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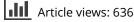
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# Medicaid Home and Community-Based Services: How Consumer Access Is Restricted by State Policies

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State Medicaid programs have expanded home and community-based services (HCBS). This article compares trends and variations in state policies for Medicaid HCBS programs in 2005 and 2010. State limitations on financial eligibility criteria and service benefits have remained stable. Although the use of consumer direction, independent providers, and family care providers has increased, some states do not have these options. The increased adoption of state cost control policies have led to large increases in persons on waiver wait lists. Access could be improved by standardizing and liberalizing state HCBS policies, but state fiscal concerns are barriers to rebalancing between HCBS and institutional services.

*KEYWORDS* home and community-based services, long-term services and supports, Medicaid program, policies, state variation, trends

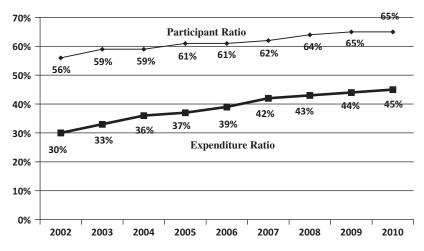
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#### INTRODUCTION

Developing home and community-based service (HCBS) alternatives to institutional care has been a priority for many state Medicaid programs over the past 3 decades. These efforts have been in response to consumer preferences (Ng, Harrington, & Kitchener, 2010) and the Supreme Court *Olmstead* decision whereby Medicaid programs that limit HCBS alternatives to institutional care can be ruled discriminatory (U.S. Supreme Court, 1999). Recent federal laws and policies, such as the Patient Protection and Affordable Care Act of 2010 (ACA), New Freedom Initiative, and the Deficit Reduction Act of 2005 (Kaiser Family Foundation, 2010; Ng et al., 2010; Ng, Harrington, Musumeci, & Reaves, 2012) have provided opportunities for states to voluntarily rebalance their provisions of Medicaid long-term services and supports (LTSS) away from institutional care, such as nursing home care, and toward HCBS.

Between 2005 and 2010, the number of HCBS participants increased by 13%, from 2.8 million to 3.1 million participants (Ng & Harrington, 2014). Growth in Medicaid HCBS spending was more than triple that for participants, rising by 49% from \$35 billion in 2005 to \$53 billion in 2010. States have steadily rebalanced their proportion of Medicaid LTSS dollars from institutional to HCBS. Figure 1 shows that the percentage of LTSS participants receiving HCBS increased from 56% in 2005 to 65% in 2010 and the percentage of LTSS expenditures for HCBS increased from 30% to 45% in the same period. Although progress has been made, rebalancing efforts have been



**FIGURE 1** Ratio of home and community-based services participants and expenditures to total long-term services and supports participants and expenditures, 2002–2010 (HCBS participant data from Ng & Harrington, 2014; institutional participant data from Centers for Medicare & Medicaid Services, 2013a; expenditure data from Eiken et al., 2011).

hindered by a number of factors, including the optional nature of HCBS provision and by restrictive state Medicaid HCBS policies (Ng et al., 2010).

Despite progress in the rebalancing of Medicaid LTSS over the past decade, there is significant variation in spending across states. In 2010, only 15 states spent half or more of their total LTSS dollars on HCBS (Ng & Harrington, 2014; Eiken, Sredl, Burwell, & Gold, 2011; see Table 1). New Mexico had the highest ratio of HCBS participants (94%) and expenditures to total LTSS (95%). Mississippi had the lowest HCBS ratio to total LTSS participants (42%) as well as expenditures (17%) in 2010.

Focusing on the total HCBS rebalancing figures obscures the serious imbalance in HCBS waiver participants and expenditures for those with intellectual and developmental disabilities (I/DD) compared to other groups (see Table 1). In 21 states, 90% to 100% of total I/DD participants received HCBS compared to institutional care and 8 states spent 90% to 100% of their LTSS expenditures on HCBS for I/DD participants. Only Mississippi had less than half (37%) of its I/DD participants receiving HCBS, and 8 states spent less than half of their I/DD expenditures on HCBS. In contrast, only 13 states had more than 50% of their non-I/DD individuals receiving HCBS and only 1 state (New Mexico, with 92%) spent more than 50% on HCBS. The proportion of HCBS to total LTSS expenditures for the aged and disabled and other groups have been constrained by stricter adherence to cost-neutrality rules and less generous HCBS funding (LaPlante, 2013).

State policies for three major Medicaid HCBS programs are examined in this paper: the mandatory home health benefit, the state plan optional personal care benefit, and the §1915(c) HCBS waiver program. While there are many federal demonstration programs including Money Follows the Person and new options to expand HCBS programs provided by the ACA, we focused this analysis on the three largest HCBS programs. Using survey data collected from states as well as CMS (Centers for Medicare & Medicaid Services) waiver data, we compared selected state policies in 2005 and 2010 for the following policies: financial eligibility, services offered, consumer direction, independent providers, service limits, reimbursement policies, waiver waiting lists, and other mechanisms states use to limit costs. These Medicaid HCBS policies were selected because they have important impacts on HCBS access, program variations, and costs.

# BACKGROUND

States may use a combination of Medicaid state plan benefits, including home health and personal care, as well as 1915(c) HCBS waivers to offer care to those with LTSS needs. Other optional state programs and 1115 waivers that provide HCBS were not included in this study.

State	I/DD Waiver	I/DD Waiver	Non-I/DD Waiver	Non-I/DD Waiver	Total HCBS	Total HCBS Expenditure Datio
State	rarucipant kauo	Expenditure Kalio	Parucipant kauo	Expenditure Kalio	Farucipant kano	Expendinte Kauo
AK	%66	98%	78%	36%	89%	69%
AL	96%	89%	27%	10%	46%	32%
AR	54%	45%	29%	14%	55%	31%
$\mathbf{AZ}^{1}$	N/A	N/A	N/A	N/A	N/A	N/A
CA	91%	77%	11%	3%	81%	58%
00	97%	91%	55%	26%	69%	54%
CT	87%	67%	25%	13%	55%	44%
DC	65%	34%	35%	11%	70%	27%
DE	86%	74%	34%	10%	50%	35%
FL	94%	64%	34%	11%	52%	31%
GA	89%	77%	30%	12%	48%	32%
$HI^2$	98%	91%	N/A	N/A	77%	%06
IA	83%	51%	47%	19%	66%	42%
Ð	82%	53%	63%	42%	75%	53%
П	65%	44%	50%	31%	57%	38%
Z	71%	62%	20%	7%	44%	34%
KS	94%	82%	61%	38%	70%	60%
KX	86%	61%	25%	5%	55%	30%
LA	61%	45%	18%	9%	56%	37%
MA	94%	61%	17%	3%	56%	38%
Ш	966	100%	18%	12%	55%	44%
ME	91%	83%	16%	9%	53%	54%
III	%66	100%	20%	6%	66%	33%
NN	85%	85%	65%	48%	78%	71%
OM	91%	76%	33%	11%	68%	45%
MS	37%	14%	31%	14%	42%	17%
MT	97%	86%	34%	18%	64%	50%
NC	83%	63%	28%	20%	72%	42%
ND	85%	48%	7%	1%	51%	31%

NE	89%	81%	38%	20%	65%	46%
HN	98%	98%	35%	16%	59%	45%
R	81%	40%	28%	12%	55%	28%
NN	95%	91%	80%	92%	94%	95%
NN	93%	79%	36%	7%	69%	46%
λN	88%	60%	17%	2%	64%	49%
НО	76%	55%	35%	19%	54%	35%
OK	77%	69%	56%	30%	64%	44%
OR	100%	100%	71%	49%	81%	72%
PA	87%	70%	31%	15%	54%	40%
$\mathbf{RI}^1$	N/A	N/A	N/A	N/A	N/A	N/A
sc	80%	63%	52%	22%	63%	40%
SD	95%	79%	22%	5%	65%	41%
NT	86%	70%	10%	3%	45%	50%
XT	66%	46%	34%	26%	72%	26%
UT	85%	72%	25%	15%	64%	47%
VA	83%	65%	41%	29%	56%	47%
$\mathbf{VT}^1$	N/A	N/A	N/A	N/A	N/A	N/A
WA	99%	77%	64%	44%	77%	54%
IW	95%	83%	53%	44%	73%	63%
WV	89%	79%	37%	14%	63%	41%
ΥW	94%	82%	56%	31%	69%	58%
U.S.	85%	65%	34%	16%	65%	45%
Note. HCB: waiver for	<i>Vote.</i> HCBS waiver data for I/DD are waiver for non-I/DD and mursing hor	are compared to total HCI home data Total HCRS in	Vote. HCBS waiver data for I/DD are compared to total HCBS waiver and institutional data for I/DD. HCBS waiver data for non-I/DD are compared to total HCBS waiver for non-I/DD and musing home data Total HCBS waivers home health and state plan personal care for all nonulations compared to total	data for I/DD. HCBS wai ne health and state plan	ver data for non-I/DD are	compared to total HCBS lations compared to total
institutional data	liour-1/ עע / Luising il data	IIUIIIC Uala, IUlai IIUUU II	ILIUUCS ITUDO WAIVUIS, IIUL	ווכ ווכמונוי, מווט אומר עומוו ן	Jersoniai care roi all popul	iauolis collipated to total

institutional data. <sup>1</sup>States did not operate 1915(c) HCBS waivers in 2010. <sup>2</sup>Hawaii did not have non-1/DD waivers and served its non-1/DD population in a managed care waiver in 2010. Sources: HCBS participant data from Ng and Harrington, (2014); institutional participant data from Centers for Medicare & Medicaid Services (2013); expenditure data from Eiken et al (2011).

