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The Best and Worst State Practices in Medicaid Long-Term Care

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Medicaid—the federal-state program that provides health care for the poor—pays for about half of public long-term care, including nursing home care and home- and community-based services such as home health care, adult day care, adult residential homes, and personal care services for the homebound. Thanks in part to the U.S. Supreme Court's Olmstead decision of 1999,[1] and states' own desire to slow growth in the cost of Medicaid programs, states are starting to catch up with consumer preference for home- and community-based care.

But much of that growth is fueled by the private market. A change that profound in Medicaid policy takes time to implement—longer in some places than in others. Nationwide, Medicaid still pays for more nursing home care than home- and community-based care, but a few states have reversed that formula. States share the cost of the Medicaid program with the federal government and are free to design their own mix of long-term care services within broad guidelines set by federal statutes, so there is tremendous variation from state to state in the range and access to services.

This brief explains why Medicaid policies lead to so much variation in current state Medicaid long-term care programs, and how those policies have been used in some states to expand the range and availability of services. It also draws lessons from innovative states to suggest reforms in national Medicaid policies that would make home- and community-based services accessible to more program participants.[2] A second brief, to follow, will examine state policies to expand the direct care workforce. Home health aide is the third-fastest growing job category in the U.S. and personal and home care jobs the fourth-fastest.[3] The number of home- and community-based direct care workers recently surpassed the number of nursing assistants in nursing homes. But the growing need for long-term care workers is expected to outpace supply growth in the next decade and states will not be able to move more recipients into home- and

Long-term care by the numbers

Number of Americans needing long-term care services: nearly 13 million

Number of nursing home residents: 1.8 million

Number receiving home- and community-based services (HCBS): 10.9 million

Number of people receiving unpaid help from family and friends: 9.8 million

Number of people receiving HCBS who get paid help: 1.4 million[4]

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This is the third in a series of policy briefs about the direct care workforce in long-term care issued by the Direct Care Alliance (DCA). This series was conceived at a meeting of labor economists, lawyers, long-term care researchers, and other experts convened by the DCA and funded by the Russell Sage Foundation. Editorial committee: Nancy Folbre, Elise Nakhnikian, Vera Salter, Leonila Vega.

The Direct Care Alliance

The Direct Care Alliance is the national advocacy voice of direct care workers. We empower workers to speak out for better wages, benefits, respect, and working conditions, so more people can commit to direct care as a career. We also convene powerful allies nationwide to build consensus for change.

community-based services without an adequate high quality workforce.

Growing Old Across the States

Suppose when you next visit your 80-year-old mother, who has been living independently for 20 years in Tennessee, you find that she can barely get out of bed or go to the toilet without assistance. You conclude that it is no longer safe for her to live on her own.

Her monthly income is less than $2,000, and while she has some assets other than her house, they would not support her in a nursing home for more than a month. Because she is poor, she is eligible for Medicaid-financed long-term care in a nursing home. However, if she goes into a nursing home, she will be required to sell her home and contribute the proceeds of the sale, along with her monthly income, toward the $70,000-a-year cost of the nursing home.

Your mother is horrified by the idea of living in a nursing home. She wants to hire someone she knows to take care of her at home, but private pay home care would cost about $36,000 per year. You find that she is eligible for a state-funded program, but there is a waiting list of 4,000 for the 2,000 slots. In contrast, there are 37,000 beds in nursing facilities.

You consider moving her to your state of residence, Connecticut, which spends almost twice the per capita national average on long-term care services for the elderly. But most of that is spent on nursing facilities. Here too, there is a long waiting list for home care services, and even if your mother did get a spot, she would not be able to hire someone she knows.

Too bad your mother doesn't live in Washington or Oregon, where about three out of every four people receiving Medicaid long-term care services live in the community. If she did, she would be eligible for a huge array of home and community-based services, including a "consumer-directed" home care program in which she could choose her own provider, and there would be no waiting list.

Spending on Medicaid long-term care costs makes up as much as 10% of states' budgets, making the program highly visible and politically vulnerable to state and federal fiscal crises.[6] Even in the best of times, long-term care services must compete for funding at the state level. It's a political process that pits stakeholders against schools and other social services—and that often pits nursing homes against home care providers.[7]

Within broad guidelines established by federal statutes, regulations, and policies, each state establishes its own eligibility standards; determines the type, amount, duration, and scope of services to be offered; sets the rate of payment for services; and administers its own program. Thus, a person who is eligible for Medicaid in one state may not be eligible in another state, and the services one state provides may differ considerably in amount, duration, or scope from services provided in another state. Services don't even remain stable within states, since the legislatures may change Medicaid eligibility, services, and/or reimbursement at any time.[8]

In many states, Medicaid does not fund enough home- and community-based services to meet its recipients' needs, so people who are eligible for Medicaid long-term care make do with unpaid family care instead. The large unmet need for home- and community-based services has been well documented in national surveys, and is made manifest in the waiting lists many states maintain for these services.[9] Several states have been sued for this lapse, charged with failing to comply with the Olmstead ruling.

