

MEMO

To: Office of Management & Budget
From: Brian J. Hartman, on behalf of the following organizations:

Disabilities Law Program
Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens
State Council for Persons with Disabilities

Subject: Division of Developmental Disabilities Services FY 15 Budget
Date: November 26, 2013

Please consider this memo a summary of the oral presentation of Brian J. Hartman, Esq. on behalf of the Disabilities Law Program ("DLP"), 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., development of a family support waiver.

As you know, the FY14 budget bill directs the Division to submit a plan to establish a family support waiver to the Legislature and Administration by April 1, 2014.¹ This initiative enjoys widespread support among the Division's constituents and partner agencies.

As background, more than 70% of the Division's clients live at home with their family.² In raw numbers, this equates to 2,664 clients living at home out of a total census of 3,743 individuals.³ This group is increasing in size. Between FY11 and the end of FY13, it grew from 2,165 to 2,664, a 19% increase.⁴ Consistent with national trends, many of the Delaware caregivers in those families are aging.⁵ The percentage of aging caregivers is increasing annually as the "boomers" progress into old age.⁶ Given declines in health and resiliency attributable to aging, such caregivers will predictably need an increasing level of supports to continue in their role.⁷

¹A copy of §169 of H.B. No. 200 (FY14 budget bill) is included as Attachment "A".

²See DDDS FY14 JFC Presentation (February 21, 20113) at 5. [Attachment "B"]

³The latest (September, 2013) DDDS census report is included as Attachment "C".

⁴See Attachment C and D. Braddock, The State of the States in Developmental Disabilities (2013) at 115. [Attachment "D"]

⁵See Braddock, at pp. 58-60. [Attachment "D"]

⁶AARP, "The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers (August, 2013) [Attachment "E"]

⁷CDC, "Family Caregiving: The Facts" [Attachment "F"]

Almost all states offer family support programs for caregivers of individuals with developmental disabilities. The national average of spending per family is \$8,610. Unfortunately, although DDDS is adept at identifying families needing support (ranking 12th), it spends less than 10% of the national average in per-family supports (ranking 47th).⁸ This underscores the justification to develop an enhanced family support system.

Economics also buttress the worth of a robust family support system.

First, subsidizing families providing in-home support obviates the necessity of providing more costly residential services.

Second, nationwide, Medicaid waivers finance 79% of all family support services.⁹ This represents a tremendous leveraging of federal funds to assist state residents. Conversely, Delaware's lack of a family support Medicaid waiver results in unnecessary reliance on unmatched State funds and few resources for Delaware families. A recent study highlights that Delaware is essentially "leaving money on the table" by eschewing available Medicaid funding. Delaware ranked 6th among the states in the percentage of unmatched funding devoted to individuals with developmental disabilities.¹⁰

In closing, we wholeheartedly endorse development of a plan to establish a family support waiver. We also encourage approval of the necessary funds to prepare and secure CMS approval of the waiver.

Thank you for your consideration.

Attachments

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⁸See Braddock, p. 55. [Attachment "B"]

⁹See Braddock, p. 56. [Attachment "B"]

¹⁰See Braddock, p. 204. [Attachment "B"]

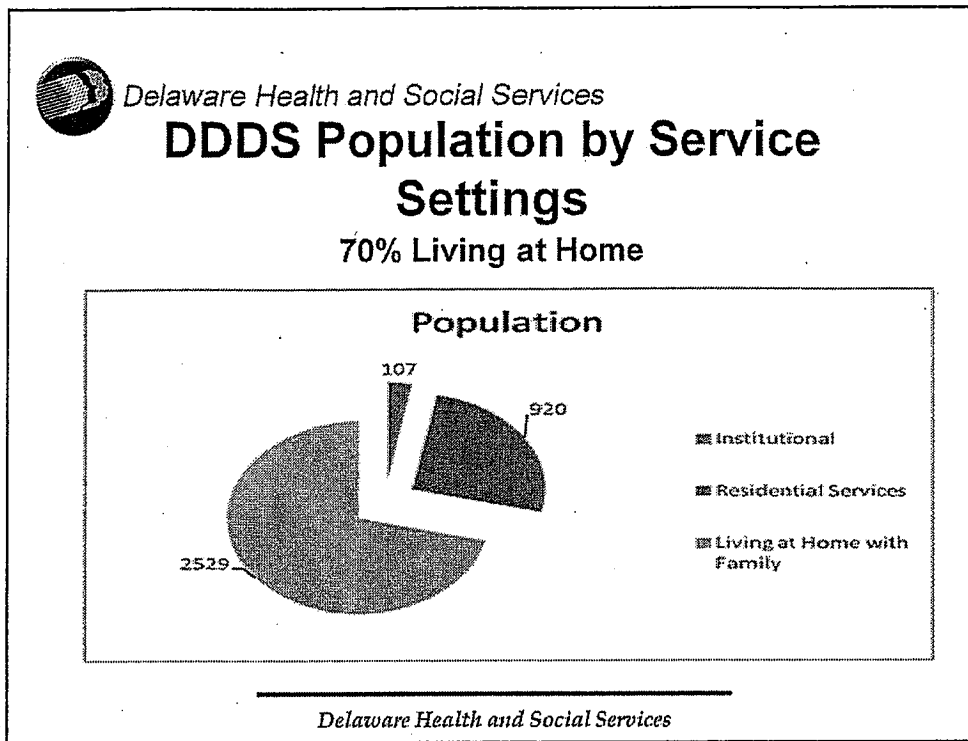
1 **Section 166.** Section 1 of this Act provides an appropriation to the Department of Health and
2 Social Services, Visually Impaired Services (35-08-01) for Contractual Services. Of that amount, \$15.9
3 shall be used to compensate correctional inmates for the purpose of producing Braille materials for visually
4 impaired school children.

