

MEMO

To: Joint Finance Committee
From: Brian J. Hartman, on behalf of the following organizations:

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

Subject: Division of Developmental Disabilities Services FY 15 Budget
Date: February 27, 2014

Please consider this memo a summary of the oral presentation of Brian J. Hartman, Esq. on behalf of the Disabilities Law Program ("DLP"), Developmental Disabilities Council ("DDC"), Governor's Advisory Council for Exceptional Citizens ("GACEC"), and the State Council for Persons with Disabilities ("SCPD"). We are addressing one (1) component of the DDDS budget, i.e., development of a family support waiver.

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

As background, the Division first proposed a family support waiver nine years ago (2005) and start-up funds were included in the FY09 budget.² The initiative was deferred given the economic downturn at that time. The justification for a waiver is even more compelling today. More than 70% of the Division's clients live at home with their family.³ In raw numbers, this equates to 2,690 clients living at home out of a total census of 3,783 individuals.⁴ This group is expanding. Between FY11 and the end of FY13, it grew from 2,165 to 2,664, a 19% increase.⁵ Consistent with national trends, many of the Delaware caregivers in those families are aging.⁶ The percentage of aging caregivers is

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

²Materials describing the waiver and planned implementation are compiled in Attachment "B".

³See DDDS FY14 JFC Presentation (February 21, 20113) at 5. [Attachment "C"]

⁴The latest (December, 2013) DDDS census report is included as Attachment "D".

⁵See Attachment D and D. Braddock, The State of the States in Developmental Disabilities (2013) at 115. [Attachment "E"]

⁶See Braddock, at pp. 58-60. [Attachment "E"]

increasing annually as the “boomers” progress into old age.⁷ Given declines in health and resiliency attributable to aging, such caregivers will predictably need an increasing level of supports to continue in their role.⁸

Almost all states offer family support programs for caregivers of individuals with developmental disabilities. The national average of spending per family is \$8,610. Unfortunately, although DDS is adept at identifying families needing support (ranking 12th), it spends less than 10% of the national average in per-family supports (ranking 47th).⁹ This underscores the justification to develop an enhanced family support system.

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

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

Second, nationwide, Medicaid waivers finance 79% of all family support services.¹⁰ This represents a tremendous leveraging of federal funds to assist state residents. Conversely, Delaware’s lack of a family support Medicaid waiver results in unnecessary reliance on unmatched State funds and few resources for Delaware families. A recent study highlights that Delaware is essentially “leaving money on the table” by eschewing available Medicaid funding. Delaware ranked 6th among the states in the percentage of unmatched funding devoted to individuals with developmental disabilities.¹¹

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

Thank you for your consideration.

Attachments

F:pub/bjh/legis/budget/dddsjfcbudfy15
8g:leg/dddsjfcbudfy15

⁷AARP, “The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers” (August, 2013) [Attachment “F”]

⁸See CDC, “Family Caregiving: The Facts” and The Arc, “Position Statement: Family Support” (November 8, 2008). [Attachment “G”]

⁹See Braddock, p. 55. [Attachment “E”]

¹⁰See Braddock, p. 56. [Attachment “E”]

¹¹See Braddock, p. 204. [Attachment “E”]

H.B. No. 200 (FY14 Budget)

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

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

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

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

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



Delaware Health and Social Services

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Division of Developmental Disabilities Services (DDDS)

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Contact info:
 Division of Developmental Disabilities Services
 Woodbrook Professional Center
 1056 South Governor's Avenue, Suite 101
 Dover, Delaware 19904

 Phone: (302) 744-9600
 FAX: (302) 744-9632
 E-Mail: dhssinfo@state.de.us

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).

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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✉ For more information about Delaware Health and Social Services, please email us at dhssinfo@state.de.us.

Last Modified: Fri, Dec 02, 2005

Attachment "B"



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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



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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

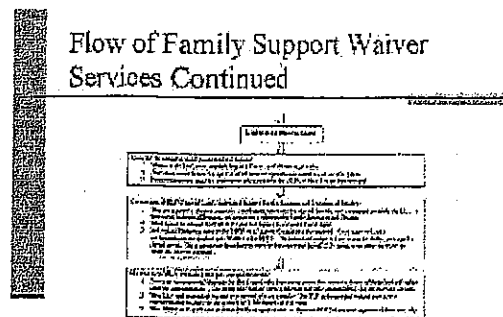
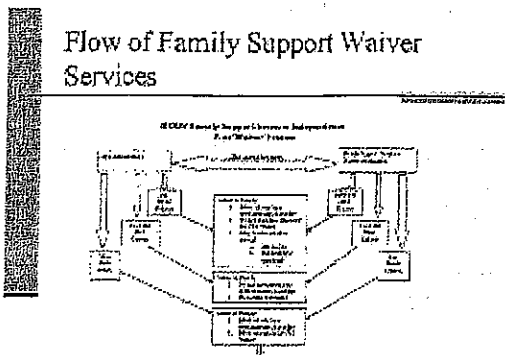
- The DDDS Family Support Services waiver offers eligible individuals and their families the opportunity to participate in a flexible program to help in achieving their personally defined goals. Delaware's waiver is based upon the belief that in order for eligible individuals with disabilities and their 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)