The table on the next page reveals huge state variations in the coverage, generosity per recipient, balance between institutional and home- and community-based services, and per capita cost of long-term care programs. It compares state programs along these four dimensions. First, it measures "coverage" as the number of people per 1,000 in the population who are receiving long-term care (LTC) services for the elderly and disabled, who are receiving those services in the form of home- and community-based services (HCBS), and who are receiving them in nursing homes. Within this dimension, states are categorized mainly by whether they provide above average (highlighted in green), average (yellow) or below the national average (red) coverage for HCBS. Generosity is measured by per recipient spending on HCBS, again highlighted in green, yellow and red. As a measure of balance, the table lists the percentage of the total Medicaid long-term care recipients who are receiving HCBS and the share of total LTC spending that is on HCBS. Finally, it shows how much the Medicaid long-term care program spends per capita in each state as a measure of the cost per person in the population. States are then placed in seven groups, based on their overall performance along the three dimensions of coverage,

State Medicaid Long-Term Care Coverage for Aging & Disabled 2006 (*2008 share of spending*)[10]

For all except the last column, green indicates that the state's performance is at least 20 percent above the national average, red indicates that the state is at least 20 percent below the national average and states within plus or minus 20 percent of the national average are colored yellow. In the last column (Cost), green indicates that per capita spending is at least 20 percent *below* average and red indicates that spending is 20 percent *above* average, in keeping with the principle that green indicates better than average performance while red is less than average performance. The states are listed in alphabetical order within each performance group. Except for expenditure data used to measure HCBS spending as a share of total LTC spending, which is from 2008, all data are from 2006, the most recent year for which both usage and expenditure data are available, so the numbers may have improved since then, but the ranking of the states remains accurate. Arizona is excluded from the table because comparable data is not available.

	COVERAGE			GENEROSITY			BALANCE		COST
	No. of recipients 2006			Spending per recipient			% of HCBS in LTC		LTC $
	LTC	HCBS	NH	LTC	HCBS	NH	Recipients 2006	Spending 2008	Per capita
	HCBS ABOVE AVERAGE			AVERAGE & ABOVE			ABOVE AVERAGE		
Alaska	13.1	11.2	1.9	$28,718	$17,245	$97,044	86%	63%	$293
California	13.8	9.6	4.2	$15,242	$10,802	$25,297	69%	51%	$210
Minnesota	14.4	8.3	6.0	$19,177	$13,217	$27,404	58%	51%	$313
New Mexico	10.4	6.7	3.7	$20,907	$17,548	$26,882	64%	64%	$242
North Carolina	12.5	7.6	4.8	$16,537	$10,570	$25,986	61%	41%	$201
Oregon	11.4	8.7	2.7	$14,316	$9,973	$28,390	76%	53%	$184
Washington	12.1	8.7	3.4	$15,577	$11,666	$25,490	72%	59%	$213
	HCBS AVERAGE			AVERAGE & ABOVE			AVERAGE & BELOW		
Kansas	11.7	5.6	6.1	$15,123	$10,630	$19,228	48%	36%	$200
Montana	10.6	5.3	5.4	$19,495	$9,953	$28,808	49%	28%	$220
New York	16.1	5.4	10.7	$30,399	$23,880	$33,705	34%	29%	$525
Washington DC	13.0	5.8	7.2	$29,419	$14,815	$41,052	44%	40%	$513
West Virginia	11.8	5.5	6.3	$23,188	$9,289	$35,394	47%	19%	$302
Wisconsin	12.4	6.2	6.3	$18,985	$10,112	$27,709	50%	28%	$218
	AVERAGE & ABOVE			BELOW AVERAGE			AVERAGE & ABOVE		
Arkansas	18.9	8.8	10.1	$12,286	$5,289	$18,352	46%	21%	$250
Idaho	11.6	8.2	3.4	$12,999	$7,072	$27,147	70%	39%	$169
Illinois	9.8	4.1	5.7	$14,058	$6,866	$19,199	42%	24%	$151
Maine	14.1	7.4	6.7	$17,565	$7,968	$28,266	53%	24%	$249
Michigan	11.8	6.5	5.3	$14,562	$4,281	$27,248	55%	19%	$183
Missouri	18.8	12.1	6.6	$9,838	$4,493	$19,635	65%	30%	$205
Oklahoma	12.7	6.6	6.0	$13,407	$6,413	$21,058	52%	29%	$205
Texas	11.6	7.4	4.2	$10,361	$5,661	$18,568	64%	33%	$118
Vermont	15.5	6.4	9.1	$14,070	$8,465	$18,047	41%	32%	$268
	HCBS BELOW AVERAGE			AVERAGE & ABOVE			BELOW AVERAGE		
Connecticut	15.0	3.7	11.2	$25,640	$8,556	$31,342	25%	9%	$392
Massachusetts	12.3	3.6	8.7	$26,977	$20,594	$29,578	29%	21%	$314
Nebraska	10.2	3.8	6.5	$22,982	$10,060	$30,522	37%	19%	$231
Ohio	11.9	3.4	8.5	$23,240	$13,490	$27,131	29%	18%	$269
Rhode Island	13.0	2.8	10.2	$24,193	$11,854	$27,597	22%	13%	$323
	HCBS BELOW AVERAGE			BELOW AVERAGE			BELOW AVERAGE		
Iowa	10.5	3.5	7.0	$16,376	$6,170	$21,534	34%	16%	$186
Kentucky	9.5	2.8	6.7	$19,874	$5,217	$25,994	29%	8%	$205
Louisiana	10.3	2.8	7.4	$16,902	$8,061	$20,296	28%	27%	$222
Mississippi	11.9	4.0	7.9	$18,945	$314	$28,400	34%	1%	$244
North Dakota	12.5	3.5	9.0	$21,968	$3,813	$29,064	28%	9%	$287
South Dakota	9.7	2.5	7.2	$18,585	$4,631	$23,405	26%	8%	$187

