

Home and Community-Based Services: Federal Funding to States.
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1. Introduction

This part of the PAS Center website reports ways in which states have obtained grant funding to reform Medicaid home and community-based services (HCBS). This report compliments information on Systems Change Grants ('Federal Systems Change Grants to States and Territories: 2001-2005') because it describes other funding opportunities for states from Federal sources, either within the Health and Human Services Department or in other Government departments. The funding mechanisms in this report either supplement home and community-based services (e.g., housing initiatives) or have been designed to support a specific population group (e.g., older people) to live in the community. Funding mechanisms that focus on other aspects of supporting people to live independently (e.g., employment) are not included in this report.

The support to facilitate community integration provided by Federal sources may pre-date the Supreme Court Olmstead ruling in 1999 (see 'Home and Community-Based Services: Introduction to Olmstead Lawsuits and Olmstead Plans') although there has been an increase in activity post-Olmstead, largely due to the establishment of the New Freedom Initiative in 2001 (see 'Federal Policy Context', below). Federal government departments are also providing assistance to states in other ways, such as technical assistance, training and information. The extent of federal support differs, so progress in areas which are important to community integration (e.g., transport), for population groups (e.g., people with mental illness) and across states differs. The National Council on Disability has criticized this variation in progress (Gran et al. 2003).

2. Federal Policy Context

On February 1 2001, President Bush announced 'The New Freedom Initiative' (NFI), a cross-governmental policy and funding initiative that aims to remove barriers to community living for people with disabilities and provide additional momentum to efforts to comply with the Americans with Disabilities Act (ADA). Later in 2001, President Bush signed an Executive Order that outlined the Government's commitment to community-based alternatives to institutional care for all people with disabilities (White House 2001). It directs Federal agencies to work with states to ensure compliance with the ADA integration mandate that was reinforced by the Olmstead ruling. Subsequently, all Federal Agencies submitted reports regarding their own compliance with the ruling (DHHS 2002).

There are several proposed pieces of Federal legislation which would affect HCBS provision. One of these is the Medicaid Community-Based Attendant Services and Supports Act (S.917/H.R.2032). Known as MiCASSA, this proposed legislation was re-introduced in 2003 after first being introduced before the Olmstead ruling in the 1990s. It

aims to eliminate the institutional bias in publicly funded LTC by requiring States to include community-based Personal Assistance Services in their Medicaid plans.

3. Department of Health and Human Services (DHHS)

The DHHS has different offices within it that are working to develop the community integration of people with disabilities. An Office of Disability was created in 2002 to help coordinate these efforts.^a

Although many people with disabilities receive HCBS through Medicaid (either under Medicaid waiver, State Plan Personal Care or Home Health programs) some also receive HCBS through Medicare. Some adaptations have been made to Medicare to help people remain in the community. For example in 2004, three states (MO, CO and MA) were awarded 2-year Medicare demonstration projects to allow a new definition of 'homebound' for people receiving home health benefits so that people with disabilities would not have limitation on the time they spent away from home (DHHS 2004).^b

3.1 DHHS: Center for Medicare and Medicaid Services (CMS)

CMS is the main agency supporting states to deliver LTC for people with disabilities. There are several ways CMS has promoted HCBS provision, including; new waiver programs (e.g., §1115 'Independence Plus' waivers), grants (e.g., Systems Change Grants), promulgating ideas and clarifying or amending policy (e.g., State Medicaid Directors letters).^c

Examples of federal policy change include those regarding Personal Assistance Retainers (PAR) and Targeted Case Management (TCM). States pay PARs to 'hold' HCBS for people who are temporarily placed in institutions. Until the policy change in 2000, retainers could only be paid for Medicaid recipients in institutions who were temporarily away from the facility. TCM is provided as part of Medicaid waiver programs and is designed to help people transition out of nursing homes. CMS changed its guidelines in 2000 to allow states to furnish Medicaid-eligible people with TCM during the last 180 days of their institutional stay in order to organize the community transition. Previously states could have provided this service but would not have received Federal funds for it. (Another type of case management, HCBS Case Management, can be provided for 180 days before a person moves out of an institution as part of a waiver program but federal funding is not available until the person leaves the institution) (CMS 2003).

3.1.1 CMS Policy Initiatives: Money Follows the Person

^a Office of Disability website is at: <http://www.hhs.gov/od/>

^b See Kaiser Commission on Medicaid & the Uninsured (2006) 'Medicare-Medicaid Policy Interactions' At: <http://www.kaiserfamilyfoundation.org/medicaid/7468.cfm>

^c CMS published a series of letters following the Olmstead ruling. These were published on January 14 2000, July 25 2000 (2 letters) and January 10 2001 (2 letters). Other relevant letters are State Medicaid Director Letter #02-008 May 9 2002, SMDL #03-006 July 14 2003 and SMDL #02-012 August 13 2003.

Money Follows the Person (MFP) describes methods for financing LTC that enable public funds to be used wherever a person receives services. It encapsulates the strategies states use to reduce bureaucratic barriers inhibiting the options for where people receive LTC and primarily describes the financial organization of moving people out of institutions. For example, funding can be transferred from nursing home care to HCBS waiver services when a person living in a nursing home funded by the state wishes to move to the community. MFP therefore describes systems that aim to be responsive to consumer need and preferences.