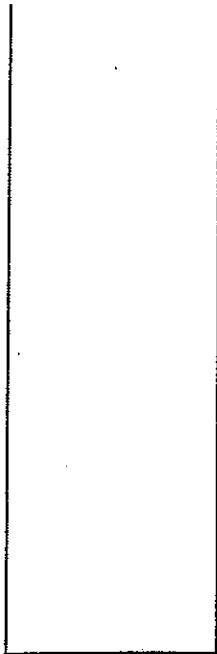


Mandatory Services In the Family Support Services Waiver

- 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

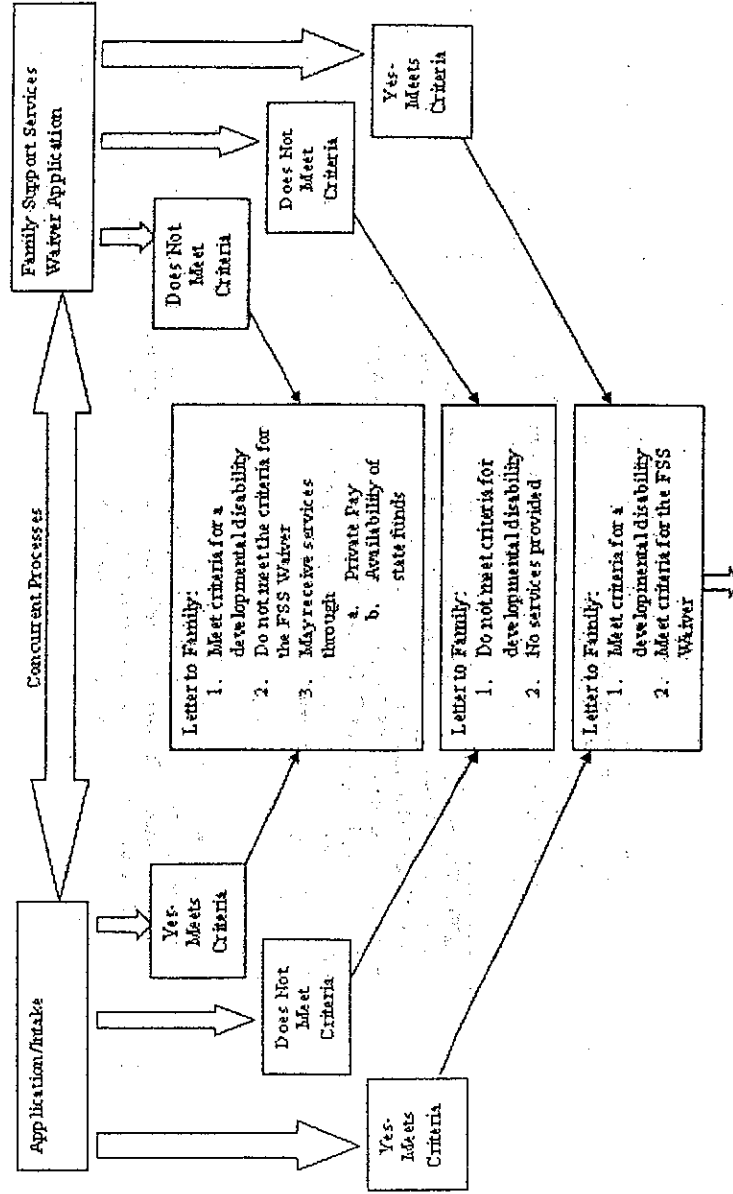
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Flow of Family Support Waiver Services

DDDS Family Support Services Independence Plus Waiver Process



ICAP Referral Made to Arbitre

Case sent to Initial Supports Coordination Agency:

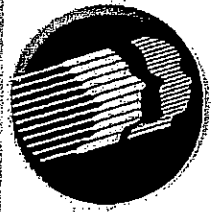
1. Meets with family to complete Registry Form and Waiver Application.
2. Facilitates selection of Supports Coordinator and provides explanations of service options
3. Sends completed registry and waiver information to the DDS within 30 days from referral

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 MMS 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 of care:

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 MMS 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 events 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!!

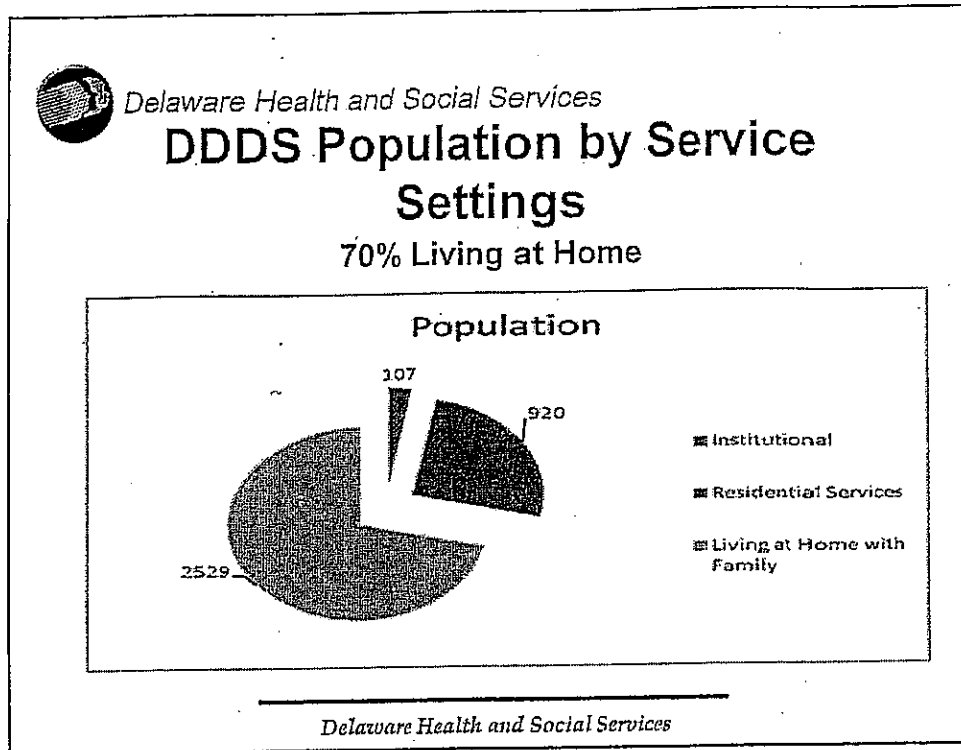


Special Points of Interest....

