

Federal Systems Change Grants to States and Territories: 2001-2004.

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Introduction

This part of the PAS Center website provides state-by-state information on Federal Systems Change Grants (SCGs) to States and Territories for the period 2001-2004. The primary aim of the table and accompanying text is to provide a summary of information that is accessible to the public, consumers, advocates, researchers and professionals.

The table shows for each state, the dollar value of SCG awards by year. The accompanying text first introduces the SCG initiative and then provides for each of the 11 forms of SCG, comparative information concerning 7 issues: (1) financial years awarded, (2) total value of grants awarded by year, (3) duration of grant, (4) conditions of the grant (purpose, eligibility); (5) state recipients by year, (6) additional information, and (7) typical activities undertaken by states using this grant. The Appendix at the end of this report lists the SCGs awarded by year. Further information about activities in each state and specific grants are available from the sources and references provided in the text.

Background to Systems Change Grants

Services and supports to enable people with disabilities to live independently in the community vary greatly in scope and innovation across the states. States' efforts to develop these services have been influenced by many factors, including the Americans with Disabilities Act, the Supreme Court decision in the *Olmstead* case and the work of advocacy groups. Another key factor has been the provision of Federal grants to improve systems of support for people with disabilities.

On February 1 2001, President Bush announced 'The New Freedom Initiative' (NFI)ⁱ, a cross-governmental policy and funding program that aims to remove barriers to community living for people of all ages with disabilities and long-term illnesses. It also aims to provide additional momentum to efforts for compliance with the Americans with Disabilities Act (ADA)ⁱⁱ. Later in 2001, in response to the Supreme Court ruling in the *Olmstead* caseⁱⁱⁱ, President Bush signed an Executive Order^{iv} outlining the Government's commitment to ensuring community-based alternatives to institutions for all people with disabilities. It directed Federal agencies to work with States to ensure compliance with the *Olmstead* ruling. Subsequently, all Federal Agencies submitted reports regarding their own compliance with the ruling^v.

The Department of Health and Human Services (HHS) oversees many programs that aim to help people to live in the community. One of the key agencies within the HHS that has undertaken this work is the Center for Medicare and Medicaid Services (CMS). The CMS administers a grants scheme called 'Systems Change Grants'^{vi}. This scheme compliments the NFI. The grants offered are described in detail below.

Other agencies within the HHS also have grants programs that compliment the grants administered by the CMS. For example: the Administration on Aging (AOA)^{vii}, the Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HSRA)^{viii} and the Substance Abuse and Mental Health Services Administration (SAMHSA)^{ix}. Other Government Departments that provide grants to promote community integration are the Department of Housing and Urban Development (HUD)^x and the Department of Labor^{xi,xii}. Some of these grants are described separately in the ‘Federal Grants to States’ section of this website.

CMS Grants

The programs outlined here relate only to the support people get to live in the community, and not to other HHS schemes such as ‘Ticket to Work’ and ‘Medicaid Infrastructure Grants’ (described in the ‘Federal Grants to States’ section of this website)^{xiii}. Many people with disabilities receive community-based services furnished by states through Medicaid waivers. These waivers (e.g. research and demonstration programs such as Pharmacy Plus) may also facilitate the development of innovative services. In some cases (e.g. Independence Plus) grants were made available specifically to help states develop the waiver program. The waivers and research and demonstration program waivers are not included in the table or descriptions below. (Information on research and demonstration waivers are included in the ‘Promising Practices in State Waivers’ section of this website).

Systems Change Grants for Community Living (SCGCL).

The overall aim of this grant program is to enable children and adults who have disabilities or long-term illnesses to; live in the most integrated setting appropriate, have choices about where they live, their service providers and the way services are delivered to them. The grants are intended to develop service infrastructure, not primarily to provide direct services.

This group of competitive grants was first offered to all states by CMS for financial year (FY) 2001 following a solicitation for one-off starter grants earlier that year (a non-competitive application for \$50,000 per state)^{xiv}. Following a high response rate (161 applications from 48 states, the District of Columbia and 2 Territories) no new applications were accepted for FY 2002 and the CMS processed remaining applications from 2001 instead. The majority of awards in FY 2002 were new grants although supplemental awards were made to 5 recipients of FY 2001 ‘Real Choice’ grants and to the technical assistance programs grantees^{xv}. The structure of the FY2003 SCGCL program differed from previous years. Only one type of grant that had been offered previously (Community-Integrated PAS & Supports grant) was offered in that year, although similar types of technical assistance grants were offered (see appendix 1)^{xvi}.

Almost \$160 million in SCGCL grants has been awarded by the CMS since 2001^{xvii} (\$70 million in FY2001, \$55 million in FY2002^{xviii}). States were encouraged to apply for more than one type of grant although no State was permitted to have more than one grant type

per year^{xix}. All the grants encouraged consumer involvement in project design and implementation as well as the development of public-private partnerships^{xix}. Grant activities did not have to be statewide but had to focus on Medicaid-eligible populations and systems that support them^{xvi}.

