

# MEMO

**To:** Office of Management & Budget  
**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:** November 19, 2015

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., its proposed family support waiver.

As you know, the FY16 budget bill (§176) directs the Division to "move forward with developing and establishing a Family Support Waiver to begin in Fiscal Year 2017". The budget bill also requires Controller General and OMB approval of the waiver application prior to submission to CMS. Id. The Councils strongly support development of the waiver which has been a priority for more than a decade.

## JUSTIFICATION

The justification for a waiver is compelling. More than 70% of the Division's clients live at home with their family.<sup>1</sup> In raw numbers, this equates to 3,052 clients living at home out of a total census of 4,243 individuals. Consistent with national trends, many of the Delaware caregivers in those families are aging as the "boomers" progress into old age.<sup>2</sup> Given declines in health and resiliency attributable to aging, such caregivers will predictably need an increasing level of supports to continue in their role.<sup>3</sup>

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).<sup>4</sup> In recent years, the Delaware rate (6.6%) of increases in public spending for community services for individuals with developmental disabilities has been

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<sup>1</sup>The latest (October, 2015) DDDS census report is included as Attachment "A".

<sup>2</sup>See prepublication proof, D. Braddock, "The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession (2015) at pp. 59-62. [Attachment "B"]

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

<sup>4</sup>See Braddock, pp. 57 - 58. [Attachment "B"]

significantly less than the rate in neighboring states ( PA - 25.7%); MD - 13.2%; N.J. - 11.8%).<sup>5</sup> 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.<sup>6</sup>

Nationwide, Medicaid waivers finance 82% of all family support services.<sup>7</sup> 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. Delaware is essentially "leaving money on the table" by eschewing available Medicaid funding. Delaware ranks 8<sup>th</sup> among the states in the percentage of unmatched funding devoted to individuals with developmental disabilities.<sup>8</sup>

## RECOMMENDATIONS

In June, 2015, the Department submitted a working draft of a waiver application with cost estimates to OMB. The draft envisions a fiscally restrained initiative which leverages federal matching funds, includes an aggregate monetary cap on many services, and expands participant eligibility incrementally. If dental services are omitted, the main fiscal impediments are ostensibly the need for nine (9) administrative positions and revisions to eligibility and claims processing systems.<sup>9</sup>

Given the above considerations, resources to implement a family support waiver merit inclusion in the FY17 budget. Ten years have passed since the waiver was originally proposed and the Department has already invested significant time, energy, and resources in developing its waiver plan.

If full funding is not possible, we recommend consideration of practical options, including a reduced cap on number of participants, adoption of a more restrained services menu, or assessment of amending an existing waiver. If the waiver application is submitted and approved, the State enjoys the advantages of an approved waiver which can be amended over time to adjust slots or services. The infrastructure for the waiver will be in place and future planning will be enhanced by generating data based on actual costs and experience. Moreover, while the current federal Administration favors waivers, that may not be the case in coming years when applications could face additional hurdles. The timing of filing a waiver application is currently favorable.

Thank you for your consideration.

Attachments

E:legis/dddsombfy17; F:pub/bjh/leg/dddsbudombfy17

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<sup>5</sup>See Braddock, p. 8 [Attachment "B"]

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

<sup>7</sup>See Braddock, p. 56. [Attachment "B"]

