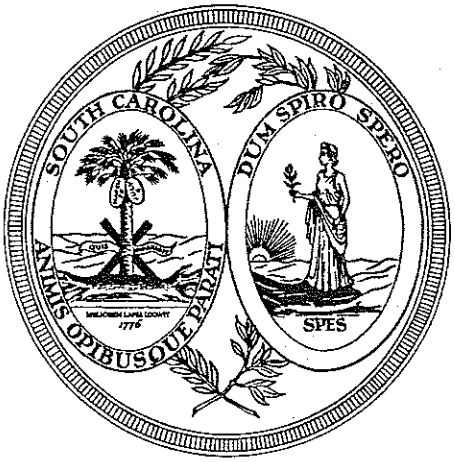
South Carolina Home and Community Based Services Task Force

THE HONORABLE JOE WILDER, CHAIR

REPORT

SUBMITTED TO

Governor Jim Hodges



August 31, 2001

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EXECUTIVE SUMMARY

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South Carolina Home and Community-Based Services Executive Summary

The decision in Olmstead v. L.C. (119 S. Ct. 2176, 1999) provided South Carolina and 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 stakeholders including state agencies, providers, consumers, families, advocates, and state government. This Executive Summary highlights the recommendations presented to Governor Jim Hodges.

The Olmstead Decision: The case of Olmstead v. LC was brought by two women in Georgia who had both 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. In June of 1999, the US Supreme Court 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.

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 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."

Process: The South Carolina Home and Community Based Services Task Force is comprised of 33 members representing state agencies, providers, consumers, families, advocates, and members of the SC Legislature. 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 agencies that provide the majority of services to persons with disabilities in institutional and community settings: (1) Department of Disabilities and Special Needs (DDSN), (2) Department of Mental Health (DMH), and (3) Department of Health and Human Services (DHHS).

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.

A. 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?

B. 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 placement into the community.
c. A "transitioning to the community" orientation program should be prepared to help 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.
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.
e. DDSN should continue to plan and budget for startup costs associated with people moving from home or from institutions to the community.
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.
g. Develop a process for identifying, assessing and setting up services.
h. Incorporate recent federal changes to the Medicaid program that give states greater flexibility in coordinating in-home services before discharge from an institution.
i. DMH should seek funding to address the current needs identified in the latest surveys of consumers in DMH hospitals who meet Toward Local Care (TLC) criteria.
j. DMH should continue to transition consumers to the community through its TLC process targeting consumers in the hospital and expand is 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.

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 increase the range of choices and experiences available to residents in such areas as food, clothing, personalized spaces, day activities, employment, and recreation.
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.
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-occuring disorders.
g. Consumer satisfaction (both child and parents) should be measured on a regular basis to monitor quality of care.

C. 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 should be trained to provide clear explanations of home and community-based services prior to obtaining a person's choice of location of services.
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.
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.
5. For all consumers deemed to be at risk of unnecessary institutionalization, a community- based pre-crisis plan should be developed.
6. A comprehensive, statewide Crisis Intervention & Support System should be developed in order to prevent unnecessary institutionalization.
7. Service coordinators should be trained to avert, minimize and manage crises in the community.
8. DHHS should assess all persons seeking nursing home placement, regardless of their funding source, prior to nursing home admission.
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 Early Periodic Screening, Diagnosis and Treatment should be expanded to include a behavioral assessment in the screening to facilitate earlier identification of children with disabilities and provision of early services.

D. WAITING LISTS

1. Waiting lists should be developed, maintained and monitored
2. An "Unmet Needs List" should be developed and include: a) services needed by people on a waiting list, and b) additional services needed by people who are currently receiving services. This list should be used to allocate resources and develop additional services and supports.

E. 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.
2. Databases should be maintained for consumers at risk for unnecessary institutionalization.
3. A centralized database should be developed to track persons directly affected by the Olmstead decision across DHHS, DDSN and DMH; and to track the state's implementation progress.
4. Information about the progress of implementation should be published to all stakeholders in a timely fashion.

F. 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.
2. Risk Management Committees should be established to review data on all critical incidents; allegations of abuse, neglect and exploitation; medication errors, emergency and programmatic use of restraints; and "unexpected" deaths.
3. Quality should be defined and measured in terms of the personal goals, outcomes and satisfaction of the individual consumer.
4. Develop follow-up quality review and monitoring for individuals who move to the community.
5. Develop a complaint system for in-home care, similar to the Ombudsman Program.
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.
8. Separate service plan development 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.
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.

G. 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.

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. South Carolina should offer a variety of options including independent, agency-based, team coordination and self-directed service coordination.
   b. Training must be provided to all service coordinators prior to serving consumers and families to ensure they have the knowledge and skills to educate and assist the consumers and families effectively.
   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. If rates are not competitive, they should be increased with annual cost of living adjustment.
   c. Acknowledge the value of direct care and personal assistance workers.
   d. Allow consumers and families more control over recruitment of providers.
   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.
   f. Support licensure of home health agencies through the currently proposed legislation.
   g. Analyze the current Medicaid State Plan and Medicaid Waivers, with consumers, families and providers, in order to determine what changes need to be made to increase the availability of both direct care and professional staff.
   h. Develop and implement additional strategies to overcome the barriers to direct service staff recruitment and retention.
   i. Additional work force issues should be considered as the service delivery system prepares to meet the demands of the Olmstead decision.

4. **Education & Advocacy**
   a. Continue to financially support the educational efforts by consumer advocacy groups.
   b. Provide consumers with more opportunities for education in self-advocacy.
   c. Work with stakeholders to develop an organized program to monitor the safety and quality of community living options using parents, neighbors, advocates, organizations, etc.
   d. Additionally, consumers deserve the dignity to risk and try new things. Implied in this is also the freedom on occasion to fail.

5. **Employment**

   Greater emphasis should be placed on supported employment programs to move a person along the independence continuum as far as they desire including: vocational rehabilitation, enclaves, mobile work crews, supported employment, and independent employment.

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.
   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 in the community and 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.
   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.
   c. Prepare additional information on service funding to inform consumers and families how monies flow and the choice/control they have in selecting/paying for services.
   d. DDSN should request additional funding to increase services to family caregivers for the next two years.
   e. Investigate how best to increase financial support to families caring for a member with disabilities in the home (e.g., "family vouchers" with state dollars; "micro boards" made up of family providers; amending federal policies on payment to family caregivers).
   f. Financial resources should be directed to those organizations that provide consumers and families with information/education on rights, choices, and person-centered planning.
   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. Reimburse family members who give up other opportunities for the care they provide.
   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.
   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.
   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 and families.
   m. DHHS should arrange for training for both consumers and caregivers, such training to be tailored to individual needs and desires.

8. **Respite**
   a. Conduct an assessment of the respite needs of caregivers to identify the type and frequency of respite most helpful to the family, and barriers to finding qualified respite providers.
   b. Make more funds available for family members to purchase respite services. Each family should have access to a number of days of respite each year to be used as the family desires. Ensure funding and flexibility that allow families to access natural supports.
   c. Ensure that respite, back-up, and emergency services are available.
   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 keep abreast of new developments in the field; provide assessments to match people with devices; assist with procurement and funding; train consumers and families on use of the device; and provide resources for maintenance and repair.
   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 all public transit systems are fully accessible and compliant with the ADA.
       - 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.

11. **Housing/Residential Supports**

    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.
    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.
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 funded. New independent housing 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. 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.
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.
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/assistance for home modifications and assistive technology in the home.
p. Fully enforce the Federal Fair Housing Act to ensure access to private multi-family housing and prevent discrimination based on disability.
q. Modify the state building code to conform to the Fair Housing Act, Americans with Disabilities Act Accessibility Guidelines and "visitability" standards.
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.
d. DMH should collect data on consumers who have developed an advanced psychiatric directive and educate them on how to use that to establish 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 effective services: consumer direction, flexibility and availability of quality personnel.

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. 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.
b. Make consumers and families aware of all service options. Consumers and families should be involved in all service planning, monitoring and choosing service providers.
c. 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.
d. 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.

H. OTHER SIGNIFICANT ISSUES

1. Public Awareness & Support

a. Each agency will prepare a brief pamphlet on the Olmstead decision and its implications for South Carolina to inform better the general public of these issues.
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 or those initial investments.

2. Information/Identification of Eligible Unserved

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.

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 provide continuous, integrated services to children with special needs from the time the disability is identified (e.g. referral of infants by pediatricians) to transition from school to adult services.
b. Develop and implement, or refine, policies and procedures that would mandate coordinated care for children across agencies.

4. Amend the Nurse Practice Act

a. Amend the Nurse Practice Act to implement a Medication Administration Technician Certification, and to authorize delegation of routine procedures to trained direct care staff.

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.

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 of using functional limitations rather than diagnosis/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 including economic analysis showing the 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. Review Long Term Care and medical insurance currently available in the market for institutional bias, and opportunities to increase consumer control and community integration, and to prevent unwanted and unneeded institutionalization. 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 equalizing service packages and waiting lists so that home and community-based waiver services are based upon need rather than condition.

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 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 in the Medicaid state plan.
l. Include the Medically Needy eligibility category option in the Medicaid state plan.
m. Investigate and incorporate all appropriate options to expand Medicaid services and coverage. One example of a needed expansion is comprehensive rehabilitation for brain injury and spinal cord injury consumers.
n. 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.
o. Fully implement TWIIA to allow Social Security recipients to retain Medicaid and other vital benefits when they obtain employment.
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.
t. 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.
u. DMH should negotiate the buying of existing, but vacant, waiver slots from DDSN to assist with the mentally retarded/mentally ill population.
v. Pursue block grant funding and explore additional grant funds for activities related to Olmstead, community reintegration, and crisis diversion.
w. 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 Minimum Data Set (MDS) data to enable them to identify nursing home recipients desiring to return to the community and to 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 Supplemental Security Income 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, ages 18-64, in state Institute on Mental Disease (IMD) psychiatric facilities.

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.

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.

d. DHHS, DDSN and DMH should prepare a cost analysis and timeframe for implementing the recommendations in this report.

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.
   ii. Inter-departmental Service Sharing: Many individuals have multiple needs best met by services that span the traditional administrative structures. Affected departments need to identify and eliminate barriers to sharing appropriate consumer services.
   iii. Continuum of Care/Transition Planning Throughout Life: A study to examine the lapses that may occur as an individual goes through the natural age cycles of life.

I. 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. There is broad public support for the basic idea that individuals should have the choice of receiving necessary services and supports in the community.

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 then 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.

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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<u>Agency Staff:</u>
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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.

A. 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."

B. 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.

C. 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.

D. 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.

E. 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.

B. 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 casesloads 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. 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. 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 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. 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., prevocational hab., and supported employment.	Head, spinal cord injuries or similar disabilities who meet ICF/MR or nursing facility level of care. FY 00-01 – 423 served	203	$9,400,000

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. 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 FY 99-00 – Avg. 106 served each month	N/A	$2,590,427
Children's Personal Care	DHHS	Personal care services	Children birth-21st birthday who meet nursing home level of care FY 99-00 – 437 served	N/A	$1,596,760
Other services					
Optional State Supplement	DHHS, 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) 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) 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 (BSS)	Transportation, home care, nutrition services and health promotion	Persons 60 and older, and in certain cases, persons under 60 (e.g., child being cared for by 60+ year old FY 99-00, 29,000 served	1600 for meals; 1600 for home care	Federal/state. Federal dollars have not increased 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: • 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). Cap550/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. Cap220/avg212 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

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 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 (TWIIA) 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.

A. 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.

B. 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 is 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*™ seeks to eliminate the plagues of the long term care insitution: 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-occuring disorders.
g. Consumer satisfaction (both child and parents) should be measured on a regular basis to monitor quality of care.

C. 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.

D. 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

E. 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.

F. 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.

G. 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 paridigm 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 behalves, 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.

G. 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 or 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**
   1. 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
   2. Create an exception from the definition of nursing for self-directed (supervised by the consumer or family) attendant services provided in the community.
   3. 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**
   1. 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.
   2. 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.
   3. 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**
   1. Monitor waiting lists to justify increases in funding.
   2. 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.
   3. 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.
   4. 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 reoccuring 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 then 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.

APPENDIX A

Executive Order No. 2000-26

Jim Miles
SECRETARY OF STATE
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State of South Carolina

Executive Department

Office of the Governor

EXECUTIVE ORDER NO.

2000-26

WHEREAS, the State of South Carolina is committed to providing community-based alternatives for persons with physical, mental, or developmental disabilities and recognizes that such services advance the best interest of all South Carolinians; and

WHEREAS, South Carolina is committed to providing community-based services that effectively foster independence and acceptance of persons with physical, mental, or developmental disabilities; and

WHEREAS, programs such as home and community-based services provide the opportunity for persons with physical, mental, or developmental disabilities to live productive lives in their own communities; and

WHEREAS, as Governor of the State of South Carolina, I am committed to ensuring access to care and the provision of services to persons with physical, mental, or developmental disabilities in accordance with the Americans with Disabilities Act; and

WHEREAS, South Carolina must build upon its many successes and undertake a broader review of our programs for persons with physical, mental, or developmental disabilities and ensure services are offered in the most appropriate setting.

NOW, THEREFORE, I do hereby establish the South Carolina Home and Community-Based Services Task Force. The objective of the Task Force shall be to develop a comprehensive, effective, working plan as recommended by the United States Supreme Court in its recent decision in Olmstead v. LC., 119 S.Ct. 2176 (1999). The Task Force shall:

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 plan.

3. Submit a comprehensive written report of its findings to the Governor no later than June 29, 2001. The 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.

5. All affected agencies and other public entities shall cooperate fully with the Task Force research, analysis and production of the report.

6. The South Carolina Developmental Disabilities Council shall provide staff support as necessary to assist the Task Force in carrying out the directives of this Executive Order.

GIVEN UNDER MY HAND AND THE GREAT SEAL OF THE STATE OF SOUTH CAROLINA, THIS 2nd DAY OF November, 2000.

Jim Hodges

JIM HODGES
Governor

ATTEST:

Jim Miles

JAMES M. MILES
Secretary of State

State of South Carolina

Executive Department

Jim Miles
SECRETARY OF STATE
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Office of the Governor

EXECUTIVE ORDER NO.

2001-08

WHEREAS, in Executive Order 2000-26, I established the South Carolina Home and Community-Based Services Task Force and charged it with the responsibility of providing me with a final report and recommendation by June 28, 2001; and

WHEREAS, the Task Force should have a full opportunity to evaluate the options available to our State in addressing the fundamental issue of community-based alternatives for persons with physical, mental, or developmental disabilities; and

WHEREAS, I have been informed that the Task Force needs additional time to complete its work and to prepare the report and recommendation.

NOW, THEREFORE, I hereby extend the time for the Task Force to provide me with a final report from June 28, 2001 to September 3, 2001.

This Order shall take effect immediately.

