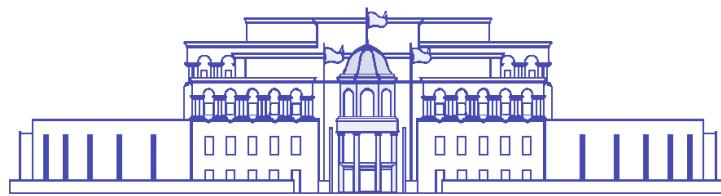


Study of State Programs for Providing Services to Persons With Disabilities



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**LEGISLATIVE COMMISSION'S SUBCOMMITTEE
TO STUDY STATE PROGRAMS
FOR PROVIDING SERVICES TO PERSONS
WITH DISABILITIES**

January 2003

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SUMMARY OF RECOMMENDATIONS

This summary presents the recommendations approved by the Legislative Commission's Subcommittee to Study State Programs for Providing Services to Persons with Disabilities. The Subcommittee will submit these proposals to the 72nd Session of the Nevada Legislature.

A. Subcommittee Recommendation: Items Recommended for Bill Draft Request (four BDRs).

- 1. Establish an ongoing statutory legislative committee and other related requirements (BDR would include the following four Subcommittee recommendations).**
 - i. Establish an ongoing Legislative Committee on Persons with Disabilities, similar to SCR 32 from the last regular session, as a statutory committee. This committee should also: comprehensively review, evaluate and recommend improvements to the state of Nevada's programs, including, without limitation, whether the state is complying with the American with Disabilities Act (ADA) in light of the Olmstead decision and the state's progress toward implementing its Olmstead Plan; assess the quality, effectiveness and need for changes to the policies and systems for providing long-term care services to adults and seniors with disabilities; assess the quality, effectiveness and need for changes to the policies and systems for providing long-term care services to children with disabilities and their families; ensure that data systems effectively provide consistent cross-agency information and meaningful outcomes specific to each service, as needed for the state to effectively make decisions, plan, budget, and track and monitor costs and outcomes of services; and examine the restructuring of services provided by state agencies to outsource all direct service, care and case coordination to non-profit or private entities to strengthen and add independence to the functions of planning, coordination and quality assurance at the state level.
 - ii. Require the Department of Human Resources to examine the impact of assessments of persons with disabilities, including, without limitation, any savings in costs incurred as a result of such assessments, and report the results of its examination annually to the Legislative Committee on Persons with Disabilities before July 1 in even-numbered years and before October 1 in odd-numbered years.
 - iii. Require the Department of Human Resources to report annually to the Legislative Committee on Persons with Disabilities on the expansion of the Medicaid Buy-In Program, and on its progress toward the goal of equitably providing, by 2008, medical insurance coverage or wraparound services to all persons with disabilities who, by virtue of becoming employed, have established an income above poverty level, but cannot obtain the health care coverage and services needed to terminate reliance on public benefits. This report would be required to be provided to the Legislative Committee on

Persons with Disabilities by July 1 in even-numbered years and by October 1 in odd-numbered years.

- iv. Require the Department of Human Resources to study the development of a rider to the Medicaid budgets, based on the model used in the state of Texas, where the money follows the person for children and adults who have been assessed and determined to be in unnecessarily restrictive residential environments, and report the results of its study to the ongoing Legislative Committee on Persons with Disabilities.
- 2. Changes in state agencies/ombudsman (BDR would include the following two Subcommittee recommendations).**
 - i. Establish an Office of Disability Services within the Department of Human Resources. Transfer the Office of Community-Based Services from the Department of Employment, Training and Rehabilitation, Rehabilitation Division, to the Department of Human Resources. The Office of Disability Services should: coordinate planning across systems and agencies that provide services to persons with disabilities and across disability populations; monitor the implementation of strategic planning goals; ensure compliance with the provisions of the ADA; oversee the development of a comprehensive data system that works across agencies; and ensure that state and county resources are coordinated.
 - ii. Fund, through legal services, an Office of Ombudsman Services for persons with disabilities, which will serve as a last resort for persons with disabilities to access after going through the Office of Disability Services. Appropriate \$130,000 each year to fund this office. The ombudsman will mediate issues related to integrated settings, the ADA, and the Individuals with Disabilities Education Act (IDEA), which remain unresolved after other remedies have been exhausted.
- 3. Develop and implement a statewide 211 universal access telephone communication system (BDR).**

Establish, develop and fund a 211 universal access line in the state of Nevada. Ensure that this is the one system that will be used by people to obtain information on social services. Require the Department of Human Resources to assist with the development and establishment of the 211 line.
- 4. Consolidate and streamline SSI/Medicaid application processes (BDR).**

Require the Department of Human Resources to establish a single eligibility application for SSI and Medicaid to ensure that all eligible at-risk children and adults quickly receive the assessments and Medicaid services they need.

B. Subcommittee Recommendation: Items Recommended for Legislative Resolution (six recommendations included in the Resolution).

1. Encourage the Executive Branch, in planning budgets and making decisions concerning programs associated with services for persons with disabilities, to consider persons with disabilities and services in a more holistic manner so that decisions made concerning one population or service do not occur in isolation of decisions made concerning other populations or services. This goal should not lead to a reduction in services for any disabled population.
2. When planning budgets and making decisions concerning programs associated with services for persons with disabilities, current regulations and policies prohibit budgetary provision for persons with disabilities and their families whose incomes exceed current guidelines and limitations, regardless of the identified need for services. Without such services, undue economic and emotional hardship would fall upon these families. The Subcommittee encourages the Executive Branch to revise current guidelines and requirements and consider making budgetary provisions for needed disability services to include persons with disabilities, and their families, whose incomes exceed current guidelines.
3. Recognize the *Nevada Strategic Plan for People with Disabilities* developed pursuant to Assembly Bill 513 from the 2001 Legislative Session as the plan developed in this state to comply with Title II of the Americans with Disabilities Act (ADA) in light of Olmstead and the Olmstead plan. Also recognize the need for the Department of Human Resources to monitor, review and revise the plan as necessary to ensure that the state of Nevada complies with the ADA.

The 1999 United States Supreme Court case known as Olmstead v. L.C. and E.W. involved two ladies with mental retardation and mental illness who were patients at a state-operated hospital in Georgia. The ladies did not want to remain in the institution, and state treatment professionals felt they could live in a community setting with appropriate support. The state of Georgia refused to move the ladies because there were no community-based services placements available.

The U.S. Supreme Court ruled against the state of Georgia and determined that the women's continued institutionalization was a violation of their rights under the Americans with Disabilities Act (ADA) because the women were not in the most integrated setting possible and did not wish to be in an institution.

The court suggested two ways by which a state can show compliance with the Olmstead decision:

- A state may develop a comprehensive, effective working plan, including timetables and progress reports, for placing qualified people in community-based settings.

- A state may maintain a waiting list for community-based services, but the list must move at a reasonable pace and may not be motivated by a desire to fill institutions.
4. Encourage the Executive Branch to identify and transfer persons in institutional care who can be served in the community, to the community if the persons do not oppose such transfer. This should include appropriate discharge planning, transitional supports and targeted services coordination. Also, encourage the Executive Branch to identify persons who are at risk of being improperly institutionalized and take action to prevent people from being improperly institutionalized. The Department of Human Resources should report to the Legislature, before the 2005 Session, the results of its efforts to transfer or divert persons with disabilities from institutions to community settings.
 5. State that the Legislature, when considering legislation that will impact children or adults with disabilities, recognize the importance of the potential effects of the legislation on the lives of such persons, including, without limitation, their ability to access services.
 6. Encourage the Governor to consider funding for programs that provide critical health, mental health, nutritional and personal assistance services to children and adults with disabilities, poor children, and frail seniors, as a high priority to the extent reasonably possible during times of budget shortfalls.

C. Statements of Intent and General Recommendations (14 recommendations).

1. Ensure that persons with disabilities are involved in the process of developing policies concerning services provided by the state to persons with disabilities, and in monitoring programs that provide such services.
2. Support the collection of accurate and meaningful data for planning, budgeting, measuring and monitoring services provided to persons with disabilities.
3. Encourage the Executive Branch to establish budgetary policies ensuring, within the limits of available funding, that adequate and continued funding is made available for services to persons with disabilities to reduce waiting lists and ensure that waiting lists move at a reasonable pace. The Legislative Commission's Subcommittee to Study State Programs for Services to Persons with Disabilities would encourage establishing a target goal of a maximum of 90 days, subject to available funding, for waiting lists associated with services critical to community integration, medication clinics and treatment for mental illness, home and community based services (HCBS), and personal assistance for children and adults with disabilities.
4. Encourage the Executive Branch to work toward the state of Nevada funding all long-term care services provided to Medicaid-eligible persons in nursing facilities, instead of the county funding 50 percent and the state funding 50 percent of the

services, to eliminate any bias or perceived bias of the state for institutionalizing persons.

5. Encourage the Executive Branch to develop, as part of the state of Nevada's Olmstead plan, quality assurance measures in all state programs that provide services to persons with disabilities, and ensure that persons with disabilities are involved in the development and implementation of such measures.
6. Encourage the Board of Regents of the University and Community College System of Nevada to provide programs for persons with disabilities that are accessible to such persons, including, without limitation, an AA degree in independent living and non-degree courses for persons with disabilities.
7. Encourage the state of Nevada and counties and other local governments to work with persons with disabilities and the Nevada Association of Counties (NACO) to ensure that buildings in this state are accessible to persons with disabilities, including, without limitation, ensuring that housing is accessible in all counties of the state, and that the state and local governmental entities are in compliance with the ADA and other relevant federal and state laws.
8. Encourage the Executive Branch and the Legislature to establish appropriate provider rates for personal assistance services for all state programs.
9. Encourage the Department of Human Resources to develop a pilot program to examine the feasibility of developing a statewide system of outsourced mobile units to provide services, including, without limitation, outreach, assessment, and referral services to persons with disabilities who are homeless and in crisis. The department's findings, conclusions, and recommendations should be presented to the 2005 Legislature.
10. Encourage the Task Force for the Fund for a Healthy Nevada to: (1) support programs which ensure that families providing primary care to a severely disabled family member receive respite within 90 days after applying for the respite; (2) seriously consider funding the Nevada Positive Behavioral Supports Program at a level that will at least support adequate training and service delivery to 1,500 children with autism and brain injuries, and others in need of such interventions; and (3) support programs which provide home and environmental modifications to allow persons with disabilities access to the community and the ability to return to the community from institutional care.
11. Encourage the Executive Branch to train persons who provide personal assistance to persons with autism, other pervasive developmental disabilities, and brain injury to ensure that the caregivers understand the special needs of the persons to whom they are providing services, and to ensure that the caregivers are adequately trained regarding the individual particular characteristics and special needs of the persons to whom they are providing services.

