

PUBLICLY FUNDED FAMILY SUPPORT SERVICES IN SELECTED STATES: A PILOT STUDY

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Support for children and adults with I/DD living in the family home, hereafter referred to as "family support," varies greatly across the nation. States have great latitude in determining what services and supports will be included in their family support program, as well as in determining whether children, adults, or both children and adults, will be eligible to receive the supports. States also vary in how they define "family" (Turnbull et al., 2007). Family members with I/DD can receive instrumental support from siblings, aunts and uncles, grandparents and others in addition to the parents. Regardless of the variation in state definitions, the goals of family support are largely agreed upon by advocates, family members, policymakers, and researchers. A principal goal is keeping the family intact and building upon the family's existing strengths and resources in order that the individual with a disability can continue to live in the family home. Another important goal is helping to assure that the child supported in the family home has the best possible transition to adulthood ("Synthesis of discussion group perspectives," 2006).

While family caregivers are the largest source of long-term care for individuals with I/DD, funding levels to support individuals with I/DD living in the family home have lagged substantially behind funding levels for out-of-home residential care (Braddock, Hemp, & Rizzolo, 2008).

Background

Services and supports that states offer to families with children or adults with I/DD vary across the nation. In 2006, the State of the States in Developmental Disabilities Project undertook a pilot study, in collaboration with the NASDDDS, to help establish more uniform categories of family support across the states. A taxonomy was developed based on 2004 data provided by 34 states. The taxonomy's 10 major services categories are presented in *Table 1*. In December 2007, the taxonomy

Table 1	
CATEGORIES OF FAMILY SUPPORT SERVICES	
I.	Respite Services
II.	Financial Support
III.	In-Home Support, Education and Training
IV.	Assistive and Medical Technology
V.	Health and Related Professional Services
VI.	Family Training/Counseling
VII.	Transportation
VIII.	Case Management/Service Coordination
IX.	Recreation/Leisure
X.	Other Family Support

was extended to 12 subcategories and 61 discrete family support services, as detailed in *Appendix I* (Braddock & Hemp, 2008)

The taxonomy was reviewed in May of 2008 by the NASDDDS Research Committee. Research Committee member states Arizona, Connecticut, Georgia, New York, South Carolina and South Dakota agreed to pilot the State of the States survey of services received by children and services received by adults. The families supported in these six pilot states constituted 20% of all families receiving support in the U.S. in 2006 (Braddock, et al., 2008).

Family Support Services Offered by the States

Appendix I compares the numbers of children and adults receiving the 61 services in 34 states in 2004 and for the six pilot states in 2006, respectively. The pilot states reported that, in 2006, they were providing a higher proportion of family support services than in 2004 in the following subcategories: *education and habilitation* (and the service *early start program*); *therapies and behavioral management, nursing and home health services, assessments/diagnostic services, family counseling, family training, parent support groups, and life planning*. More of the pilot states also reported providing services in the major categories *transportation, case management/service coordination, and recreation/leisure* compared to the data reported by 34 states in 2004.

Family Support Services for Children versus Adults

In 1998 65% of families supported nationwide were families with children (generally 17 years of age or younger; n=35) (Braddock, Hemp, Parish, & Westrich, 1998). In 2004, the 34 reporting states indicated that 59% of the families they supported were providing care for children with I/DD (Braddock, Hemp, Rizzolo, Coulter, Haffer, & Thompson, 2005; Rizzolo, Hemp, & Braddock, 2006). The six pilot states (data for 2006) reported that 55% of their supported families provided care for children and 45% of families provided care for adults. The pilot states varied in the extent to which they provided services to families with children, ranging from 25% in South Carolina and South Dakota to 67% in New York (Braddock & Hemp, 2008). In summary the proportion of families supporting children declined from 65% in 1998, to 59% in 2004, and to 55% in the seven sample states in 2006.

