U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

# A COMPENDIUM OF CURRENT FEDERAL INITIATIVES IN RESPONSE TO THE OLMSTEAD DECISION

July 2001

## Office of the Assistant Secretary for Planning and Evaluation

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the Department of Health and Human Services (HHS) on policy development issues, and is responsible for major activities in the areas of legislative and budget development, strategic planning, policy research and evaluation, and economic analysis.

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## Office of Disability, Aging and Long-Term Care Policy

The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report was prepared under contract #HHS-100-97-0019 between HHS's ASPE/DALTCP and the MEDSTAT Group. Additional funding was provided by the HHS Centers for Medicare and Medicaid Services, Disabled and Elderly Health Program Group. For additional information about the study, you may visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, SW, Washington, DC 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The DALTCP Project Officer was Andreas Frank.

# A COMPENDIUM OF CURRENT FEDERAL INITIATIVES IN RESPONSE TO THE OLMSTEAD DECISION

The Home and Community-Based Services Resource Network

July 10, 2001

Prepared for
Office of Disability, Aging and Long-Term Care Policy
Office of the Assistant Secretary for Planning and Evaluation
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# INTRODUCTION

The July 1999 Supreme Court decision in ***Olmstead v. L.C.*** challenges not only state governments, but federal and local governments, to increase opportunities for persons with significant disabilities to live where they choose. In response to the direction provided by the Supreme Court in the Olmstead case, all levels of government are increasing their efforts to increase access to long-term supports and services for persons with disabilities in home and community-based services (HCBS) settings.

State governments have the lead role in expanding opportunities for persons with significant disabilities to live and work in community settings, and to function as independently as possible. However, the Federal Government also plays a key role, both as a funder (primarily through the Medicaid program) and as a provider of information and technical assistance. In addition, both the states and the Federal Government share responsibility for ensuring that the supports and services which persons with disabilities receive in the community are of the highest quality possible. While persons with significant disabilities are becoming increasingly independent, and exercising greater control over their own lives, federal and states governments remain jointly accountable for ensuring the health and safety of those who are receiving publicly-financed services.

As part his New Freedom Initiative, President Bush issued an Executive Order on June 19, 2001, charging the Attorney General, the Secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the Commissioner of the Social Security Administration to evaluate the policies, programs, statutes, and regulations of their respective agencies to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities. The Executive Order also specifies that this review should focus on identifying affected populations, improving the flow of information about supports in the community, and removing barriers that impede opportunities for community placement. The Order mandates that the Secretary of Health and Human Services should report to the President on the results of this evaluation within 120 days.

To fulfill the mandate of the President's Executive Order, HHS has established the New Freedom Initiative Workgroup to review interagency efforts that have been already initiated in response to the Olmstead decision, and to recommit and refocus the Administration's efforts in promoting the full participation of adults with disabilities in community life.

In addition to working with states, the Federal Government has established a number of partnerships with private organizations to promote the development of improved HCBS systems in response to Olmstead. For example, for the Office of the Assistant Secretary for Planning and Evaluation and the Centers for Medicare and Medicaid Services (CMS) have partnered with the Robert Wood Johnson Foundation in supporting the Cash and Counseling Demonstration, and CMS is partnering with the

National Conference of State Legislatures in efforts to increase awareness among state legislatures about the implications of Olmstead.

This report is intended to serve as a compendium of selected projects which are currently operational at the federal level to promote the expansion of long-term supports and services in community-based settings. Some of these initiatives (e.g., the Cash and Counseling Demonstration Program) were initiated even prior to the ruling of the Supreme Court in Olmstead v. L.C. but all reflect the guiding principles enumerated above. For each project, we present information on both the funding and implementing organization, the purpose of the project, a brief description of the activity, and contact information on where people can go to obtain more detailed information about the project. While we have tried to identify the major projects currently in operation at the federal level to support states' efforts to expand long-term supports and services for persons with disabilities, the report undoubtedly fails to include *all* of the activities going on at the federal level in response to the Olmstead decision.

# STATE MEDICAID LETTERS ISSUED BY THE CENTERS FOR MEDICARE AND MEDICAID SERVICES

## Funding Organization:

- Centers for Medicare and Medicaid Services (CMS)

## Implementing Organization:

- Centers for Medicare and Medicaid Services (CMS)

## Purpose:

As of July 2001, CMS has issued five state Medicaid letters designed 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. State Medicaid letters are a mechanism which CMS uses to communicate administrative decisions on Medicaid statute and regulations on key programmatic issues.

## Description:

### Olmstead Letter No.1

### January 14, 2000

The first Olmstead letter provides states with background information on the Americans with Disabilities Act (ADA) and the implications of the Supreme Court's decision in Olmstead v. L.C. on the interpretation of the ADA as it applies to publicly-funded programs for persons with disabilities. The letter clarifies that the Olmstead decision applies to all states programs, but acknowledges that Medicaid is the primary funding source for both institutional and community-based services for persons with disabilities, and therefore the implementation of Olmstead will have its most significant impact on state Medicaid programs.

The letter also addresses the Supreme Court's guidance to states regarding how they might come into compliance with the ADA by developing comprehensive, effectively working plans. The letter discusses key principles and practices which states should consider as they move forward with the development of plans. Finally, the letter discusses next steps for the Department of Health and Human Services in its own implementation of Olmstead, including providing consultation to states, addressing issues and questions raised by states, and providing technical assistance.

## Olmstead Update No.2
## July 25, 2000

The second state Medicaid letter provides a series of commonly asked questions and answers regarding state implementation of the Olmstead decision. It provides additional guidance on how states might develop comprehensive, effectively working plans, definitions of disability and populations covered by the ADA, and more information on how states can obtain assistance from the Department on ADA and Olmstead issues.

## Olmstead Update No.3
## July 25, 2000

In the third state Medicaid letter, CMS reports on the results of an internal review of federal Medicaid policies and regulations related to home and community-based services (HCBS), and makes a number of policy changes and clarifications to facilitate state efforts to provide services and supports to persons with disabilities in the most integrated setting. These changes include:

- Clarifications regarding the earliest date of eligibility for waiver services for which federal financial participation can be claimed.
- Clarifies services that may be covered under HCBS waiver programs.
- Clarifies that Medicare "homebound" requirement does not apply to Medicaid home health services.
- Clarifies coverage of case management services for individuals being transitioned from institutional settings.
- Clarifies coverage of assessment for environmental modifications to improve accessibility of a waiver recipient's home or vehicle, as well as coverage for the cost of making modifications themselves.
- Clarifies coverage of personal assistance services for periods when a waiver recipient is hospitalized or otherwise unavailable to receive services.
- Clarifies coverage of services provided out-of-state.
- Clarifies coverage of "nurse-delegated services."

## Olmstead Update No.4
## January 10, 2001

The fourth state Medicaid letter provides clarification on a number of additional questions related to state discretion in the design and operation of 1915(c) waiver programs. These include:

- Clarifies that under Medicaid law, states may establish a limit on the number of persons who may receive services under a HCBS waiver.

- Clarifies that states may limit the number of persons served by a HCBS waiver in accordance with state legislative appropriations for the waiver program.

- Clarifies that states cannot arbitrarily limit the number of persons eligible to receive specific types of waiver services, although states may apply appropriate utilization control procedures based upon the need of individuals for specific services.

- Clarifies CMS policy regarding the amount, duration and scope of services covered under HCBS waiver programs.

- Clarifies instances in which states may seek amendments to approved waivers to reduce the total number of persons who may be served by the waiver.

- Clarifies state discretion in establishing targeting criteria in HCBS waiver programs.