12. Encourage the Department of Human Resources, in developing a Medicaid Home and Community Based Services Waiver for Persons with Cognitive Impairments, to seriously consider the behavioral services needed by persons with brain injury, autism, and other pervasive developmental disabilities and mental illnesses to address their behavioral and independent living needs.
13. Encourage businesses to employ persons with disabilities.
14. Encourage the Executive Branch and the Legislature to expand funding to the Homeless Mentally Ill Outreach initiative, Homeless Outreach Pilot Education (HOPE) program, to implement ongoing programs providing intensive outreach and case management services, including, without limitation, immediate access to necessary medications and housing.

**REPORT TO THE 72ND SESSION OF THE NEVADA LEGISLATURE FROM THE
LEGISLATIVE COMMISSION'S INTERIM SUBCOMMITTEE
TO STUDY STATE PROGRAMS FOR PROVIDING SERVICES
TO PERSONS WITH DISABILITIES**

I. INTRODUCTION

The Legislative Commission's Subcommittee to Study State Programs for Providing Services to Persons with Disabilities was created by the Legislative Commission to study Nevada's services for the disabled. Since the 2001 Legislature passed Assembly Bill 513 that called for strategic plans in the areas of health services for the aged, the disabled, and seniors, it was an appropriate time to coordinate legislative efforts with those of the Executive Branch to formulate a single unified and cohesive plan to address the needs of the disabled in Nevada.

The Subcommittee, chaired by Senator Dina Titus and co-chaired by Senator Raymond Rawson, outlined two primary goals of the Subcommittee. The first goal was to take an inventory of all federal, state, and local services, programs, agencies and statutes that currently serve and affect the disabled community. Public and private agencies would be asked to participate and provide valuable information to the process that would otherwise not be available for the Subcommittee's consideration. Once that inventory of services was identified, a clearinghouse of information would be created to determine the best method to disseminate that information to as many people as possible.

The second goal established by the Subcommittee was to evaluate the feasibility of creating a one-stop system of services for the disabled. Realizing the reality of the state's current fiscal position, the Subcommittee noted that full implementation of a one-stop service system may not be fiscally possible at this time. However, the Subcommittee also recognized that, while full implementation of a one-stop service delivery system may not be feasible, providing at least a partial number of services and information under one roof would be beneficial to persons with disabilities.

The Legislative Commission's Subcommittee worked closely with the Department of Human Resources, which, under Assembly Bill 513, received an \$800,000 appropriation to create four long-term strategic plans concerning the health care needs of the citizens of Nevada, including a strategic plan for persons with disabilities. The Subcommittee's primary intent was to fully identify the needs of the disabled and come forth with a joint administrative plan to improve the state's delivery system for persons with disabilities.

II. BACKGROUND

The Legislative Commission's Subcommittee to Study State Programs for Providing Services to Persons with Disabilities was one of six interim study committees approved by the 2001 Legislative Commission and was based upon Senate Concurrent Resolution 32 (Appendix A), which was introduced and adopted by the 2001 Nevada Legislature's Committee on Legislative Affairs and Operations on April 11, 2001. Due to the time constraints resulting from redistricting and other critical issues of the 2001 Legislature, final passage of SCR 32 did not occur prior to adjournment of the 2001 Legislative Session. If SCR 32 had been passed by the 2001 Legislature, it would have produced a comprehensive set of recommendations that would form the foundation for redesigning the state's current delivery system of services to persons with disabilities. Even though SCR 32 was not officially adopted, the Legislative Commission determined that the issues associated with services to Nevada's disabled citizens warranted special consideration, and therefore the Commission sponsored the effort.

The Legislative Commission appointed a Subcommittee consisting of six legislators to carry out the provisions originally encompassed in SCR 32 – three Assembly representatives and three representatives from the Senate, with Senator Dina Titus serving as chairwoman.

Senator Dina Titus, Chairwoman
Senator Raymond D. Rawson
Senator Randolph J. Townsend

Assemblywoman Sharron Angle
Assemblywoman Vonne Chowning
Assemblyman Jerry D. Claborn

Legislative Counsel Bureau staff services for the subcommittee were provided by Robert Guernsey, Principal Deputy Fiscal Analyst, Fiscal Analysis Division; Jim Rodriguez, Program Analyst, Fiscal Analysis Division; Leslie Hamner, Principal Deputy Legislative Counsel, Legal Division; and Jo Rasey, Committee Secretary, Fiscal Analysis Division.

The Subcommittee worked in cooperation with the Department of Human Resources and other agencies of the Executive Branch to coordinate informational resources. The Department of Human Resources' Task Force on Disability, created as a result of passage of Assembly Bill 513 by the 2001 Legislature (Appendix B), did an excellent job in bringing many groups together and formulating a number of committees, subcommittees and task forces to involve as broad a spectrum of disability service groups as possible and to address as wide a spectrum of services as possible.

The Legislative Commission's Subcommittee held five public meetings from November 6, 2001 to September 23, 2002 and coordinated its efforts closely with those of the Task Force on Disability. Between the two, 53 public meetings, hearings and training sessions were conducted, which involved testimony from representatives from over 40 state and local government disability service-related agencies and private organizations associated with the delivery of services for persons with disabilities. The Subcommittee addressed various disability issues, including availability of services, service gaps, transportation, eligibility, housing, service accessibility, availability of information on disability services, financial assistance and funding, and recommendations for improvement to the current

system. The Task Force on Disability presented 78 recommendations to the Subcommittee aimed at resolving over 180 perceived barriers to services and information. In addition, the Department of Human Resources presented the Legislative Commission's Subcommittee with six recommendations on the *Nevada Strategic Plan for People with Disabilities* for its consideration.

During the course of the interim study, the Subcommittee reviewed information on a number of issues designed to provide a solid foundation for services to individuals with disabilities in Nevada and to provide a broad understanding of national trends in disability services and long-term care for the disabled. Specifically, the Subcommittee reviewed:

- Adherence to Olmstead and implications to states that do not provide for an adequate Olmstead plan (refer to Appendices C and D);
- Alternatives to institutionalization for long-term institutional care in Nevada;
- Models that simplify and promote a single point of entry into a state's disability service system to avoid the fragmentation of services;
- Community-based options such as the feasibility of maximizing home and community-based service programs and exploring residential alternatives to institutionalization;
- The important role of caregivers and their need for better support systems and training;
- Identification of "gaps" in services available to the disabled community; and
- Identification of housing and transportation services to the disabled community.

Assembly Bill 513 was enacted by the 2001 Legislature to complete a comprehensive review of the state's existing disability services delivery system. A.B. 513 challenged state agencies and representatives of Nevada's community of disabled persons to work together to develop a comprehensive long-term plan for disability services. Key elements of the plan included estimating existing and future service needs, recommendations to eliminate system inefficiencies in service delivery, recommendations for cost-effective and accessible systems of care, and assistance to Nevadans with disabilities in order to allow them to become as productive and self-supporting as their condition permits.

The 2001 Legislature appropriated \$800,000 to the Nevada Department of Human Resources for the development of four long-term strategic plans relating to the health care needs of the residents of Nevada. Funding was allocated as follows:

- \$100,000 to develop a Seniors Strategic Health Care Plan;
- \$150,000 to develop a Rural Health Care Plan;
- \$150,000 to develop a Strategic Plan for People with Disabilities; and
- \$400,000 to develop a Comprehensive Rate Plan for health care services in Nevada.

Four task forces were established to concentrate on each of the plan areas. The actual process of developing the *Nevada Strategic Plan for People with Disabilities* was exceptionally productive and provided an unprecedented opportunity for service consumers in the disabled community, service providers, and regulators to identify, within the current service delivery system, what works and what does not work, and to provide input as to what could be done to make the system work more efficiently, with more compassion and dignity toward the disabled community. As a result of this cooperative process, a broadly representative consensus of Nevada's disabled community has defined its overall service needs. Every possible effort was made to assure representation in the final disability plan and proposed implementation schedule included all disability groups, regardless of size or perceived significance. Also unprecedented was the consensus that was reached by all parties involved in the plan and the development of the resulting recommendations.

In Assembly Bill 513, the 2001 Legislature appropriated \$150,000 to the Department of Human Resources to prepare the *Nevada Strategic Plan for People with Disabilities* and to establish a task force of consumers, advocates, parents, and providers to guide plan development. In turn, the Task Force on Disability appointed four subcommittees, consisting of 49 additional consumers and advocates, and a technical advisory group for issues related to the Olmstead decision.

Focus groups held meetings throughout the state in 2001, and upwards of 200 consumers and advocates provided recommendations on how the plan should be developed, what should be studied, how participation of people with disabilities and families would be assured, who should conduct the study, and how the resulting plan would be monitored and outcomes reported.

Tony Records and Associates, a private firm, was hired by DHR to address issues associated with civil rights and Olmstead. Demographics of people with disabilities in Nevada were provided by the University of California, San Francisco's Disability Statistics and Research Center, and the Special Education Department of the University of Nevada, Las Vegas.

The Legislative Commission simultaneously appointed the Subcommittee to Study State Programs for Providing Services to Persons with Disabilities, which was chaired by Senator Dina Titus. The Subcommittee worked cooperatively with the Task Force on Disability in an effort to more effectively utilize available resources and to develop a more comprehensive, integrated plan that would be free of institutional biases or shortsightedness of either the Legislative or Executive Branches of government.

The Task Force on Disability and its subcommittees held 45 meetings and training sessions and three public hearings in the process of developing its plan and the resulting recommendations to the Subcommittee to Study State Programs for Providing Services to Persons with Disabilities. A major milestone of the A.B. 513 process was completion of a survey of state and community programs providing services to children and adults with disabilities. Findings from that survey laid the foundation for the Task Force's investigation and analysis for the *Nevada Strategic Plan for People with Disabilities*. General findings were as follows:

- There exists, in Nevada, a significant gap between the documented needs of people with disabilities and the services available in integrated community-based settings.
- Nevada's entire system of services for people with disabilities is grossly under-funded.
- The primary problem in Nevada is the lack of an effective overall information system for people with disabilities.
- There appears to be a potentially significant Olmstead compliance problem with regard to people with disabilities who live in institutionalized long-term care facilities.
- Reportedly, there are more than 125 Nevadans with disabilities living in out-of-state residential programs due to the lack of adequate in-state programs.
- Community-based options for Nevadans with severe disabilities, such as traumatic brain injuries or autism, appear to be extremely limited.
- Reportedly, there are 28-30 children attending out-of-state residential school programs due to a lack of in-state programs.
- It is reported that at least 158 Nevada youths in correctional facilities have a disability. A national study indicates that up to 40 percent of youths in correctional facilities have disabilities. This may be a trend or statistic related to a system with inadequate care facilities for these types of youths, rather than a case of law.
- Compliance with Olmstead is not limited to Medicaid or other federally funded programs.
- The absence of a well-managed waiting list system in Nevada presents a significant compliance and liability issue for the state with regard to Olmstead and the Americans with Disabilities Act (ADA).

