I. OVERVIEW OF THE OLMSTEAD DECISION

The 1999 Supreme Court Olmstead Decision requires states to administer their services, programs and activities, "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." The following questions and answers will assist in providing you with a general understanding of the provisions of the Olmstead Decision.

What is an Integrated Setting?

An "Integrated Setting" is a setting that enables individuals to interact with non-disabled persons to the fullest extent possible.

Who does the Olmstead Decision apply to?

The Decision's "integration" requirement applies to all individuals with qualifying disabilities protected from discrimination under Title II of the ADA.

The scope of the Olmstead Decision is not limited to Medicaid beneficiaries or to services financed by the Medicaid program.

What is required of states?

Under the Olmstead Decision, states are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when:

- The State's treatment professionals reasonably determine that such placement is appropriate
- The affected persons do not oppose such treatment
- The placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others who are receiving state-supported disability services.

How does a state comply with the Olmstead Decision?

The Court suggests that a state could establish compliance by demonstrating that it has:

- A comprehensive and effective plan for placing qualified persons with disabilities in less restrictive settings
- A waiting list that moves at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated.

What did the Olmstead Decision not do?

The Decision did not:

- Create new benefits
- Create a new eligibility group

- Change federal or state eligibility thresholds (either financial or medical)
- Eliminate the use of available community resources
- Provide for additional funding.

Does the ADA or the Olmstead Decision recommend termination of institutional care?

Nothing in either the ADA or the Olmstead Decision condones termination of institutional settings for persons unable to cope with, or benefit from, community settings.

II. ALABAMA'S OLMSTEAD PLANNING INITIATIVE

The Alabama Medicaid Agency (Medicaid), as the lead agency for the Olmstead Planning Initiative in collaboration with the Governor's Office on Disabilities (GOOD) began to discuss preliminary plans and activities in the spring of 2000. First steps included meeting with other state agencies to discuss the Olmstead Decision and the impact on the State of Alabama. Further discussions included how to involve not only the provider community, but how to involve consumers and advocates in substantial numbers in the entire process from the outset. We recognized a major weakness of the current system was the fact that the bureaucrats "decided" what the consumers needed without asking the consumers what they needed. Based upon this realization, our mission became focused on substantial consumer and advocate involvement.

In August 2000, Medicaid submitted a proposal to the Centers for Health Care Strategies, Inc., for an Olmstead Planning Grant, and was awarded $100,000 to begin the planning activities.

During the first months of the initiative, Medicaid and GOOD worked collaboratively with other state agencies and stakeholders to ensure that information regarding the Olmstead Decision was disseminated to consumers, advocates, and the provider community in an accurate and timely manner.

On October 26, 2000, Medicaid hosted a meeting for state agencies and advocacy groups with staff from the Office of Civil Rights (OCR) and the Centers for Medicare and Medicaid (CMS) as our special guest. The primary objective of this meeting was to provide the State of Alabama the opportunity to present an overview of our Olmstead Planning Initiative and for OCR and CMS to offer technical assistance and provide insight into the experiences and lessons learned by other states.

Following the meeting with OCR and CMS, we began to plan for the Statewide Focus Group meetings. Medicaid and GOOD had several internal meetings to plan for the Statewide Focus Group meetings. These meetings were held in six (6) regions of the state, in both rural and urban Alabama. The focus group meetings were designed to promote feedback and consumer input on areas that were important to consumers and their families. Many of the issues discussed were consistent throughout the state. Participants repeatedly expressed their concerns related to consumer involvement and flexibility in the provision of community services. Primary caregivers expressed the need for public awareness of the available resources and the need for more respite services. In all areas of the state, the participants were concerned about current state funding and future funding for the implementation of the Olmstead Plan.

During the focus group meetings, the groups were reminded that the Olmstead Planning Initiative was not a "Medicaid Initiative" but a "State of Alabama Initiative" that would require collaboration and consolidation of all available state resources.

