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Home and Community Based Services (HCBS) Waivers: A Nationwide Study of the States

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Abstract

In fiscal year (FY) 2009, the Medicaid program funded over 75% of all publicly funded long-term supports and services (LTSS) for individuals with intellectual and developmental disabilities (IDD) in the United States (Braddock et al., 2011). The majority of spending was attributed to the Home and Community Based Services (HCBS) Waiver program. In FY 2009, federal–state spending for the HCBS Waiver program reached over $25.1 billion and constituted almost half of total funding across the nation that year (Braddock et al., 2011). Considerable effort has been spent investigating Medicaid program expenditures, however, due in part to the unique and state-specific nature of HCBS programs, national-level analysis on the types of services offered to individuals with IDD has not been available. A full understanding of the supports available through the Medicaid program is critical as the United States considers strategies for economic recovery among competing state and federal budget priorities. This article presents the results of an analysis of 88 Medicaid HCBS Section 1915(c) waiver applications for individuals with intellectual and developmental disabilities in 41 states and the District of Columbia. It analyzes IDD data and trends close to the real time intent of states and empowers advocates in presenting timely solutions to real-time issues.

Key Words: *HCBS waiver; intellectual and developmental disabilities (IDD); IDD funding; Medicaid funding*

Efforts to track and estimate U.S. Medicaid spending has long been a topic of inquiry (e.g., see Kaiser Commission on Medicaid and the Uninsured & Health Management Associates, 2010, and Braddock et al., 2011). The Medicaid program provides funding for several long-term supports and services (LTSS) through a variety of mechanisms in a range of settings. In fact, Medicaid serves as the primary payer for LTSS in the United States. According to the Kaiser Commission on Medicaid and the Uninsured (2010), 33.9% of all Medicaid expenditures was for LTSS in 2008. The commission also reported that although children and their parents represent nearly three fourths (74%) of Medicaid enrollees, over two thirds (67%) of Medicaid spending can be attributed to the elderly and people with disabilities.

The Medicaid program funded over 75% of all publicly funded long-term supports for individuals with intellectual and developmental disabilities (IDD) in the United States in fiscal year 2009 (Figure 1) (Braddock et al., 2011). The majority of this spending was attributed to the Home and Community Based Services (HCBS) Waiver program. The HCBS Waiver was first authorized by Congress in 1981 as an avenue for states to target groups of beneficiaries at risk of institutionalization, including frail seniors who would otherwise require care in nursing homes as well as individuals with IDD who would otherwise need care in an intermediate care facility (Gettings, 2012). The demand for community-based services continued to grow as a result of increased advocacy promoting deinstitutionalization and a host of class-action litigation promoting access to home and community-based supports. States were able to use the new flexible Medicaid HCBS Waiver program to fund expansion of their community services and received federal matching dollars for doing so. The HCBS Waiver ultimately became the primary funding source for promoting long-term services and supports for people with IDD. Its use has increased

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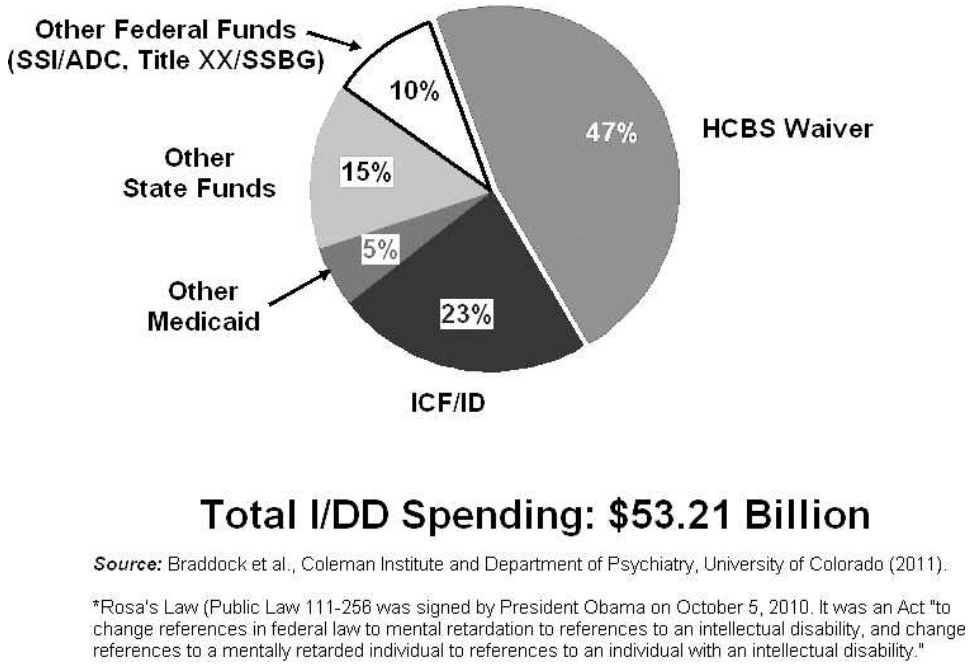

Figure 1. Federal–state Medicaid is the majority of total intellectual and developmental disabilities spending in fiscal year 2009.

each year since 1981, and over 572,000 individuals with IDD were supported in 2009 (Figure 2) (Braddock et al., 2011). In FY 2009, federal–state spending for the HCBS Waiver program reached over $25.1 billion and constituted almost half of total funding across the nation that year (Braddock et al., 2011).

The HCBS Waiver program reimburses states for a variety of community-based supports and services, including habilitation training, respite

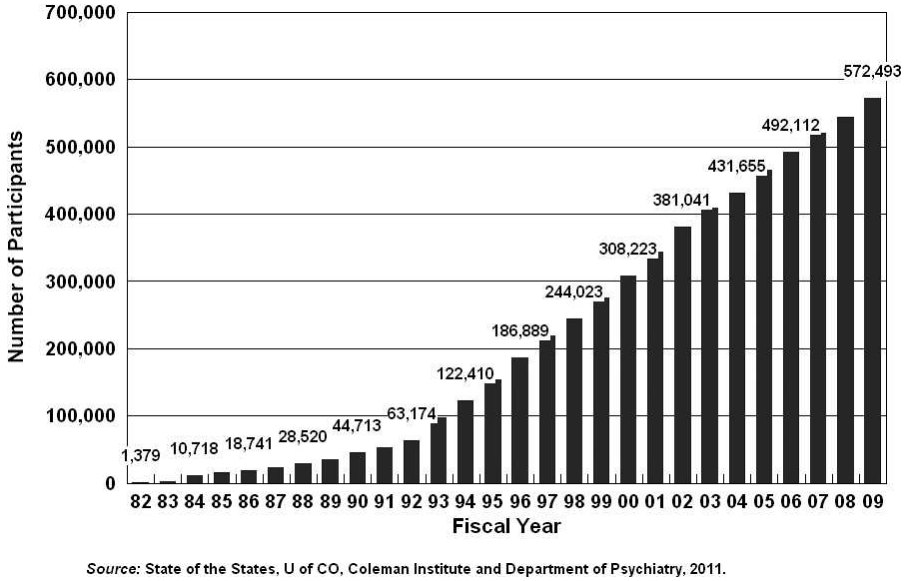

Figure 2. United States HCBS Waiver participants.