III. DISCUSSION OF RECOMMENDATIONS

The findings and final recommendations of the Legislative Commission's Subcommittee to Study State Programs for Providing Services to Persons with Disabilities reflect a coordinated effort among the Executive and Legislative Branches of government, private and public service providers, as well as valuable input from members of the disabled community. The Subcommittee's primary goal was to develop a comprehensive set of short-term and long-term recommendations for changes to the state's system of providing services to persons with disabilities. Short-term recommendations would address real issues concerning the state's current disability services delivery system that could feasibly be adopted and implemented by the 2003 Legislature. Those recommendations would provide immediate relief to the users of the system, provide immediate improvements to service, and increase accessibility to information regarding the availability of disability services information. Short-term actions included consideration of recommendations for changes to system processes and procedures, changes to existing statutes or administrative code, and changes to eligibility requirements that impede public-sector and private-sector service providers from efficiently getting disability services to those who need them. All recommendations considered here would have to be measured and evaluated based on whether the recommended system change would be economically and administratively feasible to implement, given the state's current budgetary situation.

Throughout the proceedings, the Subcommittee stressed the importance of streamlining access to services for persons with disabilities to provide better coordination of services. One major recommendation considered by the Subcommittee was the concept of "one-stop shopping" or "no-wrong door" where information and referral services for persons with disabilities could be obtained in a centralized or highly integrated environment. The Subcommittee also considered the establishment of a 211 telephone line to assist citizens needing services as a great improvement over the current fragmented system.

Long-term recommendations developed by the Subcommittee addressed issues that targeted additional needed changes to statutes, possible expanded program services, new programs, consolidation of services and service organizations, and the creation of a dedicated state agency to manage and administer the state delivery system of services to persons with disabilities. The Subcommittee adopted a total of 28 recommendations that resulted in 4 bill draft requests, 6 legislative resolutions and 14 Subcommittee recommendations. All recommendations would be contingent upon available funding in any given biennium.

Subcommittee Recommendations

1. Establish an ongoing statutory legislative committee to study the state's programs for providing services to persons with disabilities.

A great deal of progress has been made in developing an action plan for the state to comply with the Olmstead decision (see Appendices C and D). If established in statute, the Legislative Committee on Persons with Disabilities would be able to work closely with the Executive Branch in a joint effort to review, evaluate and recommend

improvements to the state programs; ensure that the state is complying with the Americans with Disabilities Act (ADA) in light of the Olmstead decision; and monitor the state's progress toward implementing its Olmstead plan. The committee would also work with other levels of government, non-profit entities and private entities to strengthen the functions of planning, service delivery and quality assurances.

- 2. Require the Department of Human Resources to examine the impact of assessments of persons with disabilities, including, without limitation, any savings in costs incurred as a result of such assessments, and report the results of its examination annually to the Legislative Committee on Persons with Disabilities before July 1 in even-numbered years and before October 1 in odd-numbered years.**

The Director of the Department of Human Resources indicated this evaluation could be accomplished without additional funding. The Subcommittee concurred that an important part of a strategic plan was the need for ongoing monitoring. The strategic plan developed by the Department of Human Resources and the Task Force on Disability, which was established by A.B. 513 in the 2001 Legislature, is a ten-year plan that cannot be completed in one biennium. Ongoing monitoring would be an important function for the proposed ongoing legislative committee.

- 3. Require the Department of Human Resources to report annually to the Legislative Committee on Persons with Disabilities on the expansion of the Medicaid Buy-In Program, and on its progress toward the goal of equitably providing, by 2008, medical insurance coverage or wraparound services to all persons with disabilities who, by virtue of becoming employed, have established an income above poverty level, but cannot obtain the health care coverage and services needed to terminate reliance on public benefits. The Department of Human Resources would be required to provide this report to the Legislative Committee on Persons with Disabilities by July 1 in even-numbered years and by October 1 in odd-numbered years.**
- 4. Require the Department of Human Resources to study the development of a rider to the Medicaid budgets based on the model used in the state of Texas where the money follows the person for children and adults who have been assessed and determined to be in unnecessarily restrictive residential environments, and report the results of its study to the ongoing Legislative Committee on Persons with Disabilities.**

The Director of the Department of Human Resources felt the development of such a rider was feasible and would provide greater flexibility and program options to persons with disabilities in a non-restrictive setting.

- 5. Establish an Office of Disability Services within the Department of Human Resources. Transfer the Office of Community Based Services from the Department of Employment, Training and Rehabilitation, Rehabilitation Division, to the Department of Human Resources. The Office of Disability Services should:**

coordinate planning across systems and agencies that provide services to persons with disabilities and across disability populations; monitor the implementation of strategic planning goals; ensure compliance with the provisions of the ADA; oversee the development of a comprehensive data system that works across agencies; and ensure that state and county resources are coordinated.

The Director of the Department of Human Resources testified that in order to improve coordination and eliminate duplication of services being provided to persons with disabilities, reorganization would be needed to align service-related agencies under the Department of Human Resources and employment-related agencies under the Department of Employment, Training and Rehabilitation.

- 6. Fund, through legal services, an Office of Ombudsman Services for persons with disabilities, which will serve as a last resort for persons with disabilities to access after going through the Office of Disability Services. Appropriate \$130,000 each year to fund this office. The ombudsman will mediate issues related to integrated settings, the Americans with Disabilities Act (ADA), and Individuals with Disabilities Education Act (IDEA) that remain unresolved after other remedies have been exhausted.**

The Director of the Department of Human Resources testified in support of the need for ombudsman services for persons with disabilities. The ability of persons with disabilities to seek assistance and guidance from knowledgeable individuals was recognized as an important goal and led the Subcommittee to recommend the establishment of an ombudsman function. A description of the role of the Office of Ombudsman Services and a detailed budget as developed by the Task Force on Disability is attached as Appendix E.

- 7. Establish, develop, and fund a 211 universal access line in the state of Nevada. Ensure that this is the one system that will be used by people to obtain information on social services. Require the Department of Human Resources to assist with the development and establishment of the 211 line.**

One of the most important tools to assist persons with disabilities and their families in order to avoid the current frustration and confusion of trying to access services would be the establishment of a 211 telephone system, which was recommended by the Task Force on Disability and the Department of Human Resources. The 211 access line, or “no-wrong-door” program, would provide important information, referral and resolution assistance for persons with disabilities and their families. The proposal has the support of the United Way, which indicated a strong desire to take the lead in the 211 planning process. The establishment of a single call-in center would greatly improve the ability of disabled individuals to access services they need in the shortest period of time and would assist with a “no-wrong-door” approach to human services.

- 8. Require the Department of Human Resources to establish a single eligibility application for Supplemental Security Income (SSI) and Medicaid to ensure that all eligible at-risk children and adults quickly receive the assessments and Medicaid services they need.**

The Director of the Department of Human Resources testified that under the current system, when an individual applies for SSI, the process could take several months, and once a decision is made regarding the SSI application, the individual is then required physically to apply for Medicaid. A single eligibility application process would create an automatic addition of the applicant to the Medicaid rolls, saving time for both consumers and families.

- 9. Encourage the Executive Branch, in planning budgets and making decisions concerning programs associated with services for persons with disabilities, to consider persons with disabilities and services in a more holistic manner so that decisions made concerning one population or service do not occur in isolation of decisions made concerning other populations or services. This goal should not lead to a reduction in services for any disabled population.**

Representatives of the Task Force on Disability testified on the importance of an “across-the-board” review by the Executive Branch regarding the determination of the need for a particular service, taking into account all who need the service prior to decisions concerning programs associated with a service.

- 10. Encourage the Executive Branch to revise current guidelines and requirements, with consideration for budgetary provisions for needed disability services, to include persons with disabilities and their families whose incomes exceed current guidelines, when planning budgets and in making decisions concerning programs associated with services of persons with disabilities. Current regulations and policies prohibit budgetary provisions for person with disabilities and their families whose incomes exceed current guidelines and limitations, regardless of the identified need for services. Without such services, undue economic and emotional hardship would fall upon these families.**

In testimony before the Subcommittee, representatives of the Task Force on Disability indicated this recommendation was aimed at people who were not the “poorest of the poor.” The recommendation would target people who had continuously worked and then become disabled, as well as the children whose families were working and had always worked and, because of the length of time employed or because of family employment, were included in the range just above Medicaid or waiver service eligibility. The Task Force discovered that many of these individuals with disabilities and families of individuals with disabilities became impoverished and eventually qualified for Medicaid assistance because they had virtually lost everything. At that point, many such people are placed in institutional care, which could be avoided if they had been given the option of

personal assistance. Most of these people would not need Medicaid if a program existed to keep them from becoming impoverished.

- 11. Recognize the long-term strategic plan developed pursuant to Assembly Bill 513 from the 2001 Session as Nevada's Olmstead plan for persons with disabilities. The Nevada plan is to comply with Title II of the ADA in light of Olmstead. Also, recognize the need for the Department of Human Resources to monitor, review and revise the plan as necessary to ensure that the state of Nevada complies with the Americans with Disabilities Act (ADA).**

It was brought to the Subcommittee's attention that on June 22, 1999, the United States Supreme Court held in Olmstead v. L.C. that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The Court ruled that the Americans with Disabilities Act may require states to provide community-based services for people with disabilities, who would otherwise be entitled to institutional services, when: (1) the state's treatment professionals reasonably determine that such placement is appropriate; (2) the affected person does not oppose such treatment; and (3) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving services.

Recognizing the need to be in compliance with the criteria laid down in the Olmstead decision regarding Nevada's services to persons with disabilities, the Department of Human Resources recommended to the Subcommittee that the *Nevada Strategic Plan for People with Disabilities* that was developed by the Task Force on Disability be recognized as Nevada's Olmstead plan.

- 12. Encourage the Executive Branch to identify and transfer persons who are in institutional care who can be served in the community to the community if the persons do not oppose such transfer. This should include appropriate discharge planning, transitional supports and targeted services coordination. Also, encourage the Executive Branch to identify persons who are at risk of being improperly institutionalized and take action to prevent people from being improperly institutionalized. The department should report to the Legislature, before the 2005 Session, the results of its efforts to transfer or divert persons with disabilities from institutions to community settings.**

It was pointed out to the Subcommittee that this is one of the most important recommendations with regard to Nevada's compliance with the Olmstead decision. The need to develop alternative placements for persons with disabilities from institutional care into a community setting was recognized as an important element in treating people in the most appropriate setting. When people with disabilities are given an alternative placement option, it can lead to an improved quality of life and may be a less costly and more appropriate option.

