

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

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Updated November 2004.

1. 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 aim of the two tables and accompanying text is to provide a summary of information that is accessible to the public, consumers, advocates, researchers and professionals.

Table 1 shows for each state, the dollar value of SCG awards by year and Table 2 shows the total value of the grants awarded each year to states. The accompanying text first introduces the SCG initiative and then provides for each of the 11 forms of SCG, comparative information concerning seven 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 provided.

1.1 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 (ADA, 1990),¹ the 1999 Supreme Court decision in the Olmstead case,² 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)³, a cross-governmental policy and funding program that aims to remove barriers to community living for people with disabilities and provide additional momentum to efforts to comply with the ADA. Later in 2001, President Bush signed an Executive Order outlining the Government's commitment to ensuring community-based alternatives to institutions for all people with disabilities.⁴ 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.⁵

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' which is part of the NFI.⁶ These grants are described in detail below.

Other agencies within the HHS also have NFI programs including grants that compliment those administered by CMS. For example: the Administration on Aging (AOA), the Health Resources and Services Administration (HSRA) and the Substance Abuse and Mental Health Services Administration (SAMHSA). Other Government Departments that provide grants to promote community integration are the Department of Housing and Urban Development (HUD) and the Department of Labor.⁷ Some of these grants are described separately in the 'Federal Funding to States' report on this website.

1.2 Grants included in this report

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'.⁸ Most publicly funded HCBS is furnished by states through Medicaid waivers. These waivers (including research and demonstration programs) may also facilitate the development of innovative services and in some cases grants were made available specifically to help states develop waiver programs (e.g. Independence Plus grants). Details on waivers themselves are not included in this report.⁹

2. Systems Change Grants for Community Living (SCGCL).

The overall aim of this grant program is to enable children and adults who have disabilities to; live in the most integrated setting appropriate and to 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. Over \$180million in SCGCL grants has been awarded by the CMS since 2001.¹⁰

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).¹¹ 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.¹² Grants offered in FY2003 and FY2004 differed from previous years with only one type of grant that had been offered previously (Community-Integrated PAS and Supports) being offered in 2003. Grants for national technical assistance center have remained similar throughout (see appendix 1).¹³

States have been encouraged to apply for more than one type of grant although no State was permitted to have more than one grant type per year.¹⁴ All grants encouraged consumer involvement in project design and implementation as well as the development of public-private partnerships.¹⁴ Grant activities do not have to be statewide but are required to focus on Medicaid-eligible populations and systems that support them.¹³

Many of the grants compliment existing state efforts to develop HCBS, 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). The way funding is categorized may mask the sorts of initiatives being developed, for example, Iowa is developing systems to transition people from institutional care to HCBS through a Real Choice grant, not a Nursing Facility Transition Grant.¹⁵

Details of each of the grants are below. All of these grants; (1) are administered by CMS, (2) aim to promote the community integration of people with disabilities, and (3) have been offered after the Olmstead decision (1999). Information on the types of activity undertaken for grants awarded in 2001, 2002 and 2003 is also given.

2.1 Systems Change Grants (SCGCL) awarded at a state level

*'Real Choice' Systems Change Grants (Real Choice)*¹⁴

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

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

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.

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. Starter grants were worth \$50,000 per state and expected to last 3-6 months.

Typical activities undertaken by states using this grant:¹⁵

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 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. (E.g. 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)*¹⁴

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

Conditions of the grant: Only states that did not receive grants in FY01 or FY02 could apply in FY03. Up to 20% of the grant funds can be used for direct services.¹²

Purpose of the grant: To improve consumer-directed PAS and ensure PAS provide maximum consumer control.

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.

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

Typical activities undertaken by states using this grant:¹⁵

These grants are used primarily to develop consumer-directed PAS and single points of entry into LTC. For some states, this involves change to service delivery systems and the need for capacity building (e.g. in Alaska technical assistance for providers).

- Development or improvement of consumer directed PAS (e.g. the extension of the current PAS waiver for adults to include children in Rhode Island and in Oklahoma, the development of an intermediary service where Centers for Independent Living act as business agents for consumers with employer responsibilities).
- Workforce initiatives such as recruitment, training, standards and competency tests for PAS workers. (E.g. reform of the 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 consumer website in Nevada).
- Needs assessment (E.g. a community services gap analysis in New Hampshire).
- Evaluation. (E.g. the evaluation of 'client-directedness' and independence outcomes in Colorado and peer evaluation of consumer satisfaction with PAS in Nevada).

*Nursing Facility Transitions, Independent Living Partnership Grants (NFT CIL)*¹⁴

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

Purpose of the grant: To promote partnerships between states and Independent Living Centers that support individuals to transition from institutions to the community.