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care, employment, transportation, and behavior management and other therapies. No state provides all of these options, yet a considerable amount of variation exists among states with respect to services offered. When submitting HCBS Waiver applications to the Centers for Medicare and Medicaid Services (CMS), states have the flexibility to determine eligibility criteria, offered services, and provider requirements. States are also allowed to waive certain federal Medicaid regulations such as comparability, state-wideness, and income and resource rules. By waiving the comparability requirement, states are able to target certain groups of at-risk individuals. For example, states can target adults with developmental disabilities, people with traumatic brain injury, or children with autism. By waiving the state-wideness requirement, states are able to target waivers to specific areas of the state, such as rural areas or areas of great need. Finally, when states waive the income and resource rules, they are able to enroll individuals in the waiver who would otherwise only be eligible to receive services in a nursing home or intermediate care facility for the intellectually disabled (ICF/ID), or whose spouse or parent's resources deem them ineligible. Thus, states are allowed a substantial level of flexibility to provide services to individuals with disabilities and their families though the waivers must demonstrate cost neutrality.

As previously stated, considerable effort has been spent investigating Medicaid program expenditures; however, due in part to the unique and state-specific nature of HCBS programs, national-level analysis on the types of services offered to individuals with IDD has not been previously available. A full understanding of the current services and supports made possible through the Medicaid program is critical as the United States considers strategies for economic recovery among competing state and federal budget priorities. The present study examines projected spending allocations and priorities in the states for long-term care supports for individuals with IDD in FY 2010 and the impact of the Great Recession on HCBS Waivers in the states. To this end, this article presents the results of an analysis of 88 Medicaid Home and Community Based Services (HCBS) Section 1915(c) waiver applications for individuals with IDD in 41 states and the District of Columbia.

Method

Waiver data for this analysis were obtained by reviewing each waiver application that was available on the CMS Medicaid.gov Web site over a period of 20 months (May 2010 to January 2012). It should be noted that the authors were aware of at least 25 additional waiver programs that were operating in the states in FY 2010; however, these programs were not available on the CMS Web site for inclusion in the analysis. This is similar to the method used in a previous study by Hall-Lande, Hewitt, and Moseley (2011), in which the authors examined the extent to which states had included services for individuals on the autism spectrum in their HCBS Medicaid waiver programs. To be included in this analysis, the waiver application had to specify that the target group served by the waiver included either autism (ASD), developmental disability (DD), or mental retardation (MR). No age limits were used in the selection criteria. In addition to a review of the over 450 waiver applications available on the CMS Web site, the state developmental disability agency or division Web sites were reviewed, and staff agency were contacted when study staff were aware of an IDD waiver application that was unavailable online. Through this three-step process, we were able to amass 88 separate 2010 waiver applications for analysis from 41 states and the District of Columbia. For each waiver application, the waiver year most closely aligned with July 1, 2009 to June 30, 2010 (i.e., FY 2010) was utilized. For many states, this was the state fiscal year used in their waiver applications. Some states used the federal fiscal year of October 1, 2009 to September 30, 2010, whereas some states used the 2010 calendar year. For consistency, the term *fiscal year* (FY) will be used throughout this summary. The data presented in this summary represent the latest data that was available to the researchers as of January 1, 2012. Over half of the waivers analyzed were amended at least one time over the 20-month period of analysis.

Data was extracted from each waiver application to determine the types of services available, the projected number of users, the average units of service per user, and the average cost of each unit of service. States are required to enter this information in their application to CMS to demonstrate the cost neutrality mandate for HCBS Waivers. States project future waiver years' spending based

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Table 1
FY 2010 Spending by Category

Category	Total proposed spending (in millions)	%
Residential habilitation	$ 12,381.1	52.616%
Day habilitation	$ 4,413.4	18.755%
Companion/homemaker/chore/personal assistance/ supported living	$ 2,653.4	11.276%
Prevocational	$ 718.8	3.055%
Supported employment	$ 594.3	2.526%
Family training and counseling	$ 537.1	2.283%
Family training and counseling	$ 23.5	0.100%
Family supports	$ 513.5	2.182%
Transportation	$ 495.4	2.106%
Care coordination	$ 454.0	1.929%
Health and professional services	$ 451.8	1.920%
Dental	$ 12.8	0.054%
Clinical and therapeutic services	$ 207.1	0.880%
Nursing and home health	$ 207.4	0.881%
Crisis	$ 24.6	0.104%
Respite	$ 330.2	1.403%
Assistive and medical technologies	$ 287.0	1.220%
Assistive technology and environmental modifications	$ 126.2	0.536%
Medical equipment and PERS	$ 160.8	0.683%
Community transition supports	$ 160.0	0.680%
Financial support services	$ 25.6	0.109%
Adult day health	$ 21.7	0.092%
Individual goods and services	$ 4.0	0.017%
Self-advocacy training	$ 2.1	0.009%
Education	$ 0.7	0.003%
Recreation and leisure	$ 0.3	0.001%
Total	$ 23,531.0	

Note. PERS = personal emergency response system.

on prior years' data with certain adjustments. Furthermore, states cap the number of persons who may be enrolled in the waiver, and many waivers cap the maximum cost per person so that they do not exceed the cost-neutrality limit. Additionally, the definitions of each waiver service provided in the 88 waivers (n = over 1,300) were analyzed to determine patterns across services. This analysis aided in the creation of a taxonomy of services very similar to one developed by Thompson Reuters and Mathematica during the same period (Eiken, 2011, September). The present taxonomy, however, was specifically tailored to IDD waivers.

Finally, an analysis of 93 amendments to the 88 HCBS waivers (some states filed more than one amendment for each waiver) included in the study that were filed with CMS over a period of 20 months allowed for the evaluation of the reasons states provided for amending their previously approved waivers.

Findings

Total Spending

The total IDD spending proposed by the states to CMS for FY 2010 (41 states and DC; 88 waivers) was $23.5 billion. Data reported in the *State of the*

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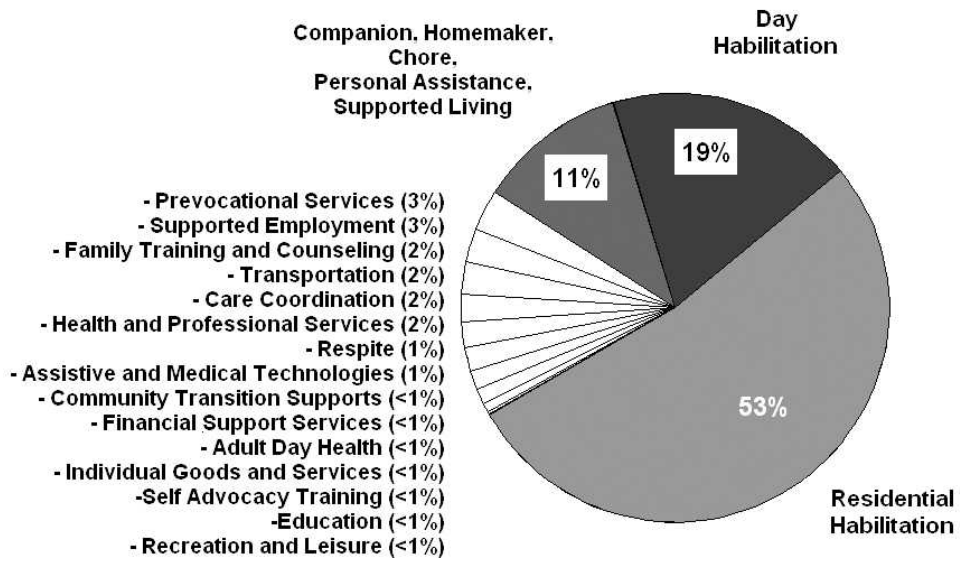

Figure 3. Distribution of services available through the HCBS Waivers, fiscal year 2010.

