DEPARTMENT OF HEALTH & HUMAN SERVICES
Health Care Financing Administration

Center for Medicaid and State Operations
7500 Security Boulevard
Baltimore, MD 21244-1850

SMDL #01-007

Olmstead Update No: 5
Subject: New Tools for States
Date: January 10, 2001

Dear State Medicaid Director:

This is the fifth in a series of letters designed to provide guidance and support to States in their efforts to enable individuals with disabilities to live in the most integrated setting appropriate to their needs, consistent with the Americans with Disabilities Act (ADA).

In the attachments to this letter, we outline a number of additional tools available to improve State health and long term service systems so as to fulfill the promise of the ADA.

Federal agencies have certain responsibilities to enforce the nation's laws prohibiting discrimination on the basis of disability. Equally important, however, is our additional role of partnering with States to achieve the goals of these laws. We have therefore committed ourselves to examining federal policies, practices and procedures that may present obstacles to fulfillment of the goals of section 504 of the 1973 Rehabilitation Act, the Americans with Disabilities Act (ADA), and the U.S. Supreme Court's decision in Olmstead v. L.C. We are also committed to providing active assistance to States in their conscientious efforts to build better health and long term service systems that enable integrated, community living.

In this spirit of partnership, we are very pleased to convey a brief overview of some new tools you may find exceptionally useful. They include:

Health Coverage Options Under Section 1902(r)(2): We promulgated on January 10, 2001, a final rule that removes barriers that previously prevented States from providing effective health and long term care coverage to selected groups of individuals. Examples of some ways that section 1902(r)(2) of the Social Security Act may be used are summarized in Attachment 5-A.

Nursing Facility Transition Grants and "Access Housing:" The U. S. Department of Housing and Urban Development (HUD) is collaborating with us to assist States (and partnering organizations) in the appropriate transition of people from institutional to community settings. About $12-$15 million in grant funds will be awarded in State program grants for eligible individuals of all ages. In addition, about 400 HUD section 8 vouchers will also be available for

eligible non-elderly individuals who have a disability. These opportunities are described in Attachment 5-B.

Real Choice Systems Change Grants: These systems change grants represent a major new initiative to promote the design and delivery of home and community-based services that support individuals with a disability or chronic illness to live and participate in their communities. Congress and the Administration have made $50 million available for this initiative.

Medicaid home and community-based services play an increasingly critical role in enabling individuals of all ages who have a significant disability or chronic illness to live fuller, more self-directed lives in their own homes and communities than ever before. Despite continuing progress on this front, however, States wishing to improve the availability and quality of these services still face significant challenges in this regard. Accordingly, Congress and the Administration have envisioned a new grant program to assist States and the disability and aging communities to work together to find viable ways to expand such services and supports. The new grant funds are meant to be used to bring about enduring system improvements in providing long term services and supports, including attendant care to individuals in the most integrated settings appropriate to their needs. These opportunities are outlined in Attachment 5-C.

Community-Based Attendant Services with Consumer Control: Grants totaling $5-8 million will be available in 2001 to support State efforts to improve community-based personal assistance services that are designed to ensure that people who have a disability or chronic illness have maximum control over their lives. Additional information is provided in Attachment 5-D.

We appreciate your efforts to improve our nation's health and long term service system. More details regarding these and other initiatives relevant to Medicaid and the ADA will be posted on the ADA/Olmstead website at **http://www.hcfa.gov/medicaid/olmstead/olmshome.htm**. In addition, a technical assistance Primer for ways Medicaid may assist with Home and Community Based Services is available online at **http://aspe.hhs.gov/daltcp/whatsnew.htm**.

Sincerely,

Timothy M. Westmoreland
Director

Enclosures

Attachment 5-A "New State Health Coverage Options Under Section 1902(r)(2)"
Attachment 5-B "Nursing Facility Transitions and Access Housing 2000"
Attachment 5-C "Real Choice Systems Change Grants"
Attachment 5-D "Community-Based Attendant Services with Consumer Control"

cc:
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Attachment 5-A
Subject: New State Health Coverage Options Under Section 1902(r)(2) of the Social Security Act
Date: January 10, 2001

A recent administrative rule change permits additional State options for using section 1902(r)(2) of the Social Security Act to provide health and long term service coverage to selected groups of individuals.