25

# Home Health

Medicaid home health is a mandatory state plan benefit for individuals aged 21 and older who need skilled nursing or therapy services. In addition, this benefit provides home health aide services as part of LTSS as long as some skilled services are needed by participants. Medicaid home health is considered an important part of state HCBS programs because nursing and home health aides under this program may provide both post-acute and long-term supports in the home. Medicaid home health has generally been included in non-institutional Medicaid participants and expenditures even though Medicaid reports do not separate post-acute and long-term care home health data (CMS, 2010; Ng et al., 2010; Ng, Harrington, & Musumeci, 2011; Eikin et al., 2011). If a state chooses to cover the medically needy eligibility group under its Medicaid program, it must also extend home health services to those medically needy individuals who meet the program's medical necessity criteria. For all covered eligibility groups, states can determine the amount, scope, and duration of benefits (U.S. DHHS, 2010).

In 2010, 808,000 persons were served in all 51 Medicaid home health programs across the nation at a cost of more than \$5.7 billion, although there are wide variations in expenditures among states (Ng & Harrington, 2014). Home health expenditures in New York made up 44% of the national total, and the state had the highest per capita expenditures (\$95) compared to less than a dollar in other states in 2010 (Eikin et al., 2011; data not shown).

# Personal Care Services

Since 1975, states have had the option of offering personal care services as a Medicaid state plan benefit. States have considerable discretion in defining the state plan personal care option, but programs typically offer non-medical assistance with activities of daily living (ADL; e.g., bathing and eating) for Medicaid participants with disabilities and chronic conditions. If a state chooses to offer this state plan option, it must make it available to all categorically eligible groups. States can also opt to make it available to other groups, such as the medically needy (designed for those who spend down to the state financial standard because of high medical expenses relative to their income; Kitchener, Ng, & Harrington, 2007a; U.S. DHHS, 2010). States may also set their own needs criteria for benefit eligibility.

In 2010, 952,000 persons were served in 32 states by the Medicaid state plan personal care option at a cost of \$10.2 billion (Ng & Harrington, 2014). There were wide interstate variations in expenditures whereby California accounted for 36% of the total U.S. expenditures while New York spent another 22%, the highest per capita expenditure in the nation (\$171 in 2010; Eikin et al., 2011; data not shown). States may also offer personal care services through a §1915(c) waiver program, through 1115 waivers and through the consumer-directed personal care option authorized by the ACA.

#### Waivers

Since 1981, states have used the authority under §1915(c) of the Social Security Act to waive certain federal Medicaid requirements (including comparability in amount, duration, or scope of services, as well as the statewide provision of services) to establish HCBS "waiver" programs (Kitchener, Ng, & Harrington, 2007b; Ng et al., 2010; U.S. DHHS, 2010). These programs allow states to provide a wide range of HCBS to participants who must qualify for an institutional level of care. Among the services offered under waivers are personal care services, home health, therapies, case management, transportation, and home modifications (Harrington, Carrillo, Wellin, Norwood, & Miller, 2001).

States may also set an annual limit on the number of available HCBS participant "slots" for each waiver and are allowed to establish waiting lists to control enrollment and therefore costs. States may also limit waiver programs to certain geographical areas (e.g., a county) and target groups such as individuals with I/DD, persons aged 65 and older, individuals with physical disabilities, and/or children, among others (Ng et al., 2010, 2011).

For HCBS waivers to be approved, states must demonstrate costneutrality, so that the average expenditures for each waiver may not exceed state estimates of Medicaid expenditures for comparable levels of institutional care. States must also limit waiver services to individuals who meet the state's need criteria for institutional care. Need criteria vary by states and may be based on a ratings scale or a combination of the number of ADL, such as bathing and feeding, or the number of instrumental ADL, such as shopping, that require assistance (Kitchener, Ng, Miller, & Harrington, 2005). This design component is intended to ensure that waivers are used as substitutes for institutional care (Ng et al., 2010; Kitchener et al., 2005).

In 2010, the HCBS 1915(c) waiver program was the largest Medicaid HCBS program, with 1.4 million persons served in 288 waivers across 47 states and the District of Columbia at a total cost of more than \$36.6 billion (Ng & Harrington, 2014). Waiver per capita expenditures ranged from \$32 in Nevada to \$361 in Connecticut in 2010 (Eikin et al., 2011).

# METHODS

For this study, we collected data from state Medicaid programs and analyzed them by state to show the variations in policies across the three major HCBS programs as well as over the study period. The following four data sources were used by the authors to collect the data from all states for 2005 and 2010: (1) national surveys of Medicaid 1915(c) waiver policies, (2) national surveys of Medicaid optional state plan personal care policies, (3) national surveys of Medicaid home health policies, and (4) CMS Form 372s that include the number of participants, services, and expenditures for HCBS 1915(c) waivers.

Arizona, Rhode Island, and Vermont provided HCBS to Medicaid participants through 1115 waivers and not 1915(c) HCBS waivers. They were included in this study.

The state surveys included questions about policies such as cost control measures and financial eligibility criteria. Survey requests (using e-mail, fax, and telephone) of state officials produced responses from about 90% of all reported waivers in each year. Missing survey data were extrapolated from previous year's surveys and cross-checked against information published on CMS's as well as the state's website. Through October 2011, responses were gathered from all survey recipients (51 home health programs, 32 state plan personal care programs, and 288 HCBS waiver programs) about policies in 2005 and 2010.

#### Analysis

All responses to the surveys were coded using a standardized protocol and then entered into, and stored as, an SPSS data set. At the end of the data collection period, descriptive statistics for each survey item across the study period were produced. Due to the complexity of the financial eligibility requirements, the survey data on eligibility were crossed-checked against a 2009 survey conducted by the Congressional Research Service (Stone, 2011). Discrepancies between the two surveys were resolved by either contacting state officials or checking against the waiver application published on the state's website. We also cross-checked selected policy survey responses from states with other available data sources, including those from CMS and state websites.

Because waiver eligibility criteria are established by states on a waiverlevel basis, not on a statewide basis, states with multiple waivers may have differing criteria for different waivers. The largest waivers for individuals with I/DD and for the aged and/or physically disabled were selected for analysis because they usually serve the largest number of waiver participants in most states (overall about 89% of waiver participants; Ng, Harrington et al., 2012). For the service analysis, we elected to examine case management, personal care, therapy, emergency support/respite, and transportation, because they were among the most widely used HCBS services in the waivers. The tables show the policies for 2010, and variations in policies from 2005 are presented in the text.

#### RESULTS

# Financial Eligibility

Medicaid eligibility rules for individuals aged 65 and older and individuals with disabilities, many of whom utilize Medicaid HCBS, are linked to the federal cash welfare program Supplemental Security Income (SSI). Individuals

receiving SSI generally qualify for Medicaid in all but 11 states (referred to as 209(b) states) that were allowed to use financial and/or disability criteria that were more restrictive than SSI when the program began in 1972 (Stone, 2010). In 2010, 100% of SSI was about \$674 a month or about 74.7% of the federal poverty level (FPL). Another commonly used eligibility criteria for individuals aged 65 and older and persons with disabilities is 100% of FPL (\$902.50 a month or \$10,830 a year in the continental United States, \$13,530 in Alaska, and \$12,460 in Hawaii in 2010; U.S. DHHS, 2010). States also may elect to allow the medically needy pathway for people with relatively high medical expenses that spend down to the Medicaid level and the buy-in pathways for disabled individuals who are working. Medically needy eligibility has the highest income eligibility threshold because it does not have an income cap.

Most states set their Medicaid nursing facility financial eligibility at 300% of SSI and/or had medically needy programs that allow for individuals with higher incomes to spend down. In §1915(c) HCBS waivers, states can extend coverage of HCBS waivers to persons who (1) require care provided by a nursing home or other institution for at least 30 consecutive days, (2) meet the resources threshold determined by the state (often not to exceed \$2,000 in savings), and (3) have income that does not exceed 300% of SSI payment.