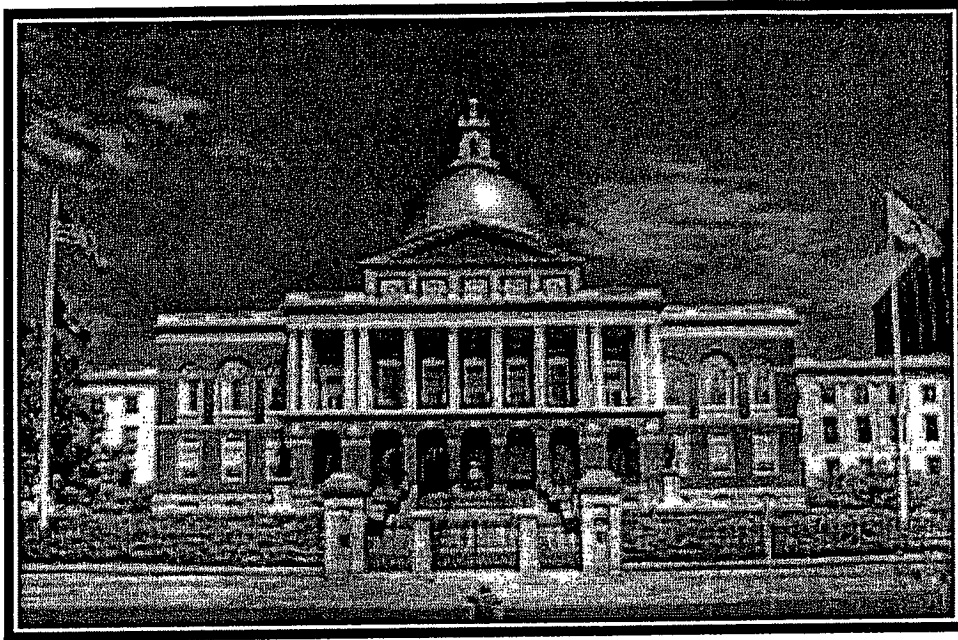
<sup>8</sup>See Braddock, p. 202. [Attachment "B"]

<sup>9</sup>The DHSS Summary (p. 6) estimates the annualized cost of the nine(9) positions would be \$454,851 and the systems revisions would be \$107,500.



EXCERPT

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



*PRE-PUBLICATION PROOF DISTRIBUTED TO INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES STATE AGENCY DIRECTORS AND  
THE ARC FOR FISCAL YEAR 2016 APPROPRIATIONS  
PLANNING AND ADVOCACY*

*JANUARY 2015*

STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES PROJECT  
UNIVERSITY OF COLORADO SCHOOL OF MEDICINE  
DEPARTMENT OF PSYCHIATRY  
COLEMAN INSTITUTE FOR COGNITIVE DISABILITIES  
BOULDER, COLORADO  
[Stateofthestates.org](http://Stateofthestates.org)

FINAL PUBLICATION WILL BE DISTRIBUTED BY  
THE AMERICAN ASSOCIATION ON  
INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

ATTACHMENT "B"

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

| State                | Community Spending |                 | % Real Change        | State          | Community Spending |                  | % Real Change        |
|----------------------|--------------------|-----------------|----------------------|----------------|--------------------|------------------|----------------------|
|                      | 2013               | 2011            | 2011-13 <sup>1</sup> |                | 2013               | 2011             | 2011-13 <sup>1</sup> |
| 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      | \$161,983,207    | 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  | \$63,235,790,070   | \$47,538,572,618 | 8.5%                 |

<sup>1</sup>Inflation-adjusted percentage change, 2011 to 2013.

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

Total I/DD 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*, page 10). 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 all three years. However 18 states had these reductions in 2011, four in 2012, and eight in 2013.

The largest community services spending reductions from 2012 to 2013 were in Arkansas (9%) and Idaho (7%). In 2012, the largest reductions were in Hawaii and Rhode Island (7%) and in Florida (6%).

However, in fiscal year 2011, community spending dropped five percent or more in nine jurisdictions: District of Columbia (20%); Idaho (11%); Rhode Island (10%); Mississippi (8%); New Mexico (7%); and Colorado, Indiana, Maine, and Utah (5%). Twenty-four states did not reduce community spending in 2011.

As noted, inflation-adjusted family support spending in the U.S. dropped 0.4% during 2011-13 (Figure 23), 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; 2009; 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 Waiver. Conversely, nine states opted to finance their family support initiatives solely through state funding.