Under normal eligibility rules, States are required to use the processes (methodologies) of the cash assistance programs (SSI and the old AFDC program) in determining eligibility for Medicaid. However, section 1902(r)(2) of the Social Security Act (the Act) allows States to use less restrictive income and resource methodologies in determining Medicaid eligibility for most groups than would normally be permitted under the cash assistance program rules. In other words, section 1902(r)(2) permits States to disregard (i.e.,"not count") additional kinds and amounts of income and resources beyond what is allowed under the cash assistance programs.

However, until now, a HCFA administrative interpretation of how section 1902(r)(2) applies to income effectively prevented States from taking advantage of the full flexibility that section 1902(r)(2) would otherwise permit. The final rule fixes this problem. The rule change means that the full flexibility offered by section 1902(r)(2) is now available to States. The final rule change was published in the *Federal Register* on January 10, 2001.

Following are some examples of how States can use section 1902(r)(2) to improve their health and long term service systems for elderly or people with a disability. Please note that section 1902(r)(2) may be used to make similar improvements in health coverage for children and their families. Those examples are very important but are not addressed here in the context of Olmstead/ADA.

Medically Needy Income Limits

Under a medically needy program, States can choose to provide health coverage under Medicaid to individuals with income that is above the SSI limits but whose medical expenses so erode their income that little is left to pay for personal living expenses. If, after subtracting incurred medical expenses from income, an individual's remaining income is less than the State's medically needy income limit, then the person may obtain health coverage through Medicaid provided all other program requirements are met. This process is known as spending down excess income or "spenddown."

However, in many States the medically needy income standard is very low. In at least 22 States the medically needy income standard is actually lower than the income standard for SSI benefits ($530 a month for an individual in 2001). In four States, the medically needy income standard is less than $200 a month. This means, for example, that an elderly person with just $531 in countable income would need to incur $331 or more per month in medical expenses before obtaining health coverage under Medicaid. This would leave only $200 for food, clothing,

shelter, and other personal expenses. Ironically, if the person had just $1 less in income and met all other program requirements, the person would meet the SSI eligibility test and secure Medicaid health coverage and have more income to meet the cost of basic living expenses. Section 1902(r)(2) may be used by States to fix this problem.

Under the Medicaid statute, States cannot simply increase their medically needy income levels to deal with this problem. However, a State could use section 1902(r)(2) of the Act to disregard specified amounts of income under its medically needy program, effectively reducing the large "spenddown" liability described in the example above. It is largely a matter of State discretion to specify the precise amount and type of income that would be excluded. States use section 1902(r)(2) by amending their State plan. No Medicaid waivers are required.

Helping People Move from Institutions to the Community

The medically needy spenddown problem described above can also have adverse effects for people in medical institutions who prefer to live in community settings. By "medical institution" we refer to such institutions as hospitals, nursing facilities, and Intermediate Care Facilities for the Mentally Retarded (ICFs-MR). Since Medicaid will pay for room and board expenses in a medical institution, the individual needs to retain relatively little income after application of the medically needy spenddown requirement. However, Medicaid will not pay for room or board expenses in a community setting. Few individuals will be able to move from a medical institution to the community if they are permitted to retain only $200-$400 after meeting Medicaid spenddown requirements.

The practical effect of this is that many people residing in institutions who would like to move to the community, and who would normally be able to manage in a community setting, remain in the institution because they literally cannot afford to leave. The final rule gives States opportunities to correct spenddown problems so that more people could leave institutional settings and live in the community.