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.

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

Nursing Facility Transitions, State Program (NFTSP)¹⁴

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

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.

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

Typical activities undertaken by states using Nursing Facility Transition grants:¹⁵

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

- Outreach activities to nursing home residents (E.g. the development of a video, word board and picture book in Colorado, a toll-free phone line in West Virginia and the recruitment, training and supervision of peer outreach advocates in Alabama).
- Identification of people living in nursing homes or to diversion of people from institutions (E.g. the development of a tool for assessing 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, such as utility deposits in Connecticut. Utah Center for Independent Living proposed a skill building program to prepare people for moving out of institutions).
- Increased community-housing capacity (E.g. the development of a 'Home Team' in Maryland to collaborate with housing authorities and providers).

Community-based treatment alternatives for children (CTAC)¹²

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 to develop comprehensive, Medicaid community-based mental health services for children with serious emotional disturbances who would otherwise need care in a Psychiatric Residential Treatment Facility (PRTF).

Organization permitted to apply: Any state agency.

Number of grant recipients (states): 6

Additional information: Medicaid 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 waivers and provide HCBS instead of institutional care.

Typical activities undertaken by states using this grant:¹⁵

States receiving these grants aim to research (including needs assessments, policy and fiscal analyses) the different options for serving children with serious emotional disturbances, including developing waiver programs or improving existing services.

*Respite for Children (RFC)*¹²

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 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.

Typical activities undertaken by states using this grant:¹⁵

The activities proposed by states using these grants mainly involve research into how respite for family caregivers can be improved, in some cases by developing new Medicaid programs. Some states have targeted specific populations of children.

- In Alabama, caregivers of children with serious emotional disturbance are being targeted, a needs assessment will be carried out and an implementation plan for including respite in the state Medicaid plan is proposed.
- Arkansas aims to expand the number of participants in an existing respite program for children with special healthcare needs from 132 to 275.

*Respite for Adults (RFA)*¹²

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 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 for caregivers of adults with a particular condition, e.g. an adult with mental illness.

Typical activities undertaken by states using this grant:¹⁵

Some states are using these grants to explore how to improve existing services and others exploring new models of service delivery.

- New York is exploring support for caregivers of Medicaid and non-Medicaid eligible adults with mental and/or physical disabilities, including research of models used in other states.
- Rhode Island's Respite Care for Adults Feasibility study aims to determine the acceptability of respite as an alternative to institutional or other HCBS.

*Living with Independence, Freedom and Equality (LIFE) Account Feasibility & Demonstration*¹⁶

Financial Years awarded: 2004

Total value of grants awarded: \$199,999¹⁷

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

Approximate value of individual grants: \$99,999 (University of New Hampshire), \$100,000 (Wisconsin state health agency).¹⁷

Duration of grant: up to 36 months

Purpose of the grant: To study the feasibility of establishing a savings program for children and adults that would enable them to control their own Medicaid-funded HCBS.

Organization permitted to apply: Any state.

Number of grant recipients: 2

*Money Follows the Person (MFP)*¹²

Financial Years awarded: 2003

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

Conditions of the grant: 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 reform the design of state long-term care so that funding 'follows the person' and finance arrangements enable individuals to transition between institutions and the community.

Organization permitted to apply: State agencies

Number of grant recipients (states): 9

Typical activities undertaken by states using this grant:¹⁵

Some states are exploring broad plans or pilots for community integration that would include policy and financial changes, others aim to improve consumer experience by developing coordinated assessment tools and consumer directed services.

- California Pathways is a pilot project in a single community that will test new financing models to transition people out of nursing facilities and into the community.
- Idaho is building Real Choice grant work by continuing an anti-stigma campaign and conducting an economic and policy analysis of state service utilization since 1995.

Quality Assurance and Improvement in HCBS (QAQI)^{12, 18}

Financial Years awarded: 2003, 2004

Total value of grants awarded: \$9.2 million (2003) \$4.3million (2004)

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 (2003), \$417,849 - \$500,000 (2004)

Duration of grant: up to 36months

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 and (c) develop improved methods to involve individuals and community members in quality assurance systems.

Organization permitted to apply: Any state agency, in 2004 those that already received a QAQI grant in the previous year were not eligible to apply.

Number of grant recipients (states): 19 (2003), 9 (2004)

Typical activities undertaken by states using this grant:¹⁵

Activities tend to focus on improving the monitoring of HCBS waiver programs, with some states focusing on programs serving particular population groups and others focusing on improving quality assurance across all waiver programs.