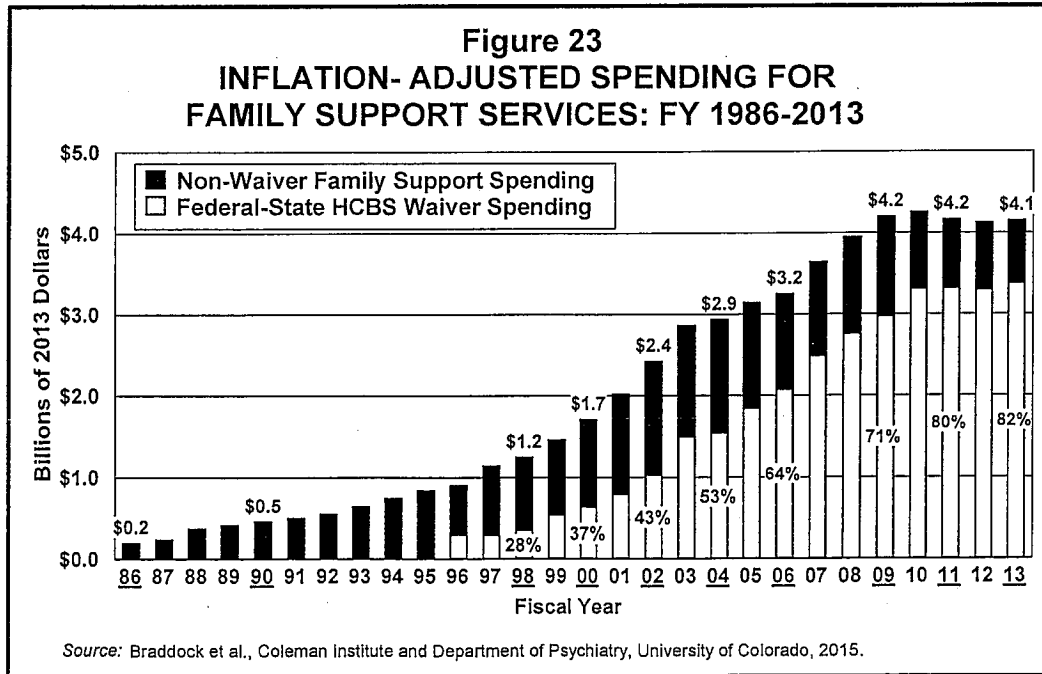


TABLE 19  
FAMILY SUPPORT IN THE STATES:  
SPENDING FOR PARTICIPANTS WITH I/DD IN FY 2013

| State                   | Total Family Support <sup>1</sup> |                 | Spending Per Family | Rank <sup>2</sup> | Families Supported |                   | Cash Subsidy |              | Other Family Support |                 |
|-------------------------|-----------------------------------|-----------------|---------------------|-------------------|--------------------|-------------------|--------------|--------------|----------------------|-----------------|
|                         | Families                          | Spending        |                     |                   | Per 100K           | Rank <sup>3</sup> | 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 <sup>4</sup> | 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                    | \$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 <sup>4</sup> | 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                           | \$4,144,365,306 | \$8,931             |                   | 147                |                   | 21,989       | \$58,485,938 | 443,005              | \$4,085,869,367 |

<sup>1</sup> 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.

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

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

<sup>4</sup> In 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.

TABLE 20  
ESTIMATED NUMBER OF I/DD CAREGIVING  
FAMILIES COMPARED TO FAMILIES SUPPORTED  
BY STATE I/DD AGENCY FEDERAL, STATE, AND  
LOCAL FUNDS: FY 2013