5 **Section 167.** Section 1 of this Act provides an appropriation of ~~\$1,231.5~~ \$1,232.8 ASF in the
6 Department of Health and Social Services, Child Support Enforcement (35-10-00 35-10-01) for the
7 operation of the division. Revenue from child support collections shall fund this account and the related 2.5
8 ASF FTEs. The department shall continue its efforts to maintain collections related to child support
9 programs, and all revenue in excess of the division's ASF authority shall be deposited as designated by 29
10 Del. C. § 6102.

11 **Section 168.** Section 1 of this Act provides an appropriation to the Department of Health and
12 Social Services, Child Support Enforcement (35-10-00 35-10-01) for Contractual Services. Of that amount,
13 \$211.1 is for programming costs for the Delaware Automated Child Support Enforcement System
14 (DACSES) Redevelopment Project. Child Support Enforcement shall have the authority to contract for IT
15 resources needed to augment existing programming staff for the duration of this project. At the project's
16 conclusion, the division shall have the authority, with approval from the Director of the Office of
17 Management and Budget and the Controller General, to transfer these funds to Personnel Costs and establish
18 up to 3.0 positions and 5.0 NSF positions in order to support DACSES system maintenance.

* 19 **Section 169.** The General Assembly is supportive of families who care for individuals with
20 disabilities in the community. The Department of Health and Social Services, Division of Developmental
21 Disabilities Services (35-11-00) is directed to move forward with developing a plan to establish a Family
22 Support Waiver. The plan, including a review of necessary funding, shall be submitted to the Co-Chairs of
23 the Joint Finance Committee, the Controller General and the Director of the Office of Management and
24 Budget by April 1, 2014.

25 **Section 170.** (a) The Department of Health and Social Services, Developmental Disabilities
26 Services (35-11-00) may rebase, once every one to three years, its Inventory for Client and Agency Planning



As of the December 2012 DDDS census report, the Division provides services to over 3,500 individuals and their families. Of these, 2,529 people live at home with their families, 920 receive residential services in the community, and 107 individuals with intellectual disabilities are receiving specialized services in institutions, including Stockley Center and nursing facilities. In summary, 97% of the people we serve receive community-based services and only 3% receive institutional services.

Over 70% of the Division's clients live at home with their family. At present, DDDS contracts with Family Support Coordinators who assist the individuals and their family to navigate a complex service system. The other major family support is funding for respite. Families who are supporting individuals living at home are looking for new and flexible systems of support. Therefore, over the next year, DDDS will be working with families to evaluate a variety of family support service models with an expected outcome of a new comprehensive array of services that will be designed to recognize the diverse support needs of families and to create a family support program that is flexible, comprehensive and cost effective.



MONTHLY CENSUS REPORT

September 2013

A. STOCKLEY CENTER
MARY ANN COVERDALE CENTER
102 WAPLES WAY (ICF/MR)

Number as of the
last day of the
month

	49
	12
A.	61

B. COMMUNITY SERVICES/ RESIDENTIAL PLACEMENTS	NEW CASTLE	KENT	SUSSEX
NEIGHBORHOOD (GROUP) HOMES including CLA2 & CLA3	554	88	150
SUPPORTED LIVING	9	3	11
SHARED LIVING	23	55	51
OUT OF STATE	20	1	1
ETLA (Emergency Temporary Living Arrangement)	7	2	3

	792
	23
	129
	22
	12
B.	978

C. DPC (DELAWARE PSYCHIATRIC CENTER)	2	0	0
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C.	2
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D. FAMILY SUPPORT	1468	590	606
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D.	2,664
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E. NURSING HOMES	NEW CASTLE	KENT	SUSSEX	OUT OF STATE
NURSING HOMES	25	8	5	0

