

# MEMO

**To:** Joint Finance Committee  
**From:** Brian J. Hartman, on behalf of the following organizations:  
Developmental Disabilities Council  
Governor's Advisory Council for Exceptional Citizens  
State Council for Persons with Disabilities  
**Subject:** Division of Developmental Disabilities Services FY 16 Budget  
**Date:** March 26, 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 FY15 budget bill (§175) directs the Division to "move forward with developing and establishing a Family Support Waiver to begin in Fiscal Year 2016". The budget bill also requires Controller General and OMB approval of the waiver application prior to submission to CMS. *Id.* Although the Governor's proposed FY16 budget bill (§168) contains the identical authorization to establish the waiver, necessary funding is omitted. The lack of funding for the waiver is disheartening to the Division's constituents and advocacy agencies.

## BACKGROUND

As background, the Division first proposed a family support waiver ten years ago (2005) and start-up funds were included in the FY09 budget.<sup>1</sup> The initiative was deferred given the economic downturn at that time.

Recognizing the potential fiscal and societal benefits of a waiver, the FY14 budget bill (H.B. No. 400, §169) directed the Department to submit a report outlining options. On April 29, 2014, the Department shared its favorable "Family Support Waiver Report" with the Legislature. It included cost estimates.<sup>2</sup> In her Fall FY16 budget request, the Department Secretary unsuccessfully requested \$944,200 to cover the state share of personnel (\$379,000) and dental services (\$565,200) for 980 participants.<sup>3</sup>

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<sup>1</sup>Historical materials describing the waiver and planned implementation are compiled in Attachment "A".

<sup>2</sup>The Report is published at <http://dhss.delaware.gov/dhss/ddds/fsw.html>. An excerpt is included for facilitated reference. [Attachment "B"]

<sup>3</sup>The relevant excerpt from the November 20, 2014 presentation is included as Attachment "C". Based on a revised estimate of federal match, we understand the projected personnel costs were subsequently reduced to \$312,500.

## JUSTIFICATION

The justification for a waiver is compelling. More than 70% of the Division's clients live at home with their family.<sup>4</sup> In raw numbers, this equates to 2,894 clients living at home out of a total census of 4,066 individuals. Consistent with national trends, many of the Delaware caregivers in those families are aging as the "boomers" progress into old age.<sup>5</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>6</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>7</sup> In recent years, the Delaware rate (6.6%) of increases in public spending for community services for individuals with developmental disabilities has been significantly less than the rate in neighboring states ( PA - 25.7%); MD - 13.2%; N.J. - 11.8%).<sup>8</sup>

Economics and federal law 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. This includes diversion from disfavored institutional and non-integrated placements which risk federal scrutiny based on potential violation of the ADA. Increasing the State's capacity to offer community-based services enhances the ability of the State to fulfill CMS regulations promoting community options.<sup>9</sup>

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<sup>4</sup>The latest (January, 2015) DDDS census report is included as Attachment "D".

<sup>5</sup>See prepublication proof, D. Braddock, "The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession (January, 2015) at pp. 59-62. [Attachment "E"]

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

<sup>7</sup>See Braddock, pp. 57 - 58. [Attachment "E"]

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

<sup>9</sup>DHSS recently submitted its March 17, 2015 plan to CMS outlining steps it will undertake to ensure that HCBS funds are devoted exclusively to conforming integrated, community settings. See <http://www.dhss.delaware.gov/dhss/dmma/>.

Second, nationwide, Medicaid waivers finance 82% of all family support services.<sup>10</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>11</sup>

## RECOMMENDATIONS

We highly recommend that the requisite funding to implement the family support waiver be included in the FY16 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 delayed implementation to the end of FY16, a reduced cap on number of participants, and adoption of a restrained services menu.<sup>12</sup> 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

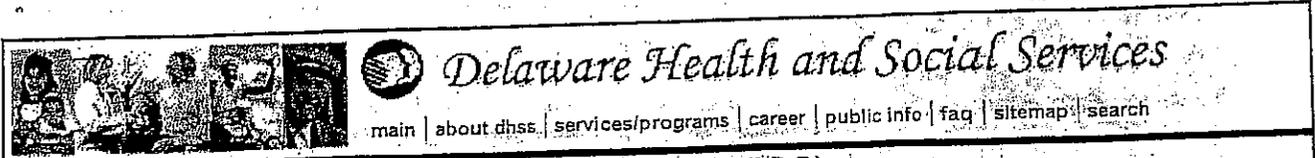
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E:legis/dddsfy16jfc

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<sup>10</sup>See Braddock, p. 56. [Attachment "E"]

<sup>11</sup>See Braddock, p. 202. [Attachment "E"]

<sup>12</sup>Such options are discussed in the Department's April 2014 report at pp. 5-6 [Attachment "B"].



Division of Developmental Disabilities Services (DDDS)

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Waiver Press Release

Dover - Delaware Health and Social Services (DHSS), Division of Developmental Disabilities Services (DDDS), will host three **informational meetings** during the month of January 2006 regarding its proposed Family Support Waiver.

This proposed waiver would offer an array of supports and services to persons living with their natural families. These services are designed to promote individual choices and empowerment.

This proposal also echoes the principles of The New Freedom Initiative that was announced by President Bush on February 1, 2001, followed up by Executive Order 13217 on June 18, 2001, which is a nationwide effort to remove barriers to community living for people of all ages with disabilities and long-term illness. It represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, choose where to live and participate in community life ( For more information on the New Freedom Initiative visit: [www.cms.gov](http://www.cms.gov) ).

It also marks the third goal that the DDDS has engaged in over the past several years to empower individuals with a range of additional services, support, individual funding and greater provider choices towards enhanced independence and self-determination.

We hope you will join us during the month of January for this exciting look at our proposed services and support via this Home and Community Based Waiver Program.

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Last Modified: Fri, Dec 02, 2005

ATTACHMENT "A"



# Delaware Health and Social Services

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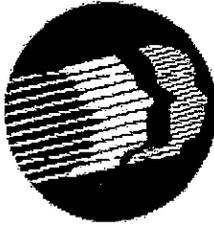
## Events and Meeting Notices

- **January 10th 2006 6 - 9pm** - DDDS Family Support Service Waiver Informational Meeting at the Dover Terry Campus, Corporate Training Center, Room 407 - **Contact Valerie Smith** at the Woodbrook Professional Center for more information.
- **January 17th 2006 6 - 9pm** - DDDS Family Support Service Waiver Informational Meeting at the Stanton Campus, Room A116 - **Contact Valerie Smith** at the Woodbrook Professional Center for more information.
- **January 18th 2006 6 - 9pm** - DDDS Family Support Service Waiver Informational Meeting at the Georgetown Owens Campus, Room 344A - **Contact Valerie Smith** at the Woodbrook Professional Center for more information.