According to CMS, Money Follows the Person systems embrace “self-direction and consumer control” and are based on a “market-based approach that gives individuals more choice over the location and types of services they receive.” (CMS 2003a). CMS suggests that MFP systems tackle four issues; (1) access (e.g. people enter the LTC system through a single agency), (2) responsiveness, (3) quality and (4) co-ordination of funding streams so they appear seamless to consumers. MFP is associated with the concept of ‘rebalancing’ LTC, so that the bias towards institutional care is reduced.

CMS has encouraged states to rebalance LTC systems and enable money to follow the person through grants to states as well as making policy changes, providing guidance and proposing legislation. For example, recent CMS policy guidance advised on the main features of reformed LTC systems and highlighted examples of state innovation (in CA, ME and NV, CMS 2004). Nine states received ‘Money Follows the Person’ grants in 2003 and 7 states received similar ‘Rebalancing Initiative’ grants in 2004 (see the report ‘Federal Systems Change Grants to States and Territories: 2001-2005’). A recent study notes that states have used three strategies for rebalancing LTC; (1) legislative action (setting policy and creating budgetary mechanisms to enable money to move around); (2) market-based approaches (giving consumers more information to enable them to make their own choices, therefore creating increased demand for community services); and (3) fiscal and programmatic linkages (improving co-ordination between services and increasing community services). The report notes four states (MI, OR, WA and WI) have used these strategies to achieve a more balanced LTC system (Crisp et al 2003).

Texas is an example of a state that has developed MFP legislation to enable this type of systematic LTC reform. In response to Olmstead, the Texas Legislature added a rider to the state Appropriations Bill for the FY 2002-2003 biennium (Texas HHS 2002). The Rider states: “It is the intent of the legislature that as clients relocate from nursing facilities to community care services, funds will be transferred from Nursing Facilities to Community Care Services to cover the cost of the shift in services” (Klein et al 2004). Recipients of Medicaid-funded care in nursing facilities who are eligible for the state Medicaid Community Care program are covered by this clause and can transition into the community without joining waitlists for the HCBS program. The state housing department supported this by setting aside 35 Section 8 housing vouchers, funded through the Federal Project Access grant program (see housing section below). Since 2003, over 2000 people have moved out of facilities under the Rider. Other states have used legislation to ‘rebalance’ their LTC system (e.g., UT, VT, MO, MD, NV and ND).

MFP is included within the ‘New Freedom Initiative Medicaid Demonstration Act of 2003’ (‘Money Follows the Person Rebalancing Initiative’) proposed by the President. The Act proposes \$1.75 billion over five years (\$350 million per year between 2004 and 2008) for competitive grants to states in order to increase the proportion and total amount of Medicaid funds for HCBS (CMS 2003b). These grants would reimburse states for one year of Medicaid services for people who move from institutions into the community. After then, states would continue care at the regular Medicaid matching rate.

Another federal legislative proposal is the ‘Money Follows the Person Act’ (S.1394). It was proposed around the same time as the ‘NFI Medicaid Demonstration Act’. However this Act concentrates exclusively on the concept of MFP, it proposes financial incentives for states to balance LTC systems as well as a grant scheme for states.

Currently the MFP “rebalancing” initiative was included in the Deficit Reduction Act of 2005 and implemented by CMS. CMS recently announced seventeen states will receive more than \$23 million in grants and up to \$900 million for demonstration programs for FY 07 (CMS 2007). These grants will help these states (AR, AZ, CT, IA, IN, MD, MI, MO, NE, NH, NY, OH, OK, SC, TX, WA and WI) offer greater choices and more benefits in their long-term care programs.

3.1.2 Other CMS Initiatives: Workforce and Employment

CMS organizes projects to support people with disabilities to join or re-join the workforce. These initiatives (which include grants such as Medicaid Infrastructure Grants) are part of the Ticket to Work and Work Incentives Improvement Act (1999) and are described elsewhere on the PAS Center website.

CMS also has an initiative to develop the long-term care workforce called the ‘Demonstration to Improve the Direct Service Community Workforce’. This competitive grant program for states was launched in 2003 and aims to help states to increase the pool of direct care service workers through recruitment and retention strategies (Federal Register 2004). Five grants were awarded for FY 2003 and a further five for FY 2004 (DHHS 2003).^d This scheme complements the Robert Wood Johnson Foundation’s program ‘Better Jobs, Better Care’ (CMS 2003c). More information about federal and state initiatives regarding the Direct Care Workforce are available from the Direct Care Clearinghouse.^e

3.2 DHHS: Administration on Aging

The Older Americans Act (OAA) is an important mechanism for providing HCBS for older people and their families, and was first enacted in 1965 and covers 50 states (plus D.C. and 5 territories) and has the broad aim of ensuring the well being of older people. Title III sets the structure for financing and delivering HCBS for older people and is the

^d In FY03, \$1.4 million each was awarded to NM, ME & NC. \$680,000 each was awarded to the University of Delaware & Volunteers of America (LA). In FY04, \$1.4 million was awarded to Bridges Inc. (IN), Home Care Quality Authority (WA), VA Dept of Medical Assistance Services. \$680,000 each was awarded to Seven Counties Services Inc (KY) & AR Human Services.

^e <http://www.directcareclearinghouse.org>

largest program under the OAA. Whilst funding for the OAA is small compared to the major source of LTC funding (Medicaid) it provides a safety net for people who might otherwise “fall through the cracks” in LTC provision because their income is too large to be Medicaid eligible but they require non-Medical support (Kassner 2001).