Many of the grants compliment existing state efforts to develop community services for people with disabilities, including Medicaid HCBS waivers and *Olmstead* plans. There is variation between states in the way that grant-funded activities are targeted, some activities are statewide, whilst others focus on a specific geographic or population groups. Some states have linked the activities between Systems Change Grants as well as with activities funded by grants from other sources (including other Federal grants). It is important to recognize that the activities states are the way funding is categorized may mask the sorts of initiatives being developed. For example, Iowa is developing initiatives to facilitate people's transition into the community through a Real Choice grant, not a Nursing Facility Transition Grant^{xx}.

Details of the Systems Change grants are below. These grants are (1) administered by the CMS, (2) aim to promote the community integration of people with disabilities, and (3) offered in financial years after the *Olmstead* decision (1999). Information on the types of activity undertaken for those grants that were awarded in 2001 and 2002 is also given.

'Real Choice' Systems Change Grants (Real Choice)

Financial Years awarded: 2001, 2002 (also "starter" grants in 2001).

Total value of grants awarded: \$40,819,854 (FY01), \$35,604,143 (FY02)

Range of value of grants: \$673,000 - \$2,300,000 (most were around \$1,300,000).

Duration of grant: 36 months^{xix}

Purpose of the grant: To help states work in partnership with communities to expand and improve community-based long- term care systems^{xix}.

Organization permitted to apply: States and territories agencies, with the support and active participation of either: (a) the Governor, State Medicaid Agency, or (b) the agency administering the 1915(c) HCBS waiver^{xix}.

Number of grant recipients (states): 25 (FY01), 25 (FY02, plus 5 supplementary awards to FY01 recipients)

Additional information: Congress expressed the preference that State and Consumer Task Forces should jointly develop the applications^{xix}. Starter grants were worth \$50,000 per state and expected to last 3-6 months.

Typical activities undertaken by states using this grant^{xx}:

Activities undertaken using grants awarded in this category are commonly closely related to the state *Olmstead* response activity. Many of the grants are used to develop single point of entry systems and to improve existing home and community-based service delivery, including waiver programs and improved housing options.

- Single point of entry systems. (E.g. in Florida, the development of statewide Clearinghouse on Disability Information, a web-based information system in Hawaii).
- Improved partnerships between providers and services, including the coordination of care. (E.g. a review of Maine's PAS policies and the development of interdepartmental quality improvement, the integration of funding models in

Massachusetts and the development of a policy center in New Hampshire to review laws and regulations that create barriers to community integration).

- Consumer-directed long-term care initiatives. (E.g. in North Carolina, the development of a consumer-directed care model).
- Eligibility determination and assessment. (E.g. develop a format and procedural guidelines for developing person-centered plans in Illinois).
- Information for consumers. (E.g. the development of an Information, Referral and Assistance model in Minnesota).
- Involvement of consumers in planning and evaluation of services. (E.g. the development of a consumer satisfaction tool in Michigan).
- Needs assessment. (E.g. a needs and resources assessment in Idaho, leading to a plan for change).
- Workforce initiatives. (E.g. Arkansas proposed the development of a worker registry and strategies to recruit and retain in-home workers (including the establishment of a career path). Maine proposed the development of a direct worker's Guild and Kentucky aimed to develop a curricula and standards for staff).
- Tests on new methods of providing support and delivering services. (E.g. increasing access to Assistive Technology in Delaware).

Community-Integrated Personal Assistance Services and Supports Grants (CPASS)

Financial Years awarded: 2001, 2002, 2003

Total value of grants awarded: \$7,551,690 (FY01), \$5,800,000 (FY02), \$4,537,084 (FY03)

Range of value of grants: \$300,000 - \$900,000 (most around \$700,000).

Duration of grant: 36 months^{xix}

Conditions of the grant: Only states that did not receive grants in FY01 or FY 02 were permitted to apply in FY03. Only up to 20% of the grant funds can be used for direct services^{xv}.

Purpose of the grant: to improve consumer-directed PAS and ensure PAS provide maximum consumer control^{xix}.

Organization permitted to apply: States and territories agencies or any other organization if they have the support and active participation of either the Governor, State Medicaid Agency or agency administering the 1915(c) HCBS waiver^{xix}.

Number of grant recipients (states): 10 (FY01), 8 (FY02), 8 (FY03)

Typical activities undertaken by states using this grant^{xxi}:

These grants are used primarily to develop consumer-directed PAS and single points of entry into the long-term care system. For some states, this involves quite dramatic changes to service delivery systems, leading to the need for building the capacity of services (e.g. in Alaska technical assistance for providers).