GIVEN UNDER MY HAND AND
THE GREAT SEAL OF THE
STATE OF SOUTH CAROLINA,
THIS 26 DAY OF MARCH,
2001.

JIM HODGES
GOVERNOR

ATTEST:

JAMES M. MILES
SECRETARY OF STATE

APPENDIX B

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APPENDIX C

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2001 DHHS Home & Community-Based Workgroup

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APPENDIX E

DMH Workgroup Members

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Olmstead Working Committee Members

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General Counsel
Department of Mental Health

Bonnie Pate, Director
SC Self Help Association Regarding
Emotions (SHARE)

Mallory Miller
Toward Local Care Program
Department of Mental Health

Gloria Prevost, Director
Protection and Advocacy for Persons with
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Robin Wheeler
Protection and Advocacy for Persons with
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Angela Flowers
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Department of Mental Health

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Department of Mental Health

Felicity Costin Myers, Director
Continuum of Care

Laurie Hammond
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Charles Wadsworth
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Linda Pickens
Consumer Advocate

David Ball
Community Builder,
US Department of Housing

Mr. David Almeida, Executive Director
National Alliance for Mental Illness

David Little
SC Association of Residential Care Homes

Louisa Prescott, Executive Director
Mental Health Association

Linda Parker
Consumer Advocate

Charles Bevis, Director
Pee Dee Community Mental Health Center

Ken Shull
SC Health Alliance

Randy Lee
SC Health Care Association

Alice Molenbrock
Consumer Advocate

David Leopard, Executive Director
SC Housing Finance and Development
Authority

APPENDIX F

Public Comments

ETV Teleconference - Olmstead Public Comments – June 18, 2001

Betty Easler – Enable.com

Commended efforts to date and made following recommendations:

1. For implementation purposes, there needs to be some assurance that there will be a commission or panel of individuals, not entirely made up of people who were involved with the development of the plan to ensure credibility with implementation and to give persons with disabilities who are provided a service and are not happy with that service an opportunity to have someone to listen to their grievances. That is necessary for credibility purposes.
2. The level of care and the type of care to be provided and the determination of whether a person lives in the community or goes into a community facility must be in the hands of the person's physician and the individual with disabilities and their family. If that is left in the hands of a service provider, I think we are back to ground zero. There should be additional assurances that that does not occur.
3. There is not some determination of the length of time for a service to be provided. I don't want an individual to come to an agency or case coordinator and get caught up in the bureaucracy of time and money constraints, etc. There needs to be a determination of the time an individual can be served.

Barbara

Question: What is Governor's plan to fund the community resources deemed necessary in the draft report? What is legislative plan to fund the community resources deemed necessary in the draft report?

Reine Lantz

Parent and caregiver of child with mental health needs. Was a threesport athlete and involved in community. Once sick, the community marginalized, ostrasized and persecuted him. Difficulty with the schools and local mental health service provider. Notified Mental Health of son's deterioration and need for help, but did not get services. Three other young men have turned 18 and all are in hospital. Once her son was in the hospital, she has not been able to get involvement.

There is a need for crisis prevention programs such as full PACT programming (Programs for Assertive Community Treatment) through the Continuum of Care for youngsters and full PACT programming for young adults through DMH. What has Plan done in the way of PACT programming that could save money on both ends?

Anderson Parent of Child with Autism and former worker at DSN Board

I like how the panel is stressing the importance of getting information to families and training of service coordinators. DSN has always stressed this, but has failed. What does state plan to do differently so that I do not have to train another service coordinator?

Man in Studio: Service Provider issue. Has there be consideration about certification of service coordinators rather than training while they are doing it? We have been through 6 service coordinators in 3 years. Most were learning on the job and did not have the answers to our question or give direction to us. This should be a professional position with professional requirements and income appropriate to a professional position.

Barbara – Parent of child at the Coastal Center, President of Parents and Guardians Association at Coastal Center
Supports that Olmstead doesn't include closing of the regional centers because that choice needs to be there. All the recommendations and approvements that are being applied to community based services should also be applied to individuals who choose to live in the regional centers. Also, there is a great need for adult day care for profoundly retarded adults. Had that been available, her son would not have gone to the Coastal Center when he did.

Suzie Cornelius – Oconee County resident
Possibility of funding for housing, transportation. State's receive federal funding in block grants. These are processed through different agencies. The federal government authorized $5 billion for community development block grant programs. I would like to take the potential of these block grants funds and direct them back into communities and take them away from the institutions. I would like the final plan that the Governor supports require that the state and counties have an obligation to reduce its support to the existing institutions in lieu of support to community supports. Example: In Oconee County, the County Council has just approved $4.5 million to add on to the existing county nursing home in spite of Olmstead. They see a potential need because the county is growing and this does not take into account that these people could stay in home and in the community if the county would direct the funding that way.

Our county has received a 1/2 billion dollar block grant from the Appalachian area block program. They are proposing improvements to an area in Walhalla, but not even considering that part of those housing improvement be directed to the disabled or aging. We need some teeth in this report that gives citizens an opportunity to go to the county councils and the block grants to get the money directed into the community. There is a HUD program, Section 8.1.1. provides housing for disabled. This does not have to be legislation, but could be addressed through rules or agency policies.

Linda in Greenville: How is plan addressing the concern for people with disabilities who are currently incarcerated and are getting out and need assistance with transitional housing, employment, etc.

Provider in Columbia – Until reimbursement rates are brought in line with national standards and comparable to what other states pay providers, there will not be freedom of choice in providers. There are a limited number of providers who accept Medicaid. Finding a Dentist to do a cleaning with our pediatric patients is almost impossible. As a provider, I can not hire the quality of nurses that need to be in the home taking care of these children. The pay for in-home nursing is minimal compared to pay in the hospitals for equal or more work. Parents do not have freedom of choice because there are not enough providers.

Danny Weaver (Brain Injury Survivor) - Hartsville
What is the group doing to make sure that the rural areas in SC will be served and made aware of Olmstead and what it will do for them? Funding – we will need funding to receive quality care.

What agency will spearhead the Olmstead implementation and what will be their criteria for who receives the services?

Relay Speech to Speech call: Robert Dubose (Cerebral Palsy)
Works for the County DSN Board. When my nursing assistant does not show up to get me up for work in the morning, then my caregiver who works at the group home where I live has to get me up. I dealt with this since I lived with my mom and I've been dealing with this for quite a number of years.

Fran, Columbia
Calling for her son who does not talk or walk and lives at Midlands Center. Concern over residential facilities that were not made for individuals with heavy orthopedic and medical equipment. Stressing the need for the facilities to accommodate the needs of the individual, provide a quality environment and to allow for family visiting.

Janet (TTY Call) related to children who are deaf and have an emotional disability. Concerned about the closing of the Pine Ridge program at the School for the Deaf without prior notice to the families. The number of children who are deaf with emotional challenges is greater than the state has acknowledged.

Mary Catherine Miller in Columbia – 20 year old son who was in a car accident 2 years ago resulting in TBI. Had to seek services in Charlotte and Texas because services didn't exist in SC. He has relearned to walk and talk and is now ineligible for services, but he sits home. The incidence of head injury is significant in South Carolina. In SC, there are only acute care facilities and only 1 CARF accredited facility (Roger C. Peace in Greenville). Half of the head injuries in SC are a result of not wearing helmets. Because SC doesn't have a helmet law, we are not receiving federal funding available. Average age of head injuries are males 19-23. That is a group with the least amount of insurance coverage. It is not just Medicaid consumers that need help. Families with insurance need help, because the insurance companies are not providing needed coverage. We need a continuum of care – from acute care to community living. Service must go with the individual not the facility or providers. Consumers need choice.
Value the human spirit. Each person in need of these services has a spirit, a will, and a purpose on this earth and we need to all work to allow these people to live the best quality of live in whatever setting they choose.
Funding is crucial and if the General Assembly does not fund these efforts, nothing will happen.

Jason – Conway – Wants to live on his own in a safe community. He has little money. What will the plan include related to safety in housing?

Ms. Johnson from Charleston – daughter who is 26 years old. Is anything being done to provide more day programming for people over 21 who have severe disabilities? There is a need for activities for the individual and the need for a break for the caregivers, especially aging caregivers.
Is there a ratio of service coordinators to consumers so that they have reasonable numbers of cases to deal with? Need for training of service coordinators.

Phil Clarkson – President of Brain Injury Association of SC.
Related to funding, we must recognize that as people with disabilities move into employment, there will be a payback to the state.
Related to Medicaid funding: There are cases where it is said that the coverage is there, however, it is not enough to cover the continuum of services.

Patricia Dawson – ARC and Brain Injury Alliance
Son's behavior creates challenges in employment. Also, some employers take advantage of him. Difficulty managing money. Need for money management support to pay bills, and get individuals from being taken advantage of. Aging caregivers concerned for the security of adult children.

Carol Neiderhauser – parent of child with autism
Concerned about housing for adults with disabilities. Very few options. In most counties, the options are one provider through one board. This means we have less competition for housing than other states. I would like DDSN to look at what is keeping new service providers out for housing and other services and work to remove these barriers so that we can have more choice and control in our lives.

Mary Stanton – parent of son in regional center and president of SC PADD.
For individuals who choose to live in a regional center, I wants to see a standardized set of procedures for admission to a regional center as well as community services. The procedures should be equalized so that a person choosing to receive services in the regional center do not come up against a wall where it is more difficulty to gain admission to a regional center.

Dolph Pace – 36 years old with Down Syndrome – lives in Marion
Lives with parents, but wants to live independently. Has been on a waiting list for 2 years to live in community. To do this, I need a job and job training. Parents are 70 years old. Waiting list should be only 5-6 months, not years.

07/18/81 11:06 AM [illegible] itula-

07/18/81 11:07 AM
comment from janet in columbia ... mr. binkley you stated you are concerned about children at risk for institulation .. i am most concerned aobut deaf children with emotional disturbance .. the number of these children, while not huge, are far more extensive than the state has acknowledged ... the only progrm in the state that services these children was summarily closed in may, parents simply received a letter stating her children would not be welcome back at the school for the deaf in spartanburg ... now at least 1 of those children is institulized, ready for discharge and with no place to go, so he sits in an inpatient unit in aderson, sc ... i want to know how it is that such a program can be shut down with out any notification to parents, and then why nothing is available for thos children? and why can the school for the deaf just throw these kids out all of who are in danger of institutionalization

Home and Community Based Services Public Hearing
Capital Senior Center, Columbia, SC
July 31, 2001
Attendance: 31

Comments from the Audience

Assessment

1. Have independent assessment for all waiver evaluations using an interdisciplinary, cross agency process.
2. It is of critical importance that the assessment process be independent, cross-disciplinary and based on functional limitations rather than diagnosis.
3. Each person should be seen as an individual with individual needs and not evaluated based on what the family has or has not been able to provide.

Service Coordination

1. Care coordination should be outside the agency that administers the program. Care coordinators for children with medical conditions need medical expertise and training.
2. Service coordination should be independent – it needs "out of the box" thinkers.
3. Service coordinators should be trained prior to serving families. Should be independent and possibly specialize in (a) children's services (birth to 21 to be able to address school and other issues) and (b) adult services (over 21 for housing, and other issues).
4. Service coordination needs to be independent. Coordinators need to be supported from the state to be able to fight for the person and not to be intimidated by the agency or fear for job security if they advocate for the consumer/family.

Monitoring implementation of the plan

1. An interdisciplinary group should be set up to monitor implementation of the plan.
2. Must have a system to monitor to ensure that implementation is consistent with the plan. Implementation will be a gradual process. Changes may conflict with the plan and monitoring will be essential to maintain the integrity of the process.
3. Must have an oversight committee that is on-going (meets regularly and not just once a year) with continued involvement from consumers and families.

Housing

1. Want quality housing available to individuals with disabilities with limited income.
2. Concern over quality in boarding homes and monitoring of boarding homes by DHEC.
3. Young people need group home options with other young people. Example was a friend's son who is 19 years old and is in a group home with individuals 50 and older. Another example is a young man with a head injury who was living in a boarding home with persons who are elderly and persons with mental illness.
4. Referenced Pennsylvania study cited in the Wall Street Journal that shows that it costs the same to treat individuals with mental illness in the community (housing, employment, community mental health services) as it does not to treat them. Untreated, many go into institutions or are incarcerated.
5. Cited the Women's Shelter as a model housing program in Columbia.

Unavailability of in-home providers

1. Unreliability of PCAs. Family trains and the PCA leaves after 2 weeks.
2. Lack of in-home nursing care (shortage of nurses) results in unnecessary hospitalization.

Criteria for services

1. Home and Community Based waiver for ventilator dependent children which is administered by DDSN was originally intended to cover all related disabilities. As implemented, family must prove mental retardation status. That is wrong. Recommendation to remove the MR criteria for the HCB ventilator dependent waiver.
2. Concern over burden of proof of mental retardation placed on the family. Example is 72 year old individual who has lived at home with her parents for her entire life. The family never sought public services until now. Although the child had spinal meningitis at age 2, there are no school or other records to prove MR prior to age 22. Therefore, she has been deemed not eligible for services.
3. Head Injury survivors falling through the cracks. They are not eligible for many services needed and available to other disability groups with similar functional limitations.
4. Another family penalized for providing care for 16 years. It was difficulty to get child into a residential facility when he became to difficulty to care for safely at home.

Resources for children

1. There is no system of interim residential services for children. No step down from the hospital. Children are captured in the hospital because there is no place to go.
2. More resources must be devoted to children.

Need for information to the public

1. Need for information to be disseminated to the public and education of the public on the Olmstead decision and the need for community based services and what the state is doing.
2. A lot of families do not have the educational level to fight for themselves or to understand this report. There must be education on this issue and what it means.

Commission for the Blind should be included in this report to be a part of the services provided. This consumer not happy with Commission for the Blind services.

Waiting lists are too long.
Reduce the paperwork requirements for parents.

Public and Advocacy Group roles

1. To improve the funding, disability groups need to come together as a voting block.
2. Consumers, families and the general public must be vocal and speak out to the legislature about what you want. Contact legislators with your story.
3. Consumers and families need to track legislation and support those that support community based services. Contact legislators when related bills go before the legislature. Need public support to move the legislature.

Questions:

1. What is the next step regarding funding for these wonderful ideas?
2. What happens when timelines expire?
3. Are there plans to present the report to the legislature?