Table 2 shows the most generous income eligibility thresholds that states had in 2010 for home health, state plan personal care option, and the two largest HCBS waiver groups, those for elders and for individuals with I/DD.

The eligibility data in the home health and state plan personal care columns show the maximum income criteria for accessing those services for individuals who do not qualify for Medicaid HCBS waiver services. If they qualify for Medicaid HCBS waiver services, then the maximum income criteria for accessing all of the services represented in this table are shown in the HCBS waiver column. With the exception of the 11 §209(b) states, all states extended home health, the state plan personal care option, and HCBS waivers to individuals who meet the SSI-related program criteria. For the home health benefit, 24 states used 100% of SSI as the financial criteria but 10 of those states also allowed the medically needy to spend down (see Table 2). These eligibility criteria have remained constant since 2005.

Out of 32 states that provided the state plan personal care option, 17 states extended this benefit to medically needy individuals, but 5 states that could have allowed eligibility to the medically needy did not. Basically, the state plan personal care option in the 32 states had the same financial eligibility as the home health program except for the five states that did not allow the medically needy to receive the services. Compared to 2005, there have been no changes in eligibility criteria for the personal care state plans, although Kansas added the service to its Medicaid state plan in 2007.

	100% SSI 100% SSI 100% FPL/MN 100% FPL/MN 100% FPL/MN 100% SSI/MN 100% FPL/MN 100% SSI/MN 100% SSI/MN 100% SSI/MN 100% SSI/MN	100% SSI Not offered 100% FPL Not offered 100% FPL/MN Not offered Not offered 100% FPL		
	100% SS1 100% FPL/MN 100% FPL 100% FPL 100% SS1 100% SS1 100% FPL/MN 100% FPL/MN 100% FPL/MN 100% FPL/MN 100% SS1/MN	Not offered 100% FPL Not offered 100% FPL/MN Not offered Not offered 100% FPL	250% SSI	
	100% FPL/MN 100% FPL 100% FPL/MN 100% SSI 125% SSI/MN 100% FPL/MN 100% FPL/MN 100% SSI/MN 100% SSI/MN 100% SSI/MN 100% SSI/MN	100% FPL Not offered 100% FPL/MN Not offered Not offered 100% FPL	300% SSI	
	100% FPL 100% FPL/MN 100% SSI 125% SSI/MN 100% FPL/MN 100% FPL/MN 100% SSI/MN 100% SSI/MN 100% SSI/MN 100% SSI/MN	Not offered 100% FPL/MN Not offered Not offered 100% FPL	300% SSI	
	100%FPL/MN 100% SSI 125% SSI/MN 100% FPL/MN 100% FPL/MN 100% SSI/MN 100% SSI/MN 100% SSI/MN 100% SSI/MN	100% FPL/MN Not offered Not offered 100% FPL	300% SSI	
	100% SSI 125% SSI/MN 100% FPL/MN 100% SSI 100% FPL/MN 100% SSI/MN 100% SSI/MN	Not offered Not offered 100% FPL	100% FPL/MN	
	125% SSI/MN 100% FPL/MN 100% SSI 100% FPL/MN 100% FPL/MN 100% SSI/MN	Not offered 100% FPL	300% SSI	
	100% FPL/MN 100% SSI 100% FPL/MN 100% FPL/MN 100% FPL/MN 100% SSI/MN	100% FPL	300% SSI	
	100% SSI 100% FPL/MN 100% FPL/MN 100% FPL/MN 100% SSI/MN		300% SSI	
	100% FPL/MN 100% SSI/MN 100% FPL/MN 100% SS1/MN	Not offered	250% SSI	
	100% SSI/MN 100% FPL/MN 1000% SSI/MN	100% FPL/MN	300% SSI	
	100% FPL/MN	Not offered	300% SSI	
	1000% SST/MINI	Not offered	100% FPL	
	NTIM / ICC 04.00T	Not offered	300% SSI	
	100% SSI	100% SSI	300% SSI	
	100% FPL/MN	Not offered	100% FPL/MN	
	100% SSI/MN	Not offered	300% SSI	
	100% SSI/MN	100% SSI/MN	300% SSI	
	100% SSI/MN	Not offered	300% SSI	
	100% FPL/MN	100% FPL/MN	300% SSI	
	100% FPL/MN	100% FPL/MN	300% SSI/MN	
	100% SSI/MN	100% SSI/MN	300% SSI	
ME	100% FPL/MN	100% FPL/MN	300% SSI/MN	
	100% FPL/MN	100% FPL/MN	300% SSI	100% FPL
7	95% FPL/MN	95% FPL/MN	300% SSI	
MO	Aged: 85% FPL	Aged: 85% FPL	175% SSI	85% FPL
Bli	Blind/Disabled: 100% FPL	BliNd/Disabled: 100% FPL		
MS	100% SSI	Not offered	300% SSI	
MT	100% SSI/MN	100% SSI/MN	100% SSI/MN	
NC	100% FPL/MN	100% SSI	300% SSI	

TABLE 2 Maximum Eligibility Threshold for Home Health, State Plan Personal Care Program, and States' Largest HCBS Waivers for the Elderly