- Development or improvement of consumer directed PAS (e.g. the development of PAS for children in Rhode Island to extend the current waiver-based PAS for adults, the development of a database for tracking individual's budgets in Guam and the in Oklahoma, the development of an intermediary service in Centers for Independent Living to act as business agents for consumers with employer responsibilities).

- Workforce initiatives (such as recruitment, training, standards and competency tests for PAS workers. E.g. the reform of Nursing Practice Act language to enable the delegation of nursing tasks in Oklahoma).
- Training for PAS users and the creation of consumer information (e.g. the development of a website for consumers in Nevada).
- Needs assessment of people requiring PAS (e.g. a community services gap analysis in New Hampshire).
- Evaluation. (E.g. the evaluation of ‘client-directedness’ and independence outcomes in Colorado and the development of a peer evaluation project to look at consumer satisfaction with PAS in Nevada).

Nursing Facility Transitions, Independent Living Partnership Grants (NFT CIL)

Financial Years awarded: 2001, 2002

Total value of grants awarded: \$2,058,178 (FY01), \$1,807,500 (FY02)

Range of value of grants: \$270,000 - \$450,000

Duration of grant: 36 months^{xix}

Purpose of the grant: To promote partnerships between states and Independent Living Centers to support eligible individuals in making the transition from nursing facilities to the community^{xix}.

Organization permitted to apply: Independent Living Centers, with the support and participation of the State Medicaid agency (or agency administering a relevant section of the 1915(c) HCBS waiver) and at least 2 other consumer-governed organizations^{xix}.

Number of grant recipients (Centers for Independent Living): 5 (FY01), 5 (FY02)

Nursing Facility Transitions, State Program (NFTSP)

Financial Years awarded: 2001, 2002

Total value of grants awarded: \$9,028,889 (FY01), \$6,735,216 (FY02)

Range of value of grants: \$552,000 - \$800,000

Duration of grant: 36 months^{xix}

Purpose of the grant: To help individuals make the transition from nursing facilities to the community, a range of activity is permitted (e.g. the development of housing strategies).

Organization permitted to apply: States and territories agencies, with the support and active participation of either the Governor, State Medicaid Agency, or agency administering the 1915(c) HCBS waiver^{xix}.

Number of grant recipients (states): 12 (FY01), 11 (FY02)

Typical activities undertaken by states using Nursing Facility Transition grants^{xxii}.

The proposals in this grant category may include quantified outcomes, such as the number of nursing facility residents transitioned in the program (150 in the Connecticut State Program, 24 in Georgia). In several cases, the grants provide funding for additional staff to undertake the work.

- Information and outreach activities to nursing home residents (e.g. the development of a video, word board and picture book in the Colorado State Program, a toll-free phone line in West Virginia and in Birmingham Independent Living Center, Alabama the recruitment, training and supervision of peer outreach advocates).

- Identification and assessment of people living in nursing homes or who may need diversion from institutions (e.g. a worker to identify people who wish to live in the community in Delaware and the development of a comprehensive tool for targeting clients in South Carolina).
- Development of support systems for transitioning clients (e.g. the establishment of a 'Common Sense Fund' to pay for items not usually covered by Government programs, such as utility deposits in Connecticut, a similar proposal was put forward in North Carolina. Utah Center for Independent Living proposed a skill building program to prepare people for moving out of institutions).
- Increase community-housing capacity (e.g. the development of a 'Home Team' in Maryland to collaborate with housing authorities and providers).
- Feasibility Study Grants

Community-based treatment alternatives for children^{xv} (CTAC)

Financial Years awarded: 2003

Total value of grants awarded: \$592,421

Conditions of the grant: No grant funds to be used for direct services

Approximate value of individual grants: \$100,000

Duration of grant: up to 36 months

Purpose of the grant: to assist states in developing comprehensive, community-based mental health services through Medicaid for children with serious emotional disturbances who would otherwise require care in a Psychiatric Residential Treatment Facility (PRTF). The grants are intended to assist states in assessing community-based alternatives to residential treatment or institutionalization.

Organization permitted to apply: Any state agency.

Number of grant recipients (states): 6

Additional information: The rationale for these grants is that Medicaid currently provides inpatient psychiatric services for children under 21 in hospitals and extends Medicaid benefits to children in PRTFs despite the fact that PRTFs do not meet the CMS definition of hospitals. This means that although PRTFs are the primary providers of services for children with serious emotional disturbances, states have been unable to use the 1915(c) waiver authority to provide Medicaid funded home and community-based alternatives.

Respite for Children^{xv} (RFC)

Financial Years awarded: 2003

Total value of grants awarded: \$573,673

Conditions of the grant: No grant funds to be used for direct services

Approximate value of individual grants: \$100,000

Duration of grant: up to 36 months

Purpose of the grant: To enable states to conduct feasibility studies and explore the development of Medicaid respite projects for caregivers of children. These projects are expected to develop elements that are responsive to individual needs and offer the opportunity for consumer direction.