- Missouri proposes that it will consolidate information systems and improve methods of tracking complaints.
- Tools that states are developing to help consumers become involved in quality assurance include training. In Connecticut, one aim is to establish a Self Advocate Leadership Institute and in Pennsylvania a consumer Help Line is proposed.

*Independence Plus Initiative (IP)*¹²

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 intends to assist states in meeting CMS expectations for the approval of self-directed IP waiver programs.

Organization permitted to apply: State agencies.

Number of grant recipients (states): 12

Additional information: IP waiver programs are expected to include person-centered planning, individual budgeting, self-directed supports, quality assurance and improvement systems.¹⁹ IP is similar to the Cash and Counseling project²⁰ where consumers are provided with a monthly allowance based on an individual budget that allows them to manage their own PAS.

Typical activities undertaken by states using this grant:¹⁵

IP grants are being used to help amend existing waiver programs to allow consumer direction, to develop new consumer-directed programs or to improve the quality of existing consumer-directed programs. For example:

- Colorado has 4 consumer-directed programs and aims to use the grant to set up an emergency back-up system for these.
- Maine intends to develop a consumer-directed HCBS program for adults with MR/DD or autism using a 1915(c) IP template.

Rebalancing Initiative^{16, 18}

Financial Years awarded: 2004

Total value of grants awarded: \$2,023,382

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

Range of value of grants: \$249,500 - \$300,000

Duration of grant: up to 36 months

Purpose of the grant: To help states develop and implement strategies that decrease reliance on institutional service and increase the availability and diversity of community support. States were required to target a specific issue (e.g. development of a single point of entry and coordinated transport system) and address access, financing LTC, consumer-directed supports and quality management.

Organization permitted to apply: State agencies. States that received a MFP grant in 2003 who applied were required to explain how this would not duplicate existing activity. No state that received a MFP grant was awarded a Rebalancing Initiative grant in 2004.

Number of grant recipients (states): 7

Comprehensive Systems Reform Effort^{16, 18}

Financial Years awarded: 2004

Total value of grants awarded: \$7,589,863

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

Range of value of grants: \$2,089,863 (Vermont) & \$5,500,000 (Wisconsin)

Duration of grant: up to 36 months

Purpose of the grant: To enable states to develop and implement a comprehensive LTC reform plan, incorporating; a planning and management structure, improvement of access, financing (removal of barriers in state budgets which inhibit funds from moving around the system and improved consumer control), efforts to ensure the type and supply of services meet the needs and preferences of the population (including workforce development and training) and setting quality and evaluation mechanisms.

Organization permitted to apply: State agencies.

Number of grant recipients: 2

Additional Information: This grant is different to the Rebalancing Initiative grant also offered in 2004 as it assists states in developing comprehensive, not targeted rebalancing. Vermont intends to use the grant to integrate the financing and delivery of acute and LTC services for seniors and people with disabilities.

Integrating Long Term Supports with Affordable Housing^{16, 18}

Financial Years awarded: 2004

Total value of grants awarded: \$6,728,653

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

Range of value of grants: \$720,000 - \$900,000

Duration of grant: up to 36 months

Purpose of the grant: To coordinate housing with LTC services and increase capacity of accessible housing for people using HCBS. It is not intended to fund nursing home transition or to pay for housing costs.

Organization permitted to apply: State agencies.

Number of grant recipients: 8

Additional information: States must already have or plan to develop, dedicated housing coordinators and should develop one of the following; (1) a model for helping seniors to age in place, avoid or reduce risk of institutionalization, (2) a new or amended HCBS waiver program, or (3) an infrastructure for transitioning individuals from institutions.

Mental Health: Systems Transformation^{16, 18}

Financial Years awarded: 2004

Total value of grants awarded: \$3,255,907

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

Range of value of grants: \$262,318 - \$300,000

Duration of grant: up to 36 months

Purpose of the grant: To improve the ability of States to offer evidence-based, consumer-directed and recovery-oriented services to consumers with mental illness.

Organization permitted to apply: State agencies (two universities were also awarded grants – University of Massachusetts Medical School and Portland State University, OR).

Number of grant recipients: 11

Portals from EPDST to Adult Supports^{16, 18}

Financial Years awarded: 2004

Total value of grants awarded: \$1million

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

Range of value of grants: \$500,000 each to Nebraska and the District of Columbia

Duration of grant: up to 36 months

Purpose of the grant: To support innovative HCBS practices in screening, assessment and transition for people transferring from children's services to adult services.

Organization permitted to apply: State agencies.