Encouraging Paid Employment

Legislation enacted in the last few years (e.g., the Ticket to Work and Work Incentives Improvement Act - "TWWIIA") has given States new options to provide or continue health care coverage via Medicaid for individuals with disabilities who work. The section 1902(r)(2) rule change provides States with additional options. For example, section 1902(r)(2) may be used to disregard earned income on the part of people who may qualify as medically needy while treating unearned income in the normal manner. States may select the amount of earned income to disregard. By allowing people to keep more of the income they earn without forcing them to spend more for medical care under a medically needy spenddown, States can enable more employment on the part of people with disabilities. Section 1902(r)(2) may be used in the same way to encourage employment on the part of any other group that does not readily fit into one of the new TWWIIA work incentives groups.

States may also permit special savings accounts established from the proceeds of employment. Both the interest earned and the principle may be disregarded, so that workers with a disability

may save toward a more desirable and independent future without fear of losing vital health care coverage.

Administrative Simplification

Under normal eligibility rules, States are required to count many kinds of income. Some of these types of income are administratively burdensome (e.g., the cost of administering them may exceed the benefit). Others may be so small that they do not materially affect the outcome of the eligibility determination in most cases. Examples include the value of food or shelter provided to an applicant (called in-kind support and maintenance) and low amounts of income such as interest earned on very small savings accounts. Under the final rule, States can use section 1902(r)(2) to disregard this kind of income to simplify the process of determining eligibility by not counting types of income that primarily impose an administrative burden.

We plan to develop more detailed explanations of these matters and to post them on our website. You can assist us by sending your questions and comments via e-mail to Roy Trudel at rtrudel@hcfa.gov and copying Aimee Ossman at aossman@hcfa.gov. For issues concerning coverage to children and their families, please send your comments and questions to Judy Rhoades at jrhoades@hcfa.gov.

Attachment 5-B
Subject: Nursing Facility Transitions and Access Housing
Date: January 10, 2001

In this attachment, we describe grants available to enable individuals to move from institutional to community-integrated living. Approximately $12 - $15 million in grant funds will be available from HCFA. In addition, approximately 400 or more HUD section 8 vouchers will be available for eligible non-elderly individuals with a disability.

For a number of years the Health Care Financing Administration, in association with the Department of Health and Human Services' Assistant Secretary for Planning and Evaluation, has sponsored grant initiatives to help transition people from institutional living arrangements to community settings. We appreciate the pioneering work of those States that successfully implemented these research and demonstration efforts, as well as the interest of those States that applied in the past but were not funded.

We have learned a number of lessons from the nursing facility transition initiative. First, many additional States are seeking this type of support, particularly in the current context of the Olmstead v. L. C. decision and the Americans with Disabilities Act (ADA). Second, the lack of affordable and accessible housing in the community often represents a substantial barrier to success. For many people with a disability, market rent in the community exceeds all available income. For others with mobility impairments, existing housing units are often not physically accessible. Third, there has not been an effective means by which people in the different States can learn from each other, share effective practices, actively assist one another on-site, and disseminate the lessons learned.

We have therefore made a number of improvements in the initiative based on experiences from the pioneer States. First, Congress and the Administration increased the funding level to permit more States to participate. Second, the Department of Housing and Urban Development (HUD) and the Department of Health and Human Services began collaborating in a more active manner to address the housing challenges. We call our overall effort "Access Housing." As part of that effort, HUD will make available 400 section 8 rent vouchers for use in association with the nursing facility transition efforts of States, with the possibility of additional vouchers in future years. Third, we expanded on the independent living partnership concept from previous years and added a technical assistance exchange.

We hope you will begin now to engage with your many partners in planning for these grants. To aid your thinking and planning, we offer the following preliminary information about the grants. We reserve the right to adjust the terms for the final grant solicitation.

Purpose: To enable people of all ages who reside in nursing facilities to transition to community residence and participate in community life to the extent possible and desired by the individual.

Eligible Applicants: The District of Columbia, Puerto Rico, Guam, the United States Virgin Islands, American Samoa, the Commonwealth of the Northern Mariana Islands, Independent Living Centers recognized under State law, and any of the 50 States or their instrumentalities (including State universities).

