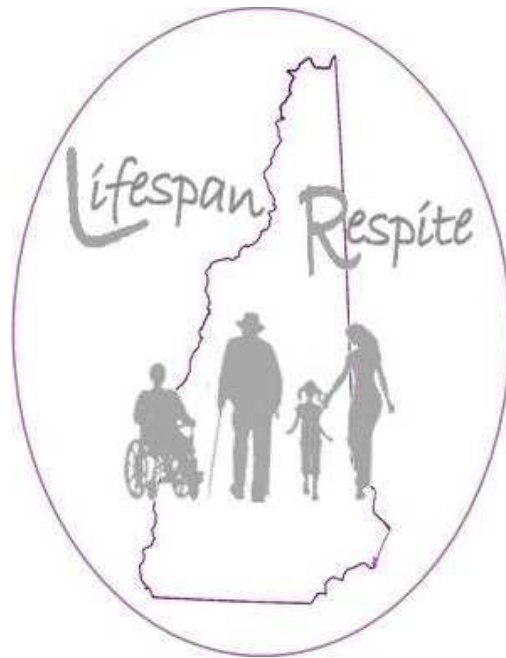


New Hampshire Lifespan Respite Caregiver Needs Assessment 2011



Special Medical Services
Division of Community Based Care Services
NH Department of Health and Human Services
August 2, 2011

A special thank you to Martha Anne Bose, B.S., graduate student in Rollins School of Public Health at Emory University, Atlanta, Georgia. Through the Maternal and Child Health Information Resource Center (MCHIRC) Graduate Student Internship Program, she designed, implemented, analyzed and summarized “New Hampshire Lifespan Respite Caregiver Needs Assessment Survey” for Special Medical Services, Children with Special Health Care Needs, Title V, Maternal and Child Health Program in NH.

The Caregiver Needs Assessment was developed to meet the requirements of the NH Lifespan Respite Care Project Grant received by Special Medical Services from the Administration on Aging, Title IV Grant Reward Number 90LR0009/01

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Introduction

Through New Hampshire's Department of Health and Human Services and within it the Division of Community Based Care Services, Special Medical Services conducted a statewide Caregiver Needs Assessment during the summer of 2011 in order to better understand the needs of primary caregivers who support individuals of varying ages and special health care needs across the lifespan. The purpose of this needs assessment survey was to gain better insight into the distribution of caregivers across the state, the demographics of these caregivers and the individuals they care for, their experiences associated with caregiving, and what role respite services may play in their lives. Respite literally means a time of rest or relief. Respite care provides a primary caregiver a temporary, short-term break from the constant responsibilities of caring for a dependent child or adult. Therefore, the survey inquired about the need and use of respite care by caregivers.

The recent publication by the AARP Public Policy Institute entitled "Valuing the Invaluable: 2011 Update, The Growing Contribution and Costs of Family Caregiving" was utilized to contrast national caregivers statistics to the results of this Caregiver Needs Assessment¹. However, it is important to note that unlike the NH needs assessment, the AARP publication does not factor in U.S. caregivers of individuals younger than 18 years old. The AARP publication states this exclusion is due to the difficulty in differentiating the caregiving responsibilities involved in "normal" parenting versus the greater responsibilities associated with children with special health care needs. Despite this challenging distinction, the NH Caregiver Needs Assessment includes caregivers of individuals with special health care needs younger than 18 years old. Accordingly, this survey allowed caregivers to identify how their responsibilities may be amplified due to the special health care needs of the children and youth they provide care for.

The survey was created by compiling input from various stakeholders and duplicating some question elements from a brochure publication about respite services.² In order to maximize the delivery of this survey, several distribution methods were

¹ Feinberg, Lynn, Susan C. Reinhard, Ari Houser, and Rita Choula. "Valuing the Invaluable: 2011 Update, The Growing Contribution and Costs of Family Caregiving." AARP Public Policy Institute. July 2011. <<http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html>>

² Lund, Dale A., et al. "Respite Services: Enhancing the Quality of Daily Life for Caregivers and Care Receivers." June 2010: 1-15. <[http://sociology.csusb.edu/docs/Respite%20Brochure%20\(2010\).pdf](http://sociology.csusb.edu/docs/Respite%20Brochure%20(2010).pdf)>

utilized. Unfortunately, there is no current statewide registry identifying caregivers across NH. Instead, nearly 100 different organizations and their liaisons were contacted and asked to make their caregiver constituents aware of this Caregiver Needs Assessment. These organizations consisted of government agencies, non-profits, Adult Day Care centers, and more. Depending on the contact information available to them, these organizations were encouraged to distribute the survey electronically through email or in paper format in person or through postal mail. Additionally, we aimed to improve the accessibility of the survey by offering third party translation services over the phone. Through these efforts, the NH Caregiver Needs Assessment captures the responses of 407 caregivers within NH, with a 77.6% completion rate. Through these survey responses, the following evaluation summary identifies the types and needs of caregivers within the state and how they compare to caregivers nationally.

Caregiver Demographics

According to the AARP report, nationally 65% of caregivers are females and on “average” 49 years old. According to the AARP’s state specific statistics, there are 183,000 caregivers at any given time in NH (nearly 14% of the state population). This needs assessment reflects similar finding as demonstrated in Table 1 and Figure 1, respectively. In particular, the survey results reveal that the majority of NH’s caregivers are female (84.3%, n=343) and nearly a third of caregivers (n=127) are between 45-54 years old.

