

FINDS Community Report Data Tables

Contents

Background 3

Inclusion Criteria 3

Limitations..... 3

Demographic Characteristics of Caregivers and their Family Members..... 4

Caregiver characteristics 4

Family member characteristics..... 5

Caregivers’ Work Experiences 6

Caregiver works outside of home..... 6

Caregivers’ Employee Benefits 7

Caregivers’ Status 9

Self-reported health status 9

Self-reported stress level 9

Caregiver Out-of-Pocket Expenses for Care 10

Balancing Caregiving Responsibilities and Personal Care 10

Additional Caregiver Responsibilities..... 11

Home and Community Supports 11

Hours of care provided to family member with disabilities..... 11

Living arrangement of family member 11

Supports Provided by Caregivers 13

ADL supports 13

IADL supports provided by caregivers..... 13

Health supports provided by caregivers..... 14

System supports provided by caregivers..... 14

Behavior supports provided by caregivers 14

Family Member Access to Formal Supports 15

Family member supports are increasing/decreasing 15

Family member is waiting for services..... 15

Length of time family member has been on waiting list 15

Family Member Has Involvement with Criminal Justice System 16

Work and Employment Supports..... 17

Family member has paid employment 17

Employment supports received by family member 17

Family member makes minimum wage..... 17

Family member wants employment if not working..... 18

Family member’s activities if not working..... 18

Community Inclusion..... 19

School Inclusion..... 19

Reasons for post-secondary education 21

Caregiver challenges supporting social activities 22

Rights, Choice and Supports..... 22

Guardianship status 22

Caregivers explored alternate decision-making 23

Self-directed Services 23

Advocacy Services and Training..... 24

Caregivers Are Advocates 24

Person-Centered Supports..... 25

Family member has a support plan..... 25

Helped develop plan..... 25

Plan meets needs 25

Caregiver Supports Self-Advocacy..... 26

Has a plan for the future..... 26

Ideal living arrangement 27

Caregiver worries about the future 28

Difficulties finding direct support professionals..... 29

Difficulties finding respite services 30

Difficulties finding after-school care..... 30

Suggested Citation

Anderson, L*, Hewitt, A*, Pettingell, S*, Lulinski, A**, Taylor, M***, & Reagan, J*. (2018) Family and Individual Needs for Disability Supports (v.2) Community Report 2017. Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

* Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

** Coleman Institute for Cognitive Disabilities, University of Colorado

*** Consultant, LittleWing

Background

The FINDS was originally fielded by The Arc of the United States in 2010 as an on-line survey of family caregivers of adults and children with intellectual or other developmental disabilities (I/DD) and of adults with I/DD. The FINDS 2017 was created by the University of Minnesota's Research and Training Center in collaboration with The Arc. The FINDS 2017 builds on the original FINDS survey adding items adapted from the Caregiving in the US survey, The National Core Indicators family surveys, and The National Survey of Children with Special Health Care Needs.

The survey was an English on-line survey. The FINDS survey was administered beginning January 17, 2017. A paper/pencil version was also available in English and Spanish. Survey administration was through April 30, 2017. Paper copies of the survey were available in English and Spanish upon request. The Arc of the United States recruited participants through its affiliate chapters.

Inclusion Criteria

People were invited to participate in the survey if they met the following inclusion criteria. The participant was an adult family caregiver providing paid or unpaid supports to a child or adult with IDD in the previous 12 months. Individuals whose primary relationship is as a direct support professional or paid caregiver for that individual(s) were excluded from this study.

Care or support for a child is defined as more than the typical care required for his/her age including an ongoing medical condition or emotional, behavioral, or developmental concerns. Care or support also includes helping an adult relative or friend 18 years or older with intellectual or developmental disabilities to care for themselves. This care was defined as helping with personal needs or household chores. It also included managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with the participant.

Limitations

The FINDS survey was an on-line survey. The number of people responding was large and provides important information about the experiences and outcomes of family caregivers of individuals with I/DD in the United States. However, the sample isn't reflective of the racial and economic diversity of the United States. This should be taken into consideration when interpreting this data.