| State             | Total IDD Caregiving Families | Families Supported by I/DD Agencies | % of Families Supported | Rank <sup>1</sup> |
|-------------------|-------------------------------|-------------------------------------|-------------------------|-------------------|
| Alabama           | 58,602                        | 987                                 | 2%                      | 48                |
| Alaska            | 8,349                         | 1,377                               | 16%                     | 17                |
| Arizona           | 81,495                        | 19,002                              | 23%                     | 11                |
| Arkansas          | 32,708                        | 414                                 | 1%                      | 49                |
| California        | 445,877                       | 104,099                             | 23%                     | 10                |
| Colorado          | 60,240                        | 2,183                               | 4%                      | 43                |
| Connecticut       | 39,585                        | 3,069                               | 8%                      | 33                |
| Delaware          | 10,993                        | 2,610                               | 24%                     | 8                 |
| Dist. of Columbia | 6,833                         | 753                                 | 11%                     | 24                |
| Florida           | 234,210                       | 15,617                              | 7%                      | 37                |
| Georgia           | 118,188                       | 3,273                               | 3%                      | 46                |
| Hawaii            | 15,891                        | 1,740                               | 11%                     | 25                |
| Idaho             | 18,040                        | 0                                   | 0%                      | 51                |
| Illinois          | 142,194                       | 4,945                               | 3%                      | 44                |
| Indiana           | 74,095                        | 6,661                               | 9%                      | 31                |
| Iowa              | 32,953                        | 739                                 | 2%                      | 47                |
| Kansas            | 32,798                        | 2,811                               | 9%                      | 32                |
| Kentucky          | 51,201                        | 2,771                               | 5%                      | 39                |
| Louisiana         | 53,458                        | 12,558                              | 23%                     | 9                 |
| Maine             | 14,437                        | 480                                 | 3%                      | 45                |
| Maryland          | 69,653                        | 7,516                               | 11%                     | 26                |
| Massachusetts     | 74,991                        | 11,759                              | 16%                     | 19                |
| Michigan          | 101,261                       | 16,699                              | 16%                     | 18                |
| Minnesota         | 53,920                        | 13,711                              | 25%                     | 5                 |
| Mississippi       | 35,057                        | 4,859                               | 14%                     | 20                |
| Missouri          | 68,387                        | 4,621                               | 7%                      | 36                |
| Montana           | 11,378                        | 2,856                               | 25%                     | 6                 |
| Nebraska          | 20,796                        | 2,569                               | 12%                     | 23                |
| Nevada            | 34,167                        | 2,426                               | 7%                      | 34                |
| New Hampshire     | 15,005                        | 3,142                               | 21%                     | 13                |
| New Jersey        | 103,375                       | 4,564                               | 4%                      | 42                |
| New Mexico        | 23,879                        | 5,725                               | 24%                     | 7                 |
| New York          | 198,592                       | 54,309                              | 27%                     | 2                 |
| North Carolina    | 110,692                       | 10,021                              | 9%                      | 30                |
| North Dakota      | 7,445                         | 779                                 | 10%                     | 27                |
| Ohio              | 119,026                       | 21,882                              | 18%                     | 15                |
| Oklahoma          | 45,279                        | 4,496                               | 10%                     | 28                |
| Oregon            | 38,885                        | 2,030                               | 5%                      | 40                |
| Pennsylvania      | 142,608                       | 25,429                              | 18%                     | 16                |
| Rhode Island      | 11,736                        | 1,575                               | 13%                     | 21                |
| South Carolina    | 56,541                        | 11,764                              | 21%                     | 14                |
| South Dakota      | 8,529                         | 1,922                               | 23%                     | 12                |
| Tennessee         | 76,416                        | 4,761                               | 6%                      | 38                |
| Texas             | 296,704                       | 20,156                              | 7%                      | 35                |
| Utah              | 34,542                        | 1,723                               | 5%                      | 41                |
| Vermont           | 6,652                         | 1,774                               | 27%                     | 3                 |
| Virginia          | 98,928                        | 325                                 | 0.3%                    | 50                |
| Washington        | 76,927                        | 7,436                               | 10%                     | 29                |
| West Virginia     | 19,656                        | 2,544                               | 13%                     | 22                |
| Wisconsin         | 58,660                        | 23,192                              | 40%                     | 1                 |
| Wyoming           | 5,413                         | 1,389                               | 26%                     | 4                 |
| UNITED STATES     | 3,557,246                     | 464,043                             | 13%                     |                   |

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

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

**Unmet need for family support.**

National trends in family support spending and number of families supported demonstrate an effort to maintain support for family caregivers, despite the impact of the Great Recession. However, in nearly all states and in the nation as a whole, the number of families supported is a pitifully small portion of all families providing care for a child or adult with I/DD.