OAA Title III is split into 5 parts which; (1) set the formula by which funds are allocated to states, (2) provide Supportive Services and Senior Centers (including LTC, healthcare, transport, I&A, housing, legal assistance), (3) provide nutrition programs for homebound older people and those in congregate settings (e.g. senior centers), (4) concern health promotion and illness prevention, and (5) establish the National Family Caregiver Support Program (part 5 was added in 2000) (AoA, 2006).

Unlike Medicaid HCBS waivers, states do not have to apply to receive funding, Title III funds are primarily allocated according to the number of people aged 60+ in each state and all people 60 years of age and older are eligible for OAA services. Exceptions to this age limit are the Senior Community Service Employment program (this offers part-or full-time employment to low-income persons who are 55 years of age or older) and the National Family Caregiver Support Program funds (these are allocated through a formula based on the proportion of the state population who is 70 or older) (AoA 2006a).

States participating in Title III are required to set up a State Unit on Aging (SUA) to develop a 2-4 year statewide aging plan covering OAA programs. Many states have divided the state into local Area Agencies on Aging (AAAs) to administer OAA programs (13 states and Territories have single planning areas - there are 56 SUAs and 655 AAAs). The SUA develops an intrastate formula for allocating funds to AAAs to reflect local demographics. AAAs assess the needs of older people (preference is given to older people with greatest economic and social need) and are expected to spend at least some funds on; (1) access (transport, outreach, I&A, and case management), (2) in-home services (homemaker, home health aide, chore and supportive services) and (3) legal assistance. In many cases, AAAs subcontract with provider organizations and do not provide direct services.

Means tests cannot be used for any services under Title III but service providers can develop a suggested contribution schedule although services cannot be denied because older people cannot or will not contribute to the cost. States set their own eligibility criteria, however there are some restrictions on the criteria: (1) SUAs cannot include a means test in the state eligibility criteria for in-home services (economic need is assessed using the federal poverty guidelines); and (2) they are required to prioritize people 60 or over who are frail (have a physical or mental disability, Alzheimer’s disease or a related disorder which restricts normal daily tasks) and/or homebound due to illness or disability.

Title III funds are intended to be a catalyst bringing together public and private resources in the community. All services are required to be statewide and the non-Federal share of the funding should not be less than 15 percent (match-funding requirements for AAAs are determined by SUAs). Each state is required to spend at least the average amount of state funds it spent over the last 3 years to avoid a state allotment reduction. A recent

study suggests federally appropriated OAA funding has “increased slightly each year but has not kept pace with inflation and the growth of the older population” (Kassner 2001).

3.2.1 Title III funded HCBS: Table of State expenditure.

The OAA requires states to submit annual State Program Reports (SPRs) to the AoA. These reports contain information on expenditures for 14 services (including personal care) by client group served and services provided which are funded wholly or partly by OAA. Table 1 presents the data published for HCBS funded under Title III in 2005 by state. It shows that Pennsylvania had the largest total expenditure on personal care through the OAA (\$39.7 million in 2005) and served the most people (17,419 people). It is important to note that a state’s total expenditure on these services may include funds from other sources (including state and other federal sources). National Family Caregivers Support Program expenditures are not included in this table but are described below.

3.2.2 OAA Title III funded HCBS: The National Family Caregivers Support Program

Authorized until FY 2005 under the Older Americans Amendments Act 2000, this program aims to stimulate state innovation in assisting families and informal caregivers of older people and seniors who are caregivers (DHHS 2001). The program has provided over \$400 million to states and territories since 2001. The Act also established a Native American Caregiver Support Program.

Funds are allocated to SUAs using a formula based on the state’s proportion of the population who are 70+ years old and are intended to provide direct services to support family caregivers of older adults (and grandparents and relative caregivers of children). Funds must provide five services; (1) information, (2) assistance in accessing services, (3) individual support (e.g. counseling and support groups), (4) respite and (5) supplementary care (Family Caregiver Alliance 2006b). There is also a competitive grant program for demonstration projects on systems development, service components, links to special populations and new approaches to support. There are also grants for national projects that contribute to and support state level activities (AoA 2004).^f

Several studies have examined the impact of the NFCSP on state caregiver support systems (Friss Feinberg et al. 2002, 2004). Findings include that the design and administration of programs varies between and within states, although most HCBS programs are administered by SUAs and are available statewide. 36 percent of states began providing support to caregivers for the first time as a result of NFCSP funds although most state programs have multiple funding sources, the four main sources being; state general funds, NFCSP, HCBS waivers and client contributions. Limited funding, lack of coordination with other HCBS programs and workforce shortages were identified as major barriers to services, with NFCSP funding too low to meet the varied needs of caregivers.

^f 11 projects were awarded grants of between \$150,000 & \$192,000 in 2002. AoA (Sept 2002) Press Release: ‘HHS Awards \$7 million for innovative projects to support family caregivers’

3.2.3 OAA Title IV funded HCBS: Naturally Occurring Retirement Communities

Authorized under Title IV of the OAA (Training, Research, and Discretionary Projects & Programs), the Naturally Occurring Retirement Communities (NORC) grant program aims to help organizations within states to evaluate new methods for assisting older people who have ‘aged in place’ (rather than moved to senior housing) to remain in the community and avoid unnecessary institutionalization. In common with the prevention program (see below) the focus is on access to and links between services that sustain older peoples’ independence. The program aims to ensure older people (aged 60 or over) can access comprehensive support and healthcare services, including; on-site assessments, information and education, referral services, case management, counseling, transport, shopping, financial management, recreation and socialization programs. Healthcare services may include nursing, health screening, in-home assessment, medication management and physician home visits.