Caregiver Gender n=407	
Male	64
Female	343

Table 1: Caregiver Gender

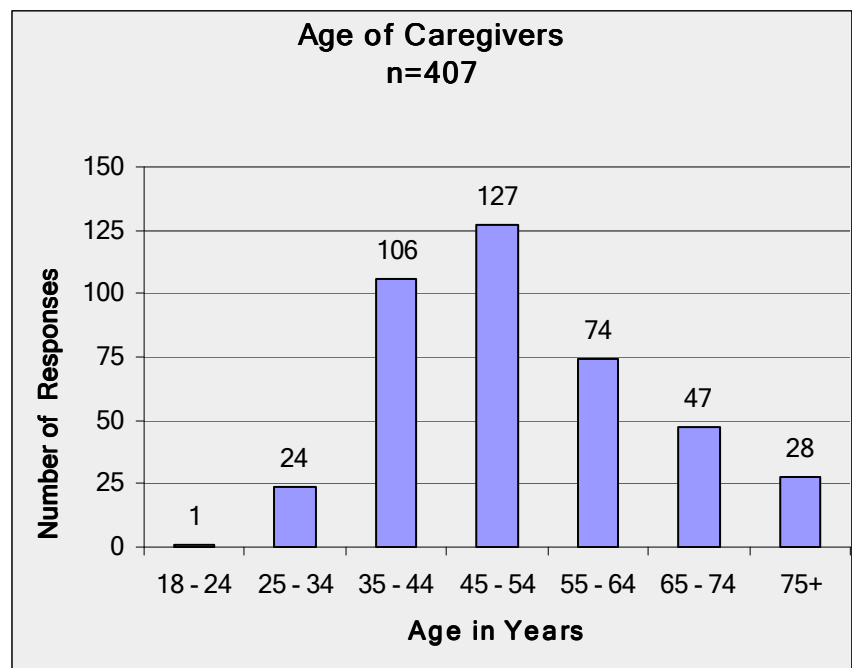


Figure 1: Age of Caregivers

The majority caregivers who participated in this survey also reported to be the “Son/daughter”, “Parent”, or “Spouse/partner” of the individual they provide care for. However, there were a variety of caregiver relationships to the individuals they provide care for (Figure 2). Moreover, caregivers are oftentimes responsible to provide care for more than one individual. Therefore, some participating caregivers identified more than one type of relationship to care recipients. Those who identified themselves as “Other” provided more response options such as “guardian”, “mother-in-law”, “widowed”, but the majority just elaborated on their roles.

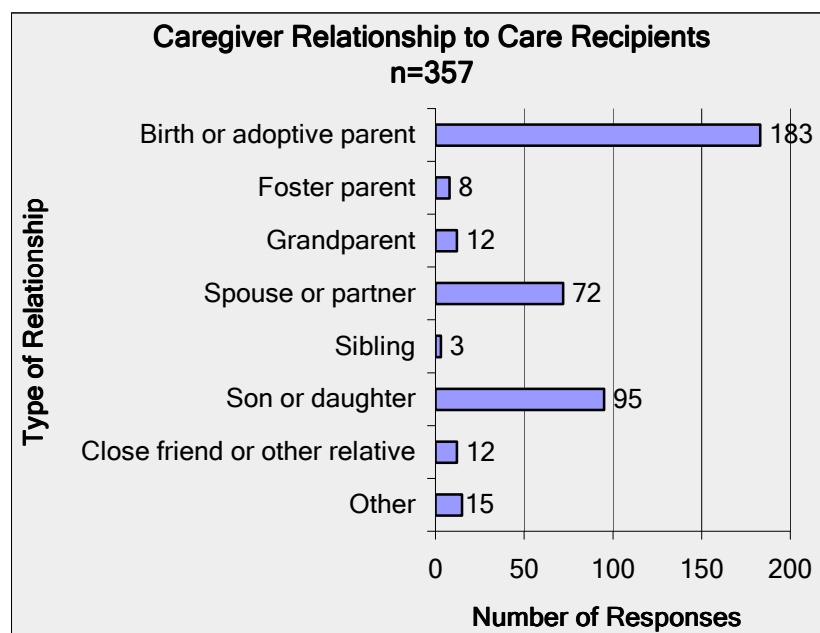


Figure 2: Caregiver Relationship to Care Recipients

The overall county population statistics provided in Figure 3 and caregiver responses rates per county in Figure 4 enables a rough estimation on the proportion of caregivers throughout NH.³ By comparing Figures 3 and 4, it becomes apparent the two most populated counties within NH (Hillsborough and Rockingham) represent the greatest number of caregivers. However, the unexpected larger response rates from Grafton and Strafford counties demonstrate potential areas within NH that may need

³ United States Census Bureau. State and County QuickFacts: New Hampshire. 28 July 2011
 <<http://quickfacts.census.gov/qfd/states/33000.html>>

more resources allocated to caregivers. The overall results of this needs assessment demonstrates the presence of caregivers within every county of NH.

