Summary Report: DDS Family Supports Survey

The Massachusetts Department of Developmental Services (DDS) is planning for the future of family support services. As families are the principal care providers for individuals with an intellectual or developmental disability (ID/DD), the primary goal of family support services is to maintain the family unit, keeping the family member with ID/DD in the home. Types of support services vary and can include respite care, personal care assistance, medical equipment, therapies, training, support groups, recreational and social activities as well as flexible funding to pay for extraordinary expenses. DDS and the Center for Developmental Disabilities Evaluation and Research (CDDER) developed the Family Supports Survey to hear directly from families/caregivers about what they need to support their family member with ID/DD at home and in their respective community.

The survey was designed to get input from those who are the primary caregivers of a child or adult with ID/DD who lives at home, and for whom they have day-to-day responsibility for providing care. Delivered via web link, the survey was available through a number of avenues, distributed to various community, advocacy and provider organizations as well as at the DDS Caregiver Forums. The survey was open from November 17, 2011 until December 8, 2011. (Additional surveys were manually entered after this date.) Appendix A: Survey Instrument

Survey Response:

A total of 747 caregivers responded to the survey (26 responses were manually entered at CDDER). The respondent families averaged 2.45 adults and 1.85 children per household. 95.5% of the respondents are the primary caregiver/parent of a family member with ID/DD and 93.7% of the time the family member lived full time with the caregiver. Respondents resided across the Commonwealth. Appendix B: Map of Zip Code Distribution

Demographics of Caregiver:

57.8% of the respondents indicated that primary care giving responsibility fell to the Mother alone, followed by 38.5% of the respondents indicating that the Mother and Father shared responsibility. It is important to note that 24.2% of the respondents reported to be single parents. When broken down by age, of the primary caregivers for individuals under age 18 only 1.4% are age 60 and older. For those caregivers of individuals over age 18, 32.7% are age 60 and older. (Table 1) Caregivers for individuals under age 18 are more likely to have another person in the home with a developmental disability than caregivers of individuals age 18 and older (12.8% versus 8.4%). The younger caregivers are also more likely to have primary day-to-day responsibilities of other members of the family, either in or out of the home, be that another child(ren) or elderly parents (74.9% versus 43.9%).

Table 1: Caregiver Age		
Caregiver Age	% Who Care for Individual Under Age 18	% Who Care for Individual Over Age 18
18-39	***22.4%***	1.7%
40-59	***77.6%***	***68.6%***
60-64	1.1%	***17.8%***
65-74	0.3%	***13.2%***
75+	N/A	1.7%

Demographics of family member with ID/DD:

Overall, respondents indicated that the person they care for is most likely to be male (69.3%), with 51.9% between the ages of 6-17 and an additional 39.2% between the ages of 18-39. The majority of the people cared for were white (86.5%) and 94.5% report English as their primary language. Additionally 69.4% reported being eligible for services from DDS and 61% had a diagnosis of Autism or ASD.

Those with a reported Autism diagnosis are more likely to be male and under age 18. (Table 2) The group is also less likely to be eligible for DDS services. 63.7% of caregivers of an individual with an Autism diagnosis report that a family member is eligible for DDS versus 76.7% of those with no Autism diagnosis.

Table 2: Age, Gender and Autism Diagnosis				
Age of Individual with ID/DD	Autism Diagnosis		No Autism Diagnosis	
	M	F	M	**F**
Under Age 18	***82.8%***	18.5%	56.8%	43.2%
Over Age 18	71.0%	31.5%	52.6%	48.0%

Demographics of additional family members with ID/DD:

Second person: Eighty-one respondents (10.8% of total respondents) indicated there was a second person in the home with ID/DD. 58% are between the ages 6-17 and an additional 18.5% are between 18-22 years old. Again, the majority are male at 66.9%, 58% with an Autism or ASD diagnosis and 38.3% eligible for DDS. The majority are white and English is the primary language spoken in the home. Most attend school (67.1%) and 29.1% receive medical care more than once per week. Most require either moderate or complete help for activities someone their age would usually do on their own and for participation in community or social activities, 56.3% need either some or a lot of support for managing self-injurious or destructive behavior, but 89.5% walk independently.

Third person: Eleven (1.5% of total respondents) responded that, yes, there was a third person in the home with ID/DD, 27.3% between ages 6-17, and 27.3% between the ages of 23-39. Again the majority are male at 81.8%, and 63.6% have a diagnosis of Autism or ASD and 63.6% are eligible for DDS services. As with the other family members, the majority are white and English is the primary language. Only 45.5% attend school and 36.4% receive medical care a few times a year. Most require complete help in all aspects of daily living and social activities, 54.6% require some or a lot of support for managing self-injurious or destructive behavior, however 72.7% walk independently.