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?

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



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

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

MONTHLY CENSUS REPORT

December 2013



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

Number as of the
last day of the
month

	48
	12
A.	60

B. COMMUNITY SERVICES/ RESIDENTIAL PLACEMENTS	NEW CASTLE	KENT	SUSSEX
NEIGHBORHOOD (GROUP) HOMES including CLA2 & CLA3	560	98	152
SUPPORTED LIVING	10	4	14
SHARED LIVING	22	54	48
OUT OF STATE	20	1	1
ETLA (Emergency Temporary Living Arrangement)	4	2	4

	810
	28
	124
	22
	10
B.	994

C. DPC (DELAWARE PSYCHIATRIC CENTER)	2	0	0
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C.	2
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D. FAMILY SUPPORT	1480	594	616
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D.	2,690
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E. NURSING HOMES	NEW CASTLE	KENT	SUSSEX	OUT OF STATE
NURSING HOMES	24	7	5	1

E.	37
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Total Census:
(A to E)

3783

Attachment "D"

Census Comparison First Quarter FY 13 to First Quarter FY 14	Change During FY13	Difference Since Start of FY14						
		July, 2013	August, 2013	September, 2013	October, 2013	November, 2013	December, 2013	
A. STOCKLEY CENTER CENSUS	-3	61	61	61	60	59	60	-1

B. COMMUNITY SERVICES/ RESIDENTIAL PLACEMENTS								
NEIGHBORHOOD (GROUP) HOMES		768	792	792	785	814	810	42
SUPPORTED LIVING		18	22	23	23	28	28	10
SHARED LIVING		121	125	129	128	125	124	3
OUT OF STATE		22	22	22	31	22	22	0
ETLA		21	9	12	13	7	10	-11
Total Placements	B. 107	950	970	978	980	906	994	44

C. PSYCHIATRIC PLACEMENTS	C. -1	2	2	2	2	2	2	0
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D. FAMILY SUPPORT	D. 142	2,625	2,629	2,664	2,658	2,662	2,690	65
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E. NURSING HOME CENSUS	E. -2	27	37	38	35	38	37	10
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Total Census: (A to E)	243	3665	3699	3743	3735	3757	3783	118
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Excerpts

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



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

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

and

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

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

Attachment "E"