Greenville Olmstead Hearing -7/31/01

Crisis intervention, especially for persons with mental retardation who may have mental illness or behavioral issues

Service coordination- adequate numbers and trained

Funding needs to increase and where appropriate pursue relevant grants

Staff pay

Efficient, well coordinated(i.e., avoid redundancy), timely services

Finalize budget for Olmstead Plan implementation

Stress the favorable economic aspects of community services

Public awareness needs to be strengthened, families need to able to get their stories out to encourage support community support and understanding

Information for families about services generally and to deal with specific concerns, for example, how to appeal eligibility and service decisions

Frustration with special education services and the long-term impact of not dealing with issues earlier on that may become more problematic later

State of South Carolina
Office of the Governor

Jim Hodges
Governor

Office of Executive
Policy and Programs

July 31, 2001

Mr. Charles Lang
Developmental Disabilities Council
Division of Constituent Services
Governor's Office
1205 Pendleton Street
Columbia, SC 29201

Dear Mr. Lang;

As you know, I have been concerned about the lack of attention paid to the needs of children and their families throughout the development of the Home and Community Based Services Plan. In reading the final draft, I appreciate the fact that comments related to children were included. However, those of us who work with children and their families were not able to gather information in a systematic fashion to assist us in our recommendations and had to rely on our joint fund of information and the input of the few families who met with us. I do hope that, as plans for implementation are "fleshed out" by the three agencies, children will be appropriately represented in all planning and implementation meetings.

In reading the draft report, I am disturbed that the three agencies do not agree on a strategy for assessing the needs of individuals effected by the Olmstead decision. I support the position that the departments of Mental Health and Health and Human Services have taken in recommending that a neutral entity carry out these assessments. Furthermore, I feel that assessments should be carried out in a uniform manner across agencies and hope that the recommendation from the Governor's Office be that all assessments, regardless of disability, be carried out by a neutral entity.

This lack of unity among agencies regarding assessments is an example of the fragmentation of services prevalent in this state at this time. My main concern with the report was the inadequate attention given to cross-disability issues and to individuals with multiple disabilities. By approaching this issue on an agency by agency basis, we undermine our ability to honestly and accurately perceive the complex needs of the individuals we are charged to serve.

Continuum of Care for Emotionally Disturbed Children
220 Stoneridge Drive, Suite 300 * Columbia, South Carolina 29210

It is my hope that the Governor's Office will keep these concerns in mind when reviewing this report and will take steps to ensure that our state agencies work cooperatively to meet the needs of our constituents rather than viewing their responsibility in the narrow window of their separate mandates. One of the chief complaints expressed by families with children with disabilities is that agencies do not view their children as children, rather they view them as diagnoses and disabilities and the agencies all work independently of each other. This system of service delivery is both inefficient and inappropriate. I sincerely home that the Governor's Office will use the opportunity afforded to us by the Olmstead decision to require all state agencies to shift their service delivery practices to better meet the needs of the individuals we serve.

Sincerely,

Felicity Costin Myers, Ph.D.
Director, Continuum of Care for Emotionally Disturbed Children

July 27, 2001

MEMO TO TASK FORCE MEMBERS

Strategic Housing Plan for Home and Community Based Services

June 22, 1999, the U. S. Supreme Court affirmed policy under the Olmstead ruling in that unjustifiable institutionalization of a person who, with proper support, can live in the community is discrimination.

January 14, 2000, the U. S. Dept. of Health and Human Services (HHS) sent a letter to every state governor citing *Olmstead* encouraging governors to develop and implement the comprehensive working plans the court had suggested.

November 2, 2000, Governor Hodges issued Executive Order No. 2000-26 establishing the South Carolina Home and Community-Based Services Task Force whose objective is to develop a comprehensive, effective, working plan for integrative community living as recommended under *Olmstead.*

February 2, 2001, President Bush announced his New Freedom Initiative, which promotes full access to community life in accordance with the *Olmstead* decision and signed an executive order directing federal agencies to coordinate research and pilot programs to make public health agencies more accountable under this law through outcome measures.

July 2, 2001, the Task Force issued a draft report of its South Carolina Home and Community Based Services Plan. July 18, 2001, a public hearing was held around the state where Task Force members received comments on the draft proposal.

In response to an audience comment about the lack of provision in the report for establishing community housing necessary for de-institutionalization Joe Wilder, Chair and Bonnie Pate, Director of SC SHARE requested information with housing implications that can be considered for inclusion in the final report.

Thus, the following ideas are submitted for consideration:

1. Housing experts local to the community should be included in the planning and implementation of the Task Force Plan.

2. Make provision for counties to establish a housing and service consortium that includes state Medicaid officials. The purpose of the consortium: (a) funnel distribution of state Medicaid certificates of need and waivers based on local level need; (b) find and distribute funds for housing; (c) establish the location and kinds of housing to be created; (d) establish measurement standards and quality controls. For example, the consortium may coordinate available public housing to channel federal funds into "elderly only" public housing creating assisted living units. Another example of activity can be establishing small residence homes in districts throughout the county with services provided by existing agencies.

The financing shown on the attached design for a strategic housing plan are influenced by billions of dollars of funding for more than 20 HUD programs issued to state in block grants and are important in Olmstead related planning because;

(a) The programs determine what type of housing will be funded, and

(b) Which low-income groups will receive priority.

The Consolidated Plan is a master plan, which describes how the state or locality will spend HUD funds. A description of health and social services provided by public and private agencies must be described in this plan. The "ConPlan" may be substantially amended at any time in priorities, purpose or scope and new housing activity. These are the four federal programs financed under the ConPlan:

1. Community Development Block Grants (FY 2001 $5,057 billion)
2. HOME Program (FY 2001 funding is $1.8 billion to state and local governments)
3. Emergency Shelter Grants
4. Other Housing Opportunities.

Public Housing Agency officials may now create elderly-only public housing with Sec. 8 voucher assistance. There are awards set aside for people with Medicaid funded Home Community Based waiver services.

The Sec. 202 Assisted Living Conversion Program is an initiative to expand housing options for low-income seniors.

HUD Sec. 811 provides funds to non-profit organizations to acquire, develop, or rehabilitate rental housing with supportive services for very low-income people with severe disabilities that include the frail elderly population. There is also a new rental assistance component of this program.

Information contained in this memo is obtained from press releases posted to the Internet, the U.S. Department of Housing and Urban Development (HUD) and the July 2, 2001 draft of the South Carolina Home and Community Based Services Task Force report.

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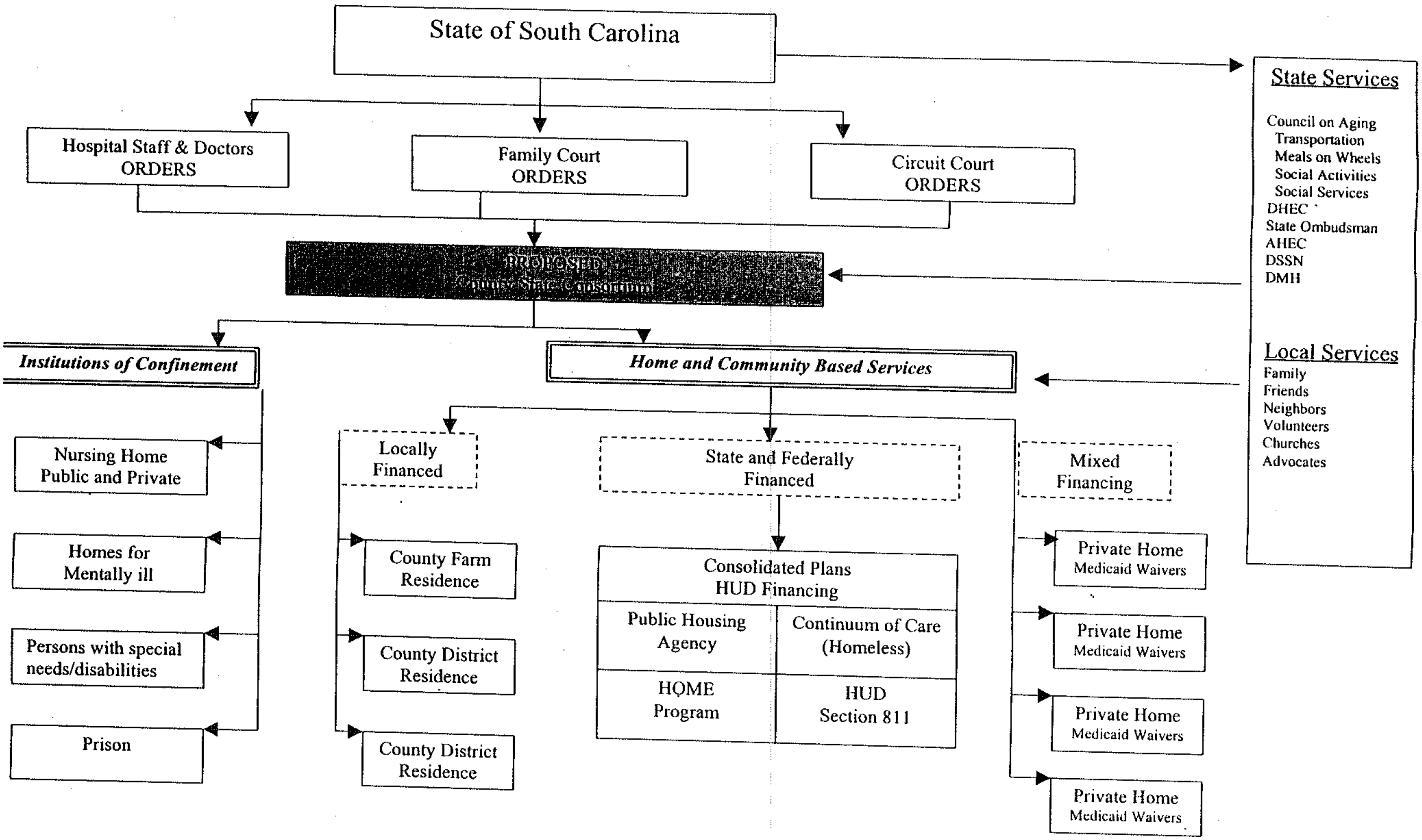
STRATEGIC HOUSING PLAN DESIGN
HOME AND COMMUNITY BASED SERVICES



Prepared July 27, 2001:
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July 31, 2001

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Columbia, SC 29201

Dear Mr. Lang:

Thank you for the opportunity to provide input into the development of South Carolina's Home and Community Based Services Plan. This has been a very important process in having input from consumers, families, service providers, and state agencies in shaping future services to meet the needs of people with disabilities. The Task Force and Work Groups are to be commented for having an open process through opportunities for comments and public hearings.

While this is a comprehensive State Plan the following key elements still need to be addressed:

(1) **Assessment Process** – Real choice should be the cornerstone of any plan. People should have the services that they need and want. Meaningful assessments should be done and consumers should be at the core of any assessment process, whether in is agency based or independent. Input from families, friends, Circles of Support, and other significant people in a person's life is critical to supporting the person in achieving true self-determination.

(2) **Service Coordination** – People should have real choices and options. It is imperative that people receive information and support in making important decisions about their services. The service coordinator is a vital resource in not only coordinating services but providing information to the person and their families and empowering them to have control in decisions affecting their lives. The key to successful service coordination is training – not only for the service coordinators but also for the person and their families. People should have a choice of service coordination providers, including agency based or independent.

(3) **Implementation of the Home and Community Based Services Plan** – There should be a formalized oversight, ad hoc, advisory committee or other mechanism to monitor the Plan on a continuing basis. Consumer input and monitorship is critical to an evolving plan.

(4) **Consumer Information** – It is imperative that consumers, families, service providers, service coordinators, and staff receive information about services, funding resources, and provider choices. There needs to be an ongoing mechanism for information sharing. Consumers cannot have true self-determination unless they have adequate information to make informed decisions about choices and options.

(5) **Gaps and Barriers** – While the Plan has addressed many issues, there still remains many critical areas that need to be incorporated into the State Plan. This can be addressed by the monitoring/oversight committee with continuing input from consumers.

Thank you for this opportunity to share my thoughts. Much work has been done but **"We still have miles to go before we sleep."**

Sincerely,

Redick C. Loring

Redick C. Loring
Executive Driector

From: Keri Weed <KERIW@AIKEN.SC.EDU>
To: GMSOEPP.OEPPMAIL(CLang)
Date: Tue, Jul 31, 2001 9:18 PM
Subject: SC Home and Community Based Services Plan

I am a developmental psychologist at USCA, on the Board of the ARC of the Midlands, and also have a brother with mental retardation and cerebral palsy. I have comments related to each of the three areas open for public comments from the draft report. My first comments relate to assessing needs of children, adults, and elderly people who currently reside in institutional settings. The draft report covers at least four different types of the assessments, which may need different procedures.

· The first assessment need is a screening to determine the person*s desire to reside in a community setting. I believe that this type of assessment should probably be incorporated into an agency specific assessment process as suggested by DDSN on page 30 of the report. The only disadvantage with this is those consumers who may feel that expressing a desire to relocate suggests they are dissatisfied with the care they are currently receiving. I have spoken with several consumers residing at long-term care facilities who hesitate to voice their opinion due to fear of hurting their current caregivers feelings, or fear of retaliation by the current caregivers. Perhaps an independent check on those consumers desiring to remain in institutional care or a sample of those consumers would be warranted.
· However, once an institutionalized person had indicated a desire to transition to a community setting, I believe a more in-depth, comprehensive assessment protocol needs to be implemented. I agree with the suggestions of DMH as stated on page 27. The assessment plan should involve participation of relevant stakeholders, but be independent from the service provider. I believe a parallel assessment process should be implemented across disability types, provided there is flexibility to meet needs of specific disabilities. The independent assessment services may be arranged through a contractual service agreement. The purpose of this more comprehensive assessment would be to determine the clients* current adaptive or functional level as well as their need for services and supports to adapt successfully to the community setting. Integration of assessment protocols across agencies by independent assessment contractors will reduce any conflict of interest in the outcomes of the assessments, and may provide better services to those with dual diagnosis of mental retardation and mental illness.
· A third type of assessment covered in the draft report, was assessment of people at-risk for institutionalization. This should include an initial screening of risk, more appropriately conducted by the agency itself. Those deemed at high risk, may be referred to the independent assessment contractor for follow-up, and more comprehensive assessment of functional level and needs.
· Finally, the draft report included assessment of community assets and needs. This might be more appropriately handled through an RFP procedure through the governor*s office.

My next comments relate to the section on Service Coordination. Quality service coordination involves several difficult issues. While I agree that it is critically important to allow consumers choice in service coordination, I also agree that the coordinator needs to be responsible to consumers and families rather than to the agencies providing the services. Service coordination may also need to be provided at various times of transition in a consumer*s life, necessitating a continuum or range of options. I believe, however, that service coordination needs to be provided by an unbiased, objective professional, independent of the services themselves. While this may limit the consumer*s choice to some extent, it helps ensure all consumers are equally knowledgeable of their service options, and have equal access to all services. Further, families of persons with disabilities exert pressures in many different directions. An independent coordinator working in the consumer*s best interest, may assist the consumer in understanding and acting on their own choices rather than a loved one choice for them. However, as many consumers and families have developed trusting relationships with their current service coordinators, this should be implemented over a period of several years, with perhaps an initial period where consumers could opt for agency provided or independent service coordination. This phase in process is critical for successful implementation of service changes.

