



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 HHS TECHNICAL ASSISTANCE ACTIVITIES RELATED TO THE ADMINISTRATION'S COMMUNITY-INTEGRATION INITIATIVE

May 2002

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 by HHS's ASPE/DALTCP. For additional information about this subject, you can 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, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The DALTCP Project Officer was Andreas Frank.

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The New Freedom Initiative Workgroup

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

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services.

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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 settings.

On June 18, 2001, President George W. Bush signed Executive Order No. 13217, "Community-Based Alternatives for Individuals with Disabilities." The Order calls upon the federal government to assist states and localities to implement swiftly the decision of the United States Supreme Court in Olmstead v. L.C., stating: "The United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interest of the United States."

To fulfill the mandate of the President's Executive Order, the Department of Health and Human Services has established the New Freedom Initiative Workgroup to review 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. As part of this effort, members of the New Freedom Initiative Workgroup felt it would be helpful to compile 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. 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. The Workgroup plans to update this compendium on a quarterly basis.

I. MEDICAID TECHNICAL ASSISTANCE ON SYSTEM STRUCTURE AND FINANCING

PRIMER FOR THE MEDICAID PROGRAM

Funding Organization:

Office of the Assistant Secretary for Planning and Evaluation

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.

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 home and community-based services 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.

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

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

Funding Organization:

Centers for Medicare and Medicaid Services

Implementing Organization:

Centers for Medicare and Medicaid Services

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.

The first Olmstead letter provides states with background information on the 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 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. 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, 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. 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. 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.

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>.

PROMISING PRACTICES IN HOME AND COMMUNITY-BASED SERVICES

Funding Organization:

Centers for Medicare and Medicaid Services

Purpose:

The Centers for Medicare and Medicaid Services (CMS) is creating a repository of Promising Practices in Home and Community Based Services to assist states, in partnership with their disability and aging communities, to strengthen their community long term support systems. These reform efforts are designed to enable persons 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 preferences;
- Exercise meaningful choices about their living environment, their service providers, the types of supports they receive, and the manner in which supportive services are provided; and
- Obtain quality services in a manner consistent with their living preferences and priorities.

Effective models of long term support abound and new innovations are being designed and implemented by state and local programs continuously. Yet information about these efforts is not widespread and the practical knowledge needed to make significant improvements in long term support systems often goes unshared among states. The purpose of the Promising Practices Reports is to disseminate timely information on program and policy innovations so that all states and stakeholders may benefit from the experiences of their peers across the country. The Promising Practices Reports are being developed by The MEDSTAT Group under contract with the Disabled and Elderly Health Program Group within CMS.

Some states are undertaking comprehensive reform of their entire system of home and community based services. Others are identifying specific components as targets for incremental improvement. Thus, some reports will focus on "whole systems". More frequently, the Promising Practices Reports will focus on discrete components of home and community-based service systems, such as person centered planning, eligibility systems, personal assistance services, financing mechanisms, quality improvement systems, and case management systems, that can be incorporated into an overall program design.

Innovations are undertaken within the context of a state's unique characteristics, history and environment. States and communities seek accurate, timely information to consider whether the adoption of a specific practice would be a good fit within their

existing policies and programs, and if so, what types of modifications would be needed to achieve replication.

Finally, promising practices can be found in a wide range of home and community based services programs targeted toward diverse populations. A program's funding source does not necessarily limit its broader applicability. In fact, any one specific program is often supported by a combination of funding streams such as the Medicaid Home and Community Based Services (HCBS) waiver program, regular Medicaid state plan options, programs funded by other federal agencies, and state and local resources.

Each report contains the following key elements:

- Introduction: describes the challenge the promising practice was designed to address and its intended benefit to people who need long term supports.
- Background: provides contextual information on the home and community-based services system in which the practice was implemented.
- Intervention: describes the practice and how it operates.
- Implementation: Outlines how the practice was put in place and, where possible, costs associated with its adoption.
- Impact: summarizes evidence of the practice's effectiveness in achieving its objective, the people it benefits and its ongoing cost.
- Contact Information-lists the name, phone number and email address of a person to contact for more information and a related web site link.

In sum, the Promising Practices Reports are intended to stimulate HCBS program changes, spark creative ideas, and serve as a launching pad for the next generation of program innovations. Promising Practices Reports do not, however, represent an endorsement of any practice by CMS or by MEDSTAT. Rather, they are a starting point for fostering a dynamic examination of ways to improve community support systems for persons of all ages with disabilities.

By design, most reports succinctly describe promising practices in two to three pages. Additional Promising Practices Reports are continuously being developed and will be posted on the website periodically. Case studies that provide more in-depth information about selected practices will be included at a later time as well.

CMS and MEDSTAT always welcome new ideas for additional Promising Practices Reports. If you are implementing a Promising Practice or know of one you think would be of interest to other states or communities, please send your suggestion to CMS at promisingpractices@cms.hhs.gov.

The reports can be found on the CMS website at:
<http://www.hcfa.gov/medicaid/promisingpractices/default.htm>.

NEW OPPORTUNITIES FOR COMMUNITY LIVING: A SYSTEMS CHANGE CONFERENCE

Funding Organization:

Centers for Medicare and Medicaid Services

Purpose:

The first annual Systems Change conference was held in Washington, DC on May 24-25, 2001, sponsored by the Centers for Medicare and Medicaid Services and facilitated by the HCBS Resource Network. The conference was targeted toward States, consumers, providers and advocates to share information and ideas on home and community based systems change initiatives. These initiatives will enable more integrated, community living for persons with disabilities of all ages. The conference also provided a national forum to present various major grant initiatives from the Centers for Medicare and Medicaid Services. The overall objective of the conference was to help States improve their long term support systems. Information was exchanged among stakeholders, meritorious practices shared, and profiles of complementary Federal programs presented. The webcast highlights two distinct tracks from the conference, Choice and Responsibility, and Whole Person Support Systems, as well as offering the plenary sessions.

2010 EXPRESS: A 10-YEAR ACTION PLAN TO ACHIEVE COMMUNITY-BASED SERVICE SYSTEMS FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES

Funding Organization:

Health Resources and Services Administration, Maternal and Child Health Bureau,
Division of Services for Children with Special Health Needs

Purpose:

Families and professionals alike continue to be frustrated by the fragmentation of services for children with special health care needs. We know that all children and youth with special health care needs and their families require the same basic opportunities -- comprehensive system of services and supports that allows them to live at home, go to school, play, and build relationships in their own communities. The present fragmentation of services is unnecessary, expensive, inefficient, and a barrier to true family-centered care.

As one step in addressing this problem, a new definition of children with special health care needs has been developed and is now widely accepted. "Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." This definition is purposely broad and inclusive. It encompasses children and youth who not only require health and health-related services, but who may also have other needs, including early intervention services, special education and related services, vocational education, mental health and substance abuse services, and social services. Moreover, their families may require family support and other services, such as transportation, respite care, and employment as they raise their children in this nation's homes and communities.

The 2010 Express is a comprehensive 10-year plan for the nation to meet six goals for children and youth with special health care needs, including:

- Families of children with special health care needs will partner in decision making and will be satisfied with the services they receive;
- Children with special health care needs will receive coordinated ongoing comprehensive care within a medical home;
- Families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need;
- Children will be screened early and continuously for special health care needs;

- Community-based service systems will be organized so families can use them easily;
- Youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

Technical assistance is available for state and local implementation of each goal.

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TA EFFORTS FOR CSHCN AND THEIR FAMILIES THROUGH THE FEDERAL INTERAGENCY COORDINATING COUNCIL (FICC)

Funding Organization:

Health Resources and Services Administration, Maternal and Child Health Bureau,
Division of Services for Children with Special Health Needs

Purpose:

The FICC, authorized under the Individuals with Disabilities Education Act, promotes the integration of early childhood services in communities through Federal, State and community collaborative planning, implementation and evaluation of services. The FICC strives to support collaborative efforts to create seamless, coordinated and integrated service systems in all communities so that services are organized in a way that is appropriate and easily accessible to families. To achieve this goal, the FICC will support collaborative training and technical assistance to multi-agency providers and families they serve to reinforce a common vision of and coordinated implementation strategies for integrated community services for young children and their families. The FICC endeavors to promote this training and technical assistance based upon community needs, and across traditional agency lines, enabling community agencies, providers and families to better deliver and access the services they need.