Time Period of the Grant Awards: We expect grant awards to be made by September 14, 2001, with an effective date before September 30, 2001, and continuing for up to 36 months depending on the proposal and the availability of appropriations. No State match is required, but States and other entities are expected to contribute in-kind assistance and additional financial resources to maximize the potential benefits of the grant award.

Standard Components: There are two components of the initiative that we expect most States will want to combine:

> ***State Program Grants:*** These grants provide resources to States to design, implement, and/or provide outreach for the transition and the on-going support system that will enable identified individuals to transition to a community arrangement. We expect the State program grants to range from $300,000 to $1,000,000 for the grant period. Examples of activities that States have found particularly useful in the past include:

- Staff Resources: basic staffing for the design and implementation of the initiative;

- Transitional supports, such as housing access support, temporary rent payments; furniture and clothing; special equipment; direct cash payments to the individual and/or his/her family to ensure that direct services are provided;

- Self-direction and consumer management infrastructure, such as the development of support systems that help people with a disability or chronic illness to direct and manage as much of their supports or services in the community as is desired and appropriate;

- Improvements to on-going supports, such as transportation, psychosocial supports, personal assistance services, employment supports, crisis intervention to prevent loss of housing during periods of hospitalization, consumer-run services (such as self-help and peer support services), etc. Grant funds may not be used to pay for on-going supports or services, but they may be used to design and implement the improvements. An important part of each grant application will be an assurance that the agency will make available the on-going supports necessary to sustain each individual in the community after the initial transition has been accomplished.

- Interagency collaboration, especially the collaboration between human service agencies, the disability and aging communities, State and federal housing finance agencies, and/or public housing authorities to make the most effective use of housing options, including the use of HUD section 8 rental vouchers for individuals who make the transition.

> ***HUD Section 8 Rent Vouchers:*** The U.S. Department of Housing and Urban Development (HUD) will make up to 400 rent vouchers available for use by eligible non-

elderly individuals who have a disability who make the transition from a nursing facility to the community, with a goal of reaching 2000 vouchers in the future depending on appropriations. The rent vouchers will be allocated to the local public housing authority that is partnering with the responsible human service agency in this initiative. We expect that States will apply for both the State Program Grant and the HUD section 8 rent vouchers as elements of a single application. However, States may apply for just one of the two. For example, a State that has received a program grant in the past may wish to apply for just the HUD section 8 rent voucher component. States applying for only HUD section 8 rent vouchers will apply through their housing authorities and must assure that the necessary human service supports will be available through Medicaid and other human service programs. States can, as always, access nursing home transition funds without a partnering housing authority also applying for the HUD vouchers.

In addition to the above rent vouchers coordinated specifically with the nursing facility transitions, HUD also provides substantial rent assistance to low-income elderly and people with a disability through its regular programs. We expect that States that successfully seek a State Program Grant will effectively coordinate with both state and local housing authorities to achieve superior results through collaboration between all human services and housing programs.

Additional Opportunities: In addition to the standard program components, States and Independent Living Centers may be interested in the following companion elements of this national endeavor:

Independent Living Partnerships: Independent Living Centers recognized under State or federal law may apply for partnership grants. The purpose of the grants is to develop outreach, technical assistance, specific aspects of the infrastructure needed to make the nursing facility transition initiatives successful. We expect to award 5-7 such grants that range from $120,000 to $350,000 over the total project period. Successful independent living centers will include multiple age and disability groups within the scope of their activities and will evidence effective partnerships with other consumer-directed organizations to create cross-disability competence. Applications from Independent Living Centers must have the support of the State Medicaid Agency or the State agency administering the relevant home and community-based waiver(s) under section 1915(c) of the Social Security Act.