MN100% FPL/MNMN100% SSI/MNMN100% SSI/MNMN100% SSIMN100% SSIMNNot offeredMNNot offeredMN100% SSIMN100% SSI <th>ND</th> <th></th> <th>111% SSI/MN</th> <th>111% SSI/MN</th> <th></th>	ND		111% SSI/MN	111% SSI/MN	
Income Sary Mark     Income Sary Mark     Income Sary Mark     Decome Sary Mark <thdecome mark<="" th="">     Decome Sary Mark</thdecome>		100% FPL/MN 102% SSL/MN	100% FPL/MN 102% SSI/MN	100% FPL/MN 200% sst/MN	
Income SNIM	Į	NTAT/ISC 0/201	NTAT/TSC 0/201	2000% SCI	
100% SSI     100% SSI     100% SSI     300% SSI       100% SSI/MN     100% SSI     300% SSI     300% SSI       87% SSI/MN     100% SSI     300% SSI     300% SSI       100% SSI     100% SSI     300% SSI     300% SSI       100% SSI     100% SSI     300% SSI     300% SSI       100% FPL/MN     Not offered     300% SSI     300% SSI       100% FPL/MN     100% FPL/MN     300% SSI     300% SSI       100% FPL/MN     100% SSI     300% SSI     300% SSI       100% FPL/MN     100% SSI     300% SSI     300% SSI       100% SSI	W	100% SSI/IMIN 100% SSI	100% SSI/MIN	ISS 92000	
100% SSI/MN     100% SSI     300% SSI       87% SSI/MN     Not offered     300% SSI       106% SSI     106% SSI     300% SSI       106% SSI     100% SSI     300% SSI       100% FPL/MN     Not offered     300% SSI       100% FPL/MN     Not offered     300% SSI       100% FPL/MN     Not offered     300% SSI       100% SSI     100% SSI     300% SSI       100% SSI     300% SSI     300% SSI       100% SSI     300% SSI     300% SSI       100% SSI     1000% SSI     300% SSI       100% SSI     300% SSI     300% SSI       100% SSI     100% SSI     300% SSI       100% SSI     100% SSI     300% SSI       100% SSI     100% SSI     300% SSI       1000% SSI     1000% SSI     3	10	100% SSI	100% SSI	300% SSI	
87% SSI/MN     Not offered $300\%$ SSI       106\% SSI     100\% SSI     300\% SSI       100\% SSI     100% SSI     300\% SSI       100% FPL/MN     Not offered     300\% SSI       100% SSI     100% SSI     300% SSI       100% FPL/MN     Not offered     300% SSI       100% SSI     100% SSI     300% SSI       100% FPL/MN     100% FPL/MN     300% SSI       100% SSI     100% SSI     300% SSI       100% SSI     300% SSI     300% SSI       100% SSI     100% SSI     300% SSI       100% SSI     100% SSI     300% SSI       100% SSI     100% SSI     300% SSI       100% SSI     1000% SSI     300%	Y	100% SSI/MN	100% SSI	300% SSI	
106% SSI     106% SSI     106% SSI     100% SSI     300% SSI	H	87% SSI/MN	Not offered	300% SSI	
$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	<b>DK</b>	106% SSI	106% SSI	300% SSI	
100% FPL/MN     Not offered $30\%$ SSI       100% FPL/MN     Not offered $30\%$ SSI       100% FPL/MN     Not offered $30\%$ SSI       100% SSI     100\% SSI $30\%$ SSI       100% SSI     Not offered $30\%$ SSI       100% SSI     Not offered $30\%$ SSI       100% FPL/MN     Not offered $30\%$ SSI       100% FPL/MN     100% FPL/MN $30\%$ SSI       100% FPL/MN     100% FPL/MN $30\%$ SSI/MN       100% FPL/MN     100% SSI $30\%$ SSI/MN       100% FPL/MN     100% SSI $30\%$ SSI/MN       100% SSI $100\%$ SSI $30\%$ SSI/MN       100% SSI $100\%$ SSI $30\%$ SSI/MN       100% SSI $100\%$ SSI $30\%$ SSI/MN       100% SSI $30\%$ SSI $30\%$ SSI/MN       100% SSI $30\%$ SSI $30\%$ SSI $100\%$ SSI $100\%$ SSI $30\%$ SSI $100\%$ SSI $30\%$ SSI $30\%$ SSI $100\%$ SSI $30\%$ SSI $30\%$ SSI $100\%$ SSI $100\%$ SSI $30\%$ SSI	<b>JR</b>	100% SSI	100% SSI	300% SSI	
100% FPL/MN     Not offered $200\%$ FPL/MN       100% FPL     100% FPL     Not offered $300\%$ SSI       100% FPL     Not offered $300\%$ SSI $300\%$ SSI       100% SSI     100% SSI $300\%$ SSI $300\%$ SSI       100% FPL/MN     100% FPL/MN $300\%$ SSI $300\%$ SSI       100% FPL/MN     100% FPL/MN $300\%$ SSI $300\%$ SSI       100% FPL/MN     100% SSI/MN $300\%$ SSI $300\%$ SSI       100% FPL/MN     100% SSI $300\%$ SSI/MN $300\%$ SSI/MN       100% SPL/MN     100% SSI $300\%$ SSI/MN $300\%$ SSI       100% SPL/MN     100% SSI $300\%$ SSI $300\%$ SSI       100% SSI     Not offered $300\%$ SSI $300\%$ SSI       100% SSI     Not offered $300\%$ SSI $300\%$ SSI       100% SSI $100\%$ SSI $300\%$ SSI $300\%$ SSI       100% SSI $100\%$ SSI $300\%$ SSI $11$ states       100% SSI $100\%$ SSI $100\%$ SSI $100\%$ SSI $11$ states       MN = 33 states     MN = 15 states	<b>V</b>	100% FPL/MN	Not offered	300% SSI	
$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	<b>U</b> ¹	100% FPL/MN	Not offered	200% FPL/MN	
$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	ũ	100% FPL	Not offered	300% SSI	
$ \begin{array}{llllllllllllllllllllllllllllllllllll$	Q	100% SSI	100% SSI	300% SSI	
$ \begin{array}{llllllllllllllllllllllllllllllllllll$	Z	100% SSI	Not offered	300% SSI	
$ \begin{array}{llllllllllllllllllllllllllllllllllll$	X	100% SSI	100% SSI	300% SSI	
$ \begin{array}{llllllllllllllllllllllllllllllllllll$	T		100% FPL/MN	300% SSI/MN	
$\begin{array}{c ccccccccccccccccccccccccccccccccccc$	IA.		Not offered	300% SSI/MN	300% SSI
$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	$T^{1}$		100% SSI/MN	300% SSI/MN	
$\begin{array}{c ccccccccccccccccccccccccccccccccccc$	X/A	100% SSI/MN	100% SSI	300% SSI	
$\begin{array}{c ccccccccccccccccccccccccccccccccccc$	NI NI	100% FPL/MN	100% FPL/MN	300% SSI/MN	
100% SSI = 24 states 100% SSI = 24 states 100% SSI = 24 states 100% SSI = 16 states 100% FPL = 20 states 00% FPL = 11 states 00% FPL = 11 states 00% FPL = 11 states MN = 33 states MN = 17 states Not offered = 19 states 100% SSI = 19 states 100% SSI = 20 state	٧V	100% SSI	100% SSI	300% SSI	
100% SSI = 24 states 100% SSI = 16 states 100% FPL = 20 states 100% FPL = 11 states 000% FPL = 11 states 000% FPL = 11 states MN = 33 states MN = 17 states Not offered = 19 states Not offered = 19 states 1000% SSI = 20	ΥY	100% SSI	Not offered	300% SSI	
100% FPL = 20 states100% FPL = 11 states00% FPL = 11 states000% FPL = 11 states $MN = 33$ states $MN = 17$ states $MN = 33$ statesNot offered = 19 states	U.S.	100% SSI = 24 states	100% SSI = 16 states	300% SSI = $40$ states	
Others = 5 states MN = 17 states Not offered = 19 states		100% FPL = 20 states	100% FPL = 11 states	Less than $300\%$ SSI = 11 states	
		Others $= 7$ states	Others = 5 states	MN = 13 states	
Not offered $= 19$ states		MN = 33 states	MN = 17 states		
			Not offered $= 19$ states		
	Sources: St.	ate survey data for 2010 from Stone (2	(011); Section 1115 and 1915(c) waiver	details from Centers for Medicare and Medicaid Se	rvices (CMS) at http://
sources: State survey data for 2010 from Stone (2011); Section 1115 and 1915(c) waiver details from Centers for Medicare and Medicard Services (CMS) at http://	www.medi	icaid.gov/Medicaid-CHIP-Program-Infor	mation/By-Topics/Waivers/Waivers.htm	l?filterBy=%28b%29%28c%29#waivers.	1
Sources: State survey data for 2010 from Stone (2011); Section 1115 and 1915(c) waiver details from Centers for Medicare and Medicaid Services (CMS) at http:// www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers.html?filterBy=%28b%29%28c%29#waivers.					

Most states (40 states and the District of Columbia) provided HCBS waiver services to individuals with income up to 300% of the SSI benefit level and 13 states allowed the medically needy to spend down, but 11 states used more restrictive financial eligibility standards for HCBS waivers (for those who were not medically needy) than for nursing facilities (see Table 2). Over the study period, there have been few changes in waiver eligibility criteria. In 2005, 189 out of 255 waivers (74%) reported having its maximum financial eligibility threshold at 300% of SSI; by 2010, 72% (208 out of 288 waivers) reported the same criteria.

# Consumer Direction and Independent Providers

In response to the ACA, New Freedom Initiative, Deficit Reduction Act, and consumer demands, many states have incorporated some form of consumer direction within their Medicaid HCBS programs. Consumer direction may include initiatives such as consumer choice in the allocation of service budgets or the hiring and firing of service providers. By 2010, 44 states allowed consumer direction within some or all three of the Medicaid HCBS programs (see Table 3), with only Idaho, Nebraska, and West Virginia offering it in all three. This was an increase from the 35 states that allowed consumer direction in 2005.

States may offer HCBS using either agency providers or independent providers for personal care workers and cash and counseling programs. The use of independent providers (paid directly by the state or by fiscal intermediaries) has also grown over the years. Thirty-seven states allowed independent providers within one or more of their waiver programs, and 21 state plan personal care programs allowed independent providers in 2010. This is an increase compared to the 32 states that allowed independent providers in their waiver programs and 11 state plan personal care programs that allowed them in 2005, mainly due to the expansion of the cash and counseling program in 2006.

In addition, states with the state plan personal care option may also allow family members of participants to be providers. However, only states with the 1915(j) self-directed personal assistance services state plan option can allow legally responsible family members, such as spouses and legal guardians, to be paid personal care providers (CMS, 2009). In 2010, 21 states allowed family members to be paid personal care providers. Out of these, only 4 states—California, Florida, New Jersey, and Texas—allowed legally responsible family members to be paid personal care providers. Nonetheless, this reflects an increase from the 10 states that allowed family members to be paid providers, of which none allowed legally responsible persons to be paid providers in 2005. States may also allow family member to be providers in waivers or other HCBS programs, but such analysis was beyond the scope of this study.