Total value of grants awarded: \$3.7 million (FY 2002), \$5.6 million (FY 2003), \$5.1 million (FY 2004) (AoA 2002, 2003a, 2004).

Approximate amount of award: \$150,000-\$400,000 (per year)

Duration of the grant: at least 12 months

Organizations permitted to apply: Service organizations within States

Number of grant recipients: 22 (16 new in 2004, 6 continuations).

3.2.4 Alzheimer’s Disease Demonstration Grants to States

The Alzheimer’s Disease Demonstration Grants to States Program (ADDG) was established under the Public Health Service Act and the Health Professions Education Partnerships Act of 1998 (AoA 2006c). The program aims to improve HCBS for people with Alzheimer’s disease or related disorders, their families and caregivers.⁸ The grants have been awarded for some time, most recently offered in FY 2005. Two new requirements were added in 2004 to ensure that; (a) grant recipients link ADDG funded activities to other state LTC systems change efforts and (b) all project proposals were based on research. The current recipients of these grants are shown on Table 1.

Total value of grants awarded: \$8 million (FY01), \$12 million (FY03), \$6.8 million (FY04), \$10.5 million (FY05).

Approximate amount of award: \$150,000-\$400,000 (per year)

Duration of the grant: Mostly 3 years. (2 states received a one-year grant in FY 2004) (DHHS 2004a).

Organizations permitted to apply: State governments.

Number of grant recipients: 48 (10 new awards in 2005) (AoA 2005).

Additional information: States are required to provide cash or in-kind contribution equal to at least 25% of the total project cost in the first year, 35% of the cost in the second year and 45% in the third year (Federal Register 2004a).

⁸ The program has a website, <http://www.aoa.gov/alz>

3.2.5 Evidence-Based Disease Prevention Program

Launched in 2003, this grant program is run by the AoA jointly with the Robert Wood Johnson Foundation, the John Hartford Foundation and the Horizon Foundation. AoA provided \$6 million over 3 years to fund 13 local projects in 9 states (CA, CT, FL, ME, MI, NY, OR, PA, TX) and a national technical assistance center at the National Council on Aging. In September 2006, AoA awarded \$13 million to 16 states (CA, CO, FL, HI, IA, IL, MD, ME, NJ, NY, OH, OK, OR, SC, TX and WI) to improve the health and quality of life for older Americans (AoA 2006).

The program aims to test how recommendations from national research (e.g. from the Centers for Disease Control and Prevention, the Agency for Healthcare Research and Quality and the National Institute on Aging) can be used in practice through service provider organizations to help prevent disability in older people (e.g., through falls prevention and disease self-management).

3.2.6 Aging and Disability Resource Center Grants

CMS and AoA offered these competitive grants to states in 2003, 2004 and 2005. They aim to help states develop ‘one-stop shops’ at the community level to help people make informed decisions about their support options and provide a single point of entry to LTC. (See ‘Federal Systems Change Grants to States and Territories: 2001-2005’ for more information on these grants). As of August 2006, 63 ADRCs operated in 25 states (Lewin 2006).

Total value of grants awarded: \$4,910,790 (2003) \$8,970,493 (2004), \$14,836,177 (2005) (DHHS 2004b, 2005a)

Conditions of the grant: Activities must target the elderly and at least one other target population (such as people with serious mental illness).

Range of value of grants: \$200,000 - \$800,000

Duration of grant: up to 36 months

Organization permitted to apply: State agencies (SUAs and Medicaid agencies must be involved).

Number of grant recipients (states): 12 (2003), 12 (2004), 19 (2005)

Additional information: This program builds on models in Wisconsin and other states (Reinhard and Salmon 2001).^h

3.3 Health Resources and Services Administration (HRSA)

3.3.1 Traumatic Brain Injury (TBI) grants

This grant program is administered through the Maternal and Child Health Bureau in HRSA and was re-authorized in 1996 under the Children’s Health Act (HRSA 2002, 2004). The program aims to improve access, availability and appropriateness of health care and other services for individuals with traumatic brain injury (TBI) and their

^h The national technical assistance center is at: <http://www.adrc-tae.org>.

families. There are three categories of grants for state agencies (these cover planning, implementation and post-demonstration projects), as well as grants for Protection and Advocacy agencies. Since 1997, 51 States and Territories (including the District of Columbia) have received at least one grant and in FY 2005 TBI program funding was \$8.9 million (MCHB 2006). States have to provide 50 percent match funding for the grants (non-Federal contributions not less than \$1 for each \$2 of Federal funds provided).

TBI Planning Grants

Approximate amount of award: up to \$75,000

Duration of the grant: 2 years

Purpose of the grant: To assist the development of a TBI program infrastructure.

Organizations permitted to apply: State governments are the only eligible applicants

Number of grant recipients: Up to 7 states (FY 2004).