National Technical Assistance and Evaluation Exchange ("The Exchange"): The purpose of the Exchange will be to provide an effective means by which people in the different States can learn from each other, share effective practices, and disseminate the lessons learned so that all States may benefit. The Exchange will be particularly helpful in assisting State human service agencies and public housing authorities to work together to assure access to both affordable housing and necessary community-based services. We expect to fund this technical assistance function with a grant ranging from $1.2-$1.8 million, and an additional $150,000-300,000 to collect and analyze data needed for the national evaluation of the program. Only States or their instrumentalities (such as State universities) may apply.

Please refer any questions concerning this attachment to Tammi Hessen via e-mail at thessen @hcfa.gov.

Attachment 5-C
Subject: Real Choice Systems Change Grants
Date: January 10, 2001

Congress and the Administration have made $50 million available for grants that will assist States in working with their disability and aging communities to improve their health and long term service systems so that people with a disability or chronic illness will have better choices and support to live in the community, consistent with the ADA.

Across the country States are actively working with their citizens to strengthen our communities. This includes efforts in most States to strengthen the capacity of our communities to enable people of all ages with disabilities to reside in their own homes and take part in all facets of family and community life. This work is vital to implementing the principles of the ADA and the preferences of most children and adults to live in their own home in the community. It constitutes a very substantial agenda. Creating the service options that make community and job participation possible, such as effective personal assistance services, is one example of the challenges that States face. Creating the infrastructure that will protect the health, well being, and life choices of such individuals is another example. Creating the service designs that mesh with and support family caregiving, such as adult day services, respite services, and other family supports, is a third example.

Adequate infrastructure and service options are vital if we are to succeed in making community systems truly capable of fulfilling the promises made to our citizenry under State and national laws that hold forth the prospect of community-integrated living, such as the Americans with Disabilities Act.

As a result of the bipartisan efforts of Congress and the Administration, we will now be dedicating specific grant funding to support State efforts to improve community long term service systems. Approximately $50 million will be awarded to States and partnering organizations. The grants will assist States to partner with the disability and aging communities to design or implement effective and enduring improvements in systems that support people with a disability or chronic illness to live in the community. Although the grants will be awarded through competitive application, we strongly encourage all States, the District of Columbia, Puerto Rico, Guam, the United States Virgin Islands, American Samoa, and the Commonwealth of the Northern Mariana Islands to participate.

We plan to issue a full grant solicitation in March-April 2001. Applications would then be due in July 2001. We are providing advance notice now because it will take time to develop effective proposals and involve people of all ages who have a disability or chronic illness in the planning process. The bipartisan sentiment reflected in the conference report from Congress for these grants, co-sponsored by Senators Specter and Harkin, places strong emphasis on the meaningful and effective participation by people who have a disability or chronic illness in all aspects of the initiative. Such participation must include a Consumer Task Force, as described below.

We hope you will begin now to engage with your many partners in planning for these grants. To aid your thinking and planning, we offer the following preliminary information about the grants. We reserve the right to adjust the terms for the final grant solicitation.

Purpose: To assist States to partner with their disability and aging communities in designing or implementing effective and enduring improvements in customer-responsive long term service systems that support people of all ages who have a disability or chronic illness to: (a) live in the most integrated community setting appropriate to their needs and strengths; (b) exercise meaningful choices about their supports; and (c) have quality services arranged in a manner as consistent as possible with their community living preferences or priorities.

Eligible Applicants: Eligible applicants are the District of Columbia, Puerto Rico, Guam, the United States Virgin Islands, American Samoa, the Commonwealth of the Northern Mariana Islands, and any of the 50 States or their instrumentalities, including State universities. Each individual State application must be developed in collaboration with a Consumer Task Force comprised of a broad range of individuals who have a disability or chronic illness, as described below.