State	Consumer Direction	Independent Providers	Family Providers	Hourly Limits	Monetary Limits	Waiver Wait Lists
AK	HH, PCS	PCS	PCS	M		982
T	M	M		HH. W	M	3.750
LR	PCS, W	PCS, W	PCS	PCS, W	M	991
Z	×	Ŵ		~	НН	N/A
<b>A</b> C	PCS, W	PCS, W	PCS	PCS, W	W	2,030
00	Ŵ				HH, W	4,307
T	W				HH, W	1,917
S		M		HH, PCS, W		0
DE				HH	W	0
ĩ	PCS, W	PCS, W	PCS	M	W	32, 753
<b>V</b> E	×	Ŵ		HH		11, 242
II	M	W				100
V	M	M		HH	M	2, 860
D	HH, PCS, W	W		HH, PCS	W	0
L	M	M			W	33,114
Z	W	M			W	32, 355
<b>CS</b>	PCS, W	M		W		5,445
X	M	M		HH, W		0
V	НН			HH, PCS	W	23, 839
ИА	PCS, W	PCS	PCS		W	0
<b>D</b>	M	PCS, W	PCS	PCS, W	PCS, W	27,810
ИЕ	PCS, W	PCS, W	PCS	M	M	205
II	PCS, W	PCS	PCS	M	W	3,469
AN N	PCS, W	PCS, W	PCS	HH, PCS	PCS, W	Unknown
МО	PCS, W	PCS, W	PCS	HH, PCS	PCS, W	169
MS	M	M		HH, W		7, 983
TM	PCS, W	M		PCS	M	1,380
NC	PCS, W	M		PCS	M	3, 753
Q,	HH	W			HH	0
<b>H</b>	HH. PCS. W	PCS. W	PCS	PCS	HH. W	2. 390

PCS     PCS <th>State</th> <th>Consumer Direction</th> <th>Independent Providers</th> <th>Family Providers</th> <th>Hourly Limits</th> <th>Monetary Limits</th> <th>Waiver Wait Lists</th>	State	Consumer Direction	Independent Providers	Family Providers	Hourly Limits	Monetary Limits	Waiver Wait Lists
PCS PCS, W				<i>f</i>	······ <i>(</i>	· · · · · · · · · · · · · · · · · · ·	
PCS, WPCS, WPCSPCSPCSPCSPCSWW0PCS, WPCS, WPCS, WPCS, WPCS, WPCS, WWW $44$ PCS, WPCS, WPCS, WPCSHH, WW $44$ PCS, WPCS, WPCSPCSHH, WW $44$ PCS, WPCS, WPCSPCSHH, WW $20$ PCS, WPCSPCSPCSHH, WW $20$ WWWWHH, WW $20$ WWWWHH, WW $20$ WWWWWHH, WW $20$ WWWWWW $20$ HH, W $20$ HH, WWWWMW $20$ HH, W $20$ FCS, WPCS, WPCSPCS, WPCS, WW $22$ PCS, WPCS, WPCSPCS, WPCSPCS, W $20$ HH, PCS, WPCS, WPCSPCSPCS, W $20$ PCS, WPCS, WPCSPCSPCS, WPCS $21$ states $428$ PCS, WPCS, WPCSPCS, WPCS, WPCS, W $20$ PCS, WPCS, WPCSPCSPCSPCS, W $20$ PCS, WPCSPCSPCSPCSPCS $21$ states $428$ PCS, WPCSPCSPCSPCSPCS $21$ states $428$ P	HN	PCS					0
PCS PCS PCS PCS HH, PCS, W W 0   PCS, W PCS, W PCS HH, W W HH, W   PCS, W PCS PCS HH, W W HH, W   PCS, W PCS PCS HH, W W HH, W   PCS, W PCS PCS HH, W W HH, W   PCS, W PCS PCS HH, W W HH, W   W W W HH, W W 20   W W W W W 20   PCS, W PCS, W PCS PCS, W W   PCS, W PCS PCS, W PCS 20	Ñ	PCS, W	PCS, W	PCS	PCS	M	50
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	MN	PCS	PCS	PCS		M	6, 271
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	NV	PCS, W	PCS, W	PCS	HH, PCS, W		419
WWHHWHHW $44$ PCS, WPCSPCSHH, PCSW $20$ WWHH, PCSHH, WW $20$ WWHH, WWHH, WWWWHH, WW $20$ WWWHH, WWWWHH, WWWWHH, WWWWHH, WWPCS, WPCS, WPCS, WMPCS, WPCS, WPCSPCSPCS, WPCSPCSPCSPCS, WPCSPCSPCSPCS, WPCSPCSPCSPCS, WPCSPCSPCS, WPCS<	ΥΥ	PCS, W			HH, W	M	Unknown
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	НО	M	W		HH	M	44, 293
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	OK	PCS, W	PCS	PCS	HH, W	M	5,754
	OR	PCS, W	PCS	PCS	HH, PCS	M	0
WWHHWWHH, WWWWHH, PCS, WW $W$ WHH, PCS, WWPCS, WPCS, WPCSPCS, WPCS, WPCS, WPCSPCSPCS, WPCSPCSWPCS, WPCS, WPCSPCSHH, WPCS, WPCSPCSPCS, WPCS, WPCSPCSPCS, WPCS, WPCSPCSPCS, WPCS, WPCSPCSPCS, WPCS, WPCSPCSPCS, WPCS, WPCSPCSPCS, WPCS, WPCSPCSPCS = 21 statesPCS = 21 statesPCS = 3 statesPCS = 27 statesW = 37 statesPCS = 21 statesPCS = 3 statesW = 39 statesW = 23 statesW = 32 states	PA	M			HH, W	M	20,460
	$\mathbf{RI}^1$	M	W		НН		N/A
WWHH, PCS, WW2PCS, WPCS, WPCSPCS, WW125PCS, WPCS, WPCSPCS, WW2PCS, WPCS, WPCSPCSW2PCS, WPCSPCSPCSPCS2PCS, WPCSPCSPCSPCS3PCS, WPCSPCSPCSPCS3PCS, WPCS, WPCSPCSPCS, W%PCS, WPCS, WPCSPCSPCS3PCS, WPCS, WPCSPCSPCS3PCS, WPCSPCSPCSPCS3PCS, WPCSPCSPCSPCS3W33 statesPCS = 21 statesPCS = 21 statesPCS = 3 statesPCS = 27 statesW = 37 statesPCS = 21 statesPCS = 3 statesW = 39 statesW = 37 statesW = 32 statesW = 32 states	sc		W		HH, W	M	5,807
PCS, W PCS, W PCS, WPCS PCS, W PCS, W PCS, WPCS PCS, W 	SD	W	W		HH, PCS, W	M	23
$ \begin{array}{cccccccccccccccccccccccccccccccccccc$	NL		W		M		2,666
PCS, WPCS, WPCSPCSPCSHH, WWWHH, W6PCS, WPCSPCSPCSPCS, WPCSPCSPCSPCS, WPCS, WPCSPCSPCS, WPCS, WPCSPCSPCS, WPCS, WPCSPCSPCS, WPCS, WPCSPCSPCS, WPCSPCSPCSPCS, WPCSPCSPCSPCS, WPCSPCSPCSPCS at statesPCSPCS = 21 statesPCS = 27 statesW = 37 statesPCS = 21 statesPCS = 27 statesW = 37 statesPCS = 21 statesPCS = 27 statesW = 37 statesPCS = 21 statesPCS = 27 statesW = 37 statesW = 32 statesW = 39 statesW = 32 statesW = 32 states	XL	PCS, W	PCS, W	PCS	PCS, W	M	125, 385
HH, WWHH, WHH, W6PCS, WPCSPCSPCSPCSPCS, WPCS, WPCSPCS, WWPCS, WWPCSPCS, WWPCS, WWPCSPCSPCSPCS, WPCS, WPCSPCSWHH, PCS, WWPCSPCSPCSHH = 7 statesPCS = 21 statesPCS = 21 statesHH = 5 statesPCS = 27 statesW = 37 statesPCS = 21 statesPCS = 3 statesW = 39 statesW = 37 statesW = 23 statesW = 32 states	UT	PCS, W	PCS, W	PCS	PCS		2,102
PCS, WPCSPCSPCSPCSPCS, WPCS, WPCSPCS, WWPCS, WPCS, WPCSPCS, WWPCS, WPCS, WPCSPCS, WWHH, PCS, WPCS, WPCSPCS, W $33$ HH = 7 statesPCS = 21 statesPCS = 21 statesHH = 5 states428,PCS = 27 statesW = 37 statesPCS = 21 statesPCS = 21 statesPCS = 3 statesW = 39 statesW = 37 statesW = 23 statesW = 32 states428,	VA	HH, W	M		HH, W		6, 798
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	$\mathbf{VT}^1$	PCS, W	PCS	PCS	PCS		N/A
$\begin{array}{cccccccccccccccccccccccccccccccccccc$	WA	PCS, W	PCS, W	PCS	PCS, W	M	829
HH, PCS, WPCS, WPCSPCS, W $MH$ , PCS, W $W$ $PCS$ $PCS$ , W $W$ $W$ $W$ $W$ $PCS$ $HH$ = 7 states $PCS$ = 21 states $HH$ = 21 states $HH$ = 5 states $PCS$ = 27 states $W$ = 37 states $PCS$ = 21 states $HH$ = 5 states $W$ = 39 states $W$ = 37 states $W$ = 32 states $W$ = 32 states	IW	PCS, W	W		PCS		3,963
$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$	WV	HH, PCS, W	PCS, W	PCS	PCS, W		409
HH = 7  states PCS = 21  states PCS = 21  states HH = 21  states HH = 5  states 428,  PCS = 27  states W = 37  states PCS = 21  states PCS = 3  states 8W = 32  states W = 32	WY		W				387
W = 37 states PCS = 21 states $W = 23$ states $W = 23$ states	U.S.	HH = 7 states	PCS = 21 states	PCS = 21 states	HH = 21 states	HH = 5 states	428,571
		PCS = 27 states W = 39 states	W = 37 states		PCS = 21 states W = 23 states	PCS = 3 states W = 32 states	

Note. HH = home health; PCS = state plan personal care program; W = 1915(c) waivers. Unknown means the state reported waiver wait lists but do not know how many persons are on it. <sup>1</sup>State does not have 1915(c) waiver program; service provided through 1115 waiver.