Demographic Characteristics of Caregivers and their Family Members

Caregiver characteristics

Table 1: Characteristics of Caregivers in the FINDS, Caregiving in the US and NCI			
	FINDS	Caregiving in the U.S.	National Core Indicators
Gender (N=3,169)			
Male	11%	40%	
Female	89%	60%	
Age (N=3,161)			
18-34	5%	24%	13%
35-54			59%
35-49	28%	23%	
50-64	50%	34%	
55-74			25%
65-74	15%	12%	
75+	2%	7%	3%
Race (N=3,125)			
White	89%	53%	39%
Black	4%	16%	11%
Latino	3%	16%	33%
Other	2%		6%
Two or more	2%		
Asian		15%	11%
Relationship to family member (n=2,905)			
Parent (adult child)	60%	5%	
Parent (child)	27%		66%
Sibling	6%	5%	2%
Child	*	49%	
Spouse	*	12%	
Other relative	3%	14%	3%
Non-relative	3%	15%	
Lives with family member (n=2,923)			
	80%	35%	100%
* less than 1%			

Family member characteristics

Table 2: Characteristics of Family Members with Disability in the FINDS, Caregiving in the US and NCI			
	FINDS	Caregiving in the U.S.	National Core Indicators
Gender (N=2,936)			
Male	63%	35%	68%
Female	37%	65%	32%
Age (N=3,398)			
0-5	4%		
6-13	17%		
14-21	23%		
18-49		14%	
22-40	44%		
41-64	11%		
50-74		39%	
65+	1%		
75+		47%	
Race (N=2,860)			
White	83%		
Black	4%		
Latino	2%		
Other	5%		
Two or more	7%		
Disability (N=2,935)			
ID	34%		
ASD	25%		
ID/ASD	24%		
Other	17%		
"Old age"		14%	
Alzheimer/Confusion		8%	
Mental Health		5%	
Physical Disability/Illness		53%	

Caregivers' Work Experiences

Caregiver works outside of home

Table 3a reports on the out-of-home work experiences for the entire FINDS sample.

Table 3a. Currently, or within the past 12 months, do/did you do any work for pay or profit outside of giving support/care to the person with IDD?		
	Total Sample	
	N	%
Yes, I am/was employed by someone else	1,629	52.5
Yes, I am/was self-employed	315	10.2
No	1,157	37.3
Total	3,101	100.0

A sub-sample was randomly drawn from the larger sample to reflect the race and ethnic make up of the United States using U.S. Census data to select the correct proportions for each group. The following table includes information on caregivers out-of-home paid work experiences using this sub-sample (Table 3b).

Table 3b: Currently, or within the past 12 months, do/did you do any work for pay or profit outside of giving support/care to the person with IDD?			
Race	Yes, works for someone else	Yes, self-employed	No
	%	%	%
White/Caucasian (N=708)	53.8	9.5	36.7
Black/African American (N=106)	59.4	6.6	34.0
Other (N=173)	48.6	6.8	44.6
Total (N=987)	53.5	8.5	38.0

Caregivers' Employee Benefits

This table represents all caregivers who reported working for pay or profit any time in the prior 12 months.

Table 4a. As a result of care giving, did you ever experience any of these work-related activities?			
		FINDS 2017 Total Sample	Caregiving in the US 2015
			(n=724)
		%	%
a. Went in late, left early, or took time off during the day to provide care (N=1,397) *Go in late, leave early, take time off	Yes	89	49
	No	11	
	Total	100	
b. Took a leave of absence (N=1,385) *Leave of absence	Yes	41	15
	No	59	
	Total	100	
c. Went from working full-time to part-time or cut back your hours (N=1,396) * Reduce work hours/take less demanding job	Yes	54	14
	No	46	
	Total	100	
d. Turned down a promotion (N=1,382)	Yes	33	5
	No	67	
	Total	100	
e. Lost any of your job benefits (N=1,380)	Yes	22	3
	No	78	
	Total	100	
g. Gave up working entirely (N=1,386)	Yes	31	6
	No	69	
	Total	100	
h. Retired early (N=1,372)	Yes	21	4
	No	79	
	Total	100	
i. Received a warning about your performance or attendance at work (N=1,371)	Yes	22	7
	No	78	
	Total	100	
* wording for Caregiving in the US survey			