Organization permitted to apply: Any state agency

Number of grant recipients (states): 6

Additional information: The grants could be used to explore the development of services targeted specifically for caregivers of children with a particular condition, for example, children with physical disability or mental illness.

Respite for Adults^{xv} (RFA)

Financial Years awarded: 2003

Total value of grants awarded: \$348,139

Conditions of the grant: No grant funds to be used for direct services

Approximate value of individual grants: \$75,000 - 100,000

Duration of grant: up to 36 months

Purpose of the grant: To enable states to assess the feasibility of developing respite projects for caregivers of adults through Medicaid or similar funding streams. These projects are expected to develop elements that are responsive to individual needs and offer the opportunity for consumer direction.

Organization permitted to apply: Any state agency.

Number of grant recipients (states): 4

Additional information: The grants could be used to explore the development of services targeted specifically for caregivers of adults with a particular condition, for example, an adult with mental illness.

- Research and Demonstration Grants

Money Follows the Person^{xv} (MFP)

Financial Years awarded: 2003

Total value of grants awarded: \$6,527,102

Conditions of the grant: Only up to 10% of grant funds to be used for direct services.

Range of value of grants: \$600,000 - \$700,000

Duration of grant: up to 36 months

Purpose of the grant: To enable states to develop and implement strategies to reform the financing and service designs of state long-term care systems so that funding 'follows the person' and financing arrangements enable transition services for individuals between institutions and community settings.

Organization permitted to apply: State agencies

Number of grant recipients (states): 9

Quality Assurance and Improvement in HCBS^{xv} (QAQI)

Financial Years awarded: 2003

Total value of grants awarded: \$9,202,322

Conditions of the grant: Only up to 10% of grant funds to be used for direct services.

Range of value of grants: \$351,000 - \$500,000

Duration of grant: up to 36 months

Purpose of the grant: To assist states to (a) fulfill their commitment to assuring the health and welfare of individuals who participate in the state HCBS waiver program (b) develop systematic methods to meet statutory and CMS requirements by the use of ongoing quality improvement methods and (c) develop improved methods that involve individuals and community members in the quality assurance systems.

Organization permitted to apply: Any state agency.

Number of grant recipients (states): 19

Independence Plus Initiative^{xv} (IP)

Financial Years awarded: 2003

Total value of grants awarded: \$5,405,594

Conditions of the grant: Only up to 20% of grant funds to be used for direct services.

Range of value of grants: \$175,000 - \$500,000 (most around \$400,000 to \$500,000).

Duration of grant: up to 36 months

Purpose of the grant: This grant is intended as a catalyst for an existing waiver initiative. To assist states in meeting the federal expectations established by CMS for the approval of self-directed program waivers and demonstration projects within Independence Plus.

Organization permitted to apply: State agencies.

Number of grant recipients (states): 12

Additional information: The expectations are that Independence Plus waivers will include person-centered planning, individual budgeting, self-directed supports, quality assurance and improvement systems^{xxiii}. The aims of the Independence Plus initiative are similar to the Cash and Counseling project. Cash and Counseling is a national program sponsored by The Robert Wood Johnson Foundation, the Office of the Assistant Secretary for Planning and Evaluation in the United States Department of Health and Human Services and the Administration on Aging. The approach provides consumers with a flexible monthly allowance based on an individual budget that allows them to manage their own PAS. The CMS also reviews states' Section 1115 demonstration or 1915(c) waiver applications and provides technical assistance in the waiver process. Cash and Counseling Demonstration and Evaluation projects were carried out in Arkansas, Florida, and New Jersey and due to their success the program is being expanded to 10 additional states in 2004. Each state will receive up to \$250,000 over three years. Three of these states may receive an additional \$100,000 to expand the model.^{xxiv}

- Technical Assistance Grants

National Technical Assistance Exchange for Community living (FY01)^{xix} (CLEC)

Financial Years awarded: 2001, 2002 (to the same recipients in each year)

Total value of grants awarded: \$4,871,242 (FY01), \$3,773,000 (FY02)

Duration of grant: 36 months

Conditions of the grant: No funds may be paid as profit to the recipient organization.

Purpose of the grant: To provide technical assistance and training, and disseminate information to states, grantees, consumers and the public.

Organization permitted to apply: Any organization.

Number grants awarded: 2 (FY01), 2 (FY02 supplementary awards to FY01 recipients).

Additional information: This award was called the "Community Living Exchange Collaborative: A Technical Assistance Project" in FY02 but went to the same two organizations (Rutgers Center for State Health Policy and Independent Living Research Utilization) that were awarded grants in FY01 for the same activity.

(Note: This grant is not included on the table of state grants).

Technical Assistance for Consumer Task Forces^{xv} (TACTF)

Financial Years awarded: 2003

Total value of grants awarded: \$549,999

Duration of grant: 36 months

Conditions of the grant: Only available to organizations where at least half of the board of directors or controlling structure is made up of people with disabilities. Grant not to be used for direct services.