One of the pilot states, Arizona, was also able to provide spending levels for family support services by major and sub categories

Taxonomy Index #	Family Support Service Description	Spending
I	Respite	\$37,644,424
I	Summer Care for Children	\$211,537
II	Cash Subsidy	\$136,339
III.A	Homemaker Services	\$177,398
III.A	Personal Support/Attendant Care	\$41,008,688
III.B	Habilitation Education Services	\$472,864
III.C	In Home non-Vocational Habilitation	\$42,103,562
IV.A	Environmental Modification	\$862,835
IV.B	Adaptive Equipment	\$31,555
V.B	Infant Stimulation Development	\$5,974,521
V.B	Therapies	\$20,368,152
V.C	Home Health Services	\$11,410,025
V.C	Private Duty Nurses	\$3,232,684
V.D	Assessments/Diagnostic Services	\$648,949
VI.A	Individual Counseling	\$12,869
VII	Transportation	\$263,089
VII	Transportation to Waiver Services	\$5,809,758
VIII	Case Management	\$872,500
X	Dietary Services/Nutrition	\$7,579
X	Specialized Clothing	\$88,779
	PPL Fees	\$1,550,315
	TOTAL	\$172,888,419

(Table 2). The first column of the table cross-references the study's taxonomy in *Appendix 1* (the major service category and the subcategory, when applicable). Spending for these 21 family support services in Arizona totaled \$172.9 million. Five of the services (in home non-vocational habilitation, personal support/attendant care, respite, therapies, and home health services) made up 88% of the total. These five services were comparatively more expensive and were provided to comparatively more families than other family support services in Arizona.

2008 Revision to Family Support Taxonomy

During November and December 2008, the State of the States Project worked with the Research Committee of the NASDDDS to further develop the family support taxonomy to produce an "individual and family support taxonomy" that encompassed four service/setting categories: 1) children receiving family support services; 2) adults receiving family support services; 3) adults in the family home receiving supported living services and 4) adults living in their own home or in a shared home/apartment (see *Table 3*).

In January 2009, Principal Investigator David Braddock wrote to all states announcing the State of the States project's revenue, spending and participant update for fiscal years 2007, 2008, and 2009. In addition, the letter requested individual and family support data from selected states:

Table 3
CLASSIFICATION OF FAMILY SUPPORT AND SUPPORTED LIVING

		SETTING	
		Own or shared home/apartment*	Other Home
Children	Family Support	N/A**	Foster Home or Group Home
	Family Support or Supported Living	Supported Living	
Adults	Family Support or Supported Living	Supported Living	

*If meeting other criteria for supported living (Braddock et al, 2008)
**N/A: Not applicable

...This year we are working to expand data collection on "individual and family support" (*Worksheet # 4*) and have modified our data collection instrument. In doing so, we worked with the NASDDDS Research Committee, Nancy Thaler and Chas Moseley. Your state indicated an interest in participating in the expanded "individual and family support" data collection....