A sub-sample was randomly drawn from the larger sample to reflect the race and ethnic make-up of the United States using U.S. Census data to select the correct proportions for each group. The following table includes information on the impacts on employment related to caregiving using this sub-sample (Table 4b).

Table 4b. As a result of care giving, did you ever experience any of these work-related activities?				
		White	Black	Other
		%	%	%
a. Went in late, left early, or took time off during the day to provide care	N	446	66	92
	Yes	92.8	87.9	88.0
	No	7.2	12.1	12.0
b. Took a leave of absence	N	444	66	90
	Yes	42.1	53.0	47.8
	No	57.9	47.0	52.2
c. Went from working full-time to part-time or cut back your hours	N	447	66	92
	Yes	56.4	50.0	48.9
	No	43.6	50.0	51.0
d. Turned down a promotion	N	443	66	91
	Yes	34.3	34.8	27.4
	No	65.7	65.2	72.5
e. Lost any of your job benefits	N	442	64	91
	Yes	21.9	32.8	23.1
	No	78.1	62.7	76.9
g. Gave up working entirely	N	446	65	92
	Yes	33.2	66.8	25.0
	No	40.0	60.0	75.0
h. Retired early	N	442	65	90
	Yes	16.5	21.5	15.6
	No	83.5	78.5	84.4
i. Received a warning about your performance or attendance at work	N	442	64	91
	Yes	19.9	45.3	24.2
	No	80.1	54.7	75.8

Caregivers' Status

The items reported under caregivers' status include all of the participants that responded to this item from the total sample.

Self-reported health status

Table 5: Caregivers' Self-reported Health Status		
	N	%
Excellent	188	0.0763
Very good	642	0.2606
Good	941	0.3819
Fair	562	0.2281
Poor	131	0.0532
Total	2,464	1.0000

Self-reported stress level

Table 6: Caregivers' Self-reported Stress Levels		
	N	%
Not stressed	135	6%
Somewhat stressed	1,163	47%
Very stressed	759	31%
Extremely Stressed	411	17%
Total	2,468	100%

Caregiver Out-of-Pocket Expenses for Care

This includes all respondents whether or not their family member is a recipient of formal supports and services. This should be considered when interpreting this data, as having formal supports may impact out-of-pocket expenses.

	N	%
None	180	8%
\$1 - \$100	111	5%
\$101 - \$1,000	472	21%
\$1,001 - \$5,000	681	30%
\$5,001 - \$10,000	454	20%
More than \$10,000	383	17%
Total	2,281	100%

Balancing Caregiving Responsibilities and Personal Care

	No problem		Somewhat of a problem		A major problem		Total
	N	%	N	%	N	%	N
Addressing my own health issues	859	35.2	1063	43.5	521	21.3	2,443
Balancing other family responsibilities	353	14.7	1084	45.0	970	40.3	2,407
Meeting my personal needs	346	14.1	912	37.2	1191	48.6	2,449

Additional Caregiver Responsibilities

Table 9: Additional Caregiver Responsibilities Specific to Family Member with Disabilities							
	No problem		Somewhat of a problem		A major problem		Total
	N	%	N	%	N	%	N
Dealing with difficult behaviors	816	36.6	928	41.7	483	21.7	2,227
Helping my family member find friendships	397	16.8	952	40.3	1,016	43.0	2,365

Home and Community Supports

Hours of care provided to family member with disabilities

Caregivers reporting hours of care/support provided include both those living with their family member with disabilities and those who do not.