The Maternal and Child Health Bureau contributes to the FICC initiative resources in the form of staff time, funding for awards made under the “Communities Can” program, publications, and other technical assistance activities.

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NATIONAL TECHNICAL ASSISTANCE EXCHANGE FOR COMMUNITY LIVING

Funding Organization:

Centers for Medicare and Medicaid Services

Purpose:

In FY 2001, CMS funded two organizations to provide broad-based technical assistance, training and information to States, consumers, families and other agencies and organizations for the purpose of developing and implementing effective and enduring improvements in community long-term support systems.

This technical assistance will enable States, communities, grantees and others to learn quickly from one another and will establish an effective dialog among experts (including consumers and their families) from across the country. The Exchange will be conducting activities that include the following:

- fostering on-site State-to-State Technical Assistance;
- developing technical assistance materials;
- developing or providing expertise for States and others;
- working with individual States, national associations, consumer organizations and others to collect, refine and disseminate information that aids in the effective administration of programs for community living; and,
- developing, gathering, analyzing and disseminating practical information.

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CDC STUDIES AMONG PEOPLE WITH DISABILITIES ENROLLED IN MEDICAID/MEDICARE

Funding Organization:

Centers for Disease Control, National Center on Birth Defects and Developmental Disabilities

Purpose:

The CDC currently funds five studies on risks for secondary conditions among Medicaid/Medicare enrollees with disabilities. This broadened attention to determinants of well-being among people with disabilities will assist service delivery systems in preventing additional secondary or excessive disability.

- Studies at the Oregon Health and Science Center are identifying system policies and procedures that will result in lower cancer risk for people with disabilities in the Oregon Medicaid population.
- In collaboration, investigators at Duke University Medical Center, North Carolina Office on Disability and Health, the North Carolina Department of Public Health, and Medical Review of North Carolina are developing a comprehensive health education campaign to increase awareness of breast and cervical cancer screening targeting women with disabilities enrolled in Medicare, health care providers and lay health advisors, and community health leaders.
- Researchers at the University of Montana are exploring strategies for developing cost-effective interventions aimed at reducing secondary conditions among adults with developmental disabilities living in support environments.
- University of Iowa investigators are examining medications, degree of mobility impairment and access to care as risk factors for adverse drug reactions (ADRs) among populations sampled from the Medicare aged and disabled enrollment files.
- Researchers at the University of Montana are investigating the cost-effectiveness of physical activity interventions among individuals with disabilities who are receiving Medicaid benefits.

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II. FAMILY AND INFORMAL CAREGIVERS

CAREGIVER RESOURCES AND TECHNICAL ASSISTANCE

Funding Organization:

Administration on Aging

Purpose:

The Administration on Aging provides a number of caregiving resources. On the AOA website (<http://www.aoa.gov>), are several technical assistance resources for family members, providers, as well as state and local policy makers. The Eldercare Locator -- a nationwide toll-free service, has helped older adults and their caregivers find local services for seniors. AOA makes this service available on-line so that consumers can easily link to the information and referral (I&R) services of their state and area agencies on aging.

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NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

Funding Organization:

Administration on Aging

Purpose:

The National Family Caregiver Support Program (NFCSP) was modeled in large part after successful LTC programs in States such as California, New Jersey, Wisconsin and Pennsylvania and after listening to the needs expressed by hundreds of family caregivers in discussions held across the country. Funded at \$125 million in fiscal year 2001, approximately \$113 million has been allocated to states through a congressionally mandated formula that is based on a proportionate share of the 70+ population. The program calls for all states, working in partnership with area agencies on aging and local community-service providers to have five basic services for family caregivers, including:

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to supportive services;
- Individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decisions and solving problems relating to their caregiving roles;
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

In January 2001, AoA issued guidance to states on the implementation of the new program, and on February 15, HHS Secretary Tommy G. Thompson announced the release of those funds to states. AoA is planning a technical assistance conference for the Fall. The conference will highlight innovative and successful state caregiver support initiatives that might warrant replication.

The Older Americans Act Amendments of 2000 also establishes the Native American Caregiver Support Program, with \$5 million of the \$125 million designated to assist caregivers of Native American elders who are chronically ill or have disabilities. In addition, \$6 million of the \$125 million will be used to fund competitive innovative grants, grants of national significance, conferences and training, to further develop comprehensive and effective systems of support in family caregiving.

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FAMILY SUPPORT MODEL DEMONSTRATION PROJECTS

Funding Organization:

Administration on Developmental Disabilities

Purpose:

The Administration on Developmental Disabilities funds many Family Support Model Demonstration Projects under the Projects of National Significance (PNS) Program. The PNS includes family support grants to support the development of family centered and directed systems for families of children with disabilities. Title II (Family Support) of the DD Act section 204 describes how the “Secretary shall make grants to States on a competitive basis ... to support systems change activities designed to assist States to develop and implement, or expand and enhance, a statewide system of family support services for families of children with disabilities that accomplishes the purpose of this title”. There are over 30 Family Support PNS grantees across the country. For further information on each grantee, or contact information, please contact the Administration on Developmental Disabilities.

ADD has several of its own TA contracts in place:

- ADD contracts with the Urban League of Nebraska to provide training and technical assistance to minorities with disabilities who are under-served.
- ADD contracts with the National Association of Developmental Disabilities Councils to provide technical support services to assist the government with their responsibilities of providing support to developmental disabilities programs components through the provision of technical assistance and training to the State Councils on Developmental Disabilities.
- ADD contracts with the National Association of Protection and Advocacy Systems (NAPAS) to provide technical assistance to the State Protection and Advocacy Agencies that protect the interests of individuals with mental and physical disabilities.
- ADD contracts with the Human Services Research Institute to provide technical assistance to Family Support programs.
- ADD contracts with the Association of University Centers on Disabilities (formerly AAUAP) to provide technical assistance to the University Centers for Excellence in Developmental Disabilities: Education, Research, Service.

III: EMPLOYMENT SUPPORTS FOR PEOPLE WITH DISABILITIES

MEDICAID INFRASTRUCTURE GRANTS

Funding Organization:

Centers for Medicare and Medicaid Services

Purpose:

Section 203 of the Ticket to Work and Work Incentives Improvement Act of 1999 directed the Secretary of the Department of Health and Human Services (DHHS) to establish a grant program to support State efforts to enhance employment options for people with disabilities. The Centers for Medicare and Medicaid Services (CMS) is the designated DHHS agency with administrative responsibility for this grant program. The Medicaid Infrastructure Grant program is authorized for 11 years, and \$150 million in funding has been appropriated for the first five years of the program. The minimum grant award to an eligible State is \$500,000 per fiscal year.

The goal of the Medicaid Infrastructure Grant program is to support people with disabilities in securing and sustaining competitive employment in an integrated setting. The grant program will achieve this goal by providing money to the States to develop and implement the core elements of the Ticket to Work and Work Incentives Improvement Act of 1999, so as to successfully modify their health care delivery systems to meet the needs of people with disabilities who want to work.

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CENTER FOR WORKERS WITH DISABILITIES TECHNICAL ASSISTANCE ON INFRASTRUCTURE DEVELOPMENT

Funding Organization:

Approved by: Centers for Medicare and Medicaid Services

Funded by: State Membership

Purpose:

The American Public Human Services Association established the Center for Workers with Disabilities to aid participating states implement provisions of the Ticket to Work and Work Incentives Improvement Act of 1999 or related efforts intended to enhance employment opportunities for persons with disabilities. The Center for Workers with Disabilities offers states the following services:

- Public policy support services -- technical assistance and guidance to support state efforts to design or expand Medicaid infrastructures supporting the competitive employment of persons with disabilities.
- A resource band of up-to-date information and experiences from states with more fully developed infrastructures supporting the competitive employment of persons with disabilities.
- Monitoring of federal agency issuances -- such as regulations, policy or operational guidance that will impact on programs serving people with disabilities.
- A forum sharing exemplary state practices and exchange of experiences in TWWIIA and BBA implementation through conferences, seminars, electronic list serves, and teleconferences.
- Information dissemination on promising practices in states implementing TWWIIA.