- 13. State that the Legislature, when considering legislation that will impact children or adults with disabilities, recognizes the importance of considering the potential effects of the legislation on the lives of such persons, including, without limitation, their ability to access services.**

The Subcommittee felt it was important to consider the needs of those impacted by proposed legislation and to receive input on proposed legislation from persons with disabilities to ensure the best results are achieved.

- 14. Encourage the Governor to consider funding for programs that provide critical health, mental health, nutritional and personal assistance services to children and adults with disabilities, poor children, and frail seniors, as a high priority to the extent reasonably possible during times of budget shortfalls.**

At times of budget shortfalls, the Subcommittee felt it was extremely important to ensure that needed services continue to be provided to persons with disabilities and that, whenever possible, those services be given the highest priority to minimize the possibility of budget cuts.

- 15. Ensure that persons with disabilities are involved in the process of developing policies concerning services provided by the state to persons with disabilities, and in monitoring programs that provide such services.**

This recommendation to the Subcommittee from the Department of Human Resources recognizes that the people closest to the problems related to persons with disabilities need to be included in discussions regarding the disabled individual's needs and the best way to address those needs.

- 16. Support the collection of accurate and meaningful data for planning, budgeting, measuring and monitoring services provided to persons with disabilities.**

The Department of Human Resources' recommendation on the importance of accurate data to assist decision makers in evaluating services for persons with disabilities in the allocation of limited resources was supported by the Subcommittee.

- 17. Encourage the Executive Branch to establish budgetary policies ensuring, within the limits of available funding, that adequate and continued funding is made available for services to persons with disabilities to reduce waiting lists and ensure that waiting lists move at a reasonable pace. The Legislative Commission's Subcommittee to Study Programs for Providing Services to Persons with Disabilities would encourage establishing a target goal of a maximum of 90 days, subject to available funding, for waiting lists associated with services critical to community integration, medication clinics and treatment for mental illness, home and community based services (HCBS), and personal assistance for children and adults with disabilities.**

Both the Department of Human Resources and the Task Force on Disability recognized that it is important that the state make reasonable efforts to reduce waiting lists within available resources. This recommendation addresses the needs of people who require services and recognizes that advancement on waiting lists is one of the elements to ensure compliance with the Olmstead decision.

- 18. Encourage the Executive Branch to work toward the state of Nevada funding all long-term care services provided to Medicaid eligible persons in nursing facilities, instead of the county funding 50 percent and the state funding 50 percent of the services, to eliminate any bias or perceived bias of the state for institutionalizing persons.**

This was a recommendation put forward by the Task Force on Disability, which felt the state should work toward eliminating any bias or perceived bias as a result of 50 percent match funding in nursing homes.

- 19. Encourage the Executive Branch to develop, as part of the state of Nevada's Olmstead plan, quality assurance measures in all state programs that provide services to persons with disabilities, and ensure that persons with disabilities are involved in the development and implementation of such measures.**

The Task Force on Disability recommended, and the Subcommittee agreed, that the development of quality assurance measures should be an important part of the Olmstead plan. The Subcommittee concurred that the plan could be developed by the end of calendar year 2003.

- 20. Encourage the Board of Regents of the University and Community College System of Nevada to provide programs for persons with disabilities that are accessible to such persons, including, without limitation, an AA degree in independent living and non-degree courses for such persons with disabilities.**

This recommendation from the Task Force on Disability was put forward with two goals in mind: (1) to encourage the Board of Regents of the University and Community College System of Nevada to offer programs to persons with disabilities to achieve an AA degree in independent living; and (2) to make postsecondary education options available to persons with disabilities who were in non-degree programs, similar to interest courses available at the community college level.

- 21. Encourage the state of Nevada and counties and other local governments in the state to work with persons with disabilities and the Nevada Association of Counties (NACO) to ensure that buildings are accessible to persons with disabilities, including, without limitation, ensuring that housing is accessible in all counties of the state, and that the state and local governmental entities are in compliance with the ADA and other relevant federal and state laws.**

The Subcommittee received testimony concerning problems with building codes in rural Nevada counties. NACO indicated it would assist with compliance with ADA and federal and state laws to assist persons with disabilities.

22. Encourage the Executive Branch and the Legislature to establish appropriate provider rates for personal assistance services for all state programs.

The Subcommittee acknowledged that in order to ensure quality care, it is important that fair and appropriate rates for providers and personal care attendants be established and maintained. The ability of a person with disabilities to be able to live a quality life in the community with the assistance of a personal care attendant is an important goal, both for the disabled individual and the state of Nevada.

23. Encourage the Department of Human Resources to develop a pilot program to examine the feasibility of developing a statewide system of outsourced mobile units to provide services, including, without limitation, outreach, assessment, and referral services to persons with disabilities who are homeless and in crisis. The department's findings, conclusions, and recommendations should be presented to the 2005 Legislature.

The Subcommittee recognized that not all people in need of services have the ability or means to access needed services. At times, the use of mobile outreach units may provide the best or only option to assist disabled people in need of necessary services. The Subcommittee recommends that the Department of Human Resources develop a pilot program to examine the feasibility of developing mobile-outreach units and that the department report its findings to the 2005 Legislature.

24. Encourage the Task Force for the Fund for a Healthy Nevada to: (1) support programs which ensure that families providing primary care to a severely disabled family member receive respite within 90 days after applying for the respite; (2) seriously consider funding the Nevada Positive Behavioral Supports Program at a level that will at least support adequate training and service delivery to 1,500 children with autism and brain injuries, and others in need of such interventions; and (3) support programs which provide home and environmental modifications to allow persons with disabilities access to the community and the ability to return to the community from institutional care.

This recommendation was brought forward by the Task Force on Disability, which is asking the Task Force for the Fund for a Healthy Nevada to consider using the funds to support services for persons with disabilities.

25. Encourage the Executive Branch to train persons who provide personal assistance to persons with autism, other pervasive developmental disabilities and brain injuries to ensure that the caregivers will understand the special needs of the persons to whom they are providing services and to ensure that the caregivers are adequately

trained regarding the individual particular characteristics and special needs of the persons to whom they are providing services.

It was indicated to the Subcommittee that disabled individuals with autism, other developmental disabilities and brain injuries have special needs and require a consistent and predictable environment. These disabled people have need of caregivers who understand and are trained in their special needs.

- 26. Encourage the Department of Human Resources, in developing a Medicaid Home and Community Based Services (HCBS) Waiver for Persons with Cognitive Impairments, to consider seriously the behavioral services needed by persons with brain injury, autism, and other pervasive developmental disabilities and mental illnesses to address their behavioral and independent living needs.**

It was pointed out to the Subcommittee that disabilities such as brain injury, autism, and other developmental disabilities were not included in any other waiver programs. The Department of Human Resources indicated it would examine the current waiver program and decide whether it would be best to develop a new waiver, expand an existing waiver, or develop multiple waivers regarding these impairments. An explanation of the HCBS Waiver for Persons with Cognitive Impairments is included as Appendix F.

- 27. Encourage businesses to employ persons with disabilities.**

The ability to access federal funding to provide services to persons with disabilities in the least restrictive setting and to encourage and assist those individuals, when possible, to seek and maintain employment is an important goal to improve a person's life. The employers in Nevada who assist persons with disabilities in employment opportunities are a credit to the state of Nevada, and their endeavors need to be recognized and encouraged, as these efforts go a long way in assisting people with disabilities to live productive lives in a community setting. The Subcommittee recognized the efforts of Nevada's employers to employ persons with disabilities. The Subcommittee felt it was extremely important to continue to encourage the expansion of employment opportunities for persons with disabilities in Nevada.

- 28. Encourage the Executive Branch and the Legislature to expand funding to the Homeless Mentally Ill Outreach initiative (Homeless Outreach Pilot Education - HOPE) program to implement ongoing programs providing intensive outreach and case management services, including, without limitation, immediate access to necessary medications and housing.**

The need for services for the homeless was an important recommendation from the Task Force on Disability. The Subcommittee recognized the needs of the homeless population for services such as housing, medications and case management, and is encouraging programs that provide these necessary services and expansion of such programs when possible.

IV. ISSUES REQUIRING ADDITIONAL STUDY

Although a number of significant issues and recommendations were addressed by the Legislative Commission's Subcommittee to Study State Programs for Providing Services to Persons with Disabilities over the span of its five meetings, the Subcommittee, as well as many of the participants and presenters, felt that several issues and identified needs still needed further examination and that the Subcommittee should be continued to look at those issues. Additional study is needed in these areas in order to evaluate the overall effectiveness of Nevada's short-term and long-term disability service system and to make recommendations to further improve the system. Continuation of the Subcommittee would also provide an effective mechanism to allow for establishing advisory committees made up of subject matter experts to assist the subcommittee, if needed, in carrying out its assigned mandates, much like the system of investigation the Task Force on Disability employed in its effort to develop the *Strategic Health Care Plan for People with Disabilities*.

Based on testimony provided to the Subcommittee from the various participants and presenters, and based on the recommendations finally adopted by the Subcommittee, the following are major subject areas that the Subcommittee may concentrate on in the coming interim:

- Transportation services;
- Housing information and services;
- Integrated single eligibility processing and qualification requirements;
- Additional funding for new or expanded programs;
- Development of an integrated data collection and analysis system;
- Accessibility to secondary education for persons with disabilities;
- Waiting lists;
- Medicaid home and community-based services waiver program; and
- Mobile outreach programs.

One of the major considerations in continuing the study of state services for persons with disabilities should be cost. The cost of an interim study typically includes the salary, travel and operating support costs for the legislators assigned to the subcommittee and staff costs that are already included in the Legislative Counsel Bureau's budget. The budget approved by the Legislative Commission for the Subcommittee to Study State Programs for Providing Services to Persons with Disabilities was \$5,000. In continuing the Subcommittee, the Legislative Commission should consider additional funding for consultant support to provide research, analysis and guidance to the Subcommittee on the complex and technical areas that may be part of the mission for an ongoing study. A consultant working on the Subcommittee's behalf would be an independent subject matter expert and would be intimately knowledgeable of the national trends on the issues to be considered. The use of a consultant, or consultants, would serve as a valuable resource, not only to the legislators assigned to the study, but also to members of the advisory committee, or committees, that the Subcommittee may choose to appoint to the study.