States in Developmental Disabilities 2011 (Braddock et al., 2011) indicated that states spent approximately $25.1 billion in FY 2009, so the sample of 88 waivers analyzed was highly representative of all HCBS Waivers for persons with IDD.

For each of the approximately 1,300 services offered through the 88 HCBS Waivers, we reviewed the definitions provided to CMS and created themes and subthemes. Our final taxonomy included 18 categories of support: (a) residential habilitation, (b) companion/homemaker/chore/personal assistance/supported living, (c) adult day health, (d) community transition supports, (e) day habilitation, (f) financial support services, (g) care coordination, (h) transportation, (i) prevocational services, (j) supported employment, (k) assistive and medical technologies, (l) health and professional services, (m) respite, (n) family training and counseling, (o) individual goods and services, (p) self-advocacy training, (q) education, and (r) recreation and leisure. Table 1 summarizes spending for FY 2010 for each of these categories. Data on eight additional subcategories is also presented.

The data demonstrate that the primary service category funded through the 88 IDD Waivers analyzed was residential habilitation services. Approximately $12.4 billion, or 53% of the total proposed 2010 waiver spending, was projected to be spent by the states for this service category, followed by day habilitation (19%) and companion/homemaker/chore/personal assistance/supported living, which constituted 11% of total projected spending. (See Figure 3.)

Core Service Definitions

The instructions, technical guide, and review criteria for the Home and Community-Based Wavier (Version 3.5) provide guidance to states on core service definitions. States are free to adapt or modify these definitions as appropriate and determine any limitations on the amount, duration, and frequency of their provision. Furthermore, even when multiple states use the same service definition, variations may still exist regarding allowable and unallowable costs.

Residential habilitation. In its HCBS Waiver technical guide (Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services, 2008, January), CMS defines residential habilitation as:

> … individually tailored supports that assist with the acquisition, retention, or improvement in skills related to living in the community. These supports include adaptive skill development, assistance with activities of daily living, community inclusion, transportation, adult educational supports, social and leisure skill development, that assist the participant to reside in the most integrated setting appropriate to his/her needs. Residential habilitation also includes personal care and protective oversight and supervision. Payment is not be made for the cost of room and board, including the cost of building maintenance, upkeep and improvement. … Residential habilitation may be furnished in

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Table 2
FY 2010 Home and Community-based Services Waivers

State	Waiver number	2010 Estimated grand total	Total estimated unduplicated participants	Average estimated cost per participant	Average length of stay on the waiver	Target group
Alabama	AL.0001.R06.01	$ 266,944,217	5,260	$ 50,750	351	ID
Alabama	AL.0391.R02.00	$ 8,560,240	569	$ 15,044	348	ID-child
Alaska	AK.0260.R03.02	$ 126,624,721	1,752	$ 72,274	357	DD, including ID & ASD
Arkansas	AR.0188.R04.03	$ 155,078,314	4,203	$ 36,897	356	DD, including ID & ASD
California	CA.0336.90.R1	$ 2,224,654,054	90,000	$ 24,718	327	DD, including ID & ASD
Colorado	CO.0434.R01.01	$ 761,687	121	$ 6,295	99	ASD-child
Colorado	CO.0007.R06.01	$ 286,154,494	4,569	$ 62,630	345	DD, including ID & ASD
Colorado	CO.0305.R03.00	$ 9,323,480	160	$ 58,272	289	DD-child (including ID & ASD)
Colorado	CO.0293.R03.01	$ 49,678,180	3,479	$ 14,279	336	DD, including ID & ASD
Colorado	CO.4180.R03.02	$ 6,634,233	454	$ 14,613	320	DD-child (including ID & ASD)
Connecticut	CT.0437.R01.01	$ 420,331,994	5,120	$ 82,096	356	ID
Connecticut	CT.0426.90.01	$ 107,819,128	5,578	$ 19,329	352	ID
Delaware	DE.009.R06.00	$ 94,765,878	940	$ 100,815	350	DD, including ID & ASD
Dist of Columbia	DC.0307.R02.01	$ 147,010,892	1,655	$ 88,828	314	DD, including ID & ASD
Florida	FL.0294.R03.01	$ 216,327,927	15,000	$ 14,422	333	DD, including ID & ASD
Georgia	GA.0323.90.R1.03	$ 231,824,359	6,289	$ 36,862	299	DD, including ID & ASD
Georgia	GA.0175.R04.01	$ 88,818,446	7,793	$ 11,397	292	DD, including ID & ASD
Idaho	ID.0076.R04.04	$ 111,748,473	3,210	$ 34,813	335	DD, including ID & ASD
Illinois	IL.0473.R00.01	$ 11,048,500	175	$ 63,134	320	DD-child (including ID & ASD)
Illinois	IL.0350.R02.01	$ 449,089,975	15,225	$ 29,497	335	DD, including ID & ASD
Illinois	IL0464.R01.01	$ 14,756,400	1,100	$ 13,415	333	DD-child (including ID & ASD)
Indiana	IN4151.R04.00	$ 19,146,649	530	$ 36,126	346	ASD
Indiana	IN0378.R02.01	$ 548,394,764	7,370	$ 74,409	347	DD, including ID & ASD
Iowa	IA0242.R04.01	$ 365,418,747	12,540	$ 29,140	339	ID
Kansas	KS0476.R00.01	$ 2,591,717	75	$ 34,556	260	ASD-child
Kansas	KS0224.R04.02	$ 286,702,557	8,352	$ 34,327	346	DD, including ID & ASD
Louisiana	LA0401.R01.08	$ 586,820,289	9,000	$ 65,202	356	DD, including ID & ASD
Louisiana	LA0472.R00.03	$ 19,743,447	365	$ 54,092	156	DD, including ID & ASD
Louisiana	LA0361.R02.02	$ 14,634,114	1,700	$ 8,608	294	DD-child (including ID & ASD)