E.	38
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**Total Census:
(A to E)**

3743

STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES 2013: THE GREAT RECESSION AND ITS AFTERMATH



**David Braddock, Richard Hemp, Mary C. Rizzolo
Emily Shea Tanis, Laura Haffer, Amie Lulinski, Jiang Wu**

**Department of Psychiatry and Coleman Institute
UNIVERSITY OF COLORADO**

and

**Department of Disability and Human Development
UNIVERSITY OF ILLINOIS AT CHICAGO**

**Published in Collaboration with
AMERICAN ASSOCIATION ON INTELLECTUAL
and DEVELOPMENTAL DISABILITIES (AAIDD)**

TABLE 19
FAMILY SUPPORT PROGRAMS IN THE STATES:
/IDD PARTICIPANTS AND SPENDING IN FY 2011

State	Total Family Support ¹		Spending Per Family	Rank ²	Families Supported		Cash Subsidy		Other Family Support	
	Families	Spending			Per 100K	Rank ³	Families	Spending	Families	Spending
Alabama	1,952	\$549,420	\$281	49	41	48	0	\$0	1,952	\$549,420
Alaska	1,105	\$8,154,630	\$7,380	21	155	19	0	\$0	1,105	\$8,154,630
Arizona	21,860	\$360,286,868	\$16,482	9	337	3	8	\$6,454	21,852	\$360,280,414
Arkansas	528	\$548,897	\$1,040	46	18	50	0	\$0	528	\$548,897
California	101,383	\$710,614,552	\$7,009	22	271	9	0	\$0	101,383	\$710,614,552
Colorado	2,905	\$5,354,506	\$1,843	43	57	40	0	\$0	2,905	\$5,354,506
Connecticut	3,290	\$53,910,549	\$16,386	10	92	31	1,600	\$3,280,095	1,690	\$50,630,454
Delaware ⁴	2,165	\$1,604,698	\$741	47	239	12	59	\$207,574	2,165	\$1,397,124
District of Columbia	416	\$9,239,069	\$22,209	3	69	39	0	\$0	416	\$9,239,069
Florida	16,385	\$363,681,665	\$22,196	4	86	34	99	\$277,266	16,286	\$363,404,399
Georgia	7,125	\$13,317,256	\$1,869	42	73	37	0	\$0	7,125	\$13,317,256
Hawaii	1,808	\$19,962,457	\$11,041	14	132	22	0	\$0	1,808	\$19,962,457
Idaho	0	\$0	\$0	51	0	51	0	\$0	0	\$0
Illinois	5,331	\$27,114,630	\$5,086	29	41	46	299	\$2,077,942	5,032	\$25,036,688
Indiana	5,289	\$36,544,645	\$6,910	24	81	35	0	\$0	5,289	\$36,544,645
Iowa	764	\$29,057,121	\$38,033	1	25	49	297	\$1,500,000	467	\$27,557,121
Kansas	2,564	\$48,010,580	\$18,725	7	90	33	0	\$0	2,564	\$48,010,580
Kentucky	2,354	\$3,718,361	\$1,580	45	54	43	0	\$0	2,354	\$3,718,361
Louisiana	12,927	\$365,043,119	\$28,239	2	285	5	1,752	\$4,801,896	11,175	\$360,241,223
Maine	545	\$6,500,000	\$11,927	12	41	47	545	\$6,000,000	0	\$500,000
Maryland	7,006	\$40,438,454	\$5,772	26	121	25	0	\$0	7,006	\$40,438,454
Massachusetts	10,443	\$35,155,140	\$3,366	36	159	18	0	\$0	10,443	\$35,155,140
Michigan	16,122	\$55,221,114	\$3,425	34	163	16	7,163	\$18,752,369	8,959	\$36,468,745
Minnesota	14,679	\$300,721,022	\$20,486	5	276	6	2,861	\$18,394,751	11,818	\$282,326,271
Mississippi	3,722	\$19,536,865	\$5,249	28	125	23	0	\$0	3,722	\$19,536,865
Missouri	8,682	\$30,003,717	\$3,456	33	144	20	0	\$0	8,682	\$30,003,717
Montana	2,843	\$11,155,808	\$3,924	32	286	4	0	\$0	2,843	\$11,155,808
Nebraska	1,040	\$10,948,271	\$10,527	16	57	41	0	\$0	1,040	\$10,948,271
Nevada	2,467	\$6,461,063	\$2,619	40	90	32	521	\$2,334,954	1,946	\$4,126,109
New Hampshire	4,518	\$10,983,068	\$2,431	41	342	2	103	\$35,381	4,415	\$10,947,687
New Jersey	8,685	\$50,241,924	\$5,785	25	99	29	0	\$0	8,685	\$50,241,924
New Mexico	5,466	\$15,884,237	\$2,906	39	264	10	87	\$293,798	5,379	\$15,590,439
New York	52,632	\$549,174,558	\$10,434	17	271	8	0	\$0	52,632	\$549,174,558
North Carolina	9,175	\$37,353,642	\$4,071	31	95	30	0	\$0	9,175	\$37,353,642
North Dakota	685	\$13,464,733	\$19,657	6	102	28	7	\$73,798	678	\$13,390,935
Ohio	20,312	\$91,984,079	\$4,529	30	176	15	0	\$0	20,312	\$91,984,079
Oklahoma	4,657	\$78,722,068	\$16,905	8	124	24	2,228	\$5,944,265	2,429	\$72,777,803
Oregon	2,083	\$951,001	\$457	48	54	42	0	\$0	2,083	\$951,001
Pennsylvania	25,842	\$81,364,739	\$3,149	38	203	14	0	\$0	25,842	\$81,364,739
Rhode Island	1,225	\$13,072,374	\$10,671	15	116	26	44	\$145,679	1,181	\$12,926,695
South Carolina	11,300	\$60,404,554	\$5,346	27	242	11	2,922	\$1,256,100	8,378	\$59,148,454
South Dakota	1,898	\$5,978,009	\$3,150	37	232	13	0	\$0	1,898	\$5,978,009
Tennessee	4,524	\$7,491,000	\$1,656	44	71	38	0	\$0	4,524	\$7,491,000
Texas	19,625	\$245,855,575	\$12,528	11	77	36	2,952	\$5,721,740	16,673	\$240,133,835
Utah	1,501	\$12,044,393	\$8,024	20	54	44	0	\$0	1,501	\$12,044,393
Vermont	1,702	\$17,757,349	\$10,433	18	272	7	0	\$0	1,702	\$17,757,349
Virginia	3,573	\$618,967	\$173	50	44	45	0	\$0	3,573	\$618,967
Washington ⁴	7,223	\$58,229,286	\$8,062	19	107	27	2,329	\$4,035,584	6,453	\$54,193,703
West Virginia	2,624	\$29,665,233	\$11,305	13	142	21	0	\$0	2,624	\$29,665,233
Wisconsin	20,100	\$68,502,758	\$3,408	35	352	1	0	\$0	20,100	\$68,502,758
Wyoming	908	\$6,341,281	\$6,984	23	160	17	0	\$0	908	\$6,341,281
United States	467,958	\$4,028,939,305	\$8,610		151		25,876	\$75,139,645	443,700	\$3,953,799,660