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## Delaware Health and Social Services

### Division of Developmental Disabilities Services

#### What is a Waiver?

Home and community-based services (HCBS) waivers allows services to be provided to individuals in their homes and community as an alternative to in patient care and services in an institution. Eligible individuals are those who would otherwise require the level of care provided in an institution — i.e. hospital, nursing facility or intermediate care facility for the mentally retarded. But with services available under the HBCS waiver program, they can be served at home or in the community instead. HCBS must be cost-effective and necessary to avoid institutionalization. HCBS waiver services are provided in addition to all of the other services available through the state's Medicaid Plan.

HCBS waivers give states Medicaid reimbursement for services that do not fit within a traditional medical model. Services available include case management, homemaker or personal attendant care, home health aide services, adult day health services, respite care, day treatment, rehabilitation and clinical services for individuals with psychiatric disabilities, and any other services requested by the state and approved by CMS.

1/09/2006



*Delaware Health and Social Services*

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## Family Support Services Waiver

### Outline

- Summary of Family Support Waiver
- Advantages of Family Support Waiver
- Flow of waiver services
- Services offered in the waiver
  - Mandatory Services
  - Consolidated Developmental Services
  - Day Services
- Cost associated with the waiver

### Summary of the Waiver

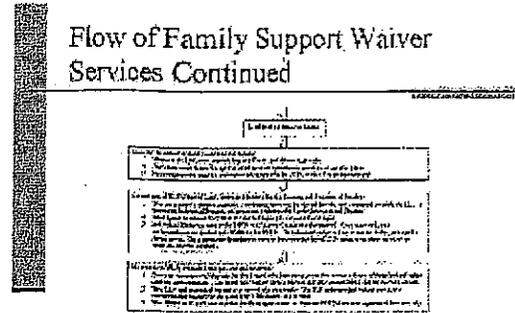
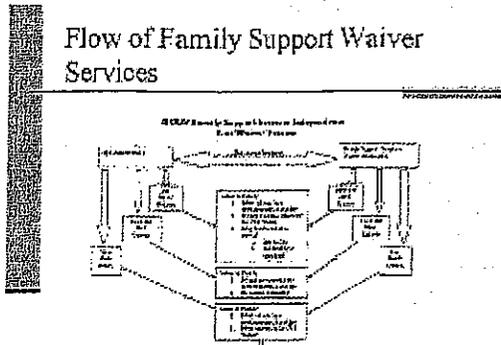
- The DDDS Family Support Services waiver offers eligible individuals and their families the opportunity to participate in a flexible program to help in achieving their personally defined goals. Delaware's waiver is based upon the belief that in order for eligible individuals with disabilities and their families to fully participate in their community, they must define the life they seek and be supported with relevant choices of service. The waiver program will offer participants freedom of choice using DDDS contracted agencies or participant chosen individuals or agencies.
- **Provider Selection**
  - Individuals and their families will have the flexibility to select qualified providers of their choosing within the criteria established by DDDS.
- **Participant Eligibility**
  - To be eligible for the Delaware Family Support Services Waiver, the individual must meet standards and procedures as outlined in the Family Support Services Waiver and Intake Policy. The procedure is outlined below.
  - Year 1- Number of Participants 1076
  - Year 2- Number of Participants 1225
  - Year 3- Number of Participants 1398

### Advantages of Family Support Waiver

- Larger array of services
- Increase the individual's/family's choices along with empowerment and independence
- Promote access by individuals to needed supports and services that allow them to maintain their community residence and avoid or delay a costly residential placement.
- Assists individuals and their families to guide the purchase of supports that are cost-effective and that meet their individual needs
- Enhance the decision making capacity of individuals and their families and assist families to understand the nature and impact of developmental disabilities with the goal of building a supportive home environment
- Increase the individual's satisfaction and quality of life

## Flow of Family Support Waiver Services

(Click on the images below to enlarge)

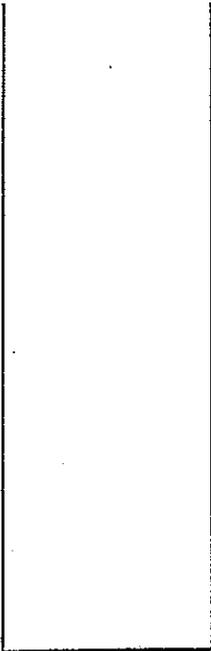


## Mandatory Services In the Family Support Services Waiver

- **Supports Coordination**
  - Supports Coordination is the service of assisting individual's, family's, or guardian's effort in identifying, developing, coordinating and accessing community based supports and services, regardless of the funding source, in order to develop and implement support strategies to promote individuality and personal choice.
- **Fiscal Agent**
  - The Fiscal Agent will serve as a fiscal intermediary working with the DDDS, the participant, and prospective employees/providers. The DDDS contracted Fiscal Agent will handle the financial processing of payments including verification of services.
- **Family Education and Training**
  - Family Education and Training is training given to families of consumers enrolled in the Family Support Waiver. The purpose of family education and training is to enhance the decision making capacity of the family unit, provide orientation regarding the nature and impact of developmental disability upon the consumer and his or her family and teach them about service alternatives. The information and knowledge imparted in family education and training increases the chances of creating a supportive environment at home and decreases the chance of a premature residential placement outside the home.

## Consolidated Developmental Service

- The Consolidated Developmental Services will consist of a range of home and community-based services intended to improve and maintain the participant's opportunities and experience in living, socializing and recreating, personal growth, safety and health. It is anticipated that this service will support the family as the primary caregiver of the participant. The maximum dollar amount per year for these services is \$3800.00. The specific array of services within the Consolidated Developmental Service include:
  - Personal Care
  - Respite
  - Emergency Temporary Living Arrangement (ETLA)
  - Extended Day Care
  - Environmental Modifications



- Assistive Technology
- Support Assistance Stipends
- Physical Therapy
- Occupational Therapy
- Speech Language Therapy

### Day Services

- The Family Support Waiver will also contain day service programs (currently covered on the state plan) including:
  - Day Habilitation
  - Prevocational Employment
  - Supported Employment
  - Adult Day Health
  - Transportation