## Olmstead Update No.5
## January 10, 2001

The fifth state Medicaid letter announces the availability of some new tools that states can use in their efforts to expand access to long-term supports and services for persons with disabilities. These tools include:

- A new CMS administrative interpretation of how states may use Section 1902(r)(2) of the Social Security Act expand financial eligibility criteria for persons applying for HCBS waiver programs. Specific examples are provided on how states may use Section 1902(r)(2) to facilitate eligibility for persons transitioning out of nursing homes, to overcome medically needy income limits applied under the general state plan, to encourage paid employment, and to implement simplified administrative procedures in determining financial eligibility.

- The announcement of three new grant programs that provide funds to states and other entities to develop innovative models for HCBS service programs and to promote comprehensive systems change. These grant programs are: (1) Nursing Facility Transitions grants; (2) Community-Integrated Personal Assistance

Services and Supports grants; and (3) Real Choice Systems Change grants. Total available funding for these grant programs is approximately $70 million. These grant programs are described in greater detail elsewhere in this report.

## Contact Information:

Complete versions of the five state Medicaid letters are posted on the CMS ADA/Olmstead website at: http://www.hcfa.gov/medicaid/olmstead/olmshome.htm.

# HEALTH CARE FINANCING ADMINISTRATION SYSTEMS CHANGE GRANTS

## Funding Organization:

- Health Care Financing Administration (HCFA)

## Implementing Organization:

- Health Care Financing Administration (HCFA), Disabled and Elderly Health Program Group (DEHPG)

## Purpose:

As part of the FY 2001 Department of Health and Human Services budget, Congress specifically appropriated $70 million for "Systems Change for Community Living" grants that will assist states and others, in partnership with their disability and aging communities, to design and implement effective and enduring improvements in community long-term support systems. These systemic changes will be designed to enable children and adults of any age who have a disability or long-term illness to:

- Live in the most integrated community setting appropriate to their individual support requirements and their preferences.

- Exercise meaningful choices about their living environment, the providers of services they receive, the types of supports they use and the manner by which services are provided.

- Obtain quality services in a manner as consistent as possible with their community living preferences and priorities.

## Background:

Medicaid home and community-based services play an increasingly critical role in enabling individuals of all ages who have a significant disability or long-term 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. 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 Systems Change 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.

## Description:

Four distinct grant solicitations comprise the "Systems Change for Community Living" grants that are the subject of this coordinated invitation. They are:

- **"Nursing Facility Transitions" grants**: HCFA is making available between $10-$14 million to help states transition eligible individuals from nursing facilities to the community. Two types of grants are offered: "State Program" grants will be made to support state program initiatives; "Independent Living Partnership" grants will be made to selected Independent Living Centers (ILCs) to promote partnerships between ILCs and states to support nursing facility transitions.

- **"Community-Integrated Personal Assistance Services and Supports" grants**: Personal assistance is the most frequently used service that enables people with a disability or long-term illness to live in the community. Grants totaling $5-$8 million are available to support states' efforts to improve personal assistance services that are consumer-directed or offer maximum individual control.

- **"Real Choice Systems Change" grants**: The goal is to help design and implement effective and enduring improvements in community long-term 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. Approximately $41-$43 million is available in direct grants to states.

- **"National Technical Assistance Exchange for Community Living" grants**: This national technical assistance initiative will provide technical assistance, training, and information to states, consumers, families, and other agencies and organizations. Funding for the technical assistance will range from $4-$5 million. Grant applications are due to HCFA in July 2001.

Grant awards will be made prior to October 1, 2001. States will have up to 36 months to expend their funds.

## Contact Information:

Additional background information on the Systems Change grants is available on the HCFA website at: http://www.hcfa.gov/medicaid/systemschange.

# CASH AND COUNSELING DEMONSTRATION AND EVALUATION

## Funding Organizations:

- Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- Robert Wood Johnson Foundation (RWJ)

## Implementing Organizations:

- Boston College Graduate School of Social Work--National Program Office for the Cash and Counseling Demonstration
- Mathematica Policy Research, Inc. (MPR)--evaluation contractor

## Purpose:

To test whether a cash benefit enhances the ability of Medicaid-recipient elders and younger adults with disabilities to design personal assistance services that best meet their needs (while maintaining overall program budget neutrality).

## Background:

The concept behind a cash benefit--a consumer-directed approach--is that consumers choose who provides very personal and essential services (help with bathing, eating, dressing, etc.), as well as when and how they are provided. For example, consumers may hire a friend or relative, who knows their preferences, to help them on evenings or weekends when agency services may be unavailable. Consumers are also able to use their benefit to buy other services that may increase their independence (e.g., transportation, home modifications, assistive devices). Counseling and bookkeeping are offered to help consumers manage their services.

## Description:

*Phase I* of this national demonstration began in October 1995 with selection of the evaluation contractor and demonstration states. Three demonstration states--Arkansas, Florida, and New Jersey--are offering cash-option to elders (over 65 years old) and adults with disabilities (ages 18-64). Children with developmental disabilities are also included in Florida. Arkansas and New Jersey are cashing out services from the Medicaid optional personal care benefit, while Florida is including services from the state's Home and Community-Based Services waiver.

*Phase II* (October 1996-November 1998) included background research (focus groups and telephone surveys) to determine consumers' preferences for a cash-option or traditional services, completion of a Health Care Financing Administration Medicaid

1115 waiver application, coordination with other federal agencies regarding the impact of the cash benefit on eligibility for other major programs, and development of demonstration state infrastructures for outreach, counseling, and fiscal intermediary services.

*Phase III* began in December 1998 when Arkansas enrolled the first cash-option consumers. New Jersey began enrolling consumers in November 1999 while Florida began enrollment in May 2000. Each state will have open enrollment for at least one year and consumers will be followed for one year (with a promise of two years of cash). Interim project reports will be developed during program implementation, and the final report will be completed one year and three months after data collection is completed.

The evaluation randomly assigns consumers interested in the cash-option to treatment and control groups. This comprehensive evaluation focuses on consumers' service utilization and preferences, quality of care, and service costs as well as issues related to paid and informal workers. A process evaluation also documents how the cash-option was implemented in each state and identifies environmental factors that can explain program effects. Project counselors will also provide feedback on their experience with cash-option consumers. Finally, a qualitative study in each demonstration state will provide an in-depth view of how the cash-option team (consumer/representative, worker, and counselor) work together.

## Contact Information:

For contact information for the participating agencies, visit the program website: http://www.inform.umd.edu/EDRes/Colleges/HLHP/AGING/CCDemo.

Other information on this project is available from ASPE's website: http://aspe.hhs.gov/_/office_specific/daltcp.cfm.

# CONSUMER-DIRECTED CARE CONFERENCE

## Funding Organizations:

- Health Care Financing Administration (HCFA)
- Administration on Aging (AoA)
- Substance Abuse and Mental Health Services Administration (SAMSHA)
- Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- Robert Wood Johnson Foundation (RWJ)

## Implementing Organization:

- Office of the Assistant Secretary for Planning and Evaluation (ASPE), Office of Disability, Aging and Long-Term Care Policy (DALTCP)

## Purpose:

This national conference, held June 10-12, 2001 in Washington, D.C., afforded an opportunity to share lessons learned from the various consumer-directed care models being used in states. It provided an opportunity for researchers, practitioners and policymakers to come together to:

- synthesize and share results and experiences of consumer-directed care models,
- disseminate information on successful practices of state financing and administrative organization models supporting consumer-directed care, and
- stimulate debate on the implications of research and practice for policy development/planning around consumer-directed care.