¹ Total 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.

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

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

⁴ In Delaware other family support constitutes total families; 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, 2013.

TABLE 20

**ESTIMATED NUMBER OF I/DD CAREGIVING
FAMILIES COMPARED TO FAMILIES
SUPPORTED BY STATE I/DD AGENCY
FUNDS: FY 2011**

State	Total IDD Caregiving Families	Families Supported by I/DD Agencies	% of Families Supported	Rank ¹
Alabama	58,255	1,952	3%	48
Alaska	7,959	1,105	14%	19
Arizona	80,045	21,860	27%	3
Arkansas	32,304	528	2%	50
California	438,492	101,383	23%	9
Colorado	58,228	2,905	5%	42
Connecticut	39,379	3,290	8%	31
Delaware	10,791	2,165	20%	13
Dist. of Columbia	6,740	416	6%	38
Florida	228,440	16,385	7%	35
Georgia	114,566	7,125	6%	37
Hawaii	15,901	1,808	11%	22
Idaho	17,477	0	0%	51
Illinois	145,188	5,331	4%	47
Indiana	73,658	5,289	7%	34
Iowa	32,189	764	2%	49
Kansas	32,553	2,564	8%	32
Kentucky	51,240	2,354	5%	43
Louisiana	52,463	12,927	25%	8
Maine	14,198	545	4%	45
Maryland	68,410	7,006	10%	26
Massachusetts	73,614	10,443	14%	18
Michigan	103,299	16,122	16%	16
Minnesota	53,845	14,679	27%	4
Mississippi	34,184	3,722	11%	23
Missouri	68,299	8,682	13%	21
Montana	11,131	2,843	26%	6
Nebraska	20,392	1,040	5%	41
Nevada	33,645	2,467	7%	33
New Hampshire	14,726	4,518	31%	2
New Jersey	102,487	8,685	8%	29
New Mexico	23,768	5,466	23%	10
New York	195,443	52,632	27%	5
North Carolina	109,130	9,175	8%	30
North Dakota	7,001	685	10%	27
Ohio	120,739	20,312	17%	15
Oklahoma	44,302	4,657	11%	24
Oregon	38,462	2,083	5%	40
Pennsylvania	143,540	25,842	18%	14
Rhode Island	11,675	1,225	10%	25
South Carolina	55,595	11,300	20%	12
South Dakota	8,341	1,898	23%	11
Tennessee	75,371	4,524	6%	39
Texas	289,821	19,625	7%	36
Utah	33,565	1,501	4%	44
Vermont	6,736	1,702	25%	7
Virginia	96,927	3,573	4%	46
Washington	74,772	7,223	10%	28
West Virginia	19,212	2,624	14%	20
Wisconsin	59,674	20,100	34%	1
Wyoming	6,038	908	15%	17
UNITED STATES	3,514,211	467,958	13%	

¹States ranked, highest to lowest, on percent of family caregivers receiving I/DD state agency support.