Additional information: States develop 4 elements of a TBI service system; (1) a lead Designated State Agency and a staff person responsible for State TBI activities, (2) a Statewide TBI Advisory Board, (3) a Statewide Resource/Needs Assessment, and (4) a Statewide plan for a comprehensive, community-based system.

TBI Implementation Grants

Approximate amount of award: up to \$200,000

Duration of the grant: 3 years

Purpose of the grant: To help states move toward a statewide system to ensure access to comprehensive coordinated TBI services

Organizations permitted to apply: State governments are the only eligible applicants

Number of grant recipients: Approximately 7 awards (FY 2004).

TBI Post Demonstration Grants

Financial Years awarded: FY 2004

Approximate amount of award: up to \$100,000

Duration of the grant: 1 year

Purpose of the grant: To address issues including capacity building initiatives in the system of community supports.

Organizations permitted to apply: State governments are the only eligible applicants

Number of grant recipients: 11 (FY 2004).

3.3.2 Medical Home for Children with Special Health Care Needs

Authorized under the Social Security Act, this is part of the NFI and is administered through the Maternal and Child Health Bureau in HRSA. It aims to help states develop and implement a plan for community services for children with special health care needs. Children with special health care needs have or are at risk of “a chronic physical, developmental, behavioral, or emotional condition” (MCHB 2004). The program funds: (1) a National Resource Center on Medical Homes for children with special healthcare needs (\$1million to the American Academy of Pediatrics), (2) four grants (in four different states) to support community primary care practices or networks in order to improve links to early intervention, child care, schools and community programs

(\$50,000-\$250,000), (3) a grant to promote partnerships between health services (University of Florida, approx. \$200,000) and (4) a 4 year grant for investigation into early identification and interventions for children with autism (\$200,000 to the University of Wisconsin) (HRSA 2004a, b)

3.4 Substance Abuse and Mental Health Services Administration (SAMHSA)

As part of the NFI, a national Commission on Mental Health was set up to examine the publicly and privately funded mental health system. The Commission's final report noted the complexity of services for people with mental illness and recommended fundamental changes in the way that mental health services are delivered to ensure consumer involvement, patient-centered care, and comprehensive state mental health plans (New Freedom Commission on Mental Health 2003).

Meanwhile, SAMHSA provides states with Mental Health Block Grants and has had a 'Community Action Grant' program since before 1999. This covers people with mental health problems or substance use problems. SAMHSA has also developed a networking resource (the 'Olmstead Community'ⁱ) to aid states in planning more community-integrated mental health services and has worked on a LTC policy academy for states with the AoA and the National Governor's Association (SAMHSA 2006). Recent CMS Systems Change Grants have focused on the needs of children with severe emotional disturbances and the transition between children's and adult mental health services. However, there is criticism of the pace of development of HCBS for people with mental illness despite state action following the 1999 Olmstead decision (Bazelon Center 2004).

3.5 Administration on Children and Families, Office of Community Services (OCS)

3.5.1 Social Services Block Grants

Authorized under a 1981 amendment of Title XX of the Social Security Act, Social Services Block Grant (SSBG) funds are allocated to all 50 states (plus D.C., PR, GU, AS, VI and MP). In fiscal year 2007 (OCS 2007), states and territories received grants each quarter amounting to \$1.7 billion. They aim to give states flexibility to furnish social services which focus on at least one of five goals, these are:

- (1) Achieving or maintaining economic self-support to prevent, reduce or eliminate dependency;
- (2) Achieving or maintaining self-sufficiency, including reduction or prevention of dependency;
- (3) Preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interest, or preserving, rehabilitating or reuniting families;
- (4) Preventing or reducing inappropriate institutional care by providing for community-based care, home-based care or other forms of less intensive care; and
- (5) Securing referral or admission for institutional care when other forms of care are not appropriate or providing services to individuals in institutions.

ⁱ <http://www.olmsteadcommunity.org>

Within limitations specified by the Social Security Act, states can determine what services are provided, the eligible categories and populations of adults and children, the geographic areas of the state in which each service will be provided, and who provides the services (this can include contracting with private organizations). Typical services funded with SSBG may include: daycare for children or adults, protective services for children or adults, special services to persons with disabilities, adoption, counseling, case management, family planning, health-related, transportation, foster care for children or adults, substance abuse, legal, housing, home-delivered meals, congregate meals, independent/transitional living, special services for youth, employment services or any other social services found necessary by the state for its population.

States must prepare an annual report on the activities carried out with the funds made available through this program. The report must be in such form and contain such information that it can determine the extent to which funds were spent in a manner consistent with the report of projected activities submitted prior to funding. Each year States must submit a report on the intended use of funds under this Block Grant. Prior to December 1 of each fiscal year, OCS publishes a notification of allotment for States to facilitate State planning and preparation of their required reports. The total SSBG allocations for each state are published by the OCS online (OCS 2006).

4. Department of Veterans Affairs (VA)

The VA funds HCBS and institutional LTC. For example, the Aid and Attendance (A&A) allowance can be used to buy home-based care. However, the VA does not monitor the use of the A&A allowance, taking the position that it has no authority to tell veterans how to use the benefit (GAO 1998). Overall, VA expenditures on LTC were approximately \$3 billion in 2002, with \$92 million spent on HCBS (VA 2006). The number of patients the VA reported under non-institutional long-term care was 29,496 in FY 2006 (VA 2006a).