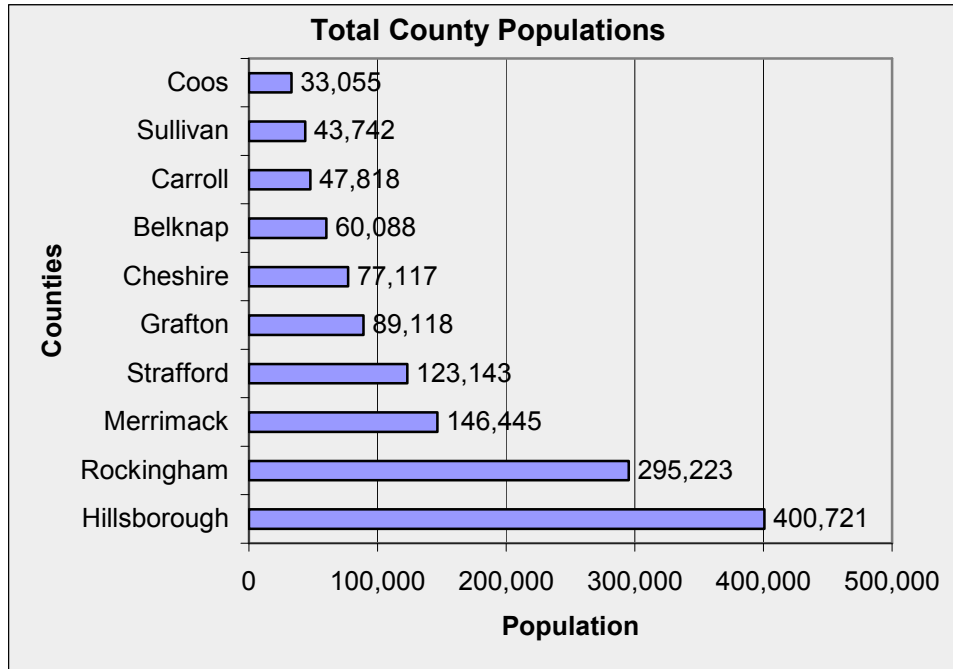


Figure 3: Total County Populations

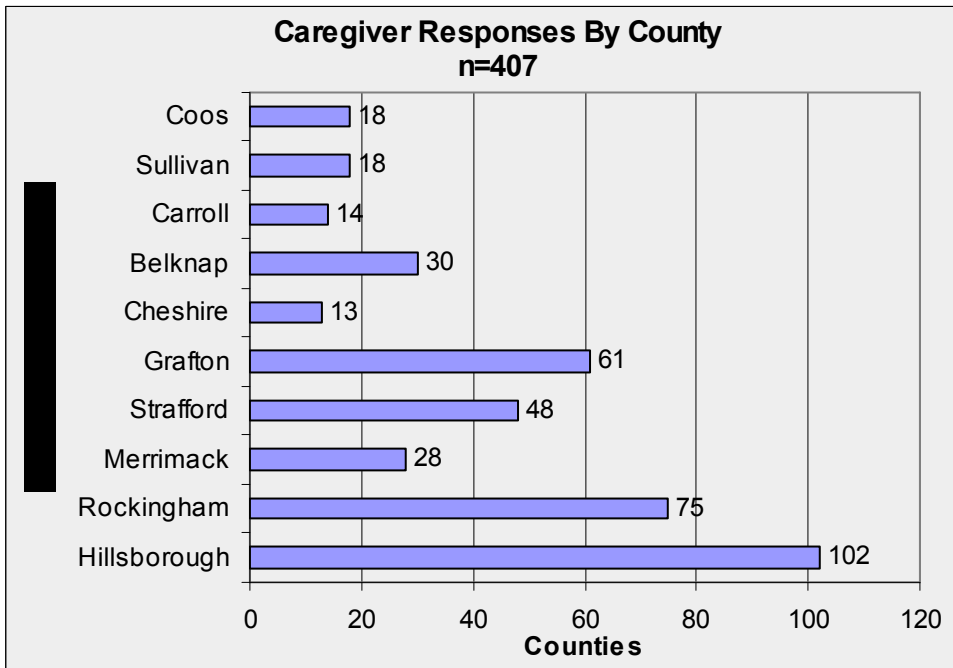


Figure 4: Caregiver Responses By County

Care Recipient Characteristics

In addition to collecting information about caregiver demographics, the Caregiver Needs Assessment survey also inquired about the individuals in which the caregivers provide care for. These questions included the age and primary special health conditions of the care recipients. Yet again, the potential for caregivers to be responsible for more than one individual was factored in. Consequently, when asked to identify the age range of the care recipient(s), caregivers were enabled to select more than one appropriate age category. Likewise, care recipients may experience more than one special health condition. Accordingly, caregivers were able to identify more than one primary condition that affected the individual(s) in which they provide care for. As a result of this multi-selection option, the number of responses selected exceeds the total number of caregivers to participate in this survey.

The 381 caregivers who provided the age ranges of their care recipients reported on the variety of ages for 460 care recipients (Figure 5). It is interesting to observe that 55.4% (n=255) of the care recipients represented in this needs assessment are children and youth with special health care needs 18 years old and younger. Consequently, a major portion of this survey's sample caregiver population is not factored into the AARP's national evaluation of caregivers. These differences between both samples highlight the drawbacks from the AARP's national report as well as the need to view comparisons between the AARP's national statistics and the NH Caregiver Needs Assessment as rough estimates.

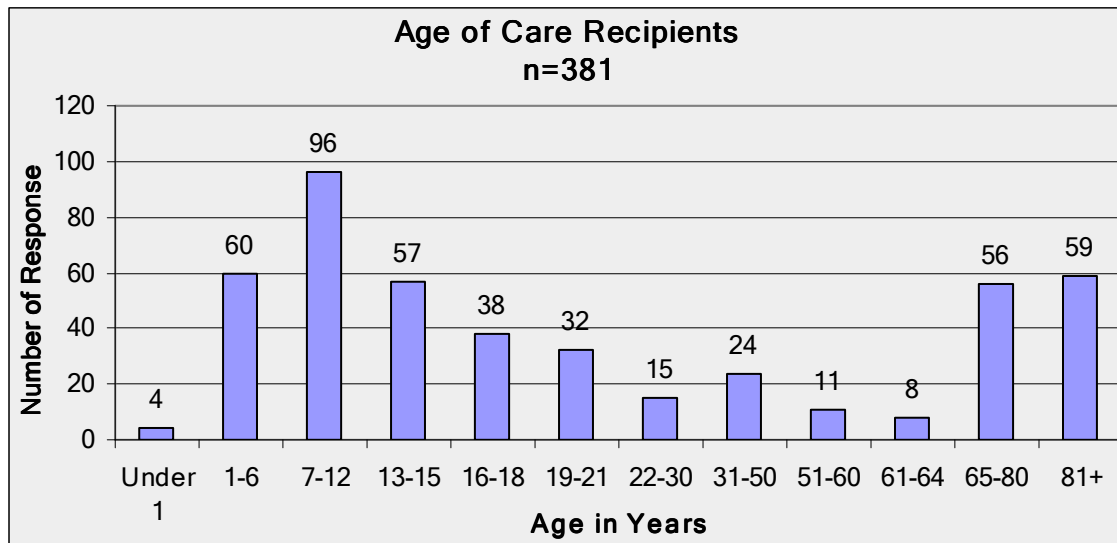


Figure 5: Age of Care Recipients

Figure 6 illustrates the primary conditions of care recipients in which surveyed caregivers provide care for. The results show that “Developmental Disabilities” is the most represented primary condition amongst care recipients. The reason for this may be due to the larger number of care recipients 18 years old and younger. However, developmental disabilities can persist into adulthood. Therefore, the associated age ranges of care recipients affected with developmental disabilities are not concrete. In addition to the primary conditions categories provided, caregivers also provided much feedback in the “Other” category. Many of these responses provided further explanations about the primary conditions categories that they selected. However, there were several primary conditions mentioned in the “Other” category that could not be captured by the provided primary conditions categories. These include epilepsy/seizure, Chronic Obstructive Pulmonary Disease (COPD), medically involved, asthma, short bowel syndrome, cancer, and Tourettes syndrome (Table 2).