Source: Braddock et al., State of the States in Developmental Disabilities, University of Colorado, 2013.

2009). Larson, Salmi, Smith and Wuorio (2012) reported that over 48% of HCBS recipients in 2010 lived with their parents or other family member.

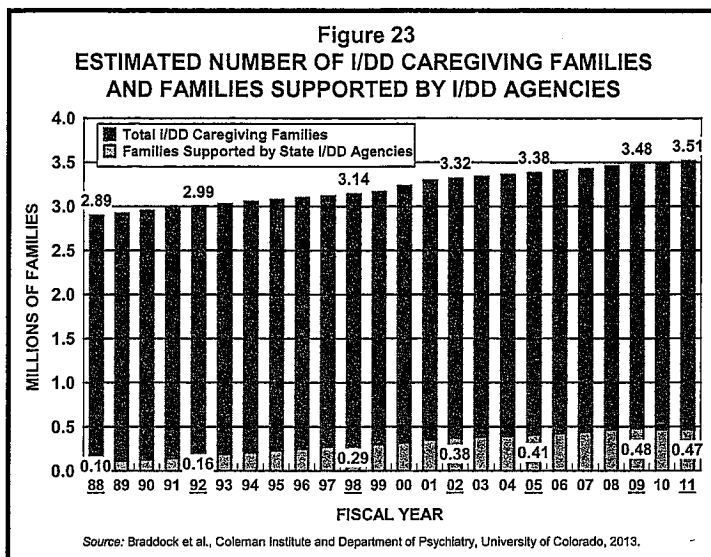
In 2011, the HCBS Waiver financed 79% of all family support services in the United States. The States varied greatly in the extent to which they utilized HCBS Waiver funds to finance family support initiatives. Twenty-five states funded 90% or more of their family support services with the Medicaid HCBS Waiver. Conversely, eight states opted to finance their family support initiatives solely through state funding.

Unmet Need for Family Support

The recent national trend in family support spending and number of families supported suggests efforts to maintain support for family caregivers in a majority of the states. However, in nearly all states and in the nation as a whole, the number of families supported is a small portion of all families providing care for a child or adult with I/DD.

The states varied greatly in the proportion of total estimated families with family members with I/DD who received cash subsidies or other forms of state agency financed family support in 2011 (*Table 20*). Of the 3.5 million families, over 3.0 million did not receive I/DD state agency family support services. The table estimates total caregiving families with children with I/DD based on Survey of Income and Program Participation (SIPP) data (Fujiura, 2012).

Fifteen states were estimated to be providing I/DD financed family support services to 20% or more of total I/DD caregiving families: Arizona, California, Delaware, Louisiana, Minnesota, Montana, New Hampshire, New Mexico, New York, Ohio, Pennsylvania, South Carolina, South Dakota, Vermont, and Wisconsin. However, it was estimated that eight states provided family



support services to 5% or less of those in need: Alabama, Arkansas, Idaho, Illinois, Iowa, Maine, Utah, and Virginia.

There was an increase in the proportion of care-giving families receiving I/DD state agency support during 1988 to 2009 (from 4% to 14%). However, support declined to 13% in 2011, primarily due to family support cutbacks in multiple states resulting from the budget impact of the *Great Recession* (Figure 23).

With the ever-expanding role of the HCBS Waiver, general problems with Waiver financing of family support services have emerged. Issues include Waiver capacity or cost-per-participant caps, cost-neutrality requirements, and various cost-containment strategies such as spending ceilings, service limits, hourly and geographic limits. All these Waiver utilization issues can have a related and sometimes exaggerated effect on the expansion and adequate financing of family support services (Harrington, Ng, Kaye, & Newcomer, 2009).

The hallmark of family support is individualization and flexibility, and data on the number of “non-duplicated” families in some states may include higher proportions of families receiving minimal services such as episodic respite care or service coordination, whereas other states might have a higher

proportion of intensive in-home supports of longer duration. Nevertheless, the data confirm the high level of unmet need in state agency I/DD supports for families and their family members with intellectual and developmental disabilities.

In forthcoming studies, we will continue to refine our taxonomy of family support services (Braddock & Hemp, 2008; Hemp, Braddock, Rizzolo, & Moseley, 2010) and continue the analysis of HCBS Support Waivers and consumer-directed services in the states (Rizzolo et al., in press).

