

MEMO

To: Joint Finance Committee
From: Brian J. Hartman, on behalf of the following organizations:
Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens
State Council for Persons with Disabilities
Subject: Division of Developmental Disabilities Services FY 17 Budget
Date: February 24, 2016

Please consider this memo a summary of the oral presentation of Brian J. Hartman, Esq. on behalf of the Developmental Disabilities Council ("DDC"), Governor's Advisory Council for Exceptional Citizens ("GACEC"), and the State Council for Persons with Disabilities ("SCPD"). We are addressing one (1) component of the DDDS budget, i.e., conversion of its current Medicaid waiver to a "Lifespan" waiver which includes family supports.

As you know, the FY16 budget (§176) directs the Division to "move forward with developing and establishing a Family Support Waiver to begin in Fiscal Year 2017". Although the Governor's proposed FY17 budget (§166) contains the identical authorization, necessary funding is omitted. Rather than establish a new waiver, the Division has developed a more restrained plan to amend its current waiver to add family support services. The Councils strongly support development of an amended waiver.

JUSTIFICATION

The justification for an amended waiver is compelling. More than 70% of the Division's clients live at home with their family.¹ In raw numbers, this equates to 3,110 clients living at home out of a total census of 4,314 individuals. Consistent with national trends, many of the Delaware caregivers in those families are aging as the "boomers" progress into old age.² Given declines in health and resiliency attributable to aging, such caregivers will predictably need an increasing level of supports to continue in their role.³

¹The latest (December, 2015) DDDS census report is included as Attachment "A".

²See D. Braddock et al, "The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession (2015) at pp. 62-64. [Attachment "B"]

³See CDC, "Family Caregiving: The Facts" and The Arc, "Position Statement: Family Support" (April 6, 2014). [Attachment "C"]

Almost all states offer family support programs for caregivers of individuals with developmental disabilities. The national average of spending per family is \$8,931. Unfortunately, although DDDS is adept at identifying families needing support, it spends less than 10% of the national average in per-family supports (ranking 48th).⁴ In recent years, the Delaware rate (6.6%) of increases in public spending for community services for individuals with developmental disabilities has been significantly less than the rate in neighboring states (PA - 25.7%); MD - 13.2%; N.J. - 11.8%).⁵ CMS statistics released in June, 2015 are also instructive, i.e. ranking Delaware as the third lowest state in HCBS spending as a percentage of total long-term care spending.⁶

Nationwide, Medicaid waivers finance 82% of all family support services.⁷ This represents a tremendous leveraging of federal funds to assist state residents. Conversely, Delaware's lack of a Medicaid waiver covering family supports results in unnecessary reliance on unmatched State funds and few resources for Delaware families. Delaware is essentially "leaving money on the table" by eschewing available Medicaid funding. Delaware ranks 8th among the states in the percentage of unmatched funding devoted to individuals with developmental disabilities.⁸

DDDS PLAN

The current DDDS waiver focuses on clients receiving residential programs and includes the following services: 1) residential habilitation; 2) supported living; 3) supported employment; 4) day habilitation and prevocational services; and 5) behavioral and nursing consultation.⁹ The Division proposes to amend the waiver in two ways:

A. expand eligibility to include approximately 1,000 non-residential clients enrolled in DDDS day services plus individuals graduating from the school system; and

B. add the following services: 1) community living supports (including personal care and respite); 2) home and vehicle modifications; 3) assistive technology; and 4) specialized equipment and supplies.

The Division anticipates that the plan would be revenue neutral for services since most of the waiver participants already receive many day services with unmatched State funds. By rolling such clients into the waiver, federal matching funds subsidize the services.

⁴See Braddock, pp. 58 - 59. [Attachment "B"]

⁵See Braddock, p. 10 [Attachment "B"]

⁶See Medicaid Expenditures for LTSS in FY13 Report (June 30, 2015) [Attachment "D"]

⁷See Braddock, p. 59. [Attachment "B"]

⁸See Braddock, p. 202. [Attachment "B"]

⁹See pp. 41-42 of current waiver published on the DDDS website at http://dhss.delaware.gov/dhss/ddds/files/de_0009_r07_00_070114.pdf.

However, DDDS would need six (6) additional staff to administer and supervise services and DMMA would require three (3) additional staff to process waiver applications. Most of these positions would qualify for a Medicaid match but require an appropriation of approximately \$450,000 in State General Funds.

RECOMMENDATIONS

The draft DDDS plan presents many advantages. First, amending an existing waiver (approved through 2019) is easier than submitting a new waiver. Second, the State secures federal Medicaid matching funds for services currently provided with solely State funds. Third, while the current federal Administration favors expansion of waivers, that may not be the case in coming years when applications and amendments could face additional hurdles.

Given these factors, the Councils encourage the JFC's favorable consideration of this initiative.

Attachments

E:legis/dddsjfcfy17; F:pub/bjh/leg/dddsjfcfy17

EXCERPT

The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession

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TENTH EDITION

 **aaidd**
American Association
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ATTACHMENT "B"

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State of the States in Intellectual and Developmental Disabilities website:

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**Trends in Spending by State:
FY 2011–2013**

During 2011–13, inflation-adjusted community spending in the U.S. advanced 8.5% (Table 3 below). Eight states reduced community services spending during 2011–13, ranging from a 0.2% reduction in New Mexico to a 9.6% reduction in Hawaii. Other large community spending reductions were in Florida (9.4%), and Rhode Island (5.2%).

The largest state increase in community spending during 2011–13 was in Kentucky (40.3%). Kentucky's community spending growth was heavily underwritten by the HCBS Waiver, the result of the *Michelle P* class action litigation (Ng, Wong, & Harrington, 2009). Other state leaders in the growth of community services spending during 2009–11 were Mississippi (39%); Louisiana, Missouri, and Virginia (35%); Alaska (30%); Pennsylvania (26%); West Virginia (23%); Montana (21%); and Georgia (20%).

Total IDD institutional and community spending during 2011–13 increased 20% or more in nine states: Mississippi (33%), Alaska (30%), Virginia (29%),

Missouri (28%), Kentucky (26%), Louisiana (24%), West Virginia (23%), Pennsylvania (22%), and Montana (20%). Thirty-three states and the District of Columbia increased spending between 0.05% and 15%.

Reductions in total inflation-adjusted intellectual and developmental disabilities spending occurred in seven states during 2011–13 (see Figure 5 on the following page). These included Hawaii (10%), Florida (9%), Illinois (7%), Rhode Island (6%) Alabama (5%), Arizona (1%), and New Mexico (0.2%).