## Background:

It has been demonstrated that consumer-directed models are cost-effective for state governments and maximize choice and control in the delivery of personal assistance services. Advocates have long argued that persons with disabilities and chronic conditions should be afforded as much independence and autonomy as possible, without placing the consumer at risk. To date, over 27 states have implemented state and Medicaid-funded consumer-directed personal assistance programs. While states and consumers are quickly embracing consumer-directed models of care, policy questions, financing issues, and system design challenges remain, and may act as barriers for the development and expansion of consumer-directed care models.

The growth of consumer-directed models of personal assistance services in the public and private sectors is an important and continuing trend that is likely to have a significant impact on people with disabilities and the elderly. Yet, the development of a knowledge base that is available to state and federal policymakers as well as consumers and their advocates for the purpose of facilitating informed decision-making about managed care and disability, has only recently begun.

## Description:

By sharing implementation experiences, this national conference addressed a variety of critical questions:

- How best can a state design fiscal intermediary services?
- What are the most effective consumer-directed care models for the elderly, people with physical disabilities, people with mental retardation or developmental disabilities, and people with mental illness?
- How should fraud and abuse issues be addressed?
- How can states best design programs so that it is easy for consumers to comply with federal tax laws?
- How can states best help consumers to identify and access the needed support services that they want?
- How are consumer protection design issues best taken into account?
- Do preferred methods for costing out benefits exist?
- What are reliable ways to measure quality of care in consumer-directed care models?
- What information systems and counseling services are available to better assist consumers in hiring, firing, and managing their personal assistants?

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Information on this project is available from ASPE's website: http://aspe.hhs.gov/_/office_specific/daltcp.cfm.

# NURSING HOME TRANSITIONS DEMONSTRATION PROGRAM

## Funding Organizations:

- Health Care Financing Administration (HCFA)
- Department of Housing and Urban Development (HUD)

## Implementing Organizations:

- Health Care Financing Administration (HCFA)
- Department of Housing and Urban Development (HUD)
- Office of the Assistant Secretary for Planning and Evaluation (ASPE)

## Purpose:

The purpose of the Nursing Home Transitions Demonstration Program is to provide direct grants to states to transition people of any age from institutional living arrangements to community settings. The objective is to provide assistance to states that will lead to sustainable infrastructures for identifying persons in institutional settings who want to transition to community settings, and for developing the supports and services required for such persons to successfully transition back into community life.

## Background:

While there has been a significant expansion in services and supports for persons with disabilities of all ages living in community settings, there are still a significant number of persons who reside in nursing homes and other institutional settings due to the lack of community-based supports that meet their needs. Many of these persons require a broad range of supports in order to successfully transition back into community life, including placement planning, housing assistance, individual counseling, medical assistance, assistance with application for public benefits, home modifications, help with assistive devices, transportation assistance, employment assistance and assistance with establishing networks of informal supports of family and friends. Thus, in 1998, HCFA and ASPE implemented the Nursing Home Transitions Demonstration Program, which provides flexible funds to states to develop programs that have the specific goal of transitioning persons living in institutions back to community life.

## Description:

Since 1998, HCFA and ASPE have awarded a small number of Nursing Home Transitions Demonstration grants to states on a competitive basis. In 1998, four grants of $150,000 each were awarded to Colorado, Michigan, Rhode Island, and Texas. In 1999, four additional grants of $500,000 each were awarded to New Jersey, New

Hampshire, Vermont and Wisconsin. In the year 2000, four more grants of $500,000 each were awarded to Arkansas, Florida, Nebraska and Pennsylvania.

In 2001, Congress significantly increased the funding level for the program, which was also renamed the Nursing Facility Transitions Program, and expanded the program to include Independent Living Partnership (ILP) grants, which will provide funding directly to Independent Living Centers (ILCs) for establishing nursing home transition programs. As part of HCFA's Systems Change Grants for Community Living initiative, approximately $8-$13 million in HCFA funding will be awarded to 10-18 states for Nursing Facility Transitions programs, and another $1-$2 million in grants will be awarded to ILCs under the ILP component of the program.

In addition, HCFA and HUD are collaborating to develop mechanisms for linking HUD resources, such as HUD Section 8 vouchers, with the Nursing Home Facilities Demonstration grants. Additional information on the specific mechanisms by which housing assistance will be made available to persons with disabilities who are transitioning from institutional settings to community life through the Nursing Facility Transitions will be communicated to the FY 2001 grantees in the future.

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# DISABILITY ADVOCACY IN A POST-OLMSTEAD ENVIRONMENT

## Funding Organizations:

- Health Care Financing Administration (HCFA)
- Department of Education (DoE)
- Department of Health and Human Services (HHS)

## Implementing Organizations:

- Institute for Rehabilitation and Research
- Brain Injury Association

## Purpose:

The purpose of this project is to hold regional training conferences on the Olmstead decision that have a primary audience of state advocacy leaders and a secondary audience of legislators, legislative staff, Governor's office representatives, Medicaid officials and other state officials.

## Description:

This project entails working with experts to: develop, test, and fine-tune national training materials and identify and select regional training materials; plan training conferences; identify attendees; and hold five regional conferences. Specific activities are presented below.

- A conference of experts was held in February 2001, where presentation materials for each segment of the training were reviewed and fine-tuned. In addition, the potential resource materials for use in the regional training sessions were identified, and material selections were made. The purpose of this conference was to ensure superior training in the regional Olmstead decision training sessions by subjecting the agenda and proposed content to a complete review by experts in the field and by providing an orientation for those who will conduct the training.

- Five regional Olmstead training conferences are planned by October 2001. Individual advocates will be invited to participate in the regional conferences, with participation limited to approximately 80 advocates in each session. Nominees for participation must be individuals who are leaders in state advocacy, and who have the full support of one or more key organizations representing people with disabilities. In addition, a smaller number of state legislators, legislative staff, Governor's office representatives, Medicaid officials and other state officials will be invited to participate. The first session was held from March 28-30 in Houston, Texas and attracted over 80 participants. The tentative schedule for the remaining sessions is as follows:

- June 28-30, Atlanta, GA
- July 18-20, Kansas City, MO
- August 14-16, Portland, OR
- October 1-3, Hartford, CT

The proposed agenda items for the regional conferences are as follows:

- Olmstead Overview
- Medicaid and Individual Long-Term Supports
- Best practices using Medicaid
- Working Together at the State Level
- Fiscal Intermediaries
- Nurse/Doctor Delegation/Assignment
- Accessible/Affordable Housing
- Home Health
- Cash and Counseling
- PAC/PC Option
- Waivers
- Moving to the Community
- Olmstead: Components of a Comprehensive Plan
- Role of Stakeholders
- Developing Statewide Coalitions
- State Strategies: Caucuses and Reports

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# HOME AND COMMUNITY-BASED SERVICES RESOURCE NETWORK

## Funding Organizations:

- Heath Care Financing Administration (HCFA)
- Office of the Assistant Secretary for Planning and Evaluation (ASPE)

## Implementing Organizations:

- The MEDSTAT Group, Inc.
- Boston College Graduate School of Social Work

## Purpose:

The Home and Community-Based Services (HCBS) Resource Network was established in September 1999 to bring the Federal Government, states, and persons with disabilities of all ages together to expand access to high quality, consumer-directed services in a cost-effective manner. The HCBS Resource Network supports state efforts to engage in collaborative planning and policy development, and focuses on practical and immediate next steps to expand access to supportive services in ways that are realistic, equitable and affordable.

