

**Home and Community-Based Service Programs:
Selected Robert Wood Johnson Foundation Grants to States.
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1. Introduction

This part of the website provides an introduction to grants funded at least in part by the Robert Wood Johnson Foundation (RWJF)¹, that are offered to states to encourage consumer direction in home and community-based services (HCBS). This paper describes the types of grants and which states are involved. The table shows the amounts awarded to states by grant and by year.

This report concentrates on RWJF-funded grant programs because of the scale of the contribution by the Foundation to fostering HCBS and increased autonomy for seniors and people with disabilities. Other Foundation grants with similar aims may be available to states however they may not be directly aimed at support for people with disabilities or may only be available in specific geographic areas of the nation. Although less than 50 percent of all states have received RWJF grants, they are significant indicators of activity and intent towards community integration.

All the RWJF grants reported here were offered nationwide to state agencies. Each grant program has a national project office to provide technical assistance and disseminate information. There are many other ways in which states can obtain funding for similar activities and other grants that are not part of a national program but are offered by national organizations may also have been accessed². States may also provide their own 'mini-grants' for activity with specific populations or geographic areas within the state.

2. Background

The RWJF has been stimulating research in the field of consumer direction for some time. In 1992, a (now closed) national program called 'Building Health Systems for People with Chronic Illnesses' was initiated and awarded over \$14 million to 32 projects³. This program spawned the development of a 'self-determination' model for people with developmental disabilities. Another grant-funded program called 'Self-determination for people with developmental disabilities' ended in 2001 after awarding grants to 19 states.⁴ This project had begun with an RWJF-funded experimental project in New Hampshire in 1993 that aimed to give individuals greater control over the services they receive. Further information on the RWJF consumer choice programs is provided in the RWJF anthology 'To Improve Health and Health Care'⁵.

The grants included in this summary primarily aim to develop HCBS for people with disabilities and chronic illnesses, and the activities were begun after the Olmstead Supreme Court decision (1999). The RWJF national program on 'vulnerable populations' is the most pertinent to the issues of personal assistance services (PAS) and community

integration. For example, one of the grant programs within the vulnerable populations program is Cash and Counseling.

Most of the grant programs reported here started before the availability of the Federal Government Systems Change grants⁶. For example, Cash and Counseling was first introduced in 1995 although the projects in states did not begin until much later. Many of the projects have led to the development of sustainable state programs through Medicaid waivers⁷. However, it is important to consider the sustainability of grant projects⁸ and whether states may have obtained complimentary funding (including from their own legislature) to contribute to the HCBS provided. The target groups for these grants may differ, even between states with the same grants award.

3. Information and table on Selected RWJF grants to states.

State	Consumer Direction			Community Integration	Cash & Counseling		Total amount awarded per state
	2002	2003	2004		1998 ⁹	2004 ¹⁰	
AK					\$246,898		\$246,898
AL				\$96,387		\$250,000	\$346,387
AZ			\$2,500				\$2,500
FL					\$535,095		\$535,095
GA				\$64,612			\$64,612
IA		\$2,500				\$250,000	\$252,500
IL			\$2,500				\$2,500
KY				\$99,165		\$250,000	\$349,165
LA			\$2,500				\$2,500
MD				\$83,525			\$83,525
ME				\$84,814			\$84,814
MI						\$250,000	\$250,000
MO		\$2,500		\$75,070			\$77,570
MN						\$350,000	\$350,000
NC	\$2,500						\$2,500
NJ			\$2,500		\$494,053		\$496,553
NM						\$349,153	\$349,153
NV	\$2,500						\$2,500
OK		\$2,500					\$2,500
PA		\$2,500				\$250,000	\$252,500
RI						\$250,000	\$250,000
SC	\$2,500						\$2,500
UT				\$100,000			\$100,000
VT						\$249,416	\$249,416
WA	\$2,500					\$250,000	\$252,500
WV	\$2,500					\$250,000	\$252,500
Total no. of grants	5	4	4	7	3	11	34
Total \$ awarded	\$12,500	\$10,000	\$10,000	\$603,573	\$1,276,046	\$2,948,569	\$4,860,688

3.1 Supporting Consumer Direction in Aging Grants. (Consumer Direction)

- Aims of the grant program: To increase opportunities for older consumers to direct the services they receive by evaluating and reforming current HCBS programs with a focus on consumer direction.
- Program duration: 2002-2005¹¹