**Changes in Inflation-Adjusted Spending
by Fiscal Year: 2011, 2012, and 2013**

Recovery from the Great Recession was analyzed in terms of inflation-adjusted change in spending by state, service sector, and year (2011, 2012, and 2013) (Table 4 on page 12). The number of states with community spending reductions dropped from 27 states in 2011 to 12 states in 2013. States reducing total spending fell from 31 states in 2011 to 13 states in 2013. Only Florida had community and institutional spending reductions

**TABLE 3
PUBLIC I/DD SPENDING FOR COMMUNITY SERVICES IN THE STATES: FY 2011-13**

State	Community Spending			State	Community Spending		
	2013	2011	% Real Change 2011-13 ¹		2013	2011	% Real Change 2011-13 ¹
Alabama	\$365,940,032	\$335,133,155	5.8%	Montana	\$157,188,442	\$126,331,727	20.6%
Alaska	\$201,532,918	\$150,136,938	30.1%	Nebraska	\$303,290,065	\$257,632,033	14.1%
Arizona	\$814,217,645	\$800,391,291	-1.4%	Nevada	\$150,226,860	\$143,232,796	1.6%
Arkansas	\$366,739,903	\$365,157,752	-2.7%	New Hampshire	\$277,181,929	\$248,652,647	8.0%
California	\$5,829,780,987	\$5,420,881,085	4.2%	New Jersey	\$1,233,843,626	\$1,069,375,545	11.8%*
Colorado	\$485,138,119	\$477,983,086	-1.6%	New Mexico	\$361,742,908	\$351,276,212	-0.2%
Connecticut	\$990,379,182	\$838,600,414	14.4%	New York	\$9,760,945,439	\$9,043,498,300	4.6%
* Delaware	\$133,358,929	\$121,190,479	6.6%	North Carolina	\$1,154,938,136	\$1,036,177,229	8.0%
District of Columbia	\$282,030,691	\$245,219,678	11.4%	North Dakota	\$241,835,860	\$208,298,958	12.5%
Florida	\$1,271,150,396	\$1,360,248,844	-9.4%	Ohio	\$2,786,453,131	\$2,590,553,534	4.2%
Georgia	\$810,848,458	\$655,346,776	19.9%	Oklahoma	\$432,124,497	\$404,499,262	3.5%
Hawaii	\$161,577,571	\$173,161,665	-9.6%	Oregon	\$801,630,481	\$747,094,612	4.0%
Idaho	\$184,025,096	\$179,571,122	-0.7%	Pennsylvania	\$3,007,010,916	\$2,317,542,892	25.7%*
Illinois	\$1,201,616,397	\$1,120,981,935	3.9%	Rhode Island	\$251,949,523	\$257,524,408	-5.2%
Indiana	\$1,304,942,929	\$1,158,423,978	9.2%	South Carolina	\$494,096,042	\$423,610,612	13.0%
Iowa	\$647,046,377	\$559,042,334	12.2%	South Dakota	\$142,353,692	\$136,002,204	1.4%
Kansas	\$432,012,358	\$417,207,115	0.3%	Tennessee	\$839,053,133	\$751,907,116	8.1%
Kentucky	\$603,706,311	\$417,100,930	40.3%	Texas	\$1,844,431,103	\$1,613,805,131	10.8%
Louisiana	\$1,237,479,247	\$886,051,292	35.3%	Utah	\$213,014,638	\$189,915,884	8.7%
Maine	\$439,111,984	\$377,534,453	12.7%	Vermont	\$178,644,406	\$161,638,207	6.9%
* Maryland	\$974,146,551	\$833,914,912	13.2%	Virginia	\$1,029,622,204	\$738,332,272	35.1%
Massachusetts	\$1,896,320,622	\$1,634,851,221	12.4%	Washington	\$877,718,743	\$839,649,029	1.3%
Michigan	\$1,456,707,667	\$1,328,070,686	6.3%	West Virginia	\$442,947,586	\$347,965,236	23.4%
Minnesota	\$1,682,313,990	\$1,619,492,116	0.7%	Wisconsin	\$1,234,424,509	\$1,137,462,282	5.2%
Mississippi	\$208,859,530	\$145,811,171	38.8%	Wyoming	\$125,023,297	\$118,384,129	2.3%
Missouri	\$913,115,019	\$656,360,936	34.8%	United States	\$53,235,790,070	\$47,538,572,618	8.5%

¹ Inflation-adjusted percentage change, 2011 to 2013.
Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

2% from 2011–13. The Waiver was a principal factor in maintaining family support spending in the states. Federal-state Waiver funds constituted 82% of family support spending in 2013.

In 2013, the average family support spending per family (both subsidy and non-subsidy) in the U.S. was \$8,931. Table 19 below provides state-by-state data on the allocation of family support resources for cash