Quality of Life:

When asked to rate the quality of life of the family member and themselves, the respondents were more likely to respond “good” for both the family member and themselves, however, the caregiver was also more likely to rate the family member’s quality of life excellent but their own quality of life as only fair. (Table 3)

Table 3: Quality of Life

	Family Member	Caregiver
Excellent	***22.1%***	12.5%
Good	***54.6%***	***44.4%***
Fair	21.1%	***36.8%***
Poor	2.6%	6.3%

Level of Support:

When asked what the person does during most weekdays, for those under age 18 the majority (87%) of the caregivers responded that the person they care for attended school. For those over 18, 42% reported attending a day or employment program and 33.2% attending school. Forty-three respondents indicated “other” in their response, which included such comments as home-schooled, awaiting placement, or some combination of work/volunteer or day program.

When asked how the person gets around most the the time, 88.8% of the respondents indicated that the person they care for is able to walk independently. (For those over age 18 that drops to 83.8%). However, when describing support needs, *more than half* of all respondents indicated that the person they care for needs complete help in daily activities such as doing things others their own age would do, (meal preparation and playing games); and participating in community or social activities. Additionally, 30.6% indicate that the person they care for needs a medium amount of help in daily activities like bathing and dressing. (Table 4).

Table 4: Support Needs				
	No extra help needed	A little help	A medium amount of help	Complete help needed
Taking care of themselves in daily activities like bathing dressing and eating.	17.0% (118)	26.7% (185)	***30.6%*** ***(212)***	25.7% (178)
Doing things that somebody their age would usually do. (for example, meal preparation, taking the bus, playing games)	4.0% (28)	15.9% (110)	29.5% (204)	***50.6%*** ***(350)***
Participating in community and social activities (for example, going to the movies or a restaurant, school clubs, swim classes...)	3.6% (25)	13.6% (94)	29.4% (203)	***53.4%*** ***(369)***

Further, When looking at all respondents, 41.8% indicated that they person they care for needed some support and 21.8% needed a lot of support to manage self injurious, disruptive or destructive behavior. However, when breaking out by age and Autism diagnosis it is clear that age and diagnosis can affect the level of support needed. (Table 5)

Table 5: Support Needs for Behavior					
	All Respondents	Under Age 18		Over Age 18	
		Autism Diagnosis		Autism Diagnosis	
		Yes	No	Yes	No
No Support Needed	36.4%	23.6%	42.0%	26.6%	63.4%
Some Support Needed	41.8%	48.9%	38.6%	46.8%	27.3%
A lot of Support Needed	21.8%	27.5%	19.3%	36.6%	9.3%

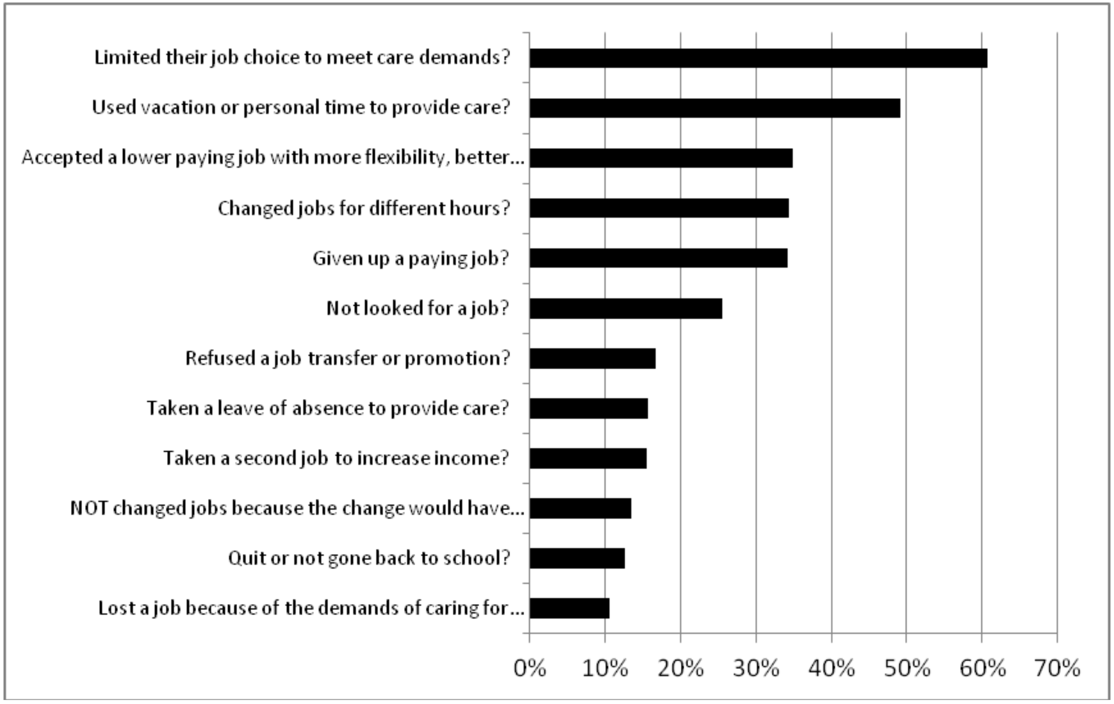
Overall, respondents indicated that 35.2% of the family members they care for were in need of medical care only a few times a year. However, when breaking out by age, 37.9% of respondents who care for a family member under age 18 report that they required a medical care or therapy appointment more than once per week. (Table 6)

