

**Home and Community-Based Services:
Medicaid Research and Demonstration Waivers.
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1. Introduction

This part of the website provides an introduction to the ways in which states are using Medicaid waiver programs to fund new Home and Community-Based Services (HCBS). Firstly, there is an introduction to Medicaid waivers and an explanation of the approaches that they represent (e.g. Independence Plus). Secondly, the paper describes the aims of the waiver programs, the way that they are funded, which states are involved, where to find out further information and concludes with key trends. An accompanying table shows summary information about the waivers, including the population group covered and examples of the services offered.

2. Medicaid Waivers

Waiver programs are so-called because they involve the ‘waiving’ of some statutory rule(s) of Medicaid such as the requirement that all eligible persons within a state be offered the same services. States apply to the Center for Medicare and Medicaid Services (CMS) for waiver approval. Medicaid waivers can be tailored by states to meet their local needs and so may have specific eligibility criteria applied (e.g. serving a particular population group or area). States can limit the number of people served on waiver programs by specifying a certain number of ‘slots’. The waivers have limited time duration and states are required to apply for extensions if necessary.

2.1 Types of Medicaid Waivers

Two Medicaid waivers frequently used by states are 1915(b) and 1915(c) waivers (referring to different sections of the Social Security Act). 1915(b) waivers provide managed care services to Medicaid populations and 1915(c) waivers enable states to provide HCBS to people who would otherwise be institutionalized. There are different sub-groups of these waivers, for example 1915(c) ‘model’ waivers are intended to allow states to test new HCBS and have an upper limit of 200 slots. Programs authorized under Section 1115 of the Social Security Act allow experiments, pilot or demonstration projects that promote the objectives of the Medicaid policy¹. The way 1115 ‘Research and Demonstration’ waivers are used varies because each is a unique project to test new ideas of policy merit. They do not have a standard application process like 1915 waivers.²

2.2 Medicaid 1115 waivers

Programs authorized under 1115 waivers are policy experiments developed in consultation with CMS. They are generally approved for 5 years and can be extended with CMS approval. 1115 authority provides flexibility for the provision of services that would not otherwise be matched by federal funding and allows eligibility for those who

would otherwise not be eligible for the Medicaid program. Like 1915(c) programs, 1115 programs must be budget neutral. However, for 1115 programs this means that the program cannot cost Medicaid any more than the state would have spent in the absence of the waiver¹ whereas 1915(c) programs should not cost more than providing state plan services, such as nursing home care, to the same population.

1115 waiver programs have 5 stages, these are:²

1. The Concept Phase, where states present a proposal and get feedback from CMS;
2. The Proposal Review Phase, a formal proposal is submitted for review, negotiations take place and CMS develops ‘operational protocol’ for the program.
3. The Pre-Implementation Phase is the time between CMS approval and the start of the program, during this time CMS staff will visit the state to check preparations.
4. The Operational Phase where services are delivered and quarterly reports are made.
5. The Evaluation Phase is where the research and public policy value of the program is assessed (CMS has responsibility for this). Evaluations include state specific and cross-state analyses of utilization, insurance coverage, expenditures, quality and satisfaction.

2.3 Waiver programs included in this report.

There are several types of waiver programs that can be categorized as ‘innovative’ HCBS programs. This paper and accompanying table concentrate on those which aim to ensure people with disabilities can live in the most integrated setting appropriate using HCBS (including moving people out of institutions or helping people at risk of institutionalization) although they may be restricted to specific populations. The projects are reported on the CMS website and are currently underway or pending approval.³

This report does not represent all 1115 waiver programs as some do not specifically aim to reform HCBS. For example, 1115 ‘Health Insurance Flexibility Act’ programs, Managed Care and ‘Pharmacy Plus’ programs are not included.⁴ A small number of 1915(c) waiver programs are reported as they have developed using the ‘Independence Plus’ (IP) template, other 1915(c) waivers are not included as the data are reported elsewhere⁵. The exclusion of all 1915(c) waiver programs except those developed under the IP template does not mean that new ways of delivering services are not being tested under 1915(c) waivers. Most states have developed consumer-directed HCBS, many operating under 1915(c) waivers.^{6,7}

2.4 Cash and Counseling

This initiative started in Arkansas, Florida and New Jersey in 1998 (Oregon developed a similar initiative at the same time).¹¹ The states were provided with grants from the Robert Wood Johnson Foundation (RWJF) and applied for 1115 waivers to set up a Medicaid HCBS program where recipients directed services. The initiatives all had an experimental design, with volunteer participants being assigned to a case (self-directed services) or control group (receiving ‘standard’ HCBS). Participants in the case group were given a monthly allowance to pay for their services and were permitted to save money from the monthly allowance to purchase items to increase their independence.