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NATIONAL CONSORTIUM FOR HEALTH SYSTEMS DEVELOPMENT/TECHNICAL ASSISTANCE ON INFRASTRUCTURE DEVELOPMENT

Funding Organization:

Approved by: Centers for Medicare and Medicaid Services

Funded by: State Membership

Purpose:

The National Consortium for Health Systems Development (NCHSD) represents states that have joined together to assist other state agencies, legislatures, consumers and advocates in their efforts to build systems that support competitive employment for individuals with disabilities. The primary means for achieving this goal is through state-to-state information sharing, individualized technical assistance, and the dissemination of best practices to a broad array of involved stakeholders in states around the country. The NCHSD is an efficient venue to facilitate state-to-state information sharing about best practices and challenges encountered in building supportive health care and social support systems for people with disabilities who wish to work. Many of the state partners in NCHSD are among the first group of states in the country to implement work incentive options in their Medicaid programs. Additionally, they have been in the forefront of building inter-agency partnerships for the purpose of creating integrated and comprehensive approaches to workforce policy development for individuals with disabilities.

NCHSD operates on the premise that the best policy happens when all stakeholders are at the table and actively involved in setting the policy agenda. By providing opportunities for meaningful collaboration between states, advocates and consumers, in partnership with federal and other key stakeholders, NCHSD activities can create the conditions that foster the relationships necessary to build comprehensive, consumer-driven health systems' development.

The type of assistance available includes:

- assessment tools and assistance in examining existing state policies and programs that serve as barriers to employment;
- design of model benefit packages and innovative delivery system enhancements;
- development of accurate cost estimates for expanding Medicaid options;
- state-to-state problem solving and development of issues' resolution strategies to overcome structural, policy and political barriers to system change;
- development of on-going research and evaluation methods and tools to monitor the outcomes and impacts of systems and policy change;

- development of model training modules for state Medicaid eligibility workers, VR counselors, community mental health workers and others who provide support to individuals with disabilities; and
- technical assistance and best practice strategies for engaging the employer community.

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CDC STUDY OF THE PROTECTIVE RELATIONSHIP BETWEEN EMPLOYMENT AND SECONDARY CONDITIONS AMONG PEOPLE WITH DISABILITIES

Funding Organization:

Centers for Disease Control, National Center on Birth Defects and Developmental Disabilities

Purpose:

Researchers at MedStar Research Institute are investigating the possible protective relationship between employment status and the occurrence of secondary conditions among working-age adults with disabilities using the 1997 and 1998 National Health Interview Survey data and the 1996 Medical Expenditure Panel Survey data.

The researchers aim to: (1) examine employment disparities between adults ages 18-64 with and without disabilities as identified in HP2010 Objective 6-8; (2) examine the occurrence of secondary conditions among working-age adults with disabilities by employment status; (3) investigate direct and indirect benefits of employment and their relationship to secondary conditions; (4) investigate the prevalence of health risk factors and their relationship to reported secondary conditions for employed and unemployed working-age adults with disabilities.

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IV: PERFORMANCE MANAGEMENT AND QUALITY IN COMMUNITY SETTINGS

WAIVER QUALITY INITIATIVES

Funding Organization:

Centers for Medicare and Medicaid Services

Purpose:

To improve the quality of programs administered under the Home and Community-Based Services (HCBS) Waiver Program. Three waiver quality assurance/improvement projects are under implementation by The MEDSTAT Group: (1) Development of a Centers for Medicare and Medicaid Services Regional Office 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 CMS Regional Office HCBS Waiver Monitoring Guide (The Protocol)

During CY 2000 MEDSTAT developed a monitoring protocol for CMS Regional Office (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 CMS Regional Office Work Groups -- one focused on process and the other on content issues, as well as CMS Central Office staff. CMS also instituted a public comment period during last July and August, and based on comments received, certain sections of The Protocol were revised. CMS 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 CMS RO staff were invited to a one-day session where The Protocol was showcased. CMS's Central Office has also provided additional training opportunities for CMS RO staff conducting waiver reviews. In an effort to insure that The Protocol is implemented as intended, CMS 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. CMS 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 CMS, 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 use to review frequencies of survey items, and to assess 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 CMS RO representatives, website solicitations, and letters to state units on aging. MEDSTAT is currently in the process of speaking with a number of states (PA, TX, SC, MI, OR, AZ, FL, NC) 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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REINVENTING QUALITY: FOSTERING PROMISING PRACTICES IN PERSON-CENTERED SERVICES AND QUALITY ASSURANCE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Funding Organization:

Administration on Developmental Disabilities

Implementing Organization:

National Association of State Directors of Developmental Disabilities Services (NASDDDS)

Subcontractors:

- Human Services Research Institute
- Research and Training Center on Community Living, University of Minnesota

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. 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.

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

Contact Information:

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

V: PROMOTING INDEPENDENCE, RESPONSIBILITY, AND CONSUMER-DRIVEN SERVICES

CONSUMER-DIRECTED CARE CONFERENCE

Funding Organization:

Centers for Medicare and Medicaid Services
Administration on Aging
Substance Abuse and Mental Health Services Administration
Assistant Secretary for Planning and Evaluation
Robert Wood Johnson Foundation

Purpose:

This national conference, held June 10-12, 2001 in Washington, DC, 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 policy makers to come together to:

- synthesize and share results and experiences of consumer-direct 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.

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 policy makers as well as consumers and their advocates for the purpose of facilitating informed decision-making about managed care and disability, has only recently begun.

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Further information is available from ASPE's website:
http://aspe.hhs.gov/office_specific/daltcp.cfm.

CDC TECHNICAL ASSISTANCE WITH COMMUNITY-BASED CONSUMER-DRIVEN HEALTH PROMOTION

Funding Organization:

Centers for Disease Control, National Center on Birth Defects and Developmental Disabilities

Purpose:

"Living Well With A Disability" is a health promotion curriculum delivered in consumer-controlled ILCs to address secondary conditions associated with existing disabilities. The curriculum is a theory-based, 10-week modular health promotion and behavior-modifying intervention, copyrighted by researchers at the University of Montana's Rural Institute on Disabilities. The curriculum is implemented nationally in conjunction with collaborators at the University of Kansas and constituents throughout the country at Independent Living Centers (ILCs). Participants in the *Living Well* curriculum engage in therapeutic interventions delivered by trained peer educators at ILCs. The curriculum is divided into modules focusing on goal-setting, information-seeking, and problem-solving strategies, and developing healthy reactions to frustration and stress, overcoming depression, engaging in and maintaining exercise habits, and enhancing nutritional intake. Study results have demonstrated that this programmatic health promotion intervention is beneficial, cost-saving, and potentially cost-effective. The next steps include extending that demonstration into managed care, Medicaid, and privately insured payment environments.

Using an instrument called, Life Quality and Health For Adults with Developmental Disabilities: A Secondary Conditions, Risk and Protective Factors Surveillance Instrument, the investigators measured the prevalence of an array of secondary conditions commonly affecting people with disabilities. After participating in the *Living Well* curriculum, post-test results indicated a 37 percent overall reduction in the prevalence of reported secondary conditions among participants, and a reduction in the number of physician visits by 45 percent during the six months following the intervention. Additional results from a longitudinal cost-effectiveness analysis of the curriculum indicated that savings in direct medical expenditures among *Living Well* participants who are the most frequent utilizers of medical care services would offset the cost of the intervention within two months, and that expenditures among average utilizers would be recouped within six months. More information about *Living Well* is available at: <http://ruralinstitute.umt.edu/rtrural/health/SecondaryCondition.htm>

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CDC TECHNICAL ASSISTANCE WITH ASSESSING BARRIERS IN COMMUNITIES AND HEALTH FACILITIES

Funding Organization:

Centers for Disease Control, National Center on Birth Defects and Development Disabilities

Purpose:

The CDC currently funds five projects aimed at developing environmental checklists and measuring community accessibility. These assessment tools will be useful in helping communities become accessible to residents with disabilities.