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Table 2
Continued

State	Waiver number	2010 Grand total	Total estimated unduplicated participants	Average estimated cost per participant	Average length of stay on the waiver	Target group
Louisiana	LA0453.R01.01	$ 26,471,540	2,500	$ 10,589	310	DD, including ID & ASD
Maryland	MD0023.R05.04	$ 676,516,444	12,450	$ 54,339	344	DD, including ID & ASD
Maryland	MD0339.R02.00	$ 33,668,963	1,000	$ 33,669	355	ASD-child
Maryland	MD0424.R01.02	$ 16,008,527	400	$ 40,021	268	DD, including ID & ASD
Massachusetts	MA064.92.R4	$ 752,282,792	12,500	$ 60,183	332	ID
Massachusetts	MA40207.00	$ 2,178,212	84	$ 25,931	332	ASD-child
Minnesota	MN0061.90.R3.09	$ 1,163,200,458	15,571	$ 74,703	355	DD, including ID & ASD
Mississipi	MS0282.R03.00	$ 49,773,293	2,400	$ 20,739	361	DD, including ID & ASD
Missouri	MO0698.R00.00	$ 3,082,162	175	$ 17,612	274	ASD-child
Missouri	MO40185.R03.00	$ 1,692,144	216	$ 7,834	350	DD-child (including ID & ASD)
Missouri	MO0404.R01.02	$ 8,854,750	1,217	$ 7,276	305	DD, including ID & ASD
Missouri	MO40190.90.R1	$ 8,132,648	95	$ 85,607	310	DD, including ID & ASD
Missouri	MO0178.R04.02	$ 326,305,574	7,775	$ 41,969	308	DD, including ID & ASD
Montana	MT0208.R04.02	$ 88,092,901	2,300	$ 38,301	345	DD, including ID & ASD
Montana	MT667.R00.01	$ 2,521,992	55	$ 45,854	335	ASD-child
Montana	MT0371.R02.02	$ 1,962,786	320	$ 6,134	345	DD, including ID & ASD
Nebraska	NE4154.R04.02	$ 23,661,971	425	$ 55,675	306	DD-child (including ID & ASD)
Nebraska	NE0454.R01.02	$ 1,270,224	260	$ 4,885	306	DD, including ID & ASD
Nevada	NV0125.R05.02	$ 93,752,222	2,058	$ 45,555	337	DD, including ID & ASD
New Hampshire	NH0053E.90	$ 175,902,777	3,305	$ 53,223	300	DD, including ID & ASD
New Jersey	NJ0031.R01.00	$ 670,008,739	12,265	$ 54,628	355	DD, including ID & ASD
New Mexico	NM0448.R01.00	$ 7,388,592	225	$ 32,838	315	DD, including ID & ASD
New York	NY40200.R02.00	$ 1,641,811	220	$ 7,463	332	DD-child (including ID & ASD)
New York	NY40176.R03.00	$ 1,902,424	220	$ 8,647	332	DD-child (including ID & ASD)
New York	NY0470.R00.00	$ 19,892,779	624	$ 31,879	224	DD-child (including ID & ASD)
New York	NY238.R04.00	$ 5,333,609,057	69,354	$ 76,904	340	DD, including ID & ASD
North Carolina	NC0662.R00.02	$ 511,854,712	10,325	$ 49,574	352	DD, including ID & ASD
North Carolina	NC0663.R00.02	$ 8,419,497	1,150	$ 7,321	209	DD, including ID & ASD
North Dakota	ND0421.R01.00	$ 1,131,885	135	$ 8,384	338	DD-child (including ID & ASD)

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Table 2
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State	Waiver Number	2010 Grand Total	Total Estimated Unduplicated Participants	Average Estimated Cost Per Participant	Average Length of Stay on the Waiver	Target Group1
North Dakota	ND0037.R06.02	$ 100,100,753	4,000	$ 25,025	310	DD, including ID & ASD
Ohio	OH0231.R03.02	$ 1,109,161,748	17,500	$ 63,381	327	DD, including ID & ASD
Ohio	OH380.90	$ 105,453,399	5,329	$ 19,789	345	DD, including ID & ASD
Oklahoma	OK0351.R02.01	$ 10,011,909	1,425	$ 7,026	305	ID-child
Oklahoma	OK0343.R02.02	$ 32,490,332	2,240	$ 14,505	328	ID
Oklahoma	OK0179.R01.02	$ 249,865,333	3,845	$ 64,984	323	ID
Oklahoma	OK0399.R01.02	$ 114,523,606	800	$ 143,155	361	ID
Oregon	OR375.R02.03	$ 53,381,799	7,052	$ 7,570	326	DD, including ID & ASD
Oregon	OR0117.R04.06	$ 425,463,181	6,593	$ 64,533	340	DD, including ID & ASD
Oregon	OR40194R02.00	$ 250,472	143	$ 1,752	338	DD-child (including ID & ASD)
Pennsylvania	PA0147.R04.03	$ 1,460,035,579	17,619	$ 82,867	342	ID
Pennsylvania	PA0354.R02.04	$ 191,890,226	12,045	$ 15,931	300	ID
Pennsylvania	PA0593.R00.04	$ 13,188,672	300	$ 43,962	155	ASD
South Carolina	SC0456.R01.01	$ 21,440,458	700	$ 30,629	346	ASD-child
South Carolina	SC0676.R00.00	$ 15,192,415	2,530	$ 6,005	260	DD, including ID & ASD
South Carolina	SC0237.R04.02	$ 278,662,353	6,300	$ 44,232	338	DD, including ID & ASD
South Dakota	SD0044.R06.00	$ 102,935,271	2,633	$ 39,094	345	DD, including ID & ASD
South Dakota	SD0338.R02.01	$ 4,547,455	932	$ 4,879	340	DD-child (including ID & ASD)
Tennessee	TN0427.R01.03	$ 27,010,994	1,802	$ 14,989	330	ID
Texas	TX0110.R05.04	$ 799,723,711	19,695	$ 40,605	329	ID
Texas	TX0281.R04.00	$ 8,813,532	176	$ 50,077	355	DD-non-ID
Texas	TX0221.R04.02	$ 200,365,769	4,804	$ 41,708	338	DD-non-ID
Virginia	VA0358.R02.04	$ 11,008,108	654	$ 16,832	348	DD-non-ID
Virginia	VA0372.R02.07	$ 495,781,911	8,570	$ 57,851	344	ID
Virginia	VA0430.R01.01	$ 3,358,964	300	$ 11,197	352	ID
Washington	WA40669.R00.00	$ 2,011,073	71	$ 28,325	195	DD, including ID & ASD
Wisconsin	WI0229.R04.00	$ 196,461,984	3,900	$ 50,375	198	DD, including ID & ASD
Wisconsin	WI0484.R00.02	$ 12,888,747	687	$ 18,761	284	DD, including ID & ASD
Wisconsin	WI0368.R02.01	$ 513,497,678	13,891	$ 36,966	289	DD, including ID & ASD

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Table 2
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State	Waiver Number	2010 Grand Total	Total Estimated Unduplicated Participants	Average Estimated Cost Per Participant	Average Length of Stay on the Waiver	Target Group1
Wyoming	WY0226.R04.02	$ 88,866,176	1,353	$ 65,681	351	DD, including ID & ASD
Total		$ 23,530,973,356				

Note: ID = intellectual disability; DD = developmental disabilities; ASD = autism spectrum disorder.
Source: Eiken, Burwell, Gold, & Sredl (2010, August).

the following living arrangements: participant's own home, the home of a relative, a semi-independent or supported apartment or living arrangement, or a group home….

For this summary, we limited residential habilitation to those supports provided in a facility (e.g., apartment owned or leased by provider agency, group home, or licensed foster care). Supports provided in the individual's home or other nonfacility-based settings were included in the personal assistance/supported living category.

Day habilitation. The second most requested service in the 2010 HCBS Waivers analyzed was day habilitation (nonresidential) services, which comprised 19% of the total spending analyzed. *Day habilitation* is defined in the HCBS Waiver technical guide (and again, this definition is adapted and modified by the majority of states as appropriate) as:

> Assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills that takes place in a non-residential setting, separate from the participant's private residence or other residential living arrangement. Activities and environments are designed to foster the acquisition of skills, appropriate behavior, greater independence, and personal choice. Services are furnished 4 or more hours per day on a regularly scheduled basis for 1 or more days per week or as specified in the participant's service plan. … Day habilitation services focus on enabling the participant to attain or maintain his or her maximum functional level and shall be coordinated with any physical, occupational, or speech therapies in the service plan. In addition, day habilitation services may serve to reinforce skills or lessons taught in other settings.