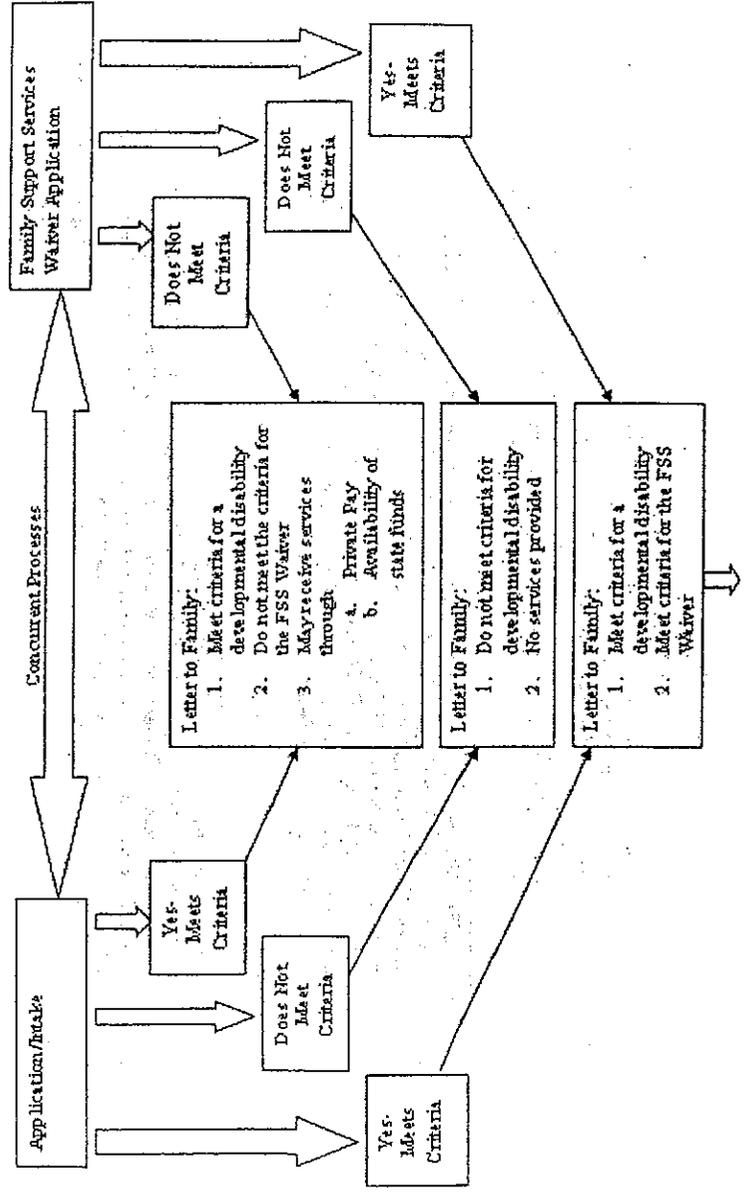
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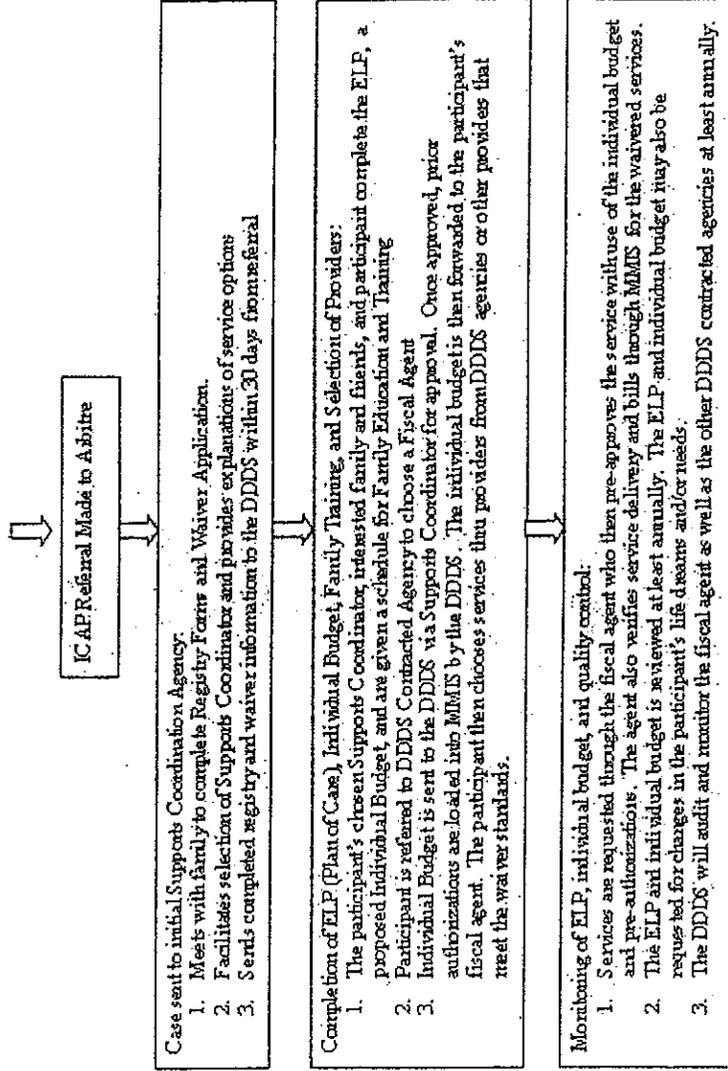
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*Last Modified: Mon, Dec 05, 2005*

# Flow of Family Support Waiver Services

## DDDS Family Support Services Independence Plus Waiver Process





ICAP Referral Made to Abitare

Case sent to initial Supports Coordination Agency:  
1. Meets with family to complete Registry Form and Waiver Application.  
2. Facilitates selection of Supports Coordinator and provides explanation of service options  
3. Sends completed registry and waiver information to the DDS within 31 days from referral

Completion of ELP (Plan of Care), Individual Budget, Family Training, and Selection of Providers:  
1. The participant's chosen Supports Coordinator, interested family and friends, and participant complete the ELP, a proposed Individual Budget, and are given a schedule for Family Education and Training  
2. Participant is referred to DDS Contracted Agency to choose a Fiscal Agent  
3. Individual Budget is sent to the DDS via Supports Coordinator for approval. Once approved, prior authorizations are loaded into MMIS by the DDS. The individual budget is then forwarded to the participant's fiscal agent. The participant then chooses services thru providers from DDS agencies or other providers that meet the waiver standards.

Monitoring of ELP, individual budget, and quality control:  
1. Services are requested through the fiscal agent who then pre-approves the service with use of the individual budget and pre-authorizations. The agent also verifies service delivery and bills through MMIS for the waived services.  
2. The ELP and individual budget is reviewed at least annually. The ELP and individual budget may also be requested for changes in the participant's life/dwains and/or needs.  
3. The DDS will audit and monitor the fiscal agent as well as the other DDS contracted agencies at least annually.



A Publication of the Office of  
Training and Professional  
Development

# What's The Buzz?

"Helping You To Bee Informed"



## Happy New (Fiscal) Year!!!!

**DO YOU KNOW THAT...**

Life expectancy in the USA has reached a record high of 78 years! The high was driven by declines in all but one of the major causes of death. Despite this good news, the USA ranks only 29th in life expectancy among the United Nations' member nations. We need to do better!!