Table 6: Age and Medical/Therapy Visits			
	All Ages	Under Age 18	Over Age 18
More than once a week	26.9%	***37.9%***	12.0%
2-4 times per month	23.1%	24.9%	21.4%
Once a month	14.8%	13.6%	17.1%
A few times per year	***35.2%***	23.6%	***49.5%***

Financial Impact:

Caring for a family member with ID/DD in the home can have an financial impact on the family, not only in the amount of dollars spent on services but also the more difficult to measure "loss of income." Asked if the caregiver had done any of the following to meet the needs of the family member with ID/DD at home, 60.7% of the respondents indicated that they had limited their job choice to care for the family member. Additionally, 49.1% used vacation or personal time to care for the family member. Respondents could check more than one response and many caregivers did so. Caregivers also included additional comments indicating that families are using a variety of mechanisms to care for the person at home (not only those listed) including: retiring early, working 3rd shift, choosing to remain at home rather than return to the workforce, and selling a business. (Figure 1)

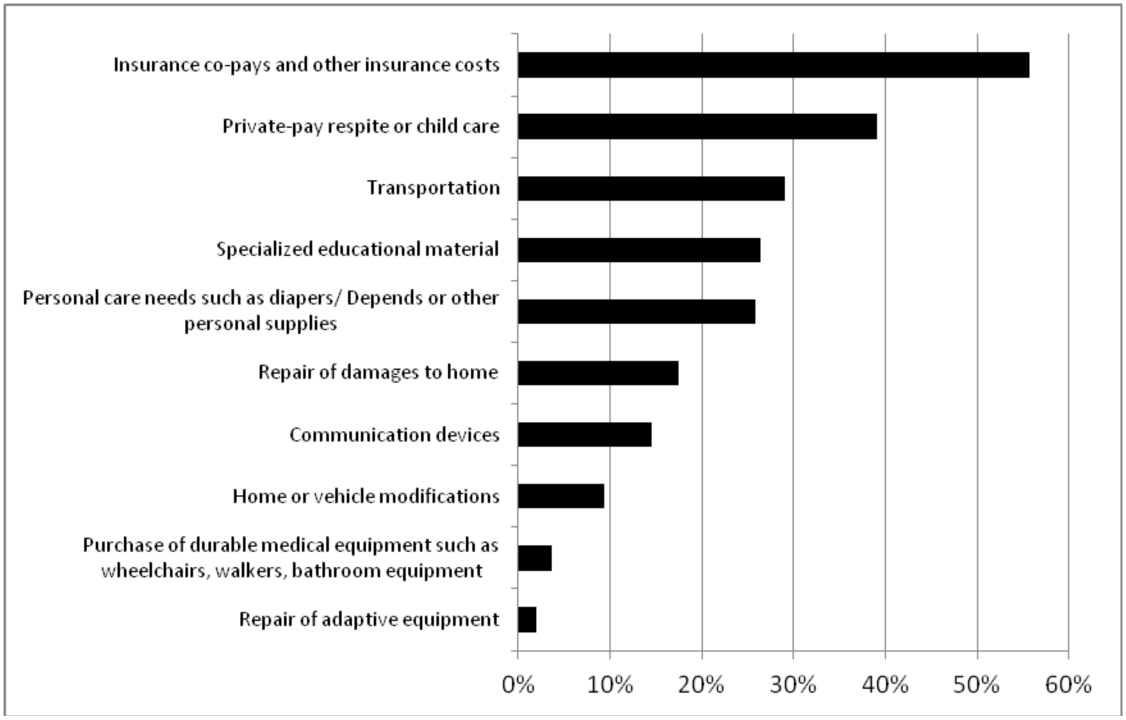
Figure 1: Career/Job Impact
(could check all that applied)



Nearly 70% of respondents pay between $500-$10,000 in out of pocket costs. (Table 7) By far the largest reported costs were associated with insurance co-pays and other insurance costs at 55.6%. The next highest at 39.0% was respite care. In addition 134 respondents identified "other" items including: social and recreational activities, medical items and therapies not covered by insurance, nutritional items, and legal and advocacy fees. (Figure 2)

Table 7: Approximate Out-of-Pocket Expenses on Medical services equipment, therapies and other supports	
	%
Under $500	*24.8*
$501-$2000	***41.4***
$2001-$10,000	***28.2***
More than $10, 000	5.9

Figure 2: Type of Out-of-Pocket Expenses in Last Year
(could choose up to 3)