Consumer Task Force: To receive a grant, each State must develop its proposal in collaboration with a Consumer Task Force comprised of a broad range of people of all ages who have a disability or chronic illness and rely on long term services and supports. The Consumer Task Force should also include representatives of families of children with disabilities and other advocates. Additional members may include people representing a broad range of organizations publicly recognized as promoting the interests of people with a disability or chronic illness as their primary purpose. Examples of such organizations include State Independent Living Councils, Commissions on Aging, Developmental Disabilities Councils, State Mental Health Planning Councils, Statewide consumer organizations, etc. The State must make a commitment to continue active participation on the part of people of all ages who have a disability or chronic illness throughout the duration of the initiative. While gubernatorial appointment is the preferred method of selection, it is not required. We appreciate the time constraints under which States will labor. Therefore, we will accept any other method of appointment the State devises. Grant funds may be used to support the continued operation of the Consumer Task Force.

Other Stakeholders: While providers, professional associations, and others are not part of the Consumer Task Force, grant funds may be used for activities that would enable effective participation by such key stakeholders.

Size and Time Period of Grant Awards: We expect grant awards to be made by September 14, 2001, with an effective date before September 30, 2001, and enduring for up to 36 months thereafter depending on the proposal and the availability of appropriations. We expect the funding for a State to range from $250,000 to $2.5 million for the project period. No State match will be required, but in-kind match is expected. Funding for an applicant that successfully competes for a grant to provide national technical assistance, as described below, will not count against the above dollar limits. Finally, we expect that the size of the grant award

will correlate with the significance of the proposed endeavor rather than simply correlate with the size of the State.

Technical Assistance and Learning Collaborative: We will fund one entity to host a national technical assistance and learning collaborative for the purposes of (a) fostering on-site State-to-State technical assistance; (b) developing technical assistance materials and expertise for States and people with a disability or chronic illness; (c) working with consumer organizations, States, the National Governors' Association, the National Council of State Legislatures, and national associations of State agencies to collect, refine, and disseminate information that aids the effective administration of programs for community living; and (d) gathering and analyzing information needed for a national evaluation. We expect total funding to range from $1.8 - $2.4 million for the technical assistance, and an additional $400,000-$750,000 for the data collection and analysis necessary to support a national evaluation.

States Receiving More Than $750,000: All States must develop and implement their proposals in a manner that includes effective consumer participation. In addition, any State receiving more than $750,000 must include the first two initiatives that are described below; that is: (a) improvements in personal assistance services, and (b) improvements in quality assurance or quality improvement systems for home and community-based services.

Examples of Activities: The list below represents only a few examples of activities that States might consider. The list is not intended to limit State creativity. The key question applied to any proposed activity should be: does this activity promote an enduring systems improvement that will significantly advance the purpose for which these grants were made? However, it is not the intent of this initiative to fund direct services to individuals.

> ***Development of Infrastructure to Improve Personal Assistance Services:*** Develop the infrastructure to improve the availability, reliability, and adequacy of the State's personal assistance services under Medicaid.
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> ***Quality Assurance and Quality Improvement:*** Improve the systems by which the State assures that: (a) quality will characterize its home and community-based services and will be designed into each aspect of the system; (b) frequent and accurate customer feedback and other information from the sites of service delivery are obtained and used effectively to correct or prevent problems; (c) quality problems are systematically identified and remedied; and (d) the capacity to improve is built into the service delivery system through competent quality improvement functions.
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> ***Comprehensive Long Term Service System Reforms:*** Design, demonstrate, or implement reforms for one or more target groups that create an effectively working system of comprehensive long term care services that (a) enable flexible long term service funding to follow each individual across the sites of preferred and appropriate living arrangements; (b) maximize the opportunities for community participation and ensuring the most integrated community living possible; and (c) support self-direction and the exercise of personal responsibility.

Coherent and Timely Access: Design, demonstrate, implement, or evaluate reforms that offer "one-stop shopping" for all long term care services, characterized by (a) timely access to clear information about options for long term care services; (b) prompt eligibility determinations for any relevant service program; (c) effective referral and follow-up service; (d) emergency or crisis intervention services, including temporary support to individuals or their families while they are on a waiting list for on-going services; (e) improved access to on-going services if needed; and (f) effective grievance and ombudsperson support to fashion solutions in response to conflict or problems in services.