Purpose of the grant: To provide expanded technical assistance to the consumer task forces involved with the RCSCG program and ensure that consumers are involved with state planning and implementation of systems change.

Organization permitted to apply: Consortia of consumer-controlled organizations were only allowed to apply. Consumers are people with a disability or long-term illness.

Number grant recipients: 1

Additional Information: The Technical Assistance for Consumer Task Forces website: http://www.tilrc.org/real_choice/Real_Choice_Homepage.htm, linked to the Topeka Independent Living Resource Center <http://www.tilrc.org/>.

(**Note:** This grant is not included on the table of state grants).

National State-to-State Technical Assistance Program for Community Living^{xv} (STS)

Financial Years awarded: 2003

Total value of grants awarded: \$4,399,959

Duration of grant: 36 months

Conditions of the grant: Grant not to be used for direct services.

Purpose of the grant: To ensure that all FY2003 Systems Change grantees have adequate support (including the Technical Assistance for Consumer Task Forces grantee). This includes (a) providing on-site state-to-state assistance, (b) developing technical assistance materials, (c) working with individual states, national associations of state agencies, consumer organizations, the National Governor's Association and the NCSL to collect refine and disseminate information to aid the effective administration of programs for community living (d) provide and develop expertise for states and people with a disability (e) develop, collate and disseminate practical information.

Organization permitted to apply: Any organization or entity.

Number of grant recipients: 1

Additional information: Rutgers: The State University of New Jersey received this grant. This supplemented the work established by the University through the National Technical Assistance Exchange for Community Living grant (see above). (www.cshp.rutgers.edu).

(**Note:** This grant is not included on the table of state grants).

Family to Family Health Care Information and Education Centers^{xv} (FTF)

Financial Years awarded: 2003

Total value of grants awarded: \$1,342,963

Duration of grant: 36 months

Conditions of the grant: Endorsement from the State Medicaid Director or Governor. Existing Centers of this type (funded through the HRSA) were not eligible to apply. No funds available for direct services.

Purpose of the grant: To enable organizations to establish statewide family-run centers that (a) provide education and training opportunities for families with children with special health care needs (b) develop and disseminate health care and HCBS information to families and providers (c) collaborate with other Family-to-Family centers to benefit children with special health care needs and (d) promote the philosophy of individual and family-directed supports.

Organizations permitted to apply: Any non-profit organization.

Number of grant recipients (various organizations, not state agencies): 9 (approx. \$150,000 per state)

Additional information: The Health Resources and Services Administration collaborated with CMS to provide this grant.

Administration on Aging and CMS joint grant

Aging and Disability Resource Center Grants Program (ADRC)

Financial Years awarded: 2003, 2004^{xxv}

Total value of grants awarded: \$4,910,790 (2003) \$8,970,493 (2004)

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

Purpose of the grant: 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 long-term care services.

Organization permitted to apply: State agencies (state units on aging and Medicaid agencies must be involved).

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

Additional information: This program builds on models developed in Wisconsin and other states^{xxvi}. At a recent conference^{xxvii} two grant recipients (New Jersey and Montana) presented their progress so far in creating a single point of entry system. Montana has established a site in a mall for people to go to for information. New Jersey is working on streamlining services for adults and seniors by reforming long-term care financial eligibility and pre-admission screening structure as well as developing a management information system^{xxviii}.

Key Trends

All 51 states, the District of Columbia and 4 Territories (Guam, American Samoa, the Northern Mariana Islands and Puerto Rico) have received some Systems Change Grants in the time period 2001-2004. The total amounts awarded in grants vary from \$50,000 (a starter grant to American Samoa) to \$4,903,000 (the total for Michigan). Several states have been awarded 8 different sorts of grants (Maryland received 9 awards, but one of these was a supplemental 'Real Choice' grant award in 2002).

In total, 4 states and 2 territories received less than \$1 million (AS, AZ, ND, PR, SD, WY), 10 states received \$4 million or more in grants. 16 states received \$3 million or

more, 17 received \$2 million or more and 4 states and 2 territories received \$1 million or more in total grants.

Appendix 1 – Systems Change Grants (by year awarded)

FY2001

1. Real Choice
2. Community-integrated Personal Assistance Services and Supports
3. Nursing Facility Transition
 - (a). Independent Living
 - (b). State Programs
4. National Technical Assistance Exchange for Community Living Grant

FY2002

1. Real Choice
2. Community-integrated Personal Assistance Services and Supports
3. Nursing Facility Transition
 - (a). Independent Living
 - (b). State Programs
4. Technical Assistance Grant Exchange for Community Living Grant

FY2003

1. Feasibility Studies and Development Grants
 - (a) Respite for Adults
 - (b) Respite for Children
 - (c) Community-based Treatment Alternatives for Children
2. Research and Demonstration Grants
 - (a) Quality Assurance & Quality Improvement in HCBS
 - (b) Independence Plus
 - (c) Money Follows the Person
 - (d) Community-integrated Personal Assistance Services and Supports
3. Technical Assistance Grants
 - (a) National State to State Technical Assistance Program
 - (b) Technical Assistance for Consumer Task forces
 - (c) Family-to-Family Health Care Information and Education Centers.