Table 10: Hours of Care Provided to Family Member with Disabilities				
	Children		Adults	
	N	%	N	%
9 or fewer hrs per week	112	8.2	418	17.7
10 to 20 hrs per week	103	7.5	357	15.1
21 to 30 hrs per week	50	3.7	203	8.6
31 to 40 hrs per week	96	7.0	167	7.1
41 to 80 hrs per week	238	17.4	321	13.6
More than 80 hrs per week	767	56.1	896	37.9
Total	1,366	100.0	2,362	100.0

Living arrangement of family member

Living arrangement only includes those who do not reside with the FINDS survey respondent.

Table 11: Living Arrangement of Individuals with IDD not Living with Respondent		
	N	%
The home of a family member or friend	99	16.7
Own Home	220	37.1
Individual setting with 3 or fewer people	75	12.6
Congregate setting with 4 or more people	178	30.0
An intentional or planned community	13	2.2
A school dormitory (post-high school such as a college/trade school)	7	1.2
Total	592	100.0

Family member's use of technology

Table 12: Technology Use by Family Member with Disabilities			
		N	%
Smartphone (such as an iPhone or similar device)	Yes	1,026	38.6
	No	1,633	61.4
	Total	2,659	100
Laptop/desktop computer	Yes	1,231	46.3
	No	1,427	53.7
	Total	2,658	100
Tablet (such as an iPad or Surface)	Yes	1,855	67.7
	No	885	32.3
	Total	2,740	100
Smart home technology (such as sensors, voice activated switches, or smartphone enabled controls)	Yes	166	6.6
	No	2,350	93.4
	Total	2,516	100
Picture communication software (enables use of pictures and symbols to communicate)	Yes	527	20.5
	No	2,042	79.5
	Total	2,569	100
Wearable technology	Yes	204	8.1
	No	2,314	91.9
	Total	2,518	100
Console video games system (such as Xbox, PlayStation or Wii)	Yes	1,172	44.7
	No	1,452	55.3
	Total	2,624	100
Has Broad Band	Yes	2,523	88.6
	No	276	9.7
	Do Not Know	48	1.7
	Total	2,847	100.0

Supports Provided by Caregivers

ADL supports

Table 13: Numbers of Activities of Daily Living Supports Provided by Caregivers		
	N	%
0	687	24.2
1	388	13.7
2	346	12.2
3	313	11
4	290	10.2
5	249	8.8
6	221	7.8
7	343	12.1
Total	2,837	100

IADL supports provided by caregivers

Table 14: Numbers of Activities of Daily Living Supports Provided by Caregivers		
	N	%
0	13	0.5
1	19	0.7
2	47	1.7
3	76	2.7
4	87	3.1
5	117	4.2
6	127	4.5
7	223	7.9
8	334	11.9
9	600	21.3
10	1,173	41.7
Total	2,816	100.0

Health supports provided by caregivers

Table 15: Numbers of Health Supports Provided by Caregivers		
	N	%
0	96	3.4
1	235	8.4
2	1,295	46
3	976	34.7
4	212	7.5
Total	2,814	100

System supports provided by caregivers

Table 16: Numbers of Service and System Supports Provided by Caregivers		
	N	%
0	17	0.6
1	41	1.5
2	63	2.3
3	104	3.8
4	126	4.6
5	205	7.4
6	300	10.9
7	383	13.9
8	477	17.3
9	536	19.4
10	424	15.4
11	84	3.0
Total	2,760	100.0

Behavior supports provided by caregivers

Table 17: Behavior Supports Provided by Caregiver		
	N	%
Yes	1,897	71.6
No	753	28.4
Total	2,650	100

Family Member Access to Formal Supports

Family member supports are increasing/decreasing

Table 18: Are you noticing that support services in your community are:		
	N	%
Increasing	180	7
Staying about the same	1,035	40.2
Decreasing	952	36.9
Do not know	410	15.9
Total	2,577	100.0

Family member is waiting for services

Table 19: Family member is on a waiting list for government-funded services/supports		
	N	%
Yes	654	25.8
No	1,718	68.0
Do Not Know	156	6.2
Total	2,528	100.0