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

State	Total Family Support ¹		Spending Per Family	Rank ²	Families Supported Per 100K		Cash Subsidy		Other Family Support	
	Families	Spending			Families	Rank ³	Families	Spending	Families	Spending
Alabama	1,952	\$549,420	\$281	49	41	48	0	\$0	1,952	\$549,420
Alaska	1,105	\$8,154,630	\$7,380	21	155	19	0	\$0	1,105	\$8,154,630
Arizona	21,860	\$360,286,868	\$16,482	9	337	3	8	\$6,454	21,852	\$360,280,414
Arkansas	528	\$548,897	\$1,040	46	18	50	0	\$0	528	\$548,897
California	101,383	\$710,614,552	\$7,009	22	271	9	0	\$0	101,383	\$710,614,552
Colorado	2,905	\$5,354,506	\$1,843	43	57	40	0	\$0	2,905	\$5,354,506
Connecticut	3,290	\$53,910,549	\$16,386	10	92	31	1,600	\$3,280,095	1,690	\$50,630,454
Delaware ⁴	2,165	\$1,604,698	\$741	47	239	12	59	\$207,574	2,165	\$1,397,124
District of Columbia	416	\$9,239,069	\$22,209	3	69	39	0	\$0	416	\$9,239,069
Florida	16,385	\$363,681,665	\$22,196	4	86	34	99	\$277,266	16,286	\$363,404,399
Georgia	7,125	\$13,317,256	\$1,869	42	73	37	0	\$0	7,125	\$13,317,256
Hawaii	1,808	\$19,962,457	\$11,041	14	132	22	0	\$0	1,808	\$19,962,457
Idaho	0	\$0	\$0	51	0	51	0	\$0	0	\$0
Illinois	5,331	\$27,114,630	\$5,086	29	41	46	299	\$2,077,942	5,032	\$25,036,688
Indiana	5,289	\$36,544,645	\$6,910	24	81	35	0	\$0	5,289	\$36,544,645
Iowa	764	\$29,057,121	\$38,033	1	25	49	297	\$1,500,000	467	\$27,557,121
Kansas	2,564	\$48,010,580	\$18,725	7	90	33	0	\$0	2,564	\$48,010,580
Kentucky	2,354	\$3,718,361	\$1,580	45	54	43	0	\$0	2,354	\$3,718,361
Louisiana	12,927	\$365,043,119	\$28,239	2	285	5	1,752	\$4,801,896	11,175	\$360,241,223
Maine	545	\$6,500,000	\$11,927	12	41	47	545	\$6,000,000	0	\$500,000
Maryland	7,006	\$40,438,454	\$5,772	26	121	25	0	\$0	7,006	\$40,438,454
Massachusetts	10,443	\$35,155,140	\$3,366	36	159	18	0	\$0	10,443	\$35,155,140
Michigan	16,122	\$55,221,114	\$3,425	34	163	16	7,163	\$18,752,369	8,959	\$36,468,745
Minnesota	14,679	\$300,721,022	\$20,486	5	276	6	2,861	\$18,394,751	11,818	\$282,326,271
Mississippi	3,722	\$19,536,865	\$5,249	28	125	23	0	\$0	3,722	\$19,536,865
Missouri	8,682	\$30,003,717	\$3,456	33	144	20	0	\$0	8,682	\$30,003,717
Montana	2,843	\$11,155,808	\$3,924	32	286	4	0	\$0	2,843	\$11,155,808
Nebraska	1,040	\$10,948,271	\$10,527	16	57	41	0	\$0	1,040	\$10,948,271
Nevada	2,467	\$6,461,063	\$2,619	40	90	32	521	\$2,334,954	1,946	\$4,126,109
New Hampshire	4,518	\$10,983,068	\$2,431	41	342	2	103	\$35,381	4,415	\$10,947,687
New Jersey	8,685	\$50,241,924	\$5,785	25	99	29	0	\$0	8,685	\$50,241,924
New Mexico	5,466	\$15,884,237	\$2,906	39	264	10	87	\$293,798	5,379	\$15,590,439
New York	52,632	\$549,174,558	\$10,434	17	271	8	0	\$0	52,632	\$549,174,558
North Carolina	9,175	\$37,353,642	\$4,071	31	95	30	0	\$0	9,175	\$37,353,642
North Dakota	685	\$13,464,733	\$19,657	6	102	28	7	\$73,798	678	\$13,390,935
Ohio	20,312	\$91,984,079	\$4,529	30	176	15	0	\$0	20,312	\$91,984,079
Oklahoma	4,657	\$78,722,068	\$16,905	8	124	24	2,228	\$5,944,265	2,429	\$72,777,803
Oregon	2,083	\$951,001	\$457	48	54	42	0	\$0	2,083	\$951,001
Pennsylvania	25,842	\$81,364,739	\$3,149	38	203	14	0	\$0	25,842	\$81,364,739
Rhode Island	1,225	\$13,072,374	\$10,671	15	116	26	44	\$145,679	1,181	\$12,926,695
South Carolina	11,300	\$60,404,554	\$5,346	27	242	11	2,922	\$1,256,100	8,378	\$59,148,454
South Dakota	1,898	\$5,978,009	\$3,150	37	232	13	0	\$0	1,898	\$5,978,009
Tennessee	4,524	\$7,491,000	\$1,656	44	71	38	0	\$0	4,524	\$7,491,000
Texas	19,625	\$245,855,575	\$12,528	11	77	36	2,952	\$5,721,740	16,673	\$240,133,835
Utah	1,501	\$12,044,393	\$8,024	20	54	44	0	\$0	1,501	\$12,044,393
Vermont	1,702	\$17,757,349	\$10,433	18	272	7	0	\$0	1,702	\$17,757,349
Virginia	3,573	\$618,967	\$173	50	44	45	0	\$0	3,573	\$618,967
Washington ⁴	7,223	\$58,229,286	\$8,062	19	107	27	2,329	\$4,035,584	6,453	\$54,193,703
West Virginia	2,624	\$29,665,233	\$11,305	13	142	21	0	\$0	2,624	\$29,665,233
Wisconsin	20,100	\$68,502,758	\$3,408	35	352	1	0	\$0	20,100	\$68,502,758
Wyoming	908	\$6,341,281	\$6,984	23	160	17	0	\$0	908	\$6,341,281
United States	467,958	\$4,028,939,305	\$8,610		151		25,876	\$75,139,645	443,700	\$3,953,799,666

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

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

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

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

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

TABLE 20

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

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

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

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

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

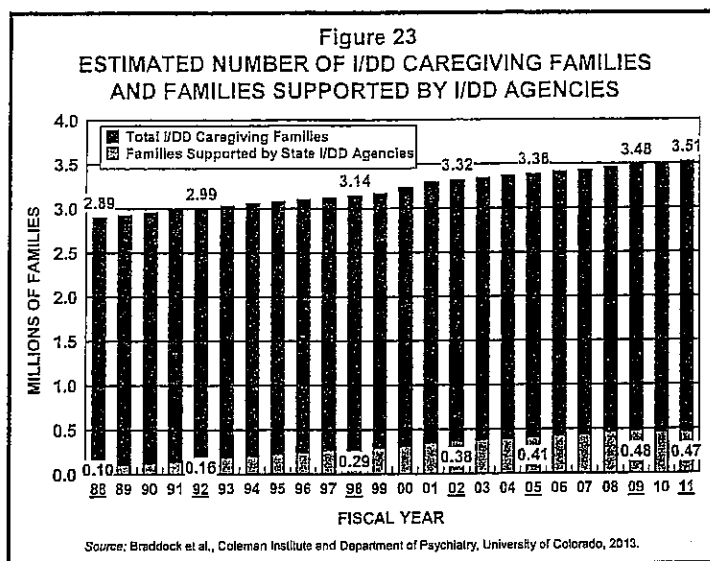
In 2011, the HCBS Waiver financed 79% of all family support services in the United States. The States varied greatly in the extent to which they utilized HCBS Waiver funds to finance family support initiatives. Twenty-five states funded 90% or more of their family support services with the Medicaid HCBS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