This program focused on measuring the impact on consumers, caregivers, public costs and program implementation and evaluations found that participants perceived an improvement in quality of life and satisfaction with services and unmet need was reduced, without compromising safety or health.¹⁰ All the programs (including in Oregon) have continued under the 1115 IP template. Due to the program's success, 11 more states received grants for the development of consumer-directed HCBS in 2004.⁸

2.5 Independence Plus

The Independence Plus (IP) initiative was established in May 2002 by CMS⁹ and consists primarily of 2 templates for states that are applying for consumer directed¹⁰ Medicaid HCBS waiver programs. IP is defined as “a program that presents individuals with the option to control and direct Medicaid Funds identified in an individual budget and in which the participants live in their own homes.”⁷ It builds on the ‘Cash and Counseling’¹¹ and ‘Self-determination’ programs that preceded it.¹² Many states operate consumer-directed HCBS under Medicaid waivers without using IP templates¹³ but the templates aim to make the waiver application process quicker and simpler.¹⁴

The IP template has four ‘essential elements’ that states must include to adhere with Medicaid law and fulfill consumer-direction principles.¹⁵ These are:

1. *Person-centered planning*. The consumer directs the care planning process, where a mixture of paid and unpaid services and supports are identified and put into place.
2. *Individual budget*. This is the total dollar value of the supports specified in the care plan and is under the control of the consumer. It can include Medicaid and non-Medicaid funded care although there must be a clear audit trail for Medicaid funding. The individual budget is not an expenditure cap on the amount of services received and the individual must receive all medically necessary services provided under the waiver. The state has to ensure consumers have information on how individual budgets are calculated, the total dollar value of services and how to request budget adjustments.
3. *Self-directed supports*. States are required to help consumers develop, implement and manage services, including; (a) Brokerage/Counseling (to help consumers with employer responsibilities and serve as the agent on their behalf) and (b) financial management services (to deal with purchasing, payroll and billing and to monitor the budget).
4. *Self-directed quality assurance and improvement*. States are required to develop incident management systems and individual and statewide emergency back-up systems.

States can choose to operate IP under 1115 or 1915(c) waivers depending on how they wish to design their program. Grants were provided to some states to help them develop IP programs (see information on Federal Systems Change Grants to States on this website). The two types of IP waiver programs are similar in that they can operate statewide or in specific regions of a state and can have an enrollment cap if the states choose. There are differences between programs operated under 1915(c) and 1115 IP templates, though and these primarily result from the fact that 1915(c) authority does not ‘waive’ as many legal provisions as 1115 authority. The 8 key differences are:

1. *Direct payments.* 1115 authority allows states to decide whether individuals can receive cash to purchase services. Under 1915(c) authority states cannot give individuals money directly, payments to providers are made by the Medicaid Agency or another eligible entity so individuals arrange services but a third party (under contract with the state) provides financial management. Both allow individual budgets.
2. *Services covered.* States that use 1115 waiver authority may allow consumers to direct any state plan or waiver service.¹⁶ CMS supplies a checklist of commonly included state plan services such as personal care, medical equipment, non-emergency transport and home health. 1915(c) authority only allows consumer direction of waiver services.
3. *Program participation.* While participation in 1115 IP programs must be voluntary this is not the case for 1915(c) IP programs, as states can require people receiving HCBS to participate in 1915(c) IP programs.
4. *Service providers.* States can permit the hiring of family members to provide services in 1115 IP programs, they cannot under 1915(c) IP programs.
5. *Level of care requirements.* 1915(c) IP programs can only enroll people who require an institutional level of care whereas states can enroll all people requiring personal assistance to 1115 programs without requiring them to meet a specific level of care.
6. *Provider Agreements.* 1115 IP programs do not require provider agreements whereas provider agreements must be executed in 1915(c) IP programs¹⁷.
7. *Payment for services.* 1115 IP programs allow providers to be paid before service delivery whereas reimbursement is after service delivery in 1915(c) IP programs.¹⁷
8. *Populations covered.* Any combination of population group can be covered under 1115 IP programs. 1915 (c) programs limit combining populations to aged/disabled, mentally retarded/Developmentally Disabled, mentally ill or a subgroup of these populations.¹⁷

States with 1115 IP programs report to CMS for the first 3 months of implementation, then submit quarterly and annual progress reports covering enrollment numbers, expenditure, quality assurance and findings from beneficiary surveys. The state also provides a final report at the end of the program.¹⁸ 1915(c) IP programs report through the annual HCBS waiver reporting protocol.¹⁹

2.6 Other HCBS programs under 1115 authority.

Some states have large, multi-faceted 1115 demonstration waiver programs that may cover HCBS and some (e.g. Oregon)²⁰ have been developed specifically to restructure state Medicaid programs to contain costs in response to state budget problems.²¹ Some states (e.g. Tennessee)²² are negotiating amendments to existing 1115 waivers that may affect overall Medicaid coverage (including HCBS) for people with disabilities. Three distinctive examples of 1115 programs that focus on HCBS are described below.

