implementation of the plan.
- b. Those state agencies that have external governing bodies should ensure that those entities are fully informed about the Olmstead decision, South Carolina's Home and Community Based Services Plan, and the respective agency's responsibilities under the plan. Those agencies should periodically share information with their respective governing bodies to

facilitate cooperation in monitoring efforts to support implementation of activities in the Home and Community Based Services Plan.

- c. Annual reports should be made by each of the affected agencies of their progress in implementing the recommendations of the Governor's Task Force. At the same time, agencies may make recommendations for plan modifications. TIMELINE: Annually
- d. DHHS, DDSN and DMH should prepare a cost analysis and timeframe for implementing the recommendations in this report. Such analysis should include:
 - Identification of services and strategies
 - Costs, both state and federal, with future projections
 - Potential sources of funding
 - Proposed planning and implementation dates and priorities
 - Reporting requirements
 - Outcome measures
 - Potential changes in state laws, regulations, practices and federal waivers
- e. DHHS should prepare a study to determine the impact of health care, Medicaid, and Older Americans Act dollars on South Carolina's economy.
- f. Executive/Legislative Support for the following studies is necessary to enable much needed interdepartmental efforts to improve home and community based services:
 - i. Inter-departmental information sharing to provide services to consumers that cross agency lines needs to be effectively coordinated. One of the problems in identifying eligible populations under the Olmstead decision is the fact that some may have needs served by more than one agency. For example, people with head injuries may be identified by DDSN, DHHS, or DMH. For a comprehensive plan to be effective, it is essential for these departments to identify and eliminate barriers to sharing consumer information. This could be achieved by an interagency agreement on how persons who have similar types of needs and are served by more than one agency have their services properly coordinated.
 - ii. Inter-departmental Service Sharing: After a more complete identification of eligible populations has taken place, history has shown that some of these individuals may have multiple needs that can best be met by services that span the traditional administrative structures of state government. They may have medical/ nursing needs, residential and employment needs, mental health/ counseling needs, as well as other needs. Affected departments need to identify and eliminate barriers to the sharing of appropriate consumer services.
 - iii. Continuum of Care/Transition Planning Throughout Life: An executive or legislatively authorized study may be helpful to examine the potential lapses that may occur as an individual progresses through the natural age cycles of life. For example, what are the barriers to identification, information sharing, and service continuity between early intervention/pre-school and entrance into the public school system? The same question needs to be asked as an eligible person ages out of public school and into the adult services world that is more prone to use waiting lists. Lastly, as a person reaches their elder years, with their associated problems, are there provisions for "aging in place" and receiving the services and supports that will maintain a person as close to

their own home as possible for as long as possible? There is a need to ensure continuity in care and support.

V. CONCLUSION

South Carolina has the basic foundation for a continuum of care that allows a person the choice of receiving services in the community or, when necessary, in an institutional setting. However, funding is a key issue along that continuum. Our deliberations and discussions around the state indicate that there is broad public support for the basic idea that individuals should have the choice of receiving necessary services and supports in the community. Many individuals and families are extremely frustrated by their current situations and afraid of what will happen in the future. Even many individuals and families who are happy with the choices they have made express regret that more choices are not available.

Many of the concerns we have heard center on safety. We need to educate the public to the fact that nothing in Olmstead or this report will force individuals out of facilities, if they feel that a facility is the best option for them. We also need to demonstrate that, while complete safety is never possible, appropriate community services and supports can provide a safe environment for seniors and persons with disabilities outside of the institution.

The final message is that people with long-term care needs are entitled to equal freedom, choice, and respect. Although they need assistance in some areas, in other areas they may be fully competent, capable, and in control. Service delivery systems need to identify the strengths and abilities of these people as well as their needs, and avoid the stereotypes that depict them as helpless, dependent and childlike. The best public education will be to develop systems that integrate seniors and persons with disabilities into the community. They will be the best messengers.