34

TABLE 3 (Continued)

# Monetary and Service Controls

Although HCBS waivers must meet the CMS cost-neutrality requirements with institutional services, most states impose additional cost control policies to keep costs low. More than half of all states (27) utilized either monetary or hourly service limits in their home health benefits in 2010. Hourly service limitations were used in 22 of these states, but none of them used both forms of limitations (see Table 3). Between 2005 and 2010, states with home health program cost controls doubled from 14 states that used such limitations in 2005. Out of these, 11 states had hourly service limits and 6 had monetary limits.

Among states with the state plan personal care program, 21 utilized some form of cost controls, with Maryland, Minnesota, and Missouri using both monetary and hourly service caps in their state plan personal care programs in 2010. This reflected an increase from 17 states that used such controls in 2005, with 16 utilizing hourly service limitations and 2 having monetary limits.

Four-fifths of all states (40 states and the District of Columbia) utilized some form of cost controls above and beyond the federally mandated costneutrality formula on their waiver programs in 2010, with 14 states using both forms of cost controls in their waivers (see Table 3). In 2005, slightly fewer (39) states used any forms of cost controls. There was a general upward trend in the use of cost controls among all Medicaid HCBS programs over the study period.

# Waiting Lists

In addition to hourly or monetary limitations, HCBS waivers may also set up waiting lists if there are more individuals in need of waiver services than the number of available spaces or "slots." In 2010, 40 states reported waiting lists in 149 waivers. There were a total of 428,571 persons on these wait lists, with the largest number of persons waiting in Texas (see Table 3). This was a 64% increase over the 260,916 persons on 102 waiver wait lists in 30 states in 2005. In 2010, the average wait time across the nation for an individual to obtain waiver services was 21 months (Howard, Ng, & Harrington, 2011). Some states did not keep records of their waiting lists so these data are most likely to be under-reported.

# **HCBS** Program Services

Medicaid HCBS programs have the flexibility to deliver a range of services to eligible persons. Table 4 shows that case management was provided by all states through waivers (either through 1915(c) HCBS waivers or, for Arizona, Rhode Island, and Vermont, through §1115 Research and Demonstration waivers) but was provided in fewer state plan personal care programs and home health programs.

State	Case Management	Personal Care	Therapy	Emergency Support/Respite	Transportation
AK	HH, PCS, W	HH, PCS	HH, W	HH, W	PCS, W
AL	M	HH, W	HH, W	W	M
AR	W	HH, PCS, W	НН	W	M
$\mathbf{AZ}^{1}$	W	HH, W	W	HH, W	M
CA	HH, W	HH, PCS, W	HH, W	HH, PCS, W	PCS, W
00	M	HH, W	НН	HH, W	M
CT	W	HH, W	НН	Ŵ	W
DC	W	HH, PCS, W	W	W	PCS, W
DE	M	HH, W	НН	M	M
FL	W	HH, PCS, W	W	W	M
GA	M	HH, W	HH, W	M	M
IH	M	HH, W	НН	M	M
IA	M	HH, W	НН	M	M
Ð	PCS, W	HH, PCS, W	НН	M	PCS, W
IL	M	HH, W	HH, W	M	M
Z	M	HH, W	HH, W	M	M
KS	PCS, W	HH, PCS, W	HH, W	M	PCS
KY	M	HH, W	HH, W	W	
LA	M	HH, PCS, W	НН	PCS, W	PCS
MA	M	HH, PCS, W	НН	M	PCS, W
MD	M	HH, PCS, W	HH, W	M	M
ME	M	HH, PCS, W	HH, W	M	PCS, W
IM	PCS, W	HH, PCS, W	HH, W	M	W
NW	M	HH, PCS, W	HH, W	W	PCS, W
MO	M	HH, PCS, W	HH, W	W	W

TABLE 4 Services Provided in Home Health, State Plan Personal Care Programs, and HCBS 1915(c) Waivers, 2010

S	M		HH, W	W	W
	M	HH, PCS, W	HH, W	W	PCS, W
~	M		HH, W	W	PCS, W
~	PCS, W		НН	W	PCS, W
(*)	M	HH, PCS	НН	W	W
F	M	HH, PCS, W	НН	W	
	PCS, W		HH, W	W	W
I	M		HH, W	HH, W	PCS, W
7	W	Γ	НН	M	
2	HH, PCS, W		НН	HH, W	W
F	, W		HH, W	Ŵ	W
×	W	HH, PCS, W	Ŵ	W	M
~	PCS, W		HH, W	PCS, W	W
	Ŵ		HH, W	Ŵ	W
_	M		HH, W	W	
	W		HH, W	W	W
_	HH, PCS, W	HH, PCS, W	НН	W	
	HH, W	HH, W	HH, W	W	W
	PCS, W	HH, PCS, W	HH, W	W	
	HH, PCS, W		НН	W	PCS, W
	M	HH, W	HH, W	W	
-	HH, W	HH, PCS, W	НН	W	
	PCS, W		HH, W	W	PCS, W
	M		НН	W	PCS, W
Δ	HH, W		НН	W	M
Y	M	HH, W	HH, W	W	
è.	U.S. $HH = 8$ states	HH = 51 states	HH = 47	HH = 6 states	PCS = 16 states
	PCS = 12 states	PCS = 32 states	states	PCS = 3 states	W = 40 states
	W = 51 states	W = 49 states	W = 32 states	W = 51 states	

*Note.* HH = home health (2010 data); PCS = state plan personal care program (2010 data); W = 1915(c) waivers (2008 data). <sup>1</sup>State does not have 1915(c) waiver program; service provided through 1115 waiver.

Personal care was provided through HCBS waivers in all states except Nebraska and Alaska, where the service was provided through their home health and the state plan personal care programs and was the only service consistently offered by all states across two or more programs.

Only one new state added the state plan personal care program between 2005 and 2010. Of the 15 states with the highest HCBS expenditure ratio (Table 1), 12 of them had state plan personal care programs (Table 4).

Therapy services were offered in most states either through the home health or the waiver programs, while transportation was not offered in 9 states. States may, however, provide these services through other Medicaid state plan programs. Emergency support and respite services were provided by all states through the waiver programs and in some state plan personal care and home health programs. Table 4 shows that across the nation, the state plan personal care and home health programs provided a more limited number of services than the waiver program. The HCBS waiver program, being the most flexible of the three programs, provided all five services in most states. An analysis of service provision within the HCBS programs shows that there were no changes in the services offered between 2005 and 2010.

#### **Reimbursement** Policies

States have wide flexibility in developing reimbursement policies for HCBS programs and providers, which may also serve as cost controls. Reimbursement rates were collected for the home health and the state plan personal care program but not for waiver programs due to the varying array of services and reimbursement rates within waiver programs. In 2010, states provided an average reimbursement to agencies of \$89 per home health visit, with New Mexico providing the highest reimbursement and Florida providing the lowest (see Table 5). This was a 2% increase from the agency rate (\$87 per home health visit) in 2005, which did not keep up with the rate of inflation in the same period of 12% (Bureau of Labor Statistics, 2013). Among states that paid registered nurses (RNs) or home health aides (HHA) directly or mandated their payments within the home health program, the average rate was \$96 per visit for RNs and \$54 per visit for HHAs in 2010. This was a 28% and 38% increase, respectively (\$75 per RN visit and \$39 per HHA visit), from 2005.