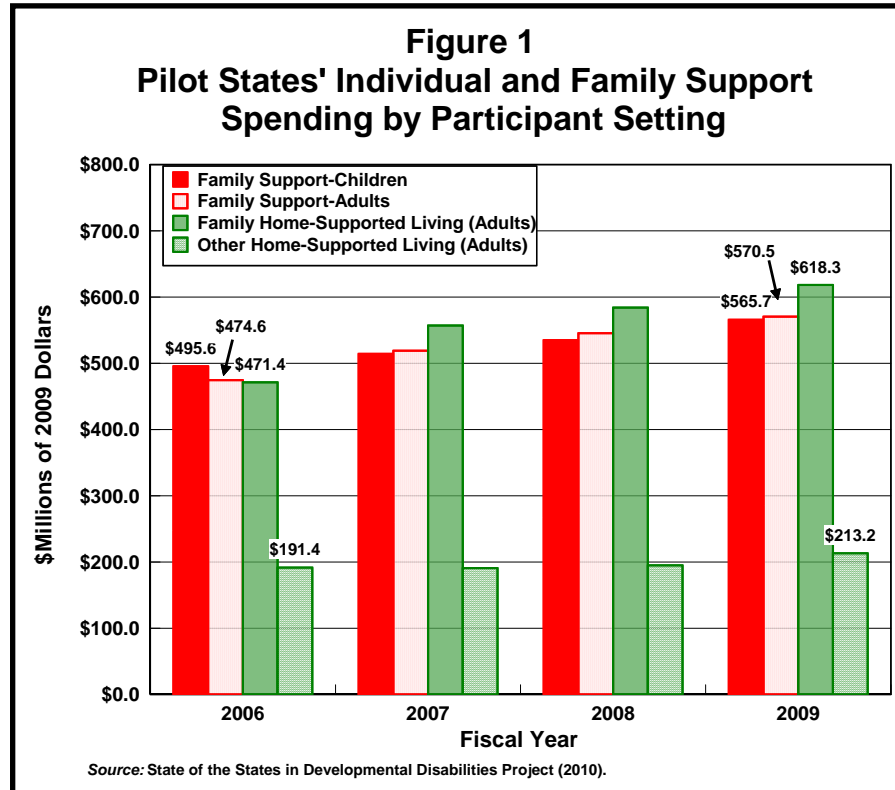
Six NASDDDS Research Committee states (Arizona, Connecticut, Georgia, New York, Pennsylvania, and South Carolina) agreed to participate in this more in-depth analysis of spending and participants. Each pilot state was to complete the worksheet, and was asked to "cross-walk" the data with the Study's ongoing family support, supported living and supported employment data. That is, the State of the States ongoing data collection of spending, revenue and participant data for individual and family support was to be presented by the pilot states in greater detail to provide a more comprehensive picture of supports.

The data collection worksheet focused on: 1) what services were offered to children and adults living in each of the four "individual and family support" settings; 2) how many individuals in each of the four service settings received each of the support services (e.g., respite,

financial support, in-home supports, transportation, etc.), and 3) how much funding was allocated to each setting and to each support within that setting.

Preliminary Findings from the Pilot States

Spending for services provided in the family home versus services provided in an adult's own or shared home. As of July 2010, complete data had been received from three of the six pilot states: Arizona, New York, and South Carolina. *Figure 1* summarizes aggregated individual and family support spending by setting for these three states. Spending in the pilot states for family support services for children totaled \$565.7 million in 2009, a 14% advance from the inflation-adjusted \$495.6 million expended in 2006. For adults, family support services advanced 20% to \$570.5 million in 2009. The largest level of spending, both absolutely and in terms of real dollar increase from 2006 to 2009, was for adults in the family home receiving supported living services (\$618.3 million in 2009 and an increase of 23% from 2006).



Data from the three pilot states indicated the comparatively small amount of spending for adults receiving supported living outside the family home. Supported living spending for adults living in their own home or a shared home was \$213.2 million in 2009, versus \$1.75 billion for the other three settings (i.e., services provided in the family home).

Individual and Family Support Spending by Age in Five Service Categories.

Figure 2 summarizes non-vocational individual and family support spending for children compared to adults in the five most heavily financed services in the three-state sample. By far, personal assistance was allocated the largest share of individual and family support resources. Personal assistance was followed by in-home supports and health services in being allocated the