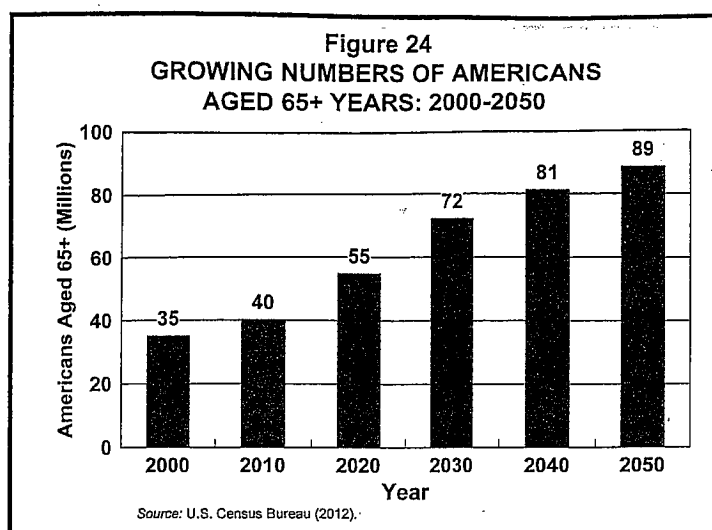
VIII. DEMAND FOR SERVICES AND SUPPORTS

Formal out-of-home residential services were being provided to 613,184 persons in the states in 2011. 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 more than 40% since 1999, with an average annual growth rate of 3% per year during 1999-2011. U.S. general population annual increases were only 1%.

Aging Caregivers

The aging of our society directly influences demand for intellectual and developmental disabilities (I/DD) services because of the number of people with I/DD residing with family caregivers. As these caregivers age beyond their care-giving capacities, formal living arrangements must be established to support their relatives with disabilities (Braddock, 1999).



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 (2012) to reach 55 million in 2020 and 89 million in 2050 (*Figure 24*). 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. For example, 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, and 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 the 1994/95 data from the National Health Interview Survey-Disability Supplement (NHIS-D), Larson et al. (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, 71.5% of persons with developmental disabilities in the U.S. resided with family caregivers, and 28.5% 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 2011 out-of-home residential system, and the U.S. general population in 2011.

The results are presented in *Figure 25* (page 59), which indicates that 3.51 million of the 4.90 million persons with intellectual and developmental disabilities in the U.S. population in 2011 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 (613,184 persons). 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).

In *Figure 26*, we further examined the data in the previous figure to draw specific attention to the size of the aging family caregiver cohort (891,783 persons) in 2011. 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 I/DD 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%) (U.S. Census Bureau, 2012).

State-by-state estimates of the number of individuals with intellectual and developmental disabilities living with older caregivers appear in *Table 21* (page 60).

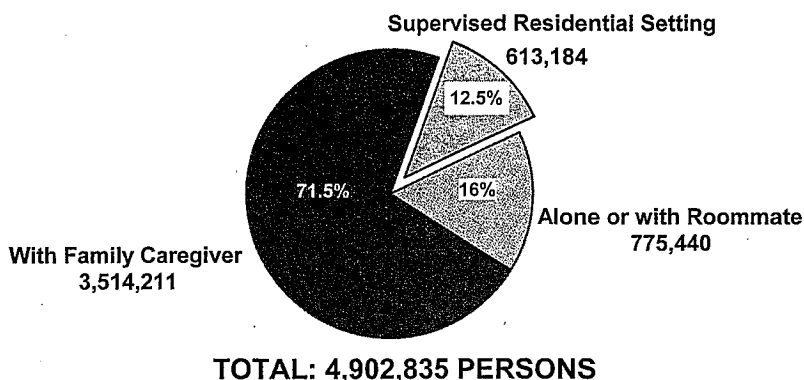
Increased Longevity

A second factor contributing to the growing demand for I/DD 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 to 56 years in 1993 (Janicki, Dalton, Henderson, & Davidson, 1999). The mean age at death for the general population in 1993 was 70 years (Janicki, 1999).

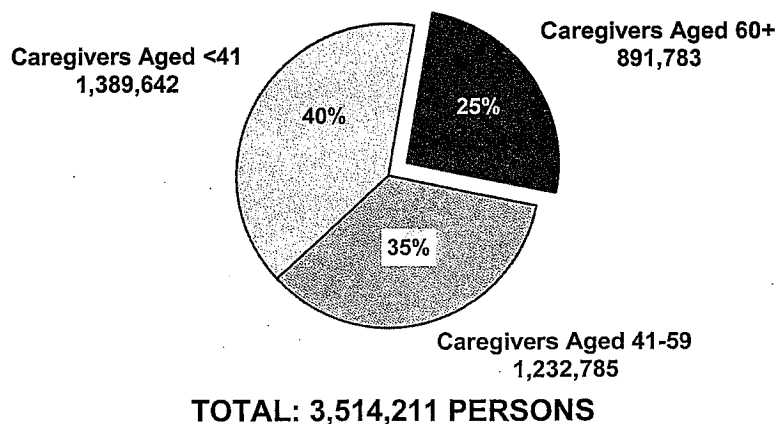
An Australian study reported the average age of death for people with mild and moderate intellectual impairment who do not have any chronic health conditions is 71 years (Bittles, Petterson, Sullivan, Hussain, Glasson,

Figure 25
UNITED STATES
ESTIMATED DISTRIBUTION OF INDIVIDUALS
WITH I/DD BY LIVING ARRANGEMENT, 2011



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013, based on Fujura (2012).