Training: Provide support to public or private entities to train and provide technical assistance activities for individuals of all ages with disabilities, attendants, providers, and other personnel (including professionals, paraprofessionals, volunteers, and other members of the community).

Community Planning: Actively engage with elderly individuals and people with disabilities to plan for improved systems of community long term care services and to develop comprehensive, effectively working plans and systems for serving people in the most integrated settings appropriate, as suggested by the U.S. Supreme Court. Support a Consumer Task Force for the overall systems change effort.

Infrastructure Development That Supports Consumer-Directed Services: Enhance system operations to support development and purchase of services that is organized around the individual and is outcome-based. Develop and implement mechanisms to further consumer-directed services, such as flexible home and community-based waiver service definitions, assistance in purchasing services (e.g., support brokerage), assistance in acquiring housing through rental or home ownership, development of provider qualifications tied to the consumer's needs, implementation of emergency back-up systems for personal assistance or other services, and involvement by people of all ages who have a disability or chronic illness (and their families) that includes personal responsibility for one's plan and budget.

Infrastructure for Cost-Effective, Non-Medical Solutions: Develop and implement strategies to modify policies or practices that eventuate in unnecessary provision of services by highly-credentialed professionals when other persons, with adequate support or training and consumer direction, might be able to perform the requisite functions competently and at less public expense.

Demonstrations: Demonstrate more effective systems of providing long term support that (a) generate more and improved options for people, and then (b) support the exercise of real choices with regard to the location of services, manner of delivery, quality, and degree of self-direction involved.

Please refer any questions concerning this attachment to Jean Tuller via e-mail at jtuller@hcfa.gov.

Attachment 5-D
Subject: Community-Based Attendant Services with Individual Control
Date: January 10, 2001

Grants totaling $5-8 million will be available to assist States in developing or improving community-based attendant service systems that offer individuals with disabilities maximum control.

As States have sought human service strategies that are more cost-effective and also resonate with the American people, they have increasingly turned to concepts of individual self-direction and self-management of services. These concepts are also very consistent with Medicaid. The Medicaid statute is premised on the principle that each beneficiary of service has the right to choose his or her own health care provider.

Over the past 20 years federal and State governments have worked together to expand the ways in which Medicaid practice can support the principle of individual choice and control. This is most clearly evident in State-initiated demonstrations that are aimed at increasing consumer choice and control with respect to Medicaid services, supports, and individual budgets over which consumers exercise responsibility and discretion. Examples of such demonstrations in recent years include Self- Determination for People with Developmental Disabilities, Cash and Counseling, and the Independent Choices initiatives.

Demonstrations conducted by States have identified certain essential elements of a self-determined or self-directed approach to organizing and delivering services. Key elements include: (a) consumer authority and responsibility over decisions regarding the development of an individual budget that supports implementation of the individual's plan of care; (b) control over one's own individual planning process and, in particular, decisions affecting the nature of the services/supports one receives and how they are delivered; and (c) the support necessary to ensure that the individual is able to personally manage services received and to make informed choices, based on comprehensive information about available options, including individually customized services and supports.

We believe that the concepts of self-direction or self-determination can help States to offer services that are cost-effective, and offer eligible individuals the opportunity, support, and authority to exercise more choice and more responsibility over key decisions in their lives. For such approaches to succeed, however, the individuals (and their legal representatives, when appropriate) must be equipped with the information, tools, and supports needed to manage the selection and provision of services or supports that meet their unique needs.

The legislative authorization focuses these grants on community-based attendant services. Nonetheless, we believe most of the infrastructure issues involved in attendant care are also relevant to the larger question of self-directed services in general.