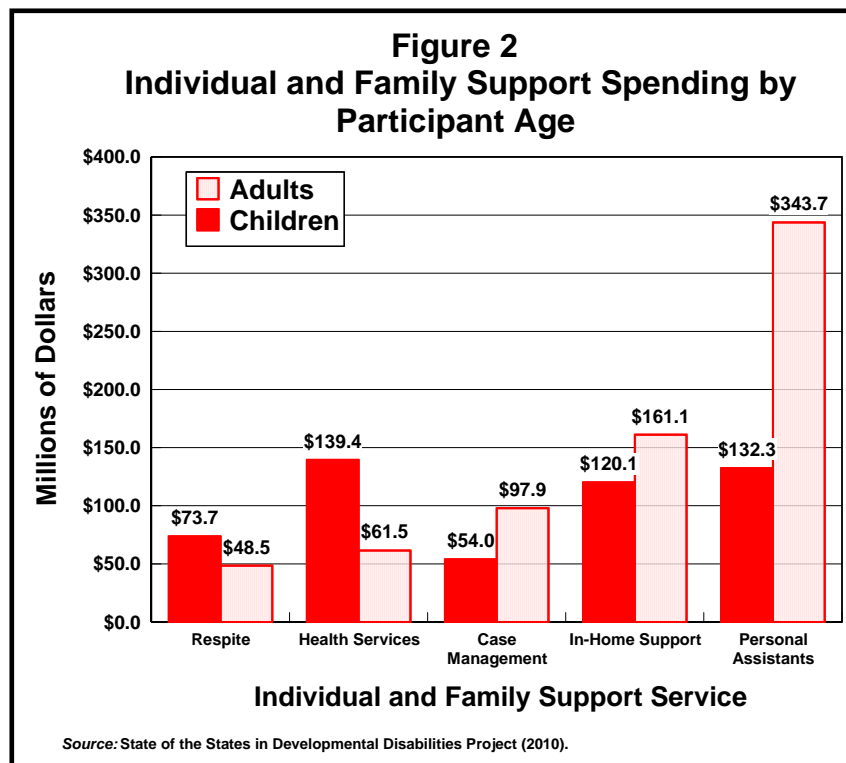
larger shares of individual and family support funding. Health services and respite care were the two services for which children received more funding than did adults.

Appendix 2 provides detail on the services funded by setting for three pilot states. The four largest categories of spending for children in family support were: 1) *health and related professional services*; 2) *personal assistance/attendants*; 3) *In-home support, education and training*; and 4) *respite services*.

For adults in the three other settings (family support in the family home, supported living services while living in the family home, supported living services in their own home or shared home), the three largest categories of spending were: 1) *day habilitation/facility*; 2) *personal assistance/attendants*; 3) *in-home support, education and training*; and 4) *case management/service coordination*.

Appendix 3 summarizes the numbers of participants by service category and by setting. This is a duplicated count; a participant may receive more than one service. Not surprisingly, the most highly funded service categories also served the most children. The highest utilized services (and the most highly funded) for children include in-home support, personal assistance, health, and respite. In addition, large numbers of children participated in case management and in *other individual/family support*. Examples of “other individual/family support” included home repair; special diets, dietary services, and nutritional evaluation; specialized clothing; out-of-home non-vocational or pre-vocational services; and family health plans. As for children, services for adults that received the most funding generally had the largest number of participants, including case management, day habilitation and personal assistance. Other highly utilized services by adults included health and other individual and family support services.

There was a large range in cost per participant for the individual and family support services in the three pilot states. For children, the highest cost services were personal assistance; self-directing families; in-home support; education and training; and assistive and medical technology (\$23,632, \$22,657, \$7,355, and \$7,017 per child, respectively). For adults, the highest costs per participant were for personal assistance; day habilitation; self-directed personal



assistance; and in-home support, education and training (\$28,623, \$23,304, \$18,966, and \$10,944 per adult, respectively).

SUMMARY AND RECOMMENDATIONS

A collaborative effort was undertaken with six pilot states to determine in greater detail the services received by children and adults in the family home and in adults' own home or shared home settings. This brief report summarizes data from three states: Arizona, New York and South Carolina.

Can any conclusions be drawn from this group of states that constituted a small but potentially important purposive sample? Important because, as Lakin, Prouty and Coucouvanis (2007) reported, 47% of Waiver participants in the U.S. lived with family members in 2006. One could conclude that states are potentially capable of providing these data that complement the services taxonomy inherent in the Home and Community Based Services Waiver (Centers for Medicare and Medicaid Services, 2008). Moreover, understanding states' individual and family support data trends is consistent with the person-centered planning priorities of the states. For example, pilot state New York was able to identify the share of individual and family support spending that supported self-directing adults with I/DD. These were supported adults who hired and fired their direct support professionals and managed their own support dollars (*Appendix 4*).