Unmet Need for Family Support

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

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

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



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

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

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

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

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

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

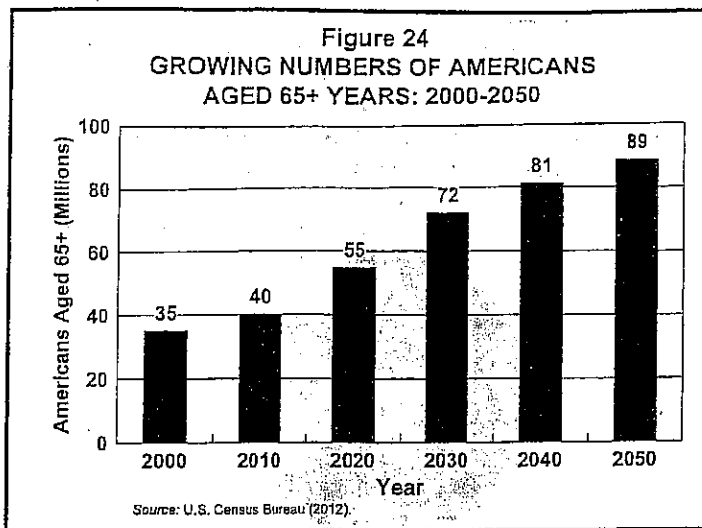
VIII. DEMAND FOR SERVICES AND SUPPORTS

Formal out-of-home residential services were being provided to 613,184 persons in the states in 2011. The vast majority of these settings are operated by private, non-profit service providers. The structure of the residential care system has changed markedly over the past 25 years as state-operated residential institutions have increasingly been supplanted by community residential services.

The nation’s overall residential system capacity increased by more than 40% since 1999, with an average annual growth rate of 3% per year during 1999-2011. U.S. general population annual increases were only 1%.

Aging Caregivers

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



The aging of our society is the product of several forces, including the size of the baby boom generation (persons born during 1946-1964), declining fertility rates, and increased longevity. Baby boomers began to reach age 65 in 2011. The number of persons in our society aged 65+ years is projected by the U.S. Census Bureau (2012) to reach 55 million in 2020 and 89 million in 2050 (*Figure 24*). Currently, 13.3% of the U.S. general population is aged 65+ years. In the U.S., 37% of persons 65 years of age and over have one or more physical disabilities as opposed to 11% of the population under age 65 (Schiller, Lucas, Ward, & Peregoy, 2012).

Americans 80 years or older are expected to be the fastest growing age group. Many countries will be affected by this demographic trend, particularly Brazil, China, India, Indonesia, and Japan. For example, the UN estimates that, by 2050, the percentage of Japan's citizens over the age of 60 will have increased from 30% to 44%. At least 16% of their population will be over age 80 (United Nations, 2009). Europe now has the oldest population, with a median age of nearly 40 years that is projected to reach 47 years in 2050. On a global basis, life expectancy at birth

was 68 years in 2005-10, and is projected to be 76 years in 2045-50 (United Nations, 2009).

Estimating the impact of aging on the increased demand for intellectual and developmental disabilities services in the states requires data on the prevalence of developmental disabilities in our society. Based on the 1994/95 data from the National Health Interview Survey-Disability Supplement (NHIS-D), Larson et al. (2001) recommended using a rate of 1.58% to estimate prevalence for persons with intellectual disability, cerebral palsy, autism, epilepsy, and

other childhood disabilities originating prior to 22 years of age.

Fujiura (1998, 2012) determined that in 2010, 71.5% of persons with developmental disabilities in the U.S. resided with family caregivers, and 28.5% lived on their own or within the formal out-of-home residential care system in the states. We updated Fujiura's analysis using data pertaining to the 2011 out-of-home residential system, and the U.S. general population in 2011.

The results are presented in *Figure 25* (page 59), which indicates that 3.51 million of the 4.90 million persons with intellectual and developmental disabilities in the U.S. population in 2011 were receiving residential care from family caregivers. This "informal" system of residential care served nearly six times the number of persons served by the formal out-of-home residential care system (613,184 persons). Fujiura (1998, 2012) determined that 25% of individuals with developmental disabilities in the U.S. lived with family caregivers aged 60+ years, and an additional 35% were in "households of middle-aged caretakers for whom transition issues are near-term considerations" (Fujiura, 1998, p. 232).

In *Figure 26*, we further examined the data in the previous figure to draw specific attention to the size of the aging family caregiver cohort (891,783 persons) in 2011. How large is the aging caregiver cohort in each of the states?

State-by-state estimates can be generated by taking into account differences in states' utilization of out-of-home placements and the number of the states' caregivers who are over age 60. For example, an estimated 5% of persons with I/DD in Arizona and Nevada live in out-of-home settings while the figure is 23% in Oregon. The percentage of individuals over age 65 in the *oldest* state, Florida (17.6%), is over two times the percentage of older individuals in the *youngest* state, Alaska (8.1%) (U.S. Census Bureau, 2012).

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

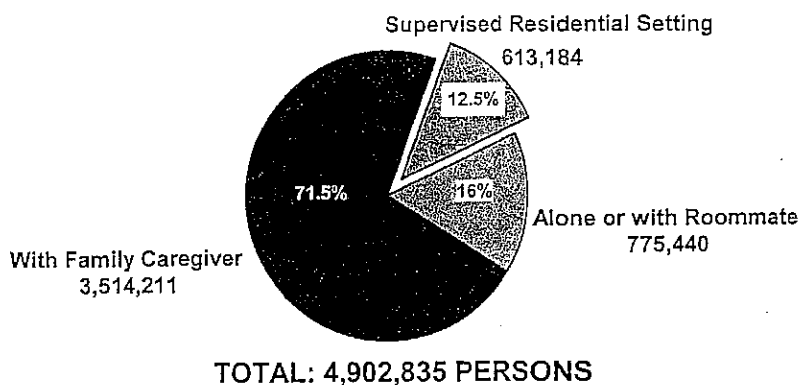
Increased Longevity

A second factor contributing to the growing demand for I/DD services is the increase in the lifespan of individuals with intellectual and developmental disabilities. The mean age of death for persons with developmental disabilities was 66 years in 1993, compared to 59 years in the 1970s and 33 years in the 1930s. The average longevity of people with Down syndrome increased from nine years in the 1920s to 31

years in the 1960s to 56 years in 1993 (Janicki, Dalton, Henderson, & Davidson, 1999). The mean age at death for the general population in 1993 was 70 years (Janicki, 1999).