Summer is racing by and we have just entered into the new fiscal year. The good news is that the Division received funding for the Self Directed Services Program (SDSP) waiver, which will benefit families served by our Family Support unit in Community Services. The waiver will offer families a larger array of services and increase the individual's/family's choice in selecting services and service providers. By enhancing access to supports and services, individuals will be able to strengthen their abilities to continue to live at home with their families. Individuals served by the SDSP waiver will be provided the following :support coordination; day program; fiscal agent (NEW), family education and training (NEW), and consolidated developmental services (NEW), which includes a range of services that the family/individual may choose from, such as personal care, respite, extended day care, environmental modifications, assistive technology, and other options. Many of our staff have worked long and hard to make this waiver a reality for the families we serve. It has taken three years but the first hurdle of acquiring funding has been met and now we will be working longer and harder to develop the infrastructure and system to make it work. Hang on to your seats—we are on the verge of a very exciting time!!!! **MUCH MORE TO COME ON THE TOPIC OF THE SDSP WAIVER!!**



### Special Points of Interest....

The latest edition of Merriam-Webster's dictionary has just debuted 100 new entries. They pick new entries by monitoring usage. When they see the word used without explanation it becomes a naturalized citizen of the English language. Go tell that to the wing nut in the corner eating edamame and discussing dirty bombs!

\*\*\*\*\*

Did you see the big news story from Idaho about a man who won the 2.5 million dollar lottery!!!! His name is Rob Johnson and he lives with his parents. Rob has cerebral palsy. When asked what he will do with his fortune, he said he plans to purchase a new lift van and travel with his parents. He thinks they need to have more fun. He also wanted to spend time in amusement parks and thought Hollywood may be a good place to live. He has some bad news for his current support staff though, because he also plans to negotiate to hire the **Dallas Cowboy Cheerleaders** to be his new staff. Now that sounds like Self Direction in action. Wonder how that fits into Consolidated Developmental Services?

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*It is the mission of the DDDS to help people it serves achieve the quality of life they desire.*

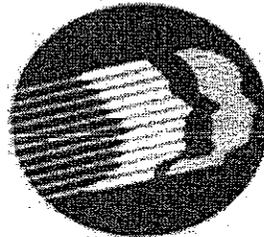
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EXCERPT

**FAMILY SUPPORT  
FOR  
INDIVIDUALS WITH INTELLECTUAL DEVELOPMENTAL DISABILITIES**

**A REPORT TO  
CO-CHAIRS OF THE JOINT FINANCE COMMITTEE,  
THE CONTROLLER GENERAL,  
AND  
THE DIRECTOR OF THE OFFICE OF MANAGEMENT AND BUDGET  
Department of Health and Social Services**

**Rita M. Landgraf  
Secretary**



**Submitted by**

**The Division of Developmental Disabilities Services**

**Jane J Gallivan  
Division Director**

**Marie Nonnenmacher  
Deputy Director**

**April 2014**

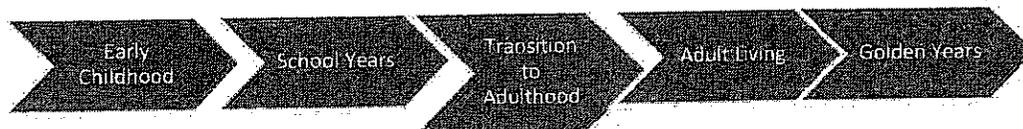
**ATTACHMENT "B"**

can be flexible and each state can design the program to meet the needs of the waiver recipients.

### **I. System Navigation and Information**

Listing and defining the package of services available in a Family Support waiver is only one piece of a comprehensive service system designed to support families. The essential element needed to support families is a quality case management system designed to understand and support the needs of individuals living at home and the support needs of the family.

At each of the meetings, the underlying issue of systems navigation permeated every topic. Families are not always in need of paid services but are desperate for information about resources and systems navigation. Since families are caregivers over the lifespan, the quest for information is continuous.



At each stage of the individual's life, the family plays a key and ever-changing role. As each family shared the story of their journey, the underlying thread of their story was the need for information and assistance in navigating a complex system of services, supports and cash assistance. The foundational elements in supporting individuals and their families are designed around a well-informed case management system focused on the family and a planning process designed to address the needs of the individual and the entire family. Currently DDDS provides little or no planning for families. Without the opportunity to plan for the future, many families shared their anxiety about not only day to day concerns but, overwhelmingly, what will happen to their loved one when they are no longer able to support them.

### **III. Use of Supports Waivers across the States**

Supports waivers, under the authority of Section 1915(c) of the Social Security Act known as Home and Community Based Waivers, have been used by many states to provide self-directed services while controlling access and costs into full 24 hour services, which are typically referred to as comprehensive waivers. The current DDDS HCBS Waiver is a comprehensive waiver. To date, 24 states have an approved supports waiver (Appendix A). Supports waivers can limit a state's financial risk by including a cost cap, limiting the benefits waiver members can receive and/or limiting the target populations who can receive waiver benefits.

States look to use supports waivers for individuals who can manage with less than 24 hour supports because they live with families or on their own with a network of natural supports. Supports waivers are an alternative to comprehensive waivers which typically include 24 hour residential supports, day supports and a variety of other essential services. A person who qualifies for a waiver service is entitled to all services in the waiver plan, based on assessed needs. For this reason, many states who want to offer a modest benefit to people living at home or on their own are concerned about entitling a group to a larger benefit and therefore create a limited "supports" waiver. As with other 1915(c) waivers, the number of people served in a supports waiver can be capped. In Delaware, having a family support waiver would help to delay paying for costly out of home placements. The annual all inclusive institutional cost at Stockley Center is approximately \$358,000 and the average residential costs for individuals on the DDDS HCBS Waiver is approximately \$80,000 annually.

Supports waivers can limit the amount of funds any person can use by limiting the types of services, the utilization or the duration of services. Most states with supports waivers have capped the amount of funds that can be spent per person per year but broaden the types of services and supports a person can purchase. By providing a flexible array of services, the waiver design can best respond to individuals and their families who can direct and customize services in a way that meets the needs they have at the time they have them.

#### **IV. General Features of Supports Waivers**

Since the intent of multiple states using supports waivers is to distinguish these services from full comprehensive services, the following attributes are common among supports waivers:

##### **A. Annual Financial Caps**

The most frequent features of supports waivers are capped annual budgets per waiver member (from \$13,500/IN to \$58,000/CT) It is important to have the benefits be sufficient enough to meet the targeted purpose such as covering day/employment services and access to family respite but not so broad as to open financial risk to the state.

##### **B. Target Group**

Supports waivers can target groups such as children, adults, high school transition age, etc. One common group in all states supports waivers are people who live in the family home. A state can set a limit of people to be enrolled and manage a wait list as long as that wait list is reasonable. Priority criteria must be specified in the waiver application for how the wait list will be managed as slots become available.

**C. Self-Direction**

Using supports waivers the state looks to partner with individuals and their families, having the person maximize supports that are part of the community before or along with public funds. The person and their family have the ability to control services by prioritizing the services that are needed, contracting or hiring the provider and managing the budget resources within the cap. States that have used capped benefits have found families and people with I/DD feel like partners in meeting their needs and the result is that they optimize natural and non-public funded supports and use only those waiver services needed over and above non-paid supports. Most often the actual cost per person is under the maximum available.