- States involved in the program: 5 states in 2002 (Nevada, North Carolina, South Carolina, Washington and West Virginia). Four states joined the program in 2003, (Iowa, Missouri, Oklahoma, Pennsylvania¹²). Four states joined in 2004 (Arizona, Illinois, Louisiana, New Jersey)¹³. Each state received \$2,500¹⁴.
- Activities undertaken: Each state is required to convene a partnership of stakeholders, including consumers and policymakers on aging. Using the Consumer Direction Tool¹⁵ the partnership assesses the degree to which current, publicly-funded HCBS programs for older people are consumer directed and present a reform agenda to address any barriers to consumer choice that are identified. The programs may also include other population groups, such as adults with disabilities and children.¹⁶ Plans which result may include the amendment of an existing waiver or applying for further grants (such as Cash and Counseling grants).
- Further information: The National Council On Aging (NCOA) and the National Association of State Units on Aging (NASUA) serve as the National Project Office for this program (they were also the National Project Office for 'Independent Choices'¹⁷). The NCOA focus on community services, whereas the NASUA focus on state level activity. Some of the projects have authority under the Older Americans Act and are not just 'Medicaid' programs.

Between 1997 and 1999, a total of \$3million was awarded by RWJF for research and demonstration projects under a grant program called 'Independent Choices: Enhancing Consumer Direction for People with Disabilities'¹⁸. These grants were awarded to state agencies and involved the completion of an assessment of the state HCBS programs and the identification of ways to reform the program and enable increased consumer direction and choice. Eight states were involved in this program; Arkansas, Massachusetts, Maryland, Maine, North Dakota, New Hampshire, Pennsylvania and Rhode Island¹⁹. The success of the 'Independent Choices' grants lead to the RWJF introducing a one-off grant to the National Association of State Units on Aging (NASUA) to develop the program in other states through the 'Promoting Consumer Direction in Aging' grants. This means that 23 states have used the Consumer Direction tool in total.

3.2 Community Integration Grants

- Aims of the grant program: To aid states in developing a comprehensive response to the Olmstead decision.
- Program Funding: Up to \$100,000 per state was available in 2000.
- States involved in the program: In 2000, 23 states applied for the grants, 7 were successful (Alabama, Georgia, Kentucky, Maine, Maryland, Missouri and Utah).
- Activities undertaken by states: The projects for each state are listed below.
 1. Alabama's HCBS Expansion Project.
 2. Georgia: Commitment to Improvement in Community-Based Long-Term Care Service
 3. Develop a Long-Term Care Network in Utah
 4. Develop a comprehensive interdepartmental plan for sustainable community services for persons with disabilities in the state of Maine

5. Developing a Quality and Innovative Plan for Maryland in Response to the Olmstead Supreme Court Decision
 6. Developing a Comprehensive Response to Olmstead in Kentucky
 7. Development of a Statewide plan to ensure the orderly transition of Missouri's Placed in the Community.
- Further information: This was a one-off grant program, which responded to the Olmstead decision and pre-dated the Federal Government Systems Change Grants scheme. The grants were administered and funded by the Center for Health Care Strategies, Inc (CHCS) under the Robert Wood Johnson Foundation's Medicaid Managed Care Program²⁰. The programs funded by the grants ended in 2002. The states focused on planning for community integration. Key themes addressed by the programs were systemic barriers (e.g. regulatory/financing restrictions and inadequate infrastructure in terms of housing, workforce, service flexibility and information management), public awareness of community-based options and consumer involvement^{21, 22}.

3.3 Cash and Counseling Grants:

- Aims of the program: To develop an infrastructure to secure a statewide model of consumer-directed supportive services for older people and adults with disabilities.
- Program Funding: Up to \$250,000 each for up to 10 states over three years (2004-2007). Three of the states may receive an additional \$100,000 to expand the Cash and Counseling model.
States involved in the program: Cash and Counseling Demonstration and Evaluation projects were carried out in 3 states Arkansas, Florida, and New Jersey²³. In each state, participants enrolled in the demonstration project were assigned either to a 'treatment' group that received cash allowances or a control group that received PAS through an agency²⁴. The program is being expanded to up to 10 more states (successful grant applicants to be announced in Summer 2004).
- Activities undertaken: The demonstration projects developed models operating under 'waiver' programs authorized by Section 1115 of the Social Security Act (called 1115 waivers). Consumers decide how and when care is delivered using a monthly allowance valued at the level of care that they would receive under Medicaid personal care or HCBS programs. The basic principles of Cash and Counseling are similar across the projects, although the projects differ between states. The principles covered are²⁵:
 1. Person-centered planning for PAS;
 2. Consumer-directed individualized budgets, with flexibility to hire workers (who could be family or friends) and/or buy other goods and services (e.g. equipment);
 3. Client supports (e.g. Counselors to help participants make decisions about their options and to help them with their employer's responsibilities); and
 4. Quality Assurance and improvements systems (e.g. back-up assistance for consumers and incident management systems).