Number of grant recipients: 2

*Family to Family Health Care Information and Education Centers (FTF)*¹²

Financial Years awarded: 2003, 2004

Total value of grants awarded: \$1,342,963 (2003) \$1,500,000 (2004)

Duration of grant: 36 months

Conditions of the grant: Endorsement from the State Medicaid Director or Governor. 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 information to families and providers, (c) collaborate with other Family-to-Family centers, and (d) promote the philosophy of individual and family-directed supports.

Organizations permitted to apply: Any non-profit organization. 2003 grantees were not eligible to apply in 2004. Existing Centers of this type (funded through HRSA) were not eligible to apply (i.e. California, Florida, Maine, Minnesota, Tennessee, Vermont).¹⁶

Number of grant recipients (various organizations, not state agencies): 2003 - 9 (approx. \$150,000 per state), 2004 - 10 (\$150,000 per state)

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

Typical activities undertaken by states using this grant:¹⁵

These projects are similar in their aims of providing parents with information, networking and training opportunities and supporting professionals working with parents. For example, Indiana's Family-to-Family project aims to improve the ability of at least 100 families in each of two regions to care for their child with special healthcare needs.

2.2 National Technical Assistance Grants (These are not included on the Tables).

*National Technical Assistance Exchange for Community living (CLEC)*¹⁴

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 that received grants in FY01 (Rutgers Center for State Health Policy and Independent Living Research Utilization).

*Technical Assistance for Consumer Task Forces (TACTF)*¹²

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 the board of directors (or controlling structure) consists of people with disabilities. Grant not to be used for direct services.

Purpose of the grant: Provide technical assistance to consumer task forces involved with the RCSCG program and ensure consumer involvement in state long-term care reform.

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, it is linked to the Topeka Independent Living Resource Center.

*National State-to-State Technical Assistance Program for Community Living (STS)*¹²

Financial Years awarded: 2003, 2004 (awarded to different organizations in each year)

Total value of grants awarded: \$4,399,959 (2003) \$4,000,000 (2004)

Duration of grant: 36 months

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

Purpose of the grant: To ensure all Systems Change grantees are supported by; (a) providing on-site state-to-state assistance, (b) developing technical assistance materials, (c) working with individual states, national associations of state agencies, consumer and national organizations to disseminate information and aid effective administration of programs (d) provide and develop expertise for states and (e) feedback to CMS.

Organization permitted to apply: Any organization or entity.

Number of grant recipients: 1 (2003) 1 (2004)

Additional information: 2003, Rutgers: The State University of New Jersey received this grant. In 2004 Independent Living Research Utilization (ILRU) received the grant (<http://www.ilru.org>). This continued work established by the organizations through the National Technical Assistance Exchange for Community Living grant (see above).

3. Administration on Aging and CMS joint grant

Aging and Disability Resource Center Grants Program (ADRC)

Financial Years awarded: 2003, 2004²¹

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.²² At a recent conference two grant recipients (New Jersey and Montana) presented their progress 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 reforming long-term care financial eligibility and pre-admission screening structure as well as developing a management information system.¹⁸

4. Key Trends (Table 1 and Table 2).

Table 2 shows that the total amount awarded to States and state-level organizations has decreased since the grant scheme was introduced in 2001, from \$62 million in 2001 to \$35 million in 2003 and 2004. All 51 states, the District of Columbia and 4 Territories (Guam, American Samoa, Northern Mariana Islands and Puerto Rico) have received Systems Change Grants in the time period 2001-2004. There have been 18 different sorts of grants available to state agencies, 2 other types (Nursing Facility Transitions, Independent Living Partnership and Family to Family Health Care Information and Education Center grants) were available to other state-level organizations.

Several states have been awarded 10 different types of grants (Massachusetts has received 11 different awards but one of these was a supplemental 'Real Choice' grant in 2002). The total amount awarded to states vary from \$50,000 (a starter grant to American Samoa) to over \$11 million (Wisconsin) and the mean average total award to states was \$3,517,000. 2 states and 2 territories received less than \$1 million in total over the 4 years (American Samoa, Puerto Rico, South Dakota and Wyoming).

Appendix 1 – Systems Change Grants (by year awarded)

FY2001

- Real Choice
- Community-Integrated Personal Assistance Services and Supports
- Nursing Facility Transition (a). Independent Living, (b). State Programs
- National Technical Assistance Exchange for Community Living Grant

FY2002

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

FY2003

- Respite for Adults
- Respite for Children
- Community-based Treatment Alternatives for Children
- Quality Assurance & Quality Improvement in HCBS
- Independence Plus
- Money Follows the Person
- Community-integrated Personal Assistance Services and Supports
- National State to State Technical Assistance Program
- Technical Assistance for Consumer Task forces
- Family-to-Family Health Care Information and Education Centers.