- Investigators at Washington University and the Paraquad Independent Living Center are developing a set of objective, reliable, and valid measures of the physical, social and cultural environments that are relevant to the community participation of people with disabilities, particularly those with mobility limitations. The measures developed will provide a Community Health Environment Checklist (CHEC) to be used by people with disabilities, health professionals, employers, recreational site planners, telecommunication operators, transportation providers and commercial establishment owners to assess the barriers and facilitators to participation and reduce community inaccessibility, a risk factor for poor health and well-being.
- Investigators at the University of Washington are developing and testing measurement instruments that identify and assess important community factors that affect accessibility for people with disabilities. The investigators are (a) identifying important aspects of community environments, (b) selecting and designing measures of physical and social access, and (c) collecting environmental and individual data from neighborhoods in two cities, Seattle and Spokane, in partnership with their local health districts. This community research assumes the importance of meaningful participation by people with disabilities and the need for measures that can point to realistic interventions that increase access and participation.
- Investigators at Craig Hospital recently developed and validated the Craig Hospital Inventory of Environmental Factors (CHIEF), a survey instrument to assess the frequency and magnitude of perceived physical, attitudinal, and policy barriers that keep people with disabilities from doing what they want or need to do. This instrument demonstrated that people with disabilities encounter frequent and problematic environmental barriers. Moreover, the CHIEF has demonstrated that the impact of barriers is associated with the type and severity of the disability. In ongoing studies, the investigators are developing three new

- Investigators from university of North Carolina, Gallaudet University and the Center for Discovery in New York are developing reliable, valid, and generalizable measurement instruments to assess environmental factors affecting children and youth with disabilities in their communities. The conceptual and taxonomic framework of the International Classification of Functioning, Disability and Health - ICF (World Health Organization, 2000) serves as the basis for defining and documenting environmental factors affecting functioning and secondary conditions of children and youth with disabilities. The study will yield a set of psychometrically sound and efficient measures of the environment that will be disseminated widely for use in public health surveillance, community intervention and evaluation efforts.
- Investigators at the University of Illinois at Chicago, in coordination with the existing network of Disability and Business Technical Assistance Centers (DBTACs), are developing two standardized instruments to measure the accessibility of community-based recreation and fitness facilities, including parks, pools, trails, fitness centers, community recreation centers, etc. by people with mobility impairments, *caregivers* professional staff. This project, AIMFREE, will assist facilitate community integration [<http://www.aimfree.org>]

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CDC TECHNICAL ASSISTANCE WITH CONFERENCES ON WELLNESS AND INCLUSION

Funding Organization:

Centers for Disease Control, National Center on Birth Defects and Development Disabilities

Purpose:

In 2002, the CDC, Disability and Health (DH) program will support four conferences on wellness and inclusion of people with disabilities to stimulate dialogue, share information, establish public health priorities, and undertake next steps.

- 2001 October 15-16. *Conference: Celebrate Wellness II Oregonians w/Disabilities*. Held at the Hilton Eugene and Conference Center Eugene, Oregon. Hosted by the Disability and Health Programs at the Oregon Health and Science University, Oregon Department of Human Services and the Centers for Disease Control and Prevention. Celebrate Wellness II will highlight wellness issues including women's health, multicultural health, mental health, violence/abuse, employment, health promotion and research, disability and aging, complementary and alternative medicine, self-advocacy and determination, **community inclusion**, alcohol and drug use/abuse. For information contact Traci Goff at gofft@ohsUniversity.edu, or 800/452-3653 ext 1204, 503/494-7373.
- 2002, June 21 and 22. *Improving the Health and Wellness of Women with Disabilities: A symposium to establish a research agenda*. To be held at the Texas Children's Hospital, Houston, Center for Telehealth. Hosted by the Baylor College of Medicine Center for Research on Women with Disabilities. This symposium on Improving the Health and Wellness of Women with Disabilities will bring together researchers, constituents, and disability funding agencies to discuss the state of the science in research, clinical and **community interventions**, and consumer. For information contact Kathy Fire at kfire@bcm.tmc.edu or 713-960-0505.
- 2002, September 12-14. *Workshop on Developing Summary Health Measures that Address the Concerns of People with Disabilities*. Washington, D.C. Hosted by the University of Maryland, Institute for Philosophy and Public Policy. At this workshop, participants will examine current summary health measures and their limitations in estimating environmental and social factors that influence the health of people with disabilities; interactions between the body, person, environment and society; post-disability adaptive perspectives of health; and the use of inclusive and habilitation terms versus strict medical or rehabilitation terms. For information contact Dr. David Wasserman at 301/405-4764.

- 2002, September 20-21 **HP2010 Chapter 6 National Forum**. Held at: Atlanta, GA. Hosted by the Disability and Health Program, NCBDDD, CDC. In follow-up to the December 2000 HP2010 Chapter 6 workshop, the Disability and Health program, at NCBDDD, CDC will host a national Chapter 6 conference to undertake next steps to achieve the 13 objectives, three of which specifically facilitate community integration. Themes include children, emotional support, community participation, environmental barriers, caregiving, and health. Groups focusing on science, policy, and programs will decide on a few steps to which groups can commit to pursuing during the next 36 months. For information contact Jewel Cripe at Courtesy Contractors jcripe@courtesyassoc.com

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VI: DEVELOPING AND SUPPORTING A QUALITY LONG-TERM CARE WORKFORCE

TECHNICAL ASSISTANCE ON DEVELOPING A QUALITY LONG-TERM CARE WORKFORCE

Funding Organization:

Office of the Assistant Secretary for Planning and Evaluation
Centers for Medicare and Medicaid Services

Implementing Organization:

Institute for the Future of Aging Services
Paraprofessional Healthcare Institute

Purpose:

This project, in partnership with the Paraprofessional Healthcare Institute, will seek to address the shortage of high quality and committed workers in long-term care by developing a comprehensive, national workforce improvement initiative. The purposes of the initiative are to:

- increase public recognition of the critical role played by these workers;
- promote innovation at the state, community and provider level to improve recruitment and retention;
- create a national clearinghouse database on the long-term care workforce with search capacity;
- increase understanding of the causes of worker shortages and the likelihood they will persist in the future so that new policies, programs, and practices can be implemented to resolve them, and
- collaborate with potential funders to plan and implement a systematic program of applied research, demonstration and evaluation to improve workforce recruitment and retention and the delivery of high quality long-term care services.

The National Clearinghouse on the Direct Care Workforce is an informational resource center. The Clearinghouse collects, analyses and disseminates information concerning home health aides, nursing aides, personal care attendants.

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Further information is available from ASPE's website:
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RESEARCHING THE ADEQUACY AND AVAILABILITY OF COMMUNITY-BASED PERSONAL ASSISTANCE SERVICES

Funding Organization:

Centers for Medicaid and Medicare Services

Purpose:

The purpose of this technical assistance project is to evaluate the size and scope of the shortage of personal assistance services and to explore policies and practices that influence the recruitment and retention of qualified personal assistance services workers. Work under this project is being completed by the Paraprofessional Healthcare Institute (PHI). Specifically, this task order modification will result in:

- The development of practical, useful, community-based products that can be used to address workforce shortage issues.
- An electronic database of resources, contacts and tools to be used by federal, State, and Local organizations in designing and implementing policies and programs to increase the availability of personal assistance services workers. This database will include querying capabilities.
- Development of a foundation for future research in community-based personal assistance services and supports.
- An identification of areas needed for additional research or for policy or programmatic changes.
- Immediate assistance to new projects funded under the Systems Change grants prior to the availability of other technical assistance efforts.

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FRONTLINE WORKERS IN LONG-TERM CARE TECHNICAL EXPERT PANELS

Funding Organization:

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

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.

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.

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Further information is available from ASPE's website:
http://aspe.hhs.gov/_office_specific/daltcp.cfm.