The "great recession" that began in December 2007 (National Bureau of Economic Research, 2010) clearly had an impact on pilot states' abilities to provide the requested individual and family support data. Even in the best of economic conditions, the level of detail that was obtained from three pilot states would most likely be difficult, if not impossible, for large numbers of the other states to provide. Each of the three responding states did so with considerable effort that included meetings within their agencies and across agencies and contractual data management organizations. Many of the meetings involved conference calls with State of the States Project personnel, as well as numerous e-mail and telephone communications between the Project and the data analysts in the pilot states.

Recommendation One. This preliminary report should be reviewed by a selected number of states including the six pilot states and other states identified by the Research Committee of the NASDDDS. These states' representatives should consider the value of such data, the difficulty of providing the data, and recommendations about the most important data that can be most readily obtained from all states.

Recommendation Two. Continue to collect a "minimum data set" of individual and family support data. As noted, the State of the States Project previously collected data on the numbers of children and numbers of adults receiving family support services (Braddock et al., 1998, 2005; Rizzolo et al., 2006, 2009). Furthermore, in the current study (2007-09), Project personnel requested that all states provide data on the number of supported living participants who were living in the family home. Such family support and supported living participant data would constitute a state-by-state data set on the four categories of participants in individual and family support settings: 1) children receiving family support; 2) adults receiving family support;

3) adults in the family home receiving supported living services; and 4) adults receiving supported living services in their own home or in a shared home.

In summary, a reasonable alternative to the in-depth individual and family support data collection effort just concluded with selected states might well be the ongoing collection of a valuable subset of those data across all states. Consistent, longitudinal data on the numbers of children and adult participants by setting is an important goal for ongoing data collection.

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APPENDIX I 2004 RESPONDENT STATES AND 2006 PILOT STATES: FAMILY SUPPORT SERVICES PROVIDED^{1, 2}		Reporting States 2004 for Children (n=34)	Reporting States 2004 for Adults (n=34)	Proportion of States 2004: Services to Children or Adults (n=34)	Pilot States 2006 for Children (n=6)	Pilot States 2006 for Adults (n=6)
I. RESPITE SERVICES		31	27	91%	6	6
Day Care		4	3	12%		1
Respite Care		31	28	91%	6	6
Sitter services for siblings to take person with I/DD to appointments, etc.		6	5	21%	1	
Summer care for children in special education the rest of the year		1		3%	2	
II. FINANCIAL SERVICES		15	9	38%	5	5
Cash Subsidy		14	7	38%	3	3
Travel/motel		1	1	3%		
Other disability-related living costs as needed		2	2	9%	2	3
Short-term loans					1	1
Voucher/stipend		3	3	9%	2	2
III. IN-HOME SUPPORT SERVICES		24	22	79%	6	6
A. In-Home Support		21	19	68%	5	5
Companionship services		1	1	3%	1	2
Homemaker services		11	11	35%	2	2
Personal support/care services/assistance/attendant		16	15	50%	5	5
In-home supportive services		8	6	24%	2	2
B. Education and Habilitation		7	7	29%	3	3
Early Start program					3	
Education		3	3	12%	2	2
Habilitation/education services		7	6	21%		1
C. In-Home Training and Habilitation		8	11	38%	5	5
In-home non-vocational habilitation		4	4	12%	3	3
Employment services/in-home pre-vocational training		4	6	18%		
In-home training/supports		6	6	21%	4	4
IV. ASSISTIVE AND MEDICAL TECHNOLOGY		23	20	76%	6	6
A. Assistive Technology & Environmental Modification		22	19	71%	5	5
Architectural adaptation of the home		8	6	24%	2	2
Assistive technology		14	11	41%	3	3
Environmental mod. for safety, independence, access to community-home, car		22	19	65%	5	5
B. Medical Equipment & PERS		18	16	62%	6	6
Adaptive Equipment/medical equipment/supplies/prescriptions		18	15	56%	6	6
Personal emergency response systems		6	5	18%	1	2
V. HEALTH AND RELATED PROFESSIONAL SERVICES		17	19	74%	6	6
A. Health & Professional Services		14	15	53%	4	4
Dental services		6	7	21%	2	3
Early mental health initiative/services		1	0	3%		
Enhanced medical/health plans		1	1	3%		
Mental illness/mental health treatment/psychiatric services		5	6	18%	2	2
Miscellaneous medical services		12	11	38%	1	1
Physicians		3	3	9%	1	1
Respiratory therapy		1	1	3%		
Professional services		4	5	18%	2	2
B. Therapies and Behavioral Management		14	14	47%	6	6
Behavioral management services		11	9	35%	6	6
Infant stimulation/infant development		1	1	3%	4	
Therapies (speech, PT, OT, audiology art, music)		12	12	41%	4	4
C. Nursing and Home Health Services		7	7	26%	6	5
Home health services		4	6	18%	4	3
Private duty nurses		1	1	3%	1	1
Skilled nursing care		6	5	21%	4	3
D. Assessments/Diagnostic Services		4	4	15%	3	3