Following the Statewide Focus Group meetings, we began to receive nominations for the Olmstead Core Workgroup focusing on substantial consumer and advocate participation. The initial meeting of the Olmstead Workgroup focused on issues and concerns presented by the consumers and their family members. These discussions were ongoing for several weeks. We began to formalize the goals and objectives for this initiative, and developed the "Principles for Olmstead Planning," to guide the activities of the Olmstead Core Workgroup and Olmstead Subcommittees. The principles fell into three categories. The first was a set of foundations on which all planning should be based. The second set related to how the planning process should take place. The third spoke to the elements that should be included in the plan, that is, the desired outcome. I have included a copy of the principles with this report.

Out of the Olmstead Core Workgroup, the Olmstead Subcommittees were established. Each subcommittee consists of consumers and advocates as Co-chairs and a Resource Person from the Medicaid Agency or the GOOD.

The four Olmstead Subcommittees are:

- Needs Assessment
- Best Practices
- Consumer Task Force
- Resource Development and Coordination.

The over-arching goals of the State's Olmstead Planning Initiative are to (1) enhance access to home and community-based services through improved information dissemination and service coordination; (2) create and expand system-wide opportunities for consumer choice and control over home and community-based services; and (3) expand resources for home and community-based services through effective planning, advocacy, and education.

I have included a copy of the Olmstead Core Workgroup membership and the Olmstead Subcommittees and their charges.

III. STATES SUCCESSES

A. Ticket to Work/Medicaid Infrastructure Grant

The Olmstead Planning Initiative has fueled other opportunities for the State of Alabama. The State was awarded $625,000 through the **Ticket to Work/Medicaid Infrastructure Grant** in January 29, 2002 for an effective date January 1, 2002 through March 31, 2003. This grant is a collaborative effort between Medicaid and the Alabama Department of Rehabilitation Services. The grant will allow the State of Alabama to assist individuals with disabilities to secure and maintain competitive employment through the provision of the Personal Assistance Service.

Personal Assistance Service is a range of services provided by one or more person designed to assist an individual with a disability to perform daily activities on and off the job. Such services are designed to increase the individual's independence and ability to perform every day activities on and off the job.

Other provisions of the **Ticket to Work/Medicaid Infrastructure Grant** include:

- Development of a consumer-based Policy Consortium to bring key stakeholders together to assess, review, and recommend policies and procedures to enhance employment supports for Alabama's citizens with disabilities
- Development of Requests for Proposal for a Medicaid Buy-In feasibility Study and evaluation of the Medicaid Infrastructure Grant
- Establishment of contract with a vendor for Case Management Redesign and Training
- Establishment of contract with a vendor to develop and pilot a Training Module for Personal Assistance Service Utilization for the Consumer
- Establishment of contract with a vendor to conduct Personal Assistance Service Provider Training and Develop an Attendant Registry for Consumer Use
- Development of an Outreach, Information, and Dissemination Learning Plan.

B. Real Choice Systems Change Grant

Medicaid also received $2,000,000 in federal funds to implement the **Real Choice Systems Change Grant**. Our proposal was developed in conjunction with the State's Olmstead planning process. The Olmstead Core Workgroup has drafted a unifying theme as a title for Olmstead plan, designed to catch the imagination of the state's citizenry and population: **Sweet Home Alabama: Under Construction.** It is an appropriate metaphor for the work we must do to build a cohesive system of supports that is predicated on community, real choice, and consumer direction. This same theme was used to create our Systems Change proposal. The **architects** of the proposed systems changes are its stakeholders, with special emphasis on the substantial and meaningful participation of people with disabilities and family members. The proposed grant activities are our **building blocks,** targeted to achieve enduring systems change in three areas: access, consumer choice/control, and expanded resources for home and community-based services. These building blocks will assist in assuring the success in our Olmstead

Planning Initiative. Responses from consumers and families revealed the following realities that will assist the State construct a system or network that will offer real choices for the consumer through the development of community alternatives in lieu of institutional care.