Length of time family member has been on waiting list

Table 20: Length of Time Family Member Has Been on Waiting List		
	N	%
Less than a year	102	15.6
1 year	65	10.0
2 years	71	10.9
3-5 years	144	22.1
6-10 years	137	21.0
More than 10 years	133	20.4
Total	652	100

Family Member Has Involvement with Criminal Justice System

Table 21: Family Member Has Involvement with Criminal Justice System			
		N	%
Victim of a crime	Yes	262	11.1
	No	2,103	88.9
	Total	2,365	100.0
Witness to a crime	Yes	62	2.7
	No	2,271	97.3
	Total	2,333	100.0
Suspect in a crime	Yes	70	3.0
	No	2,268	97.0
	Total	2,338	100.0
Defendant in a criminal charge	Yes	71	3.0
	No	2,274	97.0
	Total	2,345	100.0
Convicted of a crime	Yes	46	2.0
	No	2,297	98.0
	Total	2,343	100.0
Incarcerated upon conviction of a crime	Yes	25	1.1
	No	2,316	98.9
	Total	2,341	100.0
None	Yes	1,250	54.5
	No	1,043	45.5
	Total	2,293	100.0

Work and Employment Supports

Family member has paid employment for individuals 22 and older

Table 22: Family Member Has Paid Employment		
	N	%
Yes	575	35.6
No	1042	64.4
Total	1617	100

Employment supports received by family member

Employment supports were calculated differently in the 2010 report. The percentages of each category were calculated from the total sample.

Table 23: Type of Employment of Family Member if Working				
	2010		2017	
	N	%	N	%
Integrated employment	177	7	329	58.1
Paid facility-based employment (such as a sheltered workshop)	152	6	138	24.4
Community-based group employment (enclave)	76	3	68	12.0
Self-employment	25	1	31	5.5
Not in paid employment	2,099	85		
Total	2,529	100	566	100

Family member makes minimum wage

Table 24: Family Member Receives at Least Minimum Wage (\$7.25 per hour)		
	N	%
Yes	490	76.0
No	155	24.0
Total	645	100.0

Family member wants employment if not working

Table 25: Family Member Wants a Paid Job if not Working		
	N	%
Yes	1,059	48.4
No	1,129	51.6
Total	2,188	100

Family member's activities if not working

Table 26: Family Member's Activities if Not Employed		
	N	%
Stays home	349	31.4
Unpaid facility-based activities	259	23.3
Unpaid community activities	505	45.4
Total	1,113	100.0

Community Inclusion

School Inclusion

If an individual has ID and another disability, such as ASD or CP, they are included in the ID group for the 2010 FINDS survey. In 2017, individuals who had ID and ASD are in separate groups, although individuals with ID and other developmental disabilities such as CP are in the ID group.

Table 27: School Inclusion for Family Members with Disabilities									
	2010				2017				
	ID	ASD	Other	Total	ID	ASD	ID/ASD	Other	Total
Levels of School									
Pre-K	1,975	828	374	3,177	782	613	594	373	2,362
Fully included	33.8	35.7	39.8	35.0	32.2	36.7	22.1	41.0	32.2
Partially included	19.3	22.3	16.6	19.8	24.7	26.9	31.0	24.7	26.8
Regular school, not included	15.6	14.6	12.3	15.0	19.7	18.6	27.6	20.6	21.5
School only for students with disabilities	31.2	27.3	31.3	30.2	23.4	17.8	19.4	13.7	19.4
Kindergarten	2,056	828	382	3,266	857	616	617	375	2,465
Fully included	35.1	42.8	49.7	38.7	32.2	41.6	21.4	47.7	34.2
Partially included	28.5	28.3	19.9	27.4	34.0	31.7	39.5	27.2	33.8
Regular school, not included	13.6	10.1	11.8	12.5	15.5	15.7	23.8	15.5	17.6
School only for students with disabilities	22.9	18.8	18.6	21.3	18.3	11.0	15.2	9.6	14.4
Primary School	2,179	871	414	3,464	893	610	638	391	2,532
Fully included	24.4	36.1	39.9	29.2	21.2	36.6	11.8	37.1	25.0
Partially included	40.2	38.3	32.4	38.8	45.1	37.9	48.0	39.9	43.3
Regular school, not included	11.7	7.6	8.9	10.4	15.8	11.6	23.2	13.8	16.4
School only for students with disabilities	23.7	18.0	18.8	21.7	17.9	13.9	17.1	9.2	15.4
Middle School	2,022	718	393	3,133	818	485	580	346	2,229
Fully included	22.5	41.4	38.9	28.9	15.3	28.5	7.4	29.5	18.3
Partially included	40.0	32.8	32.3	37.1	44.4	39.6	43.8	39.9	42.5