My final comments relate to the section on oversight and plan modification. Oversight of this plan involves complex issues and understanding of federal rules and regulations. It involves collection, analyses and interpretation of a considerable amount of data from a variety of agencies, communities, and institutions. Although utilizing an existing commission or council to provide this service may seem to avoid duplication of services, it would be imperative to integrate this process across agencies. There should only be one group to monitor and track implementation and progress across agencies, and this group should be independent of those agencies. Staff who collect the data and prepare the reports should not be paid out of the agency budgets.
My comments may be summarized by 3 assumptions: first, that assessments, planning, or monitoring of services are generally less biased and more to the benefit of the consumer if the outcomes of these processes do not directly impact the evaluator. Second, allowing competitive bids, not tied to specific counties or agencies, for these services may increase quality while keeping costs reasonable, and third, integrating these services across types of disabilities may avoid duplication and better serve consumers with dual diagnoses, yet flexibility is also important to address situations unique to a particular disability.
Thank you for your consideration of my comments.

Keri Weed, Ph.D.
Professor of Psychology
USCA

From: Clarkson, Philip (LGE-SP) [SMTP:pclarkson@lg.com]
> Sent: Monday, July 23, 2001 2:19 PM
> To: Dr. Peterson - DDSN (E-mail)
> Subject: SC Home and Community Based Services Plan - Comments on
> DRAFT of 2 July
>
> Dr. Peterson - You represented the spirit of Olmstead & DDSN quite well
> during the 18 July teleconference I felt.
>
> Please forward these comments to the appropriate person. Some were sent
> to me from BIASC board members. 1. under IV.F.6.a. - The wording
> appears to ignore some of the disability groups served by DSN. DDSN
> should clearly include employment initiatives for Autism & HASCI. 2.
> under IV.G.5- Please add wording to draw attention to Brain Injury along
> with progressive disease. Even though BI is mentioned under III.G.5
> those brain injured who do not qualify will easily fall through the
> cracks if not specifically identified. 3. under IV.G.6.k - Please add
> "Brain Injury" along with spinal cord injury for comprehensive
> rehabilitation. 4. under IV.G.6. - Please make a recommendation that
> current levels of Medicaid coverage be sufficient to promote a continuum
> of services. We can not /should not consider a service "covered" if
> providers will not accept the level of Medicaid reimbursement.
>
> Many Thanks, Phil Clarkson
>
>

From: Richard E Hering <yaherin@juno.com>
To: GMSOEPP.OEPPMAIL(CLang)
Date: Fri, Jul 27, 2001 10:44 AM
Subject: Olmstead

Dear Mr. Lang,

We are parents of a 3l year old mentally handicapped son. At this time he lives with us, because there is no adequate housing available for him. The only way that we could get housing for him now is if we die or become disabled. There are over l600 individuals waiting for housing in this state! We would like to have more housing providers beside Babcock. We know there are faith based providers willing to provide services in this state but there have been stalled by SCDDSN. It seems that Babcock has a monopoly with services provided to handicapped individuals in the Columbia area, it should be opened to other responsible providers.

Thank you for your time,

Richard and Yvette Hering

From: Harriet Johnson <HarrietJohnson@compuserve.com>
To: Charles Lang <clang@govoepp.state.sc.us>, Terri Vi...
Date: Mon, Jul 23, 2001 2:26 PM
Subject: Comments - Terri Vincent

Charles, I just received the comment below.

I agree that there is a place for private philanthropy and volunteerism, and that we should encourage charitable giving that deals with systemic issues as opposed to specific disability groups. However, I do not think private voluntary effort should be relied upon to any substantial degree for services that are essential to prevent unwanted institutionalization.

I concur with the comment about information systems. What she is describing sounds very much like an augmented version of SCHISIS, which got torpedoed in the last budget cuts. If we haven't addressed this clearly, we should recommend restoration and expansion of the information system.

HarrietJohnson@compuserve.com

Harriet,

I tried to send this to the email address given at the hearing, but there was a transmission error. I must have copied the address down wrong. Would
you please forward this to the right person/people? Thanks for your help.

Terri

July 23, 2001

Dear Task Force Members:

I attended the public hearing for the Olmstead Act at the SCETV station in Columbia on July 18th, and I am writing to submit my comments and suggestions to you, the task force. First, let me introduce myself. I am Terri Vincent, a law student here in Columbia, and the mother of David Keim,
a young man with cerebral palsy.

David lives with his father in Phoenix, Arizona where he attends public school. In Arizona, David is eligible for public education until his 22nd birthday (David will turn 22 a year from August). The school program David

is currently enrolled in emphasizes job placement in the community. Each student is employed in the community and has a job mentor attend work with them until they are functioning independently at their job. The students are taught life skills such as handling money, using public transportation,

and filling out a job application. They are also taught skills such as grocery shopping and writing checks. As much as I want David to live with me, I cannot take him out of such a good program and bring him to South Carolina. I hope and pray that once David graduates from this program in Arizona, I can find appropriate work and social activities for him here in South Carolina, and can have him move here then.

The biggest barrier to having these services in place is a lack of funding.

We have so many agencies and interest groups vying for the same limited pool of state and federal money. South Carolina has a limited tax base and cannot begin to fund all of the services needed. Obviously, the first thing that needs to be done is to maximize available federal funding. But I believe in order to find the money necessary to accomplish all that we want to accomplish, we need to look beyond these limited resources. We need to look at where the money is, and then develop ways to draw it to us.

If we look around us, there is lots of money in South Carolina. Where is it? It is in the hands of businesses, corporations and private individuals. We need to remember that the people who control the money are just that " people. Even if they are fortunate enough to enjoy good health themselves, they have aging parents. Or they have physically and mentally challenged children and grandchildren. Their friends and neighbors have suffered from head trauma and spinal cord injuries. And they all want the same thing we do " they want their loved ones to have the freedom and choice to live their lives as fully and freely as possible. None of us want to see people institutionalized unnecessarily. I firmly believe that if we educate the people with the money as to what they can do to improve the quality of life for their loved ones, they will give willingly and generously.

But first, we need to educate ourselves. What tax and other incentives exist for private donations? Is there any way funds can be given to a general fund (such as for improving public transportation for everyone) as opposed to a specific fund (such as ARC)? If the necessary tax incentives aren"t in place, we need to lobby to get them. What private endowments, grants and fellowships are available that aren"t being used? What are other areas of the nation doing to attract private funding? How effective would it be to get articles published in the Chamber of Commerce newsletter and other local business publications promoting fundraising projects such as employers matching employee donations? I don"t want to get too specific here. I am not familiar enough with the existing environment to know what is already being done or what can be done. The point I am trying to make is, we need to be creative in attracting new resources.

Money is not the only resource available to us. We also need to focus on maximizing volunteer resources. There are unlimited volunteer resources available everywhere. Everyone can volunteer and contribute in one way or another. With good recruitment and education, the people of South Carolina

could make a huge difference in increased volunteer efforts. Simple things like shopping services and transportation - volunteer specialties - can make the difference between whether or not a person can live independently.

However, all of the services, money and volunteers in the world won"t solve

the problem if the people in need of them don"t know they are available. I

suggest that a central registry be developed where all service providers, volunteers, funders, and individuals can register (while maintaining privacy, of course). Individuals can post what services they need and shop

for what is available. Service providers can look to see what services are

needed and adapt their services to meet the existing demand. Individuals interested in providing care can be matched with consumers in their neighborhood. If there are funds available to people that meet certain qualifications, post it on the registry. An on-line registry would be ideal for many of us, but for those without access to the internet, there would need to be phone access as well.

I believe we are all working towards the same common goal. Nobody should be forced into an institution. We should all be given the freedom and choice to live our lives as fully and independently as possible. Let"s work together to make it happen.

Sincerely,

Terri Vincent

1452 Moss Tree Rd
North Charleston SC 29405
843-740-1861

July 18, 2001

TYPESCRIPT OF STATEMENT DICTATED BY INELL BROWNLEE TO S.C. GOVERNOR'S TASK FORCE ON HOME & COMMUNITY BASED SERVICES

My name is Inell Brownlee. I live in a DDSN Community Training Home with my husband, Joe Brownlee, and two other people with cerebral palsy. My husband and I would like to live in our own apartment in Charleston. It would have to be handicap accessible because we are both in wheelchairs. We would need someone to help us get up in the morning and get to our jobs, and then to help us after work until bedtime, and then to be on call at night. We need to be able to choose who we want to come into our apartment. We don't have much privacy where we're living now. This is better than the big institution we used to live in, but it's not good enough. Will the plan make things better for us?

INELL

POSTSCRIPT: Inell told me after the meeting that she would like to hear from someone about her options now. Telephone contact is best.

HARRIET JOHNSON

FYI

Post-it® Fax Note 7871	Date 7-18	# of pages ▸ 2
To Harriet Johnson	From Aleta Pollick	
Co./Dept.	Co.	
Phone #	Phone # 803-253-3681	
Fax # 843-577-0460	Fax #	

July 18, 2001

Mr. Charles Lang
Office of Executive Policy and Programs
P.O. Box 11369
Columbia, SC 29211

Dear Mr. Lang:

I have reviewed the complete "South Carolina Home and Community Based Services Plan" and wish to submit a few comments. First, I wish to applaud the herculean efforts of the distinguished Task Force in compiling such a timely, comprehensive and insightful evaluation of the present obstacles in South Carolina impeding compliance with the Supreme Court's mandate in *Olmstead*. The Task Force has accurately summarized the concerns of diverse groups with sometimes divergent orientations, e.g., persons with disabilities, family members of persons with disabilities, lawmakers, state agency personnel, and nursing home representatives, on the central issue of how accelerated transition from institutional to community-based services can best be guaranteed. The Report astutely considers not only those persons already identified as receiving services, but also how best future users of supports and services can be identified early so that plans can be implemented to avoid allowing a crisis situation to propel such persons into an institution.

I strongly echo the Report's advocacy for expansion of options for residency-centered extension of services and supports. By the term "residency-centered" supports and services I refer to a system in which the supports and services are determined not by the name of the individual's medical condition, but by the person's unique needs. In such a system the needs are delivered lifelong, wherever that person chooses to live. Funding for such services would follow the person and not be dependent on "beds" or allotments. This shift to an individualized-analysis based system is fully consistent with the mandate of the Americans with Disabilities Act. I understand one key question under such a model is whether to preserve the traditional nurse or agency-supervised extension of services, or to change to a self-directed services system in which the disabled person may directly supervise caregivers. As with so many issues raised by this plan, no one formula will fit every situation. Therefore, I would envisage a system in which some affected individuals possessing the requisite abilities choose to self-direct the provision of services to them whereas other persons maintain the traditional scheme. It must be remembered that the traditional nurse or agency-supervised model arose during paternalistic times in which disabled individuals were thought to be incompetent to manage their affairs. While this may be true for a very limited number, it is certainly not the case for most affected individuals.

The proposed changes will entail modification of South Carolina's Medicaid laws to expand the extension of personal care services in the home, and expanded installation of assistive technology. Steps should be initiated immediately in the legislature to prepare for passage of such legislative changes.

Without attempting to trivialize the superb work of the Task Force thus completed, it must be recognized that the most difficult challenges are ahead of us. Now that the Task Force has isolated the staggering array of issues impeding accelerated extension of community-services, the true size of the task confronts us. A multiplicity of issues remain in contention. I do not profess to possess special expertise in the analysis and resolution of such problems. Therefore, I do not feel especially qualified to render an opinion on many outstanding issues. However, with respect to the question of whether service coordinators should be independent of service agencies, or should be agency-based, my inclination, once again, is to offer a system with dual options, at the disabled person's election. The efficacy of such a dual system will be rapidly determined, and modifications can be made to adjust for any duplication of effort. The most important thing to do statewide is to promote information sharing among multiple agencies dealing with a disabled person. In these days of instantaneous communication and sophisticated information technology, we are nearly in the Stone Ages in utilizing the advantages of this technology statewide in the provision of services to disabled individuals.

My final comment is addressed to the issue of Oversight and Plan Modification. I am strongly of the opinion that an ad hoc (not agency commission-based) group be empaneled to monitor compliance with the plan. While I would certainly include agency representatives in such a group, I think it is critical that affected individuals not tied to any agency-orientation take the lead role in such a group. Although I have not discussed the proposal with her, I would heartily endorse Harriet Johnson, Esquire, for the leading role in this ad hoc group. As an affected individual who may (like all of us) someday require services, as an attorney at law familiar with the legal challenges of such a plan, as an independently-based disabilities rights advocate, Harriet possesses unique qualifications to see this monumental task through. We are, indeed, extremely fortunate in South Carolina to have someone of Harriet's caliber and integrity.

I hope that my comments have been of assistance to you. I appreciate your extending me a forum for such response.

Sincerely yours,

Aleta M. Pillick

Aleta M. Pillick
230 Meredith Square
Columbia, SC 29223
(home) 419-2800
(work) 253-3681

2380 Ole King Street
Conway, S.C. 29526

July 20, 2001

Charles Lang
DD Council
1206 Pendleton Street
Suite 372
Columbia, S.C. 29201

Dear Mr. Lang,

Congratulations to you and your Task Force on the draft of the report on Home and Community Based Services. It is great to see that the community at large will have the same lease restrictive environment standard as the public schools. The plan is very thorough.

My son Jason Silverman and I participated in the closed circuit broadcast at the Horry Georgetown Technical College site. When we arrived at HGTC, we were told that the building was closed for the summer. However, the custodial staff went to work cranking up the AC and trying to correct the thick atmosphere. The contact person, Janey Lewis came and adjusted the TV monitor and brought a TTY and a phone. These apparently didn't work,. and the phones across the hall were locked up. Another participant loaned Jason a personal cell phone so he could call in his comment. After a seemingly endless busy signal, he was able to get through. He was tremendously pleased to be heard. The comment format was very understandable to him, and if it is offered again the "bugs" will probably be worked out.

Jason is fortunate to have the kind of job that he can take off a day and make it up later. I am thinking that the few individuals in our community who might identify themselves as having disabilities and with full time employment probably couldn't participate. Jason is also fortunate because I was able to transport him because I have a school calendar. It is only because of prior efforts, such as Partners in Policymaking that he valued the opportunity to participate, and had the background to put the issue into context in his own life.

The issue of service coordination is a major one, if there should be any housing opportunities available. The turnover at DDSN as pointed out by the studio audience is a major hurdle. Scouting a path through the maze of steps is virtually impossible without a knowledgeable guide. We are ever hopeful.