Barriers to Access:

- Lack of adequate coordination among available services---waiver programs in particular
- Information and referral are often haphazard, leading to a "revolving door" perception among consumers
- Eligibility criteria are often confusing, categorical, and exclusionary.

Few Opportunities for Real Consumer Choice:

- Consumers and family members need to be more meaningfully involved in planning for and evaluating home and community-based services.
- Real Choice of services and supports is limited due to funding of programs instead of people.

Limited Resources for Expanding Availability of Community Supports and Services:

- There are gaps in available services and providers.
- The State's community integration initiatives have been delayed by budget constraints.

Other provisions of the **Real Choice Systems Change Grant include:**

- Establish a Long Term Care Outreach and Education Unit within the Long Term Care Division to provide education and training to consumers, advocates, and providers on long term care initiatives
- Establish a Disability/Aging Policy Advisory Group, a consumer-based group within the Long Term Care Division. The group's mission is to develop and formalize mechanisms for ongoing consumer input and enhanced coordination of services for the elderly and disabled
- Conduct a study on the feasibility of a single point of entry system within the State. The system will be a streamlined process for consumers to access needed services, application procedures, eligibility determination, and other processes that may be accomplished at a single point.
- The Alabama Department of Senior Services (ADSS) will revise the existing assessment tool used for waiver clients to ensure that the tool is more client-centered and that it incorporates the cognitive, social, and spiritual needs of the consumer
- The Alabama Department of Mental Health and Mental Retardation has opened the Office of Consumer Empowerment that will allow for the development of a Grassroots Advocacy Committee of consumers to voice their concerns
- The Volunteer and Information Center will maintain an information and referral clearinghouse through the 211 Connects call center.

In addition to the Real Choice Systems Change Grant awarded to Medicaid, the State was also awarded two (2) nursing facility transition grants. The first was awarded to the **Birmingham Independent Living Center (BILC)** with the second being awarded to the **Alabama Department of Senior Services**. Medicaid has been actively involved in the grant with the BILC.

IV. DEVELOPMENT OF COMMUNITY SUPPORTS

In order to have an Olmstead Plan that can be successfully implemented, alternatives to institutional care must be available. The following home and community-based waiver programs have either been approved or awaiting approval by CMS:

A. Technology Assisted Waiver for Adults

The Technology Assisted Waiver for Adults will provide private duty nursing, personal care/personal assistance service, assistive technology, and medical supplies to individuals with disabilities who would otherwise require more costly nursing facility care. Individuals served by this waiver received private duty nursing services under the federally mandated EPSDT Program for children under the age of 21, but upon reaching age 21, are no longer eligible for the EPSDT Program benefits. This waiver was approved by CMS on February 11, 2003, for an effective date of February 22, 2003, and will serve 30 individuals in the first year.

B. HIV/AIDS Waiver

The HIV/AIDS Waiver will provide personal care, respite care, skilled nursing, and companion services to individuals with a diagnosis of HIV/AIDS and related illness who would otherwise require more costly nursing facility care. Upon approval by CMS, the waiver will serve 150 individuals in the first year.

C. Specialty Care Assisted Living Facility Waiver

The Specialty Care Assisted Living Facility Waiver (SCALF) will provide assisted living service, case management, and medical supplies to individuals with a diagnosis of Alzheimer's or Dementia who would otherwise require more costly nursing facility care Upon approval by CMS, the waiver will serve 500 individuals in the first year.

D. HOPE VI Research and Demonstration Project

The HOPE VI Research and Demonstration Project will provide assisted living services and case management services to individuals age 65 and over who meet specific criteria and who reside in the Central Plaza Towers Public Housing Complex in Mobile, Alabama. Upon approval by CMS, the waiver will serve 40 individuals in the first year.