Figure 26
UNITED STATES
ESTIMATED NUMBER OF INDIVIDUALS WITH I/DD
BY AGE GROUP LIVING WITH FAMILY CAREGIVERS, 2011



Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013, based on Fujura (2012).

TABLE 21

**ESTIMATED NUMBER OF
PERSONS WITH I/DD LIVING WITH
AGING CAREGIVERS IN 2011¹**

State	Persons with I/DD
Alabama	16,060
Alaska	1,294
Arizona	21,776
Arkansas	9,013
California	99,069
Colorado	12,243
Connecticut	11,070
* Delaware	2,987
DC	1,495
Florida	78,979
Georgia	22,927
Hawaii	4,451
Idaho	4,082
Illinois	34,934
Indiana	18,143
Iowa	9,329
Kansas	8,455
Kentucky	13,054
Louisiana	12,928
Maine	4,349
Maryland	16,214
Massachusetts	19,590
Michigan	25,722
Minnesota	12,945
Mississippi	8,515
Missouri	18,407
Montana	3,270
Nebraska	5,444
Nevada	8,073
New Hampshire	3,724
New Jersey	27,255
New Mexico	6,618
New York	51,936
North Carolina	26,417
North Dakota	2,080
Ohio	32,138
Oklahoma	11,876
Oregon	9,791
Pennsylvania	43,226
Rhode Island	3,193
South Carolina	14,883
South Dakota	2,357
Tennessee	19,579
Texas	59,381
Utah	5,917
Vermont	1,899
Virginia	23,574
Washington	17,816
West Virginia	5,987
Wisconsin	15,653
Wyoming	1,666
United States	891,783

¹ Caregivers aged 60 years and older.

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.

& Montgomery, 2002). Information is beginning to emerge on genetic and nonspecific neuro-developmental conditions, linked to intellectual disabilities, 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 neuro-developmental conditions include cerebral palsy (e.g., osteoporosis and degenerative joint disease), autism (e.g., digestive system disorders and neuropsychiatric factors) and spina bifida (e.g., neuromotor and other organ system consequences) (Janicki, Henderson, & Rubin, 2008).

In an international review, Katz (2003) summarized research on life expectancy for persons with intellectual disability from several countries including the U.S. He concluded that life expectancy for the vast majority of persons with mild and moderate degrees of intellectual disability did not differ significantly from the general population. Patja et al. (2000) noted, however, a 19 to 35% diminishment of life expectancy in the much smaller cohort of persons with severe and profound degrees of intellectual disability (cited in Katz, 2003, p. 268). The Patja et al. study was carried out in Finland.

As persons with intellectual and developmental disabilities live longer, they require services and support for longer periods of time, as well as supports for aging caregivers. This directly impacts the finite capacities of state service delivery systems. The increased life expectancy of persons with I/DD since 1970 accounts for a significant percentage of the increased demand for residential services in the states today.

The likelihood of older persons with I/DD living into their own retirement and outliving their family caregivers has increased substan-

**APPENDIX I:
STATE AND LOCAL FUNDS POTENTIALLY AVAILABLE TO MATCH
ADDITIONAL FEDERAL MEDICAID FUNDING, BY STATE: FY 2011^{1,2}**