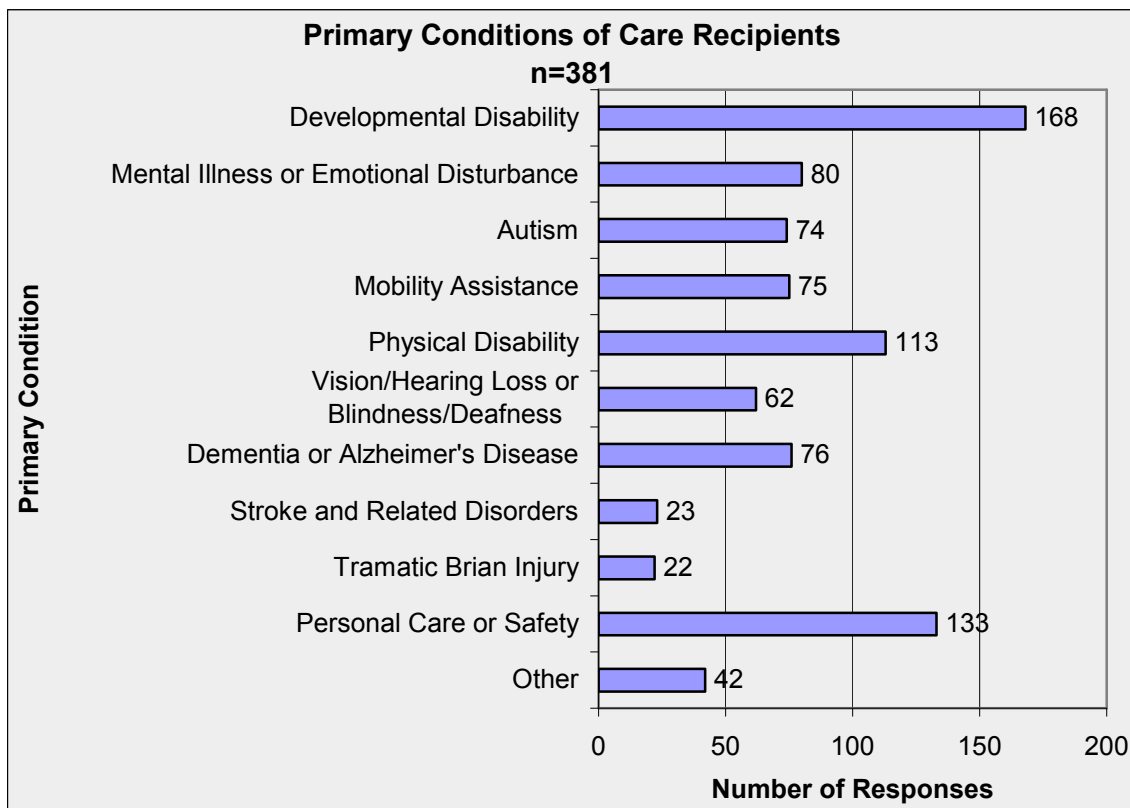


Figure 6: Primary Conditions of Care Recipients

"Other" Primary Conditions	
Epilepsy/seizure	15
COPD	5
Medically involved	11
Asthma	4
Short Bowel Syndrome	1
Cancer	7
Tourettes Syndrome	1

Table 2: "Other" Primary Conditions

In addition to the types of primary conditions of their care recipients, caregivers also reported on daily living activities in which they provide assistance. Again, caregivers were allowed to select more than one applicable daily living activity. Consequently, there are more responses than the number of surveyed caregivers. Figure 7 shows the several ways in which caregivers provide aid, "Transportation" and "Preparing Meals" ranking highest. Of the numerous responses for the "Other" category, there were a few topics repeatedly mentioned that were not represented in the daily living activity list. These include seizure monitoring, 24/7 monitoring/assistance, personal care/safety, management of medical appointments/equipment etc, communication assistance, and provide appropriate socialization activities (Table 3).

"Other" Assisted Daily Living Activities	
Seizure monitoring	4
24/7 monitoring/assistance	18
Personal care/safety	12
Management of medical appts/equipment etc	27
Communication assistance	7
Provide appropriate socialization activities	12

Table 3: "Other" Assisted Daily Living Activities

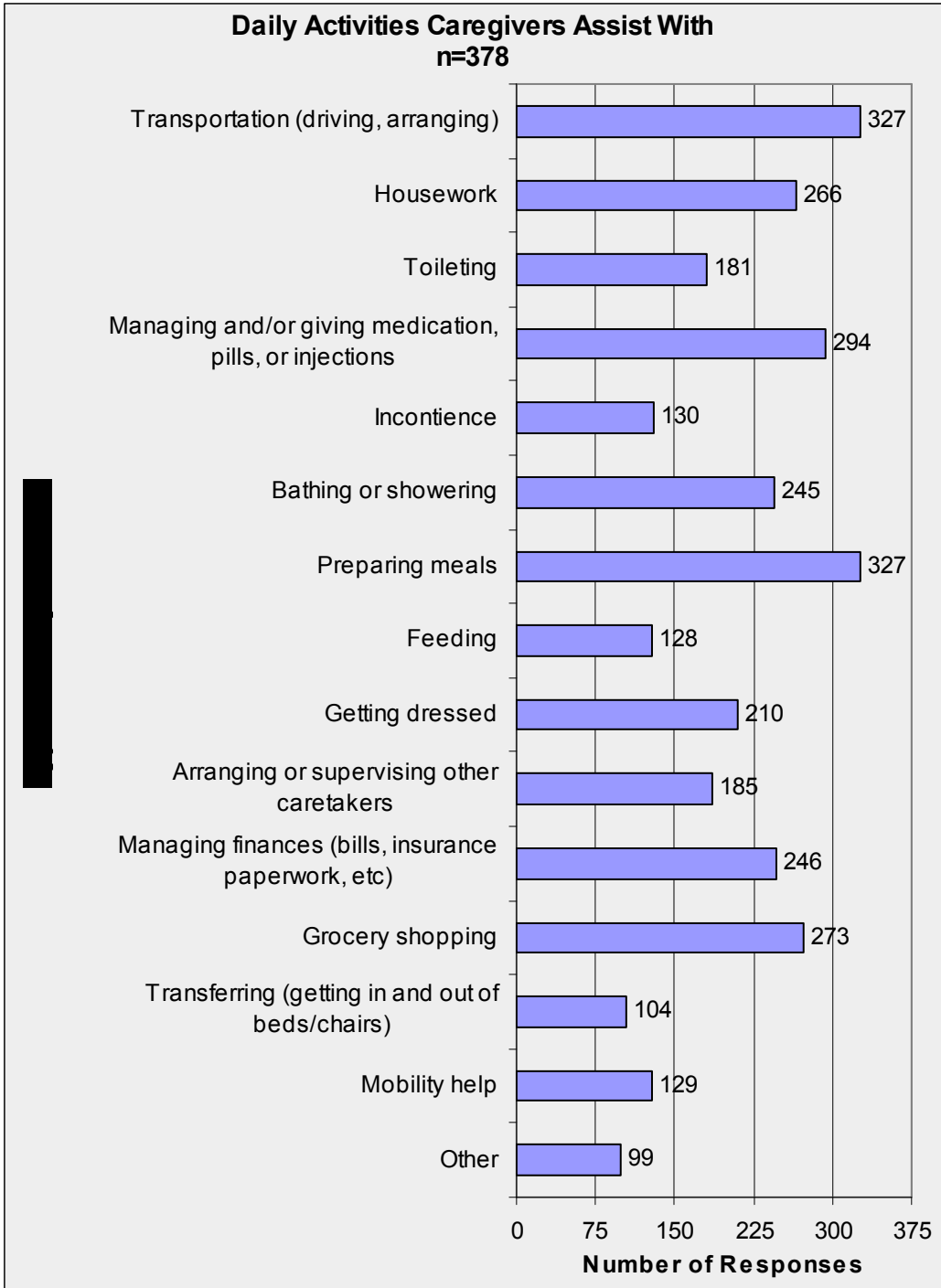


Figure 7: Daily Activities Caregivers Assist With

Caregiver Stress

These assorted responsibilities of caregivers oftentimes lead to caregiver stress. As mentioned, caregivers can be simultaneously responsible for more than one individual with special health care needs at a time. The AARP reports that, nationally, one-third of caregivers are responsible for more than one care recipient at a time. Moreover, the AARP reports that 10% of caregivers are responsible for three or more care recipients at any given time. In addition to this, the AARP also reports that the average caregiver spends roughly 20 hours per week caregiving. Within the NH sample specifically, the needs assessment reveals that 19% (n=70) of caregivers care for more than one individual at a time and only 6.8% (n=25) of caregivers provide care to three or more people at any given time (Figure 8). However, the weekly average time spent providing care within this sample was much higher than the national average. As Figure 9 exemplifies, nearly 60% (n=197) of the caregivers who participated in this survey provided care for over 71 hours per week.