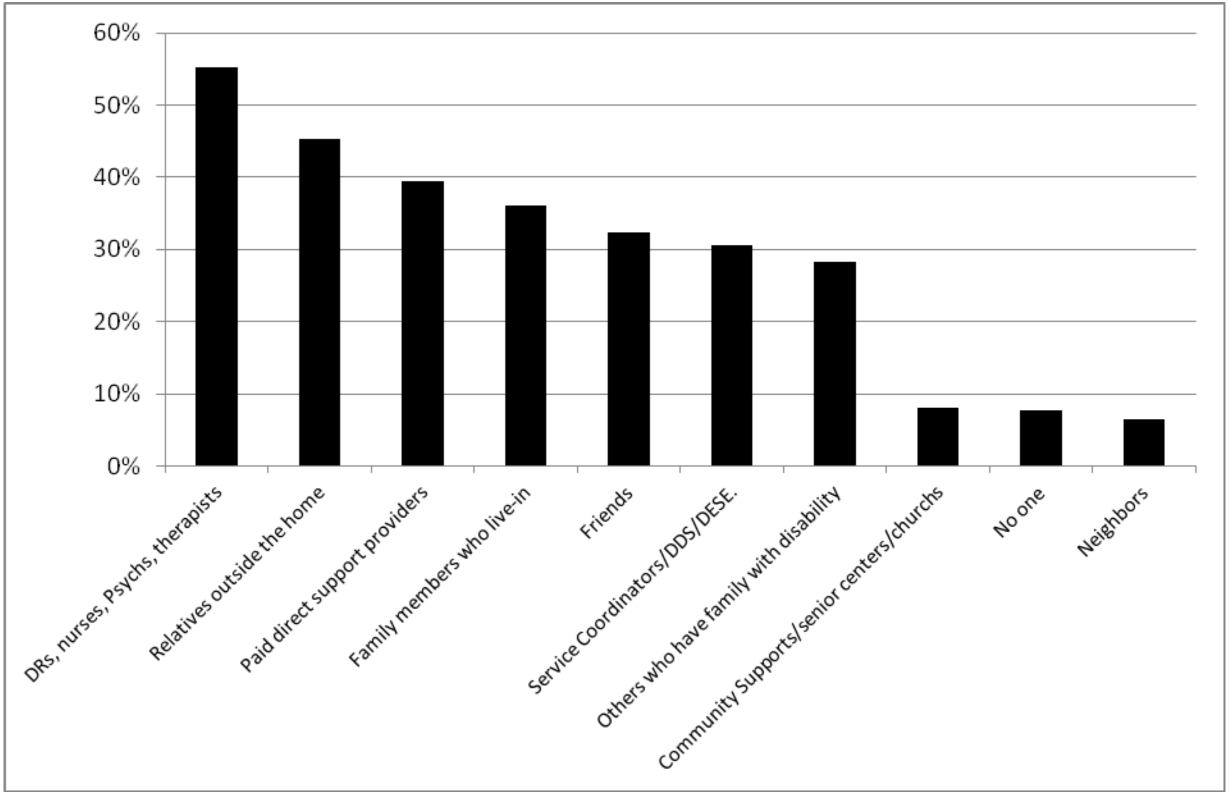


Formal/Informal Family Supports:

Caring for a family member with ID/DD is a long-term or lifetime commitment. If the family does not have sufficient support, it can prove to be physically and emotionally exhausting. When asked if the family received enough support from their community or other resources or organizations, such as churches, 77.3% responded "No." Additionally, 69.9% of the respondents indicated they do not receive enough support from state agencies such as DDS.

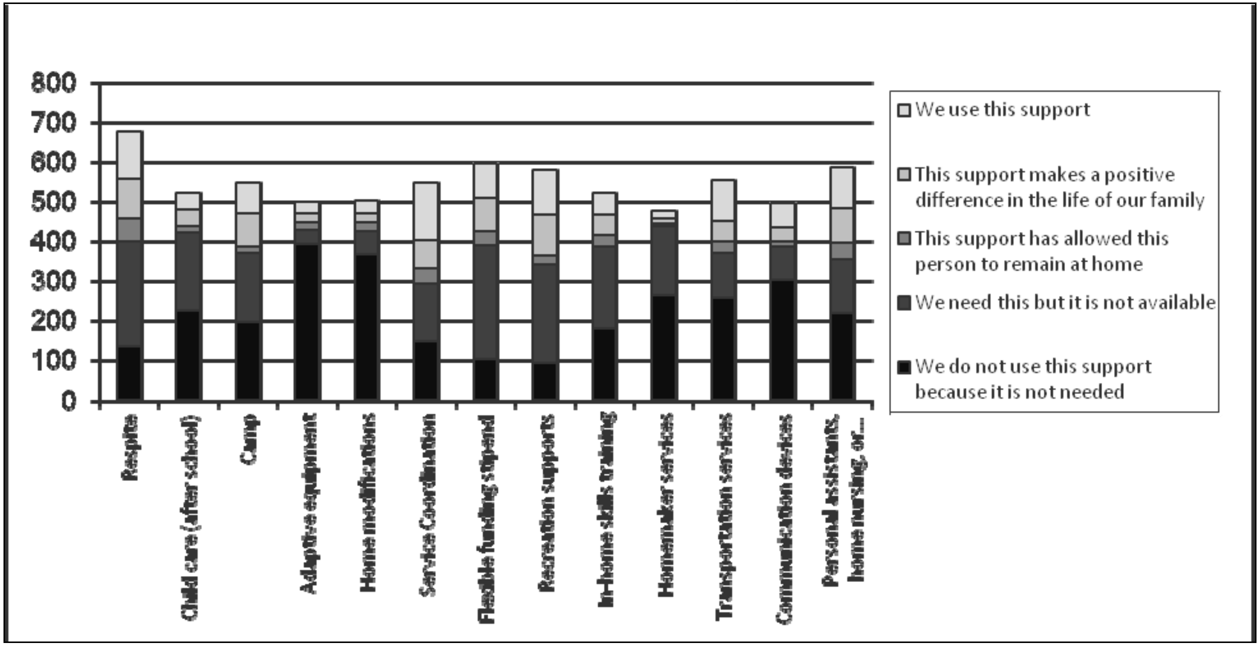
When asked who the family counts on to help deal with challenges related to the family member's disability, 55.1% reported paid professionals, such as doctors, nurses, psychologists, and therapists. The next most frequent response (45.4%) was relatives outside the home (many indicated more than one response). Fifty-nine respondents wrote comments in “other”, revealing that they often turned to the family member’s school or teacher and provider agencies such as the ARC for support. (Figure 3)