E. Alabama' s Living At Home Waiver

The Alabama's Living at Home Waiver will provide a wide array of services for individuals with a diagnosis of Mental Retardation who would otherwise require more costly services in an Intermediate Care facility/Mentally Retarded. This waiver was

approved by CMS effective October 1, 2002, and will serve 204 individuals in the first year.

F. Alabama's Long Term Care Ombudsman Program

The Older American's Act requires there to be an Ombudsman program that is responsive to the needs of persons in long term care facilities. The States has not been funded at a level to meet the requirements of the law. Medicaid provides matching federal dollars to ADSS that enables each Area Agency on Aging to hire, at a minimum, a full-time Ombudsman to provide education and advocacy supports to individuals in long term care facilities. The Ombudsman Program began August 1, 2002.

V. EXISTING LONG TERM CARE COMMUNITY PROGRAMS

As stated earlier, in order to have a plan that can be implemented successfully, we must have available community options in lieu of institutionalization. Following is a brief description of the existing Medicaid long term care community programs.

- **Elderly and Disabled Waiver**: This waiver is a collaborative effort among Medicaid, Alabama Department of Public Health, and ADSS and provides services to persons who might otherwise be placed in nursing homes. The five (5) basic services covered are case management, homemaker service, personal care, adult day health, and respite care. This waiver is approved to serve 7500 individuals.
- **Mentally Retarded and Developmentally Disabled Waiver**: This waiver is a collaborative effort between Medicaid and the Alabama Department of Mental Health and Mental Retardation and serves individuals who meet the definition of mental retardation or developmental disability. This waiver provides an array of services to meet the needs of the individuals on this waiver.
- **State of Alabama Independent Living Waiver**: This waiver is a collaborative effort between Medicaid and the Alabama Department of Rehabilitation Services and serves disabled adults with specific medical diagnoses who are at risk of being institutionalized. The services provided under this waiver include case management, personal care, respite care, environmental modifications, medical supplies, personal emergency response system, and assistive technology.
- **Home Health**: Skilled nursing and home health aide services prescribed by a physician are provided to eligible recipients on a part-time or intermittent basis.
- **Durable Medical Equipment and Supplies**: Appliances and durable medical equipment are mandatory benefits under the home health program.
- **Hospice Care Services**: Hospice care is a comprehensive home care program which primarily provides reasonable and necessary medical and support services for terminally ill individuals. The goal of hospice is not to cure a terminal illness, but rather, to provide relief of symptoms.
- **In-Home Therapies**: Physical, speech, and occupational therapy in the home are limited to individuals under 21 years of age.
- **Private Duty Nursing**: Private duty nursing services in the home are covered for eligible recipients under 21 years of age requiring continuous skilled nursing care.

VI. LESSONS LEARNED

The "lessons learned" are a result of the analysis of the strengths and weaknesses of the current system from the perspective of consumers, state agencies, and the Olmstead Core Workgroup. The identification of needs, in particular, is based largely on a series of statewide consumer/family focus group meeting. The following is a summary of what consumers and their families told us.

COMMENTS FROM CONSUMERS AND FAMILIES:

Individual Choice: Focus group members consistently pointed out that individuals and families have the real expertise. They know more about their own or their family members' lives and needs for supports than providers. State agencies and providers should not be making decisions about care; individuals and families should be making the decisions about their care. Services should be flexible and individualized, according to individual and family needs, not driven by provider programs. Funding should be based on individual plans, not budgeted to certain programs. Many felt that the "choice" they were offered was an illusion; often the choice was simply "take it or leave it."

Access/Information Resources: They said it's frustrating to be led on a circle of phone calls to different places without receiving any real information. Consumers need better ways to find out what's available—they should not have to accidentally stumble across the information. Some suggested a person should be able to call one number to learn about services, like a centralized clearinghouse, with operators who are informed and welcoming. Providers, too, should be more aware of and suggestive of services such as Medicaid waivers, etc. State and local agencies should be doing better customer service, especially case management.