Supports to live in own or family home. The third most frequently proposed service included supports aimed at maintaining the individual to live in his or her own or in a family's home. After analysis of each of the services provided in the 88 HCBS Waivers, we created a larger category that included the following subcategories: (a) companion services, (b) homemaker services, (c) chore services, (d) personal care/personal assistance services, and (e) supported living services that were not provided in a facility owned or leased by a provider agency (those supported living services that were provided in a facility by a licensed provider were included under residential habilitation). The underlying aim of these services was to provide assistance to individuals with IDD with tasks they were unable to accomplish on their own, which in the absence of support may have resulted in placement into a more restrictive setting. These services composed 11% of total projected costs across the 88 waivers analyzed.

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CMS provides the following definitions of these services (although, again, states are free to modify or adapt them as appropriate):

Companion services.
Non-medical care, supervision and socialization, provided to a functionally impaired adult. Companions may assist or supervise the participant with such tasks as meal preparation, laundry and shopping. The provision of companion services does not entail hands-on nursing care. Providers may also perform light housekeeping tasks that are incidental to the care and supervision of the participant. This service is provided in accordance with a therapeutic goal in the service plan.
Homemaker services.
Services that consist of the performance of general household tasks (e.g., meal preparation and routine household care) provided by a qualified homemaker, when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for him or herself or others in the home.
Chore.
Services needed to maintain the home in a clean, sanitary and safe environment. This service includes heavy household chores such as washing floors, windows and walls, tacking down loose rugs and tiles, moving heavy items of furniture in order to provide safe access and egress. These services are provided only when neither the participant nor anyone else in the household is capable of performing or financially providing for them, and where no other relative, caregiver, landlord, community/volunteer agency, or third party payor is capable of or responsible for their provision. In the case of rental property, the responsibility of the landlord, pursuant to the lease agreement, is examined prior to any authorization of service.
Personal care.
A range of assistance to enable waiver participants to accomplish tasks that they would normally do for themselves if they did not have a disability. This assistance may take the form of hands-on assistance (actually performing a task for the person) or cuing to prompt the participant to perform a task. Personal care services may be provided on an episodic or on a continuing basis. Health-related services that are provided may include skilled or nursing care and medication administration to the extent permitted by State law.

Supported living. No specific definition is given for supported living in the CMS instructions, technical guide, and review criteria for the §1915(C) HCBS Waiver. The following is compiled from various state waiver definitions submitted to CMS: This service is designed to provide support to participants who may have limited natural supports and have an assessed need for assistance with acquisition, retention, or improvement in skills related to activities of daily living, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting. Payment for supported living is not made for cost of room and board, the cost of home maintenance, upkeep and improvement, modifications or adaptations to a home, or to meet the requirements of the applicable life safety code.

Together, these three categories (residential habilitation, day habilitation, and companion/homemaker/chore/personal assistance/supported living in a nonlicensed facility) composed approximately 83% of the projected cost of all services. The remaining services each made up 3.1% or less of the total projected cost of $23.5 billion: prevocational services and supported employment (3% each); family training and counseling, transportation, care coordination, and health and professional services (2% each); and respite and assistive and medical technologies (1% each). Finally, community transition supports, financial support services, adult day health, individual goods and services, self-advocacy training, education, and recreation and leisure each composed less than 1% of the national total projected spending for the 88 waivers analyzed (see Figure 3). It should be noted that self-advocacy and/or self-determination was a subcomponent of other services in almost half the states. References to understanding and promoting self-advocacy were included in various residential habilitation, individual goods and services, day habilitation, family and individual support services, and supported employment service definitions. The self-advocacy training category in the proposed taxonomy consisted of the four waivers in two states in which the entire service was devoted to self-advocacy training.

Table 2 delineates the total spending projected by the state for FY 2010, the total estimated unduplicated number of participants for that year, the average estimated cost per participant, and the average length of stay for each of the 88 waivers analyzed.

Average Spending per Waiver

States varied greatly in the average estimated cost per waiver participant. Further variation was evident when comparing more traditional comprehensive waivers that included residential supports in licensed settings outside the family home to support waivers that typically cover the same services as the comprehensive waiver with the exception of residential habilitation (Smith, Agosta, Fortune, & O'Keefe, 2007). Average

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estimated cost per person, including both comprehensive and support waivers, ranged from $1,752 per year in Oregon's behavioral intermediate care facility for the developmentally disabled (ICF/DD) model children's waiver (OR40194), to over $143,000 per person in Oklahoma's Homeward Bound Waiver, which supports plaintiffs from the *Homeward Bound et al. v. The Hissom Memorial Center et al.* litigation (Table 2). The average spending per participant across the 88 waivers analyzed was $37,583. The median spending per participant was $34,813.

Waivers targeting children, specifically, had lower average costs per person ($27,292 for ASD child waivers; $21,889 for DD, including ID and ASD, child waivers; $11,035 for ID child waivers). Many of these children's waivers were designed specifically to be support waivers that typically rely on unpaid natural support systems in addition to the covered HCBS Waiver services. The highest average estimated cost per participant was found in waivers specifically targeting individuals with intellectual disability ($49,113 per participant).

Average cost per person in comprehensive versus support waivers. We further analyzed 16 sets of waivers (i.e., instances in which we were able to identify both a comprehensive waiver and a support waiver with similar target groups in a given state: The 16 states for which we had both a comprehensive and support waiver to compare included Alabama, Colorado, Connecticut, Illinois, Georgia, Lousiana, Missouri, Montana, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, South Carolina, South Dakota, and Virginia). We found the cost of the support waivers was roughly 20% of the average cost per person in comprehensive waivers. The reasons that states have evolved toward offering this tiered system of supports include their reducing the average per person cost by eliminating the cost of 24-hr residential care in the support waiver, utilizing natural supports provided by family caregivers, maximizing federal reimbursement for services previously paid for solely by state and local dollars, and addressing the growing waiting list for services in the states (Smith et al., 2007).

Total Estimated Unduplicated Participants

States also varied in the average number of participants supported through their waivers. The average number of participants supported ranged from 71 individuals to an estimated 90,000 in California's comprehensive waiver (CA336). The average number of unduplicated participants estimated in FY 2010 was 5,910, and the median number was 2,240 individuals. The autism specific waivers reported lower estimated numbers of participants (M = 338) than DD waivers that included ID and autism (M = 8,404); DD–child waivers (including ID and autism) (M = 500); DD non-ID waivers (M = 1,878); and ID-specific waivers (M = 7,708). The two waivers that targeted children with intellectual disability also served lower numbers of children (569 and 1,425). There are myriad reasons to account for the great variation among waivers in enrollment. Some waivers are targeted at a smaller group of beneficiaries, such as Washington's 40669 (Children's Intensive In-Home Behavioral Support) Waiver, which targets children with DD, including autism, between the ages of 8 and 20 years old, whereas others target a much larger population, such as individuals with IDD regardless of age. Other factors that can impact a waiver's enrollment level include eligibility guidelines, the presence of alternative waivers in the state, state population, and use of other long-term service and supports (e.g., the ICF/DD program). States specify the maximum number of participants that may be served during each waiver year, and this number is instrumental in the state's cost-neutrality calculation that is mandated by federal policy. That is, states must demonstrate that "federal expenditures may not increase more than they would have in the absence of the waiver program" (National Health Policy Forum, 2009).