Cordially,
Grace Gifford

July 19, 2001

Sarah O'Brien
9604 Highgate
Columbia, SC 29223

Charles Lang
Executive Director
South Carolina Developmental Disabilities Council
1205 Pendleton Street
Columbia, SC 29201

Dear Mr. Lang:

I was unable to attend the Olmstead Public Hearing. I have a 23-year-old son who lived at home until age 15, and because of hip surgery and the lack of appropriate and dependable family support services, residential placement became necessary. He is in a CTH II, and given what we had to do to secure that placement, feel that I must provide comments on the South Carolina Home and Community Based Services Plan. My comments are as follows:

1. **Assessing Needs of Children, Adults, and Elderly.**
   I support DHHS and DMH's proposals that an independent assessment process is in the best interest of the individual and family. One of the biggest barriers and problems for families is that we are pitted against the agency or systems and are afraid that if we are too vocal or assertive our individual will have services taken away. Having an independent agency or team that combines all agencies and other stakeholders providing services for that individual, as well as representatives from the family, the individual's circle of friends and any other organizations or representatives that may be able to assist in the assessment would ensure a fair and reasonable assessment of the individual and his/her right to live in the community with the supports that he/she needs.

2. **Service Coordination.**
   I support establishing a system of independent service coordination. It is a conflict of interest to have service coordinators employed by the agency that provides services to the individual. Service coordinators should be independent, well trained, well informed about resources available and should be accountable to the consumer and the family, not to an agency they work for. The individuals fimding should follow the individual not be controlled by the provider.

3. **Monitoring the implementation of the plan**
   I support establishing an ad hoc group that has the authority to refine the current plan and monitor agencies' progress in complying with all aspects of the plan, the group should cut across all disabilities and the specific needs of the different populations. It is important that agencies identify and eliminate barriers in sharing consumer information and services.

Should you have further questions, you may contact me at 898-0348.

Sincerely,

Sarah O'Brien

Sarah O'Brien

REPORT ON PUBLIC HEARING

SC HOME AND COMMUNITY BASED SERVICES

Site Location: Williamsburg Technical College, Kingstree, SC

Site Coordinator: Karen E. Ham, Vital Aging of Williamsburg County, Inc. (843) 354-5496

Number in attendance: 4

Comments: Viewer mentioned gratitude for solicitation of public input. Reported that the plan addresses pertinent issues regarding the Olmstead Act.

From: <XFLORPRST009@ddsn.state.sc.us>
To: GMSOEPP.OEPPMAIL(CLang)
Date: Thu, Jul 19, 2001 10:38 AM
Subject: Olmstead Teleconference

Final Site Report: Florence Darlington Technical College
Dawn S. Johnson/Florence County Disabilities and
Special Needs Board
19 attendees

Below are concerns given to me by a parent at the teleconference.
"We understand that there were only three parents of children in regional centers the Task Force. We do not feel this was fair representation."

Page 17 Quality Institutional Care

Not factual - quality in regional centers is superior to that in the community I have recently retired from a county board after 27 years of service and I know.
People in regional centers do have choices/experiences—gymnasium, swimming pool, trips. Also, they have ready access to medical and dental services, physical and occupational therapy, speech therapy, adaptive equipment, etc, etc.

Some of our individuals with severe disabilities and severe behavioral problems, as well as being medically fragile, need the intensive care they receive in a regional center.

County boards do good work and so do regional centers.

Other concerns that were expressed:
Our location was changed and no notice was given.
How were people notified about the teleconference.

Please let me know if any additional information is needed. Thanks

Dawn S. Johnson
FCDSNB
509 Clyde St
Florence SC 29506
843-678-8576 ext. 205

CC: GMSOEPP.GWIA("ghsingletary@fcdsn.org","hdavis@fcds...

Olmstead Taskforce Comment

DATE: July 24, 2001

Person: Ms. Kathy Baldwin

Type of contact: Telephone call

Comments: Very happy with the services being provided by Coastal Center. She does not believe persons with disabilities living in the communities are truly a part of the community. She does not feel the community at large accepts persons with disabilities, especially very severe disabilities.

UNIVERSITY OF SOUTH CAROLINA
SCHOOL OF MEDICINE

OFFICE OF CLINICAL AFFAIRS

July 23, 2001

Charles Lang
South Carolina Developmental Disabilities Council
1205 Pendleton Street
Columbia, SC 29201

Dear Mr. Lang:

Although unable to attend the Olmstead Public Hearing, I would like to offer comments through the public comments process. I am a pediatrician who has served children with special health care needs through a variety of venues during my twenty-three years in South Carolina. Through the University of South Carolina School of Medicine, I currently provide medical consultation to both the Children's Rehabilitative Services and BabyNet Programs. I am also the medical director of the Medically Fragile Children's Program, a Palmetto Health Alliance program which provides all-inclusive care to medically fragile children in foster care. I believe my experience qualifies me to comment on the South Carolina Home and Community Based Service Plan:

1.Assessing Needs of Children, Adults, Elderly.

I wholeheartedly support the recommendation for an independent assessment process. Only through assessment by a truly independent, interdisciplinary group of professionals can we establish consistency, impartiality and compliance with state and federal regulations which are vital to assure provision of all appropriate services to all South Carolina's needy.

2. Service Coordination

I strongly support that a system of service coordination which is independent of provider agency be adopted. Having had much experience with multiple manifestations of service coordination, uniformly I have found that no provider agency provides pure, family centered coordination in a systemic way to assure that ALL the family's needs are met through the variety of programs/agencies for which they may be eligible. This service coordination must include individuals with knowledge of medical conditions and understanding of the agencies who provide services in order to bring support and empowerment to the family.

3. Children with Special Needs

I strongly support the Committee's recommendations and emphasize the necessity for interdisciplinary teams which cross agency lines.

4. Expand South Carolina's Medicaid Options

I fully support the Committee's recommendations, particularly in the area of expansion to include personal care and private duty nursing services as options in the State plan.

5. Oversite and Plan Modification

Lastly, I agree with the need for a statewide, cross-*agency* implementation of the Olmstead Plan. The plan must be independent and consistent in its application and implementation.

Sincerely,

R. Porter

Ronald C. Porter, MD

From: "Hubert Walton" <intouch@bww.com>
To: "Nina Dorman" <Ninadorman@aol.com>
Date: Wed, Jul 25, 2001 10:44 AM
Subject: Special Needs of Children of South Carolina

To the Governor's Specially Appointed Task Force,

My name is Christine Walton and we live in North Augusta, SC. I attended the teleconference on last Wednesday at Aiken Tech, but we were unable to dial in. It was very important that I talk to you and you even mentioned that there were no comments relating to children. So I decided to email you with my comments.

We have a son with special needs. His name is Jonathon Walton, and Jonathon will be 2 years old this coming November. Currently, Jonathon is a long-term patient at the MCG-CMC in Augusta, GA. My husband and I brought Jonathon in to the emergency room at 3am on May 6, 2001. We expected the ER doctors to treat Jonathon for an infection and send him home within a couple of days. Less than 48 hours later we were informed that Jonathon does not have an infection, instead he has a massive tumor in his liver that has grown so large his lungs are not able to expand properly. It has been 11 1/2 weeks and I still do not have my son back at home. Jonathon has already been through 2 rounds of chemotherapy and a third round will start later this week. The Pediatric ICU doctors are doing a great job with Jonathon, but we have asked them to get Jonathon stable so we can bring him home.

Can you imagine what Jonathon is going through? Can you understand why we want to bring him home as soon as possible? Just a few thoughts to maybe help you understand our situation...

1.When I get to Jonathon's bedside, the first thing I do is take off the restraints. I have walked in and his little fingers have turned blue from being tied down all day. The nurses tie him down so they do not have to watch him, they can just come check on him from time to time.

2.When I have freed Jonathon's arms and hands, and calmed him down - he likes to tell me just what he thinks about being tied down like an animal - the next thing I like to do is check out his bed, very thoroughly. I take all the trash out of his bed, things like used alcohol pads, extra IV parts, thermometer protectors, saline vial caps, and lots of other dangerous items that could cause big trouble if he were to get these things in his mouth. (He is teething, four to six molars presently.)

3.I replace the bible back on his bed. This gesture really seems to offend some people, but we choose to protect him even when we are not there. In fact, the hospital will not even allow the Gideon International to place bibles in the patient rooms and waiting rooms. I know this because my father has been a Gideon most of my life.

4.There are many days that I am not able to get to the hospital. In order for me to be at the hospital I have to take my husband to work in Aiken, then drive to Augusta, then drive back to Aiken to bring him home at night back to North Augusta. I am on the road all day and all night just to be able to spend a few hours with Jonathon while Jonathon's brothers - Junior, age 8 1/2, Christian, age 7, and Britt, age 2 months - are being shuffled around town, getting up early and being out late every night. Now we are at a point in our finances that keeping the van on the road so much has cut seriously into our budget. We have to make a choice, buy groceries or spend time at the hospital. What would you choose?

5.When Jonathon was born, we knew then that he would require care that a day care could not give him. He was born premature, had several complications and setbacks, and I have not held a paying job since. I know all about Jonathon's care. I've become an expert on raising a child with special needs.

6.Jonathon has a nursing schedule already in place at home. His primary nurse visits with him every other day in the hospital and is up-to-date on his case. The funding for his nursing at home is already in place, we just have to adjust to bringing him home with a ventilator this time.

7.Finally, we need to put our family back together. We have a very close family bond and we have spent almost no time together as a family since the first week of May when Jonathon was admitted to the hospital.

With all of this in mind, I'm sure you can see that Jonathon would benefit greatly from being home during this time especially. He needs emotional and spiritual support that the hospital cannot give him and we are anxiously waiting to give to him, at home. We would never have to tie down his hands, we would never leave trash in his bed, and we would always be there to give him the care and attention that he wants and needs. IN HOME CARE is the best care for our son and we need to have him home just as much as he needs to be at home with us.

Thank you for your attention. Please feel free to contact me for any additional information or questions.

Christine M. Walton

AKA : Jonathon's Mommy

PS: I have been encouraged to contact you because many other families are not willing to for various reasons. There are many other stories similar to ours, maybe they will come forward soon. I have even offered to speak with them to encourage them to speak up for their children.

CMW

CC: "Charles Lang" <clang@govoepp.state.sc.us>

From: Penny Thompson <Penthompson@InfoAve.Net>
To: GMSOEPP.OEPPMAIL(CLang)
Date: Wed, Jul 25, 2001 12:57 PM
Subject: Olmstead Draft/Public Hearings

Dear Charles,
Enjoyed talking with you and was pleased that you asked me to serve as the SC representative to NADDC.
You know that I am happy to help in any way that I can.
As, I mentioned in our telephone conversation I have just a few comments about the Olmstead Draft.
Let me start by saying I think the task force has done a great job and they are to be commended for all their hard work.
Due to the budget constraints on all agencies, I feel it would be most helpful to try to get more involvement from the private sector. Some that I think would be helpful are the SC Chamber of Commerce, the main line religious denominations and the SC Home builder's Association and I am sure that there are many more that I am just not thinking of. Can you follow my line of thought ? The more people with disabilities that are employed the better, which will leave more funding for those that are total care and are not able to be employed. Also, church and civic groups might be able to supply some types of respite care.

I am taking a copy of the draft to a friend who has a severe disability and at present is in her own home with paid caregiver 24/7, which as you can imagine is quite expensive. This is the lady that Charles Larosa's VR is trying to get situated so she can do some free-lance writing.

Let me hear from you .

Penny T.

PROTECTION AND
ADVOCACY FOR
PEOPLE WITH
DISABILITIES, INC.

July 27, 2001

Mr. Joe B. Wilder
Post Office Box 447
Barnwell, South Carolina 29812

Dear Mr. Wilder:

Enclosed please find P&A's comments on the July 2 draft of the Home and Community Based Task Force Report. We look forward to our continuing participation in the important work of this group.

Sincerely,

Lesly Bowers
Managing Attorney for Advocacy

Cc: Harriet Johnson
Gloria Prevost
Charles Lang
Kathy Mayfield-Smith
Betsy Fuller
Kermit Short
Dr. Stanley Butkus
Jackie Robey
Mark Binkley
Bonnie Pate

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PROTECTION AND
ADVOCACY FOR
PEOPLE WITH
DISABILITIES, INC.

COMMENTS OF PROTECTION AND ADVOCACY FOR PEOPLE WITH DISABILITIES On the JULY 2 DRAFT of the SOUTH CAROLINA HOME AND COMMUNITY BASED SERVICES TASK FORCE

P&A hereby submits the following comments on the current draft of the report of the Task Force. These comments are directed at further changes and developments that we want to see in the final report, but we also want to take this opportunity to commend the Task Force for it's commitment to the principle of providing services and supports needed by people with disabilities in the places where they choose to live. The strengths of this draft include: the statement of core values; the collection of information about disability services from numerous agencies and service providers; the fact that is the most comprehensive effort of our state to date to address these issues across disabilities, age, geographic areas of the state; and the fact that it reflects many different points of view.

We first reiterate several general comments we made in response to the previous draft. As we stated and the Task Force agreed at the last full Task Force meeting, we think that the gaps and barriers section should be significantly streamlined, and not broken down by agency. Because this edit is not yet complete, we are not providing detailed comments on this section of the current draft at this time.

We appreciate the chart of services, however the sections on the numbers of people on waiting lists are incomplete. This information needs to be obtained and included. We are also concerned that the report is without a budget analysis, timetables and operational processes and terms. Clearly further study and planning will be needed for this to be an effectively working plan, and we think that the report should address this, and address the continuing involvement of the range of stakeholders who are currently participating in the Task Force, especially consumers.

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We continue to have concerns about language on page 7 regarding "levels of expertise in care" as regards the continuum of service sites. We think that this report should reflect a clear and consistent commitment to the continuing development of services that allow even individuals with very severe functional limitations to live in the community and control their lives to the maximum extent possible.

We recommend several other specific changes in this draft. First, we recommend the addition of the phrase "or by agency policy or procedure" to the end of the first sentence paragraph 5 on page 25. It is our experience that many people with disabilities are found to be ineligible for services due to an agency's policy or procedure, whether for reasons of priority setting or definitional categorizing. Services should be available to people with disabilities on the basis of functional need rather than category or definition of disability.

Next, referring to the first paragraph of section A on page 27, we think that "health and safety issues" should not prevent a community choice. Resolving such issues and/or allowing a competent individual to assume risk is an integral part of what should be done by service providers. We recommend revising this section to read as follows; "Those who want to move from institutions to the community need to be able to do so. South Carolina should ensure that people with disabilities living in state-operated institutions or private 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." This same comment applies to the health and safety language found on page 30, section 2 a.

We recommend modifying the language on page 34, section E. 1 be consistent with the recommendation that persons with disabilities have the right to self-direct unlicensed personal assistants. We suggest replacing "all consumers" with "those who use facility- or agency-based services."

We recommend the language in paragraph 5 (e) bullets 1 and 2 on page 38 addressing the dignity of risk be combined and read: "When a person returns to an institution from the community, an analysis will be done with the consumer, the community staff and the institution staff determine why the person returned to the institution and what services/supports need to be in place when they return to the community."

We also ask that a recommendation be added that consumers have access to training, support, and advocacy to make use of Social Security work incentives.