APPENDICES

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APPENDIX A

Senate Concurrent Resolution No. 32 – 2001 Legislative Session

SENATE CONCURRENT RESOLUTION NO. 32—SENATOR TITUS

APRIL 11, 2001

Referred to Committee on Legislative Affairs and Operations

SUMMARY—Directs Legislative Commission to conduct interim study concerning Nevada's program for providing services to persons with disabilities. (BDR R-937)

EXPLANATION – Matter in *bolded italics* is new; matter between brackets {omitted material} is material to be omitted.

SENATE CONCURRENT RESOLUTION—Directing the Legislative Commission to conduct an interim study concerning Nevada's program for providing services to persons with disabilities.

1 WHEREAS, The State of Nevada ranks 51st among all of the states and
2 the District of Columbia in providing per capita support services for
3 persons with disabilities, as published in *The State of the States in*
4 *Developmental Disabilities, 2000 Study Summary* by the University of
5 Illinois at Chicago; and
6 WHEREAS, Persons with disabilities represent approximately 13 percent
7 of Nevada's population; and

8 WHEREAS, There is an enormous fragmentation of services provided to
9 persons with disabilities in this state, with programs scattered across state
10 government—the Aging Services Division and the Division of Mental
11 Health and Developmental Services of the Department of Human
12 Resources, and the Rehabilitation Division of the Department of
13 Employment, Training and Rehabilitation—and dozens of other state,
14 county and local programs; and

15 WHEREAS, One agency providing services to persons with disabilities
16 may not be aware of the services provided by another agency, resulting in
17 the duplication of services; and

18 WHEREAS, The Governor, in his recent State of the State Address before
19 this body, urged the creation of an Office of Disability Resources to
20 combine the many existing services in one location and develop a long
21 range plan to better provide services to persons of all ages who have
22 disabilities; now, therefore, be it

23 RESOLVED BY THE SENATE OF THE STATE OF NEVADA, THE ASSEMBLY
24 CONCURRING, That the Legislative Commission is hereby directed to
25 appoint a committee, consisting of four members of the Senate and four
26 members of the Assembly, to conduct an interim study of Nevada's
27 program for providing services to persons with disabilities; and be it
28 further



* S C R 3 2 *

1 RESOLVED, That the committee shall review the state's compliance with
2 and the impact of federal initiatives, such as the Americans with
3 Disabilities Act, the Individuals with Disabilities Education Act, the
4 Workforce Investment Act, the Rehabilitation Act, the Ticket to Work and
5 Work Incentives Improvement Act, the Medicaid Act, the Protection and
6 Advocacy for Mentally Ill Individuals Act, the Developmental Disabilities
7 Act, and all federal block grants to the state; and be it further
8 RESOLVED, That the committee shall conduct a full review of the
9 current system in Nevada which delivers services to persons with
10 disabilities, including, employment, social services, medical and personal
11 assistance, education, public transportation, handicapped parking, housing,
12 child care and respite services, and the state laws relating to persons with
13 disabilities; and be it further
14 RESOLVED, That the committee shall examine the possible options to
15 improve the delivery of those services to maximize resources, consolidate
16 duplicating and overlapping services, expand community-based services,
17 increase consumer choice, input and review, increase outcomes per cost of
18 service, unify advocacy and appeal processes, and increase cooperation
19 between state and local programs and community providers; and be it
20 further
21 RESOLVED, That the study must also include an in-depth examination of
22 the coordination of the various services offered to persons with disabilities
23 in this state to ensure that a full range of services is provided to such
24 persons, that available funding is used to its maximum advantage and that
25 services provided by the state are coordinated with community services
26 that are available through such organizations as the United Way and
27 Opportunity Village for Retarded Citizens; and be it further
28 RESOLVED, That the committee shall also explore the feasibility of
29 establishing a single state agency to coordinate services provided to
30 persons with disabilities including careful study and substantial public
31 input on a wide range of related issues to ensure that no interrelated
32 services are overlooked; and be it further
33 RESOLVED, That any recommended legislation proposed by the
34 committee must be approved by a majority of the members of the Senate
35 and a majority of the members of the Assembly appointed to the
36 committee; and be it further
37 RESOLVED, That the Legislative Commission shall submit a report of
38 the results of the study and any recommendations for legislation to the
39 72nd session of the Nevada Legislature.

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* SCR 32 *

APPENDIX B

Assembly Bill 513 - 2001 Legislative Session

Assembly Bill No. 513—Committee on Ways and Means

CHAPTER.....

AN ACT making an appropriation to the Department of Human Resources for the development of four long-term strategic plans concerning the health care needs of the citizens of Nevada; and providing other matters properly relating thereto.

**THE PEOPLE OF THE STATE OF NEVADA, REPRESENTED IN
SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:**

Section 1. 1. There is hereby appropriated from the state general fund to the Department of Human Resources the sum of \$800,000 for the development of four long-term strategic plans relating to the health care needs of the residents of Nevada to be allocated as follows:

(a) For a plan to ensure the availability and accessibility of a continuum of services that appropriately meets the basic needs of Nevada's senior citizens and supports their ability to lead independent and active lives..... \$100,000

(b) For a plan to ensure the availability and accessibility of a continuum of health care services in rural areas of Nevada..... \$150,000

(c) For a plan to:

(1) Ensure the availability and accessibility of a continuum of services that appropriately meet the basic needs of persons with disabilities in Nevada, including, without limitation, autistic persons;

(2) Support the ability of persons with disabilities in Nevada to lead independent and active lives within their community in accordance;

(3) Continue the effort of the State of Nevada to provide community-based services which match the need of the client and provide choice between appropriate services; and

(4) Ensure that persons with disabilities in Nevada receive the services that they are entitled to receive pursuant to state and federal statutes and case law \$150,000

(d) For a plan:

(1) To develop and implement a sound methodology for the establishment and periodic adjustment of rates paid by the State of Nevada for contracted health and human services which accurately reflect the required costs of providing those services; and

(2) Where applicable, to establish reimbursement rates at appropriate, consistent and competitive levels that will attract a sufficient number of providers so as to ensure the effective delivery of an appropriate range of service options for Nevada's health and human services.. \$400,000

2. In developing each of the long-term strategic plans authorized pursuant to subsection 1, the Department shall:

(a) Contract with one or more persons who have knowledge about and experience in facilitating group discussions which include divergent points of view and perspectives to achieve consensus and mutual satisfaction in an effective planning process;

(b) Conduct public hearings in a broad range of settings and locations in this state to ensure that it receives information from all interested persons, including, without limitation, senior citizens, rural Nevadans, persons with disabilities, their representatives, governmental representatives and

representatives of persons who provide institutional and community-based services to persons with disabilities; and

(c) Cause the development of each such long-term plan only after the testimony and information presented by the public has been fully considered throughout the process.

3. Any remaining balance of the appropriation made by subsection 1 of this act must not be committed for expenditure after June 30, 2003, and reverts to the state general fund as soon as all payments of money committed have been made.

Sec. 2. This act becomes effective upon passage and approval.

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APPENDIX C

Implications of the Olmstead Decision
Leslie Hamner, Principal Deputy Legislative Counsel

APPENDIX C

IMPORTANCE AND IMPLICATIONS OF OLMSTEAD

1. Summary of the Olmstead Decision

Olmstead was decided by the Supreme Court in June of 1999 and it involves Title II of the Americans with Disabilities Act, or the ADA. Title II of the ADA prohibits discrimination in public services furnished by governmental entities. Respondents in Olmstead were two mentally retarded women, L.C. and E.W., who filed suit against the state of Georgia.

L.C. was voluntarily admitted to a hospital, where she was confined for treatment in a psychiatric unit. A year later her condition had stabilized, and her treatment team agreed that her needs could be met appropriately in a community-based program supported by the state. However, she remained institutionalized for almost three additional years until the state placed her in a community-based treatment program.

E.W. was voluntarily admitted to the same hospital in early 1995 and was also confined for treatment in a psychiatric unit. By 1996, her treating psychiatrist concluded that she could be treated appropriately in a community-based setting. However, she remained institutionalized until 1997, a few months after the District Court issued its opinion in the case.

In bringing this case against the state of Georgia, the two women argued that the state's failure to place them in a community-based program, once their treating professionals determined that such placement was appropriate, violated Title II of the ADA. They requested that the state place them in community care residential programs and that they receive treatment, with the goal of integrating them into the mainstream of society. The question in this case, as framed by the United States Supreme Court, was whether the proscription of discrimination in Title II of the ADA may require the placement of persons with mental disabilities in community settings rather than in institutions.

The court answered this question with a "qualified" yes. It concluded that a disabled person must be placed in a community setting rather than an institution when three criteria are satisfied. First, the state's treatment professionals must have determined that community placement is appropriate; second, the transfer must not be opposed by the affected person; and third, the placement can be reasonably accommodated, taking into account the resources available to the state and also the needs of others with mental disabilities in that state.

The Supreme Court's decision in Olmstead is based solely on statutory grounds - the ADA and the regulations adopted pursuant to the ADA. The court emphasized the opening provisions of the ADA in which Congress stated that society has tended to isolate and segregate individuals with disabilities, and that such forms of discrimination continue to be a serious and pervasive social problem. Additionally, Congress noted in the ADA that "discrimination against individuals with disabilities persists in such critical areas as institutionalization."

The provision of Title II of the ADA specifically at issue in Olmstead prohibits a public entity from discriminating against a disabled person based on his or her disability. In enacting the ADA, Congress instructed the Attorney General to issue regulations implementing this provision. The Attorney General enacted two regulatory provisions that are relevant to the Supreme Court's decision in Olmstead. The first relevant provision requires a public entity to "administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

The second relevant provision requires a public entity 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."

The Supreme Court noted that, in its opinion, in enacting the ADA, Congress had a rather comprehensive view of the concept of discrimination. In addition, the Court recognizes that institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. The Court further recognizes that confinement in an institution severely diminishes the everyday life activities of persons, such as family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. Thus, the Court concluded that unjustified isolation is properly regarded as discrimination based on disability.

However, the Court's analysis does not stop after it reaches this conclusion. The Court further concludes it would be inappropriate to remove a person from a more restrictive setting if such a move was not supported by the state's treatment professionals. In addition, the Court notes that there is no federal requirement imposing community-based treatment on a person who does not desire such treatment.

Finally, the Court addresses the issue of the state's defense to a claim of discrimination such as the claim brought against the state of Georgia. The Court concludes that a state is required to provide community-based treatment for persons with mental disabilities only when the placement can be reasonably accommodated by the state. The Court recognizes the state's need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the state's obligation to administer services with an even hand. Thus, a court determining whether a placement can be reasonably accommodated by a state must consider these factors. That is, a court must consider, in view of the resources that are available to the state, not only the cost of providing community-based care to the individual, but also the range of services the state provides to others with mental disabilities and the obligation of the state to mete out those services equitably.