The Arkansas and New Jersey programs include adults with disabilities and seniors across the state. The program in Florida also included adults and children with developmental disabilities (across the state) but only adults with disabilities and

seniors in Central and South Florida were included²⁶. The formula for determining the monthly cash allowance differed between states and the *average* monthly cash allowance varied too: Florida provided \$300, Arkansas provided \$350 and New Jersey provided \$1,300²⁷.

- Further information: The RWJF, the Office of the Assistant Secretary for Planning and Evaluation in the United States Department of Health and Human Services (ASPE) and the Administration on Aging (AoA) co-sponsor the program. The Center for Medicare and Medicaid Services (CMS) reviews states' Section 1115 demonstration or 1915(c) waiver applications and provides technical assistance in the waiver process. The National Program Office is at Boston College Graduate School of Social Work²⁸. Qualitative evaluation of the projects in New Jersey, Florida and Arkansas were completed by Mathematica Research and The University of Maryland^{29, 30}.

States applying for this grant in 2004 had to demonstrate plans to submit a HCBS Medicaid waiver (or a Medicaid demonstration application) and the ability to secure Medicaid Federal Financial Participation match funding²⁵. Over time, it is expected that states will enroll at least 10-15% of their eligible Medicaid populations in the Cash and Counseling programs.

4. Community Partnerships for Older Adults

Another RWJF funded competitive grants program is The Community Partnerships for Older Adults program. This program aims to stimulate community partnerships to develop LTC and support older people to stay independent and live in the community (up to \$20 million has been allocated for this program). Funding has been provided for a national technical assistance center and for development and implementation grants. Development and implementation grants are not intended to be statewide, they are aimed at communities with more than 10,000 and are not awarded to state agencies or for-profit organizations.³¹

The development grants have been awarded in two cycles, firstly in 2002 (\$150,000 for 18 months) and in 2004. These grantees have the opportunity to compete for 4-year implementation grants of up to \$750,000. Grantees are required to educate the community about LTC options, develop coordination amongst LTC, healthcare and other support service providers and leverage public and private resources in response to the needs identified by the community. The first round of implementation grants were awarded in 2004 to organizations and communities in; Georgia, New York, Massachusetts, Texas (2), California, Hawaii, Wisconsin. Development grant awardees who did not receive implementation grants are in; Vermont, California, Arkansas and Michigan (2).³²

References

¹ Robert Wood Johnson Foundation is the largest US health and health care philanthropy www.rwjf.org

² The Community Living Exchange has an option to search for projects by state <http://www.hcbs.org>

³ Information at: <http://www.rwjf.org/reports/npreports/bhsp.htm>.