(cont'd on page 4)

State Medicaid Long-Term Care Coverage for Aging & Disabled 2006—*2008 share of spending* *(cont'd from page 1)*

	COVERAGE			GENEROSITY			BALANCE		COST
	No. of recipients 2006			Spending per recipient			% of HCBS in LTC		LTC $
	LTC	HCBS	NH	LTC	HCBS	NH	Recipients 2006	Spending 2008	Per capita
	BELOW AVERAGE			ABOVE AVERAGE			BELOW AVERAGE		
Delaware	5.8	1.6	4.3	$35,467	$12,516	$43,861	27%	9%	$221
Georgia	5.9	1.6	4.3	$24,784	$10,531	$29,927	27%	19%	$170
Hawaii	5.6	1.8	3.9	$33,321	$17,569	$40,497	31%	19%	$212
Maryland	6.1	1.5	4.6	$30,970	$14,736	$36,074	24%	12%	$201
New Hampshire	7.7	2.2	5.5	$32,777	$13,497	$40,314	28%	15%	$268
New Jersey	8.7	3.3	5.4	$30,164	$15,204	$39,211	38%	20%	$267
Pennsylvania	8.8	2.1	6.7	$39,988	$17,213	$46,926	23%	11%	$349
Virginia	5.4	1.7	3.7	$21,985	$15,546	$25,025	32%	30%	$136
	BELOW AVERAGE			BELOW AVERAGE			AVERAGE & BELOW		
Alabama	7.7	2.0	5.7	$25,355	$6,607	$31,842	26%	11%	$201
Colorado	7.0	3.4	3.6	$17,577	$7,177	$27,339	48%	23%	$132
Florida	8.7	2.3	6.4	$16,426	$4,539	$20,760	27%	12%	$149
Indiana	8.3	0.6	7.6	$19,719	$7,760	$20,730	8%	5%	$206
Nevada	5.4	3.4	2.0	$16,277	$8,110	$30,527	64%	35%	$96
South Carolina	6.7	3.0	3.7	$19,522	$8,122	$28,564	44%	23%	$145
Tennessee	5.8	0.3	5.6	$30,028	$6,131	$31,185	5%	4%	$174
Utah	3.3	1.0	2.3	$17,521	$2,487	$23,867	30%	12%	$68
Wyoming	8.5	3.1	5.5	$16,724	$6,083	$22,745	36%	16%	$155
United States	10.8	5.0	5.8	$19,598	$10,295	$27,698			$220

generosity and balance. States within each grouping are listed in alphabetical order.

We learn from this table that the seven states in group 1—Alaska, California, Minnesota, New Mexico, North Carolina, Oregon, and Washington—perform above the national average on coverage and balance, and at or above the average in generosity. These states provide useful lessons about how to construct a cost-effective long-term care system that better meets the needs of the elderly and disabled. Each of these seven states serves at least as many persons per capita as the national average, but most maintain far fewer nursing home beds and all provide far more home- and community-based services, giving consumers the home-based services they want. Despite the high level of coverage and generosity, except for Alaska and Minnesota, good balance between institutional and home- and community-based care means these states are paying no more than the per capita national average for long-term care services.

In the two bottom groups are the seventeen worst-performing states, which provide almost exclusively nursing home care services to below average numbers of people. Half of these states spend above the national per participant average on HCBS and half spend less than the national average. All have high overall per-participant cost for long-term care because they make so little use of HCBS. Per capita costs for the bottom group of 10 are low only because they cover so few people and spend so little on HCBS per participant. Oregon, in the top group, covers more than twice the number of people per 1,000 in LTC and about 30 times more people per 1,000 in HCBS than does Tennessee, which is in the bottom group. Oregon also spends 35 percent more per HCBS participant, yet its overall cost per capita is comparable to Tennessee.

Why are People's Options for Long-term Care so Varied Across States?

Under the federal Medicaid statutes, states must provide Medicaid long-term care to all aged, blind and disabled persons over the age of 21 who require an institutional level of care and are eligible for Supplemental Security Income.[11]

Medicaid statutes have historically required states to provide institutional care (beginning in 1965) and home health care (1970) to anyone who meets the physical, income and asset criteria. Home health care services must be deemed medically necessary, authorized by a doctor,

and supervised by a nurse. In 1975, states were given the option to include personal care services in the home (the PCS option) as part of the state plan.[12]

Because nursing home care was required and PCS was not, many people have been placed in nursing homes simply because they need regular assistance with activities of daily living (ADLs), such as bathing, eating, assistance with mobility, or with instrumental activities of daily living (IADLs) such as cooking, shopping, telephoning, although those needs could easily be met in their own homes.

In states where Medicaid long-term care services have been limited primarily to institutions, Medicaid participants are likely to prefer unpaid family care in their homes. This leads to the fear of what is sometimes called "the woodwork effect," a concern that if the state expands its Medicaid long-term care services to include home and community services, people who currently cost the state nothing because they are receiving unpaid care in their homes will pour out of the woodwork to demand services.