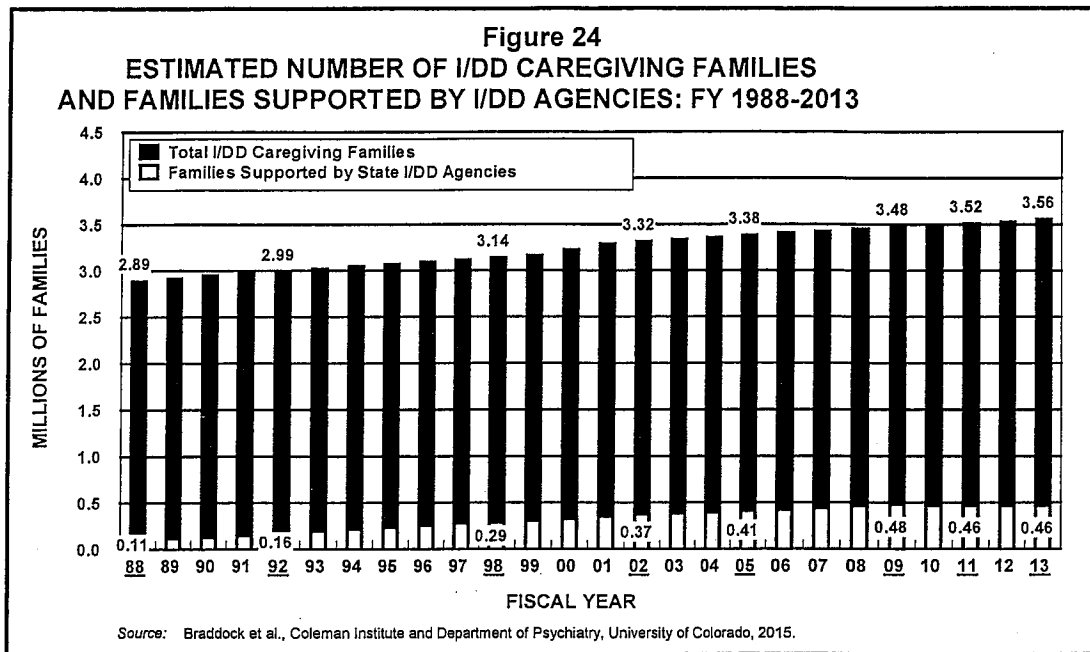
The states varied greatly in the proportion of families with family members with I/DD who received cash subsidies or other forms of state agency financed family support in 2013 (*Table 20*). Of the estimated 3.6 million families, over 3.0 million did not receive any I/DD state agency family support services. The table presents estimates of total caregiving families with children with I/DD based on *Survey of Income and Program Participation (SIPP)* data (Fujiura, 2012).

Fourteen states were estimated to be providing I/DD 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, South Carolina, South Dakota, Vermont, Wisconsin, and Wyoming. However, it is estimated that 13 other states provided family support services to only 5% or less of those in need. These states are Alabama, Arkansas, Colorado, Georgia, Idaho, Illinois, Iowa, Kentucky, Maine, New Jersey, Oregon, Utah, and Virginia.

There was an increase in the proportion of caregiving families receiving I/DD state agency support between 1988 and 2009 (from 4% to 14%). Support declined to 13% during 2009-13, primarily due to family support cutbacks in multiple states resulting from the budget impact of the Great Recession (*Figure 24*).

With the expanding role of the HCBS Waiver, general problems with Waiver fi-





ancing of family support services have emerged. Issues include limited Waiver capacity, cost-per-participant caps, cost-neutrality requirements, and various cost-containment strategies such as spending ceilings, service limits, and hourly and geographic limits. Waiver utilization issues can seriously limit expansion and adequate financing of family support services (Harrington, Ng, Kaye, & Newcomer, 2009).