Rank	State	Total Federal, State, County & Local I/DD Spending	Total Unmatched State, County & Local Funds	Unmatched % of Total Spending
1	Connecticut	\$1,582,748,066	\$673,811,118	43%
2	Massachusetts	\$1,787,117,919	\$702,714,192	39%
3	Ohio	\$3,146,775,547	\$942,115,412	30%
4	Maryland	\$906,937,255	\$268,707,355	30%
5	Georgia	\$739,728,693	\$207,851,150	28%
6	Delaware	\$177,031,977	\$42,181,813	24%
7	Nevada	\$157,072,082	\$33,667,360	21%
8	Nebraska	\$331,327,933	\$65,557,966	20%
9	California	\$6,072,270,422	\$1,158,297,865	19%
10	Montana	\$137,498,567	\$22,120,880	16%
11	Virginia	\$991,412,027	\$159,378,342	16%
12	North Carolina	\$1,368,813,513	\$194,571,478	14%
13	New Jersey	\$1,755,994,367	\$246,839,775	14%
14	Missouri	\$774,762,144	\$105,126,505	14%
15	Pennsylvania	\$2,867,460,083	\$371,676,870	13%
16	Hawaii	\$173,868,003	\$21,970,216	13%
17	Colorado	\$515,957,301	\$58,929,576	11%
18	Illinois	\$1,700,684,115	\$186,896,396	11%
19	District of Columbia	\$300,520,438	\$26,588,347	9%
20	Kentucky	\$576,541,361	\$49,076,991	9%
21	Michigan	\$1,357,741,031	\$114,817,771	8%
22	Alaska	\$150,136,938	\$12,655,795	8%
23	Mississippi	\$348,093,329	\$28,978,910	8%
24	South Carolina	\$524,870,941	\$42,805,981	8%
25	Wisconsin	\$1,312,137,289	\$105,413,285	8%
26	South Dakota	\$157,717,728	\$12,502,562	8%
27	Washington	\$1,014,658,603	\$72,368,943	7%
28	Texas	\$2,391,184,457	\$168,079,902	7%
29	Tennessee	\$879,515,075	\$61,198,829	7%
30	Oklahoma	\$486,891,443	\$31,032,330	6%
31	New Mexico	\$351,276,212	\$21,140,145	6%
32	Florida	\$1,570,558,854	\$84,642,149	5%
33	Louisiana	\$1,121,052,357	\$55,613,404	5%
34	New Hampshire	\$251,812,411	\$8,947,672	4%
35	Arkansas	\$513,992,464	\$16,189,556	3%
36	Arizona	\$829,664,337	\$26,047,597	3%
37	Maine	\$385,434,470	\$11,711,023	3%
38	Iowa	\$797,230,166	\$23,678,239	3%
39	Oregon	\$779,750,007	\$19,241,656	2%
40	Minnesota	\$1,577,520,859	\$36,636,234	2%
41	North Dakota	\$239,848,081	\$4,664,586	2%
42	Kansas	\$466,153,935	\$8,522,072	2%
43	Wyoming	\$134,896,259	\$2,030,996	2%
44	New York	\$10,099,252,729	\$92,921,996	1%
45	Indiana	\$1,213,985,986	\$9,590,524	1%
46	Alabama	\$368,182,979	\$1,967,269	1%
47	Rhode Island	\$266,192,948	\$753,064	0.3%
48	Utah	\$254,665,517	\$436,620	0.2%
49	Vermont	\$162,826,336	\$42,778	0.03%
50	Idaho	\$352,719,237	\$0	0.0%
51	West Virginia	\$226,008,302	\$0	0.0%
	United States	\$56,650,493,091	\$6,612,711,495	12%

¹States are ranked by Unmatched Funds as a percentage of total I/DD Spending. Unmatched funds consisted of total I/DD spending, minus federal-state Medicaid, federal SSVADC 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 15, p. 40).

Source: Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.

The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers

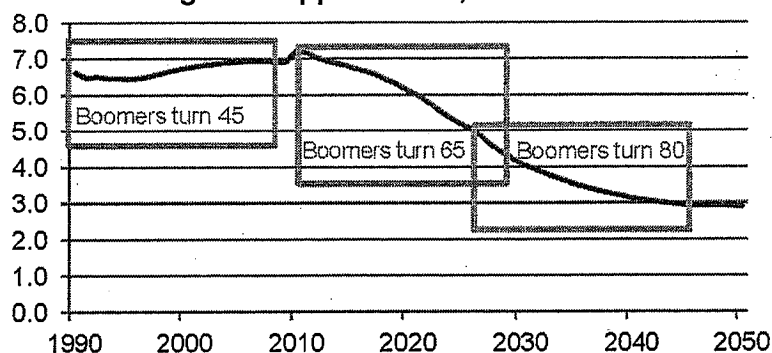
Donald Redfoot, Lynn Feinberg, and Ari Houser
AARP Public Policy Institute

This paper uses a “caregiver support ratio,” which is the number of potential caregivers aged 45–64 for each person aged 80 and older, to document the declining availability of family caregivers to provide long-term services and supports (LTSS) during the next few decades.

By tracking this ratio nationally and for all 50 states for the period from 1990 to 2050, the paper addresses the factors that will affect the availability of family caregivers as boomers age from the peak caregiving years into the high-risk years of late life. The paper finds that

- **The period from 1990 to 2010** was marked by boomers aging into the prime caregiving years. As a result, the caregiver ratio was high and increased slightly, from 6.6 to 7.2—potential caregivers aged 45–64 for every person aged 80-plus.
- **The period from 2010 to 2030** will be a time of transition as boomers progress into old age and the caregiver ratio declines sharply from 7.2 to 4.1—especially when the oldest boomers begin to reach age 80 in the 2020s.
- **The period from 2030 to 2050** will include all remaining boomers aging into the high-risk years of 80-plus, and the caregiver ratio is expected to continue to drift downward, from 4.1 to 2.9.

Caregiver Support Ratio, United States



Source: AARP Public Policy Institute calculations based on REMI (Regional Economic Models, Inc.) 2013 baseline demographic projections.

In just 13 years (2026), as the baby boomers age into their 80s, the decline in the caregiver support ratio is projected to shift from a slow decline to a free fall in all 50 states and the District of Columbia. Rising demand and shrinking families to provide support suggest that the United States needs a comprehensive person- and family-centered policy for LTSS that would better serve the needs of older persons with disabilities, support family and friends in their caregiving roles, and promote greater efficiencies in public spending.

In Brief IB 213, August 2013
A synopsis of the AARP Public Policy Institute *Insight on the Issues*, number 85
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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 "F"

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Page last reviewed: September 7, 2011

Page last updated: July 2, 2010

Content source: Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion

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