In part to address this concern, Congress allowed states to waive the statewideness and categorical eligibility rules beginning in 1981, so they could target certain home- and community-based programs only to people who would otherwise be in nursing homes.[13] Under these 1915(c) waivers, states can target services to specific groups, set fixed expenditure caps, limit the scope of services, set hourly service caps, and geographic limits, limit the number of slots in a program and maintain waiting lists.

Many states have opted to use Medicaid waiver programs instead of the PCS option, since the waivers allow them more flexibility in defining eligibility. As a consequence, we have a system that provides no services for almost three-quarters of the individuals who need them,[14] distributes inadequate paid long-term care services inequitably among the rest, and imposes a huge burden on many families.

In 1999, the U.S. Supreme Court handed down its landmark *Olmstead vs. L.C.* decision, the first serious challenge to the funding priorities of the Medicaid long-term care system. The court ruled that the Americans

State Medicaid LTC Requirements and Options

FUNCTIONAL AND INCOME ELIGIBILITY CRITERIA

- Blind, aged and disabled people are functionally eligible if they require health-related care and services above the level of room and board
- States must cover functionally eligible blind, aged or disabled individuals who are eligible for SSI (categorically needy)
- States have the option to cover blind, aged or disabled individuals (categorically related) who…
  - –are institutionalized and have incomes of 300% of the cutoff for SSI or less
  - –would be eligible for Medicaid if they were in an institution, but are in home- and community-based services instead
  - –are receiving only state supplementary income payments
  - –have income greater than the SSI benefit, but less than the federal poverty level (FPL)
  - –are working and disabled with family income of less than 250% of FPL and would be eligible for SSI if they weren't working
- States have the option to cover people who would be eligible if income was measured after deducting medical costs (medically needy)

MANDATORY SERVICES

- All states must offer institutional care to the categorically needy
- All states must offer home health care (medical services) to those eligible for Medicaid institutional care
- States are permitted to offer institutional and home health care to the categorically related and medically needy
- States can determine amount, scope and duration of benefits

OPTIONAL MEDICAID PERSONAL CARE SERVICES (PCS) (ADOPTED IN 30 STATES)

- States are permitted to offer personal care services (PCS)
- If PCS is part of the state Medicaid plan, it must be offered statewide (statewideness requirement) to all age and population groups (comparability requirement) who are defined as categorically needy
- States may also expand PCS to categorically related and/or medically needy
- States may define scope and level of all PCS

OPTIONAL 1915(C) HOME- AND COMMUNITY-BASED SERVICES WAIVERS (ADOPTED IN ALL STATES)

- Programs are limited to people who meet requirements for institutional care
- States are allowed to waive the comparability and statewideness requirements, as well as income and resource eligibility requirements for the medically needy
- The average per capita cost of the program must not exceed per capita cost of nursing home care

with Disabilities Act requires states to provide care for people with disabilities in the most integrated (i.e. community) setting when appropriate—which meant that, for the first time, states were expected to offer some home and community-based alternatives to institutional long-term care.

The Court indicated that states should make "reasonable accommodations" to their long-term care systems, but were not required to make "fundamental alterations." It suggested that compliance might be demonstrated by "comprehensive, effectively working plans" to increase community-based services and reduce institutionalization, and by ensuring that waiting lists for services move at a "reasonable pace."[15] Those comprehensive plans for rebalancing state long-term care systems so they are no longer unduly weighted toward providing nursing home care are known as Olmstead Plans.

The full potential of the Olmstead ruling has yet to be realized, as states create and execute their Olmstead Plans. Meanwhile, the interpretation of "reasonable accommodations," "fundamental alterations," and "reasonable pace" is being clarified through class action suits in various states.[16]

Best Practices Among the States

Bits of a better long-term care system are already in place in some states. Some have used waivers to expand access rather than to limit it, and both waivers and the PCS option have been used not only to keep consumers from being placed in nursing homes but also to relocate nursing home residents back to their homes, notably without increasing overall costs.

In a few states, thanks to a philosophical commitment to independent living and legislative action to provide more options—frequently in response to political pressure from advocates—the state long-term care system has been transformed to increase access to home- and community-based care. Best practices concentrate on policies that make home- and community-based care a viable option to nursing home care by:

- Increasing access to HCBS by raising income and asset caps and at least equalizing eligibility criteria for nursing home and community-based care;
- Consolidating the state's long-term care budgets and oversight entities into a single administrative agency whose mandate is to to address recipients needs and preferences cost effectively by providing the optimal mix of long-term care services, including increasing long-term care options in the community, and;
- Establishing practices that effectively divert or relocate recipients from nursing homes to home- and community based settings of their choice.