Average Length of Stay on the Waiver

The average length of stay (ALOS) conveys the average days an individual participates in the waiver each year. There are several factors that can affect ALOS, including participant turnover and the phase-in/phase-out schedule of the waiver (Disabled and Elderly Health Programs Group, 2008) as well as the package of services that are available through that waiver (i.e., whether the waiver is a traditional comprehensive waiver offering year round residential habilitation, or whether it is a support waiver that offers a multitude of services while relying also on unpaid natural supports). For example, in Colorado's 434

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Table 3
Services by Waiver by State

	0001	0391	260	188	336	434	7	305	293
Services	Alabama	Alabama	Alaska	Arkansas	California	Colorado	Colorado	Colorado	Colorado
Residential habilitation	X		X	X	X		X	X	
Companion/homemaker/ chore/personal assistance/ supported living	X	X	X		X				X
Adult day health									
Community transition supports	X	X		X	X			X	
Day habilitation	X	X	X		X		X		X
Financial support									
Care coordination			X	X				X	
Transportation			X		X		X		X
Prevocational	X	X			X				
Supported employment	X	X	X	X	X		X		X
Assistive and medical technologies	X	X	X	X	X		X		X
Health and professional services	X	X	X	X	X	X	X	X	X
Respite	X	X	X	X	X			X	X
Family training and counseling					X				
Recreation and leisure									
Individual goods and services									
Education									
Self-advocacy training									X
Average estimated cost per participant	$50,750	$15,044	$72,274	$36,897	$24,718	$6,295	$62,630	$58,272	$14,279

Waiver, the only covered service is behavioral therapy for children with autism under age 5 years. Thus, the average length of stay was much less (99 days) than in their adult DD comprehensive waiver (CO0007), which supported adults over the age of 17 years and provided residential supports (with the average participant using 345 days of residential habilitation).

The average length of stay on the waiver ranged from 99 days in Colorado's autistic children's waiver to 361 days in Oklahoma's Homeward Bound Waiver, which supports plaintiffs from the *Homeward Bound et al. v. The Hissom Memorial Center et al.* class action. The average length of stay for the waivers analyzed was 317 days, and the median number of days was 333. This variation in the number of covered waiver days is directly related to the ability of states to tailor the package of services based on each user's needs.

An Analysis of Services Across Waivers

Examination of the subcategories of services provided through the HCBS Waivers can also illuminate patterns in the states (see Table 3). An examination of one of the subcategories, family training and counseling, reveals that only 29 of the 88 waivers examined provided any type of family or caregiver training. The average annual per waiver cost of family and caregiver training and counseling was $3,471

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Table 3
Extended

4180	437	426	9	307	294	323	175	76	473
Colorado	Connecti-cut	Connecti-cut	Delaware	District of Columbia	Florida	Georgia	Georgia	Idaho	Illinois
	X	X	X	X		X		X	X
X	X	X		X	X	X		X	
	X	X						X	
X				X		X	X		
	X	X	X	X	X			X	
	X	X				X	X	X	
	X	X	X		X	X	X		
	X	X	X	X	X	X	X	X	
			X	X		X	X		
	X	X	X	X	X	X	X	X	
X	X	X		X	X	X	X	X	X
X	X	X	X	X	X	X	X	X	X
X	X	X		X	X		X	X	
X		X		X			X		
X									
	X	X					X		
$14,613	$82,096	$19,329	$100,815	$88,828	$14,422	$36,862	$11,397	$34,813	$63,134

(although the average annual spending for family training in Oklahoma's 343 and 351 waivers skewed this average; removing these two waivers resulted in an average annual cost of $1,920 per family for family training and counseling). Some waivers elected to support families to attend conferences, to receive peer-to-peer supports, or to conduct adult life planning. Only seven waivers (in five states: Illinois, Kansas, Oklahoma, Oregon, and Pennsylvania) provided family or unpaid caregiver counseling. These are just two examples of how states can utilize the information in the 1915(c) HCBS Waiver applications to see how other states are supporting individuals with IDD and their families. Analysis of current data that reflects the real time intent of the states can empower advocates to engage with policymakers in an up-to-date and timely manner about which services exist (and which services do not exist in a given state but are offered in others).

State Amendments to the HCBS Waiver

An analysis of 93 HCBS Waiver amendments (approved effective date from July 1, 2008 through November 1, 2011) revealed four general themes: amendments to revise procedures, amendments to rebalance the system, amendments to contain costs, and amendments to expand service capacity. The first general theme, amendments filed to revise

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Table 3
Extended

350	464	378	4151	242	476	224	401	472	361
Illinois	Illinois	Indiana	Indiana	Iowa	Kansas	Kansas	Louisiana	Louisiana	Louisiana
X		X	X	X		X	X	X	
X	X	X	X	X		X	X	X	
X		X	X	X					
		X	X				X	X	
X		X	X	X	X	X	X	X	
				X					
X	X							X	X
X		X		X				X	
		X		X		X		X	
X		X		X		X	X	X	
X	X	X	X	X		X	X	X	X
X	X	X	X	X	X	X	X	X	
		X	X	X	X	X	X	X	X
X	X	X	X		X		X		X
$29,497	$13,415	$36,126	$74,409	$29,140	$34,556	$34,327	$65,202	$54,092	$8,608

procedures, included among other things, changes to rates, waiting lists, and quality assurance methodologies.

Amendments to revise procedures. The first theme identified dealt with state changes to waiver processes. In Iowa (IA242), for example, an amendment was filed to change the criteria states used to remove people from the waiting list—from a first-come, first-served, basis to a system based on identified needs. Maryland (MD424) filed an amendment to allow waiver participants to purchase residential set-up items as well as to advertise for and train staff 15 days before entering into the waiver to facilitate community transition. Louisiana (LA361) filed an amendment to "Medicaid" their family support services. The stated purpose of the amendment was to reserve a portion of the participant capacity of the Children's Choice Waiver opportunities by 425. The Office for Citizens with Developmental Disabilities (OCDD) proposed to allocate a portion of existing state-funded Act 378 Family Support System dollars, which were earmarked to support children with developmental disabilities in need, by funding an additional 425 Children's Choice Waiver opportunities. This activity would leverage existing state dollars to maximize federal funding to increase access to more community-based services for children with developmental disabilities and reduce existing waiting lists.

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Table 3
Extended

453	23	339	424	64	40207	61	282	698	40185	404
Louisiana	Maryland	Maryland	Maryland	Massa-chusetts	Massa-chusetts	Minnesota	Missis-sippi	Missouri	Missouri	Missouri
	X	X		X		X	X			
	X		X		X	X	X	X	X	X
						X				
	X		X	X		X			X	X
X	X		X	X	X	X	X		X	X
			X	X				X	X	X
X	X	X	X			X	X			
	X		X	X		X		X	X	X
X							X			
X	X		X	X		X	X			X
X	X	X	X	X	X	X	X	X	X	X
	X	X	X				X	X	X	X
X	X	X	X	X	X	X	X	X	X	X
	X	X	X		X	X				
					X					
$10,589	$54,339	$33,669	$40,021	$60,183	$25,931	$74,703	$20,739	$17,612	$7,834	$7,276

Meanwhile, North Carolina (NC662 and NC663) amended its waivers to revise the way in which rates for waiver services are calculated to ensure they are "adequate and appropriate." Finally, under this theme, North Dakota (ND37) requested to combine its self-directed waiver (ND421) with its traditional waiver (ND37). Some examples of quality assurance changes included expansion of data sources to be utilized in quality assurance reviews (plans of correction, critical events and incidence reports, and complaint reports) in Colorado (CO0007) and South Carolina (SC456); a shift in responsibilities for collecting incident report data from providers community centered boards (CCBs) to case managers in (CO0007) and revisions to the required frequency of consumer surveys of familiarity of complaint process in Colorado (CO0007); clarification of quality improvement strategies (NE4154) and implementation of annual reviews of individual and family service plans to ensure compliance with waiver recipient's vision (NE4154) in Nebraska; changes in frequency of reviews (SC456) in South Carolina; changes in measures of quality (TX110) in Texas; and changes to remediation process for allegations of abuse and neglect in Nebraska (NE4154).