## Description:

The HCBS Resource Network is governed by a 12-member Project Board, equally comprised of representatives of state HCBS agencies, and consumers of HCBS services. The Board is currently co-chaired by Lex Frieden, Senior Vice President of the Institute for Rehabilitation and Research in Houston, Texas, and Lee Bezanson, Medicaid Director of New Hampshire. The federal sponsors of the HCBS Resource Network, ASPE and HCFA, work in partnership with the Project Board. The specific activities of the Resource Network are managed under a contract to the MEDSTAT Group, in collaboration with the Boston College Graduate School of Social Work.

The HCBS Resource Network engages in the following activities:

- The HCBS Resource Network has developed a website that includes the following services:
  - An inventory of key resources on HCBS with abstracts of relevant articles.
  - Data tables including a wide range of expenditure data by state on a variety of Medicaid expenditures.
  - Extensive links to other websites providing information about consumer-direction, the Olmstead decision, and many other HCBS issues.

  - A "What's New" section that provides timely updates on new federal initiatives.
  - An interactive discussion forum in which states and stakeholders may discuss HCBS issues openly and raise questions about federal policy and initiatives.

- The HCBS Resource Network works directly with states to provide technical assistance in developing or enhancing their HCBS systems. The following states have received or are currently receiving direct support from the HCBS Resource Network:
  - Alabama
  - Connecticut
  - Georgia
  - Kansas
  - New Mexico
  - Ohio

- The HCBS Resource Network facilitated the systems change conference on ***"New Opportunities for Community Living"*** held in May 24-25, 2001 in Washington, D.C., and provided reimbursement to enable persons with disabilities to attend the conference.

The HCBS Resource Network is planning a number of activities to help states and stakeholders continue the development of HCBS, including the following:

- Organizing and conducting national teleconferences on consumer-direction and systems change issues.

- Organizing and hosting HCBS retreat meetings in which groups of states/stakeholders working on similar issues can discuss and problem-solve the issues with one another.

- Sponsoring (or co-sponsoring) regional policy forums on HCBS issues.

- Developing and disseminating useful information products regarding HCBS issues and best practices to all stakeholders.

- Continuing to moderate the discussion forums, to update the resource inventory and to maintain other components of the website so that it will serve as an essential and timely resource for states and other stakeholders.

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Information on this project is available from ASPE's website: http://aspe.hhs.gov/_/office_specific/daltcp.cfm.

# NATIONAL EVALUATION OF THE MEDICAID HOME AND COMMUNITY-BASED SERVICES WAIVER PROGRAM

## Funding Organization:

- Health Care Financing Administration (HCFA), Office of Strategic Planning

## Implementing Organizations:

- The Lewin Group
- Subcontractors:
  - The Urban Institute
  - University of Minnesota
  - Mathematica Policy Research, Inc. (MPR)
  - The MEDSTAT Group

## Purpose:

To design and implement a study of the impact of Medicaid home and community-based services (HCBS) programs on quality of life, quality of care, utilization and cost.

## Description:

The scope of the study will include Medicaid HCBS waiver programs as well as other Medicaid-funded long-term care services. The research project will study the financing and delivery of services to older and younger people with disabilities in six states and the Medicaid financing and delivery of services for individuals with mental retardation and developmental disabilities in another six states. The specific activities of the project, divided into two phases, are described below.

*Phase I* is now complete, and entailed cases studies and site visits. The case studies characterized key program variables such as eligibility criteria, service use, quality of care and care management controls. As part of the case studies, site visits were made to selected states to conduct unstructured in-person interviews with state officials, home care providers, trade associations and aging and disability advocacy groups. Aggregate level data were also collected on service use, costs, participant characteristics, and satisfaction, where available. Interviews were conducted between December 1999 and July 2000.

- The Urban Institute developed case studies of the HCBS financing and delivery system for older and younger adults with disabilities in each of six states (Alabama, Kentucky, Maryland, Michigan, Washington and Wisconsin).

- The University of Minnesota conducted case studies in six additional states (Kansas, Indiana, Louisiana, New Jersey, Vermont, and Wyoming) for individuals with mental retardation and developmental disabilities.

- In addition, the Lewin Group made a site visit to the Texas Star Plus program to explore its managed and capitated system for HCBS in the Houston area.

*Phase II* is underway and includes surveys and analyses of administrative data. Mathematica Policy Research will conduct surveys of Medicaid HCBS users. The MEDSTAT Group will also obtain administrative data (Medicare and MSIS data) to research program costs in the selected sites. The Lewin Group, the Urban Institute, and the University of Minnesota will analyze survey and administrative data to examine data on service use, costs, participant characteristics, and satisfaction.

Outcomes from each of the sites studied will be assessed by controlling for participant characteristics (e.g., age, disability level, caregiver availability) to determine the independent effect of each program on the outcomes. The features and structure of programs gathered through the process portion of the study will be used in order to compare programs with more favorable outcomes to those with lower ratings on outcomes to draw inferences on the promising program design features. This approach would treat program designs as complete packages and permit variation in more than one key dimension.

Also as part of Phase II, the characteristics and care patterns that influence outcomes at an individual level will be examined. Questions to be examined include: Does receiving more services produce a higher quality of life? Do people in residential settings have a lower quality of life than people living at home? And, are people who live alone significantly less disabled than those living with others? The study will use a quasi-experimental design that gathers data from Medicaid recipients of both developed and developing HCBS systems. Information will be collected from several sources: site visits; surveys of recipients and proxies (where necessary) each within two groups of enrollees--elderly in the community and young disabled adults); interviews with state officials, advocacy groups, provider representatives and other key stakeholders; and secondary data sources, including MSIS data, and state administrative data.

The analyses will center on four major areas for developed programs relative to developing programs, as well as the influence of individual characteristics and care patterns. The analyses will include: (1) greater access to, choice among, and autonomy related to HCBS; (2) better outcomes (including fewer avoidable hospitalizations, lower death rates, higher levels of satisfaction with life and care, less unmet need); (3) differences in patterns of care provided (fewer nursing facility admissions and more discharges from nursing facility to community, greater use of alternative residential facilities); and (4) differences in the cost of care provided (HCBS versus institutional, total health care costs, acute care spending versus long-term care spending).

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# PRIMER FOR THE MEDICAID PROGRAM

## Funding Organizations:

- Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- Health Care Financing Administration (HCFA)

## Implementing Organizations:

- Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- Health Care Financing Administration (HCFA)

## Purpose:

The Primer for the Medicaid Program describes the many options states have to use the Medicaid program to fund long-term care services and supports; and is designed to encourage use of the Medicaid program in a manner that minimizes reliance on institutions and maximizes community integration in a cost-effective manner.

## Description:

The Primer spans the full range of Medicaid choices. It addresses program modifications states can implement as a state plan option (without special waiver of federal law), as well as those for which federal waiver approval must be obtained. In addition to comprehensive explanations of program features states can implement to achieve these goals, the Primer presents examples of state programs that have taken advantage of Medicaid's flexibility to expand home and community-based services (HCBS) for people of all ages with disabilities. Designed to serve as a reference guide, it is written in easily understood language, but with sufficient annotation of source material to fulfill its technical support role. Some issues remain unresolved, because particular provisions of Medicaid regulations and state interpretations thereof are being challenged in the courts. Major unresolved issues are discussed where relevant.

Its intended audience is policymakers and others who wish to understand how Medicaid can be used--and is being used--to expand access to a broad range of HCBS and supports, and to promote consumer choice and control. The Primer is written with the notion that it is up to state policymakers working with the disability and aging communities to identify the unique needs and goals of the state, and then use the Primer (a) to choose the options best suited to a particular state and (b) to decide how the options chosen can be best used in that state. The design of the Primer results from a series of discussions among federal officials, state policymakers, service providers, and advocates on maximizing the document's utility.