BUILDING A HIGH QUALITY LONG-TERM CARE PARAPROFESSIONAL WORKFORCE

Funding Organization:

Agency for Health Care Research and Quality

Purpose:

On February 7-9, 2001, the ULP held a workshop to provide State and local health policy makers with an overview of the major issues underlying the shortage of paraprofessional workers in long term care settings and potential strategies to address the problem. The workshop included sessions on the supply and demand of paraprofessional workers, working conditions and job design, management of the work environment, and wages and benefits. The workshop also highlighted industry and State initiatives that address these issues including workforce recruitment strategies, new models for organizing long-term care services, and the role of “informal” caregivers.

VII: ENSURING COMPLIANCE WITH CIVIL RIGHTS

OFFICE OF CIVIL RIGHTS TECHNICAL ASSISTANCE ACTIVITIES

Funding Organization:

Office of Civil Rights, Department of Health and Human Services

Purpose:

Through its headquarters and 10 regional offices, the Office for Civil Rights (OCR) is responsible for promoting compliance with a panoply of federal civil rights statutes that prohibit discrimination based on race, color national origin, disability, age and in certain circumstances, sex and religion, in health and social services that are funded by HHS. OCR also has jurisdiction to enforce laws prohibiting discrimination based on disability in programs operated by the Department and by state and local public entities.

OCR plays a critical leadership role in the Department's overall initiatives to promote compliance with the Olmstead decision and the Americans with Disabilities Act. OCR co-chairs with CMS the Department's New Freedom Initiative Group which focuses on implementing President Bush's New Freedom Initiative. OCR also has a nationwide program of outreach and technical assistance to assist states to resolve complaints filed with OCR by individuals with disabilities alleging discrimination and to promote improved access to community based services. Specific technical assistance activities include:

- Outreach and education to state and local authorities, legislatures, community groups and others on the Olmstead decision and the requirements of Title II of the ADA and Section 504 of the Rehabilitation Act.
- Direct staff consultation with states and other public entities to resolve complaints alleging unlawful discrimination and to improve compliance with the law.
- Expert consultation, written guidance and other information to assist states to undertake and implement comprehensive, effectively working plans to improve availability of community-based services for individuals with disabilities.
- Periodic technical assistance teleconferences to broadly disseminate information on key issues such as housing.
- A website with information about Departmental guidance and available resources.
- A library of complaint summaries and other information a identifying best practices in state compliance efforts. (In development).

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VIII: MULTI-FACETED TECHNICAL ASSISTANCE ACTIVITIES

HOME AND COMMUNITY-BASED SERVICES RESOURCE NETWORK

Funding Organization:

Centers for Medicare and Medicaid Services
Office of the Assistant Secretary for Planning and Evaluation

Implementing Organization:

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

Purpose:

The Home and Community-Based Services 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 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.

The Resource Network engages in the following technical assistance activities:

- The HCBS Resource Network has developed a website that includes the following services:
 - An inventory of key resources on home and community-based services 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 home and community-based systems. The following states have received or are currently receiving direct support from the Resource Network:
 - Alabama
 - Kansas
 - Connecticut

- New Mexico
- Georgia
- Ohio
- The HCBS Resource Network facilitated the systems change conference on “***New Opportunities for Community Living***” held in May 24-25, 2001 in Washington, DC 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 home and community-based services, including the following:
 - Organizing and conducting national tele-conferences 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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Boston College Graduate School of Social Work
401 McGuinn Hall
Chestnut Hill, MA 02467
(617)552-2809
URL: <http://hcbs.org>

NATIONAL CONFERENCE OF STATE LEGISLATURES ACTIVITIES

Funding Organization:

Robert Wood Johnson Foundation
HCBS Resource Network
George Washington University
Various Other Sources

Purpose:

NCSL technical assistance activities are designed to reach all state legislators with information about home and community-based services (HCBS), with an emphasis on ensuring that information is tailored to meet the specific needs of persons with varying levels of expertise in this area.

NCSL activities cover a broad range of areas aimed at educating state legislatures, including: sponsoring activities at conferences; disseminating information via printed material, audio cassettes, call-in audio conferences, and the internet; and conducting research. A description of NCSL activities is presented below.

- Conducting a survey of all 50 states, the territories and the District of Columbia in order to collect information on the status of each state's activities related to the Olmstead Supreme Court decision.
- Building an Olmstead home page on the NCSL website.
- Producing a two-page legislative brief on trends in mental retardation/developmental disabilities services and expenditures, within the context of the Olmstead decision. This brief will be distributed to all 7,424 state legislators.
- Revising the chapter in its "Medicaid Survival Kit" on HCBS to reflect recent changes related to Olmstead.
- Planning, in collaboration with the HCBS Resource Network, an "audio conference" on Olmstead and HCBS policy with one-and-a-half-hour session, where approximately 70 legislators and legislative staff will call in. A half-hour presentation is planned, followed by a question-and-answer period.
- Producing two briefing papers on Olmstead-related issues: one that summarizes what Olmstead means for state development of HCBS services; and one that summarizes state activities related to planning or implementing programs under Olmstead.

- Providing “information assistance” to legislators, legislative staff, and others who make inquiries related to Olmstead issues.
- Developing an information clearinghouse related to Olmstead and other issues concerning policy decisions that affect people with disabilities.

Contact Information:

Martha King, Health Care Program Director
National Conference of State Legislatures
1560 Broadway, Suite 700
Denver, CO 80202
(303)894-3193

WEBSITE FOR OBTAINING MEDICAID ASSISTANCE: MEDICAID DESK REFERENCE

Funding Organization:

Administration on Developmental Disabilities

Implementing Organization:

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. This project will develop an interactive Web site with descriptions of Medicaid programs presented in a language that persons with disabilities can understand, including persons with cognitive disabilities. The Web site will be constructed primarily around 10 individual state Medicaid programs, although national-level information about Medicaid and Medicaid-financed services will be provided. For each of the 10 states, a team of experts specific to that state will be available to answer specific Medicaid-related questions. Initiation of the first “live” state Web-site is planned for October 2001. Selected brochures will also be printed. The grant began in October 2000, and will run for three years.

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.
- 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 Web sites.
- What's New in Medicaid.
- A "waiver wire" providing up-to-date information on the status of each state's HCBS waiver services programs.
- Evaluation and Review: designed to elicit feedback on the Web site from users.
- Partners and Philosophy: designed to articulate guiding principles of the project, and on the information presented.

Contact Information:

Charles Moseley
University of New Hampshire
Institute on Disability/UAP
7 Leavitt Lane, Suite 101
Durham, NH 03824-3522
(603)862-4810

NATIONAL AND STATE COALITIONS AT THE SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Funding Organization:

Substance Abuse and Mental Health Services Administration (SAMHSA)

Purpose:

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.

SYSTEMS CHANGE GRANTS

Funding Organization:

Centers for Medicare and Medicaid Services

Purpose:

As part of the FY 2001 DHHS 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; and
- Obtain quality services in a manner as consistent as possible with their community living preferences and priorities.

These system change grants represent a major new initiative to promote the design and delivery of home and community-based services that support people with a disability or long-term illness to live and participate in their communities. 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 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.

Contact Information:

Centers for Medicare and Medicaid Services
Disabled and Elderly Health Programs Group
7500 Security Boulevard, Mailstop S2-14-26
Baltimore, MD 21244

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY ACTIVITIES

Funding Organization:

Agency for Healthcare Research and Quality, Department of Health and Human Services

Purpose:

Beyond Olmstead: Making Community Based Services Work for All Persons with Disabilities

On July 11-13, 2001 ULP conducted a workshop to provide State and local policymakers with tools to improve their ability to work collaboratively with consumers, providers, advocates and others on accurately assessing consumer needs and planning for successful transitions from institutions, or alternatively, increasing the types and level of support for persons already living in the community. The workshop included sessions on:

- consumer centered planning and budgeting;
- planning community based delivery systems;
- strategies to ensure successful transitions from institutions to communities;
- linking system design, budgeting and consumer preferences;
- consumer directed care;
- integrating supportive services with primary and specialty care; and
- expanding Medicaid eligibility to promote entering the workplace.