The section on Assistive Technology on page 40, should include several additional recommendations to address the identified gaps/barriers. These recommendations should include making assistive technology available to individuals in hospital or other facilities so they can learn how to use it before moving to the community, and maximizing Medicaid and other funding for devices that can increase independence and/or decrease the need for recurring services.

We recommend reordering and clarifying sections 13-14 on page 42. We think that the discussion of self-directed services is important enough to be given its own section and more prominence, perhaps grouped with some of the other "autonomy" recommendations. Also, when family is discussed, there should be a clear statement that families are involved with planning and the provision of support services for competent adults only if that adult so chooses. Any competent individual may opt to have other trusted people (friends, lovers, clergy, etc) fulfill the "family" role, or may choose to act autonomously and independently of the support structure. Family support is important to most people and systems should be available to strengthen families, but there are people in the system who do not want the state involved with their family relationships. They should have the option to just sign up for funding for self-directed attendant services.

There are several issues raised in this draft which remain unsettled. One is whether service coordinators should necessarily be independent of the agencies providing services. P&A takes the position that service coordination is a function that should be independent of any service-providing agency. If an individual only wants an agency-based waiver slot and "program," an independent coordinator may not be necessary; a caseworker employed by the agency could help her/him through the process. Also, the option should be available for people to coordinate their own services.

Assessment is another area that presents unsettled issues in the draft. P&A supports a unified, cross-disability identification and assessment process, coordinated by DHHS with appropriate resources, input and cooperation from the relevant agencies upon initial entry into the long-term services system. We recommend this as an addition to, not a replacement of the agencies' on-going and internal assessment processes once people enter their service delivery system. But, for the existing client base, each agency should incorporate Olmstead/community integration issues into routine planning and evaluation, including habilitation plans, treatment plans, person-centered plans, etc.

In the months since the Task Force was convened, P&A advocates in just a small area of the upstate have found numerous young adults and middle aged individuals with severe disabilities who are living in nursing homes for lack of appropriate community services and housing resources. Most of these individuals had not been identified by any of the agencies for whose services they are eligible. Thus these individuals, and many more across the state, we believe, are not even represented on our current waiting lists. To obtain an accurate assessment of the extent of the need for community services in our state, it will be essential to conduct a state-wide, unified cross-disability search as well as individual assessments of citizens who desire to move to the community. The HHS work group's report included a description of a unified assessment process together with specific steps that such a process should include. We recommend that description be used in this report. We also think that DHHS, as the fiscal agent for the majority of funds supporting people with disabilities in South Carolina, and as a non-service provider, should maintain and monitor all waiting lists. This would provide the state and our legislature with a cross-agency independent wait list to better inform our state's community services planning efforts.

Another unsettled issue in this draft is whether a moratorium on new nursing home and institutional beds is called for, or whether some new growth is needed. We would call for a moratorium on all new residential beds unless the entity seeking the new beds can show (a) that the beds are needed to prevent immediate, serious harm or to provide an alternative to more restrictive placements, (b) no non-residential option is feasible, and (c) all possible steps have been taken to reduce capitalization or sunk costs and/or to make capital recoverable or convertible to other uses when expansion of community services make such beds unnecessary.

As regards the recommendation on page 32, paragraph 3 concerning nursing home units for younger people with disabilities, we support funding streams that allow people to live together and pool resources in their own places rather than encouraging nursing homes and agencies to develop such specialized units. It is our experience that young people's nursing home units are often proposed by people who cannot envision severely disabled people living in a non-institutional setting. Past experience has shown that clustering young people does not make a happier institutionalized population.

Other large issues still remain unanswered in this draft. How will the plan be implemented? Who will crunch the budget numbers? What systems are needed to ensure quality? How do we measure outcomes and ensure accountability? The report should include recommendations that each agency have responsibility to implement the plan in its own programs and report periodically to its governing board and to the public. DHHS should provide a full budget and fiscal impact analysis and further data should be developed as assessment and waiting list management becomes centralized. A cross disability and agency working group, including consumers and advocates, should define operational objectives, measurable outcomes, and accountability techniques. The Joint legislative committee on disability should be revived for broad oversight and to coordinate legislative changes. The Legislative Audit Council should be called upon to conduct periodic monitoring and provide reports to the legislature. Structures should be created to ensure consumer/advocacy involvement at all levels.

In conclusion, we submit a final general comment that applies to the report in its entirety. Throughout the draft we should avoid implying that institutionalization is "appropriate," "necessary" or "needed" for people in general or any particular class of people. There is a wide range of philosophical and practical opinion on whether institutionalization is ever truly "necessary" and, if so, when. This report stands for the proposition that people should be offered choices suiting their individual needs and desires. We have seen the successful deinstitutionalization of many individuals who, 10 or 15 years ago, would have been considered unable to live in the community. While we have made it clear that we would not force anyone out of an institution or disrupt life choices already made against their will, we should avoid pre-judging anyone's needs as we begin the next stage of this process.

Respectfully submitted,

Harriet Johnson by LAO

Harriet Johnson
Gloria Prevost
Protection and Advocacy for People with Disabilities

APPENDIX G

Contacts for Workgroup Reports

Contacts for Workgroup Reports

If you would like a copy of one or more of the individual Workgroup Reports, you may obtain the reports from the contacts listed below:

Health and Human Services Workgroup
Ms. Elizabeth M. Fuller, Deputy Director
Department of Health and Human Services
Office of Senior and Long Term Care Services
P.O. Box 8206
Columbia, SC 29202
Ph: 803-898-2501
or Ms. Marvel Frick
Email: fullerb@dhhs.state.sc.us or frick@dhhs.state.sc.us

Disabilities and Special Needs Workgroup
Paul P. Peterson, Ph.D., Director
Division of Quality Assurance
Dept. of Disabilities and Special Needs
3440 Harden Street Ext.
Columbia, SC 29240
Ph: 803-898-9691
Email: PPeterson@ddsn.state.sc.us

Mental Health Workgroup
Ms. Mallory Miller
Department of Mental Health
TLC Program Consultant
7901 Farrow Road
Columbia, SC 29203
Ph: 803-935-5376
Fax: 803-935-5054
MGM43@DIRM.DMH.STATE.SC.US

APPENDIX H

Other Comments

Stanley J. Butkus, Ph.D.
State Director
Robert W. Barfield
Deputy State Director
Administration
Brent H. Koyle, Ph.D.
Deputy State Director
Services and Supports

SOUTH CAROLINA
Department
OF
Disabilities
AND
Special Needs

3440 Harden Street Ext (29203)
PO Box 4706, Columbia, South Carolina 29240
V/TTY: 803/898-9600, FAX: 803/898-9653
Toll Free: 888/DSN-INFO
Home Page: www.state.sc.us/ddsn/

August 16, 2001

Mr. Charles Lang
Director, Developmental Disabilities Council
Office of the Governor
1205 Pendleton Street, Ste. 372
Columbia, South Carolina 29201

Dear Charles:

Thanks for the opportunity to provide the feedback/comments on the Draft Olmstead Plan.

I would like to comment on several areas. My comments will reflect on what we are doing now and what we might need to change to meet the intent of Olmstead.

I. Assessment

A. Persons in Institutions

There is interest in having independent assessment for persons in institutions and those at risk of going into institutions. The recommendation and thinking is that this should be completed across agencies and by an independent entity. It certainly makes sense that persons in institutional programs have a review mechanism. Agencies have different approaches. At DDSN there are several mechanisms in place for DDSN consumers served in institutions.

1. There is a Medicaid requirement for persons placed in institutions (known as ICFs-MR) that state professionals review on an annual basis the continuing need for such placement and interest in going to a community option.

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Regional Office - Phone: 843/832-5562
9995 Jamison Rd., Summerville, SC 29485
Coastal Center - Phone: 843/873-5750

MIDLANDS REGION
Regional Office - Phone: 803/935-7412
8301 Farrow Road, Columbia, SC 29203
Midlands Center - Phone: 803/935-7500

PEE DEE REGION
Regional Office - Phone: 843/664-2601
PO Box 3209, Florence, SC 29502-3209
Pee Dee Center - Phone: 843/664-2600
Saleeby Center - Phone: 843/332-4104

PIEDMONT REGION
Regional Office - Phone: 864/938-3101
PO Box 239, Clinton, SC 29325
Whitten Center - Phone: 864/833-2733

2. Each year those institutions are independently reviewed by DHEC and among other things, DHEC certifies that each person who is there needs to be there because they require that level of care.

3. Since January of this year there is a new federal requirement that a national contractor independently reviews the DHEC surveys within 30 days of DHEC's own review.

These levels of review, we believe, exceed Olmstead's requirements.

B. Persons at Risk of Inappropriate Institutionalization

In 1998 DDSN began implementation of person-centered services – a key element is the person-centered planning process. Trained plan facilitators independent of DDSN and service providing agencies, develop a plan based on life goals with the assistance of a circle of support or social network chosen by the consumer and family. The emphasis is on how services help individuals achieve life goals. The list of qualified individuals was broadened, at the request of families, to include designated disability board staff who have been trained to competency in plan facilitation. The plan is the driving force. It identifies life goals and how services can assist in their achievement. As part of this process relevant assessments are also reviewed and considered. Determining life goals and needs, and preferences for how those needs can be met is essential and individually authentic to the person.

Persons at risk of institutional placement have this independent process available to them as well as those persons choosing to move from the institution. Persons who require immediate assistance are put on a critical list, which is monitored closely by local boards, regional field offices and our central office.

Independent Service Coordination

There is interest in independent service coordination. DDSN's position is that it should be a choice that the consumer/family may make among several qualified providers of service coordination. It may or may not be done by the entity providing direct services. The rationale is that many consumers/families are satisfied with their current service coordination. By allowing choice rather than mandating independence the consumer/family maintains choice and control. If independence is mandated one important choice is eliminated. If independence is mandated and service coordination is provided by only one entity, there is no consumer/family choice. Services including service coordination have an increased likelihood of being responsive when the consumer has the power to choose who they want.

The opportunity to choose an independent plan facilitator when combined with the opportunity to choose a service coordinator ensures that the consumer/family is in a strong position.

Service Fragmentation

There has been commentary on service fragmentation. Problems exist where there is poor coordination. Creating generic intake and assessment is not the answer for poor coordination, improved coordination is the answer. Where coordination is not the problem, it is usually a lack of resources to address agreed upon needs. In terms of coordination there needs to be trained professionals in social work, psychology, nursing and psychiatry who have the skill and experience to do differential diagnoses. Simply re-aligning current employees will suffer from the same results. The need for more resources is a constant over which we have no direct control. We do have control over how we coordinate and we can do better.

Functional Definition of Disability

There has been concern raised that there are persons whose category of disability may not be included in current agency responsibilities. Persons with MS and MD are often cited as examples.

In discussions with co-chairs recently, there seemed to be some agreement that definitions for persons served by DDSN and DMH are clear and have a long standing body of clinical practice and data that support them. They are in fact, tied directly to functional deficits. It seems, consequently, that the groups that are not served by category of disability should more logically be grouped with an agency that has responsibility for persons who have long-term chronic health problems. For example, the major alternative to nursing home placement is the community long-term care waiver. Admission to that program is based on an assessment of functional deficits. For those additional populations that may be considered it would be important to develop an estimate of the number of individuals and an estimate of per person cost so that an accurate request for legislative support might be developed.

In short the mechanisms to do functional assessment are already being employed in South Carolina. The fact that they are located in two agencies with responsibilities for specific populations and a third that is responsible for more generic health needs is an advantage. It makes sense to have specialized capacity to properly evaluate the needs of persons with a range of disabilities. Who among us seeks out a general practitioner if we have a serious cardiac problem?

As a general summary comment, much effort and good thinking went into the development of the plan. There are areas in which improvements can be made. The key is how we define the problems because that will help us to review paths to their resolution. If we "misdiagnose" symptoms as problems we may be very frustrated down the road that we have not reached the results to which we aspire.

It has been a pleasure to work with this group of people. South Carolina has many good service delivery systems on which we can build.

Sincerely,

Stan Butkus, Ph.D.
State Director

SB/jst

Patrice L. Crogen
1500 Brookview Road
Columbia, SC 29212
1-803-749-4042

August 16, 2001

Mr. Charles Lang, Executive Director
SC DD Council
1205 Pendleton St., Room 372
Columbia, SC 29201

Dear Mr. Lang,

I was unable to attend the public hearing regarding the Olmstead ruling. Redick Loring suggested that if I could not attend to be sure to write you a letter regarding my concerns about services for our special needs citizens.

My son, Christopher was born with Rubinstein-Taybi Syndrome in 1984. He has some physical limitations as well as significant mental disabilities. Chris attends a special education classroom at Irmo High School.

A huge roadblock facing myself and parents of other special kids aged 13 to 21 is the absolute lack of safe, affordable and available after school and summer care programs for our kids. I call the years 13 to 21 the "Lost Years" when it relates to these programs. Our kids are too old to go to "regular" daycare and are not old enough to attend adult day care or workshop programs. Every year we parents ask each other, "What are you doing with your child after school?" or "What have you found for your child this summer?" I know so many parents in situations where one has to curtail work hours to care for their special older child. I do not have that option as I am a single parent and must work all day, five days a week.

I have been fortunate this year in that I found a wonderful woman experienced in working with special children to care for Chris after school, from 4:00pm to 6:30pm…for a fee of $75.00/ week that I can't include on my taxes because it will hurt her tax situation. Believe me when I say I was truly lucky to find this person. However $75.00 is pretty steep for part time care. I don't know what she will charge me for school vacations at full time or if she will even be able to watch Chris during those vacation breaks. She hasn't decided that yet.

Mr. Lang, we positively need safe, supervised and affordable programs for our special children both after school and all day during the summer. The summer camps are wonderful, but they do not fulfill the need for all day programs.

Please consider this when preparing your report to Governor Hodges. Thank you for your kind consideration.

Sincerely,

Patrice L. Crog

Patrice L. Crogen

Reine S. Lantz

Member, **Family Advisory Council**
Federation of Families of South Carolina
2432-A W. Willwood Drive
Florence SC 29501

Telephone (843) 679-3306
Fax (843) 679-9790
Email: irishrose@usns.net

URGENT

17 August 2001

Mr. Charles Lang
Office of the Governor
Office of Executive Policy and Programs
Division of Constituent Services
1205 Pendleton Street
Room 463
Columbia, SC 29201

RE: Home and Community-Based Services Task Force Report of 9 August 2001

Dear Mr. Lang:

On 15 August 2001, I received a copy of the 9 August 2001 revision of the 2 July 2001 Draft Report of the *South Carolina Home and Community-Based Services Plan*, after speaking with Ms. Curlee on or about 9 or 10 August 2001, after I returned from the 4-7 August 2001 SAMHSA Conference held in Washington, D.C.