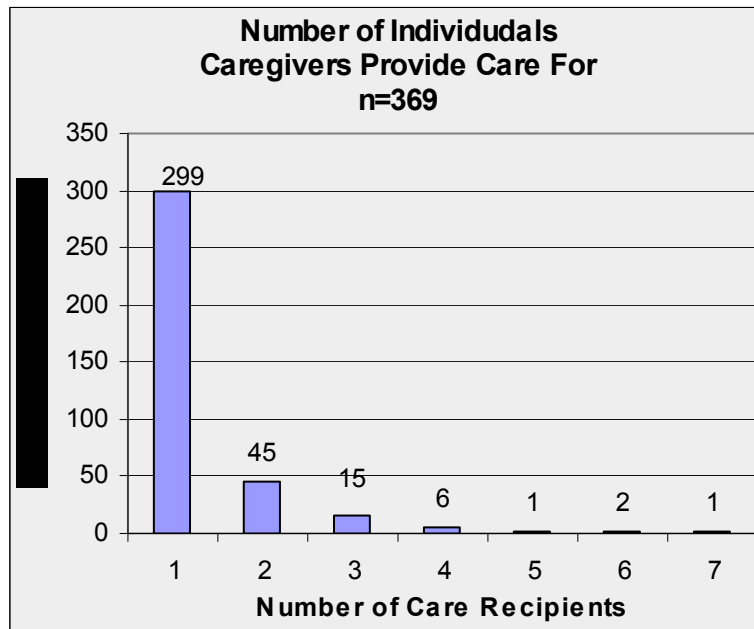


Figure 8: Number of Individuals Caregivers Provide Care For

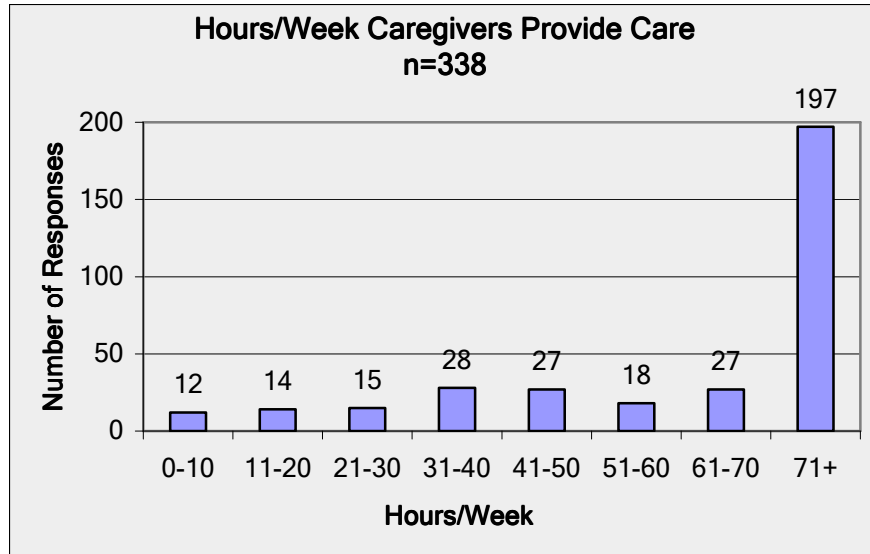


Figure 9: Hours/Week Caregivers Provide Care

The dependency on the participating NH caregivers was also measured through responses to the statements demonstrated in Table 4.

How often do you feel...	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
The person I care for needs my help to perform many daily tasks.	5	12	61	88	167
He/she is dependent on me.	1	6	35	88	202
I have to watch him/her constantly.	8	41	74	75	135
I have to help him/her with many basic functions.	19	44	72	64	132
I don't have a minute's break from his/her chores.	30	62	108	91	37

Table 4: Dependency on Caregivers

These constant responsibilities can unfortunately lead to both physical and emotional strains on caregivers. The AARP indicates that these strains are manifested through increased social isolation, depression, and financial hardships as well as decreased physical health and quality of life. These findings are also evident through the responses provided in this needs assessment. In this survey, caregivers were asked to identify all of the stressors they experience from their role as a caregiver. Figure 10

demonstrates that of the several different types of stressors that affect caregivers regularly, “Loss of free time” and “Feeling overwhelmed” is experienced most consistently amongst caregivers.