Figure 3: Who Families Count on for Help
(could check all that apply)



Caregivers access a wide range of supports with varying levels of need and access. The following questions were created to assess the need and usefulness of the particular support. The respondents could choose more than one option per row. Several supports indicate the need but no availability, including financial assistance through flexible funding (55.7%), recreation supports (48.3%), Respite (47.8%) and In-home skills training (44.5%). Additionally some supports, while important to a particular family, indicate a much lower need across the respondents, for example, adaptive equipment, home modifications and communication devices. (Figure 4)

Figure 4: Benefitted from Supports
(could check more than one per row)



Likewise emotional and planning supports are important to families and are accessed at varying degrees of need further illustrating the personal nature of family supports – what may work for one family does not necessarily work for every family. For example, while 29.4% specified they use support groups, an equal number specified they did not use the support because it was not needed. (Table 8)

Table 8: Emotional Supports
(could check more than one per row)

	We use this support	This support makes a positive difference in the life of our family	This support has allowed this person to remain at home	We need this but it is not available	We do not use this support because it is not needed
Parent to Parent Support	***34.3% (174)***	27.6% (140)	2.8% (14)	20.1% (102)	29.0% (147)
Self-advocacy organizations	26.6% (126)	21.6% (102)	4.4% (21)	20.9% (99)	***35.9% (170)***
Support groups	***29.4% (145)***	26.0% (128)	3.4% (17)	21.7% (107)	***29.4% (145)***
Professional counseling (individual or group)	28.7% (143)	22.6% (113)	2.6% (13)	20.8% (104)	***35.7% (178)***

Illustrating the caregivers' willingness to manage family member's care and services, caregivers frequently report that they access training and information about a specific disability, and information about the best ways to support a person with a disability. Caregivers also report a need for such planning supports as training on navigating/accessing services, advocacy, and person centered planning; however, it is not available to them. (Table 9)

Table 9: Planning Supports
(could check more than one per row)

	We use this support	This support makes a positive difference in the life of our family	This support has allowed this person to remain at home	We need this but it is not available	We do not use this support because it is not needed
Training or information about specific types of disability	**35.4% (186)**	25.5% (134)	5.5% (29)	17.3% (91)	28.4% (149)
Information about the best ways or practices to support a person with disabilities	**34.3% (179)**	28.2% (147)	6.5% (34)	25.5% (133)	19.2% (100)
Training or help in navigating and accessing services	30.6% (161)	20.9% (110)	6.1% (32)	**41.8% (220)**	14.6% (77)
Training or help in leadership development or advocating for services and policy changes to improve the lives of people with disabilities	28.0% (134)	18.4% (88)	4.0% (19)	**33.3% (159)**	26.8% (128)
Help with guardianship issues	23.8% (122)	9.8% (50)	3.9% (20)	28.1% (144)	**41.4% (212)**
Support for Person Centered Planning	11.9% (56)	8.5% (40)	2.6% (12)	**43.1% (202)**	38.4% (180)

Supports Most/Least Helpful:

In order to solicit more personal feedback regarding family supports, caregivers were asked a series of open-ended questions to determine the usefulness of supports, along with the availability and importance of supports.

When asked to comment on the supports caregivers found most or least helpful, 221 or 29.6% of the respondents provided comments. The responses indicate a dichotomy as some caregivers report a service be identified as "most helpful" but another caregiver can report that same service as "least helpful." For example: one caregiver may indicate PCA services as most helpful to their family, while another expresses frustration in obtaining the service and the quality of the providers. (Table 10)

Table10: Question 33: Please comment on any of the supports that you have found most or least helpful.