5. Department of Transportation

Transport is acknowledged as vital to the successful integration of people with disabilities. The funding and support available to states from the Department has been limited though, as no new funds were appropriated by the Department of Transport to develop programs for people with disabilities. Nevertheless, some assistance has been provided through the “United We Ride” program that assists in the coordination of human service transport through technical assistance, information dissemination, learning opportunities and small grants. There is also a federal Community-Based Transportation Planning Grant program to help communities create stakeholder partnerships and plans to expand transport for people with disabilities.

6. Department of Housing and Urban Development (HUD)

HUD has specific information for people with disabilities about housing initiatives including programs to ensure accessibility (HUD 2005). HUD has three competitive grant

programs specifically aimed at helping people with disabilities. These are: (1) mainstream housing for people with disabilities, (2) rental assistance for non-elderly people with disabilities related to certain developments, and (3) rental assistance for non-elderly people with disabilities in support of designated housing plans (Gran et al 2003, HUD 2006) There are also housing programs for low and moderate income persons with disabilities in rural areas (USDA 2006).

Housing and related expenses are critical for people who transition out of institutions and CMS has clarified policy for Medicaid beneficiaries moving out of institutions into community housing, as Medicaid cannot cover rent but states can use federal matching funds for Community Transition Services (under HCBS waivers) for one-off expenses (e.g. furniture or utility set-up fees) (CMS 2002). In terms of support to help people with disabilities remain in the community, HUD provided \$30 million of grants in FY 2003 to provide Service Coordinators in federally supported housing for low-income seniors and people with disabilities. These coordinators help residents to access services (e.g., health care and meals). HUD recommended that grantees of Community Development Block Grants should consider the needs of people with disabilities when preparing their consolidated plans and must identify its population of people with disabilities (HUD 2005a). However, the National Council on Disability has recommended more housing initiatives be developed, e.g., to help offset one-time costs people incur (Gran et al 2003).

6.1 Project Access

Established in 2001, this pilot program aims to help nursing home residents move to community-based settings. It is a joint venture between CMS and HUD whereby states are encouraged to apply for section 8 housing vouchers when applying for a nursing home transition grant. The program is limited to people living in nursing homes who are under 65. The Section 8 rental vouchers awarded are in addition to those vouchers awarded to Public Housing Authorities (PHA) as part of their strategic plan. In 2001, HUD made 400 vouchers available to 11 states, with the prediction that this figure would rise to up to 2000 over the project duration (HUD 2001).^j

6.2 Homeownership Voucher Program (HUD 2006a)

Launched in 2001, this pilot supports families with members with disabilities to buy a home by helping them use Section 8 housing vouchers to buy a home without paying more than 30 percent of their income. Eligible families are those whose incomes are up to 99 percent of the area median and who do not own their own home. The family minimum income requirement is an annual household income of at least \$10,000 (welfare income may be counted). The program is administered through local PHAs that participate in the Section 8 program although each family is responsible for obtaining the mortgage required. If a family defaults on the mortgage, they may be permitted to move to a new unit with continued homeownership assistance if the default was due to medical reasons.

^j Grantees; CO, FL, PA, MI, NH, NJ, NM, OK, OR, TX & WA. NM, OK, OR did not get CMS nursing facility transition grants.

6.3 Housing and Service co-ordination

\$30 million in grants was awarded to states in FY 2003 to provide Service Coordinators in federally supported housing for low-income seniors and people with disabilities. Coordinators help residents access services which enable them to remain in the community.

6.4 Support for people who are homeless

HUD, HHS and the VA developed a \$35 million initiative in 2003 to fund 11 grants for three years to provide services and permanent housing to chronically homeless people with disabilities.

6.5 Home Modification Grants

Through the federal Faith-Based and Community Initiative in the Office of Disability Employment Policy, working with HUD and the Corporation for National and Community Service, a total of \$700,000 was awarded in 2003 to local faith-based and community organizations. The 8 grants aim to enable organizations to support people with disabilities to remain in their home or to move into accessible homes through making modifications (Federal Register 2003).

6.6 Resident Opportunities and Self Sufficiency (ROSS) Elderly/Persons with Disabilities Program

HUD announced in January 2007 the award of \$8,796,564 in grants to 32 public housing agencies and non-profit organizations that provide supportive services to elderly and disabled public housing residents (HUD 2007). These grants will enable these agencies and organizations to hire project coordinators to help disabled and elderly public housing residents connect with community services.

7. Department of Labor (DoL)

However, an example of activity undertaken by the Department of Labor that affects HCBS for people with disabilities is the 'Home Modification Grants' program. These grants were administered via the Faith-based and Community Initiative in collaboration with HUD and were awarded in 8 states to help local faith-based and community organizations assist individuals with disabilities to remain in their own homes (DoL 2003). More information on DoL initiatives can be found elsewhere on the PAS Center website.