TABLE 19
FAMILY SUPPORT IN THE STATES:
SPENDING FOR PARTICIPANTS WITH I/DD IN FY 2013

State	Total Family Support ¹		Spending Per Family	Rank ²	Families Supported Per 100K		Cash Subsidy		Other Family Support	
	Families	Spending			Rank ³	Families	Spending	Families	Spending	
Alabama	987	\$502,775	\$509	49	20	48	0	\$0	987	\$502,775
Alaska	1,377	\$10,429,966	\$7,574	22	188	17	0	\$0	1,377	\$10,429,966
Arizona	19,002	\$363,769,803	\$19,144	8	288	2	1	\$4,647	19,001	\$363,765,156
Arkansas	414	\$523,859	\$1,265	46	14	49	0	\$0	414	\$523,859
California	104,099	\$729,359,025	\$7,006	23	273	8	0	\$0	104,099	\$729,359,025
Colorado	2,183	\$2,348,496	\$1,076	47	42	43	0	\$0	2,183	\$2,348,496
Connecticut	3,069	\$54,980,964	\$17,915	10	85	34	1,738	\$2,955,493	1,331	\$52,025,471
Delaware ⁴	2,610	\$2,037,800	\$781	48	283	3	95	\$575,100	2,610	\$1,462,700
District of Columbia	753	\$15,610,362	\$20,731	7	117	27	0	\$0	753	\$15,610,362
Florida	15,617	\$327,858,454	\$20,994	5	80	35	39	\$117,735	15,578	\$327,740,720
Georgia	3,273	\$17,908,146	\$5,471	30	33	46	0	\$0	3,273	\$17,908,146
Hawaii	1,740	\$24,457,501	\$14,056	14	125	25	0	\$0	1,740	\$24,457,501
Idaho	0	\$0			0		0	\$0	0	\$0
Illinois	4,945	\$33,757,975	\$6,827	24	38	44	139	\$924,048	4,806	\$32,833,927
Indiana	6,661	\$44,076,198	\$6,617	26	102	31	0	\$0	6,661	\$44,076,198
Iowa	739	\$28,027,869	\$37,927	1	24	47	217	\$659,515	522	\$27,368,354
Kansas	2,811	\$50,180,281	\$17,851	11	97	32	0	\$0	2,811	\$50,180,281
Kentucky	2,771	\$11,592,149	\$4,183	35	63	39	0	\$0	2,771	\$11,592,149
Louisiana	12,558	\$374,835,470	\$29,848	2	272	9	1,647	\$4,475,278	10,911	\$370,360,192
Maine	480	\$8,447,527	\$17,599	12	36	45	480	\$600,000	0	\$7,847,527
Maryland	7,516	\$62,678,938	\$8,339	20	127	24	0	\$0	7,516	\$62,678,938
Massachusetts	11,759	\$37,855,140	\$3,219	40	176	18	0	\$0	11,759	\$37,855,140
Michigan	16,699	\$61,707,193	\$3,695	37	169	19	6,914	\$18,272,323	9,785	\$43,434,870
Minnesota	13,711	\$284,989,320	\$20,785	6	254	10	3,164	\$13,071,304	10,547	\$271,918,016
Mississippi	4,859	\$30,769,279	\$6,332	28	163	20	0	\$0	4,859	\$30,769,279
Missouri	4,621	\$43,138,430	\$9,335	18	77	37	0	\$0	4,621	\$43,138,430
Montana	2,856	\$12,892,812	\$4,514	33	283	5	0	\$0	2,856	\$12,892,812
Nebraska	2,569	\$20,619,859	\$8,026	21	138	22	0	\$0	2,569	\$20,619,859
Nevada	2,426	\$5,866,890	\$2,418	43	88	33	595	\$2,671,856	1,831	\$3,195,034
New Hampshire	3,142	\$6,392,547	\$2,035	44	238	13	0	\$0	3,142	\$6,392,547
New Jersey	4,564	\$39,868,869	\$8,736	19	51	42	0	\$0	4,564	\$39,868,869
New Mexico	5,725	\$16,710,745	\$2,919	42	275	7	0	\$0	5,725	\$16,710,745
New York	54,309	\$545,479,789	\$10,044	17	277	6	0	\$0	54,309	\$545,479,789
North Carolina	10,021	\$39,325,866	\$3,924	36	102	30	0	\$0	10,021	\$39,325,866
North Dakota	779	\$17,004,084	\$21,828	3	109	28	6	\$86,529	773	\$16,917,554
Ohio	21,882	\$98,410,606	\$4,497	34	189	16	0	\$0	21,882	\$98,410,606
Oklahoma	4,496	\$75,002,046	\$16,682	13	117	26	2,113	\$5,792,470	2,383	\$69,209,576
Oregon	2,030	\$970,552	\$478	50	52	41	0	\$0	2,030	\$970,552
Pennsylvania	25,429	\$81,087,979	\$3,189	41	199	15	0	\$0	25,429	\$81,087,979
Rhode Island	1,575	\$33,084,019	\$21,006	4	150	21	43	\$144,743	1,532	\$32,939,276
South Carolina	11,764	\$59,768,916	\$5,081	32	248	11	2,350	\$1,211,100	9,414	\$58,557,816
South Dakota	1,922	\$6,324,861	\$3,291	39	229	14	0	\$0	1,922	\$6,324,861
Tennessee	4,761	\$7,133,400	\$1,498	45	74	38	0	\$0	4,761	\$7,133,400
Texas	20,156	\$238,841,452	\$11,850	16	77	36	0	\$0	20,156	\$238,841,452
Utah	1,723	\$11,240,253	\$6,524	27	60	40	1	\$58	1,722	\$11,240,195
Vermont	1,774	\$21,184,286	\$11,942	15	283	4	0	\$0	1,774	\$21,184,286
Virginia	325	\$1,845,355	\$5,678	29	4	50	325	\$1,845,355	0	\$0
Washington ⁴	7,436	\$50,276,399	\$6,761	25	107	29	2,122	\$5,078,384	6,170	\$45,198,015
West Virginia	2,544	\$48,347,261	\$19,004	9	137	23	0	\$0	2,544	\$48,347,261
Wisconsin	23,192	\$77,504,036	\$3,342	38	404	1	0	\$0	23,192	\$77,504,036
Wyoming	1,389	\$7,329,504	\$5,277	31	240	12	0	\$0	1,389	\$7,329,504
United States	464,043	\$4,144,355,306	\$8,931		147		21,989	\$58,485,938	443,005	\$4,085,869,367

¹Total family support consisted of cash subsidy and "other family support" that included respite care, family counseling, architectural adaptation of the home, in-home training, sibling support, education and behavior management services, and the purchase of specialized equipment.

²States' ranking, highest to lowest, on total family support spending per family supported.

³States' ranking, highest to lowest, on total families supported per 100,000 citizens of the general population.

⁴In Delaware each of the families receiving cash subsidies also received other family support; and in Washington, the majority of cash subsidy families also received other (i.e., non-subsidy) family support.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

subsidy and other family support, It also ranks the states on the basis of average spending per family and on families supported per 100,000 of the state general population, respectively. Annual per-family spending ranged from \$478 in Oregon to \$37,927 in Iowa. Thirty-two states spent more than \$5,000 per family in 2013, while three states spent less than \$1,000.

As noted, inflation-adjusted family support spending in the U.S. dropped 0.4% during 2011-13 (Figure 23 below), but growth rates exceeded 50% in West Virginia, District of Columbia, Rhode Island, and Kentucky. Conversely, 22 states reduced their family support funding between 2011 and 2013, with reductions of 10% or more in Alabama, Nevada, Florida, Washington State, New Jersey, New Hampshire, and Colorado. As noted, Idaho reported no family support spending beginning in 2011. In 2012, Virginia terminated family support spending, but in 2013 instituted a cash subsidy.

Seven states that had financed cash subsidies in 2008 no longer did so in 2013: Arkansas, Kansas, New Hampshire, New Jersey, New Mexico, Tennessee, and Texas. Total cash payments to families in the U.S. declined from \$96.8 million in 2008 to \$58.5 million in 2013 (a 45% inflation-adjusted decline).