Theme	# of Responses	Sample Text
Advocacy Support	31	• We have been able to access services at the autism support center. Unfortunately, our finances are limited and we would do far more if more money was available. • Charles River Center has been a terrific support and provides very valuable information
Respite	26	• Respite was a good support when it was available • Respite funding has been invaluable in allowing our son to have a personal connection outside of his family circle with well trained, compassionate and understanding providers. This service has allowed him to enjoy peer experiences n the home and community.
Information	25	• It is hard to know what types and levels of services and supports we are entitled to, with children who have a higher functioning disability. The family struggles, this is true, and we feel isolated and unsupported most of the time. I wonder what we can do about it. • Lack of knowledge on supports outside the home be they financial or social. Hit or miss if able to attend workshops...overwhelming amt of material out there.
Education	19	• We need help advocating for our child in the school system... and these services are not available at this time. • Early Intervention Services were wonderful but abruptly ended at age 3. We were then left completely unsupported with no information on where to go for support.
Funding	18	• We used to get flex funding. It was 500.00 a year but it helped with outside therapy that we have to pay for out of pocket. • Without the yearly stipend I would not be able to send my daughter for any recreational activities, which she really needs

Table 10 Cont'd.		
Caregiver Training	14	• Most helpful: Information about the best ways or practices to support a person with disabilities. • I go to many of your lectures to educate myself on the services available.
DDS	12	• We get NOTHING. I have called DDS and they said we do not qualify for anything. • We have a lot of gratitude for every support we have had to use. Being a caregiver is a very difficult job without some help. Thank you for all you do.
Recreational/Social/ Life skills	10	• Life skills program excellent. Work support very helpful. Would like group home help & or housing for independent living with help. • Counseling, life skills group on Wednesday evenings, job coaching. There seems to be positive changes in her mood as well as ability to clean and follow through with activities of daily living with less verbal cues since participation in life skills group
PCA	9	• The most helpful support has been the Mass Health PCA program. This service allows me and my husband to get out and do things we need to do and get a break from the 24 hr. care that my daughter requires. • Personal care attendant program - this program is awful. There is no back up support. The position pays too low, and I can't find anyone who will work part time to support my family despite the fact I advertise on college job boards, papers, on-line tools, grocery stores, community boards, etc. This program perpetually let's us down and our community is lacking in support for individuals w physical/cognitive disabilities
Day Programs/Work force	7	• Adult Day Programs EXCEPT the hours are too short 8:30 to 2:30. At least 8:00 to 4:00 would be better. • Need more jobs and help with job skills for clients that are older
Support Groups	4	• My support group I belong to • Least helpful for us, parent to parent support group and the most helpful recreation activities like swimming activities.
Location of Services	3	• We need HELP but in Plymouth County there is a big black hole and NO ASSISTANCE AVAILABLE. We cannot afford to keep driving all the way in to Boston and the Boston Suburbs to seek out care... it ends up putting more stress on us then it helps!
Other	43	• We have had to do most things completely on our own; we have sought out and found information; we have paid for practically everything ourselves; we have totally rearranged our lives for our child with a disability out of necessity • Other parents have been the best help.

One hundred and thirty-one or 17.5% of the respondents added comments on topics of importance, ranging from Education (after school care to specific programs for those with Autism) to funding for estate planning, transitioning, workforce issues, housing and mentoring. (Table 11)

Table 11: Questions 38: Are there family supports that have not been talked about in this survey that you think are important?

Theme	***# of Responses***	***Sample Text***
Recreation/Social/Life skills	18	• More social/recreational opportunities • Social groups for young adults with disability
Education	14	• In home after school care for middle school or high school age children who can't participate in sports, etc. so a parent can work. • After-school programs that provide structure and an opportunity for my child to build friendships
Respite	13	• Respite: it would be nice for my husband and me to go away for a weekend • A safe way to find people who would provide respite, companionship to my family member. • Adult Foster Care
Autism	8	• Need specific programs for people with autism
Funding	8	• Estate planning. • MONEY, tax deduction for kids with disability
Transition	7	• Transition support – what are our options and what should we be building? • Transition to adulthood services/educational and vocational training
Workforce	6	• Job placement and coaching; life coach • need for jobs and job skills, and transportation
Mentors	6	• A buddy system to incorporates a typical peer with a disabled child on a regular basis • I think families should be assigned a family partner - someone that has walked the walk, who can help them think outside the box and navigate the system. These parents should be paid (like state employees) and receive benefits. They should also be included in meetings where decisions about how DDS dollars are spent.
Housing	6	• Housing near the home of the parents or siblings. Not just anywhere there is an opening. • Relief in housing costs
Support Groups	4	• need more parent support groups
Other	42	• Legal services for mothers like me who have no more funds to help keep child safe from perpetrator. • I work hard every day and my family to keep a happy place always. • In home behavior training & management for entire family

Three hundred and eighty-two or 51.1% of the respondents completed the open-ended question, *"what support is most important to you*." While many of the themes were illustrated in previous responses, new themes include the importance of friends and family and care coordination. (Table 12)

Table 12: Question 39: What family supports are most important to you?