Funding Issues: They said the State should make better use of resources already present in the community, diverting funding from institutional care to serving people in their homes. Some felt there continued to be an institutional bias, noting that when someone leaves a nursing home, the funds don't follow him or her. In other words, the State has money to pay nursing homes, but does not have money to support people in the community. Focus group members generally believe it costs less to support someone in the community than in an institution, and said state and local agencies should explore how money can be redirected. Individuals and families need alternatives to institutions.

Consumers also said we need additional resources. Many spoke about the enormous financial costs of disability. For example, medical costs, medicine, therapy—can be astronomical, even with insurance. Medicaid levels of payment are often too low to attract sufficient/appropriate providers. Attendants and home care workers need better pay scales and benefits.

Medicaid Waiver/Community Services: Categorical eligibility requirements, as opposed to a functional eligibility standard can result in the exclusion form service of some people with the most severe disabilities. Autism is a prime example and the

prevalence of it is rapidly increasing. An MR/DD waiver is not currently available in Alabama; the "MR/DD" Waiver actually requires a mental retardation diagnosis.

A number of gaps in services were pointed out, especially in personal assistance services and home health. Availability of these services, especially in the many rural areas of the state, is a widespread problem. Even when services are available, there are unnecessary restrictions on how, where, and when services can be provided. The available providers often do not have adequate training. Focus group members suggested some potential solutions: allow family members to be hired as caregivers; allow consumers to hire caregivers of their own choosing, without adhering to rigid provider qualifications and facilitate that process by providing background checks and other employment assistance; and ensure that the consumer and families are directly involved in caregiver training.

There were many suggestions about changes that could be made. For instance, the State should look at TEFRA option to help families with children with severe disabilities. Many of today's programs are outdated and not always based on individual need. This was often attributed to a lack of consumer and family input in program development over the years. Medicaid needs a consumer/family advisory group to ensure that services and supports are responsible to their needs.

Service Coordination: Many spoke about coordination of services. They said there are pieces of services, but the gaps need to be filled and better coordinated. They also said paperwork, regulations, and red tape keep the assistance you can get from being timely enough to make a difference. Social workers and case mangers need to be better advocates and help those who need more assistance. Many asked how a "case manager's" role would be different in a consumer-directed system.

VII. FUTURE DIRECTIONS

People with disabilities or long term illnesses and their families will continue to be involved in program design, implementation, evaluation, and/or reporting through the Olmstead Core Workgroup. The Workgroup will continue its work to develop a comprehensive plan for community living, and consumer participation will continue to be valued and supported. The Workgroup will also serve as the consumer task force for the purposes of this grant, providing oversight and direction.

As we continue to explore other options to institutional care, we will consider other programs that have been successful in other states. These program **options** include:

Cash and Counseling Demonstration Waiver: This program provides a cash allowance to recipients of Medicaid personal care services and other home and community-based services. Participants use this allowance to purchase their own care instead of receiving it from an agency. The allowance does more than help people with disabilities pay for needed services; it gives them some much-cherished freedom and independence.

This program has been successful in Arkansas, Florida, and New Jersey.

Program of All-Inclusive Care for the Elderly (PACE): The Balanced Budget Act of 1997 (BBA) established the PACE model of care as a permanent provider entity within the Medicare and Medicaid programs. This provision enables states to provide PACE services to Medicaid beneficiaries as a state option, rather than as a demonstration as was formerly the case.

PACE programs are funded by both the Medicare and Medicaid programs and participants are generally eligible for both.

Explore the Option of **Long Term Care Insurance**

OUR NEXT STEPS INCLUDE:

- Consolidation of Olmstead Subcommittee reports into a draft Olmstead Plan by summer 2003.
- Publicize draft plan and schedule Public Forums to discuss draft Olmstead Plan by summer 2003.
- Revise Plan based upon feedback from Public Forums
- Schedule meetings with Governor, Legislative Body, and appropriate state agencies by fall 2003.