The information below outlines the content of the Primer by chapter:

- *Chapter One* provides a brief overview of the legislative and regulatory history of Medicaid's coverage of HCBS and information on current home and community expenditures.

- Chapter Two through Chapter Five present the basic elements involved in Medicaid's financial and functional eligibility criteria and service coverage alternatives.
  - *Chapter Two* provides an explanation of Medicaid's financial eligibility criteria, one of the most complicated areas of Medicaid law. It first discusses the general eligibility criteria all Medicaid beneficiaries must meet. It then focuses on the financial eligibility provisions most important for receiving services in home and community settings. It also discusses the options states can select to ensure that people with disabilities will be able to support themselves in home and community settings.
  - *Chapter Three* focuses on Medicaid provisions related to health and functional criteria used to determine service eligibility for home health services, the personal care option, and the waiver program. It presents examples of states with service criteria that support a social model of long-term services and supports rather than a medical model. And it discusses ways in which states can design service criteria to ensure that they appropriately and adequately measure the need for services and supports among heterogeneous populations.
  - *Chapter Four* presents the major service options states have to provide home and community services to people with disabilities and discusses the factors states need to consider when choosing among the various options.
  - *Chapter Five* provides an in-depth discussion illustrating different coverage alternatives in the context of two specific services: case management and assisted living for elderly persons.

- Chapter Six through Chapter Nine focus on key policy goals in the provision of home and community services and supports.
  - *Chapter Six* discusses factors states need to consider when developing initiatives to transition institutional residents back to home and community settings. It also presents ways in which Medicaid can be used to facilitate this transition.
  - *Chapter Seven* discusses options under Medicaid to increase consumer choice and control of home and community services.
  - *Chapter Eight* discusses ways in which Medicaid can support informal caregiving and family support through various optional services.
  - *Chapter Nine* addresses system design issues and discusses how Medicaid can be used to create comprehensive, cost-effective long-term care systems.

- The Primer concludes with a series of appendices that provide additional information about the Medicaid program. Each chapter contains an annotated bibliography, with full information on how to obtain each publication.

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This report is available from ASPE's website: http://aspe.hhs.gov/daltcp/reports/primer.htm.

# WAIVER QUALITY INITIATIVES

## Funding Organization:

- Health Care Financing Administration (HCFA)

## Implementing Organization:

- The MEDSTAT Group

## Purpose:

To improve the quality of programs administered under the Home and Community-Based Services (HCBS) Waiver Program.

## Description:

Three waiver quality assurance/improvement projects are under implementation by the MEDSTAT Group: (1) Development of a HCFA Regional Office (RO) HCBS Waiver Monitoring Guide (The Protocol); (2) Development and Testing of Performance Measures for HCBS Waiver Programs; and (3) State Readiness to Use Data in Assessing HCBS Waiver Programs. Below, each project is described in more detail.

### Development of a HCFA Regional Office HCBS Waiver Monitoring Guide (The Protocol)

During CY 2000 MEDSTAT developed a monitoring protocol for HCFA RO staff to use in their periodic reviews of the quality of the HCBS waiver programs. This protocol was developed primarily for RO staff--to encourage consistency in and comprehensiveness of reviews. However, it was also developed with state use in mind in that it operationalizes the relatively non-specific assurances that states must provide to the Federal Government as a condition of waiver approval. In other words, it specifies what the states must do in order to comply with the assurances, and what evidence the RO will be looking for as verification that the assurances have been met. The Protocol also includes sections devoted to "Quality Enhancing" activities that the states may seek to implement in their quest for quality improvement (dubbed "Recommended But Not Required").

The development of The Protocol was a collaborative endeavor. Feedback on over 50 iterations was provided by a State-Federal Work Group (that included representatives from the advocacy community), two HCFA RO Work Groups--one focused on process and the other on content issues, as well as HCFA Central Office staff. HCFA also instituted a public comment period during last July and August, and based on comments received, certain sections of The Protocol were revised. HCFA sees The Protocol as a living document, and expects the content to evolve over time.

That The Protocol is now in its third official version--Version 1.2--is evidence that this expectation is being borne out.

The Protocol went into effect on January 1, 2001. All reviews conducted by RO staff after this date must be performed using The Protocol. In July 2000, states and HCFA RO staff were invited to a one-day session where The Protocol was showcased. HCFA's Central Office has also provided additional training opportunities for HCFA RO staff conducting waiver reviews. In an effort to insure that The Protocol is implemented as intended, HCFA has assigned one of its RO waiver review staff, who is experienced both in waiver reviews and quality assurance, to accompany other RO staff on their initial reviews using The Protocol. HCFA is also currently developing a format for waiver review reports that will be consistent with The Protocol's format; adherence to this review format will be required and is viewed as yet another mechanism for insuring consistency and comprehensiveness of reviews. To date, at least five waiver reviews have been conducted using The Protocol. For all practical purposes, MEDSTAT's work on The Protocol has been completed.

### Development and Testing of Performance Measures for HCBS Waiver Programs

This project requires MEDSTAT to develop and test one or more performance measures that states may use (at their discretion) in monitoring the quality of their waiver programs. Work on this project began in the Winter of 2000. The project's State-Federal Work Group (same Work Group that provided guidance on the development of The Protocol) was assigned the task of recommending the focus of the performance measures. This group strongly suggested a Consumer Experience measure that has evolved into a Consumer Experience Survey. Through a focus-group approach, this Work Group identified five priority areas, or domains, that the survey should address:

- Choice/Empowerment;
- Satisfaction with Services;
- Access to Care;
- Respect/Dignity; and
- Community Integration/Inclusion.

Initially, the Work Group recommended that one instrument be developed that would be appropriate for telephone administration, applicable to all HCBS waiver populations, and take no longer than 10 minutes to administer. Given these recommendations, it became clear that besides being relevant to the quality of care and services provided under the auspices of the waiver, the questions had to use language that would be as "universal" as possible and response patterns limited so as to maximize comprehension and ability of the interviewee to respond meaningfully. Additional feedback sessions were held with the Work Group during the Summer and Fall of 2000--to flesh out the questions to be asked, their wording and response patterns.

During December 2000 and January 2001, MEDSTAT conducted cognitive testing with waiver participants in two states. Cognitive testing took the form of a series of follow-up questions following each survey item intended to elicit responses that would indicate whether the respondent understood the intent of the question and response alternatives. Based on these face-to-face interviews, MEDSTAT concluded that the appropriateness of the survey items varied by waiver population, as well as by the type of services provided under the auspices of the waiver. MEDSTAT recommended that the survey be more tailored to the needs and experiences of the different populations. MEDSTAT also identified item wording/responses that required more refinement and simplification.

Following the findings of these initial pretests, the instrument was adapted to a modular approach so that it was more relevant to the waiver experiences of different types of persons with disability. In addition, MEDSTAT developed a companion instrument for proxy respondents. These new instruments--one for the frail elderly and non-elderly physically disabled, one for the MR/DD population, and an MR/DD proxy--were tested in three states during Spring 2001. A third round of cognitive testing, using a phone administration mode, will follow. In addition, MEDSTAT is planning additional testing in order to estimate administration time for the various waiver populations and surrogates. These testing phases should be accomplished by Summer 2001.

Under a new contract with HCFA, MEDSTAT will conduct additional psychometric testing of the Consumer Experience Survey, to evaluate reliability and validity. These tests will include inter-rater reliability testing, and a field test in one or more states. Information from the field test will be used to review frequencies of survey items, and to asses how discriminate response categories are. Also, field testing experience will be reflected in the guidance prepared for states. This additional testing is scheduled for Fall 2001 and Winter 2002.