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- ⁴ 18 states received 2-3 year grants of \$100,000 and \$400,000 (AR, CT, FL, HI, IA, KS, MD, MA, MI, MN, OH, OR, PA, TX, UT, VT, WA & WI). See: <http://www.self-determination.com>
- ⁵ Chapter 5, Volume 5, 2002, at: <http://www.rwjf.org/publications>.
- ⁶ See 'Federal Systems Change Grants for Community Living by State & Territory'. On this site.
- ⁷ See 'Home and Community-Based Services: Medicaid Research and Demonstration Waivers' on this site.
- ⁸ The sustainability of activities initially stimulated by Foundation grant funding is discussed in Annie E Casey Foundation (2002) 'End Games: The Challenge of Sustainability' <http://www.aecf.org/>
- ⁹ AR began enrolling Cash & Counseling participants in 1998, NJ & FL started in 1999 & 2000 respectively. Phillips, B *et al* (2003) Lessons from the Implementation of Cash & Counseling in Arkansas, Florida & New Jersey: Final Report. Mathematica Policy Research Inc. <http://www.cashandcounseling.org>. The figure is the total value of grants awarded under this scheme between 1998 & 2002, each state received supplemental grants after 1998. Figures in RWJF annual reports (1995-2002).
- Florida received \$340,410 in 1998, \$144,975 in 2000 and \$49,702 in 2002.
 - New Jersey received \$332,371 in 1998, \$116,851 in 2000, \$100,000 in 2001 and \$49,997 in 2002.
 - Arkansas received \$149,936 in 2000, \$99,962 in 2001.
- ¹⁰ News Release (Oct 2004) Model Program that Improves Quality of Life for Elderly Medicaid Beneficiaries & Those with Disabilities Expands to 11 new States. <http://www.cashandcounseling.org/events/archive/2004100711.html>
- ¹¹ In 2001, The NASUA received \$1,547,048 for 3 years to "improve support for consumer-directed, long-term care services" from RWJF. (RWJF Annual Report 2001, grants and contracts chapter, 'Chronic Health Conditions' subsection. At: <http://www.rwjf.org/publications>).
- ¹² Pennsylvania also received a 'Independent Choices' Grant in 1999.
- ¹³ The program website (<http://www.consumerdirection.org/stat.php>) includes a map of state contacts.
- ¹⁴ Information from conversation with the Program Director at the NASUA
- ¹⁵ The Consumer Direction Tool, developed by NASUA & HCBS Resource Center at Boston College Graduate School of Social Work: <http://www.consumerdirection.org/tool/checklist.pdf>.
- ¹⁶ Information from 'Consumer Choice News', Issue 2, October 2002.
- ¹⁷ Information (including 'Consumer Choice News') at www.consumerdirection.org. 'Independent Choices' was evaluated between 2000 & 2002 by University of California, Los Angeles using RWJF grant (RWJF Annual Report 2000).
- ¹⁸ Examples of projects in this program in Tritz, K (2004) CRS Report for Congress: Long-Term Care Consumer-Directed Services Under Medicaid, Congressional Research Service (Order code RL32219)
- ¹⁹ News Release (July 1996) 'New \$3 million RWJF Initiative to Increase Choice, Reduce Costs for People with Long-Term Care Needs' at: <http://www.rwjf.org/news>
- ²⁰ CHCS is the national program office for RWJF Medicaid Managed Care Program <http://www.chcs.org>.
- ²¹ Chaney (2003) Promoting Community Integration: Barriers & Best Practices from 7 State Recipients of Olmstead Planning Grants http://www.chcs.org/publications3960/publications_show.htm?doc_id=213770.
- ²² Information on each state program http://www.chcs.org/info-url_nocat3961/info-url_nocat_show.htm?doc_id=206314.
- ²³ New York was originally also included in the program, but did not continue in the program (see 'To Improve Health and Health Care', Chapter 5, Volume 5, 2002. At: <http://www.rwjf.org/publications>).
- ²⁴ Evaluation reports at: <http://www.cashandcounseling.org>. Information on individual projects:
- Arkansas 'Independent Choices' <http://www.independentchoices.com/ICHome.htm>
 - New Jersey 'Personal Preference' www.state.nj.us/humanservices/dds/personal.html
 - Florida 'Consumer Directed Care' elderaffairs.state.fl.us/doea/english/cdc.html
- ²⁵ RWJF (Jan 2004) 'Call for Proposals: Cash and Counseling'
- ²⁶ University of Maryland Center on Aging 'Cash and Counseling at a Glance' <http://www.hhp.umd.edu/AGING/CCDemo/ata glance.html>
- ²⁷ Tritz, K (Feb 2004) CRS Report for Congress: Long-Term Care Consumer-Directed Services Under Medicaid, Congressional Research Service (Order code RL32219).
- ²⁸ The project website is <http://www.cashandcounseling.org>.
- ²⁹ The University of Maryland Center on Aging was awarded \$4,239,353 between 1998 and 2005 to provide technical assistance and to evaluate Cash and Counseling (reported at www.rwjf.org/programs, 'Vulnerable Populations', 'Cash and Counseling').

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- ³⁰ Evaluation reports are available at: http://www.cashandcounseling.org/project_results/evaluation.html.
- ³¹ RWJF (2004) Call for Proposals. <http://www.partnershipsforolderadults.org/content/public/loi/cfp.pdf>
- ³² Community Partnerships for Older Adults – Grantees 2004. <http://www.partnershipsforolderadults.org>