Among the 32 states that provided the state plan personal care program, the average rate paid to agencies providing personal care was \$17.73 per hour in 2010, almost no increase over the 2005 rate (\$17.65 per hour). For direct reimbursement to personal care providers or where reimbursement rates were determined by the state, the average rate was \$12

		Home Health (\$ per Visit)		State Plan P	State Plan Personal Care (\$ per Hour)	s per Hour)
State	Agency	Registered Nurse	Home Health Aide	Agency		Provider
	169.36 27 00/haur			22.78	Not offered	12.00
		114.50				14.25
			9.15/hour	20.85	Not offered	10.15
		96.26	34.15	0.07	Not offered	(T'OT
		94.26/hour	24.40/hour		Not offered	
	76.00	62.00	17.90/hour	17.80		14.50
		139.45/hour	30.80/hour		Not offered	
	24.65			15.00		15.00
	61.32	61.32	61.32		Not offered	
					Not offered	
	112.26	94.73	40.14		Not offered	
	126.23	233.05	94.74	15.56		13.36
	61.34	61.34	61.34		Not offered	
	29.05	38.96/hour	20.07/hour		Not offered	
		50.00	40.50	13.25		13.25
		88.16	34.13		Not offered	
	49.32/day	68.65/day	24.38/day	12.88		
		86.99	27.96/hour			12.48
		115.62	54.81	33.98/day		33.98/day
	85.95	26.00/hour	10.00/hour	14.57		8.52
	81.45	81.65	51.72	9.39		7.35
		32.02/hour	54.29	15.84		
	64.15	64.15	64.15	16.64		
	75.85				Not offered	
		71.81		17.64		
		105.44	48.24	14.16		
	95.24	95.24	95.24	18.75		13.16

**TABLE 5** Medicaid Home Health and State Plan Personal Care Proorams' Provider Reimbursement Rates 2010

		Home Health (\$ per Visit)		JUAIC FIAIL	State Plan Personal Care (\$ per Hour)	\$ per Hour)
State	Agency	Registered Nurse	Home Health Aide	Agency		Provider
— ш	81.89	36.71/hour	50.58			8.39
Н		87.36/hour	23.56/hour	17.84		2
1		117.21/hour	25.87/hour	16.00		
W	330.71			13.16		9.65
Λ		51.44/hour		17.00		
Y		113.12/hour	29.76/hour	20.19		
Η		38.86/hour	17.99/hour		Not offered	
K	51.48	70.87	32.09	14.52		
R		173.16	55.14	19.94		10.20
_	88.00				Not offered	
_	64.50	64.50			Not offered	
0		72.65	39.13		Not offered	
0		47.84/hour	30.92/hour	14.20		
Z					Not offered	
×		45.14/hour		10.57		
I	14.00/hour			14.00		
-		185.94	73.28		Not offered	04.0
	55 78	55 78	55 78	17 38		00.6 22.01
IM		32.66/hour	39.71	63.36		
× ×	52.00			76.61	Not offered	
.S.	\$89.36/visit	\$95.69/visit	\$54.02/visit	\$17.73/hour	_	\$11.50/hour
Average						

TABLE 5 (Continued)

per hour or 30% higher than in 2005 (\$9 per hour). In 2010, Wisconsin was one of the more generous states, paying \$63 per hour to personal care agencies while Michigan paid only \$9 per hour to personal care agencies (see Table 5).

# DISCUSSION AND CONCLUSION

Medicaid HCBS policies vary within state programs and across states and directly affect access to such programs. States have many opportunities to expand existing policies in order to increase access. In terms of financial eligibility policies, five states offering the state plan personal care program could expand coverage to the medically needy since they do not do so currently. Twenty percent of states (10) had more restrictive criteria than 300% of SSI for the categorically needy. In addition, three states had varying financial eligibility criteria across some waivers, which can cause confusion for Medicaid consumers and can limit access. Moreover, most states have not changed their financial eligibility requirements over time to allow for greater access. The standardization and liberalization of income requirements to 300% of SSI and medically needy spend down across the various HCBS programs would improve access to HCBS.

The importance of personal care services in preventing institutionalization and encouraging deinstitutionalization has been shown in previous studies (LaPlante, Kaye, Kang, & Harrington, 2004; Muramatsu & Campbell, 2002; Richmond, Beatty, Tepper, & DeJong, 1997). This study shows that personal care services are provided statewide under the state plan personal care program in only 63% of the states in 2010. In the 19 states without state plan programs, personal care was offered through the waiver program where individuals must meet the institutional need requirements and may be subject to restrictions such as possible waiting lists, limited service hours, and high monetary limits. States with state plan personal care programs tended to have the best ratios on rebalancing HCBS expenditures. This is consistent with recent findings regarding the impact of increasing access to state plan personal care services (Ruttner & Irvin, 2013).

Under the new Community First Choice 1915(k) program, established by the ACA, states are given a new option to expand their personal care programs in return for an enhanced federal matching rate of 6 percentage points. Only California and Oregon have been approved, and 6 other states (Arizona, Colorado, Louisiana, Maryland, Minnesota, and Montana) have applied (National Association of States United for Aging & Disabilities, 2013). All but 2 of these states (Arizona and Colorado) already have state plan personal care programs. It is hoped that more states will take advantage of this option to add state plan personal care programs. However, with fiscal austerity in place and the added burden of reporting and oversight required under Community First Choice, many states appear to prefer to provide personal care services in the waiver programs so that they can limit the number of individuals who can be served (Kaiser Commission on Medicaid & the Uninsured, 2011).

The home health and state plan personal care programs offered a more limited array of services than waiver programs. Case management was offered by all waivers and in some state home health and personal care programs. Therapy, transportation, emergency support, and respite services were offered in most waiver programs and showed no changes in availability between 2005 and 2010. The wide range of HCBS waiver services within state programs limit access for some target groups and may create confusion and unnecessary administrative work. States should consider standardizing service benefits across their waivers for all target groups to improve choice and access.

The most positive finding in this study was the large expansion of consumer direction for the state plan personal care program and the use of independent providers within state plan personal care and waiver programs between 2005 and 2010. The cash and counseling programs and other initiatives such as the 1915(j) self-directed personal assistance program have increased the use of independent providers, which has improved consumer satisfaction (Doty, Mahoney, & Sciegej, 2010). In spite of these positive changes demanded by consumer advocacy organizations, access to consumer direction could be expanded in 16% of state plan personal care programs, in 24% of waivers, and in 86% of home health programs that do not currently allow consumer direction. Another positive change is the almost doubling of states that allow family members to be paid personal care providers, but 61% of states still do not allow it. Policies that encourage independent providers, especially spouses and family members, may increase the supply of workers and increase participant satisfaction (Newcomer, Kang, & Dotv. 2012).

Many states have in place additional cost controls such as wait lists and service limits beyond those imposed by CMS cost-neutrality requirements. Eighty percent of states have enacted some cost controls in terms of cost ceiling and limits on hours of service or both, and the number of states using such controls has increased over the 2005–2010 period. Previous studies have shown that the per person cost for waiver services are only about one-third of the equivalent institutional cost (Harrington, Ng, & Kitchener, 2011; Grabowski, 2006). Relaxing the cost controls would increase consumer choice and access and may have little impact on program costs. The more than 60% increase in the number of persons on waiver waiting lists over the study period shows the increasing demand and unmet need for HCBS around the country. Although there has been a large increase in provider reimbursement rates paid directly to home health and personal care providers, agency

43

reimbursement rates did not keep pace with inflation over the study period. Until states are willing to change their HCBS policies to improve access to programs, we can expect the wide variations in access and the waiting lists to continue.

The federal Money Follows the Person demonstration, started in 2005, was expanded under the ACA with an enhanced federal matching rate for 1 year for each Medicaid person who transitions from an institution to the community. This program, implemented in 45 states and the District of Columbia, has been credited with the deinstitutionalization of almost 20,000 persons (CMS, 2013b; Ng et al., 2012). To the extent that states have restrictive HCBS policies on expenditures and hours of service for home health, personal care, and waivers, individuals with high care needs who have been transitioned could be at risk for re-institutionalization in some states.

The success of some states (such as New Mexico, which spent 95% on HCBS) in rebalancing their LTSS expenditures towards HCBS (Eiken et al., 2011) show the value in adopting a combination of state and federal policies to rebalance Medicaid LTSS programs. The ACA has given states more program options for expanding HCBS, such as offering HCBS waivers as a state plan benefit [§1915(i)], with a number of specific program requirements. A number of states are taking advantage of these new ACA program options, and states have continued to expand the number of their HCBS waivers (to 288 in 2010; Ng et al., 2012). While these new HCBS programs appear to be valuable, they are adding to the state administrative burden and complexity of HCBS policies and programs.

The Balancing Incentive Payment Plan under the ACA, which rewards states to rebalance their Medicaid LTSS programs towards HCBS, has had 13 states approved to receive bonus payments to increase their HCBS share of LTSS (Ng, Stone, & Harrington, 2012; National Association of States United for Aging & Disabilities, 2013). This program focuses on rebalancing efforts for statewide LTSS systems rather than for individual population groups such as I/DD or the aged and disabled. While significant progress has been made for the I/DD population, rebalancing for the non-I/DD population has been slow and should be more widely examined. States need to identify and eliminate policies that are barriers to rebalancing for non-I/DD populations.

States have expanded integrated care programs for those dually eligible for Medicare and Medicaid such as the Programs of All-Inclusive Care for the Elderly (PACE). The PACE programs provide comprehensive LTSS and have been successful in keeping nursing home costs and overall costs below fee-for-services costs (Wieland, Kinosian, Stallard, & Boland, 2013). PACE programs must meet overall CMS guidelines and are not subject to the specific policies established for Medicaid HCBS programs.