Much of the attention in national self-determination discussions has centered on ways in which consumers may gain control of key service decisions that help weave the fabric of their lives. Less clarity is present with regard to the continued responsibility of public programs to provide an environment within which individual choice and individual responsibility may flourish. Examples of some of the difficult questions that may be informed by State infrastructure grants include: how do we ensure that self-direction does not mean abandonment; how do we ensure that quality assurance includes the assured presence of an infrastructure that makes consumer satisfaction and timely problem resolution a probability rather than a possibility; by what means do we appropriately balance safety with choice and the dignity of risk; how do we ensure that consumers have an adequate supply of capable and committed attendants from which to choose and are supported by emergency back-ups; how do we best assure that consumers (as new supervisors of an employee) have the information and back-up needed to carry out their supervisory duties effectively?

We hope you will begin now to engage with your many partners in planning for these grants. To aid your thinking and planning, we offer the following preliminary information about the grants. We reserve the right to adjust the terms for the final grant solicitation.

Purpose: To assist States in the development and implementation of the infrastructure necessary to support an effective system of community-based attendant services that are consumer-directed or that offer maximum consumer control.

Eligible Applicants: The District of Columbia, Puerto Rico, Guam, the United States Virgin Islands, American Samoa, the Commonwealth of the Northern Mariana Islands, Independent Living Centers recognized under State law, and any of the 50 States or their instrumentalities (including State universities).

Size and Time Period of Grant Awards: We expect grant awards to be made by September 14, 2001, with an effective date before September 30, 2001, and enduring for up to 36 months thereafter depending on the proposal and the availability of appropriations. We expect the funding for a State to range from $150,000 for the grant period to $1.0 million. No State match will be required, but in-kind match is expected. We expect the size of the grant to correlate with the significance of the proposed endeavor.

Examples of Activities: The list represents only a few examples of activities that States might consider. It is not the intent of the initiative to fund direct services except during an initial start-up period for one-time expenses.

Support Brokerage: Develop capacity to assist consumers in implementing their plans of care and purchasing services identified in the plan of care.

Management of Personnel Tasks: Create mechanisms to assist consumers with administration of personnel tasks (e.g., tax withholding, worker's compensation, criminal record checks, and health insurance).

Recruitment and Management of Attendant Care Services: Provide training in recruitment and supervision of workers, hiring and firing workers, and understanding fiscal and legal responsibilities as an employer of record.

Consumer Controlled Providers: Create consumer-directed service delivery approaches such as personal assistance cooperatives, micro-enterprises, and similar ventures, owned and controlled by people with disabilities, families of children with disabilities, and community services workers.

Community Living Specialist: Create a cadre of paraprofessionals with and without disabilities who would help persons identify and access necessary services and supports to transition into and/or continue to live in their own communities.

Risk Management: Implementation of procedures that allow and enable consumers to exercise individual choice without exposing them to undue liability or risk.

Back-up Support: Create mechanisms whereby consumers are able to access back-up workers should a scheduled worker become unavailable.

Consumer Education and Support: Identify the knowledge and skills required for meaningful change toward consumer-directed service planning and delivery. Develop and provide training and educational forums that assist consumers in moving to being self-directed.

Provider Qualifications: Create mechanisms to make it more straightforward to qualify individuals who have been identified by the consumer to furnish home and community-based services while simplifying payments to such individuals.

Provider Training and Technical Assistance: Develop curricula and training programs to assist provider agencies to improve consumer voice and control even when the consumer is not functioning as the employer of an attendant. Provide technical assistance to such provider agencies to advance each individual's dignity, choices, and participation in the community. Provide technical assistance to provider agencies in listening to consumers, designing effective feedback mechanisms, and supporting workers in their learning and continued growth in their attendant care. Assist provider organizations in fostering a culture of respect and systematic learning from the individuals they serve.

Nursing Delegation: Strengthen ability to delegate certain tasks to personal assistants, family members, and the consumer while maintaining conformity with the State's nurse practice act.

Job Bank: Develop job banks to facilitate match-ups between workers seeking jobs and consumers seeking to hire consumer-directed attendants. Conduct certain kinds of pre-employment background checks (such as immigration status checks or criminal background checks).

Please refer any questions concerning this attachment to Mary Jean Duckett via e-mail at mduckett@hcfa.gov.