Successful Rebalancing: Washington and Oregon

Both Washington and Oregon launched major initiatives in the 1980s and 1990s to transition people out of nursing homes and into the community, and to divert new program participants to home- and community-based services. As a result, 70 percent or more of the Medicaid long-term care recipients in these states receive HCBS at a reduced overall cost to the states.[17]

In 1981, Oregon received the country's first HCBS waiver. Since then, it has led the country in maintaining a low institutionalization rate. Language in the original legislation to promote HCBS laid out a vision of a long-term care system in which people were entitled to freedom and independence. A state program called the Oregon Project Independence, launched in 1975 and paid for out of the state's general fund, also helped lay the groundwork by providing in-home services to people aged 60 and above who might otherwise be in nursing homes. Between 1982 and 1996, approximately 10,000 people were moved out of Oregon's nursing facilities.[18]

Washington reduced the number of people living in its nursing homes (on a given day) from 17,500 in 1990 to 12,300 in 2005. The enabling legislation, HB 1908, overcame nursing homes' reluctance to relocate residents by requiring the state to reduce nursing home Medicaid census rates by 1,600 beds within two years.

In order to use their Medicaid funding more efficiently, both states consolidated their budgets and administrative functions for nursing facilities and HCBS, creating a single agency to manage both. This practice is known as "global budgeting."

Both states also use their own funds to employ case workers whose goal is transitioning suitable nursing home residents—especially those recently discharged from hospitals—back into the community. Medicaid does not cover case management services for nursing home residents, so newly admitted residents who would prefer to be in a community setting probably wouldn't know about the

community option unless a state-supported case manager were there to tell them.

Washington has expanded community living options and funded the cost of transitioning from a nursing home in several notable ways. For example, it has extended medically-needy eligibility to residents of adult family homes and assisted living facilities, making those programs eligible for Medicaid funding. Like Oregon, Washington has set its asset limit much higher for people who choose community living than for those admitted to nursing homes, in recognition of the fact that people who remain in the community need more financial resources.

Washington is also one of few states that provide "spousal impoverishment" protections for people whose spouses are in community-based programs. These protections, which always apply to people whose spouses are in nursing homes, allow couples to set aside some of their assets to support the spouse who remains in the community, rather than requiring them to spend down to almost nothing before their spouse can be eligible for Medicaid.[19] Extending spousal impoverishment protections to people using HCBS is an important part of removing the state's thumb from the nursing home side of the scale. Without that protection, Medicaid recipients might agree to go into a nursing home for the sake of their spouses, though they would rather receive care at home or in the community.

Another innovation that makes Washington's program work is that the state permits new nursing home residents to avail themselves of the home maintenance allowance. This exemption—which is permitted but not required under federal regulations—allows new nursing home residents who have a good chance of returning to the community to keep part of their income (up to 100 percent of the federal poverty level) for the first six months after admission, as long as those funds are used to maintain a home. In addition, although Medicaid recipients who enter nursing homes are usually required to liquidate their assets to pay for their care, Washington does not require them to do so for the first six months.

In addition, since only limited Medicaid funds are available to pay for the costs of transitioning to the community, Washington uses state funds to supplement that amount, permitting up to $800 to cover costs related to the transition.

Washington also guarantees community providers that they will receive payment for services provided to recipients who are "presumptively eligible" for up to 90 days, while the Medicaid application is completed and reviewed. And like many other states, Washington uses a single assessment tool to determine what level of care a recipient needs, prior to making any decision about the setting. Studies show that consumer choice is more likely to occur in states which use uniform assessment tools and single-points-of-entry.[20]

As a result, there are no long waiting lists for community-based services in Washington.

Both Washington and Oregon are also encouraging the use of home- and community-based services by redirecting some of the funding that used to automatically flow to nursing homes. Both won five-year (2007–2011) Money-Follows-the-Person (MFP) Demonstration grants to simultaneously transition individuals from nursing homes to community settings and to change state policies so that Medicaid dollars for long-term care can follow the person to the most integrated setting of their choice.[21] Oregon will use its grant to move 780 individuals or 16.5 percent of its institutionalized Medicaid population into the community. Washington plans to transition 660 people, or about 6 percent of its institutionalized Medicaid population. In addition, Oregon's Independent Choices Program offers Medicaid recipients the option of receiving cash in lieu of authorized in-home services. They may use that cash to hire family, friends, or spouses as caregivers.[22]

Oregon and Washington are among the states including California, Massachusetts, Michigan and Missouri (soon) that are working to ensure that they can find and keep enough qualified personal care workers for their Medicaid-funded consumer-directed care programs. These states have adopted a public authority model for these programs, setting up governmental entities called public authorities to serve as the employer of record for the workers. These public authorities assume responsibility for paying the workers, though they are hired and managed directly by the consumers they serve. Public authorities can also negotiate with unions to set wages and benefits (with approval of the state).[23]

The advent of public authorities has given workers, who would otherwise be without any, legal collective bargaining mechanism, the bargaining power to negotiate higher wages and benefits making their jobs more stable and desirable. Wages for personal care assistants in Washington, Oregon, and California have increased much faster than the national average increase since 1999. Workers

covered under collective bargaining contracts have also gotten health care coverage and other benefits that are often unavailable to personal care workers.[24]

Public authorities help consumers as well, often handling the paperwork involved in hiring and paying workers, providing training, and sometimes helping consumers find workers. The public authorities in California, Oregon and Michigan maintain registries of available workers.

Expanding HCBS Access—Vermont

Vermont provides far less Medicaid HCBS per capita than most states, but a relatively new program is working to change that.