**D. Benefits or Package of Services**

Each state designs the set of benefits or array of services that will be available under the Medicaid 1915(c) waiver authority in a supports waiver. This can include all of the services that were presented by Delaware families at the forums: respite, in-home services, community inclusion, day services, supported employment, transportation, home modifications, services and goods and technology. When states have an overall financial cap on the amount of funds to be used, most States keep all the services on the table to allow flexibility and choice to meet individual needs.

**E. Service Coordination/Case Management**

Since most states use supports waivers to promote individual and family self-direction, the role of the service coordinator is important to facilitate and broker supports. The service coordinator assists the person in developing their plan, helps to identify what providers are available, works with the person to manage the budget and provides ongoing monitoring that the person is getting the outcomes they desired.

**V. The features of a Family Support Waiver that would benefit Delaware include**

Delaware families identified a number of supports that would assist them in creating a life for their family member. But most important, families and individuals expressed the desire to be able to design the services and in some cases self-direct those services. Self-direction is not a type of service but a way of thinking. It empowers the person to get supports and services based on individual needs, values and beliefs. The basic principles of self-determination that are incorporated in a supports waiver are:

- Freedom to plan a life with the supports what a person needs
- Authority to control supports dollars
- Responsibility for the use of public funds
- Responsibility to participate in and become a contributing member of the community

**A. Target Population**

Delaware could include both children and adults in the supports waiver. The benefit packages can be designed to fit age groups such as children, transition age youth, adults, seniors. There can be a smaller cap for children and services would not include employment or day habilitation support while the child was in school.

There are approximately 740 individuals with I/DD who are in day services paid for using the Medicaid State Plan Rehabilitation Option. Over time CMS has clarified what services are appropriate to be included under the State Plan Rehabilitative Services option versus an HCBS waiver. While day habilitation and prevocational service were previously approved by CMS in Delaware's Medicaid State Plan, more recent CMS guidance has indicated that these services are not appropriate under the State Plan Rehabilitation option. Using a supports waiver, Delaware could correct this by offering the same array of day services in a manner that is consistent with CMS expectations. The defined target population will include these individuals and the benefit package described below will include these day and employment services, so that they can be removed from the State Plan.

**B. Benefit/Service Package**

Delaware's Family Support Waiver can include a broad benefit/service package and let the financial cap be the control factor. Support Service Waivers must identify the services that can be utilized by any participant. The benefit/service package list can be inclusive and many states have the following list of benefits in their Supports Waiver:

- Respite
- In-home staff support
- Community inclusion
- Day services, non-work
- Pre-vocational
- Employment support
- Assistive Technology
- Home/vehicle modification
- Services and goods
- Behavior consultation
- Nursing consultation
- Family Network

Within the benefit/services included in the waiver, limits can be placed on individual services such as an annual or multi-year limit for home modification. The Delaware Family Support Waiver could consider an exceptional needs

category which allows services to be purchased above a financial cap for a limited amount of time under extraordinary circumstances.

**C. Financial Cap**

Delaware could establish both an annual financial cap and also cap individual services but allow a broad list of benefits for a family and person to utilize. Capping the amount of services a person can spend both empowers the individual and their families to self-direct to use what is needed at the time it is needed and provides some fiscal predictability for the state.

States that have used capped benefits have found families and people with I/DD feel like partners in meeting needs, optimize natural and non-public funded supports and use only what is needed. Often the costs per person are under the maximum available.

**D. Supporting Family Networks**

Throughout the state forums, the need for information and systems navigations was a common theme. Families are not always in need of paid services but are desperate for information about resources and systems navigation. This need can be met by supporting family-to-family networks as well by providing supports coordination. Family Networks are being established in a number of states (OR, MO, CT) where the premise is that when parents connect with other parents who share a vision of possibility, and help each other find strength, they break the cycle of loneliness and isolation commonly experienced by families of children with disabilities. In turn, their children are more likely to experience a trajectory of empowerment and success within and beyond the disability community.

**E. Supports Coordination/ Case Management**

Support Coordinators/Case Managers should be trained and immersed in person-centered and family-centered planning so they can identify, strengthen and expand all supports, whether they are natural supports or paid through public funds.

Support Coordinators/Case managers skilled in working with individuals living at home and their families, together with a comprehensive person-centered/family-centered planning process are the essential elements to a successful Family Support Waiver.

## **VI. Recommendations**

DDDS recommends that the following steps occur in FY 15 in order to prepare for the implementation of a Delaware Family Support Waiver:

1. In FY 15, DDDS will create a Targeted Case Management option in the Medicaid State Plan. The target group would be inclusive of individuals who will be enrolled in the Family Support Waiver. DDDS currently spends over \$1million in unmatched State funds on its family support specialist program. The majority of these activities the family support specialists perform would be Medicaid reimbursable, enabling us to draw down a Federal match to fund a targeted case management system making it within current budget the first year. Since this will be a State plan service as an entitlement to a target group, a budget request will need to be submitted each year to maintain caseload ratios as the target population grows.
2. In FY 15, design a planning process specifically designed for individuals living at home with their families. A solid planning process will be critical to the implementation of a waiver program, but more importantly it is the foundational piece to improving the overall support to individuals living with their families. DDDS FY '15 training funding can be used to develop this planning process.
3. DDDS will begin work on a Family Support Waiver application during FY15 (see tentative schedule in Appendix B).

## **VII. Next Steps**

### **A. Creating the application for the Delaware Family Support Waiver**

Since a Home and Community Based Services (HCBS) waiver is a partnership with Centers for Medicare and Medicaid Services (CMS), the application for the program must be approved by CMS. CMS uses a web-based application process based on the old paper application that has ten parts or appendices. The application addresses all elements of the operation of the waiver, such as how case management will be provided, how client services will be monitored, how the Division of Medicaid and Medical Services (DMMA) will provide oversight and, most recently, how states will come into compliance with the new CMS rule for the definition of community based services. The current DDDS waiver application is over 150 pages long. Development of a new application is an arduous process and will take several months to prepare before it can be submitted to CMS for review and approval. CMS initially approves 1915(c) HCBS waivers for a three year period, with renewals at five year intervals thereafter. Once CMS receives the application, they have 90 days to approve or deny it, but they can "stop the clock" at any time during this 90 day period by issuing a "Request for Additional Information". Past experience indicates that the CMS review and approval process for new HCBS waivers is likely to take at least

six months. Staff at DDDS in partnership with DMMA, have experience in this process. Upon approval to move forward, we will target a July 1, 2015 date for approval by CMS and implementation. A tentative schedule for planning and implementation is included as Appendix B.

Having a second HCBS waiver to operate and manage within DDDS will require additional personnel to perform activities that are required under the waiver such as level of care determinations, waiver enrollment, enrollment management against approved slots, management of any waiting list, financial controls, rate setting, monitoring utilization, quality assurance monitoring and waiver reporting. As of January 2014, the current approved comprehensive HCBS waiver has an active enrollment of 941 individuals. This second waiver is recommended to enroll 980 individuals in its first year and would continue to grow over time.