The final stage of the project entails the development of a user's guide and related technical assistance materials that will provide guidance to the states in fielding the survey, interpreting results, and using the results within the context of a quality improvement strategy.

## State Readiness to Use Data in Assessing HCBS Waiver Programs

The State Data Readiness initiative focuses on identifying exemplary quality improvement practices for HCBS waiver programs built around the collection of data or other information. For this initiative, MEDSTAT is in the process of identifying specific examples of the types of HCBS quality improvement activities that states are conducting (or plan to conduct), with an emphasis on the types of data and other information that is used to manage the development, implementation and monitoring of these activities. Examples of such activities could include, among others, the use of performance measures, outcomes data, systems for reporting and tracking complaints or special incidents, and surveys or focus groups to obtain waiver participant input on quality. Over the past few months, MEDSTAT has been identifying states that may be managing these activities through interviews with HCFA RO representatives, website solicitations, and letters to state units on aging. MEDSTAT is currently in the process of speaking with a number of states (Pennsylvania, Texas, South Carolina, Michigan, Oregon, Arizona, Florida, and North Carolina) about a variety of their activities. Once examples have been identified, in-depth case studies will be conducted of selected programs in order to understand how these activities have been developed and how they are managed on a day-to-day basis. It is expected that the case studies will be completed in CY 2001. Case study results will be shared broadly to assist other states in developing or implementing similar activities. The contract also calls for a series of technical assistance activities, to be determined, that would assist states in developing and using data to monitor and improve the quality of their waiver programs. Technical assistance activities are likely to occur in late CY 2001 and the first half of 2002.

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# HHS OFFICE OF CIVIL RIGHTS ACTIVITIES

## Funding Organization:

- Office of Civil Rights (OCR)

## Implementing Organization:

- Office of Civil Rights (OCR)

## Purpose:

OCR is working, on a state-by-state basis, with state and county officials, individuals with disabilities, advocates, foundations and other stakeholders to increase opportunities for individuals with disabilities to live in their own communities. OCR recently received $50 million in additional FY 2000 funds specifically for Olmstead related activities.

## Description:

OCR is involved in the following activities:

- Resolving more than 250 complaints alleging that states and other public entities have failed to provide services to people with disabilities in the most integrated setting. Specifically, OCR is working with all involved parties to build comprehensive, effectively working plans for serving qualified persons with disabilities in the most integrated settings appropriate.

- Developing, as part of the complaint review and litigation process, baseline data to be used for training OCR Regional Office (RO) staff.

- Collaborating with the Department of Housing and Urban Development to identify ways in which affordable, accessible housing can be made more readily available to individuals with disabilities.

- Planning four regional training events to bring states and advocates together.

- Reviewing litigation and settlements in order to gain familiarity with the internal landscapes within different states.

- Working with state governments and local advocates in the development of Olmstead planning coalitions in over 25 states, with work in additional states planned.

- Compiling a compendium of Olmstead expert consultants for each state, as an outcome of OCR's use of consultants to review states' Olmstead plans.

- Developing OCR's in-house capacity to work on Olmstead and home and community-based services (HCBS) issues by hiring experts and ensuring that the central office has knowledgeable staff that the ROs can work with.

- Designating an individual to serve as the Olmstead Coordinator in each of the ten OCR regions.

- Participating as a member of the Department-wide Olmstead Working Group, OCR is involved in a number of areas, including the State Medicaid Director's letters and the development of technical assistance documents related to Olmstead or HCBS.

- Discussing with the Robert Wood Johnson Foundation coordination in providing technical assistance in development of Olmstead plans, waiver development/expansion, and issues of state financing for HCBS. Of particular interest is developing synergies in the areas of: nursing home transition grants, system change grants, and Substance Abuse and Mental Health Services Administration grants/technical assistance efforts.

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# WEBSITE FOR OBTAINING MEDICAID ASSISTANCE: MEDICAID DESK REFERENCE

## Funding Organization:

- Administration on Developmental Disabilities (ADD)

## Implementing Organizations:

- University of New Hampshire Institute on Disability
- National Center for Self-Determination
- Oregon Health Sciences University 21st Century Leadership
- Oklahoma People First
- Family Voices

## Purpose:

The overall purpose of the project is to provide information to people with disabilities, families and staff with timely, accurate and useful information about Medicaid services nationally, and in their states.

## Description:

This project will develop an interactive website with descriptions of Medicaid programs presented in a language that persons with disabilities can understand, including persons with cognitive disabilities. The website will be constructed primarily around ten individual state Medicaid programs, although national-level information about Medicaid and Medicaid-financed services will be provided. For each of the ten states, a team of experts specific to that state will be available to answer specific Medicaid-related questions. Initiation of the first "live" state website is planned for October 2001. Selected brochures will also be printed. The grant began in October 2000, and will run for three years.

An Advisory Board, having a majority membership of people with disabilities or people with disabled family members, has been recruited to provide advice and guidance. At present, the primary audience for this project is persons with developmental disabilities; the secondary audience is family members of persons with developmental disabilities. The target audience may also be broadened to persons with other types of disabilities. The project hopes to involve people with disabilities in substantive paid roles in its day-to-day operation.

The following modules are under development for each of the ten states:

- Specific information about how to get help from the Medicaid program.

- Experts on hand to answer questions.

- Information on people and organizations in the state that users can turn to for assistance with Medicaid.

- Frequently asked questions.

- Facts and statistics on Medicaid-funded services in each state and nationally.

- A user-friendly description of each state's Medicaid plan.

- A description of the services and supports which are potentially available from Medicaid for people with disabilities, organized by zip code so that users have very specific information about where they might go to access services.

- Specific reference information, including links to other websites.

- What's New in Medicaid.

- A "waiver wire" providing up-to-date information on the status of each state's HCBS waiver services programs.

- How the Medicaid system works.

- Self-determination: what it is and how each state Medicaid program supports self-directed services.

- Evaluation and Review: designed to elicit feedback on the website from users.

- Partners and Philosophy: designed to articulate guiding principles of the project, and on the information presented.

In addition to the website, the project will produce a series of briefs including:

- A description and analysis of Medicaid issues from the perspective of people who receive services.

- Identification of key aspects of frequently asked questions related to Medicaid waiver and state plan services.

- Frequently asked and answered questions about Medicaid waivers.

- Analysis of the impact of self-determination initiatives on the level of consumer satisfaction, involvement and understanding of the Medicaid programs in states.

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# FRONTLINE WORKERS IN LONG-TERM CARE: TECHNICAL EXPERT PANELS

## Funding Organizations:

- Office of the Assistant Secretary for Planning and Evaluation (ASPE), Office of Disability, Aging and Long-Term Care Policy
- Robert Wood Johnson Foundation

## Implementing Organization:

- The Urban Institute
- Institute for the Future of Aging Services

## Purpose:

The purpose of this project is to heighten the awareness among federal, state, and local policymakers, long-term care providers, consumers, and foundations about issues related to the frontline long-term care paraprofessional workforce, including people who work for nursing homes, home care agencies and non-medical residential facilities and people who work as independent providers.

## Background:

Paraprofessional long-term care workers, such as certified nurse assistants, home health aides and personal care attendants, are the backbone of the formal long-term care delivery system, providing the majority of paid assistance to people with disabilities. These "frontline" workers help people by assisting with activities of daily living, such as eating, bathing and dressing, and instrumental activities of daily living, such as medication management and meal preparation. According to the Bureau of Labor Statistics, in 1998 approximately 2.0 million persons were employed as "nursing aides, orderlies, and attendants" or as "personal care and home health aides." The central role of these workers in actually providing services makes them the key factor determining the quality of paid long-term care.