FINDS Community Report Data Tables 20

Regular school, not included	12.7	7.0	7.9	10.8	19.2	11.8	24.3	17.3	18.6
School only for students with disabilities	24.8	20.3	20.9	23.3	21.1	20.2	24.5	13.3	20.6
High School	2,102	691	412	3,205	795	445	562	338	2,140
Fully included	25.1	47.5	40.0	31.9	12.1	27.6	6.8	28.4	16.5
Partially included	38.3	24.7	32.8	34.7	47.4	33.5	40.7	42.9	42.1
Regular school, not included	11.8	6.2	7.3	10.0	18.6	13.7	24	16.5	18.7
School only for students with disabilities	24.7	21.6	19.9	23.4	21.9	25.2	28.5	12.1	22.8

Reasons for post-secondary education

Table 28: Reasons Caregivers Give for Family Member to Take Post-Secondary Classes					
		2,010		2017	
		N	%	N	%
To learn about things they are interested in	Yes	2,694	73	2,190	84
	No	996	27	426	16
	Total	3,690	100	2,616	100
To obtain a non-credit skill, certificate/certificate of completion	Yes	627	17	1,450	61
	No	3,063	83	945	40
	Total	3,690	100	2,395	100
To learn how to use transportation options	Yes	590	16	1,515	63
	No	3,100	84	896	37
	Total	3,690	100	2,411	100
To gain experiences that will help them get a job	Yes	2,435	66	1,932	77
	No	1,255	34	579	23
	Total	3,690	100	2,511	100
To obtain a credit-based degree or certification	Yes	996	27	1,060	46
	No	2,694	73	1,250	54
	Total	3,690	100	2,310	100
To fulfill IEP plans	Yes	812	22	1,062	47
	No	2,878	78	1,212	53
	Total	3,690	100	2,274	100
To have college experience like non-disabled peers	Yes	1,218	33	1,358	57
	No	2,472	67	1,033	43
	Total	3,690	100	2,391	100
To learn job-related skill	Yes	2,694	73	2,040	81
	No	996	27	484	19
	Total	3,690	100	2,524	100
To earn a GED/high school diploma	Yes	517	14	743	34
	No	3,173	86	1,436	66
	Total	3,690	100	2,179	100

Social Activities

Caregiver challenges supporting social activities

Table 29a: Caregiver Supports Social Activities										
	ID Only		ASD Only		ID/ASD		Other		Total Sample	
	N	%	N	%	N	%	N	%	N	%
Yes	840	91.6	893	90.0	617	93.8	383	87.0	2,433	91.0
No	77	8.4	66	10.0	41	24.5	57	13.0	241	9.0
Total	917	100.0	659	100.0	658	100.0	440	100.0	2,674	100.0

Table 29b: Caregivers' Difficulties Supporting Social Activities										
Not at all difficult	173	20.6	82	13.8	72	11.7	101	26.4	428	17.6
A little difficult	228	27.2	147	24.8	141	22.9	98	25.7	614	25.3
Somewhat difficult	211	25.1	142	23.9	165	26.7	96	25.1	614	25.3
Difficult	145	17.3	117	19.7	139	22.5	52	13.6	453	18.6
Very difficult	82	9.8	105	17.7	100	16.2	35	9.2	322	13.2
Total	839	100.0	593	100.0	617	100.0	382	100.0	2,431	100.0