In 2012, 16 states moved some or all of their Medicaid fee-forservice programs to managed care organizations (MCOs), and 26 states are expected to develop programs by 2014 and many include LTSS (Saucier, Kasten, Burwell, & Gold, 2012). Some MCO demonstration projects combine Medicare and Medicaid funding for those who are dually eligible and are designed to integrate acute care and LTSS (including institutional and HCBS) into a single program and vary in their design. Although states' projects must meet overall CMS guidelines, states may establish their own requirements for MCOs. MCOs typically have little experience providing LTSS (Gold, Jacobson, & Garfield, 2012), and this change may result in reduced access to HCBS as well as limited data reporting on policies, participants, and expenditures. Since existing state policies for home health, state plan personal care, and 1915(c) waiver programs probably may not apply to MCOs, future research should study what policies are adopted for MCOs and how these impact the provision of HCBS.

In the future, state Medicaid HCBS policies should be tracked more closely by CMS and data made readily available to the public so that researchers can study the direct links between policy variations and outcomes on access, quality, satisfaction, and costs of HCBS. The task of tracking HCBS policies and programs has become more challenging in recent years as state HCBS programs grow in availability, size, and complexity over time, especially for HCBS programs embedded within MCOs. Continuing rebalancing efforts are needed to expand HCBS access by liberalizing and standardizing HCBS policies for all Medicaid populations.

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#### REFERENCES

- Bureau of Labor Statistics. (2013). *Consumer Price Index*. Washington, DC. Retrieved from http://www.bls.gov/cpi/
- Centers for Medicare and Medicaid Services (CMS). (2009). *§1915(j) Self-Directed Personal Assistance Services State Plan Option: Approved SPAs.* Baltimore, MD. Retrieved from http://web.bc.edu/libtools/downloadfile. php?filename=1270661696\_CMS\_Handout.pdf
- Centers for Medicare and Medicaid Services (CMS). (2010). *Medicaid and CHIP Statistical Information System (MSIS) file specifications and data dictionary. Release 3.1.* Retrieved from http://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/MSIS/downloads/msisdd2010.pdf

- Centers for Medicare & Medicaid Services (2013a). *Medicaid Statistical Information System (MSIS) state summary datamart*. Retrieved from http://www. cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/ MedicaidDataSourcesGenInfo/MSIS-Mart-Home.html
- Centers for Medicare and Medicaid Services (CMS). (2013b). *Money Follows the Person (MFP)*. Retrieved from http://medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html
- Doty, P., Mahoney, K. J., & Sciegej, M. (2010). New state strategies to meet long-term care needs. *Health Affairs*, 29(1), 49–56.
- Eiken, S., Sredl, K., Burwell, B., & Gold, L. (2011). *Medicaid expenditures for longterm services and support: 2011 update*. Cambridge, MA: Thomson Reuters.
- Gold, M., Jacobson, G., & Garfield, R. (2012). There is little experience and limited data to support policy making on integrated care for dual eligibles. *Health Affairs*, *31*(6), 1176–1185.
- Grabowski, D. C. (2006). The cost-effectiveness of non-institutional long-term care services: review and synthesis of the most recent evidence. *Medical Care Research and Review*, 63(1), 3–28.
- Harrington, C., Carrillo, H., Wellin, V., Norwood, F., & Miller, N. (2001). Access of target groups to home and community based waiver services. *Home Health Care Services Quarterly*, 20(2), 61–80.
- Harrington, C., Ng, T., & Kitchener, M. (2011). Do Medicaid home and community based service waivers save money? *Home Health Care Services Quarterly*, *30*(4), 198–213.
- Howard, J., Ng, T., & Harrington, C. (2011). Medicaid home and community-based service programs: Data update. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. Retrieved from http://kff.org/medicaid/report/ medicaid-home-and-community-based-service-programs/
- Kaiser Commission on Medicaid & the Uninsured. (2011). Moving abead amid fiscal challenges: A look at Medicaid spending, coverage and policy trends results from a 50-state Medicaid budget survey for state fiscal years 2011 and 2012. Washington, DC: Author. Retrieved from http://www.kff.org/medicaid/8248.cfm
- Kaiser Family Foundation. (2010). *Summary of new health reform law. Patient Protection and Affordable Care Act (ACA) (Public Law 111-148).* Washington, DC; Author. Retrieved from http://www.kff.org/healthreform/8061.cfm
- Kitchener, M., Ng, T., Miller, N., & Harrington, C. (2005). Medicaid home and community-based services: National program trends. *Health Affairs*, 24(1), 206–212.
- Kitchener, M., Ng, T., & Harrington, C. (2007a). Medicaid state plan personal care services: Trends in programs and policies. *Journal of Health and Social Policy*, 19(3), 9–26.
- Kitchener M., Ng T., and Harrington, C. (2007b). State Medicaid Home Care Policies: Inside the Black Box. *Home Health Care Services Quarterly*, *26*(3), 23–38.
- LaPlante, M. P. (2013). The woodwork effect in Medicaid long term care services and supports. *Journal of Aging and Social Policy*, *25*, 161–180.
- LaPlante, M., Kaye, S., Kang, T., & Harrington, C. (2004). Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences. *Journals of Gerontology: Social Sciences*, *59B*(2), S98–S108.

- Muramatsu, N., & Campbell, R. (2002). State expenditures on home and communitybased services and use of formal and informal personal assistance: A multilevel analysis. *Journal of Health and Social Behavior*, *43*, 107–124.
- National Association of States United for Aging & Disabilities. (2013). State Medicaid integration tracker. Retrieved from http://www.nasuad.org/ medicaid\_integration\_tracker.html
- Newcomer, R. J., Kang, T., & Doty, P. (2012). Allowing spouses to be paid personal care providers: Spouse availability and effects on medicaid-funded services use and expenditures. *The Gerontologist*, *52*(4), 517–530.
- Ng, T., & Harrington, C. (2014). *Medicaid home and community-based service programs: 2010 data update*. Report prepared for the Kaiser Commission on Medicaid and the Uninsured. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. March 2014. Retrieved from http://kff.org/medicaid/report/ medicaid-home-and-community-based-service-programs/
- Ng, T., Harrington, C., & Kitchener, M. (2010). Medicare and Medicaid in long-term care. *Health Affairs*, *29*(1), 22–28.
- Ng, T., Harrington, C., & Musumeci, M. (2011). *State options that expand access to Medicaid home and community-based services*. Washington, DC. Kaiser Family Foundation.Retrieved from http://www.kff.org/medicaid/8241.cfm
- Ng, T., Harrington, C., Musumeci, M., & Reaves, E. (2012). *Medicaid home and community based service programs: 2009 data update*. Report prepared for the Kaiser Commission on Medicaid and the Uninsured. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. December 2012. Retrieved from http://www.kff.org/medicaid/upload/7720-06.pdf
- Ng, T., Stone, J., & Harrington, C. (2012). *State implementation of ACA provisions to increase access to home and community based services*. San Francisco: University of California, San Francisco.
- Richmond, G., Beatty, P., Tepper, S., & DeJong, G. (1997). The effect of consumer directed personal assistance services on the productivity outcomes of people with disabilities. *Journal of Rehabilitation Outcomes Measurement*, 1(4), 48–51.
- Patient Protection and Affordable Care Act (ACA) (PL. 11-148). Signed by President Barack Obama on March 23, 2010.
- Ruttner, L., & Irvin, C. V. (2013). Implications of state methods for offering personal assistance services. Medicaid policy brief. Princeton, NJ: Mathematica Policy Research, No. 18, June.
- Saucier, P., Kasten, J., Burwell, B., & Gold, L. (2012). the growth of managed longterm services and supports (MLTSS) programs: A 2012 update. Prepared for CMS. Ann Arbor, MI: Truven Health Analytics.
- Stone, J. (2011). *Medicaid eligibility for persons age* 65+ *and individuals with disabilities: 2009 state profiles.* Washington, DC. Congressional Research Service.
- U.S. Department of Health and Human Services (U.S. DHHS), Office of the Assistant Secretary for Planning and Evaluation. (2010). *Understanding Medicaid home and community services: A primer. 2010 edition.* Washington, DC: ASPE.
- U.S. Supreme Court. (1999). *Olmstead v. L.C.* (98-536) 527 U.S. 581 (1999). Retrieved from http://supct.law.cornell.edu/supct/html/98-536.ZS.html
- Wieland, D., Kinosian, B., Stallard, E., & Boland, R. (2013). Does Medicaid pay more to a program of all-inclusive care for the elderly (PACE) than for fee-forservice long-term care? *Journal of Gerontology: A Biological Science and Medical Science*, 68(1), 47–55.