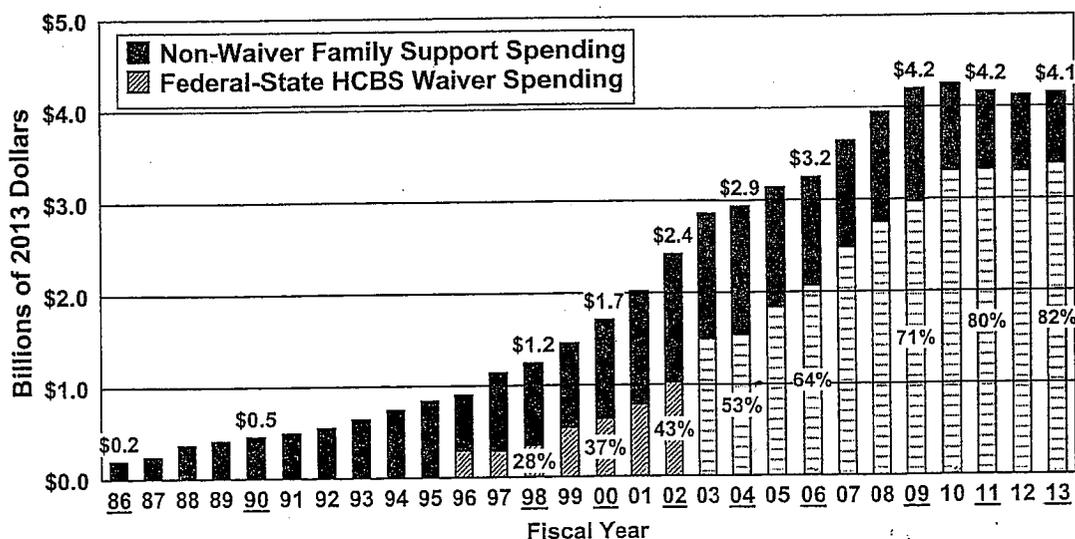
The average annual subsidy payment to a family in the U.S. in 2013 was \$2,660, ranging from \$58 in Utah to \$14,422 in North Dakota. The combined cash subsidy programs in four states, Michigan, Minnesota, Oklahoma, and Washington accounted for 75% of all subsidy payments in the nation in 2013.

HCBS Waiver's role in family support. The Medicaid Home and Community Based Services (HCBS) Waiver has been instrumental in helping states reduce their reliance on institutional settings while developing community services including family supports (Figure 23). In fact, the HCBS Waiver has emerged as the principal funding source for services that support individuals living in the family home (Rizzolo, et al., 2006, 2013). Larson, et al. (2014) recently reported that over 55% of HCBS recipients in 2012 lived with their parents or other family member, an increase from 48% in 2011 (Larson et al., 2013).

In 2013, the HCBS Waiver financed 82% of all family support services spending in the United States. The states varied greatly in the extent to which they utilized HCBS Waiver funds to finance family support initiatives. Twenty-four states funded 90% or more of their family support services with the Medicaid HCBS



Figure 23
INFLATION- ADJUSTED SPENDING FOR
FAMILY SUPPORT SERVICES: FY 1986-2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.

VIII. DEMAND FOR SERVICES AND SUPPORTS

Formal out-of-home residential services were being provided to 634,509 persons in the states in 2013. The vast majority of these settings are operated by private, non-profit service providers. The structure of the residential care system has changed markedly over the past 25 years as state-operated residential institutions have increasingly been supplanted by community residential services.

The nation's overall residential system capacity increased by 48% from 1999–2013, with an average annual growth rate of 3% per year. Growth was 1% per year in the U.S. general population.

Aging Caregivers

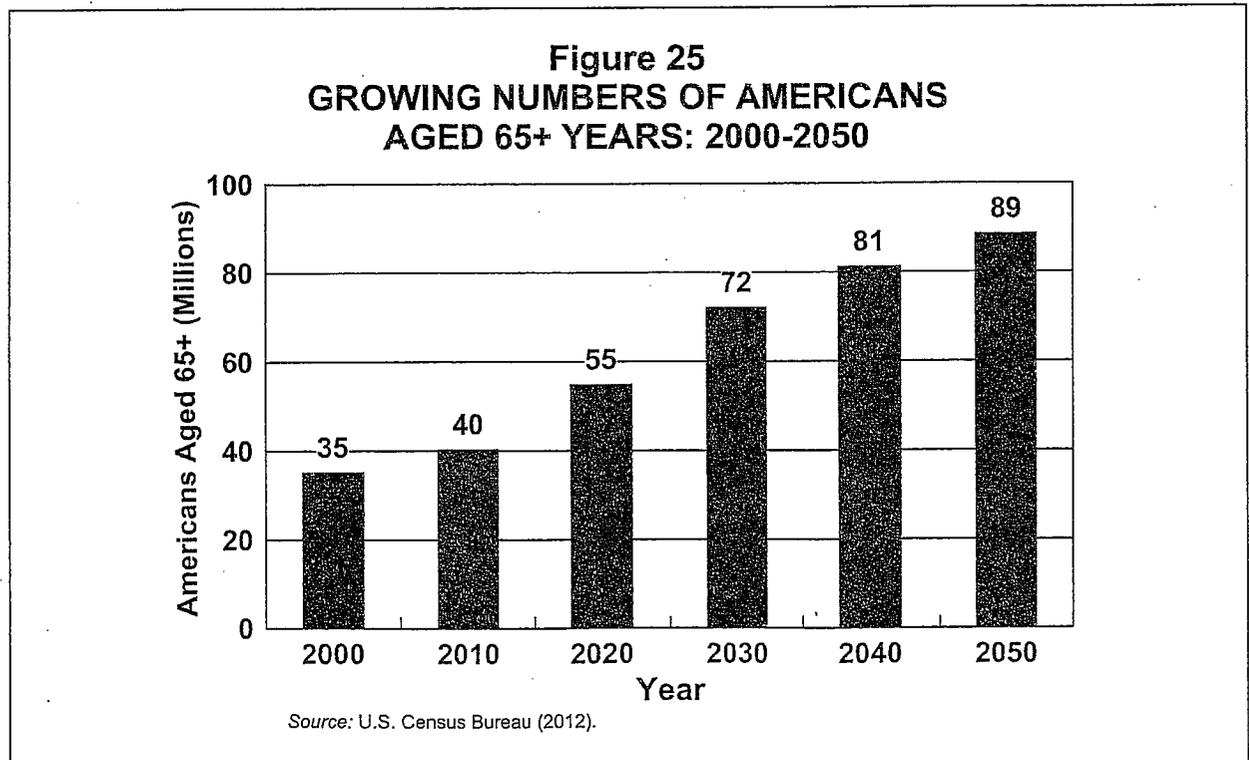
The longevity revolution directly influences demand for IDD services because of the number of people with IDD residing with family caregivers. As these caregivers age beyond their caregiving capacities, formal living

arrangements must be established to support their relatives with disabilities.