State Long Term Care Programs: Balancing Cost, Quality and Access

On May 6-8, 2002 ULP will co-sponsor a workshop with the National Governors Association to provide senior State executive branch officials with information that will help them develop policies and programs that provide choices for low income Medicaid beneficiaries who need long term care services, while addressing concerns about cost, quality and access. The workshop will include a session on workforce challenges facing policymakers and providers and the findings from a review of State efforts to strengthen the paraprofessional workforce. There will also be a session discussing the Administration's community integration initiative and how States can use waiver authority to demonstrate new ideas in the organization and delivery of care.

RESEARCH SUPPLEMENTS FOR INDIVIDUALS WITH DISABILITIES

Funding Organization:

National Institutes of Health

Purpose:

The National Institutes of Health (NIH) and its awarding components have developed an initiative that is designed to address the low participation rate for Americans with disabilities in the science and engineering research work force. This initiative extends opportunities to individuals with qualifying disabilities [e.g. total deafness in both ears, visual acuity less than 20/200 with corrective lenses, speech impairment, missing extremities, partial paralysis, complete paralysis, convulsive disorders, mental or emotional illness, learning disabilities, kidney dialysis, and severe distortions of limbs and or spine] who are capable of entering or resuming research careers. Under this initiative the NIH will offer supplemental awards to certain ongoing research grants to encourage individuals to pursue biomedical, behavioral, clinical or social science research careers. It is hoped that the availability of support will substantially increase the number of individuals with disabilities in the health-related sciences. Principal investigators holding certain NIH research grants are eligible to obtain administrative supplements to existing grants for the support and recruitment of scientists and students with disabilities into research careers. In addition, this program will provide support to accommodate the disabilities of established investigators who become disabled.

Contact Information:

For more information, visit the National Institutes of Health website at <http://www.grants.nih.gov/grants/guide/pa-files/PA-01-080.html>.

TECHNICAL ASSISTANCE CENTERS RELATED TO CHILDREN'S MENTAL HEALTH SERVICES

Funding Organization:

Substance Abuse and Mental Health Services Administration
Center for Mental Health Services

Purpose:

The following Technical Assistance Centers provide an array of services related to children's mental health that may include technical assistance, information and referrals, on-site consultation, training, library services, publications, annotated bibliographies, and other resources. Many services are available free of charge, but in some cases, charges may apply.

- National Indian Child Welfare Association
 - Technical Assistance for Community Development
 - Public Policy Development
 - Information Exchange
 - Technical Assistance and Training for Tribal grantees of the Child, Adolescent and Family Branch of the Center for Mental Health Services
- National Technical Assistance Center for Children's Mental Health
 - Information packets, issue briefs, and monographs on children and adolescents with serious emotional disturbances
 - Conferences and training institutes on planning, delivery, and financing of services
 - Consultation on systems change and services development and delivery
 - Agency and organization collaboration
- Research and Training Center for Children's Mental Health
 - Studies of children with serious emotional disturbances and service systems research
 - Annual research conference
- Research and Training Center on Family Support and Children's Mental Health
 - Research and training on family support issues, family/professional collaboration, and diverse cultural groups
 - Annual research conference on family support issues
 - Information on publications and events through an electronic bulletin board
- Technical Assistance Partnership for Child and Family Mental Health

Contact Information:

National Indian Child Welfare Association
5100 S.W. Macadam Avenue, Suite 300
Portland, OR 97201
(503)222-4044
URL: <http://www.nicwa.org>

National Technical Assistance Center for Children's Mental Health (formerly
CASSP Technical Assistance Center)
Georgetown University Child Development Center
3307 M Street, N.W.
Suite 401
Washington, DC 20007-3935
(202)687-5000
URL: <http://gucdc.georgetown.edu/>

Research and Training Center for Children's Mental Health
Department of Child and Family Studies
Florida Mental Health Institute
Louis de la Parte
13301 Bruce B. Downs Boulevard
University of South Florida
Tampa, FL 33612
(813)974-4661
URL: <http://rtckids.fmhi.usf.edu/>

Research and Training Center on Family Support and Children's Mental Health
Regional Research Institute of Portland State University
P.O. Box 751
Portland, OR 97207-0741
(503)725-4040
URL: <http://www.rtc.pdx.edu>

Technical Assistance Partnership for Child and Family Mental Health
1000 Thomas Jefferson Street, N.W.
Suite 400
Washington, DC 20007-3835
(202)342-5600
URL: <http://www.air.org/tapartnership>

GRANTS FOR STATEWIDE CONSUMER NETWORKS

Funding Organization:

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services

Purpose:

The purpose of this program is to increase the capacity of State-level mental health consumer and consumer family member/supporter organizations to manage a set of activities that will assist mental health consumers to participate in the development of State and local policies, programs, and quality assurance activities related to mental health.

The Grants for Statewide Consumer Network program funds state-level consumer network organizations to help consumers participate in developing policies, programs, and quality assurance activities related to mental health.

The program's goals include the following:

- Engaging, involving, and retaining consumers in network organizations.
- Fostering leadership and management skills for consumer network organizations.
- Strengthening organizational relationships and improving collaboration among consumers, families, advocates, providers, and administrators.
- Identifying technical assistance needs for the network organization, implementing strategies to meet those needs, and/or finding referrals to existing resources.

This is a newly established grant program that provides grantees a maximum of \$60,000 a year for 3 years. Twenty-four consumer networks in twenty-four different states have been funded. Further, each grantee will be linked to a CHMS funded consumer or consumer supporter technical assistance center in order to facilitate organizational capacity building and direct consumer participation.

Contact Information:

Neal Brown
Center for Mental Health Services
Substance Abuse and Mental Health Services Administration
5600 Fishers Lane, Room 11C-26
Rockville, MD 20587
(301)443-3653

TECHNICAL ASSISTANCE CENTERS RELATED TO CONSUMERS OF MENTAL HEALTH SERVICES

Funding Organization:

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services

Purpose:

The following Technical Assistance Centers provide an array of services related to consumers of mental health services that may include technical assistance, information and referrals, on-site consultation, training, library services, publications, annotated bibliographies, and other resources. Many services are available free of charge, but in some cases, charges may apply.

- Consumer Organization and Networking Technical Assistance Center (CONTAC)
 - Resource center for consumers/survivors/ex-patients and consumer-run organizations across the United States
 - Services include materials development and dissemination, training, skill development, interactive communication opportunities, networking, and other activities to promote self-help, recovery, and empowerment
 - Technical assistance to organizations in identifying and exemplifying points of entry into consumer programs
 - Outcome orientation for non-traditional services
 - Leadership and organizational development
 - Information sharing through a national web network
- National Consumer Supporter Technical Assistance Center
 - Information and referrals
 - Technical assistance on site and by phone
 - Resource library
 - Coordination of local coalitions
 - Training conference
- National Empowerment Center
 - Consumer technical assistance center
 - National directory of mutual support groups, drop-in centers, and Statewide organizations
 - Networking and coalition-building
 - Workshops, public speaking, and training to providers
- National Mental Health Consumers' Self-Help Clearinghouse
 - Consumer information and referrals
 - On-site consultation

- Training events
- Teleconferences and national conferences
- Consumer library
- Newsletter
- Consumer and consumer-supported nationwide database
- National Programs for Assertive Community Treatment (PACT) Center
 - Technical assistance in developing programs of assertive community treatment
 - Teleconferences on various aspects of PACT program planning and implementation
 - Information dissemination via mail and a web site

Contact Information:

Consumer Organization and Networking Technical Assistance Center
 West Virginia Mental Health Consumers Association
 1036 Quarrier Street, Suite 208A
 Charleston, WV 25301
 (888)825-8324/(304)346-9992
 URL: <http://www.contac.org>

National Consumer Supporter Technical Assistance Center
 National Mental Health Association
 1021 Prince Street
 Alexandria, VA 22314-2971
 (800)969-6642
 URL: <http://www.ncstac.org/>

National Empowerment Center
 599 Canal Street
 Lawrence, MA 01840
 (800)769-3728
 URL: <http://www.Power2u.org>