Although it has had a small state-funded attendant services program since 1983 and a Medicaid PCS option since 2001, only 21 percent of the 3,300 Vermont residents receiving Medicaid long-term care services received them through HCBS as of 1999. To increase that percentage and expand access to consumer-directed home care while containing growth in program costs, Vermont introduced Choices for Care in October 2005, using an 1115 waiver.

Under Choices for Care, the state can combine HCBS funds with nursing home funds in a single capitated global budget.[25] The program also allows the state to offer different levels of service to people with different levels of need. These features help Vermont expand access while slowing the rate of growth of costs, by shifting participants from nursing homes to less expensive community settings while limiting the overall growth of long-term care services to a fiscally sustainable rate.[26] Like Oregon's Independent Choices program, Choices for Care makes it easier to find home-based caregivers by waiving the Medicaid prohibition against paying people to provide home care to their spouses.

Under Choices for Care, the state broadened eligibility criteria to include the medically needy, increased the maximum income eligibility criteria for home- and community-based services to match the criteria for nursing home care, and created a new category of eligible people who were at risk of nursing home placement without some level of service.

People categorized as "highest need" were entitled to either nursing home or HCBS if they met the following criteria:

- Have severe cognitive limitations or require extensive or total assistance with toileting, bed mobility, eating, or transferring;
- Have a monthly income of less than about $2,000 and assets worth less than $2,000 (for nursing home care) or $5,000 (for HCBS).

The next most severely impaired group, the "high need group," had been eligible only for nursing home care and was made similarly eligible for either nursing home or HCBS services. However, the waiver stipulates that the state can maintain a waiting list for applicants in this group when projected expenditures would exceed the budget, making the high need group a financial safety valve for Vermont's long-term care budget.

Those in the "moderate need" group, people considered at risk of needing nursing home care but not yet eligible, are eligible for homemaking services, case management, and adult day services—though, again, only as long as funds are available. The state made these services available to this group because it calculated that they would help keep people out of costlier hospitals and nursing homes.

By 2009, Vermont's Medicaid long-term care program was serving about 50 percent more people, from 3,450 in 2005 to 5,145 participants, without any additional expenditure. What's more, about 60 percent of its Medicaid long-term care recipients were receiving home- and community-based services. The state reduced its nursing home resident population of 2,200 by 10 percent over that period while increasing the number of participants in home- and community-based services by 50 percent—from 1,161 to 1,815. In addition, it provided homemaker services for an additional 1,262 people in the "moderate need" group.[27] In a further indication that the state was providing its residents with the kind of care they preferred, more than 60 percent of its personal care services hours were provided under consumer direction in 2006.[28]

But financial constraints may keep Vermont from being able to provide all the long-term care services its Medicaid recipients need. In November 2009, its financial cap led Vermont to freeze enrollment in HCBS for the moderate need group.

Lessons From the States

The innovative actions described in this brief offer important lessons for other states—and, importantly, for the Centers for Medicare and Medicaid Services (CMS), which could change Medicaid rules at the national level, essentially requiring all states to adopt these best practices. A federal directive would de-politicize the process of expanding access to HCBS by equalizing eligibility criteria

and mandated services across states.

To accelerate the process of rebalancing state long-term care budgets and providing a range of care options for consumers, CMS could require states to adopt eligibility requirements and more effective nursing home diversion practices that make HCBS a viable alternative to nursing homes:

•Set the standard income and asset eligibility requirements for Medicaid-funded home- and community-based services at 300 percent or less of the Federal SSI benefit for income and well above $2000 for assets;

•Implement better spousal protection rules for home- and community-based services;

•Reduce Medicaid-funded nursing home beds to roughly 25 percent of the number of persons expected to need Medicaid long-term care services each year over the next decade;

•Integrate long-term care budgets and administration, so one agency oversees both nursing homes and all home- and community-based services;

•Implement single-points-of-entry for persons seeking long-term care services, whether in nursing homes or community settings and regardless of age and disability, where case managers, using uniform automated assessment tools and processes, will determine eligibility, assess need and help recipients develop a plan for care in the setting of their choice

•Establish policies to expand and stabilize the workforce, including mechanisms for collective bargaining, in all LTC settings.

Especially since the Olmstead decision, states have been looking for effective, cost-efficient ways to rebalance their long-term care systems, and where better to learn what works than from other states? By adopting their best practices of the states near the top of our chart, those near the bottom could streamline a mandated process. Not only could they save themselves time and money, but they could better serve the thousands of their citizens who are in nursing homes when they would rather be at home, or who are simply doing without the long-term care services they need.

End Notes

[1] In *Olmstead v. L.C.*, the Supreme Court ruled that under Title II of the Americans with Disabilities Act (ADA, 1990) the plaintiffs in the case had the right to receive care in the most integrated (i.e. community) setting appropriate and that their unnecessary institutionalization was discriminatory and violated the ADA. http://www.law.cornell.edu/supct/html/98-536.ZS.html. The Court indicated that states should make 'reasonable accommodations' to their long-term care systems, but should not be required to make 'fundamental alterations'. It suggested that compliance might be demonstrated by 'comprehensive, effectively working plans' (Olmstead Plans) to increase community-based services and reduce institutionalization, and by ensuring that waiting lists for services move at a 'reasonable pace' (Smith, J.D.E. and Calandrillo, S.P (2001) Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits After Olmstead v. L.C. Harvard Journal of Law & Public Policy, vol.24, Summer, 695. At: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=694002).