The aging of our society is the product of several forces, including the size of the baby boom generation (persons born during 1946–1964), declining fertility rates, and increased longevity. Baby boomers began to reach age 65 in 2011.

The number of persons in our society aged 65+ years is projected by the U.S. Census Bureau (2014) to reach 55 million in 2020 and 89 million in 2050 (Figure 25 below). Currently, 13.3% of the U.S. general population is aged 65+ years. In the U.S., 37% of persons 65 years of age and over have one or more physical disabilities as opposed to 11% of the population under age 65 (Schiller, Lucas, Ward, & Peregoy, 2012).

Americans 80 years or older are expected to be the fastest growing age group. Many countries will be affected by this demographic trend, particularly Brazil, China, India, Indonesia, and Japan. The UN estimates that, by 2050, the percentage of Japan's citizens over the



age of 60 will have increased from 30% to 44%. At least 16% of their population will be over age 80 (United Nations, 2009). Europe now has the oldest population, with a median age of nearly 40 years that is projected to reach 47 years in 2050. On a global basis, life expectancy at birth was 68 years in 2005–10. It is projected to be 76 years in 2045–50 (United Nations, 2009).

Estimating the impact of aging on the increased demand for intellectual and developmental disabilities services in the states requires data on the prevalence of developmental disabilities in our society. Based on data from the National Health Interview Survey-Disability Supplement (NHIS-D), Larson, Lakin, Anderson, Kwak, Lee, & Anderson (2001) recommended using a rate of 1.58% to estimate prevalence for persons with intellectual disability, cerebral palsy, autism, epilepsy, and other childhood disabilities originating prior to 22 years of age.

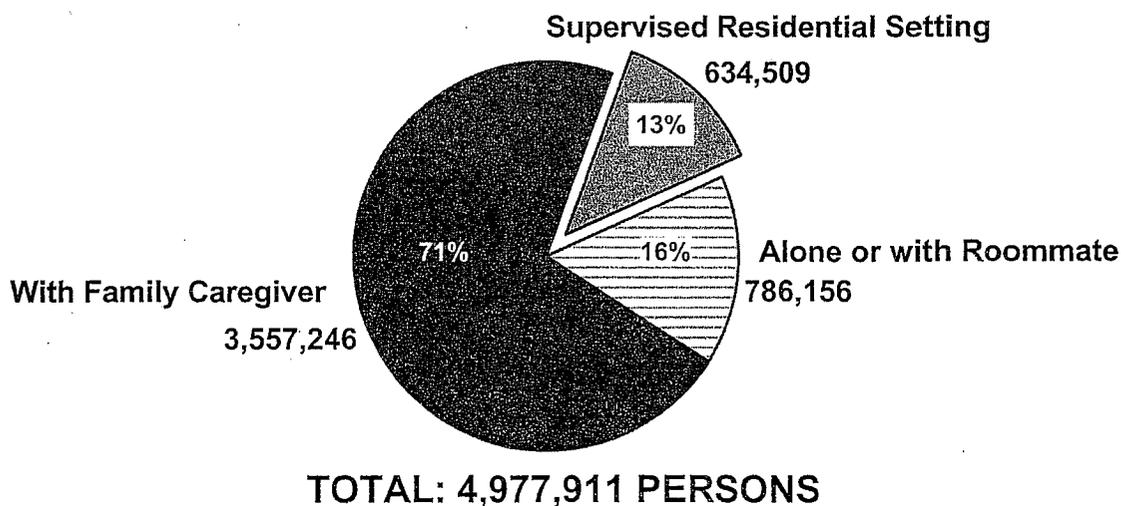
Fujiura (1998, 2012) determined that in 2010, 71% of persons with developmental disabilities in the U.S. resided with family caregivers, and 29% lived on their own or within the formal out-of-home residential care system in the states. We updated Fujiura’s analysis using

data pertaining to the 2013 IDD out-of-home residential system, and the U.S. general population in 2013.

The results are presented in Figure 26 below, which indicates that 3.56 million of the 4.98 million persons with intellectual and developmental disabilities in the U.S. population in 2013 were receiving residential care from family caregivers. This “informal” system of residential care served nearly six times the number of persons served by the formal out-of-home residential care system (634,509 persons). Moreover, Fujiura (1998, 2012) determined that 25% of individuals with developmental disabilities in the U.S. lived with family caregivers aged 60+ years, and an additional 35% were in “households of middle-aged caretakers for whom transition issues are near-term considerations” (Fujiura, 1998, p. 232). Without proper supports and coping strategies, long-term caregiving places family members at risk for physical and psychological issues as they age (Seltzer, Floyd, Song, Greenberg & Hong, 2011).

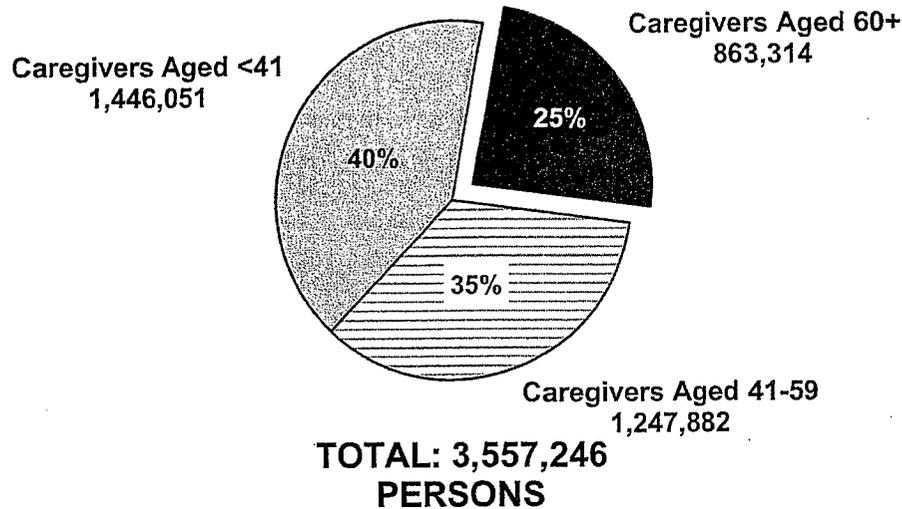
We further examined the data in Figure 26 to draw specific attention to the size of the aging family caregiver cohort in the states. It is 863,314 persons in 2013 (Figure 27 on page 64).

Figure 26
UNITED STATES
ESTIMATED DISTRIBUTION OF INDIVIDUALS
WITH I/DD BY LIVING ARRANGEMENT, FY 2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015, based on Fujiura (2012).

Figure 27
UNITED STATES
ESTIMATED NUMBER OF INDIVIDUALS WITH I/DD
BY AGE GROUP LIVING WITH FAMILY CAREGIVERS, FY 2013



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015, based on Fujiura (2012).