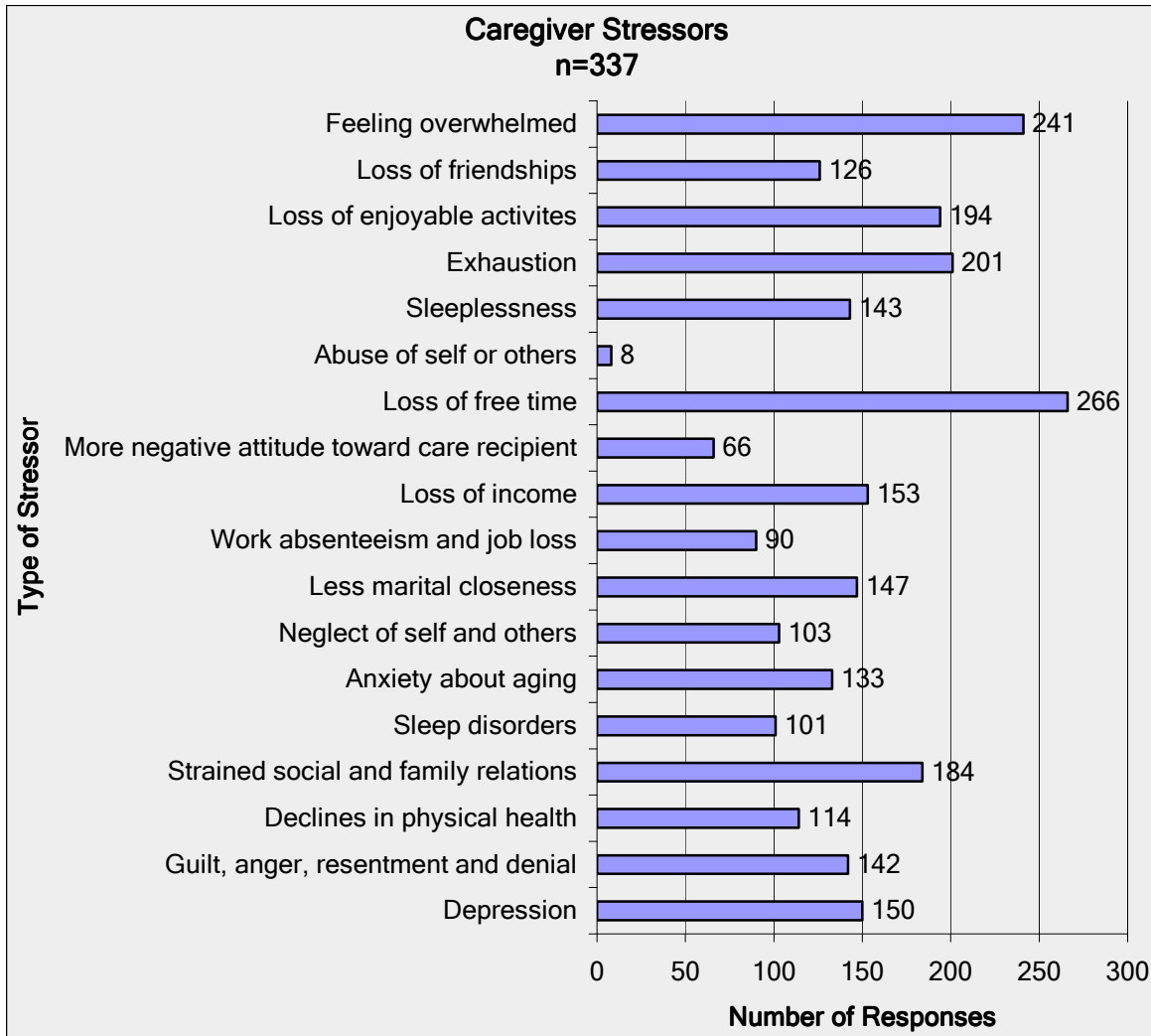


Figure 10: Caregiver Stressors

Table 5 further illustrates how NH caregivers experience stress in relation to their roles as caregivers. It appears that of all the emotional stressors listed, caregivers identified their “expectation that things would be different at this point in [his/her] life” as one experienced most often amongst caregivers.

How often do you feel...	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
I feel that I am missing out on life.	47	57	160	69	23
I wish I could escape from this situation.	78	75	135	52	15
My social life has suffered.	28	40	139	100	51
I feel emotionally drained due to caring for him/her.	35	45	158	85	36
I expected that things would be different at this point of my life.	39	49	97	101	71
I'm not getting enough sleep.	43	52	113	84	62
My health has suffered.	75	93	114	48	25
Caregiving has made me physically sick.	156	101	65	22	9
I'm physically tired.	35	46	123	93	57
I don't get along with other family members as well as I used to.	122	93	89	36	13
My caregiving efforts aren't appreciated by others in my family.	117	68	92	52	20
I've had problems in my marriage (or other significant relationships).	126	64	91	37	29
I don't get along as well as I used to with others.	141	101	81	21	11
I feel resentful of other relatives who could but do not help.	101	65	110	42	31
I feel embarrassed over his/her behavior.	143	74	90	34	16
I feel ashamed of him/her.	246	62	35	9	3
I resent him/her.	224	72	48	6	5
I feel uncomfortable when I have friends over.	192	63	69	20	12
I feel angry about my interactions with him/her.	176	88	62	20	5
I do pretty much what I have to do, not what I want to do, for him/her.	104	88	76	43	33

Table 5: Stress Experienced from Caregiving

Although caregiving can oftentimes be stressful, the needs assessment also wanted to capture how caregiving can also be rewarding. Table 6 demonstrates how caregivers in NH perceive the benefits in their roles as caregivers as well.

How often do you feel...	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
You really enjoy being with the person you care for.	3	18	65	107	163
Helping this person has made you feel closer.	9	32	70	104	135
You take care of him/her more because you want to than out of a sense of duty.	7	23	57	103	160
The person you care for can show his/her old self in spite of his/her current condition.	20	43	99	73	92
The person you care for shows real appreciation for what you do.	27	63	115	71	75
The knowledge that you are doing your best gets you through the rough times with the person you care for.	2	14	77	129	123
The person you care for gets pleasure out of some little thing that gives you pleasure.	9	43	100	102	92
That it makes you happy that the person you care for is being cared for by family.	8	10	40	89	197

Table 6: Satisfaction from Caregiving

Understanding and Preferences about Respite Services

In addition to investigating the benefits and stressors associated with caregiving, this survey inquired about how caregivers perceive respite services and what sort of preferences, if any, did they have about these services. In order to assess how caregivers understand the purpose and function of respite services, caregivers were asked to rate how true the statements were in Table 7 below. Other than not finding neglect and mistreatment to be applicable, caregivers primarily found each respite care statement to be “Very true”.

In your experience, how true is each statement about respite services?	Very true	Somewhat true	Not true at all	Does not apply
Trained respite providers met caregiving needs.	130	76	8	89
Respite offered a short-term break from caregiving.	195	36	3	73
Respite reduced the risk of neglect or mistreatment.	110	40	37	115
Respite provided safe and secure care.	174	50	4	78
Respite enabled me to focus on needs of others in my household.	138	50	7	108
Respite allowed me to enjoy social and recreational activities.	149	70	8	78
Respite reduced my stress as a caregiver.	162	62	8	74
Respite increased my ability to effectively provide care.	163	63	8	71
The person whom I provide care felt positively about respite.	128	78	11	86
Thus far, I have been very satisfied with my use of respite services.	167	47	13	76

Table 7: Caregiver Understanding of Respite Services

Shown in Table 8, caregivers also rated the importance of certain characteristics in their ideal respite provider. For the most part, caregivers rated every item as “Very important”. However, “Basic First Aid Training”, “CPR Training”, “Quality of Care Services”, and “Pre-screening or training requirements” received the most support as being very important. It appears that “Foster Parent Training” and “Available 24/7” are the least emphasized characteristics desired in respite providers.

Please rate what characteristics you think would be ideal for a respite provider.	Very important	Somewhat important	Not important at all
Alzheimer Training	130	68	64
Autism Training	129	59	61
Baby Sitting Experience	152	67	39
Basic First Aid Training	251	39	6
CPR Training	229	49	12
Red Cross Training	151	85	25
Seizure Training	140	82	39
Foster Parent Training	45	72	126
Formal Training/Education	111	110	36
Parent/Caretaker (Personal Experience)	147	113	20
Available 24/7	105	102	56
Consumer friendly and easy to use	202	72	6
Provides me with multiple options for care	181	85	10
Quality of care services	270	18	4
Options for financial assistance	199	55	16
Pre-screening or training requirements	207	59	11

Table 8: Ideal Respite Provider Characteristics

Caregivers were also asked if they preferred to train new respite providers themselves opposed to working with respite providers trained elsewhere. As Figure 11 demonstrates, roughly half of the participating caregivers prefer to train a new respite provider themselves.