[2] This brief will cover only long-term care for the elderly and physically disabled. People who are intellectually or developmentally disabled are also eligible for Medicaid long-term care services and make up 32% of the participants in long-term care programs. Nationwide, Medicaid spends 66 percent of its long-term care resources on services for the developmentally disabled. The majority is spent on home and community-based care.

[3] http://www.bls.gov/oco/ocos326.htm

[4] Kaye, H. Stephen, Charlene Harrington, and Mitchell P. LaPlante. 2010. "Long-term Care: Who gets it, who provides it, who pays and how much?" Health Affairs, 29, 1, 11-21.

[5] Mollica, Robert L., Kristin Simms Kastelein, and Enid Kassner. 2009. "State-funded home and community based services programs for older adults," AARP Public Policy Institute, accessed November 8, 2009 at http://hcbs.org/files/157/7830/State-Funded_HCBS_for_Older_Americans.pdf; Harrington, Charlene, Terence Ng, and Molly O'Malley Watts. 2009. "Medicaid Home and Community-Based Service Programs: Data Update," Issue Brief for Kaiser Commission on Medicaid and the Uninsured, Publication #7720-03, November, accessed January 18, 2010 at http://www.kff.org/medicaid/upload/7720-03.pdf.

[6] In 2002, states spent 12 percent of their general funds on Medicaid. Including federal financing for state programs, states spent 21 percent of their total budgets on Medicaid (Boyd 2003). While Medicaid currently represents less than 1/3 of state general fund expenditures and long-term care is less than 1/3 of that, expenditures on long-term care, most notably home care, are the fastest-growing component of state Medicaid expenditures, which are in turn the fastest-growing component of state budgets. Many of the costs that underlie that growth are hard to control. (Boyd, Donald J. 2003. "Health Care within the Larger State Budget," in Federalism Health & Policy, 59-109. Washington, D.C.: Urban Institute Press).

[7] In contrast, acute care for the elderly is provided under Medicare which is funded from a social insurance fund. Because the scope of Medicare services is set at the national level there is no variation across states.

[8] CMS, Office of the Actuary. 2008, ibid.

[9] Komisar, Harriet L. , J. Feder, and J.C. Kasper. 2005. "Unmet long-term care needs: an analysis of Medicare-Medicaid Dual Eligibles," Inquiry 42 (Summer):171-82; Mollica, Robert L., Enid Kassner, Lina Walder and Ari Houser. 2009. Taking the long view: investing in Medicaid home and community-based services is cost-effective. AARP PPI; Harrington, Charlene, Terence Ng, Stephen H. Kaye, and Robert Newcomer. 2009. Home and Community-Based Services: Public policies to improve access, costs, and quality. University of California, San Francisco: Center for Personal Assistance Services, January, Accessed at http://www.pascenter.org/documents/PASCenter_HCBS_policy_brief.pdf, February 3, 2010.

[10] Table sources: C. Harrington, H. Carrillo, and B. Blank. Table 4, "Nursing, Facilities, Staffing, Residents, and Facility Deficiencies;2003 through 2008," University of California, San Francisco, accessed January 18, 2010 at http://www.nccnhr.org/sites/default/files/OSCAR%20complete%202009.pdf; Harrington, Ng, O'Malley Watts. 2009, ibid and data online at http://www.statehealthfacts.org/compare.jsp.; Burwell, Brian, Kate Sredl, and Eiken, Steve. 2008. Medicaid Long Term Care Expenditures FY 2007. Thomson Reuters, October accessed at

http://www.hcbs.org/moreInfo.php/doc/2374, November 2009.

[11] Blind, aged or disabled persons whose "countable income" does not exceed the SSI benefit level ($664 in 2010) and whose "countable assets" do not exceed a value of $2,000 are eligible for SSI. (Green Book 2008 accessed at http://www.socialsecurity.gov/OACT/COLA/SSIamts.html accessed January 15, 2010).

[12] Only 30 states have included the PCS Option in their State Medicaid Long-Term Care Plan. Of those, in only 17 are the "medically needy" eligible for Personal Care Services and in only 17 are there not limits on service hours (Harrington, Charlene, Terence Ng, and Molly O'Malley. 2008. Medicaid Home and Community-based service Programs: Data Update, Issue Paper for Kaiser Commission on Medicaid and the Uninsured #7720-20, December.)

[13] U.S. Health and Human Services, Office of the Assistant Secretary for Policy Evaluation (ASPE). 2000. Understanding Medicaid Home and Community Services: A Primer. October, accessed at http://aspe.hhs.gov/daltcp/reports/primer.pdf January 12, 2010; Harrington, Ng, & O'Malley. 2008, ibid.

[14] Of the 12.7 million Americans who need assistance, 9.5 million get only unpaid care. (Kaye et al.)

[15] Smith and Calandrillo (2001).

[16] An analysis of rulings in community integration lawsuits after Olmstead has shown that lower courts have generally decided that "evidence of active engagement and slow progress" toward more community-integrated long-term care satisfies the ADA. (Teitelbaum, Joel, Taylor Burke and Sara Rosenbaum, 2004. OLMSTEAD V. L.C. and the Americans with Disabilities Act: Implications For Public Health Policy And Practice. Public Health Reports, v. 119(3): 371–374. Accessed at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1497630/pdf/15158117.pdf, Feberuary 2, 2010; Ng, Terence Alice Wong and Charlene Harrington. 2009. Home and Community-Based Services: Introduction to Olmstead Lawsuits and Olmstead Plans, PAS Center, August. Accessed February 3, 2010 at http://www.pascenter.org/olmstead/downloads/Olmstead8_4_09.pdf).