ⁱ For more details on the New Freedom Initiative, go to <http://www.whitehouse.gov/infocus/newfreedom/> or <http://www.hhs.gov/newfreedom/>.

ⁱⁱ For further information on the Americans with Disabilities Act (1990), go to <http://www.ada.gov>.

ⁱⁱⁱ Olmstead v. L.C. (98-536) 527 U.S. 581 (1999), the Supreme Court ruling is available at: <http://supct.law.cornell.edu/supct/html/98-536.ZS.html>.

^{iv} Executive Order 13217: Community-based Alternatives for Individuals with Disabilities. (June 18 2001). Available at <http://www.whitehouse.gov/news/releases/2001/06/print/20010619.html>

^v Delivering on the Promise: A Compilation of Individual Federal Agency Reports of Action to Eliminate Barriers and Promote Community Integration. (<http://www.hhs.gov/newfreedom/final/>) This report covers the Departments of; Justice, Labor, Health & Human Services, Housing & Urban Development, Transport, Education and Veterans Affairs, as well as the Office of Personnel Management and the Social Security Administration.

^{vi} The first \$50 million Systems Change Grants proposal was under the Clinton administration and was secured following the efforts of lobbyists suggesting \$1 million per state for systems change (correspondence from Blue Ribbon Advisory Committee member, 24th April 2004).

^{vii} Administration on Aging grants which might support state's efforts to increase community integration include grants for; Home and Community-based Care, Alzheimer's Disease Research and Demonstrations, Caregiving, Family/informal caregiving and Informal caregiving. A compendium of grants awarded by the AoA in FY2002 is at: <http://www.aoa.gov/doingbus/comp/FY2002%20Compendium.pdf> most of these grants were awarded under the Older Americans Act.

^{viii} For several years, the HRSA has awarded grants for Traumatic Brain Injury (TBI) through the Maternal and Child Health Bureau. These grants aim to help states better plan their infrastructure for helping people who have sustained a TBI. Further information on these grants is available in the Federal Register/ volume 66, No.111/ Friday June 8, 2001/ Notices (page 30937), available at: <http://www.gpoaccess.gov/fr/index.html>

^{ix} SAMHSA have a 'Community Action Grant' program that has been running since before 1999. This program can cover people with mental health problems or people with substance use problems. SAMHSA has also developed a networking resource for states developing more integrated services for people with mental health problems. Further information about the 'Olmstead Community' is available at: (<http://www.olmsteadcommunity.org>).

^x Further information on the work of the HUD regarding the new Freedom Initiative is available at <http://www.hud.gov/groups/disabilities.cfm>.

^{xi} An example of the activities undertaken by the Department of Labor is the 'Home Modification Grants' which were administered via the Faith-based and Community Initiative in collaboration with the HUD. They were awarded to 8 states to help local faith-based and community organizations to assist individuals with disabilities to remain in their own homes. Further details are available from: <http://www.dol.gov/odep/media/press/recipe.htm>.

^{xii} The 2004 Progress Report on the New Freedom Initiative provides a summary of the activities of each of the key departments involved in ensuring compliance with the ADA. The report, The New Freedom Initiative: A Progress Report, March 2004 (by the White House Domestic Policy Council) is available at: <http://www.whitehouse.gov/infocus/newfreedom/newfreedom-report-2004.pdf>

^{xiii} For more information on 'Ticket to Work' and Medicaid Infrastructure Grants (FY2003), go to: <http://www.cms.hhs.gov/twwiia/default.asp>. For information on Direct Service Community Workforce Grants (FY2003), go to: <http://www.cms.hhs.gov/newfreedom/dsw03.pdf>

^{xiv} The Health Care Financing Administration (now known as the CMS) had administered a grant scheme in 1998, 1999 and 2000 that was a precursor to the larger Systems Change Grant program and gave awards to 12 states. The competitive grants aimed to foster state infrastructures to enable individuals to live in the community by either transitioning people out of nursing homes or diverting unnecessary nursing home admission. Texas, Michigan, Colorado and Rhode Island received \$187,500 each in what were called 'Date Certain Grants' in 1998. The grants were called 'Nursing Home Transition Grants' in 1999 and 2000 and focused entirely on moving people out of nursing homes. Awards in both years were approximately \$500,000 and went to New Jersey, Vermont, New Hampshire, Wisconsin (1999), Pennsylvania, Arkansas, Nebraska and Florida (2000). (Information from the CMS at: <http://www.cms.hhs.gov/medicaid/services/nhtgrant.asp>)

^{xv} Federal Register/ volume 68, No.104/ Friday May 30 2003/ Notices. Available at: <http://www.gpoaccess.gov/fr/index.html>

^{xvi} CMS (July 14 2003) Questions and Answers on the invitation to apply for "Real Choice Systems Change Grants for community Living" CFDA No.93.779.