National Mental Health Consumers' Self-Help Clearinghouse
 1211 Chestnut Street, Suite 1207
 Philadelphia, PA 19107
 (800)553-4539
 URL: <http://www.mhselfhelp.org>

National Programs for Assertive Community Treatment Center
National Alliance for the Mentally Ill
Colonial Place Three
2107 Wilson Boulevard, Suite 300
Arlington, VA 22201
(703)524-7600
URL: <http://www.nami.org/about/pact.htm>

CENTER FOR PSYCHIATRIC REHABILITATION

Funding Organization:

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services
Department of Education, National Institute on Disability and Rehabilitation Research

Purpose:

The Research and Training Center at Boston University's Center for Psychiatric Rehabilitation (RTC) is a 5-year grant specifically designed to investigate the correlates of functional recovery and employment outcomes for persons with psychiatric disabilities. The overall research mission of the RTC is to develop and evaluate new knowledge for the field of psychiatric rehabilitation in order to help persons with long-term mental illness in their recovery process. The priorities for RTC include discovering facilitators and barriers to recovery, and specifically, the environmental and individual factors that impact on recovery, as well as examining traditional and alternative interventions that may promote recovery. Research staff in the RTC at the Center for Psychiatric Rehabilitation design and conduct research and evaluation studies and provide technical assistance to researchers across the country and internationally.

Contact Information:

William Anthony
Boston University Center for Psychiatric Rehabilitation
940 Commonwealth Avenue, West
Boston, MA 02215
(617)353-3549
URL: <http://www.bu.edu/sarpsych>

TECHNICAL ASSISTANCE CENTER FOR THE EVALUATION OF ADULT MENTAL HEALTH SYSTEMS CHANGE

Funding Organization:

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services

Purpose:

The purpose of this technical assistance (TA) center is to assist State and public and private non-profit entities in conducting evaluations of programs and systems and in using the results of evaluations, CMHS knowledge development activities, and mental health services research to improve the planning, development, and operation of adult mental health services provided under the Community Mental Health Services Block Grant. The Evaluation TA Center program was first begun in 1993, and Human Services Research Institute (HSRI) was awarded two previous 3-year cooperative agreements as part of the program.

To fulfill their goals, HSRI has organized the current Evaluation TA Center activities into 6 programs: Consultation, Toolkits and Materials, Multicultural Issues in Evaluation, Conference and Training, Topical Evaluation Networks, and Knowledge Assessment and Application. In order to assure that program activities are useful and in line with the priorities of the public mental health system, the Evaluation TA Center holds twice yearly meetings of a Steering Committee composed of national leaders of a variety of important stakeholder groups.

Some of the activities of the Evaluation TA Center include:

- Technical assistance to consumer groups to conduct (1) an evaluation of CMHS' Consumer Technical Assistance Centers and (2) development of recovery-oriented performance measures to be included on the Mental Health Statistics Program's Report Card for public mental health systems.
- Toolkits on how to (1) write and produce effective program manuals, (2) conduct performance improvement projects for behavioral health in managed care, (3) measure conformance to treatment guidelines, and (4) measure program fidelity.
- Management of four electronic discussion lists, with over 1000 members, about issues related to evaluation, and over 100 consultations to people or organizations in 29 States.

- Publications about evidence-based practices, use of consumer surveys and quality improvement ratings, and meta-analysis for synthesizing knowledge from multiple evaluations.

Contact Information:

Steven Leff
Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140
(617)876-0426
URL: <http://www.hsri.org/eval/eval.html>

NATIONAL GAINS CENTER FOR PEOPLE WITH CO-OCCURRING DISORDERS IN CONTACT WITH THE JUSTICE SYSTEM

Funding Organization:

Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services and Center for Substance Abuse Treatment

Purpose:

Since 1995, the National GAINS Center has functioned as the locus for the collection and dissemination of information on effective services for people with co-occurring mental health and substance use disorders in contact with the justice system. During its first years, the GAINS Center focused on helping the integration of local level treatment and criminal justice systems to improve service delivery for people with co-occurring mental health and substance use disorders. In particular, the GAINS Center achieved this through on-site technical assistance and sponsoring of Regional Forums. As the technical assistance center for the SAMHSA Jail Diversion Knowledge Development Application study, the GAINS Center helped many of the sites to develop their programs and promote their effective features. Over the years, the GAINS Center has accumulated vast knowledge of best practices programs and research to share with the field. One of the main outcomes from the first phase of the GAINS Center is the heightened awareness of and attention to the special needs of the co-occurring disorder population.

The role of the GAINS Center in its second phase is notably different in effecting change than it was during its first years. Instead of leading the field toward consensus on the importance of recognizing co-occurring disorders and the need for integrated treatment, the GAINS Center now finds itself partnering with national advocacy groups, professional membership associations and disciplinary associations to apply its accumulating knowledge base. The Center has been focused on aggressively compiling databases tracking jail diversion programs, mental health courts and other treatment programs throughout the USA. Through this, the Center has maximized its ability to provide essential information to national associations (e.g. Council of State Governments) engaged in processes for defining future policy directions for the field and to review and recommend model programs and promising practices. In addition, GAINS has continued its efforts at the local practice level, through the provision of technical assistance and sponsorship of Regional Forums.

Contact Information:

Henry Steadman
Policy Research Associates
345 Delaware Avenue
Delmar, NY 12054
(800)311-4246

CENTER FOR MENTAL HEALTH SERVICES KNOWLEDGE EXCHANGE NETWORK

Funding Organization:

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services

Purpose:

The federal Center for Mental Health Services (CMHS), a component of the Substance Abuse and Mental Health Services Administration (SAMHSA), developed the National Mental Health Services Knowledge Exchange Network (KEN) to improve access to mental health resources and information on the Internet, to provide referrals to local mental health services and facilities, and to build public awareness about CMHS efforts to improve the quality of the nations' mental health services.

The KEN web site features links to mental health resources on the Internet, A Newsroom of the latest mental health articles, an Anti-stigma section designed to dispel the myths, discrimination and stigma associated with mental illness, and a section featuring Spanish-language mental health publications. The KEN web site can be accessed on the Internet at <http://www.mentalhealth.org>.

The Knowledge Exchange Network also provides information about mental health via a toll-free telephone number (800-789-2647). The KEN staff are skilled at listening and responding to questions from the public and professionals. KEN staff quickly direct callers to Federal, State, and local organizations dedicated to treating and preventing mental illness.

Contact Information:

National Mental Health Services
Knowledge Exchange Network
P.O. Box 42490
Washington, DC 20015
(800)789-2647
URL: <http://www.mentalhealth.org>

NATIONAL RESEARCH AND TRAINING CENTER ON PSYCHIATRIC DISABILITY, UNIVERSITY OF ILLINOIS-CHICAGO

Funding Organization:

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services
Department of Education, National Institute on Disability and Rehabilitation Research

Purpose:

This is a five-year program of research, training, technical assistance, and dissemination activities designed to promote self-determination for people with psychiatric disability. The Center's overarching premise is that persons with psychiatric disability have the right to maximal independence, which grows out of making choices in the decisions that affect their lives. Center projects are comprised of five core areas: choice in treatment decision-making; economic self-sufficiency; consumer advocacy under managed care; career development through real jobs for real wages; and strengthening self-determination skills and self-advocacy. Project activities are implemented by multidisciplinary workgroups comprised of consumers, families, service providers, state agency administrators, nationally renowned researchers, and Center staff. Advanced technology is incorporated into each project's objectives and Center training and dissemination activities. The Center also provides training on psychiatric disability, research design and methodology, rehabilitation and recovery models, and consumer and family outcomes. Individualized technical assistance and training seminars are supplemented with instructional curricula, manuals, and software. Activities target rehabilitation and mental health professionals, consumers, families, psychiatrists/physicians, social workers, employers, co-workers, and educators.