Theme	# of Responses	Sample Text
Respite	84	• Respite has been invaluable • For our family has been respite; allowing our son to have paid friends but friends never the less! At the same time giving the rest of the family the opportunity to relax and take a break from caring for someone 24/7. Also, I would like to say flexible funds, they have been so helpful over the years. The DESE/DDS he had since he was 13 years of age, that was the only reason he was able to stay at home with us; I remember that children we knew with mild behaviors were place residentially but he was able to remain home do to the intensive supports provided by DESE and DDS.
Recreation/Social/ Life skills	36	• Recreational supports that will benefit the members and having them available in different parts of the community. • Life skills and social skills
PCA	36	• PCA. Help with caring for my child who is totally care dependent and weighs 120 lbs. I am still carrying him.
Financial	36	• Flexible funding where I get to decide what to do with the funding, whom to hire and what to pay them. • Financial support is the biggest thing for us now...
Housing	13	• Housing for young adults with aspergers syndrome • Having supervision and finding housing with supervision, like assisted living for someone who is mildly impaired but makes negative choices.
Education	18	• Educational Advocates • Teachers cooperation
Support Groups	13	• Support groups are important to me because I realize I'm not alone and helps a lot...only wish more parents or care givers would attend also • Helping families overcome the isolation and chronic stress level that comes with raising a child with a disability.
Day Programs/Work force	23	• Day program for someone turning 22. • A provider of program after the day program so she can interact in playing games, exercising etc. Instead of me being her playmate. • Employment opportunities that are funded by DDS for those with Autism/PDD. NOS/Aspergers with higher IQ's but huge social and communication gaps.
Autism	10	• Having activities for children with autism. • Supports for kids with Autism Spectrum Disorder.
Transition	6	• Preparing my child to leave school and start other services. • Any support that would allow me to care for my daughter and keep her in our home once she turns 22. Also funding for turning 22 is important she is 22 in three months

Table 12 Cont'd.

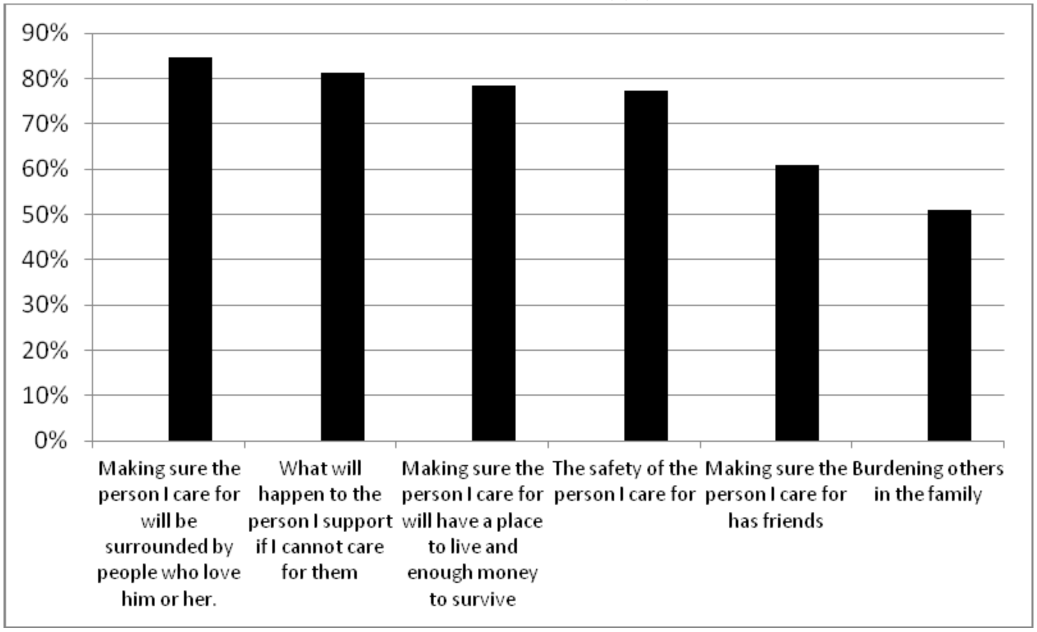
Friends and Family	8	• Having my mother live close by has been a great support to my family. • For quite some time, we have depended on our small group of relatives and a few very close friends
Other	110	• Assisting with coordinating all that is needed in the care of my child. There is not one person who knows her entire care which is overwhelming! I am constantly being sent to this person or that person to get answers. I wish there was one person who could answer my questions. I spend hours on the phone looking for answers. Same with paper work regarding her care. • Having a program that meets the needs of the individual. Having a program with one to one supports when needed. • Events that are inclusive of special needs people and their families.

***Concern for the future*:**

Caregivers frequently voice concern regarding what will happen to their family member in the future when they can no longer care for them. When asked which statement is closest to how you would like the future to be, 33.3% responded that "the person I support will live in a group setting with paid supports," followed by the person they support living with [caregiver] as an adult (26.5%), and the person they support living independently (25.3%). Ninety-one respondents included additional comments; many voicing the wish that the person they care for live independently, with supports, but knowing that it may not be possible.

When asked about their family member's future and what they are most concerned about, the most frequent response was that the family member is surrounded by people who love them (84.8%). The second most frequent response was what will happen to the family member if I can no longer care for them (81.3%). Sixty-three additional comments included, as an example, the hope that their children "have a happy and meaningful life." (Figure 5)

Figure 5: Concern for Family Member's Future
(could check all that apply)



When asked how concerned they are about the family member's future in all aspects of their life, from financial well-being to quality of life to relationships, "*Very Concerned*" scored the highest response rate in every category, with safety of the family member eliciting the highest response, demonstrating that all aspects of the family member's life are of concern and choosing one aspect over another is difficult. (Table 13)