^{xvii} The New Freedom Initiative: A Progress Report, March 2004 (p.5), The White Domestic Policy Council. Available at: <http://www.whitehouse.gov/infocus/newfreedom/newfreedom-report-2004.pdf>

^{xviii} Federal Register/volume 67, No.81/ Friday, April 26, 2002/ Notices. Available at: <http://www.gpoaccess.gov/fr/index.html>

^{xix} Federal Register/ volume 66, No. 99/ Tuesday May 22 2001/ Notices. Available at: <http://www.gpoaccess.gov/fr/index.html>

^{xx} Information regarding the grant activities in states is taken from the 2nd edition of the Compendium of the Systems change Grants for Community Living, CMS March 2003. Available at: http://www.cms.hhs.gov/systems_change/default.asp.

^{xxi} Information regarding the grant activities in states is taken from the 2nd edition of the Compendium of the Systems change Grants for Community Living, CMS March 2003. Available at:

http://www.cms.hhs.gov/systems_change/default.asp.

^{xxii} Information regarding the grant activities in states is taken from the 2nd edition of the Compendium of the Systems change Grants for Community Living, CMS March 2003. Available at:

http://www.cms.hhs.gov/systems_change/default.asp.

^{xxiii} More information on Independence Plus is available at: <http://www.cms.hhs.gov/independenceplus/>

^{xxiv} More information on Cash and Counseling is available at:

<http://www.cashandcounseling.org/index.html>

^{xxv} The HHS and AoA announced a new round of awards on 16 April 2004 (<http://www.hhs.gov/news>)

^{xxvi} Further information is contained in the paper: Navigating the Long-term Care Maze: New approaches to Information and Assistance in 3 States. Available at: http://research.aarp.org/health/2001_21_maze.pdf

^{xxvii} CMS Systems Change Conference, March 3 2004, Baltimore, Maryland (presentation by Greg Case, Nancy Day, Doug Blakley called 'Implementing Aging and Disability Resource Centers'). Available at: <http://www.nashp.org/cmsconference2004>.

Federal Systems Change Grants for Community Living (SCG), by State & Territory, in \$thousands, 2001-04
 Martin Kitchener, Micky Willmott & Charlene Harrington. UCSF National Center for Personal Assistance Services.
 May 2004

State	Real Choice			Community-Integrated PAS			Nursing Facility Transition CILs ⁱ		Nursing Facility Transition		Independence Plus	Money Follows Person	Respite for Adults	Respite for Children	Community Treatment for Children	Health Care Info Centers	Quality in HCBS	Disability Resource Centers		Annual State Total				State Total: 2001-04
	Starter	2001	2002	2001	2002	2003	2001	2002	2001	2002	2003	2003	2003	2003	2003	2003	2003	2003	2004	2001	2002	2003	2004 ⁱⁱ	
AK	50		1,385	900					800							150			800	1,750	1,385	150	800	4,085
AL	50	2,000					450			770				100						2,500	770	100		3,370
AR	50	1,025	360 ⁱⁱⁱ	900						598				75					793	1,975	958	75	793	3,801
AS	50																			50				50
AZ						600																600		600
CA	50		1,385					337				750	100				450		800	50	1,722	1,300	800	3,872
CO	50		1,120		725	595			800		391					150	450			850	1,845	1,586		4,281
CT	50		1,385						800		175						499			850	1,385	674		2,909
DC	50		1,385		725															50	2,110			2,160
DE	50	1,200						270		567							352			1,250	837	352		2,439
FL	50	2,000									502								800	2,050		502	800	3,352
GA	50		1,385				400		627		432						475		800	1,077	1,385	907	800	4,169
GU	50	673		300																1,023				1,023
HI	50	1,350			725															1,400	725			2,125
IA	50	1,025	360 ⁱⁱⁱ															800		1,075	360		800	2,235
ID	50	1,102									499	750								1,152		1,249		2,401
IL	50	800													100				800	850		100	800	1,750
IN	50		1,385		725				770							150	500		779	820	2,110	650	779	4,359
KS	50		1,385		725															50	2,110			2,160
KY	50	2,000																		2,050				2,050
LA	50		1,385			464				600 ^{iv}	500							424		50	1,385	1,388		2,823
MA	50	1,025	360 ⁱⁱⁱ			579			770		500				100			397		1,845	360	1,576		3,781
MD	50	1,025	360 ⁱⁱⁱ				450		800					100	100	150		424		2,325	360	774		3,459
ME	50	2,300									500	750					500	407		2,350		2,157		4,507
MI	50	2,000		756					770		478	750		99						3,576		1,327		4,903
MN	50	2,300		900				400									450	392		3,250	400	842		4,492
MO	50	2,000									427				99		500			2,050		1,026		3,076
MP	50		1,385																200	50	1,385	200		1,635