APPENDIX I (Cont'd) 2004 RESPONDENT STATES AND 2006 PILOT STATES: FAMILY SUPPORT SERVICES PROVIDED		States Reporting for 2004 (n = 34)			Pilot States for 2006 (n = 6)	
		Service is for Children	Service is for Adults	Percent of States Reporting for Children or Adults	Service is for Children	Service is for Adults
VI. FAMILY TRAINING/COUNSELING		14	13	59%	6	6
A. Family Counseling		10	11	35%	5	5
Family and/or individual counseling/genetic counseling/mediation/crisis intervention		11	12	35%	4	4
Genetic counseling					1	1
Individual counseling					1	1
Mediation					1	1
B. Family Training		9	7	29%	5	5
Family leadership/empowerment/advocacy training		1	1	3%	3	3
Fees for memberships/conferences/seminars		2	2	6%	1	2
Other family training		9	7	26%	3	3
C. Parent Support Groups and Life Planning		7	5	26%	3	3
Family assistance/supports		3	1	9%	1	1
Family financial & life-planning assistance		1	1	3%	1	1
Parent support groups		6	5	18%	1	1
VII. TRANSPORTATION		11	12	47%	6	6
Transportation		13	13	47%	6	6
Transportation to waiver services		2	2	6%	4	4
VIII. CASE MANAGEMENT/SERVICE COORDINATION		13	11	38%	6	6
Case management/service coordination		10	9	29%	6	6
Information/referral/outreach		3	2	9%	4	4
Translator/interpreter		2	2	6%	3	3
IX. RECREATION/LEISURE		12	12	38%	5	5
Camp		3	3	9%	3	3
Community connection (social) services/integration		6	5	18%	2	2
Recreation/leisure activities		11	11	32%	3	3
X. OTHER FAMILY SUPPORT		15	13	50%	4	4
Home repair		2	2	6%	2	2
Special diets/dietary services/nutritional eval		11	6	32%	3	3
Specialized clothing		8	8	26%	3	3
Out-of-home non-vocational or pre-vocational services		4	4	12%		
Family health plans						

¹For the 10 major categories and their 12 subcategories, the number shown is the total of states affording one or more of the discrete family support services.

²A portion of the following services reported by South Dakota included Medicaid State Plan services: Early Start program, dental services, behavioral management services, home health services; family counseling, and transportation. Connecticut's home health services were funded by the Medicaid State Plan.

Source: Braddock & Hemp (2008).