References

- Administration on Aging (2002) Annual Report. At:
http://www.aoa.gov/about/annual_report/ar_facilitating.pdf
- Administration on Aging (2003) Annual Report. At:
http://www.aoa.gov/about/annual_report/ar_full.pdf
- Administration on Aging (2004) 'The OAA National Family Caregiver Support Program: Compassion in Action'.
- Administration on Aging (Sep 12 2003a) Press Release: 'AoA Awards \$5.6 Million to Support Community Services for Seniors in Naturally Occurring Retirement Communities in 12 Cities.'
- Administration on Aging (Sep 13 2004) Press Release: 'AoA Awards \$5.1 Million to Support Community Services for Seniors in Naturally Occurring Retirement Communities in 22 Cities & Counties.'
- Administration on Aging (2005) Press Release: 'HHS Awards \$10.5 Million for Alzheimer's Disease Demonstration Grants to States \$2.6 Million for Expansion of Program in Ten States.' July 11 2005.
- Administration on Aging and Centers for Medicare and Medicaid Services (2005a) 'New grants will help families in 19 states find needed long term care services.' Press Release, August 18, 2005.
- Administration on Aging (2006) Website: 'The Older Americans Act'. At:
http://www.aoa.gov/about/legbudg/oa/legbudg_oaa_2000_resources.asp. Also 'Older Americans Act: Title III Regulations.' At: http://www.aoa.gov/about/legbudg/oa/legbudg_oaa_title_iii_reg_pf.asp
- Administration on Aging (2006a) 'The Aging Network.' At:
<http://www.aoa.gov/prof/agingnet/napis/napis.asp>
- Administration on Aging (2006b) 'About National Family Caregiver Support Program'. At:
http://www.aoa.gov/prof/oaoprogram/caregiver/overview/overview_caregiver.asp
- Administration on Aging (2006c) 'About the Alzheimer's Demonstration Grant Program'
http://www.aoa.gov/alz/public/alzabout/aoa_fact_sheet.asp
- Administration on Aging (2006d) 'HHS Announces More than \$13 Million for Community Prevention Programs for Older Americans.' Press release, September 28, 2006. At:
http://www.aoa.gov/press/pr/2006/09_Sept/09_28_06.asp
- Bazelon Center for Mental Health Law (2004) News Release: 'Legal Advocate cites ongoing segregation on Eve of Olmstead Anniversary'. June 21 2004. <http://www.bazelon.org/newsroom/archive/2004/6-21-04olmstead.htm>
- Case, G, Day, N, Blakley, D (2004) 'Implementing Aging and Disability Resource Centers'. CMS Systems Change Conference Baltimore, Maryland.
- Centers for Medicaid and Medicare Services (2002) 'Dear State Medicaid Director' letter, May 9 2002 SMDL #02-008.
- Centers for Medicaid and Medicare Services (2003) 'Dear State Medicaid Director' letter, Olmstead Update No. 3. July 25, 2003.

Centers for Medicaid and Medicare Services (2003a) 'Dear State Medicaid Director' letter. September 2003.

Centers for Medicaid and Medicare Services (2003b) President will Propose \$1.75 billion program to help transition Americans with Disabilities from Institutions to Community Living. Press Release, January 2003. At: <http://www.hhs.gov/news/press/2003pres/20030123.html>

Centers for Medicaid and Medicare Services (2003c) Grant Solicitation: 'A Demonstration to Improve the Direct Service Community Workforce'. June 2003.

Centers for Medicaid and Medicare Services (2004) 'Dear State Medicaid Director' letter. August 2004, SMDL#04-005

Centers for Medicaid and Medicare Services (2007) 'Money Follows the Person Rebalancing Demonstration Awards.' Press release, January 12, 2007. At: <http://www.cms.hhs.gov/apps/media/press/release.asp?Counter=2074&intNumPerPage=10&checkDate=&checkKey=&srchType=&numDays=60&srchOpt=0&srchData=&keywordType=All&chkNewsType=1%2C+2%2C+3%2C+4%2C+5&intPage=&showAll=1&pYear=1&year=2007&desc=&cboOrder=date;>

Crisp, S; Eiken, S; Gerst, K & Justice, D (2003) Money Follows the Person and Balancing LTC Systems: state examples. Medstat.

Department of Agriculture (2006) 'Rural Development Housing & Community Facilities Programs' At: <http://www.rurdev.usda.gov/rhs/>

Department of Health and Human Services (2001) News Release 'HHS announces new grants to support family caregivers'. October 1.

Department of Health and Human Services (2002). 'Compilation of Individual Federal Agency Reports of Action to Eliminate Barriers and Promote Community Integration'.

Department of Health and Human Services (Oct 2003) News Release: 'HHS Launches Demonstration to Recruit and Retain Personal Assistance Workers to help people with disabilities'.

Department of Health and Human Services (June 3 2004) News Release 'HHS identifies States for Medicare demonstration of new, less restrictive homebound definition'.

Department of Health and Human Services (2004a) Press Release: 'HHS Awards \$6.78 Million to Expand Alzheimer's Disease Demonstration Programs.' July 8 2004

Department of Health and Human Services (2004b) News Release: 'HHS Awards Additional \$9 Million to Help States Develop Aging and Disability Resource Centers.' 16 April 2004

Department of Housing and Urban Development (2001) News Release: 'President's Executive Order Launches Independent Living and Homeownership program for disabled'. Jun 19 2001. HUD No.01-061

Department of Housing and Urban Development (2005) 'Information for People with Disabilities'. At: <http://www.hud.gov/groups/disabilities.cfm>

Department of Housing and Urban Development (2005a) 'implementing the New Freedom Initiative and involving Persons with Disabilities in the Preparation of the Consolidated Plan through Citizen Participation'. Notice CPD-05-03, June 6 2005.