Arizona's Health Care Cost Containment System (AHCCCS) was established in 1982, but did not cover LTC until an extension was approved in 1988 (Arizona Long Term Care System, ALTCS). ALTCS is administered separately from AHCCCS and as of April 2002, almost 34,000 elderly, physically and developmentally disabled people were covered. ALTCS is a capitated LTC program that provides nursing facility care, ICF/MR services, case management and HCBS (including home health care, personal care, adult

day health, hospice, respite, transport, personal assistance services). People covered by ALTCS are enrolled with a Program Contractor and select their primary care provider.²³

The proposed Vermont Long-Term Care Plan aims to create a model system enabling seniors and adults with physical disabilities to gain equal access to LTC, increase the number of people receiving services in the community and prevent nursing home admissions.²⁴ The plan has 5 key objectives: (1) the creation of 3 eligibility levels for individual needs, (2) a public information campaign on LTC, (3) the identification and assessment of people at risk of institutionalization, (4) developing incentives for people to buy LTC insurance, and (5) counseling individuals and families about HCBS options. The program would test whether: (a) it is more cost-effective to furnish a package of HCBS to individuals based on needs rather than operate an institutional bias; and (b) a limited package of HCBS, if provided early enough, can delay or eliminate the need for institutional care.

People currently in the 1915(c) waiver program would remain there and people assessed as having the highest level of need would receive HCBS under the waiver. Participants assessed as having the second highest level of need would be provided with case management and some services whereas people in the highest need level would receive a range of services, including case management, personal care, respite, companion services, adult day services, residential care and homemaker services.

California received approval in 2004 for waiver program to provide consumer-directed personal care for children, adults and seniors with disabilities. This program started in 1973 and had used state funds but due to state budget difficulties, the In-home Supportive Services residual program was under threat of closure. The 1115 waiver provides funding to continue the program and represents the largest amount of federal funding granted under the IP initiative (\$340 million per year for five years).²⁵

3. Key Trends

The table identifies a total of 15 state ‘research and demonstration’ waivers that focus on HCBS provision; 11 states have program in place, 4 states have programs that are pending approval (Vermont, Minnesota, North Dakota) and one state has not yet implemented the program (North Carolina). Five states (Louisiana, Maryland, North Carolina, New Hampshire and South Carolina) have IP waivers approved under 1915(c) authority and one state (North Dakota) is pending approval under a 1915(c). Six states run consumer directed services under an 1115 waiver (Arkansas, California, Colorado, Florida, New Jersey, Oregon) and three used the IP template (Florida, Maryland and California). One more state (Minnesota) is awaiting approval for an 1115 IP program. California’s waiver program has the largest number of participants (52,000).

5 of the states have received federal grants to develop consumer-directed HCBS programs. Colorado, Florida and Louisiana received IP grants from CMS in 2003. (Other states that received CMS IP grants in 2003 are; Connecticut, Georgia, Idaho, Massachusetts, Maine, Michigan, Missouri, Montana and Ohio). Florida, Arkansas and

New Jersey received funding in the first round of the ‘Cash and Counseling’ project, 11 states are involved in the second round of the ‘Cash and Counseling’ project (2004) so will develop consumer-directed HCBS 1915(c) or 1115 waiver programs (Alabama, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, West Virginia).²⁶

¹ <http://www.cms.hhs.gov/Medicaid/1115/default.asp>

² <http://www.cms.hhs.gov/medicaid/1115/gensteps.asp>

³ <http://www.cms.hhs.gov/medicaid/waivers/waivermap.asp>

⁴ Pharmacy Plus aims to extend pharmacy coverage to non-Medicaid eligible disabled people or seniors. CMS ‘Pharmacy Plus Section 1115 Waiver Research and Demonstration Projects: Technical Guidance and Factsheet’. <http://www.cms.hhs.gov/medicaid/1115/RXFACTSHEET41202.pdf>.

⁵ Kitchener, M., Ng, T., Harrington, C. (2003). Medicaid Home and Community-Based Services: Program Data, 1992-2001. At: http://www.pascenter.org/publications/publication_home.php?id=38.