APPENDIX 2

PILOT STATES' ALLOCATION OF FUNDING BY SERVICE AND BY SUPPORT SETTING: 2009

	Children in Family Support		Adults in Family Support		Adults Supported, Living in Family Home		Adults in Own, Other Home	
	\$s	% Total Spending	\$s	% Total Spending	\$s	% Total Spending	\$s	% Total Spending
1. Respite	\$73,657,444	13%	\$41,847,790	7%	\$4,811,766	1%	\$1,868,399	1%
2. Financial Support	\$1,265,795	0.2%	\$1,372,914	0.2%	\$3,280,095	0.5%	\$17,158,509	8.0%
3. Fiscal Intermediary	\$688,951	0.1%	\$1,016,751	0.2%	\$526,735	0.1%	\$714,280	0.3%
3a. Self-Directing Families	\$1,314,125	0.2%						
4. In-Home Support, Education & Training	\$120,075,276	21%	\$109,504,243	19%	\$26,348,212	4%	\$25,276,407	12%
5. Personal Assistance/Attendants	\$132,310,381	23%	\$103,505,301	18%	\$188,377,156	30%	\$51,790,239	24%
5a PA, Self-Directing Adults in Family Home (SC)					\$3,087,000	0.5%	\$8,140,836	3.8%
6. Assistive and Medical Technology	\$6,182,345	1%	\$1,143,204	0.2%	\$1,320,251	0%	\$480,252	0.2%
7. Health and Related Professional Services	\$139,448,866	25%	\$28,149,783	5%	\$23,978,244	4%	\$9,371,492	4%
8. Family Training/Counseling	\$6,694,073	1%	\$11,286	0%	\$381	0.0%	\$119	0.0%
9. Transportation	\$753,588	0.1%	\$7,792,272	1.4%				
10. Case Management/Service Coordination	\$53,958,759	10%	\$32,804,881	6%	\$45,421,762	7%	\$19,692,164	9%
11. Recreation/Leisure								
12. Other Individual/Family Support	\$25,255,246	4%	\$13,598,978	2%	\$44,660,951	7%	\$530,873	0%
13. Supported Employment			\$14,787,972	3%	\$73,997,856	12%	\$4,622,572	2%
14. Competitive Employment								
15. Day Habilitation - Community	\$4,125,420	1%	\$5,286,792	1%	\$1,109,942	0.2%	\$2,350,170	1%
16. Sheltered Workshop			\$5,712,595	1%				
17. Work Activity Center								
18. Day Habilitation - Facility			\$203,971,958	36%	\$201,419,875	33%	\$71,161,497	33%
TOTAL SPENDING	\$565,730,269	100%	\$570,506,721	100%	\$618,340,226	100%	\$213,157,808	100%

* Reporting States: AZ, NY, SC

APPENDIX 3

PILOT STATES' PARTICIPANTS BY SERVICE AND SUPPORT SETTING: 2009

	Children in Family Support	Adults in Family Support	Adults Supported, Living in Family Home	Adults in Own, Other Home
1. Respite	13,417	8,096	399	176
2. Financial Support	647	659	3,578	2,052
3. Fiscal Intermediary	1,003	1,273	105	108
3a. Self-Directing Families	58			
4. In-Home Support, Education & Training	15,286	10,952	2,061	1,710
5. Personal Assistance/Attendants	5,019	4,188	5,944	1,875
5a PA, Self-Directing Adults in Family Home (SC)			138	454
6. Assistive and Medical Technology	881	163	157	75
7. Health and Related Professional Services	31,223	9,261	12,251	5,079
8. Family Training/Counseling	1,938	162	4	1
9. Transportation	786	2,395		
10. Case Management/Service Coordination	18,664	10,600	14,025	6,052
11. Recreation/Leisure				
12. Other Individual/Family Support	21,690	20,181	4,699	101
13. Supported Employment		2,406	6,172	887
14. Competitive Employment				
15. Day Habilitation - Community	1,975	1,131	4,376	154
16. Sheltered Workshop		1,166		
17. Work Activity Center				
18. Day Habilitation - Facility		9,766	7,786	2,897

* Reporting States: AZ, NY, SC. NOTE: Duplicated count, participants receiving more than one service.

APPENDIX 4

NEW YORK Self-Directed Spending Share of Total Individual and Supported Living Spending (PRELIMINARY)