Notes:

1. Systems Change Grant Program Titles are abbreviated in Table, see notes on p. 3 for full titles. 2. All figures rounded to nearest thousand \$

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State	Real Choice Systems Change			Community-Integrated PAS			Nursing Facility Transition CILs ⁱ		Nursing Facility Transition		Independence Plus	Money Follows Person	Respite for Adults	Respite for Children	Community Treatment for Children	Health Care Info Centers	Quality in HCBS	Disability Resource Centers		Annual State Total				State Total: 2001-04 \$
	Starter	2001	2002	2001	2002	2003	2001	2002	2001	2002	2003	2003	2003	2003	2003	2003	2003	2003	2004	2001	2002	2003	2004 ⁱⁱ	
MS	50		1,385												99					50	1,385	99		1,534
MT	50		1,385	850							500					150		371		900	1,385	1,021		3,306
NC	50	1,600			725					600							475		800	1,650	1,325	1,275		4,250
ND	50		900																	950				950
NE	50	2,000				600				600										2,050	600	600		3,250
NH		2,300		900					770									424		3,970		424		4,394
NJ	50	2,000						400		600						150		423		2,050	1,000	573		3,623
NM	50		1,385																799	50	1,385	799		2,234
NV	50		1,385	656								750				150				706	1,385	900		2,991
NY	50		1,385										74				496			50	1,385	570		2,005
OH	50		1,385							600	500		74				450			50	1,985	1,024		3,059
OK	50		1,385	850																900	1,385			2,285
OR	50	2,001				585								99			455			2,051		1,139		3,190
PA	50		1,385									698						405		50	1,385	1,103		2,538
PR	50																			50				50
RI	50		1,385	540						600			100	100			499	397		590	1,985	1,096		3,671
SC	50	2,300								600							500	424		50	2,900	924		3,874
SD	50															150				50		150		200
TN	50	1,769			725												453			1,819	725	453		2,997
TX	50		1,385			599	308					730			93		500			1,743		1,922		3,665
UT	50		1,385					400												50	1,785			1,835
VA	50	1,025	360 ⁱⁱⁱ			514														1,075	360	514		1,949
VT	50	2,000																		2,050				2,050
WA	50		1,385						770			608								820	1,385	608		2,813
WI	50		1,385				450		800			744				143	500		800	1,300	1,385	2,187		4,872
WV	50		1,314		725				552								450	423		602	2,039	873		3,514
WY	50									600										50	600			650
Total	2,650	40,819	35,604	7,552	5,800	4,536	2,058	1,807	9,029	6,735	5,404	6,530	348	573	591	1,343	8,954	4,911	8971	62,094	49,361	33,190	8,971	162,587

Notes:

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Abbreviations:

Community-Integrated PAS	Community-Integrated Personal Assistance Services and Supports
Nursing Facility Transition (CILs)	Nursing Facility Transitions, Independent Living Partnership
Nursing Facility Transition	Nursing Facility Transitions, State Program
Community Treatment for Children	Community-based treatment alternatives for children
Health Care Info Center	Family-to-Family Health Care Information and Education Centers
Quality in HCBS	Quality Assurance and Improvement in Home & Community-Based Services
Disability Resource Center	Aging and Disability Resource Centers

Notes:

- All States and Territories are listed in alphabetical order using their official abbreviations.
AS American Samoa, GU Guam, MP Northern Mariana Islands, PR Puerto Rico.
- A description of each type of grant is available in the paper accompanying this table.

Sources: Data was taken from lists of grants awarded published by the CMS online at:

2001 <http://www.cms.hhs.gov/systemschange/grants2001.pdf>

2002 <http://www.cms.hhs.gov/systemschange/grants>

2003 <http://www.cms.hhs.gov/newfreedom/rcc93003.pdf>

Further information: A description of the activities (by State) undertaken using the grants is available in a Compendium of the Systems Change Grants for Community Living (2nd Edition). Available at: <http://www.cms.hhs.gov/systemschange/default/asp>.

ⁱ Unlike all the other listed grants, Nursing Facility Transitions, Independent Living Partnership Grants are only available to Centers for Independent Living, not State Agencies.

ⁱⁱ The total for 2004 may change as further grant programs and awards are announced.

ⁱⁱⁱ This award was supplemental to the grant given in FY2001.

^{iv} Louisiana was awarded this grant after California declined the award (Federal Register/ volume 68, No.104/ Friday May 30 2003/ Notices).

Notes:

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