There is currently a major shortage of these workers, which is certain to grow as the demand for long-term care increases with the aging of the population. There are at least four major issues. First, paraprofessional workers receive very low wages and receive few benefits, making these jobs not competitive with other positions. Second, many of the basic requirements of the jobs are unattractive, involving caring for clients who deteriorate and die, cleaning up after incontinent consumers, and lifting bed-bound persons with disabilities. Third, there is no career ladder and little chance of advancement. And, finally, workers are often taken for granted and not involved in organizational decision-making processes.

## Description:

The project will: identify successful training, recruitment, and retention models for frontline workers; identify training needs; analyze policy options; identify data gaps; and develop a research and demonstration strategy that the government and foundations can undertake to improve policymaking. A major focus will be on developing strategies that local communities can use. An outline of the planned activities follows.

- The project will establish a technical advisory group (TAG) to guide the planning for the expert meetings, and review and comment on policy and research recommendations for the expert meetings. Individuals representing federal and state government officials, providers, researchers, unions, foundations, consumers, and others will be represented. Based on input from the TAG, three technical expert panels (TEPs) will be formed to address issues relating to frontline workers. Each TEP will consist of up to 15 members and include persons with a broad mix of expertise and experiences. The purpose of the TEPs will be to analyze specific issues related to frontline workers and to recommend research and demonstration strategy.

- Products will include an overview paper, short briefing papers for the TAG and TEPs, a paper describing state activities on this issue, a final report laying out a policy, research, and demonstration strategy, and a policy paper to be submitted to a journal such as ***Health Affairs***. A version of the final report be published and widely distributed as a monograph published by the Urban Institute. In addition, the final report will be posted on the ASPE's website as well as that of the Urban Institute. Publication of a shorter version in a professional journal, such as ***Health Affairs*** or ***The Gerontologist*** is also planned.

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Information on this project is available from ASPE's website: http://aspe.hhs.gov/_/office_specific/daltcp.cfm.

# REINVENTING QUALITY: FOSTERING PROMISING PRACTICES IN PERSON-CENTERED SERVICES AND QUALITY ASSURANCE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

## Funding Organization:

- Administration on Developmental Disabilities (ADD)

## Implementing Organization:

- National Association of State Directors of Developmental Disabilities Services (NASDDDS)
- Subcontractors:
  - Human Services Research Institute
  - University of Minnesota Research and Training Center on Community Living

## Purpose:

The purpose of the project is to identify and promote promising practices in person-centered planning and quality assurance within home and community-based service systems for persons with developmental disabilities.

## Description:

This grant began in July 1999 and will run through June 2002. It is funded at approximately $670,000 for the 3-year period.

There are three components to the project. The first component is two Consensus Conferences on Person-Centered Planning. The purpose of the first conference was to arrive at a definition of Person-Centered Services, i.e. how you would know person-centered services if you saw them. The second conference, to be held in August 2001, will provide examples of how Person-Centered Planning is being implemented at the systems level. The Consensus Conferences are being organized by NASDDDS.

The second component of the grant is a series of case studies of states which employ the principle of Person-Centered Planning.

The third component of the project is the "Quality Mall." The Quality Mall is a comprehensive, one-stop shopping center for the transfer of information about person-centered services and quality promotion practices. The quality mall is constructed on the concept of a shopping mall, which is structured around a number of "shops" which are stocked with "goods" or, in this case, information. Each shop has a designated shop manager, who has the responsibility for keeping his or her respective shop filled with quality information. While the intention is to provide information that can be read by persons with developmental disabilities, the primary target audience is people in the service system at the state, local, or provider levels.

## Contact Information:

For more information, visit the Quality Mall website at http://www.qualitymall.org.

# OLMSTEAD RELATED ACTIVITIES AT THE SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

## Funding Organization:

- Substance Abuse and Mental Health Services Administration (SAMHSA)

## Implementing Organization:

- Substance Abuse and Mental Health Services Administration (SAMHSA)

## Purpose:

As the lead agency in the Department of Health and Human Services on matters related to mental health and substance abuse, SAMHSA established an internal working group and is currently addressing policy, technical assistance and training activities to implement the Supreme Court's directives in the Olmstead decision.

## Description:

SAMHSA's response to the Olmstead decision is being directed for the Agency by the Center for Mental Health Services (CMHS). The array of actions related to the Olmstead Decision includes:

**Agency-Wide Olmstead Meetings**. Chaired by Bernard Arons, M.D., Director of CMHS and Olmstead Program Director, these meetings are held monthly or as needed to discuss Olmstead related mental health and substance abuse disorder issues as they affect SAMHSA's planning, policy and funding priorities.

**National and State Coalitions to Promote Community-Based Care for Persons with Mental Illness**. This initiative addresses barriers and recommendations at the national and state levels in support of integrated services for persons with mental illness. The primary objective is to assist states in developing and enhancing state coalitions addressing the Olmstead decision. The National Coalition's role is to help establish guidelines and recommendations, identify models, best practices and technical assistance resources, and help disseminate information on Olmstead implementation and effective community integration plans.

The National Coalition was implemented in December 2000 with a Kick-Off Meeting representing more than 60 members including a wide cross-section of federal agencies, national advocacy groups, consumer organizations, and professional associations.

**State Olmstead Coalitions**. A Financial Assistance Application ($20,000 per jurisdiction) to support state coalitions was sent out in March 2001. As of June 2001, 43 states are funded, one application is pending, one is in uncertain status, four are expected to submit applications and four declined to apply. Of the funded states, 88 percent support existing coalitions and 12 percent are starting new coalitions. All states identified a staff person to serve as the Olmstead Coordinator. These Coordinators will be invited to a three-day technical assistance meeting scheduled for September 24-26, 2001 in Washington, D.C.

### Other National and State Coalition Activities

- Developed "train the trainer" curriculum by consumers for consumers to assist in becoming informed and active participants in Olmstead planning and implementation. The document will be offered to states as part of technical assistance support.
- Developing training materials for State Olmstead Coordinators including preparing consumers for facility discharge.
- Developed a document, with input from the National Coalition, on the barriers faced by persons with mental illness as they transition to the community. A special report on the barriers faced by children is being prepared.

**State Planning and Systems Development Branch/Mental Health Block Grant (MHBG)**. The goals of the MHBG are consistent with the Olmstead decision's goals. Law mandates the MHBG to move the locus of care from institutions to the community. The 2001 National Technical Assistance annual MHBG Conference for state mental health planners, sponsored by the State Planning and Systems Development Branch, will be held August 5-7, 2001, at the Capital Hilton Hotel in Washington, D.C. The conference theme is "Partnerships for Integration: Strategies for Serving Individuals and Families," including topics on the Olmstead Decision and the Coalition initiative.

**Protection and Advocacy (P&A) Branch**. The P&A Branch works with the National Association of Protection and Advocacy Services to ensure that state P&As take a leadership role to ensure that each state's delivery of long-term care for mental health consumers and other disability groups is consistent with the Olmstead decision and the Americans with Disabilities Act (ADA) integration mandate. An array of training and technical assistance has been provided to P&A advocates and attorneys to further Olmstead implementation and planning.

**Consumer Empowerment and Related Activities**. CMHS administers two Congressionally mandated laws that require consumer participation in State Mental Health Planning Councils and State Protection and Advocacy Advisory Councils. As a result of these and other developments, CMHS has created an impressive portfolio of consumer-related activities including:

- Providing leadership on Olmstead implementation including convening meetings on the ADA and employment of persons with psychiatric disabilities, involuntary treatment and electro-convulsive therapy.