[17] Alecxih L., S. Lutzky and J. Corea, Estimated Savings from the Use of Home and Community Based Alternatives to Nursing Facility Care in Three States, (Washington, D.C.: AARP, 1996). More recently, Kaye, et al. (Kaye, H. Stephen, Mitchell P. LaPlante and Charlene Harrington. 2009. "Do noninstitutional long-term care services reduce Medicaid spending?" *Health Affairs*, V. 28, no. 1: 262 – 272) find that initially states costs may increase but after a few years, rebalancing saves states money. SEIU (SEIU Healthcare. 2010. "A Basic Element of Healthcare—Reform for Seniors: Improving Access to Long Term Care and Supports," An SEIU Healthcare Report, January) reports a projected cost saving to the Federal government, under a scenario in which the federal government increases its share of payments for HCBS, states increase the share of HCBS in response, and using the assumption that states will experience a "woodwork effect" similar to that of Oregon and Washington.

[18] Kane, Robert L., Richard C. Ladd, Rosalie A. Kane, Wendy J. Nielsen. 1996. Oregon's LTC System: A Case Study By The National LTC Mentoring Program, accessed March 3, 2010 at http://www.bcm.edu/ilru/html/publications/pas/ltc.htm.

[19] Federal law requires that a community-resident spouse of a nursing home resident retain a minimum amount of income per month ($1,822 in July 2009) and assets (the greater of $43,000 or half the couple's assets up to a maximum of $109,000), but there is no similar requirement for community-resident spouses of persons in assisted living or other residential care facilities.

[20] Summer, Laura. 2007. "Community-based long term care services financed by Medicaid: managing resources to provide appropriate Medicaid services," Georgetown Public Policy Institute, Long term Care Financing Project, Issue Brief, June. Accessed March 3, 2010 at http://ltc.georgetown.edu/pdfs/summer0607.pdf.

[21] Centers for Medicare and Medicaid Services. 2007. Money Follows the Person (MFP) Rebalancing Demonstration, updated June 7, accessed March 3, 2010 at http://www.cms.hhs.gov/CommunityServices/Downloads/MFP_AwardsSummary.pdf; Noelle Denny-Brown and Debra J. Lipson, 2009. Early Implementation Experiences of State MFP Programs, Reports from the Field, no. 3, November, accessed March 3, 2010 at http://www.cms.hhs.gov/CommunityServices/Downloads/MFPReportNo3Nov09.pdf.

[22] Participants undergo the regular HCBS functional assessment and the value of the needed services is then converted into a cash equivalent that is sent to the participant's bank account every month. Oregon uses a Medicaid 1115 demonstration waiver, which allows the state to circumvent the Medicaid prohibition against consumers hiring a custodial relative such as a spouse or parent. Section 1115 demonstrations are a broad Medicaid waiver authority that can be used by states to design innovative financing and delivery of medical and supportive services for Medicaid recipients. Both Arizona and Vermont now operate their long-term care systems as capitated managed care systems for the provision of long term care services. The Arizona Long Term Care System (ALTCS) provides all Medicaid services to Arizona Medicaid recipients in need of long-term care, including acute medical care services, institutional and HCBS long term care services and case management. (ASPE, ibid.; Harrington, Ng, O'Malley Watts. 2009,ibid; Kassner, Enid, Susan Reinhard, Wendy Fox-Grage, Ari Houser, and Jean Accius. 2008. "A balancing act: state long term care reform," AARP Public Policy Institute accessed January 2, 2010 at http://www.aarp.org/research/ppi/ltc/hcbs/articles/A_Balancing_Act__State_Long-Term_Care_Reform.html).

[23] Illinois has another model for ensuring that the state negotiates with the designated representative of the workers.

[24] Seavey & Salter, 2006, ibid.

[25] There is no federal cap on funding for programs in a state's Medicaid plan, including nursing home, home health and the personal care option. Unlike the global budgeting strategy used by Oregon and Washington, Vermont has agreed to contain overall costs—the maximum or capitated budget, regardless of the number of enrollees.

[26] In contrast, under traditional Medicaid programs, states are entitled to the open-ended matching financing from the federal government through the Federal Medical Assistance Percentage (FMAP).

[27] Vermont Department of Disabilities, Aging and Independent Living, Division of Disability and Aging Services. 2009. Choices for Care Quarterly Data Report, October. Accessed February 3, 2010 at http://www.ddas.vermont.gov/ddas-publications/publications-cfc/cfc-qrtrly-data-rprts/cfc-quarterly-report-october-2009; Crowley, J. and M. O'Malley. 2008. Vermont's Choices for Care Medicaid Long-Term Services Waiver: Progress and Challenges as the Program Concluded its third Year, Kaiser Commission on medicaid and the Uninsured, accessed at http://www.kff.org/medicaid/upload/7838.pdf November 23, 2009.

[28] Seavey and Turnham, 2006, ibid.

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