Significantly, the Court indicated that a state might satisfy the requirements of Title II of the ADA if it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and the state had a waiting list that moved at a reasonable pace that was not controlled by the state's endeavors to keep its institutions fully populated. Unfortunately, the Supreme Court did not elaborate on these suggestions for

complying with Title II of the ADA. Thus, in assuring that they are complying with the mandates of the ADA, states are not provided much guidance from the Court in determining whether a plan is comprehensive and effective, or whether a waiting list is moving at a reasonable pace. These issues have been addressed to a certain extent by the United States Department of Health and Human Services.

In addition, the Court emphasized that its opinion in Olmstead did not impose on the states a "standard of care" for whatever medical services the state renders. Further, the ADA does not require states to provide a certain level of benefits to individuals with disabilities. However, a state is required to adhere to the ADA's non-discrimination requirement with regard to the services that it does, in fact, provide.

In summary, the Supreme Court concluded in Olmstead that Title II of the ADA requires a state to provide community-based treatment for persons with mental disabilities when: (1) the state's treatment professionals determine that such placement is appropriate; (2) the affected persons do not oppose such treatment; and (3) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities in that state. While Olmstead only deals with persons with mental disabilities, because the case is based on the ADA, it applies to all persons with disabilities who are protected from discrimination by Title II of the ADA. Thus, it is not limited to persons with mental disabilities. In addition, the case is not limited to Medicaid, as Title II of the ADA prohibits discrimination in the provision of services by any public entity, which includes a state or local government and any department, agency, or other instrumentality of a state or local government. Therefore, areas such as transportation, housing and education also may be affected by the decision.

2. Direction Provided by the United States Department of Health and Human Services with Regard to Olmstead

As a result of the Supreme Court's opinion in Olmstead, the United States Department of Health and Human Services has sent various letters to state Medicaid directors to provide guidance and support to states in their efforts to enable persons with disabilities to live in the most integrated setting appropriate to their needs, consistent with the ADA. Letters from the federal DHR sets forth guidelines for a state to follow as it develops a comprehensive, effective working plan for placing qualified persons with disabilities in less restrictive settings. The DHR has noted that there is not one perfect plan, in that each state will require a different plan based on the needs of the citizens of that state and the policies of that state.

The Department also provided other information to the states concerning the Olmstead decision, including answering various questions, providing descriptions of changes and clarifications in federal policies that may assist the states in ensuring that they are in compliance with the decision, and finally, providing additional tools, including grants, to assist states. Specifically, the Department has noted that its Office for Civil Rights is responsible for investigating any complaints that it receives alleging discrimination on the basis of disability by public entities related to health and human services, and by entities receiving funds from the Department. The Department has emphasized that its response to

these complaints has been to work with the states to obtain voluntary compliance before referring a complaint to the Department of Justice for resolution, which may involve litigation.

3. Executive Order

In June of 2001, President Bush issued an executive order concerning Olmstead. This executive order is part of the New Freedom Initiative, which is the President's broader effort to remove barriers to community living for persons with disabilities. The executive order, entitled "community-based alternatives for individuals with disabilities," states the Supreme Court's holding in Olmstead and provides that the United States seeks to ensure the country's community-based programs effectively foster independence and participation in the community for persons with disabilities. To implement Olmstead, the executive order directs various federal agencies to work together to ensure that the decision is implemented in a timely manner by working with and providing technical guidance to states. In addition, these federal agencies are directed to evaluate their policies, programs, statutes and regulations to determine whether any should be revised or modified to improve the availability of community-based services for persons with disabilities. The results of this review were due to the President by October 16, 2001. Finally, the executive order requires the Attorney General and the Secretary of the Department of Health and Human Services to fully enforce Title II of the ADA, working cooperatively with states to resolve any complaints.

4. Subsequent Relevant Case Law

Hawaii

Various cases concerning the ADA have been decided since the Olmstead decision was handed down. Some of these involve the issue of whether a state is complying with Title II of the ADA in light of Olmstead. For example, persons with mental retardation who were on a waiting list for Hawaii's Medicaid home and community-based waiver program brought a case against the state arguing that the state was violating Title II. The waiting list for the program included about 800 people because of an alleged lack of state funding. Over 750 of the people were on the waiting list for longer than 90 days, and some had been waiting for more than 2 years.

The state of Hawaii argued that any modification to the program would require it to ignore state funding limits and would therefore fundamentally alter the program to an unlimited state funded program. In addition, the state argued that requiring it to ignore the population limits was a fundamental alteration. Finally, the state argued that providing more persons with services would force it to exceed its federal funding limits, making it take on 100 percent of the costs of those persons' care. The federal district court rejected these arguments by the state and concluded that the state failed to show how the modification would fundamentally alter the program, since the state merely argued that it would potentially have a problem funding the program. The court also noted that the state may be able to amend the "population limits" approved by the federal Medicaid agency to provide services for more persons. In addition, the only evidence presented by the state to decrease the waiting list was an increase in "slots" over the next few years. The court concluded that

this single piece of evidence did not show the state was complying with the ADA by acting responsibly. Thus, the court concluded that there were material questions of fact surrounding whether reasonable modifications should be made and whether any such modifications would “fundamentally alter” the program, and the court denied the defendants’ motion for summary judgment.

City of New York

In a class action brought against the City of New York, the plaintiffs argued that New York’s failure to provide safety-monitoring services, along with other personal care services, to Medicaid recipients violated the ADA. The plaintiffs, who suffered from mental disabilities, argued that without the provision of safety monitoring as an independent service, the services provided were inadequate to meet their medical needs and to allow them to continue living in their homes. The federal court of appeals first noted that New York provides identical services to mentally and physically disabled Medicaid recipients. The court then emphasized that Olmstead does not stand for the proposition that states must provide disabled persons with the opportunity to remain out of institutions; it holds only that states must adhere to the ADA’s nondiscrimination requirement with regard to the services that it does provide. Thus, the court concluded that New York did not violate the ADA by failing to provide the benefit, as it is not the court’s role to determine the Medicaid benefits the state should provide, and the ADA does not mandate the provision of new benefits. These cases are being decided on a case-by-case basis and will turn on the specific circumstances that exist in the state and the specific issues raised by the plaintiffs. These decisions should also provide clarification on the extent of the requirements on states as a result of Olmstead.

Board of Trustees of the University of Alabama v. Garrett

The last term the United States Supreme Court decided another important ADA case was Board of Trustees of the University of Alabama v. Garrett. This case involved Title I of the ADA, which deals with disability-based discrimination in employment. The court held in Garrett that a private individual may not recover money damages for a state’s failure to comply with Title I of the ADA. In this case, the court specifically declined to address whether a similar analysis would apply to Title II of the ADA, and thus preclude individuals from bringing actions for monetary damages against the State for a violation of Title II. Therefore, the Olmstead decision was not directly affected by the Supreme Court’s holding in Garrett. However, even if the Supreme Court eventually determined that such suits brought by individuals for monetary damages pursuant to Title II of the ADA were prohibited, other avenues would be available for enforcing the integration mandate of Title II. The United States could enforce the provisions of Title II in actions for money damages. In addition, private individuals might also be able to enforce the provisions of Title II by bringing actions for prospective injunctive relief. Thus, a state would still be required to comply with the provisions of Title II of the ADA. Again, however, the Olmstead decision has not been modified by the court’s holding in Garrett, as the court specifically declined to address Title II of the ADA.

APPENDIX D

**Long-Term Care and the United States Supreme Court's
Olmstead Decision**
Johanna M. Donlin, Senior Policy Specialist
National Conference of State Legislators

PRE-PUBLICATION DRAFT

NCSL State Legislative Report

Long-Term Care and the United States Supreme Court's Olmstead Decision

Johanna M. Donlin
Senior Policy Specialist

"We confront the question of whether the proscription of discrimination may require placement of persons with . . . disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes."

- Justice Ruth Bader Ginsburg
United States Supreme Court

In 1999, the United States Supreme Court ruled in *Olmstead vs. L.C.* that states can not discriminate against people with disabilities by providing long-term care services only in institutions, when certain individuals could be served in a community. The decision encourages states to reevaluate how they deliver long-term care services to people with disabilities. Because long-term care spending accounts for some 35 percent of all state and federal Medicaid funds, the *Olmstead* decision will affect Medicaid programs and budgets, as well as other state programs. This report summarizes the 1999 *Olmstead vs. L.C.* decision, its implications for state legislatures, the role of the federal government and how states can access information and technical assistance as they implement the *Olmstead* decision.

The Case

Olmstead vs. L.C. was filed on behalf of two women, L.C. and E.W. (Lois Curtis and Elaine Wilson), both of whom had mental retardation and mental illness. At the time the suit was filed against Tommy Olmstead, the commissioner of Georgia's Department of Human Resources, both women were living in a state run long-term care institution. They had requested community-based placements and their treatment professionals determined they could both live in a community setting with appropriate supports. The state of Georgia refused to move the women because there were no community placements available due to funding constraints. The state claimed the decision to keep the women in an institution was not based on their disabilities.

L.C. and E.W. believed their continued institutionalization constituted discrimination, violating their civil rights under Title II of the Americans with Disabilities Act (ADA). Under Title II of the ADA, state and local governments cannot discriminate against people with disabilities when providing public services and

must provide the services in the most integrated setting possible. The question presented before the court was whether the anti-discrimination requirement of the ADA — the most integrated setting requirement — would require placement of the two women in community settings rather than an institution.

The Supreme Court ruled against the state of Georgia and determined that the women's continued institutionalization was discrimination based on disability, and that it violated their rights under Title II of the ADA. L.C. and E. W. did not choose to be isolated in the institution and were not in the most integrated setting possible. The court stated that "Unjustified isolation ... is properly regarded as discrimination based on disability." As a result, the ruling requires states to provide community-based services for people with disabilities otherwise entitled to institutional services, whenever the following three factors are in place:

1. The state's treatment professionals have determined this is appropriate;
2. The transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and
3. The placement can be reasonably accommodated, taking into account the resources available to the state and the needs of other state citizens with disabilities.

Olmstead does not require states to close down every long-term care institution. Rather, the decision focuses on giving people with disabilities the right and opportunity to choose their long-term care setting, if the specified conditions exist. The court stated that "nothing in the ADA ... condones termination of institutional settings for persons unable to handle or benefit from community settings."

Also, the *Olmstead* decision applies to all people with disabilities. Although the plaintiffs had mental illness and mental retardation, the case is based on the ADA and therefore covers a wide range of people with disabilities. The court also specified that the case covers those who may be *at-risk* of being institutionalized and those who may need periodic institutional services. This detail requires states to look at a continuum of care for individuals whose needs may change throughout their lifetimes, inclusive of non-Medicaid resources, such as housing and transportation.