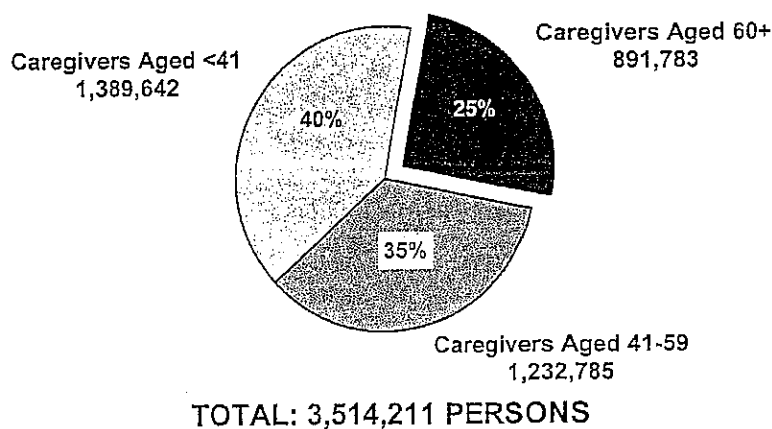
An Australian study reported the average age of death for people with mild and moderate intellectual impairment who do not have any chronic health conditions is 71 years (Bittles, Petterson, Sullivan, Hussain, Glasson,

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



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

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



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

TABLE 21

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

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

¹ Caregivers aged 60 years and older.

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

& Montgomery, 2002). Information is beginning to emerge on genetic and nonspecific neuro-developmental conditions, linked to intellectual disabilities, which are affected differently by maturation and aging. For example, Down syndrome has been linked to premature aging, Alzheimer's disease, and certain organ dysfunctions (Nakamura & Tanaka, 1998; Prasher, 2006; Pueschel, 2006).

In addition to genetic disorders, specific health problems related to the older age trajectories of several common neuro-developmental conditions include cerebral palsy (e.g., osteoporosis and degenerative joint disease), autism (e.g., digestive system disorders and neuropsychiatric factors) and spina bifida (e.g., neuromotor and other organ system consequences) (Janicki, Henderson, & Rubin, 2008).

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

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

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

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

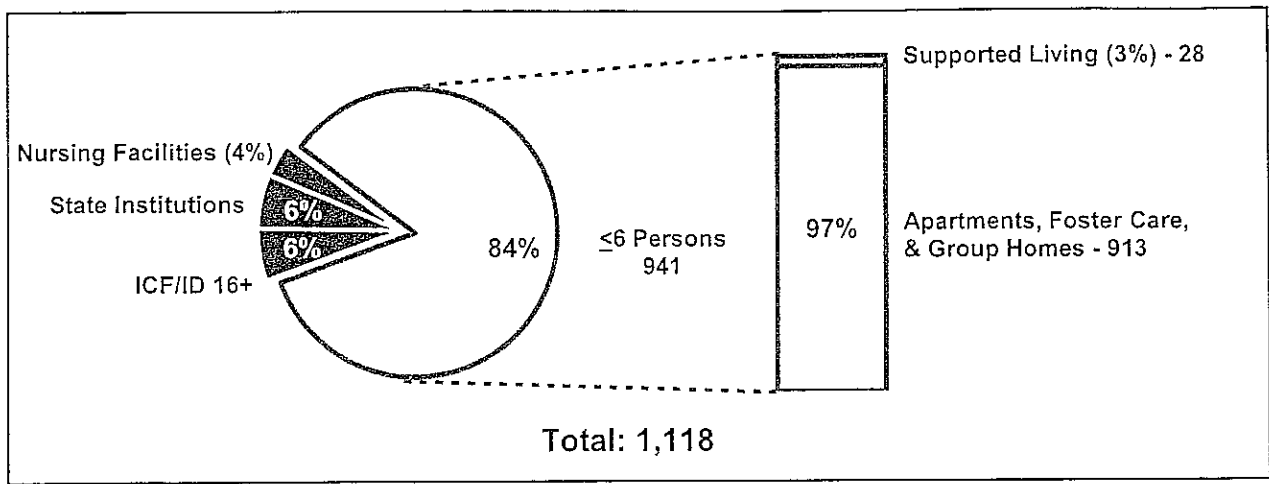
Rank	State	Total Federal, State, County & Local I/DD Spending	Total Unmatched State, County & Local Funds	Unmatched % of Total Spending
1	Connecticut	\$1,582,748,066	\$673,811,118	43%
2	Massachusetts	\$1,787,117,919	\$702,714,192	39%
3	Ohio	\$3,146,775,547	\$942,115,412	30%
4	Maryland	\$906,937,255	\$268,707,355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

¹States are ranked by Unmatched Funds as a percentage of total VDD Spending. Unmatched funds consisted of total VDD spending, minus federal-state Medicaid, federal SSI/ADC for HCBS Waiver participants, SSI state supplementation, and social services and other federal funds.