Included with the revised Draft Report were copies of written public comments and a copy of a synopsis report concerning the teleconference of 18 July 2001 (though the synopsis is titled "*Olmstead Public Comments--June 18, 2001*"). Among the written public comments was a copy of a document submitted by way of fax transmission on 3 August 2001 to Ms. Mary Curlee of the South Carolina Department of Mental Health, which I requested that Ms. Curlee then submit to you.

I note that the document is almost illegible, due to the apparent "reduction" of the text through the process of fax transmission. I have reformatted the document into larger text, and it is included under this cover letter. I respectfully request that the reformatted version be attached to the original version, so that the "open letter" can be read more easily. The "open letter" was broadcast within Florence and Darlington Counties, during the week ending 3 August 2001, as an attachment to an announcement flyer concerning a then-forthcoming meeting of our local parent support group sponsored through the Federation of Families, requesting parent participation in the public comment process.

Further, I have also included hereunder a copy of a letter dated 14 April 2001 that I submitted to the DMH Work Group through Ms. Curlee. I also respectfully request that this excerpt be entered into the public comment record.

The Chairman of the Department of Mental Health Work Group did not allow my membership on the Work Group. I did not learn that the "Olmstead Plan" process was being conducted within our state until late March 2001. Within 24 hours of learning of the process, I was on the phone with Ms. Curlee discussing it. Ms. Curlee eagerly invited my participation. On or about 6 April 2001, Ms. Curlee transmitted an email to me to tell me that her Work Group's Chairman did not want another member on the Work Group at that late date in the process.

Unfortunately, the email message was addressed improperly, and it "bounced back" to Ms. Curlee. Ms. Curlee then forwarded a copy of the email message to me through the regular mail. In response to that, I submitted the letter of 14 April 2001 to the Work Group through Ms. Curlee. My email address then changed--because my ISP unexpectedly had to change server services--to irishrose@usns.net--effective 8 June 2001.

I then learned through the Federation of Families office in Columbia that the Mental Health Association of South Carolina was to hold a "Children's Forum" in Florence, where I live. I had little time to alert our local community of parents of the forum. The "Children's Forum" was held on Tuesday, 12 June 2001. Three parents attended. The bulk of attendees was comprised of employees of various agencies, and the agency most heavily represented at the forum was the Department of Juvenile Justice.

During the forum, Louisa Prescott, Ph.D., CEO of the MHA in South Carolina, notified us that a statewide "teleconference" would be held regarding the state's "Olmstead Plan" on 18 July 2001, from 10 a.m. until 12 noon. I marked my calendar. During the week ending 13 July 2001, I attempted to learn about the specific time and place of the teleconference for this area. I had to make more than half a dozen calls into Columbia to determine the place and circumstances of the teleconference for this area--which turned out to be Florence-Darlington Technical College.

I arrived at the stated building and room on 18 July 2001 to learn that the teleconference reception room had been moved to an entirely different building, on the opposite side of the campus, without advance notice to potential attendees. I had to walk clear across the campus. After I arrived, and signed in, I learned that the Draft Report of 2 July 2001 had already been completed and published effective 2 July 2001. Only one copy of the Draft Report was available for review. During the teleconference, an internet web site address from which the Draft Report could be accessed was flashed on the screen. Later that day, I accessed the Draft Report in pdf format and printed it out. It was then that I learned of the existence of several appendices to the Report that were not available via internet.

On or about Thursday or Friday, 19 or 20 July 2001, I spoke with you at length, after having spoken with Ms. Curlee about the problems regarding the teleconference, and about my dismay at learning that the Draft Report was already well into the public comment period--and absent its referenced appendices, at that. Ms. Curlee gave me your name and telephone number. Pursuant to our conversation, you mailed the appendices and source documents for the Draft Report to me. I received them on Monday, 23 July 2001.

I was not particularly impressed with the Draft Report, nor with the source documents from which it was drawn. Among other things, the overall process through and from which the Draft Report was generated was seriously and fundamentally flawed; therefore, the conclusions and recommendations within the Draft Report are based on flawed premises, on skewed, statistically invalid data, and poor planning. The most basic and fundamental processes and approaches of good scholarship and scientific method are almost entirely absent in both the products of the Work Groups and in the Draft Report.

Further, I found that it would be impossible for me to study the Draft Report and its source documents in sufficient detail to be able to generate a properly crafted "public comment" report using proper conventional citation (such as footnotes, etc.), and proper techniques of written argument, in time to submit it by the deadline of 27 July 2001. I calculated that my own "public comment" on them would result in a report nearly equal in length to that of the Draft Report itself. I have severe bilateral carpal tunnel syndrome, and such a task, at best, would consume approximately two weeks of full-time effort if it were to be a reasonably comprehensive and well-crafted comment on both the products of the Work Groups and on the Draft Report.

Therefore, because I was scheduled to attend the SAMHSA Conference in Washington, D.C. during the time period of 4-7 August 2001, I generated the "open letter" document, attached it to our parent support group flyer, and distributed it throughout Florence and Darlington Counties on Friday, 3 August 2001. I also submitted it to Mary Curlee via fax, requesting on my cover sheet that she submit it to you.

I spoke with Mary Curlee upon my return from Washington, D.C., on or about 9 or 10 August 2001. On Wednesday, 15 August 2001, I received a package from Ms. Curlee, within which were included the 9 August 2001 revision of the Draft Report, copies of written "public comment" submissions (including a copy of my "open letter" document, showing that it is nearly illegible in that format), and a memorandum by Mr. Wilder regarding the meeting today scheduled for 1 p.m.

I then spoke with you. I alerted you to the fact that my "open letter" document is illegible, and that the synopsis of my comments made during the teleconference of 18 July 2001 both spell my name incorrectly ("Wren" instead of "Reine") and characterize my comments inaccurately.

You were not particularly pleasant during that conversation. You told me that the 9 August 2001 revision of the Draft Report is "final," that the purpose of the meeting of today at 1 p.m. is basically to present the "final" version of the Draft Report to the Task Force, and that the 9 August 2001 revision will be submitted to Governor Hodges in its current form on or about 3 September 2001.

Therefore, despite my best and persistent efforts as a taxpaying citizen and stakeholder to participate in the process of developing South Carolina's "Olmstead Plan" immediately from and after belatedly learning of the existence of the Task Force, I have been effectively foreclosed from doing so in any meaningful way at every turn.

I respectfully request that this letter, and its enclosures (reformatted "open letter" and the 14 April 2001 letter to Ms. Curlee), be submitted along with the 9 August 2001 Draft Report to Governor Hodges when the Task Force submits the Draft Report to him on or about 3 September 2001.

Respectfully submitted,

Reine S. Lantz

Enclosures: Reformatted version of "Open Letter..." of 3 August 2001
14 April 2001 letter to Mary Curlee of DMH Work Group

Copy-Signed

Reine S. Lantz

2432-A W. Willwood Drive
Florence, SC 29501

Telephone (843) 679-3306
Fax (843) 679-9790
Email: irishrose@flosc.com

14 April 2001

Ms. Mary Curlee
CFSH
c/o South Carolina Department of Mental Health
2414 Bull Street
Columbia, SC 29202

RE: Recent Email, and further considerations re: Olmstead Plan

Dear Mary:

Thank you so very much for sending me a copy of the 6 April 2001 email that "bounced back" to you. I have sent two postcards to you in brief response to the same. My correct email address is as follows:

irishrose@flosc.com

Please note that there is only one "dot" in the address, between "flosc" and "com". Also, I note that my mailing address is spelled incorrectly (no big whoop--happens all the time for some reason). Must be my "foreign accent" that does that to folks!! My correct mailing address is:

2432-A W. Willwood Drive
Florence, SC 29501

Please note that the street name is "Willwood" and not "Wildwood." "Wildwood" is the name of a street in Quinby, and "Willwood" is our little small "dead-end" drive in Florence. Don't feel bad, though. UPS, FedEx, and the USPS have actually scratched out correctly-spelled "Willwood" on envelopes and packages addressed to us, and have written in "Wildwood" many times over the years; then a letter, or package, or overnight or Express Mail item has been sent to Quinby--and of course, such a street number in Quinby does not exist--and then an item is returned to this or that dismayed sender. I have fussed and fumed to UPS, FedEx, and the USPS over the years about that.

On top of that, "Willwood" does not appear on any map--because when our apartment complex was built about 1991, "Willwood Drive" was (and I think technically still is) a "private drive" and not a "public street or road." Go figure. Then, of course, there is my "foreign accent"--borne of having been born (as a "southern gal") to two "yankees" (who remained in the south--making me a bona fide "grits"--that is, a "girl raised in the south") and then modified over the years by my attempts to sound "southern normal." (I prefer to use southern speech. While my folks did not have "harsh" "yankee accents," they did speak quite fast relative to southern speech patterns, and I have had to work hard to modulate my own to match the cadence of southern speech.) I end up just sounding "weird" to folks! Worse yet, the pollen counts lately have meant that my usual "soft voice" has ended up sounding like a fog horn! Oh, well.

I thoroughly enjoyed our conversation several weeks ago. I have been bragging ever since about you and your sensitivity and compassion toward those having psychiatric disorders and toward their families. I am so glad that South Carolina is working to comply with and to implement the requirements embodied in the *Olmstead* decision. I fully understand your work group chairman's wish to keep the work group composition in its current form. Group dynamics being what they are, adding another person could and probably would alter the dynamics to such an extent that the result might affect the work done thus far, either in a negative way, or by complicating or delaying its report. That said, I much appreciate your willingness to consider the gist of my concerns, and I am grateful for your having relayed them to your chairman. I do suggest that your work group secure the comprehensive needs assessment that I think was conducted by or on behalf of the Continuum of Care, or by or on behalf of some agency connected with the Continuum of Care. I believe that Felicity Costin Myers, Ph.D., director of the Continuum, will be able to secure a copy for you. You will find Dr. Myers to be a great resource for your work group.

PACT programming is a particular interest of mine and that of most other families with whom I have been in contact (both within South Carolina and across the country). Moreover, PACT-model service structure and delivery is the optimum response to the mandates of the *Olmstead* decision. For so many families--perhaps for the majority of families --the stresses and burdens of living with and caring for a child or for any other family member having a psychiatric disorder prove to be overwhelming. PACT-less states and communities have higher rates of psychiatric hospitalization and patient bed-days, greater rates of relapse, higher population rates of incarceration, higher high school dropout rates, higher psychiatric morbidity and mortality rates, higher homelessness rates, and higher just-about-every-thing-unpleasant than do those states with broad-based and -funded PACT programming.

The development and implementation of PACT programs as a first-line service delivery structure for anyone having any psychiatric illness would do so much toward preventing and relieving not only morbidity and mortality rates within the population of those having psychiatric illness, but also toward preventing and mitigating the "spill-over" and "ripple" effects that percolate first through affected families and then through the entire social and economic fabric of society. With 20-25% of all families being affected by this or that psychiatric illness, the true cost to society under current fractured and piecemeal forms and structures of service delivery is staggering.

I discuss only a few of the myriad of social and economic costs below:

Most affected children do not receive accurate diagnosis, nor adequate, appropriate treatment that allows them to continue their development into functional, productive members of society. Even for those very, very few children who are favored with accurate diagnosis and adequate treatment and services, their educations are poorly delivered --if their educations can be said to be delivered to them at all. For almost all children suffering from this or that psychiatric illness, their potential life trajectories are permanently altered and foreshortened, and their potential incomes, purchases and tax contributions are forever shriveled by lack of accurate diagnosis and lack of adequate treatment, and by an almost total lack of comprehensive, adequate and appropriate service delivery.

Aside from that, for most of the families with whom I have had direct contact over the years, the mother must quit working, or cannot work, due to the many burdens that must be assumed to assure some measure of treatment, management, and service delivery adequacy and appropriateness for their affected child(ren). One-income families, and sub-optimum-income families do not pay as much in taxes as do those whose incomes more closely match their income-producing potentials. Those families further have lower disposable incomes with which to purchase perishable and non-perishable goods and services than do those who have fewer asset- and income-eating obligations.

For those families reduced to subsistence levels of survival on various forms of public assistance as a direct or indirect consequence of psychiatric illness in their children or in other of their family members, they become net consumers from the public trough rather than net contributors to society.

Even for those families with above-average and above-median incomes, the presence of a chronic or catastrophic illness or injury within one or more of their members quickly drains, dissipates and then ravages their current and future financial security.

For those families whose "chronic, catastrophic illness" is that of psychiatric illness, the lack of commercially-available insurance and public-assistance coverage parity eviscerates both adequate treatment and service delivery and continuity-of-care possibilities, and those of family financial and social cohesion.

Mothers assume the unpaid and unappreciated simultaneous mantles of case manager/coordinator, clinical observer/reporter, practical nurse, legal/medical/educational advocate, appointment secretary/taxi driver, special educator, financial/insurance administrator, and legal/ medical researcher, among others. All of the children in families having at least one child suffering from psychiatric illness for all practical purposes lose their mothers to these roles. The children in intact families become at least "quasi-orphans"--in very real ways--due to the presence of psychiatric illness in themselves or in their siblings.

Stress affects every member of a family. Stress has been definitively proven to contribute to higher rates of morbidity and mortality and lost productivity across the board.

My family and I are squarely within that number. When one calculates those "hidden costs" from the aggregate of population incidence rates for psychiatric illness (which aggregate rates are much higher than are those for almost any other kind or type of chronic illness), then not to address the economic drain alone on society as a whole is more than irresponsible for those in business, for those in service delivery, for those in policy-making roles, and for those in public service.

For a large percentage of families having at least one child with any chronic illness--or with any catastrophic illness, injury or impairment--mothers often eventually also must assume the roles of sole breadwinner and sole caretaker, for most marriages and families disintegrate under the weight of the personal and financial effects of chronic or catastrophic illness or injury in their children. Fathers leave and in other ways abandon their families to uncertain fates. For example, while my marriage remains intact (our 16th anniversary was Thursday, 12 April), its edges frayed for a time while both of us grappled together and separately with the simultaneous weights and burdens of: unfathomable grief over our son's suffering and rapidly escalating and complex needs; with those imposed by deliberately opaque, labyrinthine, and adversarial service provision and payment systems; with those of profound social stigma and isolation; and under those of concomitant growing and almost unmanageable financial impact.

Our family's "divisions of labor" fell on either side of a line that is only too common within families having a child or other family member with psychiatric illness. While my husband worked 80-hour weeks to support us (not including his daily commutes totalling two hours per day), I assumed all other responsibilities and duties for our son and for our family. For the first 5- 1/2 years following our son's diagnosis, even though my husband worked 80-hour weeks with approximately 10 additional hours per week of commuting time, <u>he</u> worked only five days per week. <u>My</u> various unpaid and onerous duties and obligations as a parent of a child with psychiatric illness consumed 24 hours per day,. 7 days per week, 365 days per year. During the first 5-1/2 years following our son's diagnosis, I was able to rest from those duties and obligations for a mere three days. I was able to sleep an average of perhaps two to three hours per night. My husband likewise had perhaps three to fours hours of sleep per night. By necessity, my husband and I became mere "roommates," while our son became more than a "quasi-orphan."