How large is the aging caregiver cohort in each of the states? State-by-state estimates can be generated by taking into account differences in states' utilization of out-of-home placements and the number of the states' caregivers who are over age 60. For example, an estimated 5% of persons with IDD in Arizona and Nevada live in out-of-home settings while the figure is 23% in Oregon. The percentage of individuals over age 65 in the oldest state, Florida (17.6%), is over two times the percentage of older individuals in the youngest state, Alaska (8.1%) (United States Census Bureau, 2014).

State-by-state estimates of the number of individuals with intellectual and developmental disabilities living with aging caregivers appear in Table 21 on the following page.

Increased Longevity of People with Intellectual Disability

A second factor contributing to the growing demand for IDD services is the increase in the lifespan of individuals with intellectual and developmental disabilities. The mean age of death for persons with developmental

disabilities was 66 years in 1993, compared to 59 years in the 1970s and 33 years in the 1930s. The average longevity of people with Down syndrome increased from nine years in the 1920s to 31 years in the 1960s and 56 years in 1993 (Janicki, Dalton, Henderson, & Davidson, 1999.)

The mean age at death for the general population in 1993 was 70 years (Janicki, et al., 1999). In 2009, the life expectancy at age 65 for all Americans was 84.1 years (Centers for Disease Control and Prevention, 2013). An Australian study reported that the average age of death for people with mild and moderate intellectual impairment who do not have any chronic health conditions is 71 years (Bittles, Petterson, Sullivan, Hussain, Glasson, & Montgomery, 2002).

Information has emerged on genetic and nonspecific neurodevelopmental conditions linked to intellectual disability, which are affected differently by maturation and aging. For example, Down syndrome has been linked to premature aging, Alzheimer's disease, and certain organ dysfunctions (Nakamura & Tanaka, 1998; Prasher, 2006; Pueschel, 2006).

In addition to genetic disorders, specific health problems related to the older age trajectories of several common neurodevelopmental conditions include

STATE, COUNTY AND LOCAL FUNDS POTENTIALLY AVAILABLE TO MATCH
 ADDITIONAL FEDERAL MEDICAID FUNDING, BY STATE: FY 2013^{1,2}

Rank	State	Total Federal, State, County & Local I/DD Spending	Total Unmatched State, County & Local Funds	Unmatched % of Total Spending
47	Alabama	\$365,940,032	\$1,233,224	0.3%
24	Alaska	\$201,532,918	\$12,615,481	6%
34	Arizona	\$841,563,743	\$21,056,347	3%
42	Arkansas	\$527,999,330	\$6,685,604	1%
9	California	\$6,390,317,836	\$938,445,563	15%
13	Colorado	\$531,162,109	\$60,671,568	11%
32	Connecticut	\$1,224,322,460	\$45,189,483	4%
8	Delaware	\$169,412,299	\$25,949,293	15%
16	District of Columbia	\$282,030,691	\$27,698,821	10%
30	Florida	\$1,511,310,251	\$61,494,394	4%
2	Georgia	\$869,762,020	\$258,625,392	30%
18	Hawaii	\$161,577,571	\$12,889,415	8%
51	Idaho	\$207,799,707	\$0	0%
15	Illinois	\$1,617,099,416	\$173,303,127	11%
48	Indiana	\$1,334,739,878	\$2,373,039	0.2%
40	Iowa	\$882,275,768	\$14,079,961	2%
43	Kansas	\$490,174,045	\$5,163,175	1%
26	Kentucky	\$749,108,402	\$36,629,931	5%
31	Louisiana	\$1,433,045,715	\$54,440,240	4%
36	Maine	\$448,139,612	\$8,447,527	2%
12	Maryland	\$1,025,189,427	\$134,025,953	13%
1	Massachusetts	\$2,097,231,847	\$800,538,841	38%
17	Michigan	\$1,486,804,014	\$127,267,109	9%
35	Minnesota	\$1,717,424,059	\$35,369,566	2%
21	Mississippi	\$474,208,880	\$32,692,056	7%
14	Missouri	\$1,019,972,411	\$109,692,952	11%
6	Montana	\$169,771,070	\$33,407,081	20%
33	Nebraska	\$370,871,573	\$12,651,309	3%
5	Nevada	\$163,366,688	\$38,250,024	23%
44	New Hampshire	\$280,842,881	\$2,729,485	1%
7	New Jersey	\$1,999,346,983	\$383,683,363	19%
27	New Mexico	\$361,742,908	\$16,773,966	5%
22	New York	\$10,612,950,881	\$680,595,859	6%
11	North Carolina	\$1,496,279,728	\$195,685,611	13%
38	North Dakota	\$273,546,233	\$4,896,419	2%
3	Ohio	\$3,301,037,315	\$838,412,487	25%
25	Oklahoma	\$517,425,196	\$26,425,108	5%
37	Oregon	\$801,627,121	\$14,664,905	2%
4	Pennsylvania	\$3,596,533,856	\$865,235,035	24%
45	Rhode Island	\$257,610,278	\$1,327,616	1%
19	South Carolina	\$600,724,815	\$46,208,380	8%
29	South Dakota	\$171,431,472	\$7,222,231	4%
39	Tennessee	\$929,290,910	\$16,143,425	2%
28	Texas	\$2,672,609,039	\$118,638,738	4%
46	Utah	\$279,743,642	\$1,032,109	0%
49	Vermont	\$178,644,406	\$42,778	0%
10	Virginia	\$1,307,898,466	\$183,293,641	14%
20	Washington	\$1,053,779,340	\$72,692,088	7%
50	West Virginia	\$446,356,220	\$0	0%
23	Wisconsin	\$1,407,295,564	\$88,942,086	6%
41	Wyoming	\$147,847,342	\$1,941,779	1%
	United States	\$61,458,718,366	\$6,657,473,585	10.8%

¹States ranked lowest have the highest percentage of Unmatched Funds as a percentage of total I/DD Spending. Unmatched funds consisted of total I/DD spending, minus federal-state Medicaid, federal SSI/ADC for HCBS Waiver participants, SSI state supplementation, and social services and other federal funds.

²County governments provided 20% of Ohio's unmatched state and local funds; unmatched funds in Iowa & Wisconsin also included county and other local government funding (see Table 16, p. 41).

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015.