Amendments to rebalance the system. The second general theme for amending waivers was

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Table 3
Extended

40190	178	208	667	371	4154	454	125	53E	31	448
Missouri	Missouri	Montana	Montana	Montana	Nebraska	Nebraska	Nevada	New Hampshire	New Jersey	New Mexico
	X	X		X	X					
X	X	X		X	X	X	X	X	X	X
	X	X					X	X	X	X
	X	X	X	X	X		X	X	X	
	X									
		X	X					X	X	X
	X	X	X	X			X		X	X
							X			
	X	X		X			X	X	X	X
X	X	X	X	X	X	X		X	X	X
X	X	X	X	X	X		X	X		X
	X	X	X	X	X	X		X	X	X
		X								
				X						
		X	X							X
				X						
$85,607	$41,969	$38,301	$45,854	$6,134	$55,675	$4,885	$45,555	$53,223	$54,628	$32,838

rebalancing or filing amendments to reserve categories or "service opportunities" for individuals transitioning from institutional to community-based settings. For example, Alabama (AL001) amended one of its waivers to reserve "slots" or capacity for individuals transitioning out of nursing homes or public ICFs/DD. Arkansas (AR188), similarly, reserved capacity to transition 95 people from state human development centers (HDC) after announcement of the closure of the Alexander HDC, and Virginia (VA 372) reserved capacity for people leaving the Southeastern Virginia Training Center. Texas (TX110) added 193 placements for people living in large ICFs/DD who want to enroll in the waiver, an initiative tied to the Money Follows the Person (MFP) rebalancing demonstration. Texas later amended the waiver to add over 6,000 additional placements over waiver years two and three (September 2009 through August 2011) "in response to legislative direction." This amendment included detail on reserved capacity for those leaving small and medium ICFs/DD, large ICFs/DD, supported living centers, state conservatorship, minors at risk of institutionalization in a state-supported living center, adults in this situation, and those entering the waiver through the MFP initiative. Colorado (CO007) amended its waiver to reserve capacity specifically for children transitioning

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Table 3
Extended

40200	40176	470	238	662	663	421	37	231	380	351343		179
New York	New York	New York	New York	North Carolina	North Carolina	North Dakota	North Dakota	Ohio	Ohio	Oklahoma	Oklahoma	Oklahoma
			X	X			X	X				X
			X	X	X	X	X	X	X		X	X
				X	X		X					X
		X	X									X
		X	X	X	X		X	X	X	X	X	X
			X									
X	X	X	X					X				
				X	X	X	X	X	X		X	X
		X	X					X	X		X	X
		X	X	X	X			X	X		X	X
X	X	X	X	X	X	X	X	X	X	X	X	X
		X	X	X	X	X	X	X		X	X	X
X	X	X	X	X	X			X	X	X	X	X
		X	X	X	X		X			X	X	X
					X					X	X	
$7,463	$8,647	$31,879	$76,904	$49,574	$7,321	$8,384	$25,025	$63,381	$19,789	$7,026	$14,505	$64,984

out of foster care. Some states amended their waivers to reserve capacity for individuals in crisis, for example, Alabama and Oklahoma (AL001 and OK343, respectively) or to support individuals on the state's urgent needs waiting list, such as Virginia (VA372).

Amendments to contain costs. Cost containment, or amending waivers to reduce services or costs, was the third general theme found among the waiver amendments analyzed. For example, Florida's (FL294) amendment was filed to reduce the cap on the total annual budget from $14,792 per participant to $14,422 per participant, a 2.5% cut directed by the Florida legislature. Similarly, Louisiana (LA361) reduced its cap on the Children's Choice Waiver by 2%, from $17,000 a year to $16,600 a year. Maryland's (MD23) amendment removed the cost of living adjustment (COLA) from year 3 services because the Maryland Legislature did not grant it.

Some reductions resulted in services being minimized or cut entirely. For example, Kansas's waiver (KS224) was amended because of a decrease in state general funds. Doing so resulted in elimination of oral health services and temporary respite care effective January 1, 2010. Virginia (VA358) amended its waiver to reduce the amount of respite hours available. Prior to the amendment,

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Table 3
Extended

399	375	117	40194	147	354	593	456	676	237	44	338
Oklahoma	Oregon	Oregon	Oregon	Pennsylvania	Pennsylvania	Pennsylvania	South Carolina	South Carolina	South Carolina	South Dakota	South Dakota
X		X		X	X	X			X	X	
X	X	X	X	X	X			X	X		X
								X	X		
	X			X	X	X		X	X		
X		X		X	X	X				X	
	X			X	X						
			X	X	X	X	X			X	X
X	X	X	X	X	X			X	X		
X				X	X			X	X	X	
X	X			X	X	X		X	X	X	X
X	X	X	X	X	X	X		X	X	X	X
X	X	X	X	X	X	X	X	X	X	X	X
X	X	X	X	X	X	X		X	X		X
X	X	X	X			X					
				X	X						
$143,155	$7,570	$64,533	$1,752	$82,867	$15,931	$43,962	$30,629	$6,005	$44,232	$39,094	$4,879

there were 720 hr a year available, whereas effective July 1, 2011, this amount was reduced to 480 hr a year. Virginia's (VA372) amendment also cut 100 "slots" that were going to be phased in; however, this was reversed, and the number of individuals to be phased in actually increased to 250 additional participants in a later amendment.

Amendments to expand service capacity. While some states were filing amendments to reduce services, others were filing amendments to expand services. For example, Montana amended its MT208 waiver to add many new waiver services, including board-certified behavior analysts, a personal emergency response system (PERS), as well as adding employer authority to respite services. A later amendment to this same waiver also added numerous service options for waiver recipients who wanted to self-direct their supports. Nevada (NV125) filed an amendment to increase its grand spending total from $479 million to $524 million over the next four years of the waiver. Finally, Virginia (VA358) amended its waiver to increase the number of waiver participants.