The hallmark of family support remains individualization and flexibility. However, data on “non-duplicated” families in some states include high proportions of families receiving minimal services such as episodic respite care or service coordination. Other states may provide higher proportions of intensive in-home supports of longer duration. Our data confirm a very high level of unmet needs in the states for substantial expansion of I/DD supports for families and their relatives with intellectual and developmental disabilities.

### 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 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 caregiving capacities, formal living arrangements must be established to support their relatives with disabilities.

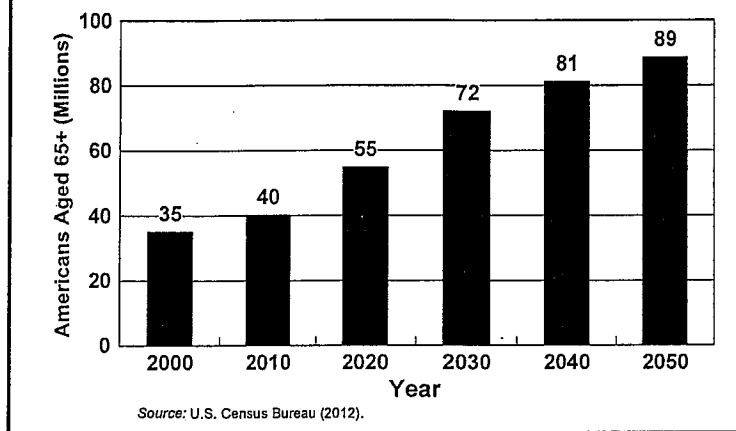
The aging of our society is the product of several forces, including the size of the baby boom generation (persons born during 1946-1964), declining fertility rates, and increased longevity. Baby boomers began to reach age 65 in 2011.

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). 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, epi-

Figure 25  
GROWING NUMBERS OF AMERICANS  
AGED 65+ YEARS: 2000-2050

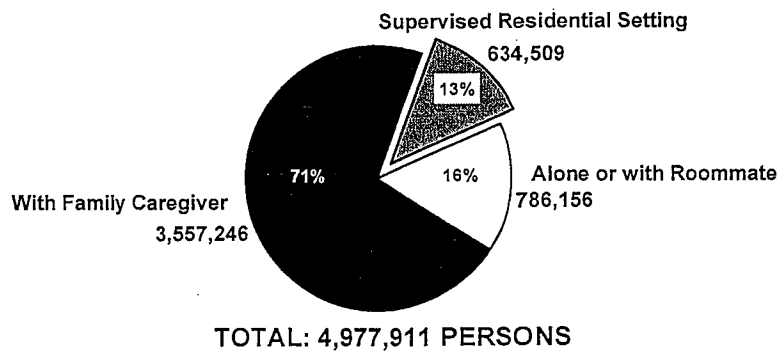


lepsy, and other childhood disabilities originating prior to 22 years of age.

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 I/DD out-of-home residential system, and the U.S. general population in 2013.

The results are presented in Figure 26, which indicates that 3.56 million of the 4.98

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).

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 care-giving 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*).

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%) (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 Disabilities

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 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).