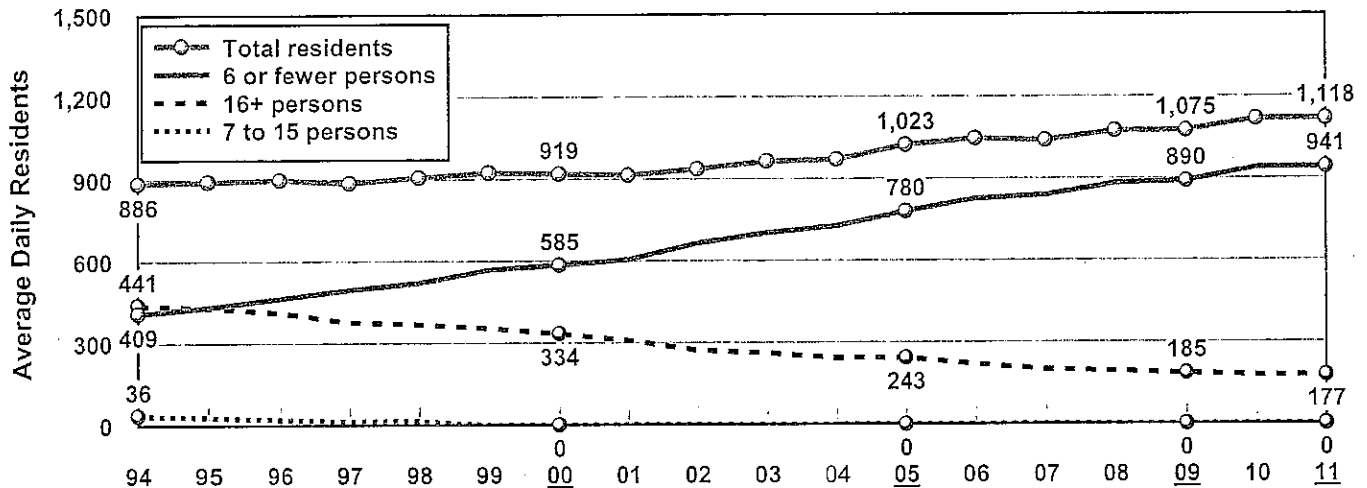
²County governments provided 20% of Ohio's unmatched state and local funds; unmatched funds in Iowa & Wisconsin also included county and other local government funding (see Table 15, p. 40).

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

PERSONS BY SETTING IN FISCAL YEAR 2011

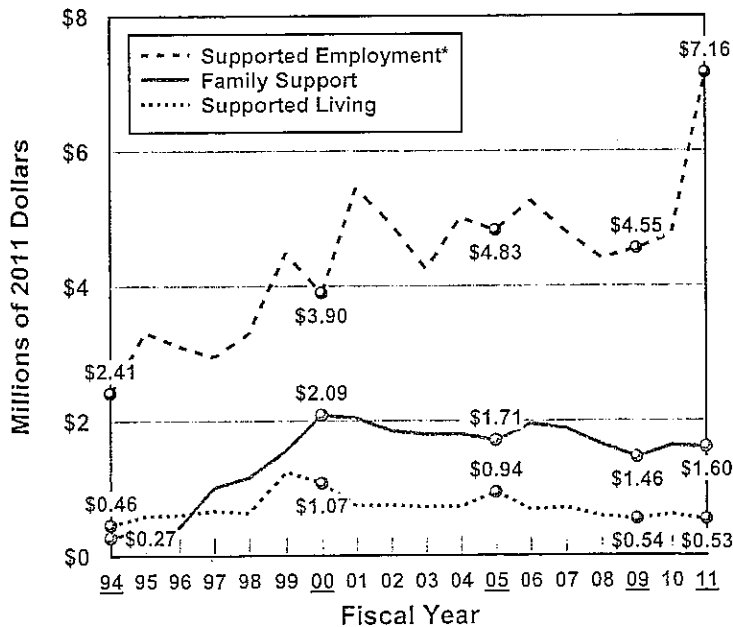


RESIDENTS WITH I/DD BY SIZE OF SETTING: 1994-2011

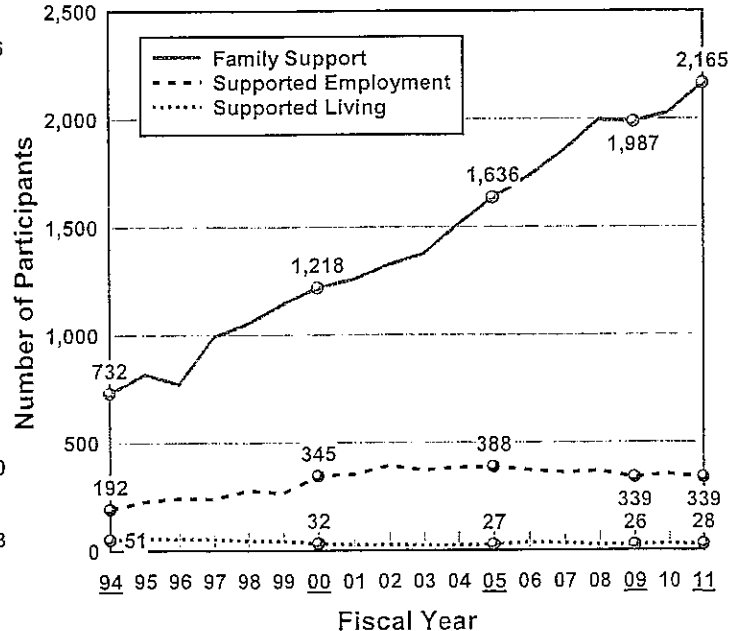


INDIVIDUAL AND FAMILY SUPPORT

SPENDING



PARTICIPANTS



*The state in 2011 paid an enhanced rate per worker; rates expected to decline in 2012-13