Contact Information:

Judith Cook
National Research and Training Center on Psychiatric Disability
104 South Michigan Avenue, Suite 900
Chicago, IL 60603
(312)422-8180
URL: <http://www.psych.uic.edu/uicnrtc>

PRIMARY CARE RESEARCH IN SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES FOR THE ELDERLY

Funding Organization:

All three Substance Abuse and Mental Health Services Administration's Centers: Substance Abuse Treatment, Substance Abuse Prevention and Mental Health Services (CMHS), with CMHS as the lead
Department of Veterans Affairs
Health Resource Services Administration's Bureau of Primary Care
Centers for Medicaid and Medicare Services

Purpose:

Many older individuals experience serious mental health and substance abuse (MH/SA) problems that affect their quality of life as well as their ability to function independently in the community. Although prevalence rates vary in epidemiological studies among the elderly, it is clear that elderly individuals experience high rates of depression and anxiety disorders, as well as alcohol abuse and dependence. With the projected increase in the number of older Americans in the years to come, it is evident that both the clinical and policy communities need to be well-informed as to the nature and effectiveness of different service delivery models for treating mental health and substance abuse problems.

The study will identify differences in clinical and cost outcomes between models referring consumers to specialty mental health/substance abuse services outside the primary care setting and those providing such services within the primary care setting itself. The 4-year study plans to randomize close to 3,000 patients with MH/SA problems to either integrated or referral models of MH/SA care, with over 2,000 persons enrolled as of June 2001. Participants are assessed at baseline, 3 months, and 6 months to determine changes in clinical symptoms and functioning over the course of treatment. Patients are being enrolled from 11 sites, which represent roughly 50 clinical settings and include a variety of providers from managed care environments, community health clinics, VA facilities, and group practice settings. The study sites represent a rich diversity of ethnic/minority and rural/urban populations.

Harvard Medical School, Brigham & Women's Hospital, and John Snow, Inc. have joined together to serve as the Coordinating Center (CC) for this multi-site study. The Coordinating Center's role is multifaceted, providing leadership, administrative support, and technical expertise in the development and implementation of the multi-site protocol. The Coordinating Center is also taking the lead in designing and implementing the cost study portion of the study. In addition, the CC is responsible for collecting and analyzing clinical outcome and cost data, as well as descriptive data on the integrated and referral models of care.

Contact Information:

For more information visit the PRISMe web site at
<http://www.hms.harvard.edu/aging/mhsa>.

Center for Mental Health Services
Substance Abuse and Mental Health Services Administration
5600 Fishers Lane, Room 11C-26
Rockville, MD 20587
(301)443-3653

SAFE SCHOOLS/HEALTHY STUDENTS ACTION CENTER

Funding Organization:

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services
Department of Education
Department of Justice

Implementing Organization:

National Mental Health Association
National Association of School Psychologists

Purpose:

The Action Center seeks to help *Safe Schools/Healthy Students (SS/HS)* grantees fully attain their goals of interagency collaboration and adoption of evidence-based practices to reduce school violence and substance abuse and to promote healthy development and resilience among their children and youth. More than a generation of research provides a solid foundation of information pertaining to the multifaceted issues of school violence prevention and the enhancement of healthy development and resilience. Yet, the translation of scientific knowledge into everyday practice requires customized, ongoing, and accessible technical assistance. The SS/HS Action Center connects communities, local educational agencies and individual families with valuable resources and materials enabling them to promote collaborative efforts in enhancing resilience and preventing school violence.

The Action Center's technical assistance (TA) model includes (1) a national network of consultant/brokers who are assigned a specific number of grantees for the duration of the grants, (2) a consortium of subject experts who possess a broad range of knowledge that spans the programmatic goals of all grantees, and (3) an Internet web-based clearinghouse: *Practices and Resources Clearinghouse (PARC)*. Community Liaisons staff will process information and referral requests from the PARC and provide limited TA to SS/HS unfunded applicants who seek to maintain collaborative partnerships.

Contact Information:

Karen Francis
Safe Schools/Healthy Students Action Center
(703)837-3375
URL: <http://www.sshsac.org>

Gail Ritchie
Center for Mental Health Services
Substance Abuse and Mental Health Services Administration
5600 Fishers Lane, Room 11C-26
Rockville, MD 20587
(301)443-1752

WOMEN, VIOLENCE, AND CO-OCCURRING DISORDERS

Funding Organization:

Substance Abuse and Mental Health Services Administration

Purpose:

The Women, Violence, and Co-Occurring Disorders study addresses the psychological and emotional impacts of physical and/or sexual abuse in women who also have co-occurring mental health and substance abuse disorders. This study has been designed to address the following constituent issues that have been raised in the course of knowledge synthesis and planning: (1) the use of consumers as "experts" on defining needed services and their evaluation, and in all other phases of planning and implementation for this study; (2) methods of reducing the use of seclusion and restraint of these women in all human service program settings, not just in hospitals and jails; (3) humane and effective methods of intervention for cases of self-injury exhibited by these women in the course of treatment; and (4) further defining and expanding implementation of "trauma informed" services in the target organizations and in other human services organizations.

Funded in 1998 and set to conclude in 2003, this study addresses the psychological and emotional impacts of physical and/or sexual abuse in women who also have co-occurring mental health and substance abuse disorders. The study, with 9 sites plus a Coordinating Center that encompasses both data analysis and technical assistance responsibilities, has begun to delineate and examine community-based strategies to integrate the formerly separate treatment interventions for this target population. The study is also in the process of developing new knowledge regarding the feasibility and efficacy of combining trauma-specific intervention strategies with other services for women in an integrated intervention. There is also a children's sub-study comprised of 4 participating sites where the same combined services approach is being tailored to and tested on the children of the mothers in the study.

Contact Information:

Susan Salasin
Center for Mental Health Services
Substance Abuse and Mental Health Services Administration
5600 Fishers Lane, Room 11C-26
Rockville, MD 20587
(301)443-3653

COMMUNITY ACTION GRANTS FOR SERVICE SYSTEMS CHANGE

Funding Organization:

Substance Abuse and Mental Health Services Administration, Center for Mental Health Services

Purpose:

Community Action Grants support communities seeking to adopt exemplary practices into their systems of care for adults with serious mental illness and children with serious emotional disturbances. Grants fund community activities designed to build consensus around the adoption and implementation of an exemplary practice. Exemplary practices are determined by strict criteria that require the grantees to demonstrate that the proposed intervention has produced positive client-level outcomes in community or clinical settings.

The program incorporates two phases of support. *Phase I Grants* provide up to \$150,000 to support the consensus building process among key stakeholders in a community or state to adopt an evidenced-based exemplary practice. *Phase II Grants* provide a second year of funding (up to \$150,000) to support the implementation of the exemplary practice into the systems of care for the target population.

Since its inception in 1997, the Community Action Grant Program has supported over 130 Phase I and II grant activities as diverse as the adoption of effective approaches to case management, supported employment and education programs, education and empowerment of consumers and their families, prevention of inappropriate incarceration, integrated mental health/substance abuse treatment, outreach to homeless adults with mental illness, and prevention practices for racial and ethnic minorities. The Community Action Grant program has been the catalyst for the development of community partnerships and lasting systems change in a number of communities, cities, and states around the nation.

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CDC TECHNICAL ASSISTANCE WITH ESTABLISHING STATE HEALTH DEPARTMENT DISABILITY AND HEALTH PROGRAMS

Funding Organization:

Centers for Disease Control, National Center on Birth Defects and Developmental Disabilities

Purpose:

The CDC provides technical assistance and funding to establish Disability and Health Programs within state departments of health.

In FY 2002 funds were made available to states for implementing projects to prevent secondary conditions and promote the health of people with disabilities. CDC currently funds 16 states under program announcement 02007 -- Washington, South Carolina, New York, North Carolina, New Mexico, Iowa, Arkansas, Massachusetts, Rhode Island, Oregon, California, Vermont, Montana, Illinois, Virginia, New Jersey. Level I projects focus on implementing health promotion programs targeting people with disabilities in the community. Level II projects focus on developing a state health plan that includes people with disabilities and planning health promotion interventions. Level III projects focus on developing state health department infrastructure and program planning to support a disability and health program. For example, North Carolina develops guidelines to removing barriers in the community such as those found in health clubs and fitness facilities, as well as health care facilities. The North Carolina guidelines will provide technical assistance to communities and residents with disabilities across the United States.

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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

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