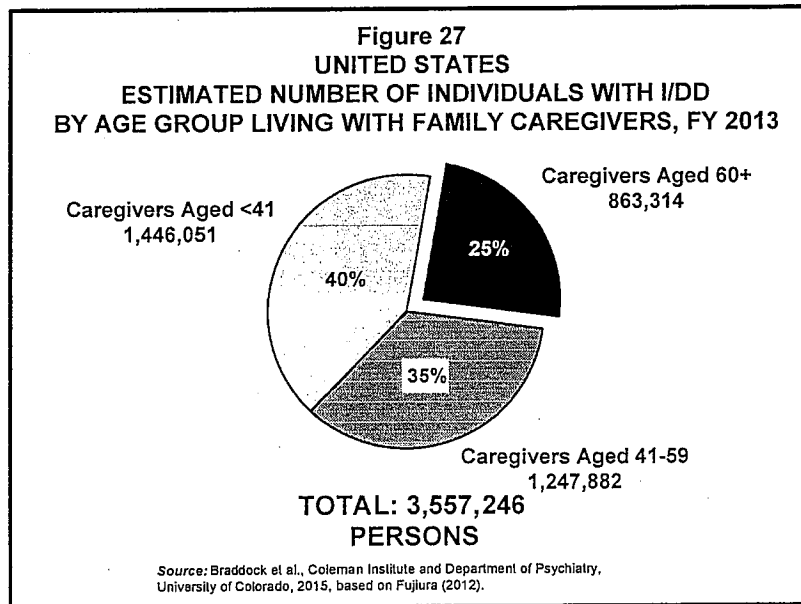


TABLE 21  
ESTIMATED NUMBER OF  
PERSONS WITH I/DD LIVING WITH  
AGING CAREGIVERS IN FY 2013<sup>1</sup>

| State          | Persons with I/DD |
|----------------|-------------------|
| Alabama        | 15,455            |
| Alaska         | 1,298             |
| Arizona        | 21,210            |
| Arkansas       | 8,730             |
| California     | 96,375            |
| Colorado       | 12,118            |
| Connecticut    | 10,645            |
| * Delaware     | 2,911             |
| DC             | 1,450             |
| Florida        | 77,467            |
| Georgia        | 22,627            |
| Hawaii         | 4,256             |
| Idaho          | 4,031             |
| Illinois       | 32,732            |
| Indiana        | 17,460            |
| Iowa           | 9,137             |
| Kansas         | 8,150             |
| Kentucky       | 12,479            |
| Louisiana      | 12,603            |
| Maine          | 4,230             |
| Maryland       | 15,794            |
| Massachusetts  | 19,092            |
| Michigan       | 24,123            |
| Minnesota      | 12,401            |
| Mississippi    | 8,355             |
| Missouri       | 17,633            |
| Montana        | 3,198             |
| Nebraska       | 5,311             |
| Nevada         | 7,843             |
| New Hampshire  | 3,631             |
| New Jersey     | 26,301            |
| New Mexico     | 6,361             |
| New York       | 50,487            |
| North Carolina | 25,635            |
| North Dakota   | 2,116             |
| Ohio           | 30,310            |
| Oklahoma       | 11,613            |
| Oregon         | 9,470             |
| Pennsylvania   | 41,085            |
| Rhode Island   | 3,071             |
| South Carolina | 14,481            |
| South Dakota   | 2,306             |
| Tennessee      | 18,991            |
| Texas          | 58,158            |
| Utah           | 5,825             |
| Vermont        | 1,794             |
| Virginia       | 23,019            |
| Washington     | 17,536            |
| West Virginia  | 5,860             |
| Wisconsin      | 14,721            |
| Wyoming        | 1,429             |
| United States  | 863,314           |

<sup>1</sup> Caregivers aged 60 years and older.

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

Information has emerged on genetic and nonspecific neurodevelopmental 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, 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, Iivanainen, Vesala, 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. (2000) 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, different types of supports, as well as supports for their 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. That demand will only grow in the future.

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

**STATE, COUNTY AND LOCAL FUNDS POTENTIALLY AVAILABLE TO MATCH  
ADDITIONAL FEDERAL MEDICAID FUNDING, BY STATE: FY 2013<sup>1,2</sup>**

| Rank | State                | Total Federal,<br>State, County &<br>Local I/DD<br>Spending | Total Unmatched<br>State, County &<br>Local Funds | Unmatched %<br>of Total<br>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%                                  |
|      | <b>United States</b> | <b>\$61,458,718,366</b>                                     | <b>\$6,657,473,585</b>                            | <b>10.8%</b>                        |

<sup>1</sup>States 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.

<sup>2</sup>County 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.



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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).

### References

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([http://assets.aarp.org/rgcenter/il/us\\_caregiving\\_1.pdf](http://assets.aarp.org/rgcenter/il/us_caregiving_1.pdf))

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ATTACHMENT "C"

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# POSITION STATEMENT

## Family Support

Family support services<sup>1</sup> 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 disabilities<sup>2</sup> (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.

<sup>1</sup> 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.