#### **B. FY15 GF Start Up Costs Necessary for a FY16 Implementation**

Fiscal year 15 start-up cost necessary for a July 1, 2015 implementation is estimated at \$264,091. More information on these costs can be found in Appendix C.

##### **Recommendations:**

1. DDDS has identified the need for six additional positions in order to manage and support this program. A new waiver cannot be implemented without additional staff to enable the division to comply with all of the CMS requirements around the operation of an HCBS waiver. The cost to add this essential staff is: \$89,113 for partial funding in FY15 and \$281,844 in annualization in FY16 for a total cost of \$370,956.
2. DMMA has identified the need for three additional positions in order to process the Medicaid waiver eligibility applications (assumes a caseload of standard of 330 cases per worker). The cost of these eligibility workers will be split 50/50 state and federal as a Medicaid administrative activity. DMMA cannot process these new applications within its existing staffing compliment. The cost to add this essential staff is: \$13,103 for partial funding in FY15 and \$65,513 in annualization in FY16 for a total cost of \$78,616.
3. In order to implement a new waiver, changes will need to be made to the Delaware Client Information System (DCIS), the Medicaid eligibility system and the Medicaid Management Information System (MMIS), the Medicaid claims processing system in order to enable the submission of provider claims for the services charged to the Family support waiver. The one-time state share of the cost for these changes is: \$121,875.

4. DDDS will also need to engage the services of a consultant to develop Medicaid reimbursement methodologies for services not currently paid by Medicaid: \$40,000 state share one-time.

### **C. Implementation for FY 16**

#### **Recommendations:**

1. **Propose the creation of two target groups under the waiver, as follows:**

- a. Target Group 1 - Individuals living with their family who receive State Plan DDDS Day Services:

DDDS recommends that the initial target group for this waiver be those individuals who are living at home and currently receiving Medicaid State Plan day services. Current Medicaid spending for these day services is \$12.5 million total funds. Available funds for these services will increase during FY 14, 15 and 16 based on additional funding appropriated for special school grads adding to that base. These funds are available to fund part of the overall capped budget for the new waiver, so the day services component of the capped budget would be cost neutral to the State, since the State is already paying for the services. Individuals would continue to have their choice of qualified providers. Individuals and their families would have more control over the expenditure of their funds by having control of their budgets.

The initial number of participants in Target Group 1 will start at 940 individuals with capped budgets of \$22,000 each for FY 16. The waiver application will propose additional participants of 100 new individuals for each of the next 2 years of the waiver (FY 17 and FY 18).

In addition to the Day Services, these individuals will be able to purchase any of the other options that families have requested, up to their annual capped budget. Families will get to choose the amount, scope and duration of each service within any individual service limits included in the waiver application, up to their capped budget.

- b. Target Group 2 - Individuals living with their family who do not receive State Plan DDDS Day Services:

These are individuals who are still in school or who may be receiving services from Vocational Rehabilitation so they do not need DDDS Day Services. These individuals will have a lower cap than Target Group 1 that will allow them to receive the full array of family support services other than the Day Services. The initial number of participants in Target Group 2 will start at 40 individuals with capped budgets of \$2,750 each for FY 16.

The waiver application will propose additional participants of 40 individuals for each of the next 2 years of the waiver (FY 17 and FY 18).

## **2. Home/Vehicle Modifications**

Individuals in both of the Target Groups under the Family Support Waiver would be allowed to access home or vehicle modifications related to accessibility or safety up to a cap of \$6,000 per person every five years. This cap is separate from the caps for Target Groups 1 and 2.

## **D. Funding for Waiver Service Costs - FY16**

Current Medicaid spending for State Plan DDDS day services was approximately \$12.5 million total funds in FY13. Available funds for these services will increase during FY 14, 15 and 16 based on additional funding appropriated for special school grads, adding to that base. These funds are available to fund part of the overall capped budget for the new waiver, so the day services component of the capped budget would be cost neutral to the State, since the State is already paying for the services.

DDDS proposes to add an additional \$1.2 million in State only funds currently being used to pay for respite and other family support services into this program to be matched with Federal funds and utilized toward the individual budget cap. This includes the \$715.5 that was appropriated to DDDS in FY14 for family support.

The total funds equivalent of this \$1.2M on state funds is approximately \$2.6M in SFY16.

The total service costs for the Family Support Waiver are projected to be as follows:

FY16: \$20,206,811  
 FY17: \$22,156,872  
 FY18: \$24,106,923

Over half of the costs above will be borne by federal Medicaid funds. Because of the combination of available Medicaid funds that are already being spent on State Plan Day services and the addition of DDDS state funding that is not currently matched the first year of the waiver (FY16) is projected to be cost neutral, assuming that the legislature continues to fund the special school graduates as they have done for the past 10+ years. The incremental costs in - FY17 and FY18 to cover additional waiver slots are as follows:

FY	Total Incremental Funds	State Incremental Funds
2017	\$1,946,872	\$898,481
2018	\$1,950,051	\$899,949

The federal Medicaid share is based on the most current available data. More information about the fiscal note can be found in Appendix D.

Over time, the number of participants and/or the capped annual budgets can grow as funding is appropriated by the legislature. Appendix D shows the fiscal impact estimate based on the anticipated number of participants and their capped costs. The fiscal note was developed assuming zero increase in the value of the annual caps. The fiscal note also assumes client growth for each fiscal year (17 and 18) is 100 for Target Group 1 and 40 for Target Group 2.

**VIII. Acknowledgements**

DDDS would like to thank the many individuals, families and advocates who participated in the forums and acknowledge families as vital partners in supporting individuals to live fulfilling, inclusive lives in their community. DDDS looks forward to working with families to redesign the service system to better meet their needs and the needs of their family.

 Delaware Health and Social Services <b>FY 16 GF Budget Request - \$1,135,329.9</b> <u><b>Enhancements</b></u>	
Substance Use Disorder Programs (DSAMH)	\$3,635.0
Addiction Prevention & School Based Educations (DPH)	\$ 100.0
Eligibility Modernization System Maintenance & Operations (DMS)	\$2,358.3
Data Warehouse Maintenance & Operations (DMMA)	\$ 275.0
Child Care Sliding Fee Scales (DSS)	\$1,139.3
Department-wide Security Initiatives (DMS)	\$ 193.0
SIM-Care Coordination Fees (DMMA)	\$1,300.0
Family Support Waiver (DDDS)	\$ 944.2
<hr/> Delaware Health and Social Services	

Our FY 16 Budget request also includes approximately \$9.9 million for enhancements:

- \$3.635 million is requested for the Division of Substance Abuse and Mental Health's Substance Use Disorder programs. The following programs are part of the redesign for the substance abuse treatment programs:
  - ✓ \$750.0 - funds the Adult Withdrawal Management (Detoxification) programs to transform the current New Castle County program and open a downstate program.
  - ✓ \$935.0 - funds the expansion of the Sober Living Residential programs for an additional 60 beds which would provide a safe, secure and drug/alcohol free housing for substance abusers (10 mos.)
  - ✓ \$1.150 million - expands the Young Adult Residential Opiate Treatment program for an additional 16 beds (11 mos).
  - ✓ \$800.0 - funds will be used to increase the residential treatment program for an additional 16 bed program (10 mos).
- \$100.0 is requested to initiate a prescription drug abuse education program in the schools.
- \$2.358 million is requested for maintenance and operational contractual support for the DSS Eligibility system.
- \$275.0 is requested to maintain and operate DMMA's Decision Support and Data Warehouse system to meet Medicaid data needs.
- \$1.139 million is requested to fund the implementation of federal mandated changes related to the Child Care Sliding Fee Scale (co-pays).
- \$193.0 is requested to increase the safety of our employees and clients through various security initiatives.
- \$1.3 million is requested to implement care coordination fees in Medicaid as part of the State Innovation Model (SIM).
- \$944.2 is requested for personnel and dental services related to the development and establishment of the Family Support Waiver.