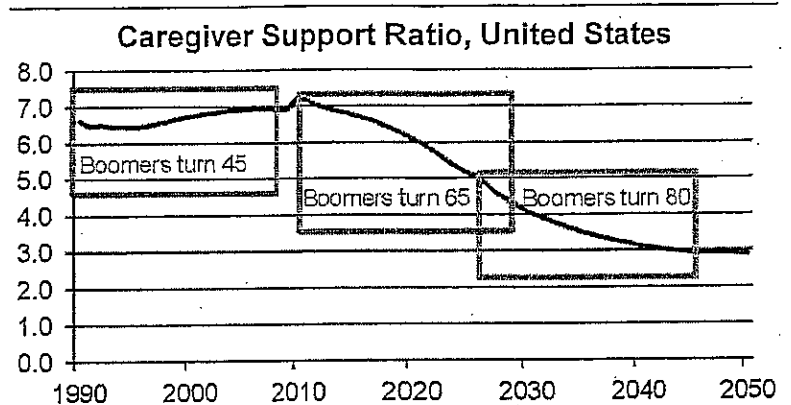
The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers

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

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

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

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



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

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

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www.aarp.org/ppi ppi@aarp.org



Centers for Disease Control and Prevention
 CDC 24/7: Saving Lives. Protecting People.™

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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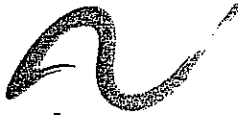
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Centers for Disease Control and Prevention 1600 Clifton Rd. Atlanta, GA
30333, USA
800-CDC-INFO (800-232-4636) TTY: (888) 232-6348 - Contact CDC-INFO





The Arc

For people with intellectual
and developmental disabilities



American Association
on Intellectual and
Developmental Disabilities

POSITION STATEMENT

Family Support

Family support services should be available to all families who need them because they strengthen the capacity of the family to support family members with intellectual and/or developmental disabilities¹ both in the home and the community in a cost effective way.

Issue

Individuals with intellectual and/or developmental disabilities, by definition, require greater intensities of support than other individuals to perform basic, daily activities and to achieve the goals of equality of opportunity, full participation, independent living, and economic self-sufficiency. Families are overwhelming the primary and often only source of support for their family member with an intellectual and/or developmental disability. Relatively small proportions of federal and state funding for persons with intellectual and/or developmental disabilities are committed to family support, even though the majority of children and adults with intellectual and/or developmental disabilities live at home with their families. Families were once offered few support options beyond out-of-home placement. With the advent of family support, much greater numbers of persons with intellectual and/or developmental disabilities are living with family members for longer periods, with better outcomes and at enormous cost savings when compared with out-of-home options. Still, for many families the needed supports are unavailable or insufficient.

For the first time in history, millions of people with intellectual and/or developmental disabilities are aging in the community. This success brings with it new challenges. Over 700,000 people with developmental disabilities live with one or more parent over the age of 65. This increasingly common living arrangement requires specialized family support. Families who have often functioned outside a provider system need to be identified. Families need to be helped to develop desired in-home support plans or transition plans to community living for adults with intellectual and/or developmental disabilities.

Position

The Arc of the United States and the American Association on Intel-

The Arc
1825 K Street, NW
Suite 1200
Washington, D. C. 20006
Phone: 202.534.3700
Toll free: 800.433.5255
Fax: 202.534.3731
www.thearc.org

lectual and Developmental Disabilities are committed to comprehensive, universally accessible family support that:

- Provides supports required by individual families to meet the basic needs of family members with intellectual and/or developmental disabilities;
- Allows families to make their own decisions, consistent with the right to self-determination of adult family members with intellectual and/or developmental disabilities;
- Assists families to remain intact;
- Supports adults with intellectual and/or developmental disabilities to live with their families as long as mutually desired;
- Supports opportunities for community inclusion and participation for individuals and families; and
- Recognizes, values and reinvests the substantial cost-benefits of family-based care and support.

The services and subsidies that constitute family support are wide-ranging but may include:

- Cash assistance, information, emotional support, specialized therapy and service coordination and logistical assistance (for example, exploring needs, identifying supports and support providers, completing applications, obtaining transportation); and
- Respite care, in-home personal care, home modifications and specialized equipment, recreation and leisure activities, health and dental services, and any other services or supports which increase and sustain a family's ability to remain effective as the primary care giving unit for persons with intellectual and/or developmental disabilities.

Such services and subsidies are most effective when they are:

- Provided in the natural environment of the family;
- Available from a range of sources including family members, friends, one-to-one peer support, parent groups/organizations, generic community resources, and specialized community resources;
- Based on the best available knowledge and accumulated family wisdom and professional expertise about the nature and qualities of family options that make family support most effective; and
- Provided with respect to cultural, religious, and economic standing.

When well-designed and adequately financed, family support achieves the following outcomes:

- Strengthens and sustains families' in-home care giving capacities and the individual's family, neighborhood and community networks that derive from family membership;
- Addresses the family's emotional well-being, health, material well-being, parenting skills, disability-related considerations, and family interactions;
- Enables families to make choices about the support they and their family member receive;
- Builds on the family's strengths, is responsive to its cultural values, maximizes the family member's self-determination, and is controlled by the family in partnership with those who provide support;
- Enhances families' community participation and quality of life;

- Assists the individual with intellectual and/or developmental disabilities in the process of attaining equal opportunity, full participation, independent living, and economic self-sufficiency;
- Sustains family commitment and success as the primary caregiver; and
- Encourages active, life-long engagement of family members, including siblings, in the lives of children and adults with intellectual and/or developmental disabilities.

"People with intellectual disabilities and/or developmental disabilities" refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

Adopted:
Board of Directors, The Arc of the United States
August 4, 2008

Board of Directors, AAIDD
August 18, 2008

Congress of Delegates, The Arc of the United States
November 8, 2008

Achieve with us.