Family Caregiving: The Facts

- More than 34 million unpaid caregivers provide care to someone age 18 and older who is ill or has a disability (AARP, 2008).
- An estimated 21% of households in the United States are impacted by caregiving responsibilities (NAC, 2004).
- Unpaid caregivers provide an estimated 90% of the long-term care (IOM, 2008).
- The majority (83%) are family caregivers—unpaid persons such as family members, friends, and neighbors of all ages who are providing care for a relative (FCA, 2005)
- The typical caregiver is a 46 year old woman with some college experience and provides more than 20 hours of care each week to her mother (NAC, 2004).
- The out-of-pocket costs for caregivers who are caring for someone who was age 50 or older averaged \$5,531 in 2007. About 37% of caregivers for someone age 50 and older reduced their work hours or quit their job in 2007 (AARP, 2008).
- Caregivers report having difficulty finding time for one's self (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%) (NAC, 2004).
- About 73% of surveyed caregivers said praying helps them cope with caregiving stress, 61% said that they talk with or seek advice from friends or relatives, and 44% read about caregiving in books or other materials (NAC, 2004).
- About 30% said they need help keeping the person they care for safe and 27% would like to find easy activities to do with the person they care for (NAC, 2004).
- Half (53%) of caregivers who said their health had gotten worse due to caregiving also said the decline in their health has affected their ability to provide care (NAC, 2006).
- Caregivers said they do not go to the doctor because they put their family's needs first (67% said that is a major reason), or they put the care recipient's needs over their own (57%). More than half (51%) said they do not have time to take care of themselves and almost half (49%) said they are too tired to do so (NAC, 2004).

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ATTACHMENT "C"

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POSITION STATEMENT

Family Support

Family support services¹ and other means of supporting families should be available to all families to strengthen families' capacities to support family members with intellectual and/or developmental disabilities² (I/DD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency.

Issue

Individuals with I/DD frequently require support to perform basic daily activities and to achieve the national goals of equal opportunity, full participation, independent living, and economic self-sufficiency. Families are overwhelmingly the primary and often the major source of support for their family member with I/DD. Nearly three quarters of people with I/DD live in the family home and, according to The Arc's Family and Individual Needs for Disability Supports (FINDS) survey, most of these family caregivers provide more than 40 hours of care per week (including 40% who provide more than 80 hours of care per week).

Changing demographics are placing even greater demands on this already limited service system. The aging of the baby boom generation is resulting in an increasing number of people with I/DD living with aging caregivers. These aging caregivers will have greater need for family support, such as assistance in developing desired in-home support plans or transition plans to community living for their family member with I/DD when they are no longer able to continue in their caregiving role.

Unfortunately, the increasing reliance on families is not being met with commensurate support. A generation ago, families were discouraged from keeping their family members with I/DD at home and encouraged to use costly publicly financed institutional placements. Today, they face the other extreme where they are expected to be willing and able to provide lifelong support to their family member with I/DD in place of appropriate community supports, even in cases when residing in the family home may not be a good option for adult offspring with I/DD or themselves.

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Our service system is increasingly being built around the expectation that adults with I/DD will reside in the family home. This is not consistent with other national policies for vulnerable populations.

Relatively small proportions of federal and state funding for persons with I/DD are committed to family support, despite increasing numbers of people with I/DD living with family for longer periods. Consequently, though family support is critical for avoiding placement in costly and inappropriate institutions for the family member with I/DD, the needed supports are frequently insufficient or unavailable.

There is no comprehensive family support system in the U.S. Instead, the vast majority of publicly provided family support services are funded through Medicaid home and community-based services (HCBS) waivers and some states provide limited family support using state general fund dollars. Consequently, beneficiaries of family support experience the same mobility and portability limitations as those receiving other Medicaid HCBS. This problem is most acutely felt by military families who move frequently and have to begin the application and waiting process anew with each move between states.

Although family support has been a policy of the federal and state governments since the 1980s, families and individuals with I/DD increasingly are using their social capital to achieve the four national goals and attain quality of life outcomes, and are also benefitting from and seeking more policies, practices, and procedures of generic governmental and private-sector entities that support families. Families' reliance on social capital and these other means for supporting families have become important as supplements to, not replacements of, governmental-sponsored family support programs.

Position

Comprehensive, universally accessible family support must be provided in order to:

- Assist families as they guide their member with a disability toward being self-determined individuals and achieving the nation's goals for people with disabilities as set out in federal legislation, namely, equal opportunity, economic productivity, independent living, and full participation;
- Strengthen the caregiving efforts of families (with special emphasis on their emotional and physical health, financial and material needs, and parenting and family interaction), enhance the quality of life of all family members, and increase their access to supports and services for themselves and their members with I/DD;
- Recognize that relying on families to provide care cannot be a substitute for creating a national solution to provide appropriate long term supports and services;
- Enable families to make informed choices regarding the nature of supports for themselves and their members with disabilities, including the use of supported decision making for family members with I/DD; and
- Help families with minor members to stay intact, preventing any type of out-of-home placements for a minor child, particularly institutions.

Policies of family support and public and private systems for supporting families must:

- Be provided in a manner that builds on the family's strengths;
- Be provided in ways that are sensitive to the family's culture, religion, and socio-economic status;
- Assist the individual and family to maximize

the self-determination of its member with I/DD;

- Be controlled, determined, and directed by the family itself, in partnership with those who provide the service;
- Be provided through best practices and state-of-the-art methods;
- Be available to all family caregivers, including, but not limited to, parents (including those with I/DD themselves), adoptive parents, foster parents, siblings, uncles, aunts, cousins, grandparents, grandchildren, and individuals who are in spousal-equivalent relationships;
- Be available to all families regardless of whether the person with I/DD resides in the family home or is presently receiving publicly funded services;
- Provide options for family members to be compensated for their time providing essential supports, while ensuring that such arrangements are mutually desired by the family caregiver and member with I/DD and do not impose inappropriate barriers under the guise of regulating medical services provided by paid family caregivers (such as requiring a nursing license to provide g-tube feeding or insulin shots as part of respite care); and
- Be defined as a system of policies, practices, and procedures for supporting families rather than as a “family support program” sponsored by a government or private-sector entity. Increasingly, these individualized supports should be available from generic (non-disability-specific) governmental and nongovernmental entities.

¹ Traditionally, government-sponsored family support has consisted of the following types of support: 1) Cash assistance from federal, state, and local governmental sources that is provided: a) Over and above, to supplement but not to supplant, any other federal cash transfer or medical, educational, or welfare benefit programs (including without limitation those under any title of the Social Security Act, Individuals with Disabilities Education Act, and Developmental Disabilities Assistance and Bill of Rights Act); b) Because of the disability of a member of a family; and c) To the family as the primary beneficiary of the family support program, not to the member of the family who has a disability as the primary beneficiary; 2) Information and emotional and instrumental support provided by: a) Professionals, including those in disability-specializing professions and entities and those in generic, non-disability specializing professions and entities; b) Members of the family of the person with a disability or friends of the family or person;; and c) Entities that support families or parents, including parent-to-parent and community-based family resource centers, or 3) Any combination of the above. Specific examples of family support services are respite, counseling, cash assistance, training, support groups, minor home modifications, and information and referral.