Division of Developmental Services  
MONTHLY CENSUS

Source: Division of Developmental Disabilities Services Client Registry System  
January 2015



*Number as of the  
last day of the month*

A. INSTITUTIONAL PLACEMENTS	NEW CASTLE	KENT	SUSSEX	OUT OF STATE
MARY ANN COVERDALE CENTER	0	0	54	0
102 WAPLES WAY (COTTAGE)	0	0	1	0
PSYCHIATRIC PLACEMENTS	2	0	0	0
NURSING HOMES	49	7	7	1

54
1
2
64
<b>A.</b> align="right">121

B. COMMUNITY SERVICES/ RESIDENTIAL PLACEMENTS	NEW CASTLE	KENT	SUSSEX
NEIGHBORHOOD (GROUP) HOMES/CLAs	571	144	178
SHARED LIVING	41	32	25
SUPPORTED LIVING	12	5	17
OUT OF STATE	16	0	1
ETLA (Emergency Temporary Living Arrangement)	5	1	3

893
98
34
17
9
<b>B.</b> align="right">1051

C. FAMILY SUPPORT	NEW CASTLE	KENT	SUSSEX
	1587	630	677

<b>C.</b> align="right">2,894
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**TOTAL CENSUS (A to C)**

**4066**

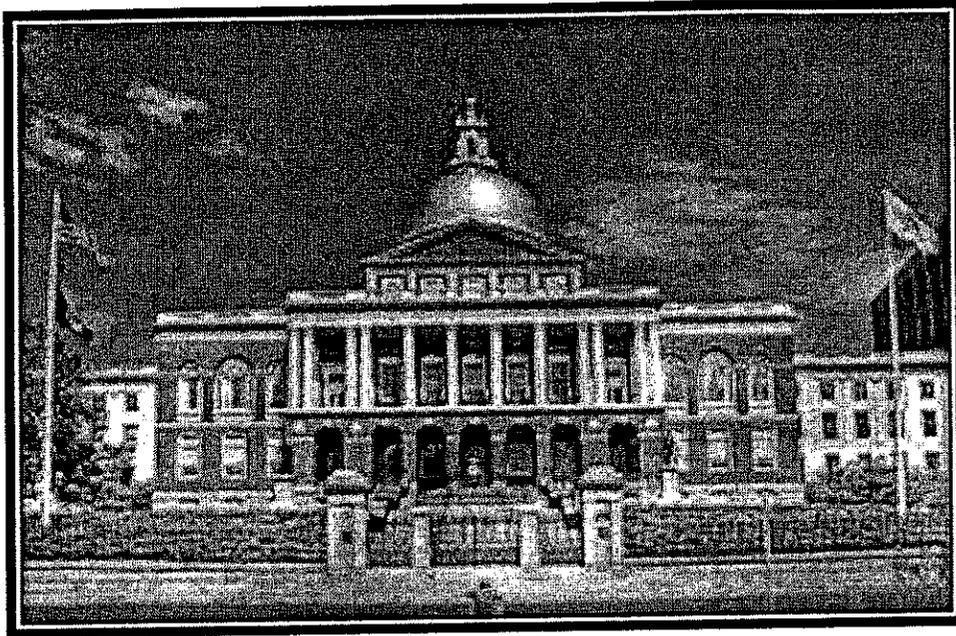
Completed: 2/5/15 lc

Revised 8/5/2014

ATTACHMENT "D"

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 DISABILITES**

**ATTACHMENT "E"**

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	\$53,235,790,070	\$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.

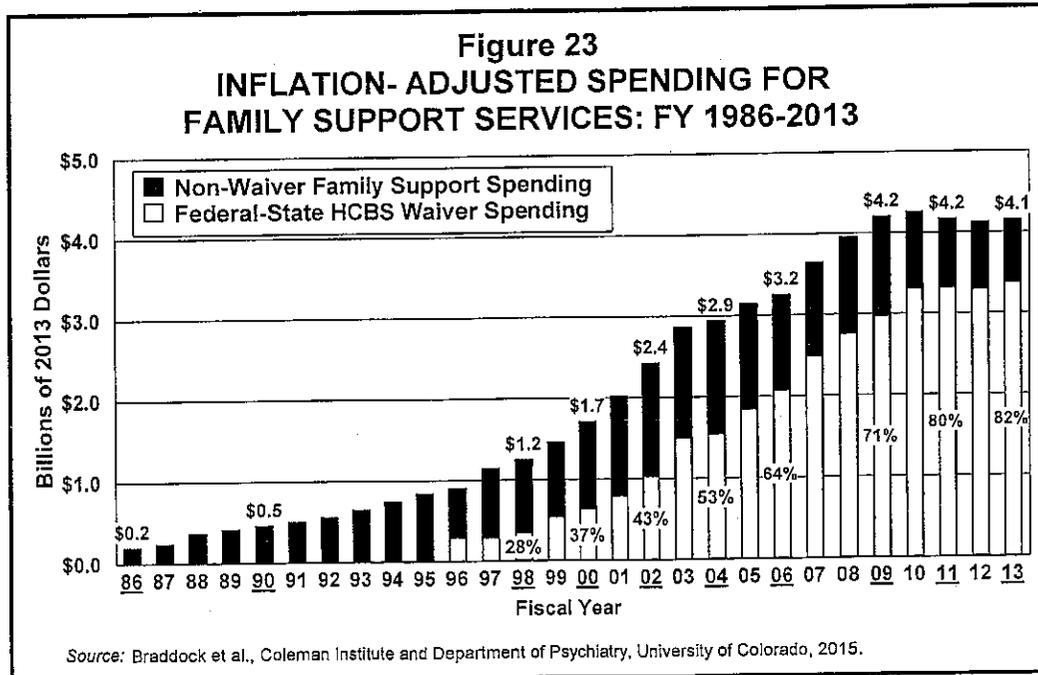


TABLE 19  
FAMILY SUPPORT IN THE STATES:  
SPENDING FOR PARTICIPANTS WITH I/DD IN FY 2013

State	Total Family Support <sup>1</sup>		Spending	Rank <sup>2</sup>	Families	Rank <sup>3</sup>	Cash Subsidy		Other Family Support	
	Families	Spending	Per Family		Supported Per 100K		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
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	1,847	\$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	\$4,144,355,306	\$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	445,677	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	74,891	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	3,557,248	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.**