Cost Does Matter in Implementation

While the decision clearly stated that improper institutionalization constitutes discrimination, the court was not as clear when it addressed the issue of state responsibility and implementation costs. The court ruled, "The State's responsibility, once it provides community-based treatment to qualified people with disabilities, is not boundless." In fact, the case leaves some flexibility for states to take into account the "available resources to the state and the needs of other state citizens with disabilities." States do not need to "fundamentally alter" their publicly funded long-term care programs.

The court took the extra step to suggest two ways by which a state can show compliance with *Olmstead*.

1. A state may develop a comprehensive, effective working plan, including timetables and progress reports, for placing qualified people in community-based settings.
2. A state may maintain a waiting list for community-based services, but the list must move at a reasonable pace and may not be motivated by a desire to fill institutions.

Proving what constitutes a "fundamental alteration" or a "reasonable pace" will be a challenge for the states. These terms will most likely be defined in the lower courts, if more people with disabilities file suits against the states.

Impact on the States

Medicaid and the "Institutional Bias"

Because the Medicaid program funds the greatest amount of long-term care services and covers a large number of people with disabilities, the *Olmstead* decision could strongly affect state Medicaid budgets.

According to the National Center for Health Statistics, almost 150,000, 8.5 percent, of the people in skilled nursing homes today are under the age of 65. They are people with physical disabilities, mental retardation and developmental disabilities, psychiatric disabilities and traumatic brain injuries, among other conditions. Most of these individuals are in a nursing home because there are limited community-based alternatives, and because Medicaid pays for the majority of their long-term care.

Medicaid long-term care spending accounts for some 35 percent of all federal and state Medicaid spending. Currently, states have the option to cover certain services in their state plans that can be used in home- and community-based settings. These optional services include: personal care services, rehabilitation services, private duty nursing, physical and occupational therapy, and transportation services. In 2000, 27 states covered personal care services in their state plans. While these optional services do provide opportunities for individuals to remain in their homes, states often limit the amount duration, and scope of these services. Therefore, individuals needing more extensive services must often times be admitted to a long-term care institution.

The federal Omnibus Budget Reconciliation Act of 1981 (OBRA-81) authorized home- and community-based services waivers (HCBS) under Medicaid and gave states more flexibility in how they can provide long-term care services. States can obtain waivers to cover a broader range of home- and community-based health and support services to Medicaid-eligible people who otherwise would be in an institutional setting. A waiver may cover personal care assistance, family supports, supported employment and other individualized services and supports.

While these waivers have helped increase home- and community-based services for people with disabilities, the Medicaid entitlement still applies only to the institutional setting. The 250 Medicaid home- and community-based services waivers operating around the country in 2000 accounted for only 27 percent of Medicaid's long-term care spending. Seventy-three percent of Medicaid long-term care spending went to institutions. Many disability advocates refer to this as the "Medicaid institutional bias," which has developed over the last four decades. The *Olmstead* decision may be the impetus for states to use the HCBS waivers and to move Medicaid long-term care dollars away from institutional settings.

Is there a "Woodwork Effect"?

Some state policymakers have feared a possible "woodwork effect" as they evaluate the costs of expanding community-based services for people with disabilities. That is, people in need of community-based services, who are already living in the community with the help of parents or some other source of support, might start "coming out of the woodwork" and seek expanded state funded community-based services. The "woodwork effect" may be limited because of the institutional eligibility requirement — to qualify for home- and community based services, an individual must first meet the Medicaid criteria for institutional placement consisting of both income and disability related standards. On the other hand, some of the underserved people who might be counted in a "woodwork effect" are already on waiting lists, but refuse to be institutionalized while they await services.

Federal Actions and Assistance

The U.S. Department of Health and Human Services (HHS) has taken the lead in working with states to implement the *Olmstead* decision. Various agencies have provided technical assistance and financial support to help states assess their long-term care systems and how *Olmstead vs. L.C.* may change their current methods of delivering long-term care services.

Enforcement

The Office for Civil Rights (OCR), a division of the Department of Health and Human Services, enforces the ADA and Section 504 of the Rehabilitation Act, both of which relate to the *Olmstead* decision and community-based services. The Office for Civil Rights:

- Investigates complaints;
- Conducts compliance reviews; and
- Provides training and technical assistance to state stakeholders on a variety of issues including but not limited to the issue of ensuring caring treatment in a most integrated setting.

The Office for Civil Rights receives numerous complaints from citizens who believe their civil rights have been violated because a state cannot provide community-based, long-term care services and, as a result, they or their family members now live in an institutional setting. Since 1999, OCR has received over 400 *Olmstead*-related complaints.

With the *Olmstead* decision, the OCR has preferred a collaborative approach with states over a punitive approach to encourage compliance. It encourages stakeholders to collaborate and compromise and views litigation as a last resort. OCR sends letters to all states against which the office receives complaints, encouraging them to implement the two criteria the Supreme Court set out as possible ways to comply with *Olmstead* — development of a comprehensive, effectively working plan and a waiting list that moves at a reasonable pace.

Education and Financial Assistance

The Centers for Medicare and Medicaid Services (CMS), another HHS division formerly known as the Health Care Financing Administration (HCFA), also plays a key role in educating states about *Olmstead* and providing technical assistance and financing to help states move the implementation process forward. In coordination with Office for Civil Rights, CMS has sent out five directive letters to all state Medicaid directors. The first letter gave guidance on how a state could comply with *Olmstead* and offered some recommendations about how a state may develop a plan that was truly "comprehensive and effectively working." Letters two through four addressed a variety of state concerns, *Olmstead* planning and implementation. The fifth letter announced HHS' plan to release up to \$70 million in "real choice grants" to assist states in developing opportunities for people with disabilities to live in more community-based settings. The letters are available on the NCSL *Olmstead* website at <http://www.ncsl.org/programs/health/disabil2.htm>.

In February 2001, Tommy Thompson, secretary of the Department of Health and Human Services, announced the availability of the first "starter grants" from the \$70 million allocation. These \$50,000 grants were intended to help states develop plans for improving their long-term support systems for community living; to include people with disabilities or long-term illness in the planning process; and to prepare for other forthcoming grant opportunities. By June 2001, 49 states had received HHS "starter grants."

In September 2001, HHS announced the recipients of the larger "Systems Changes for Community Living" grants. Thirty-seven states and one territory received a total of \$64 million to develop programs for people with disabilities and long-term illnesses. Four different types of grants make up the program:

- Real Choice Systems Change grants: to help design and implement effective and enduring improvements in community long-term care support systems to enable children and adults of any age who have a disability or long-term illness to live and participate in their communities;
- Community-Integrated Personal Assistance Services and Supports grants: to improve personal assistance services that are consumer-directed and/or offer maximum individual control;
- Nursing Facility Transitions grants: to help states transition eligible individuals from nursing facilities to the community; and
- National Technical Assistance Exchange for Community Living: to provide technical assistance, training and information to states, consumers, families and other agencies and organizations.

Both the starter grants and the systems change grants represent a key part of President Bush's "New Freedom Initiative," the Administration's policy on removing barriers to equality for 54 million Americans living with disabilities.

On June 18, 2001, President Bush signed an executive order calling for the swift implementation of the *Olmstead* decision as part of the New Freedom Initiative. Among other things, President Bush ordered several federal agencies to review their "policies, programs, statutes and regulations to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities." The designated agencies must also include involvement of consumers, advocates and other relevant representatives in their review. In response to the Executive Order, Secretary Thompson presented his preliminary report to President Bush on December 21, 2001. The report can be viewed at <http://www.hhs.gov/newfreedom/presidentrpt.html>.

State Actions

As a result of *Olmstead vs. L.C.*, legislators, executive branch officials, consumer advocacy groups and individual citizens are working together to implement the *Olmstead* decision. In some states, almost half of Medicaid long-term care spending supports community-based care for people who qualify for institutional services. In these states, *Olmstead vs. L.C.* provides an opportunity to improve community-based services that are already in place. The *Olmstead* decision is likely to have a much greater impact on state budgets and the long-term care systems in those states that are spending the majority of long-term care resources on institutional settings.

State Plans

Many states have focused on the Supreme Court's guidelines for developing an *Olmstead* state plan. As of October 2001, 40 states and the District of Columbia had task forces or commissions dedicated to the planning process. In at least three states — Missouri, Utah and Wisconsin — legislators and legislative staff are members of the commissions. Fifteen states had completed some type of written report or plan: Arizona, Connecticut, Delaware, Illinois, Maryland, Missouri, Montana, North Carolina, Ohio, Oklahoma, South Carolina, Texas and Wyoming. Another 12 states had begun the process, and reports or plans pending. The state commissions have issued numerous recommendations that address eight major issues: housing, transportation, assessment, waiver program expansion, transitioning individuals from institutions into the community, staffing, data collection and consumer/provider/state agency education and outreach. The NCSL publication *The States' Response to the Olmstead Decision: A Work in Progress* analyzes the different state plans and can be found on the NCSL Olmstead Decision website at <http://www.ncsl.org/programs/health/disabil2.htm> .

Legislative Activity

Planning also has been closely tied to the legislative process. Legislatures in California, Hawaii, Illinois and Kentucky enacted legislation to form their commissions. The Alaska Legislature enacted a law in 2000 requiring the state Department of Health and Social Services to submit an annual report concerning the waiting list for people with developmental disabilities. The governor in Kentucky issued an executive order to create an *Olmstead* Coordinating Council, and the legislature established two commissions to work on state plans for mental retardation/developmental disabilities and mental health. Likewise, although Iowa's governor had directed the Department of Human Services to be the lead agency for *Olmstead* planning in May 2000, the General Assembly's Legislative Council authorized the creation of the Mental Health and Developmental Disabilities Services Task Force in June 2000 to recommend ways to improve service delivery for people with mental retardation/developmental disabilities and mental illness.

In 2001, a few states passed substantive legislation affecting their Medicaid long-term care programs. For instance, Maryland expanded its Medicaid waiver program to include individuals with incomes up to 300 percent of the supplemental security income eligibility level. The new law also requires the Departments of Human Resources and Health and Mental Hygiene to administer a Community Attendant Services and Support Program for additional people with disabilities between ages 21 and 59.

In Missouri, the legislature enacted legislation to: increase salaries for aides caring for people with mental retardation and developmental disabilities, ensure training for staff and individuals who are interested in transferring into the community, make personal care services an entitlement, and establish a fund to allow individuals who are moving into the community to apply for a one-time grant of up to \$1,500.