<sup>2</sup> “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

The Arc  
Board of Directors  
April 6, 2014

Chapters of The Arc  
October 2, 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

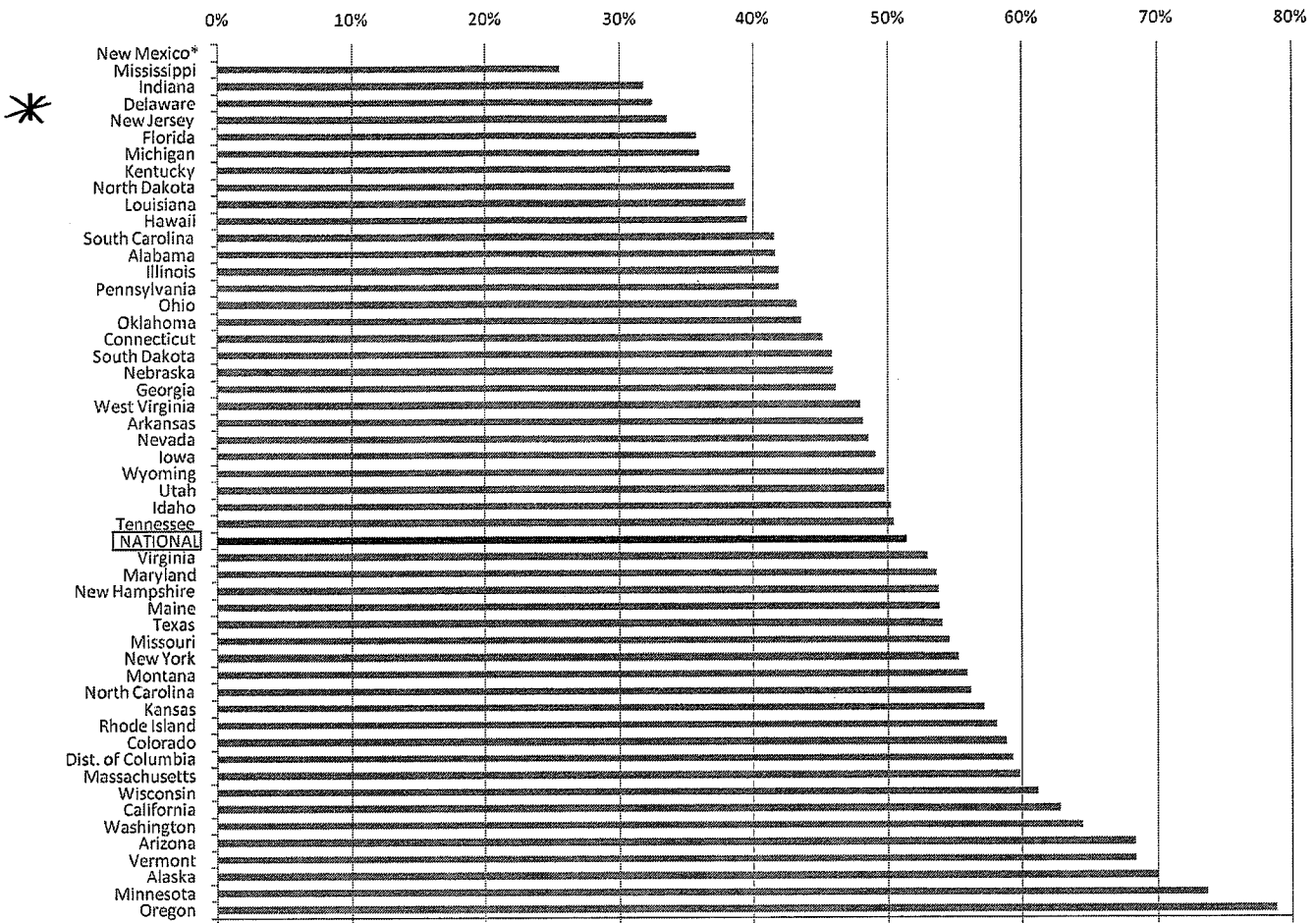
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ATTACHMENT "D"

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.