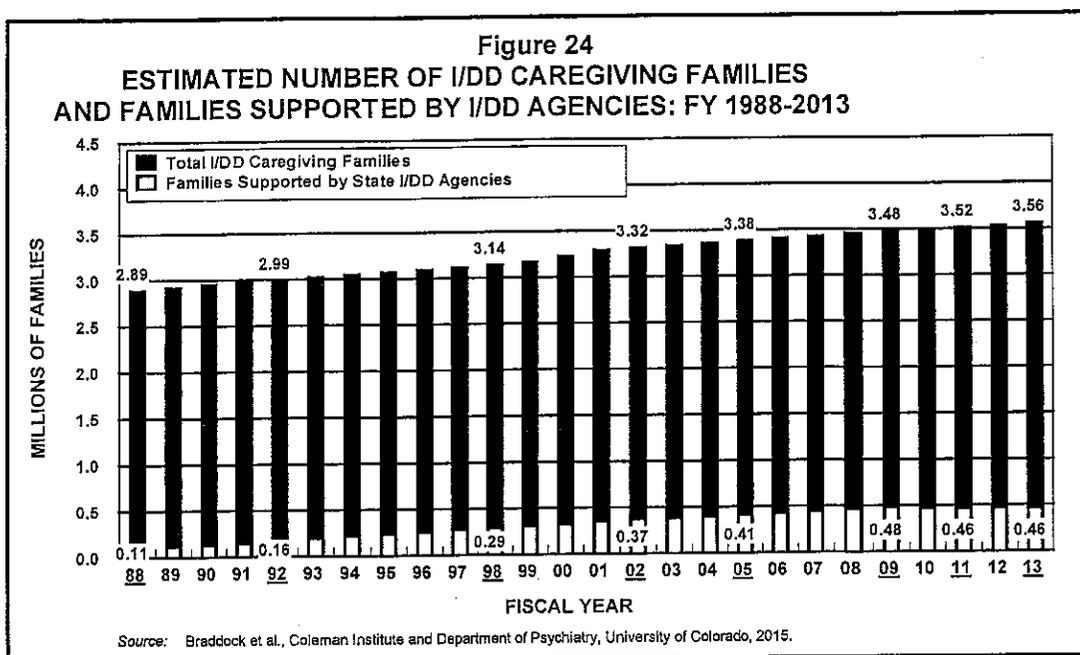
National trends in family support spending and number of families supported demonstrate an effort to maintain support for family caregivers, despite the impact of the Great Recession. However, in nearly all states and in the nation as a whole, the number of families supported is a pitifully small portion 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-



nancing 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.

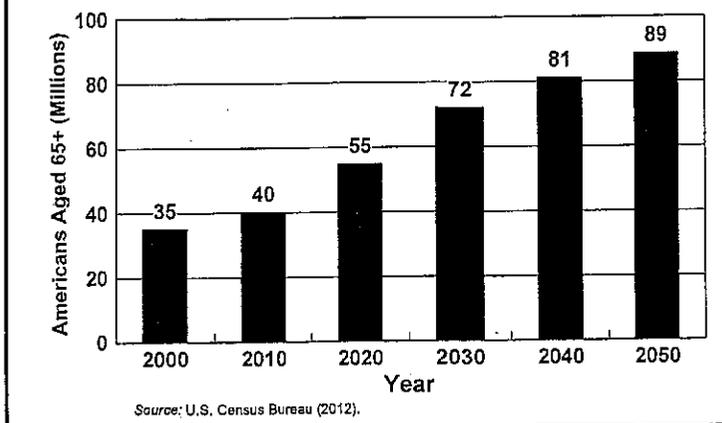
The aging of our society is the product of several forces, including the size of the baby boom generation (persons born during 1946-1964), declining fertility rates, and increased longevity. Baby boomers began to reach age 65 in 2011.

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



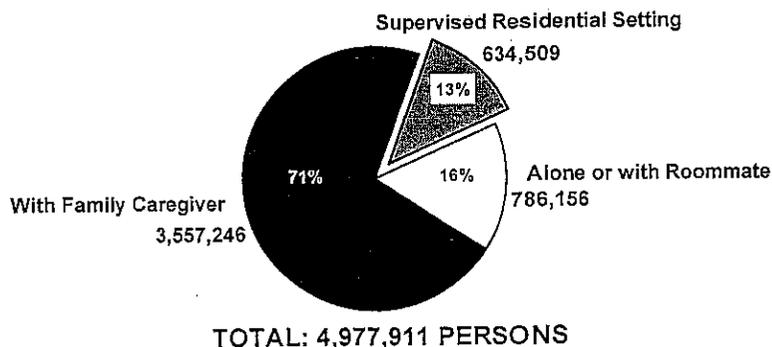
Source: U.S. Census Bureau (2012).

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).

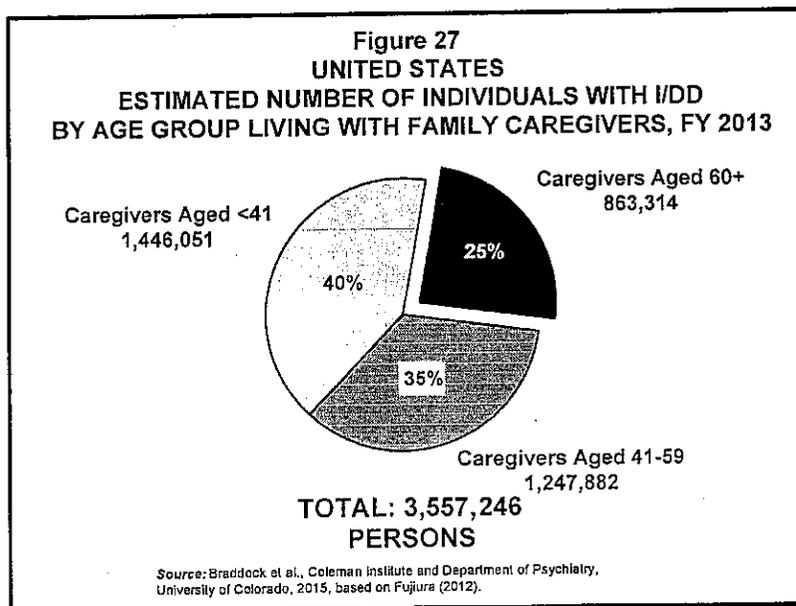


TABLE 21  
ESTIMATED NUMBER OF  
PERSONS WITH I/DD LIVING WITH  
AGING CAREGIVERS IN FY 2013<sup>1</sup>

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

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For people with intellectual  
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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.

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