- Coordinating agency-wide anti-stigma and anti-discrimination efforts and the development of a range of anti-stigma materials as well as sponsoring national anti-stigma/discrimination events including the March 2001 national mental health symposium. *Spring to Action: A National Mental Health Symposium to Address Discrimination and Stigma*. With over 400 mental health experts and consumers, a blueprint for action was developed that states and local communities can use to address discrimination and stigma on lives of people with mental illnesses.

Establishing the CMHS National Advisory Council (NAC) Subcommittee on Consumer/Survivor Issues to advise the NAC on mental health consumer issues.

Working with the MHBG Division National Technical Assistance Center on opportunities and challenges that state cultural competence coordinators face in developing state programs to meet the mental health needs of culturally diverse communities; and publishing Technical Assistance Center, Series No. 1-8 of ***The Change Agent's Tool Box: What You Need to Know About Promoting Systems Integration to Serve Consumers with Multiple Needs***, March 2001.

Funding consumer and consumer-supported technical assistance centers, state consumer networks and knowledge development and application consumer-operated services initiatives.

Supporting consumer-related materials on topics as: managed care, gay and lesbian issues, employment discrimination, co-occurring physical disability issues, recovery, self-care, trauma, advance directives, psychiatric residency training, self-advocacy skills, and internet access.

## Knowledge Development and Application Grants

The **CMHS Targeted Capacity Expansion** Grants help communities develop local cross-agency partnership infrastructures to promote access and coordination of care in such areas as co-occurring mental health and substance abuse treatment, supported employment, supported housing, jail diversion, etc. **Community Action Grants** support communities in adopting community integration practices. Grants to support **Consumer and Family Networking** help states and communities create networks focused on developing and financing exemplary community-based services. These programs include an evaluation component to help identify science-based treatment and systems development interventions.

The Consumer-Operated Services Program is a multi-site research initiative to discover to what extent consumer-operated community-based programs, as an adjunct to traditional mental health services, are effective in improving the outcomes of people with serious mental illness.

The Comprehensive Community Mental Health Services for Children and their Families program was implemented in FY 1993 to encourage the development of intensive community-based services based on a multi-agency, multi-disciplinary approach involving both the public and private sectors. Funds are available to states, political subdivisions of states, and Native American tribes or tribal organizations to build upon previously developed infrastructure and provide the array of services required to more fully meet the needs of the target population. The target population is children and adolescents, under 22 years of age, with a diagnosable serious emotional, behavioral, or mental disorder accompanied by disability, which must have been present or is expected to be present for at least one year and require services from multiple agencies. Grants are limited to five years of funding. There is an extensive evaluation on the implementation and outcomes of this service program.

In support of the 2001 Health Care Financing Administration Real Choice Grant solicitation, developed a briefing targeting state authorities and designees including information on evidence-based practices and resources on system change for all age groups.

## Center for Substance Abuse Treatment (CSAT)

Given that substance abuse treatment systems funded by the Substance Abuse Prevention and Treatment Block Grants are not institutional in nature, these funds may not be spent in hospital settings. The Block Grant focus is on assisting in closing the gap between persons in need of publicly funded treatment and those able to access it. Olmstead considerations especially come into play for those persons who are multiply affected by psychiatric, developmental and/or physical disabilities. CSAT and CMHS work in partnership on fostering appropriate community-based integrated treatment systems for these populations.

The CSAT National Treatment Plan (NTP), released in November 2000, is SAMHSA's strategic blueprint to reduce in half the number of chronic drug users, illegal drug demand, and drugs in the workplace by 2007 as set forth in the *National Drug Control Strategy*. NTP, which was developed from a national consensus process through public hearings and comments, is based on a system change paradigm that will apply federal resources including block grant funds toward a commonly accepted, evidence-based model for a continuum of services and care for substance abuse across health, human services, and justice systems. Current and future grants will define and support cross-system consensus on state of the art treatment protocols and methods/measures for continuous monitoring of quality consumer care. A specific example in the implementation of the NTP is CSAT's Community Action Grant Program which funds jurisdictions not for supporting direct service delivery but for adoption of exemplary practices through convening partners, building consensus, and eliminating barriers that will result in adaptation of service models that meet client needs at the most appropriate level of care. The ultimate goal for the consumer is that an individual needing treatment, regardless of the entry point or system he or she enters, will be identified and assessed and then will receive treatment and allied services either directly or though appropriate referral.

The Recovery Community Support program is a grant initiative designed to foster the participation of persons in recovery, their families and other allies in the development of substance abuse treatment policies, programs and quality assurance activities at the state, regional, and local levels.

### Agency-Wide Activity

SAMHSA has implemented an agency-wide strategic planning process to address the mental health and substance abuse issues and service needs of aging adults. The process includes obtaining input through discussions with both the agency's federal partners and non-government stakeholders. The outcome will be a three-year strategic plan based on SAMHSA's mission and goals.

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# OLMSTEAD RELATED INITIATIVES AT THE DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

## Funding Organization:

- Department of Housing and Urban Development (HUD)

## Implementing Organization:

- Department of Housing and Urban Development (HUD)

## Purpose:

To increase opportunities for persons with severe disabilities to live independently in community settings by providing rental and homeownership subsidies directly to individuals needing housing assistance.

## Background:

In June 2001, HUD announced two new pilot programs in response to the President's Executive Order implementing the Olmstead Supreme Court decision. The two programs are: (1) Project Access; and (2) the Homeownership Voucher Pilot Program for Disabled Families. HUD's action will help states and communities meet the goals of the 1999 Supreme Court decision in ***Olmstead v. L.C.*** The high court ruled that under the Americans with Disabilities Act of 1990, states must provide programs and services to persons with disabilities in community settings if doctors or other treatment professionals conclude it is appropriate and can be reasonably accommodated.

## Description:

In Project Access, an eleven state pilot program, HUD will distribute 400 new housing vouchers to assist disabled individuals. Project Access, will be launched in the following states: Colorado, Florida, Pennsylvania, Michigan, New Hampshire, New Jersey, New Mexico, Oklahoma, Oregon, Texas and Washington. HUD expects the first vouchers to be distributed within the next three months.

In the past year, HUD has distributed more than 13,000 Section 8 vouchers to housing authorities specifically for persons with disabilities. These vouchers will also further the goals of the Olmstead decision.

The Homeownership Voucher Pilot Program for Disabled Families will allow disabled families with incomes up to 99 percent of the area median to use Section 8 vouchers, previously used only for renting, to purchase a modest home without paying more than 30 percent of their income for homeownership expenses.

The nation's 2,500 public housing agencies that participate in the Section 8 program will oversee the homeownership pilot program, determining eligibility and enforcing the rules. To participate in the program, families must be eligible for a Section 8 voucher and be disabled under the terms as defined by law.

A family must have an annual household income of at least $10,000 and must not be a current homeowner to be considered for the program. Welfare income can be counted toward the minimum income requirement and there is no maximum term of homeownership assistance as with non-disabled families.

HUD is partnering with the Department of Health and Human Services (HHS) to implement this program. While HUD is supplying the vouchers and technical assistance, HHS, through state Medicaid agencies, will use Nursing Home Transition Grants, Medicaid funds and other resources to better help voucher holders make the transition to community living arrangements.

To obtain a printed copy of this report, send the full report title and your mailing information to:

U.S. Department of Health and Human Services
Office of Disability, Aging and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C.  20201
FAX: 202-401-7733
Email: webmaster.DALTCP@hhs.gov

NOTE: All requests must be in writing.

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http://aspe.hhs.gov/_/office_specific/daltcp.cfm

Assistant Secretary for Planning and Evaluation (ASPE) Home
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U.S. Department of Health and Human Services (HHS) Home
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