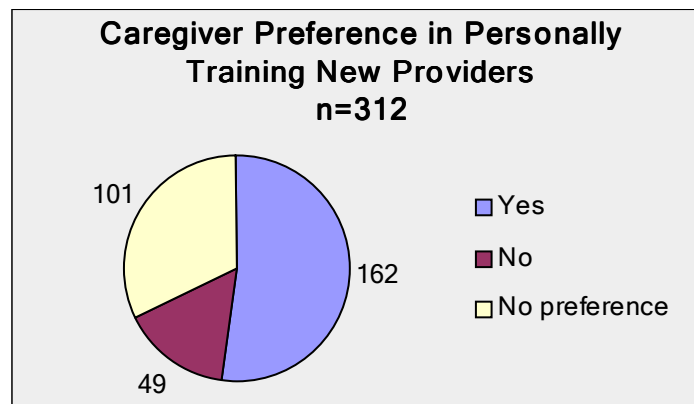


Figure 11: Caregiver Preference in Personally Training New Providers

Utilization of Respite Services

Regardless if caregivers had previously utilized respite services or not, the survey asked all caregivers about how they would use their “time off” when using respite services. As Figure 12 shows, most caregivers voiced their desire for personal relaxation time, catch up on other errands/household chores, and to spend time with friends and other family members. Through the “Other” category for Figure 12 and an additional follow up question (“Are there any activities that you used to do before becoming a caregiver that you wish you could continue to do now?”), most caregiver explained more in depth how they would ideally use free time from respite services. Most commonly, the caregiver responses included recreational and outdoor activities (golf, hiking, gardening, etc), exercise regularly, sleep, seek employment/education opportunities, spend more time with their spouses, take a vacation or weekend get away, attend church/community activities, and more. Not surprisingly, there is a correspondence between these desired activities to the stressors identified by the AARP and in Figure 10, such as social isolation, lack of sleep, decreased physical health, financial hardships, etc.

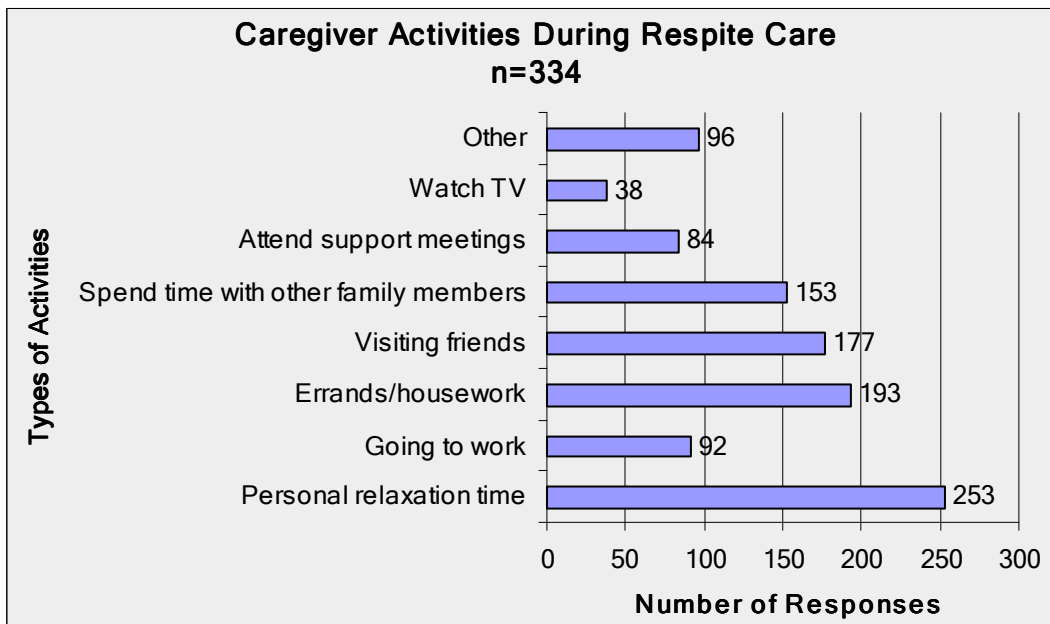


Figure 12: Caregiver Activities During Respite Care

In addition to asking how caregivers would ideally use respite services, the survey assessed the number of caregivers who have actually utilized respite care and the history of these services. When asked, “how long have you been receiving respite care?”, the majority of the respondents had either never used services (34.6%, n=117) or had been using services for over a year (44.1%, n=149) (Figure 13).

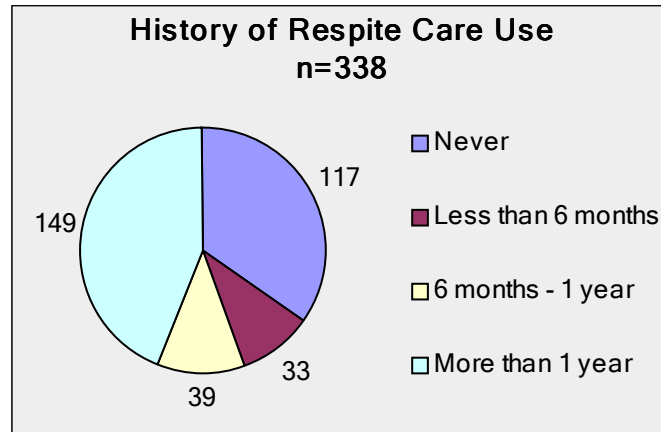


Figure 13: History of Respite Care Use

All of the caregivers that did not select “Never” (65.4%, n=221), and thus had at some point before utilized respite services, were then asked a few additional questions about their experiences with respite services. The first of these questions asked, “As a caregiver, where does your respite care take place?”. Figure 14 shows that the majority of caregivers (68.5%, n=146) received respite care in their homes, which is also where their care recipients lived as well. Of the 24.9% (n=53) of caregivers to select “Some where else”, they most often identified these other locations as various adult care centers or the home of the respite provider.