Department of Housing and Urban Development (2006) 'Grants'. At: <http://www.hud.gov/grants/index.cfm>

Department of Housing and Urban Development (2006a) 'Homeownership Vouchers'. At: <http://www.hud.gov/offices/pih/programs/hcv/homeownership/index.cfm>

Department of Housing and Urban Development (2007) 'HUD Announces Nearly \$9 million to Assist Elderly, Disabled' Press release, January 18, 2007. At: <http://www.hud.gov/news/release.cfm?content=pr07-004.cfm>

Department of Labor (2003) 'Grants Awarded by the U.S. Department of Labor, Office of Disability Employment Policy'. At: <http://www.dol.gov/odep/media/press/recipe.htm>.

Department of Veterans Affairs, Veteran Data and Information (2006) 'FY 2002 Annual Accountability Report Statistical Appendix – VA Health Care Systemwide Obligations, FY 1996-2002'.

Department of Veterans Affairs (2006a) 'Fiscal Year 2006 Performance and Accountability Report.' At: <http://www.va.gov/budget/report/2006FullWeb.pdf>

Federal Register (2003) 'Home Modification Grants'. May 29, 2003. Vol.68, No.103. 32090-32106.

Federal Register (2004) Vol 69, no.76. Apr 20 2004 Notices, 21115. Program Announcement No. AOA-04-02.

Federal Register (2004a) Volume 69, no.104. Friday May 28 2004/Notices [CMS-2195-N].

Friss Feinberg, L; Newman, S & Van Steenberg, C (2002) Family Caregiver Support: policies, perceptions & practices in 10 states since passage of National Family Caregiver Support Program. Family Caregiver Alliance

Friss Feinberg L, Newman, S, Gray L & Kolb, K (2004) The State of the States in Family Caregiver Support: A 50 State Study. Family Caregiver Alliance, San Francisco.

General Accounting Office (1998). Consumer-Directed Personal Care Programs: Department of Veterans Affairs and Medicaid Experience. Letter B-278632, January 16.

Gran, J et al. (2003) 'Olmstead: Reclaiming Institutionalized Lives' National Council on Disability, Washington DC.

Health Resources and Services Administration (2002) Annual Report.

Health Resources and Services Administration (2004) News Release: 'HRSA Awards \$1.1Million to Improve Services for Traumatic Brain Injury.' Sept 1 2004.

Health Resources and Services Administration (2004a) 'HRSA Awards \$2.2million to provide Medical Homes for Children with Special Health Needs.' Jun 18 2004.

Health Resources and Services Administration (2004b) 'Medical Home for Children with Special Health Care Needs'. Program announcement number HRSA-04-056.

Kassner, E (2001) 'The Role of the Older Americans Act in providing long-term care'. Washington DC: AARP, Public Policy Institute

Klein, J; Walker, P; Feinstein, C; Margeson, P; & Lynn Jones, D (2004) Strategies and Challenges in Promoting Transitions from Nursing Facilities to the Community for Individuals with Disabilities: A Pilot Study of the Implementation of Rider 37 in Texas. Community Living Exchange Collaborative at ILRU.

Lewin Group (2006) The Aging and Disability Resource Center (ADRC) Demonstration Grant Initiative: Interim Outcomes Report. At:

http://www.adrc-tae.org/tiki-download_file.php?fileId=26100&PHPSESSID=b0e953d49efd7df0f192ebae530abc4d
Maternal and Child Health Bureau (2004) 'Medical Home for Children with Special Health Care Needs CFDA 93.110, HRSA-04-056 - Program Guidance Fiscal Year 2004'.

Maternal and Child Health Bureau (2006) TBI Program Information. At:
<http://www.mchb.hrsa.gov/programs/tbi.htm>

Office of Community Services (2003). Social Services Block Grant Program Annual Report 2003. U.S. Department of Health and Human Services, Administration for Children and Families. At:
<http://www.acf.hhs.gov/programs/ocs/ssbg/docs/ssbg03annlrpt.pdf>

Office of Community Services (2006) 'State Allocations' website. At:
<http://www.acf.hhs.gov/programs/ocs/ssbg/docs/allocs.html>

Office of Community Services (2007) 'FY 2007 SSBG Allocations' website. At:
<http://www.acf.hhs.gov/programs/ocs/ssbg/docs/esalloc07.html>

President's New Freedom Commission on Mental Health (2003) Achieving the Promise: Transforming Mental Health Care in America. At: <http://www.mentalhealthcommission.gov/reports/reports.htm>

Reinhard, Susan C. and Jennifer Salmon (2001) Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States. AARP Research Report. Washington DC: AARP. At:
http://assets.aarp.org/rgcenter/health/2001_12_maze.pdf

Substance Abuse and Mental Health Services Administration (2006) Older Adult Programs: Policy Academy on Rebalancing Long Term Care Systems toward Quality community Living and Healthy Aging. http://www.samhsa.gov/aging/age_01.aspx

Texas Health & Human Services Commission (2002) The Revised Texas Promoting Independence Plan. At: http://www.hhsc.state.tx.us/pubs/tpip02/02_12TPIPPrev.html. The Texas project was the subject of an ILRU webcast. A handout used during the webcast is available at:
<http://www.ilru.org/html/training/webcasts/handouts/2004/03-31-KleinKafka/TexasStudypdf.pdf>

White House (June 2001) Executive Order 13217: Community-based Alternatives for Individuals with Disabilities. At:
<http://www.hhs.gov/newfreedom/eo13217.html>