Rights, Choice and Supports

Guardianship status

Table 30: Family Member Has a Legal Guardian		
	N	%
Yes	1,343	42.2
No	1,841	57.8
Total	3,184	100

Caregivers explored alternate decision-making

Table 31: Prior to obtaining legal guardianship, guardians explore the following:			
		N	%
Representative Payee	Yes	745	65
	No	401	35
	Total	1,146	100
Supported Decision Making	Yes	392	37.4
	No	656	62.6
	Total	1,048	100
Power of Attorney	Yes	421	40.4
	No	621	59.6
	Total	1,042	100
Informal Advice or Guidance	Yes	588	54.3
	No	495	45.7
	Total	1,083	100

Self-directed Services

Table 32: Caregiver Supports family Member Self-directed Services		
	N	%
Yes	855	32.7
No	1,762	67.3
Total	2,617	100
Table 31b: Level of Caregiver Difficulty with Self-directed Services		
	N	%
Not at all difficult	142	16.6
A little difficult	230	26.9
Somewhat difficult	232	27.1
Difficult	152	17.8
Very difficult	99	11.6
Total	855	100

Advocacy Services and Training

Table 33: Family Member Receives Advocacy Services and Training		
	N	%
Yes, he/she receives an adequate amount	341	13
Yes, but more is needed	499	19
No, but it is needed	1,039	39.6
No, but it is not needed	746	28.4
Total	2,625	100

Caregivers Are Advocates

Table 34: Caregivers Participation in Advocacy Activities			
		N	%
I vote	Strongly disagree	66	2.7
	Somewhat disagree	58	2.4
	Somewhat agree	409	16.8
	Strongly agree	1,905	78.1
	Total	2,438	100
I call my legislative representatives	Strongly disagree	242	9.9
	Somewhat disagree	407	16.7
	Somewhat agree	721	29.6
	Strongly agree	1,065	43.7
	Total	2,435	100
I am more involved in advocacy efforts and non-profit activities	Strongly disagree	126	5.2
	Somewhat disagree	321	13.2
	Somewhat agree	855	35.1
	Strongly agree	1,133	46.5
	Total	2,435	100
More aware of policy issues	Strongly disagree	81	3.3
	Somewhat disagree	202	8.3
	Somewhat agree	1,068	43.7
	Strongly agree	1,093	44.7
	Total	2,444	100

Person-Centered Supports

Family member has a support plan

Table 35: Family Member Has a Support Plan		
	N	%
Yes	1,754	69
No	583	22.8
Do Not Know	222	9
Total	2,559	100

Helped develop plan

Table 36: Caregiver and Family Member Helped Develop the Plan		
	N	%
Yes	1,448	82.6
No	304	17.4
Total	1,752	100.0.

Plan meets needs

Table 37: Support Plan Addresses all the Supports family Member needs or is Getting		
	N	%
Yes	979	58.8
No	686	41.2
Total	1,665	100

Caregiver Supports Self-Advocacy

Table 38a: Caregiver Supports Family Member with Self-Advocacy		
	N	%
Yes	2,516	93
No	189	7
Total	2,705	100

Table 38b: Level of Difficulty Caregiver Reports Supporting Self-Advocacy		
	N	%
Not at all difficult	415	16.5
A little difficult	555	22.1
Somewhat difficult	664	26.5
Difficult	493	19.6
Very difficult	382	15.2
Total	2,509	100

Future Planning

Has a plan for the future

Table 39: Caregiver Has a Plan for the Future When no Longer Able to Provide Support		
	N	%
Yes	1,127	45.9
No	1,331	54.1
Total	2,458	100

Ideal living arrangement

This includes parents’ of children when thinking about their child’s future, as well as caregivers of adults with IDD.