To date, the state executive branches have played the dominant role in developing *Olmstead* plans, but state legislatures will likely play their most significant roles during the 2002 legislative sessions. Most *Olmstead* commissions and work groups have developed their plans, and state agencies will be submitting budget requests to implement these plans.

Challenges

States have encountered many challenges in implementing the *Olmstead* decision, especially with budget shortfalls and declining state revenues. In a recent NCSL survey, 43 states reported revenue shortfalls and 36 states are considering budget cuts or holdbacks to address fiscal problems. In addition, 18 states reported Medicaid spending is above budgeted levels and several other states expressed concern over Medicaid expenditures in FY 2002. As states assess the expansion of community-based services, they may realize savings from decreased reliance on the generally more expensive institutional settings. However, some of the largest barriers to implementation extend beyond the delivery of direct health care services and long-term care include staffing, housing, transportation and data collection.

Healthcare Workforce Shortage. Many states are already trying to address serious shortages of healthcare workers in a variety of specialties. The shortage is especially severe in the area of long-term care— where nurses, certified nursing assistants (CNAs), home health aides and other paraprofessionals play a significant role in the day-to-day healthcare needs of people with disabilities. Low wages, limited career development, physical demands of the work and poor workplace conditions make these positions difficult to fill and result in high staff turnover. State legislators are looking at a variety of options to increase the stature of these positions by providing training and developing career paths. Some states have passed legislation to increase certain direct caregivers' salaries.

Housing. One of the biggest barriers to moving people with disabilities into the community is the shortage of affordable housing that is accessible to people with disabilities. This is an essential factor if people with disabilities are going to be fully integrated into communities around the country. The federal Department of Housing and Urban Development currently issues Section 8 vouchers to help people meet housing costs and move towards home ownership, but the numbers of vouchers are limited. Even with Section 8 vouchers, many people with disabilities cannot find any rental properties or homes that fit their specific needs, or the market is priced too high for the Section 8 vouchers to afford.

Transportation. For individuals living in a community, transportation to and from work, to school or to any other type of activity is essential to their independence. The Americans with Disabilities Act covers all public transportation, but enforcement is lagging and access to and within rural areas poses a different set of problems.

Data Collection. Before states can assess how much *Olmstead* implementation may cost, they must be able to determine how many people with disabilities are inappropriately institutionalized, and how many live in community-based settings or with family members to avoid being placed in a long-term care institution.

Conclusion

The U.S. Supreme Court clearly stated in *Olmstead vs. L.C.* that unnecessary institutionalization of people with disabilities, if certain conditions exist, is discrimination under the Americans with Disabilities Act, if certain conditions exist. States must comply with this ruling, but they will vary greatly in how they reassess and reform their long-term care systems. The Court gave states guidance on how they might comply and most states are moving forward with the early stages of implementation. As in many civil rights cases, implementation will continue over the next several years and interpretation of the details of the case may be determined in the lower courts. The process will involve a wide variety of stakeholders, and state legislators will play a significant role in transforming their state long-term care systems and helping people with disabilities move into more integrated settings where they can ultimately live more productive lives.

APPENDIX E

Role of the Office of Ombudsman Services

APPENDIX E

ROLE OF THE OFFICE OF OMBUDSMAN SERVICES

The Task Force on the Nevada Strategic Plan for People with Disabilities and its subcommittees identified 189 barriers to services and accommodations for persons with disabilities. The Task Force indicated that Nevadans with disabilities and their representatives currently have no independent in-state resource for monitoring the state's progress in implementing these Olmstead provisions. Likewise, people with disabilities and families of disabled children have no independent recourse for mediation of complaints related to the rights afforded them by these and other federal/state binding decisions and statutes. Currently, the only recourse for remedy of such complaints is a formal filing with the Department of Justice or legal action in civil court.

As noted in the goals and action strategies of the Nevada Strategic Plan for People with Disabilities, the Task Force would build on the mission of existing legal service agencies already fully knowledgeable of the principles of the Americans with Disabilities Act, and the various disability-related court decisions, to establish the Office of Disability Ombudsman.

- The goals of the Ombudsman, as envisioned by the Task Force are to:
 - Provide all citizens with disabilities with access to an independent, objective review mechanism for issues concerning their service-related legal and civil rights;
 - Increase the awareness of all citizens of the opportunity to access an independent review complaint mechanism;
 - Ensure all complaints are investigated objectively and thoroughly, in a confidential and timely manner; and
 - Monitor implementation of the state's Olmstead Plan and report progress to the state's citizens with disabilities and their representatives.
- The Ombudsman will listen to concerns, clarify procedures, discuss options and, when requested, act as an intermediary. He/she does not only advocate for the person, but advocates for fair processes. The Ombudsman works to promote the state's commitment to excellence in providing services in the most integrated settings appropriate to individual need and to building an inclusive society. Specifically, the Ombudsman will:
 - Identify issues of administrative unfairness;
 - Undertake thorough and impartial investigations;
 - Employ an approach that identifies and addresses the underlying causes of complaints;

- Attempt to resolve complaints through consultation and mediation;
 - Make recommendations and issue reports that are based on sound analysis of the facts and that are consistent with statutory mandates and the principles of natural justice and administrative fairness;
 - Identify causes of recurring unfairness and advise how they can be avoided in the future;
 - Promote the development of skills and organizational structures to enhance investigations; and
 - Use technology appropriately to facilitate investigations, manage information, identify trends, and provide public reporting.
- Benefits of the Ombudsman to the state and its citizens can be described as follows:
 - The Office will provide a missing link in an integrated conflict management system, complementing, but not replacing, formal dispute resolution process.
 - The Office will assure that consumers who feel they have been treated unfairly will have recourse to remedy without fear of intimidation or retribution.
 - The Office of the Ombudsman will provide an alternative to legal action and to the formal Department of Justice (DOJ) complaint process.
 - The Office will be flexible enough to handle virtually any dispute and can provide non-adversarial, problem-solving options.
 - The Office can prevent people with disabilities from having to contact one civil servant after another or travel from one address to the next in search of the person responsible for addressing their complaint efficiently and effectively.
 - In identifying and reporting constituent concerns, the Office can play a valuable role in ensuring accountability and promoting good administrative practice.
 - Disputes resulting from staff misunderstanding, misinterpretation, or lack of knowledge of the rights afforded people with disabilities will be impartially resolved.
 - Barriers to effective communication and service delivery will be identified, putting agencies in a better position to implement solutions and restore trust.
 - The state will consistently be able to follow and document progress in implementation of its Olmstead planning objectives.

Disability Ombudsman

Cost per consumer: \$1,733.81

150 consumers per biennium

<u>Annual Cost</u>	<u>SFY 2004</u>	<u>SFY 2005</u>
Paralegal 1.0 FTE	\$45,000	\$45,000
Attorney 0.1 FTE	\$6,000	\$6,000
Support Staff 1.0 FTE	\$35,000	\$35,000
Fringe 2.1 FTE	\$28,000	\$28,000
Travel	\$2,000	\$2,000
Equipment	\$6,000	
Supplies	\$500	\$500
Telephone	\$1,000	\$1,000
Office space	\$4,786	\$4,786
Misc (Ins, Dues, etc.)	\$4,000	\$4,000
Consultants	<u>\$3,000</u>	<u>\$3,000</u>
Total	\$135,286	\$129,286

APPENDIX F
HCBS Waiver for Cognitive Impairments

HCBS Waiver for Cognitive Impairments

People with autism, traumatic brain injury (TBI), Aspergers and other pervasive and unique pervasive developmental disabilities are not accessing the specialized services they require to maintain community independence.

These disabilities require complex, sustained, highly specialized treatment and rehabilitation and professionals trained and skilled in these very specific interventions. Among these interventions are:

- Biochemical (food allergies, medication, food and vitamin supplements)
- Neurosensory (sensorial integration, over stimulation and patterning, auditory training, facilitated communication, daily life therapy)
- Psycho-dynamic (holding therapy, psychotherapy and neuropsychological remediation programs that provide compensatory strategies for impaired attention, memory, mental flexibility and processing speed)
- Behavioral (Discrete trials (Lovaas and others) behavior modification using positive behavioral supports.)
- Pharmacological (cognition enhancing, arousal/attention disorders, acetylcholine enhancement)

Behaviors in these disabilities are considered to be bizarre and are not controlled by “usual” methods of rehabilitation, psychotherapy and pharmacology. Such methods applied without skilled knowledge of autism/traumatic brain injury, etc. can exacerbate rather than calm the problems.

Because variations of the aforementioned interventions are similarly required by these disabilities with cognitive/behavioral impacts, highly specialized services should be grouped into a HCBS waiver which could accommodate the service, professional expertise and environmental needs of these populations. This, for many of them, is the only way they will ever be able to receive services in “the most integrated setting” appropriate to their needs and live in even semi-independent community-based settings.

Task Force findings:

- The state’s service system often reportedly drops individuals from service whose behaviors are difficult to manage. This is particularly apparent when the individual functions at, or near, the upper limit of eligibility. The rationale for discontinuing service is that the individual has "chosen" to leave the system. When an individual dropped from services runs afoul of the law it is asserted that they have "chosen" criminal activity and thus deserve "natural consequences". The actuality is that people of diminished cognitive capacity and those with behavioral disorders are dropped from the system because specialized services

individual blend of peculiar characteristics, a constant change of direct care staff can be especially disturbing and destabilizing.

- Typically, ICF/MR and group homes in Nevada are programmatically and structurally designed for people with mental retardation and not for pervasive developmental disabilities including autism or for TBI. Most of these do not have staff trained and/or experienced in autism or TBI and are generally at a loss when trying to handle the unusual language, cognitive, behavioral and social deficits of autism. If staff are ignorant of successful ways of dealing with these unique deficits, behavior problems are likely to be dealt with in a punitive manner, which can quickly become severe and dangerous. It is at that point that parents are often called to come get their child or adult because “he doesn’t fit our program.”
- Although Medicaid HCBS waiver guidelines provide basically a zero-reject service, if a client is out-of-control, an understaffed agency not skilled in working with severe behaviors can discharge a person who presents a significant challenge. (“He is a danger to himself or others.” “Our program is not set-up to treat his condition.”) It is easier and less expensive to discharge the hard-to-manage clients than to retrain, supervise, monitor, and support staff for people with autism.
- Reimbursement rates for group care and day placement are typically low, so providers naturally gravitate to serving clients with less intensive needs than those with TBI or autism. When rates are the same for all clients, it makes more business sense for providers to have 1 staff to 4 clients than 1 staff to 1 client, as is needed so often when the diagnosis is autism, pervasive developmental disabilities or brain injury and a highly individualized program is critical. This is especially true for residential programs, where a client’s family can’t as easily be called to come get their son or daughter who is acting up.