² “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the Developmental Disabilities Assistance and Bill of Rights Act 2000. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

Adopted:
American Association on Intellectual and Developmental Disabilities
Board of Directors
February 19, 2014

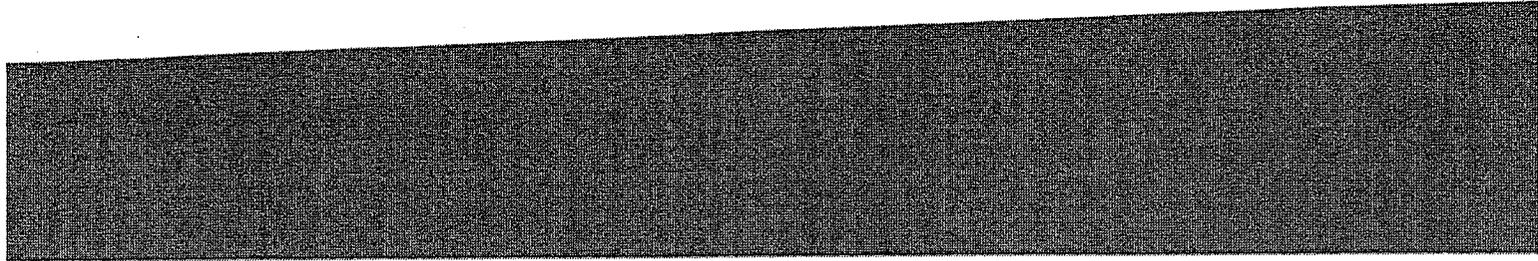
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EXCERPT



Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2013:

Home and Community-Based Services were a Majority of LTSS Spending

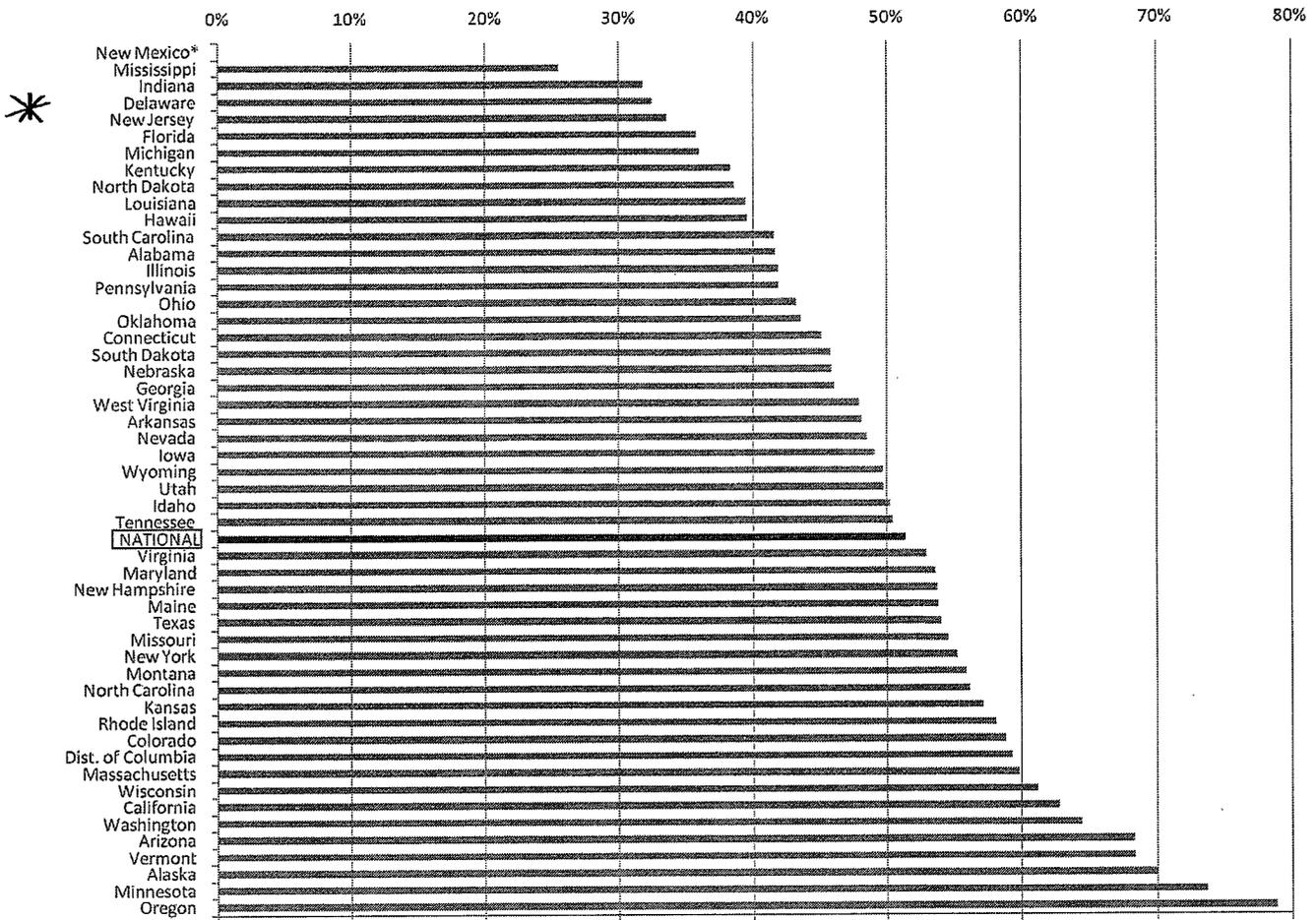
June 30, 2015

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Brian Burwell
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ATTACHMENT "D"

Figure 2. Medicaid HCBS Expenditures as a Percentage of Total Medicaid LTSS Expenditures, by State, FY 2013



*New Mexico was excluded from this analysis because it has a high proportion of LTSS delivered through managed care and detailed information about the state's managed care expenditures was not available for FY 2013.

The bar for each state represents HCBS spending as a percentage of total LTSS spending, ranging from 25.5 percent in Mississippi to 78.9 percent in Oregon. The states are almost evenly divided on either side of 50 percent, with 26 states below 50 percent of spending on HCBS and 23 states and the District of Columbia above 50 percent. New Mexico was excluded from the analysis due to lack of data. The variation demonstrates that state-level actions are important to balancing LTSS systems.