Discussion

This study sought to provide current aggregate-level information on how states are providing supports and services within the Medicaid HCBS Waiver

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Table 3
Extended

427	110	281	221	358	372	430	40669	229	484	368	226
Tennessee	Texas	Texas	Texas	Virginia	Virginia	Virginia	Washington	Wisconsin	Wisconsins	Wisconsin	Wyoming
	X	X	X		X			X	X	X	X
X	X	X	X	X	X		X	X	X	X	X
			X					X	X	X	
		X	X	X	X			X	X	X	
X	X	X		X	X	X		X	X	X	X
	X	X	X					X	X	X	
	X	X	X		X	X		X		X	X
X							X	X	X	X	
			X	X	X	X		X	X	X	X
X	X	X	X	X	X	X		X	X	X	X
X	X	X	X	X	X		X	X	X	X	X
X	X	X	X	X	X		X	X	X	X	X
X	X	X	X	X	X		X	X	X	X	X
				X			X				
									X		
								X	X	X	
$14,989	$40,605	$50,077	$41,708	$16,832	$57,851	$11,197	$28,325	$50,375	$18,761	$36,966	$65,681

program. Difficulties arise, however, when attempting to make intrastate comparisons regarding services provided via the HCBS Waiver. States have great flexibility to determine which services they offer, the scope of those services, how they define that service, what costs will be allowed under that service, and who is allowed to provide those services, to name just a few possibilities. However, with the increased utilization of the HCBS Waivers to support individuals with IDD, there is a great need to better understand the variability of services provided through this funding. The proposed taxonomy provides a tool to assist in this description.

Although the data obtained from the 88 waiver applications and presented in this article were proposed spending patterns based on previous years' actual utilization of HCBS Waiver Services (as opposed to actual expenditures), they were a reasonably accurate proxy of IDD Waiver services in the states. The findings show a substantial amount of resources being committed for residential habilitation, day habilitation, and companion/homemaker/chore/personal assistance/supported living services. Smaller portions were committed to employment, family support, transportation, health, respite, and assistive technology. The percentages spent on the larger subcategories are congruent with spending patterns

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identified by researchers at Mathematica (Irvin, 2011, September) who used 2008 Medicaid Statistical Information Systems (MSIS) claims data from 44 states and Washington, D.C., to determine trends in waiver expenditures across the states. Analysis also revealed that states estimated support waiver costs to be significantly less than that of comprehensive waivers. Future studies should monitor the evolution of these support waivers and the effect of increased utilization of unpaid natural supports.

The results of this analysis were also comparable to findings from a similar study (Walls et al., 2011), which analyzed budget cuts and service reductions in Medicaid- and non-Medicaid-funded long-term services for the elderly and people with physical disabilities obtained through the use of electronic survey and subsequent phone interviews. Using FY 2010 data, just as in the present study, Walls et al. identified four patterns: (a) the Great Recession continues to have an impact on services as indicated through service cuts, though demand increased; (b) states capitalized on the economic downturn as a means of rebalancing the system away from more costly institutional settings; (c) the American Recovery and Reinvestment Act of 2009 (ARRA) stimulus funds preserved programs by temporarily increasing Federal Medical Assistance Percentages (FMAPs) and restricting tightening of eligibility standards; and (d) states are hesitant to provide additional HCBS Waiver expansions under the Affordable Care Act (ACA) until federal guidance is presented. This illustrates the commonalities experienced across state lines with regard to Medicaid-funded supports and services, regardless of the beneficiary group. The first and second patterns identified by Walls et al., service reductions and rebalancing initiatives, respectively, were also identified in the present study.

The ARRA, signed into law in February 2009, provided an economic stimulus including a temporary increase in state FMAPs to provide relief from medical expenditures during the recessionary period. The FMAP increase was retroactively effective October 1, 2008 and was initially intended to last until December 31, 2010. In August 2010, because of the continued economic recession, the FMAP increase was extended an additional 6 months to June 2011. An additional waiver analysis beyond FY 2010 will help determine if the extension and/or expiration of the ARRA funds impacted IDD waivers nationally. For instance, the present study demonstrates that some states (e.g., Montana, MT208, and Virginia, VA358) expanded services during the study period, which may be an indication of use of the increased FMAP rates, rebalancing, or both. Additionally, a report from the Kaiser Commission on Medicaid and the Uninsured and Health Management Associates (2010, September) demonstrated how states used ARRA funds during FY 2009 and FY 2010. The findings indicated that states used the ARRA-enhanced Medicaid funds to address budget shortfalls in Medicaid-funded programs, such as those with enrollment increases, to avoid benefit and eligibility cuts.

Regardless, the Great Recession appears to have had a similar impact across the aging and IDD Medicaid beneficiary populations. Because Medicaid is second only to education in state budgets, it is constantly under scrutiny by both federal and state governments when they are balancing budgets; it is imperative that impacts of potential reforms are fully explored during the continued process of economic recovery. This is especially crucial with respect to the rebalancing initiatives within the Patient Protection and Affordable Care Act of 2010 (PPACA), such as the expansion of Money Follows the Person as well as the initiation of the Balancing Incentives Payment Program and Community First Choice Option. Given the recent challenges to the constitutionality of PPACA heard in the Supreme Court and efforts within the U.S. House of Representatives to repeal PPACA as well as block grant Medicaid, advocates of community-based supports and services should remain vigilant in following legislative priorities in addition to the economy. Current data on categorical spending, such as those presented here, can assist local and national advocacy efforts in understanding where states are investing their limited resources. By identifying where resources are being allocated, advocates will be better able to identify where greatest areas of need exist.

References

Braddock, D., Hemp, R., Rizzolo, M. C., Haffer, L., Tanis, E. S., & Wu, J. (2011). *The state of the states in developmental disabilities, 2011*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

DOI: 10.1352/1934-9556-51.01.001

Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services. (2008, January). *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, technical guide, and review criteria*. Available at http://170.107.180.99/WMS/help/version_35_1915c_Waiver_Application_and_Accompanying_Materials.zip

Eiken, S. (2011, September). *Revisiting the Name Game: A taxonomy of home and community-based services*. Presentation at the National Home and Community-Based Services Conference, Washington, DC.

Eiken, S., Burwell, B., Gold, L., & Sredl, K. (2010, August). *Medicaid HCBS waiver expenditures: FY 2004 through FY 2009*. Cambridge, MA: Thomson Reuters. Available at http://www.hcbs.org/files/193/9645/HCBSWaivers2009.pdf

Gettings, R. M. (2012). *Forging a federal–state partnership*. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Hall-Lande, J., Hewitt, A., & Moseley, C. R. (2011). A national review of home and community based services for individuals with autism spectrum disorders. *Policy Research Brief, 21*(3), 1–11. Minneapolis, MN: Research and Training Center on Community Living, University of Minnesota.

Irvin, C. [on behalf of Wenzlow, A., Peebles, V., & Kuncaitis, S.]. (2011, September). *Applying the HCBS taxonomy to person-level Medicaid data*. Presentation at the National Home and Community-Based Services Conference, Washington, DC.

Kaiser Commission on Medicaid and the Uninsured & Health Management Associates. (2010, September). *Hoping for economic recovery, preparing for health reform: A look at Medicaid spending, coverage and policy trends: Results from a 50-state Medicaid budget survey for state fiscal years 2010 and 2011*. Washington, DC: Henry J. Kaiser Family Foundation.

National Health Policy Forum. (2009). *The basics: Medicaid waivers and budget neutrality*. Available at http://www.nhpf.org/library/the-basics/Basics_MedicaidBudgetNeut_08-26-09.pdf

Smith, G., Agosta, J., Fortune, J., & O'Keeffe, J. (2007). *Gauging the use of HCBS support waivers for people with intellectual and developmental disabilities: Final project report*. Tualatin, OR: Human Services Research Institute.

Walls, J., Gifford, K., Rudd, C., O'Rourke, R., Roherty, M., Copeland, L., & Fox-Grage, W. (2011). *Weathering the storm: The impact of the Great Recession on long-term services and supports*. Washington, DC: AARP Public Policy Institute.

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