Table 40: Caregivers' Ideal Living Arrangement for Family Member		
	N	%
Where s/he lives right now	1,388	47.7
In someone else's home, like a family member	67	2.3
In an apartment or house that s/he OWNS	300	10.3
In an apartment or house that s/he RENTS	129	4.4
In military house	1	0
In a boarding home	0	0
In a group home with 3 or fewer people with disabilities that s/he is not related to	276	9.5
In a group home with 4 to 6 people with disabilities that s/he is not related to	121	4.2
In a residence that has 7 to 15 people with disabilities that s/he is not related to	13	0.4
In a residence that has more than 15 other people with disabilities that s/he is not related to	4	0.1
In an apartment building or intentional community living situation that includes both people with disabilities and those without	450	15.5
In an apartment building or community living situation that includes only people with disabilities	61	2.1
In a nursing home	2	0.1
In an institution/developmental center	17	0.6
Other	81	2.8
Total	2,910	100

Caregiver worries about the future

Table 41: Caregivers' Worries for Future When They Can't Provide Care			
		N	%
There is no one else to provide the support I am giving	Yes, a concern	1,954	80.3
	No, not a concern	480	19.7
	Total	2,434	100
The quality of support will go down if I am not there to advocate	Yes, a concern	2,255	90.9
	No, not a concern	226	9.1
	Total	2,481	100
The person with IDD will be financially exploited if I cannot oversee finances	Yes, a concern	1,553	68
	No, not a concern	730	32
	Total	2,283	100
Some form of abuse or neglect might occur	Yes, a concern	1,854	77.4
	No, not a concern	541	22.6
	Total	2,395	100
Her/his health will deteriorate	Yes, a concern	1,865	78.3
	No, not a concern	518	21.7
	Total	2,383	100
She/he will not have enough friends and social activities	Yes, a concern	1,974	81.6
	No, not a concern	444	18.4
	Total	2,418	100
I don't know where she/he will live if not with me	Yes, a concern	1,610	70.5
	No, not a concern	674	29.5
	Total	2,284	100
She/he will be moved to a congregate facility such as an institution, ICF/ID, or nursing home	Yes, a concern	1,344	62.8
	No, not a concern	796	37.2
	Total	2,140	100
She/he will have to live somewhere she/he does not want to live	Yes, a concern	1,904	81.1
	No, not a concern	445	18.9

	Total	2,349	100
She/he will have difficulty advocating for what she/he needs	Yes, a concern	2,261	91.4
	No, not a concern	214	8.6
	Total	2,475	100
She/he will not be able to contribute to major life decisions or receive support for self-determination	Yes, a concern	2,025	85.3
	No, not a concern	349	14.7
	Total	2,374	100

Direct Support Workforce

Difficulties finding direct support professionals

Table 42a: Caregiver supports with Finding Direct Support Professionals		
	N	%
Yes	1,854	68
No	873	32
Total	2,727	100
Table 42b: Caregiver Reported Difficulty Finding Direct Support Professionals		
	N	%
Not at all difficult	149	8.1
A little difficult	287	15.5
Somewhat difficult	415	22.4
Difficult	390	21.1
Very difficult	608	32.9
Total	1,849	100

Difficulties finding respite services

Table 43a: Caregiver supports Finding Respite Services		
	N	%
Yes	1,647	60.7
No	1,065	39.3
Total	2,712	100
Table 43b: Caregiver Reported Difficulty Finding Respite Services		
	N	%
Not at all difficult	136	8.3
A little difficult	240	14.6
Somewhat difficult	289	17.6
Difficult	344	20.9
Very difficult	635	38.6
Total	1,644	100

Difficulties finding after-school care

Table 44a: Caregiver supports Finding After-school Care		
	N	%
Yes	687	40.4
No	1,015	59.6
Total	1,702	100
Table 44b: Caregiver Reported Difficulty Finding After-school Care		
	N	%
Not at all difficult	120	17.5
A little difficult	143	20.8
Somewhat difficult	188	27.4
Difficult	119	17.3
Very difficult	116	16.9
Total	686	100