FY2004

- Portals from EPDST to Adult Supports Grants
- Family to Family Health Care Information & Education Center Grants
- Quality Assurance & Quality Improvement in HCBS Grants
- Rebalancing Grants
- LIFE Accounts Feasibility & Demonstration Grants
- Comprehensive Systems Reform Grants
- Integrating Long-Term Care Supports with Affordable Housing Grants
- Mental Health: Systems Transformation Grants
- National State-to-State Technical Assistance Program Grants

Footnotes and References

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- ¹ Information on the Americans with Disabilities Act (1990) is at <http://www.ada.gov>.
- ² Supreme Court ruling, *Olmstead v. L.C.* (98-536) 527 U.S. 581 (1999) At: <http://supct.law.cornell.edu/supct/html/98-536.ZS.html>.
- ³ NFI information at: <http://www.whitehouse.gov/infocus/newfreedom/>, <http://www.hhs.gov/newfreedom/>.
- ⁴ White House (Jun 2001) Executive Order 13217: Community-based Alternatives for Individuals with Disabilities. <http://www.whitehouse.gov/news/releases/2001/06/print/20010619.html>
- ⁵ 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/>)
- ⁶ The first \$50million Systems Change Grants proposal was secured during the Clinton administration following lobbying efforts that suggested \$1million per state for systems change (correspondence from Blue Ribbon Advisory Committee member, April 2004).
- ⁷ The 2004 Progress Report on the NFI summarizes activity in each of the key federal departments. The New Freedom Initiative: A Progress Report, March 2004 (by the White House Domestic Policy Council) is at: <http://www.whitehouse.gov/infocus/newfreedom/>
- ⁸ Other sections of the PAS Center website contain information on these schemes. At: http://www.pascenter.org/pas_workforce/index.php & http://www.pascenter.org/workplace_pas/index.php
- ⁹ Information on research and demonstration waivers is in 'Home and Community Based Services: Medicaid Research and Demonstration Waivers' also on this website.
- ¹⁰ The New Freedom Initiative: A Progress Report, March 2004, The White Domestic Policy Council. At: <http://www.whitehouse.gov/infocus/newfreedom/>
- ¹¹ The Health Care Financing Administration (now CMS) administered competitive grants to 12 states in 1998, 1999 and 2000 that were a precursor to the Systems Change Grant program. The grants aimed to foster state infrastructures to enable community integration by transitioning people out of nursing homes or diverting unnecessary nursing home admission. Texas, Michigan, Colorado and Rhode Island each received 'Date Certain Grants' of \$187,500 in 1998. 'Nursing Home Transition Grants' focusing on moving people out of nursing homes were awarded to New Jersey, Vermont, New Hampshire, Wisconsin in 1999 and Pennsylvania, Arkansas, Nebraska and Florida in 2000. Awards were approximately \$500,000 each. <http://www.cms.hhs.gov/medicaid/services/nhtgrant.asp>
- ¹² Federal Register/volume 68, No.104/ Fri May 30 2003/ Notices. <http://www.gpoaccess.gov/fr/index.html>
- ¹³ 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.
- ¹⁴ Federal Register/volume 66,No. 99/Tues May 22 2001/Notices. <http://www.gpoaccess.gov/fr/index.html>
- ¹⁵ CMS (March 2004), Real Choice Systems Change Grants Compendium 3rd Edition. At: <http://www.cms.hhs.gov/systemschange>
- ¹⁶ CMS (2004) Medicaid Program: Real Choice Systems Change Grants 2004 Solicitation Package CFDA No. 93.779, HHS.
- ¹⁷ Case,G, Day,N, Blakley,D (Mar 3 2004) 'Implementing Aging and Disability Resource Centers'. CMS Systems Change Conference Baltimore, Maryland <http://www.nashp.org/cmsconference2004>.
- ¹⁸ CMS (Oct 5 2004) News Release: HHS Awards \$31 million in Grants to 31 States to Help Individuals with Disabilities and Older Adults. CMS.
- ¹⁹ See 'HCBS: Research and Demonstration Waivers' on this site
- ²⁰ See 'Home and Community-Based Services: Medicaid Research and Demonstration Waivers' & 'Home and Community-Based Service Programs: Selected Robert Wood Johnson Foundation Grants' on this site.
- ²¹ HHS news Release (16 Apr 2004) HHS Awards Additional \$9 Million to Help States Develop Aging and Disability Resource Centers (<http://www.hhs.gov/news>)
- ²² Navigating the Long-term Care Maze: New approaches to Information and Assistance in 3 States. http://research.aarp.org/health/2001_21_maze.pdf