Table 13: Concerns for the Future

	Not concerned	A little concerned	Quite concerned	Very concerned
Financial well being	3.4% (20)	11.8% (69)	26.0% (152)	***58.7% (343)***
Quality of life	1.9% (11)	7.7% (45)	24.1% (140)	***66.7% (388)***
Employment	11.3% (65)	14.9% (86)	21.5% (124)	***52.3% (301)***
Housing needs	4.8% (28)	10.4% (60)	22.3% (129)	***62.6% (362)***
Independence	4.2% (24)	10.3% (59)	24.2% (139)	***61.6% (354)***
Building or having meaningful friendships	3.8% (22)	12.2% (70)	23.6% (136)	***60.6% (349)***
Having a satisfying social life	4.1% (24)	14.3% (83)	23.4% (136)	***58.1% (337)***
Health	5.5% (32)	26.2% (153)	22.0% (128)	***46.7% (272)***
Longevity of life	12.7% (73)	26.2% (151)	19.6% (113)	***41.7% (240)***
Having a happy life	2.2% (13)	9.3% (54)	22.7% (131)	***65.7% (380)***
Education	13.7% (77)	19.4% (109)	21.9% (123)	***45.2% (254)***
Safety	2.6% (15)	9.6% (55)	20.6% (118)	***67.8% (389)***

Finally, three hundred and eighty-eight or 51.9% of the caregivers responded to the open-ended question, "*What would you like to say to DDS about family supports?* " Although many of the previous themes were repeated here, many caregivers stressed the importance of DDS and its mission along with the importance of communication and information. Sixty-one respondents were thankful for DDS and its services, another 57 respondents indicated that family supports are crucial to the families. (Table 14)

Table 14: Question 40: What would you like to say to DDS about family supports?

Theme	# of Responses	Sample Text
DDS Issues	65	• I was not aware of DDS. There are so many different organizations available, as a newcomer to the disabled community, it can be VERY confusing as to where I should turn to for support. More clear information about the various organizations and the roles that they play would be helpful • It needs to be consistent. One year you may get funds but then the next year nothing. I would like better communication between dept. and families
DDS Thank you	61	• Please keep caring about our loved ones with disabilities and continue to fight for provisions of services that are very much needed • Please continue support as life is a challenge by the day
Family Supports	57	• Family support is crucial so we can keep our loved ones at home and in their community where they belong. Not only is it the most cost effective way to support people with disabilities, it is also the most humane. • Family Supports are important in all areas. It is so important for the emotional and physical well being of all involved.
Autism	33	• If the person has a diagnosis of Autism cover/support them. Remove this stupid IQ barrier. Nobody wants him to be independent more than we do, if it's not possible you should support him. Not make us beg for it, appeal for it, only to be denied. Shame on you. We don't expect a hand out, but we won't live forever, who will care for our son after we are gone if you don't cover him? Will he have to live on the street? We can/will offer financial support but can't protect him when we are gone. • That your DO NOT support the whole ASD community.
Funding	30	• Money is needed to support a quality of life lived with dignity. Lifelong supports are needed: housing, academic growth, vocational, social, daily living skills, speech therapy, occupational therapy....we all want our children to be happy. ONLY TRAINED qualified people should be hired to ensure success for the agency as well as success for the individual who struggles daily to survive. • Please, please please help maintain our funding. Also, we need help with preparing our kids for their lives from age 22 on- housing and jobs....

Table 14 Cont'd.		
Transition	28	• Reach out to families and help them in the transitional process--no matter the town or the income level! • Without the support we receive we would not enjoy the quality of life we do now. Our family member is aging and we are fearful of the health issues facing him. We hope DDS will continue to be our lifeline!
Respite	20	• Please consider all respite or family supports as something that is EXTREMELY important, valuable & an absolute necessity to EVERYONE!! Also the ability to find some kind of work/day program for them where they can learn, grow & blossom into a very productive, happy, valued of society. • We need more support-- Respite Care
Day Program/Work force	4	• Adult Day Programs need longer hours • Provide adequate funds to Seven Hills to be able to offer their programs
Other	90	• Having to testify/advocate each year to try to maintain funding is burdensome and demoralizing. • Please help us keep our special needs family members safe and with meaningful life without forever dependence on parents.

Conclusions:

It is important to note that the respondents to this survey may not be a representative sample of caregivers across Massachusetts. However, several familiar themes emerged among the large number of respondents and these themes support the information collected at the public forums. The most frequently mentioned supports included: the need for respite care; PCA services; recreational/social and life skills activities; caregiver trainings; transitioning to adulthood supports (including housing); employment and day programs; advocacy and support groups; education; eligibility concerns; and communication from DDS. Overarching all these supports are funding issues. It is also important to note that while various themes are reported here, sub-themes also emerged and more analysis can be done in this area – for example, while respite care is frequently cited – several aspects of respite are important, including funding (how to pay for), availability (after school, weekends, appointments), location (convenience, accessibility), and trained caregivers (safety).

With more than 700 respondents, clearly caregivers appreciated a chance to provide information to DDS they feel is valuable to developing family support programs. The responses make apparent that caregivers fall on a wide spectrum of familiarity and experience with family supports as some responses portray frustration and sadness while others display coping and resilience.