⁶ A 1915(c) program that is not an IP program but allows consumer direction is the Maine HCBS Waiver: Physical Disabilities (0127) which provides services to a small number of adults aged 18 and over with severe physical disabilities. CMS, Overview of State HCBS Waivers: Aged and/or Physically Disabled Adults <http://www.cms.hhs.gov/medicaid/1915c/proginfo.asp>.

⁷ Yusauskas, A & Crisp, S (Mar 1 2004) Presentation at a pre-conference session for Independence Plus grantees, Systems Change conference. <http://www.nashp.org/Files/IP-Preconc3-1-042.PDF>.

⁸ News Release (Oct 7 2004) Model Program that improves Quality of Life for elderly and Medicaid beneficiaries and those with disabilities expands to 11 new states. <http://www.cashandcounseling.org/evetns/archive/2004100711.html>.

⁹ CMS (May 9 2002) ‘Dear State Medicaid Director’ letter, SMDL #02-009, CMS. At: <http://www.cms.hhs.gov/independenceplus/>.

¹⁰ See <http://www.consumerdirection.org/> and <http://www.self-determination.org>.

¹¹ Information on Cash and Counseling is in the paper Home and Community-Based Services: Selected Robert Wood Johnson Foundation Grants to States on this website.

¹² 19 states were involved (1995-2001) and mostly operated programs under 1915(c) authority. RWJF (2002) To Improve Health and Health Care Chapter 5, Volume 5. <http://www.rwjf.org/publications>.

¹³ Tritz, K (2004) CRS Report for Congress: Long-Term Care Consumer-Directed Services Under Medicaid, Congressional Research Service, The Library of Congress, Washington DC.

¹⁴ There are many practical and legal issues in developing consumer directed programs. See Tritz, K (2004) (Reference 14, above)

¹⁵ CMS (2003) Home and Community Based Services: from Institutional Care to Self-Directed Supports and Services. Division of Disabled and Elderly Health Programs, CMS.

¹⁶ A recent critique suggests 1115 IP programs may allow inappropriate consumer direction of acute care. Crowley, J (2003) ‘An overview of the Independence Plus Initiative to promote Consumer-Direction of Services in Medicaid.’ Kaiser Commission on Medicaid and the Uninsured, Washington D.C.

¹⁷ ‘Which Independence Plus Template to Use?’ CMS presentation at the HCBS Waiver Conference Oct. 2003. Milwaukee, Wisconsin. At: <http://www.cashandcounseling.org/downloads/grl/doc/waiversheet.doc>.

¹⁸ CMS 2002 ‘Independence Plus: A Demonstration Program for Family or Individual Directed Community Services, §1115 of the Social Security Act’ <http://www.cms.hhs.gov/independenceplus/1115temp.pdf>

¹⁹ CMS (2002) Template for Independence Plus 1915(c) Waiver Version: A Waiver Program for Family or Individual Directed Community Services. <http://www.cms.hhs.gov/independenceplus/1915temp.pdf>

²⁰ Mann, C & Artiga, S (Jun 2004) The Impact of Recent Changes in Health Care Coverage for Low-Income People: A First Look at the Research Following Changes in Oregon’s Medicaid Program. Kaiser Commission on Medicaid and the Uninsured. At <http://www.kff.org/Medicaid>

²¹ Smith, V, Ramesh, R, Gifford K, Ellis, E Rudowitz, R & O’Malley, M (October 2004) The Continuing Medicaid Budget Challenge: State Medicaid Spending Growth and Cost Containment in Fiscal Years 2004 and 2005: Results from a 50-state Survey. Kaiser Commission on Medicaid and the Uninsured. Washington DC. <http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=48004>

²² Kaiser Commission on Medicaid and the Uninsured (Oct 2004) Tennessee Section 1115 Waiver Amendment Proposal Fact Sheet. At http://www.kff.org/medicaid/upload/48455_1.pdf

²³ <http://www.cms.hhs.gov/medicaid/1115/az1115ahccs.asp>.

²⁴ CMS (2003) 'The Vermont Long-Term Care Plan: A demonstration Waiver Proposal to the CMS'.
<http://www.cms.hhs.gov/medicaid/1115/vt1115ltc.asp>

²⁵ CMS (Aug 12 2004) HHS Approves California Plan to Continue Program Allowing Elderly to Receive Self-directed Home Care. <http://www.hhs.gov/news>

²⁶ Cash and Counseling News Release (Oct 7 2004) Model Program the Improves Quality of Life for Elderly Medicaid Beneficiaries and those with Disabilities Expands to 11 New States
<http://www.cashandcounseling.org/events/archive/2004100711.html>