Current service delivery and program delivery models and structures favor out-of-home placements and out-of-home moderate-term and long-term residential placements and hospitalization for youngsters having serious and severe psychiatric and related disorders. These service delivery and program delivery models and structures "orphan" parents and their children, imply that parents are at least inadequate and perhaps neglectful of their mentally ill children, and causally contribute to family dysfunction and disintegration. Parents are not inadequate or neglectful so much as that severe psychiatric illness demands time and resources beyond the reach and stamina of any single-parent or any two-parent household, especially for those households having more than one child.

When someone is so seriously ill, then it is necessary for an entire, comprehensive team of professionals and paraprofessionals from all service delivery sectors to work together to help these families and their children to stay together whenever possible for as long as possible--with minimal time apart in the sense of out-of-home placement. Conversely, though, family respite services on a more or less regular basis are necessary to prevent reciprocal "burn-out" between these "high-cost," "high-maintenance" children and their families.

For those whose psychiatrically ill family members are adults, whether those adults are siblings, spouses, or their children, similar comprehensive multi-disciplinary teams must work both with those who are ill and with their families to facilitate and optimize medication and treatment compliance, stability and functioning, independent living skills and housing, and to secure employment opportunities.

It is common knowledge that our nation's jails and prisons serve as de facto psychiatric facilities. I have seen figures drawn from studies that indicate that upwards of 60-, 75-, and even 80% of those in some way involved with the juvenile justice and correctional systems are in fact afflicted with one or more unrecognized psychiatric illnesses and comorbid difficulties such as learning disabilities. I have seen related figures that indicate that upwards of 50% or more of those involved with the adult criminal justice and correctional systems are likewise afflicted. Other studies well establish that a significant percentage of those with untreated and inadequately treated psychiatric illness "self-medicate" with alcohol and street drugs, both addictive problems then making significant contributions to the "crime rate."

Correctional and other criminal detention facilities function more as "boarding schools" to educate their residents into criminality and recidivism, than as sanctuaries of treatment, recovery or rehabilitation. Most of those in detention and correctional facilities stand accused or convicted of status and non-violent offenses. Most of them emerge from those detention and correctional facilities all-too-well schooled in the art of criminality. Such an outcome is doubly tragic, for those who emerge so schooled who also suffer from psychiatric illness then contribute to the stereotyping and stigma that society attaches to our law-abiding ill family members and by association to our long-suffering families.

It is also common knowledge among certain service-delivery-system professionals and stakeholders that those with psychiatric illness are more often *victims* (especially within jails, prisons, and other detention facilities) than they are "perpetrators." Our society "criminalizes the ill" and is beginning to "medicalize the criminal." Nevertheless, of all things for example, our own state's General Assembly legislated, and then appropriated the funds, to place repeat predatory sexual offenders within the mental health system after serving their prison terms, while the psychiatric and mental health experts steadfastly maintained that predatory sexual offenders are criminals, not ill.

Properly designed, staffed, and trained PACT teams assume the practical, personal, and professional burdens and obligations of advocacy, treatment and service delivery, recovery and rehabilitation, allowing family members and treatment consumers an opportunity to reestablish and to repair their natural relationships and the "ordinariness" of their pre-illness lives. PACT clients and their families have opportunities to remain with, or to re-enter and to contribute to society. PACT programming reduces morbidity and mortality, hospitalization and inpatient stays. PACT programming reduces the burdens on the treatment consumers and their families, on private and public inpatient facilities, on the juvenile and adult criminal justice and correctional systems, and on private commerce and public funds. PACT programming not only serves to meet the needs of treatment consumers and those of their families, but also those of the entire social and economic fabric of society. Almost thirty years of published replication research confirms that PACT programming works.

If South Carolina were to adopt PACT programming, and to make it universally available as the first-line treatment and service delivery model *from cradle to grave*, then within less than a single generation, our juvenile and adult criminal justice and detention systems alone, for example, would contract by more than 50%, more than offsetting the up-front costs of adopting and implementing the PACT model. If one then were to add to that equation the aggregate of statewide cost savings and full economic and social benefits of adopting and implementing the PACT model across-the-board, then the current state budget shortfall of 500 million dollars would shrink considerably and any possible future budget shortfalls would evaporate--without an additional dollar of tax increase, without a single state or local public job lost, and without an additional dollar of revenue-per-year being generated from taxpayers. With full statewide PACT program model adoption and implementation, just about everybody wins, and almost nobody loses.

My strongly held personal belief and personal opinion are that the Continuum of Care should have full control of and responsibility for all PACT program service delivery for those from age 0 through age 25. I believe that the Department of Mental Health should have responsibility for those from age 26 through the end of life. Both Continuum and DMH services and programs must be available not only to public assistance recipients, but also to those who are served by private practitioners and other private professionals. It is absolutely necessary for SCDMH and its satellite centers, and for the professionals who staff them, to collaborate with private practitioners, rather than to compete with them. The bases for these opinions are as complex and comprehensive as are those militating for the adoption and implementation of the PACT model itself. I do not advance them here within this letter, however. I will be more than happy to discuss them at a later time.

As to early intervention and family inclusion concepts and issues--well, both of those concepts and issues in my opinion are "no-brainers." That they are necessary is self-evident.

Again, I thank you for your interest and participation, and I look forward to copies of the report of your work group regarding the state's Olmstead Plan.

With regards,

Reine S. Lantz

Reine S. Lantz
Parent, Taxpayer, Citizen
and
Member, Family Advisory Council
of the Federation of Families for Children's Mental Health

cc: Felicity Costin Myers, Ph.D.
Director, Continuum of Care

George Gintoli
Director, South Carolina Department of Mental Health
and
Ms. Louise Johnson
Acting Director, Children and Family Division, SCDMH

Charles Bevis, Ph.D.
Director, Pee Dee Mental Health

Denatra Green
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Open Letter To all Families Who Have Children, Adolescents and Young Adults Suffering From Behavioral, Emotional, or Psychiatric Disorders:

HAVE YOU BEEN LEFT OUT OF THE LOOP??????

Under the Individuals with Disabilities Education Act (IDEA) for example, school districts are required, among many other things, to provide many different physical environments to serve children with special needs as part of a continuum of (physical) environmental placements within a construct known as "*Least Restrictive Environment.*" The "Least Restrictive Environment" construct also exists within the requirements of Sec 504 of the Rehabilitation Act of 1973 (as amended) (Sec. 504), and within those under the Americans with Disabilities Act of 1990 (ADA). "Least Restrictive Environment" requirements apply to all institutions, entities, and agencies to which IDEA, Sec. 504, or the ADA apply.

During 1999, the U.S. Supreme Court issued a decision --under Title II of the ADA (which also applies to school systems) and regarding "Least Restrictive Environment"-- now widely known and cited as the "*Olmstead* decision." (*Olmstead v. L.C.*, 119 S.Ct 2176, 1999).

Within this decision, the U.S. 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 a continuum of community-based services for persons with disabilities who otherwise would be entitled to more restrictive and live-in institutional services when three specific conditions outlined in the decision are met. Further, the decision suggested that states may be able to demonstrate that they have met their burdens of providing for individuals with disabilities if they could demonstrate that they have "comprehensive, effectively working plan[s] for placing...persons with disabilities in less restrictive settings," when those less restrictive settings meet the individual needs of people with disabilities and that "waiting list[s]" for community-based services "move at a reasonable pace... ."

IDEA, Sec. 504, the ADA, and the *Olmstead* decision all require that those disabled individuals being served thereunder be served in the "Least Restrictive Environment" possible and necessary to meet their various and unique needs. All of these statutes and the *Olmstead* decision create the presumption that this or that person can best be served within--or as physically close as possible to--his or her own community, school, and home environments. Numerous scientific and other related studies fairly definitively establish that the ultimate treatment and functional outcomes for those treated within or as close as possible to their own communities and homes--especially for those with complex and intensive needs--are markedly and measurably better than are those outcomes for those with similar needs who are served or treated far away from their homes, communities, and families.

Those studies directed toward outcomes of children establish that when they are served within their own homes and communities and community-based school districts--or as close to them as possible--the children and their families fare far better over time than otherwise they would were the children to be sent far way from their families, homes and communities.

Therefore, the "Least Restrictive Environment" requirements of the statutes cited above, and the presumption created by the *Olmstead* decision, and the findings of numerous studies, all create a preference for something known as "Community-Based Services."

So widely known as to be almost common knowledge is the fact that over time somewhere between one-in-five to one-in-four families will experience the presence of a psychiatric, behavioral or emotional illness within one or more of their members. At any one time, approximately one in ten school-age children, adolescents, and young adults are suffering significantly enough that their personal, social, and educational functioning are impaired. A large percentage of those individuals often will need intensive and comprehensive intervention, diagnosis, and treatment in specialized ways that also must address their educational needs in a unified way with their psychiatric, emotional, and behavioral needs.

Because our communities, state and local agencies, and the school districts that serve our children and young adults must meet the legal requirements regarding Least Restrictive Environment and Community-Based Services--and because without question there always will be a significant population of school-age children and young adults needing specialized psychiatric, behavioral and emotional interventions and treatments--then without question the needs of these children and young adults must be addressed by our communities, by state and local agencies, and by all school districts.

During November of 2000, Governor Hodges issued an executive order declaring that the State of South Carolina and *all relevant agencies* were to engage in the process of determining how to meet the requirements of the U.S. Supreme Court *Olmstead Decision (Executive Order #2000-26)*. Specifically, the Governor's Executive Order established an interagency task force titled the "South Carolina Home and Community-Based Services Task Force." The mandate of 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. This review shall focus on identifying affected populations, improving the flow of information about support services in the community, and [on] removing barriers that impede opportunities for community inclusion.

2. ...[E]nsure the involvement of consumers [of services], parents of consumers, advocates, providers and relevant agency representatives in developing the plan.

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. ...[Ensure that the report] contain a timeline for implementation.

The Task Force was comprised of three Work Groups primarily representing the South Carolina Department of Health and Human Services (DHHS), the Department of Disabilities and Special Needs (DSN), and the state Department of Mental Health (DMH). Each of the Work Groups included members of those state agencies, public and private service providers, some treatment and service consumers or their families, individual advocates, and members of some advocacy organizations. Each Work Group produced its own draft "*Olmstead* Plan," which it then submitted to the full Task Force.

Unfortunately, both the Work Groups and the Task Force gave little attention to the needs of children or young adults with disabilities, and even less attention to the needs of children and young adults with psychiatric, behavioral, and emotional disabilities--for all practical purposes ignoring the needs of a large and significant segment of our population, a segment of young people who suffer enormously from their illnesses. For example, suicide is the second or third (but preventable) leading cause of death nationwide (depending on the studies consulted) for teenagers and young adults who suffer from one or another psychological or psychiatric illness. In addition, the largest segment of hospital and inpatient residential "bed-days" consumed nationwide is that populated by those having psychiatric, emotional or behavioral illness. Further, for example, the largest and most significant "system" of agencies serving this population in our state--that of the "system of free public schools" established by our state Constitution--was completely absent from the table and uninvolved in the process and planning conducted by the Task Force.

During April of 2001, while the process of integrating the findings and recommendations--from the reports of the three work Groups--into a single draft Plan was being conducted, children's advocates were somewhat successful in drawing attention to this disturbing and significant oversight. These advocates managed to secure the addition of some comments and recommendations into the *"Olmstead* Plan" being developed by the Task Force. The full Task Force then undertook to abstract and summarize the findings from each Work Group's draft Plan into a 48-page document titled "*South Carolina Home and Community-Based Services Plan: Draft Report* (Submitted for Public Comment by the South Carolina Home and Community-Based Services Task Force, July 2, 2001)."

The final draft is now available for "public comment" prior to being submitted to the Governor on or about September 3, 2001. While most "teleconferences" and "public comment hearings" have concluded (the last is scheduled for August 9, 2001), it is apparent from within the body of the *Draft Report* itself that the work of the Task Force has proceeded largely out of public view and without significant, statistically valid participation of *all relevant agencies* or the populations they serve. We aim to correct this.

We urge that all who read this letter insist on being included within the loop. Too many members of the population who currently need what the state's "*Olmstead* Plan" is supposed to identify and then provide for have been "left out of the loop" during the development of the Plan. At any time in the future anyone--or anyone's child--could become a member of the disabled community and need the community-based treatments, services, supports, and related systems being contemplated as the outcome of South Carolina's "*Olmstead* Plan." We urge that everyone and every agency seek inclusion in the data collection process, and that all seek full and active participation during this planning process.

We urge that all members of our state Department of Education and local school districts, and all parents who have children or young adults with disabling psychiatric or chronic illness or injury, please contact our Governor, the Task Force, advocates, and advocacy organizations, and urge them to request that the data collection process and public participation segment required by the Governor's *Executive Order* #2000-26 be reopened for a ninety-day period to allow for the gaps and oversights in the Work Group and Task Force Draft Plan reports--regarding children, adolescents and young adults--to be filled and addressed in statistic-ally valid and useful ways.

Don't be left out of the loop. Don't complain about the problems and gaps in meeting the needs of the disabled, nor about those in our service delivery systems, without

becoming part of the solution process.

Respectfully submitted,

Reine S. Lantz

APPENDIX I

List of Acronyms

Acronyms List and Program Description -

AAA -	Area Agency on Aging
ADA –	Americans with Disabilities Act
BSP -	Behavior Support Plan
CARF -	Council for the Accreditation of Residential Facilities
CLTC -	Community Long Term Care
CMHC -	Community Mental Health Centers
CMS -	Centers for Medicare and Medicaid Services
CRCF -	Community Residential Care Facilities
CTH -	Community Training Home
DDSN -	Department of Disabilities and Special Needs
DHHS -	Department of Health and Human Services
DMH -	Department of Mental Health
DSS -	Department of Social Services
EPSDT -	Early Periodic Screening, Diagnosis and Treatment (Medicaid Program)
HASCI -	Head and Spinal Cord Injury (Medicaid Waiver)
ICF/MR -	Intermediate Care Facility for Persons with Mental Retardation
IMD -	Institute on Medical Disease
ISCEDC	Interagency System of Care for Emotionally Disturbed Children
MDS -	Minimum Data Set
MICA -	Mentally Ill/Chemically Addicted
MR/DD -	Mental Retardation/Developmental Disability
OAA -	Older Americans Act
OBRA -	Omnibus Budget Reconciliation Act
RTF -	Residential Treatment Facility
SAMI -	Substance Abuse/Mentally Ill
SED -	Serious Emotional Disorder
SMI -	Severly Mentally Ill
SSDI -	Social Security Disability Insurance
SSI -	Supplemental Security Income
TLC -	Toward Local Care
TWIIA -	Ticket to Work Incentives Improvement Act