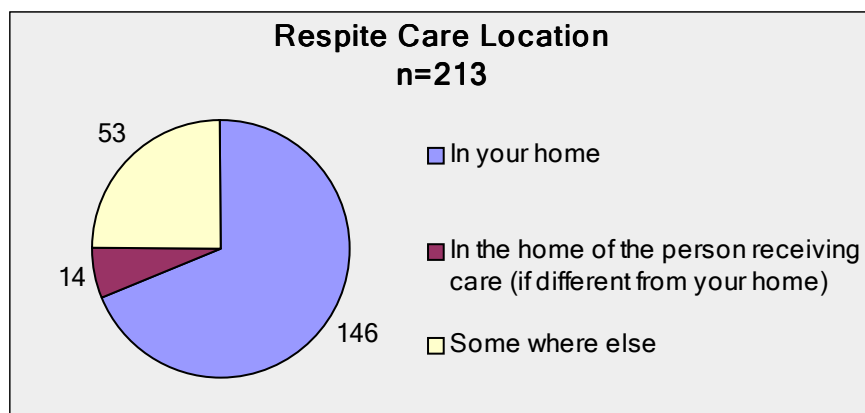


Figure 14: Respite Care Location

The next question asked, “What is your relationship to your primary respite provider?”. Figure 15 reveals that most respite providers are either “Family”, “Friend/neighbor”, or “Hired in home service provider”. Those who identified “Other” most often listed nursing staff, foster parents, or specified the day/over night facility utilized.

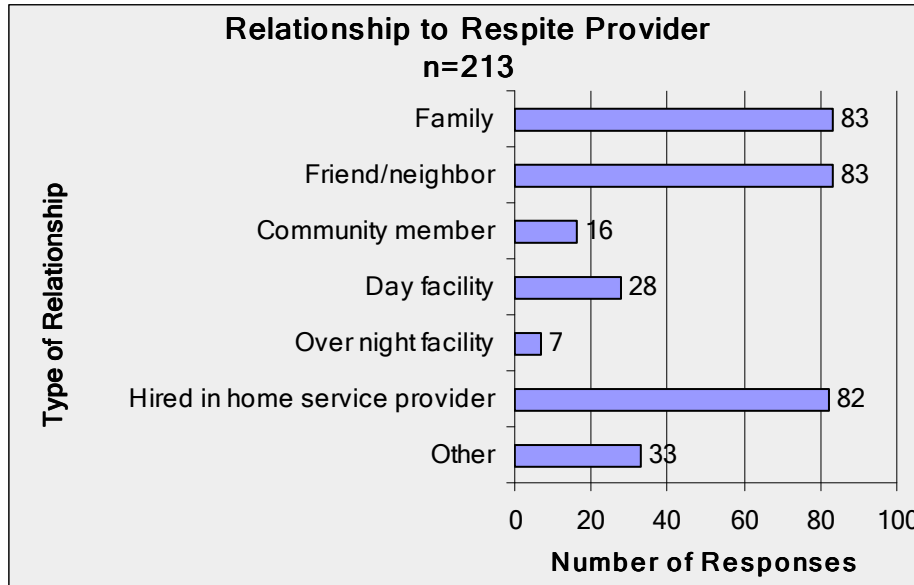


Figure 15: Relationship to Respite Provider

These caregivers who have used respite services were then asked to identify the ways in which they have found their respite providers. Figure 16 shows that most respite providers were found through a recommendation from family or friend. As the previous question reveals (Figure 15), this recommendation was probably the actual friend/neighbor or family member providing the respite services since this is the largest group of respite providers utilized. The “Other” category received the next greatest number of responses. These responses included newspaper advertisements (placed by both the caregivers and respite providers), referrals and staff from day care facilities, through school connections, and various government agencies.

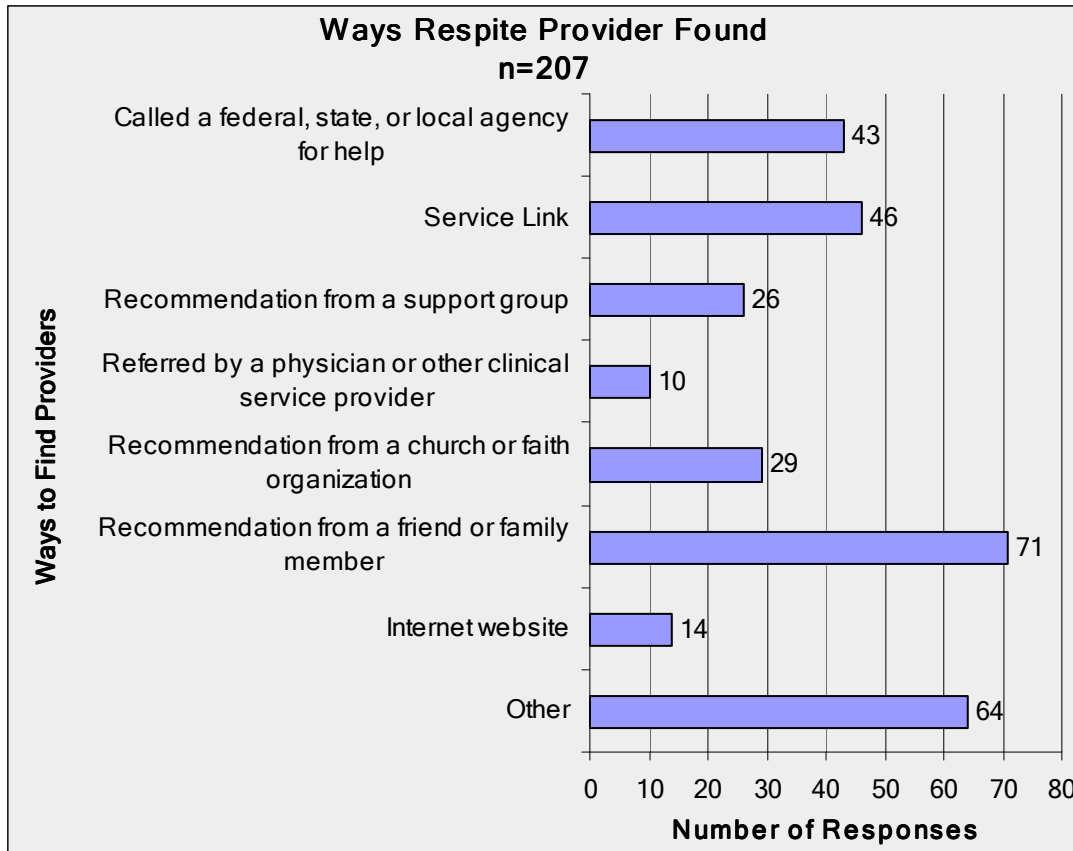


Figure 15: Ways Respite Provider Found

Caregivers also reported the type of training and/or experience their current respite providers have (Figure 17). The top three types of experience/training reported was “Parent/Caregiver (Personal Experience)”, “Basic First Aid”, and “CPR Training”. The portion of reported respite providers with “Basic First Aid” and “CPR Training” reflects to the expressed ideal characteristics voiced by caregivers, as previously demonstrated in Table 8. Likewise, the portion of respite providers with “Parent/Caregiver (Personal Experience)” corresponds to the results in Figure 15 because most respite providers were reported to be either family or friends/neighbors. Those who selected “Other” primarily listed certified adult care facilities and their staff, nurses, paraprofessionals from school, or it was unknown.

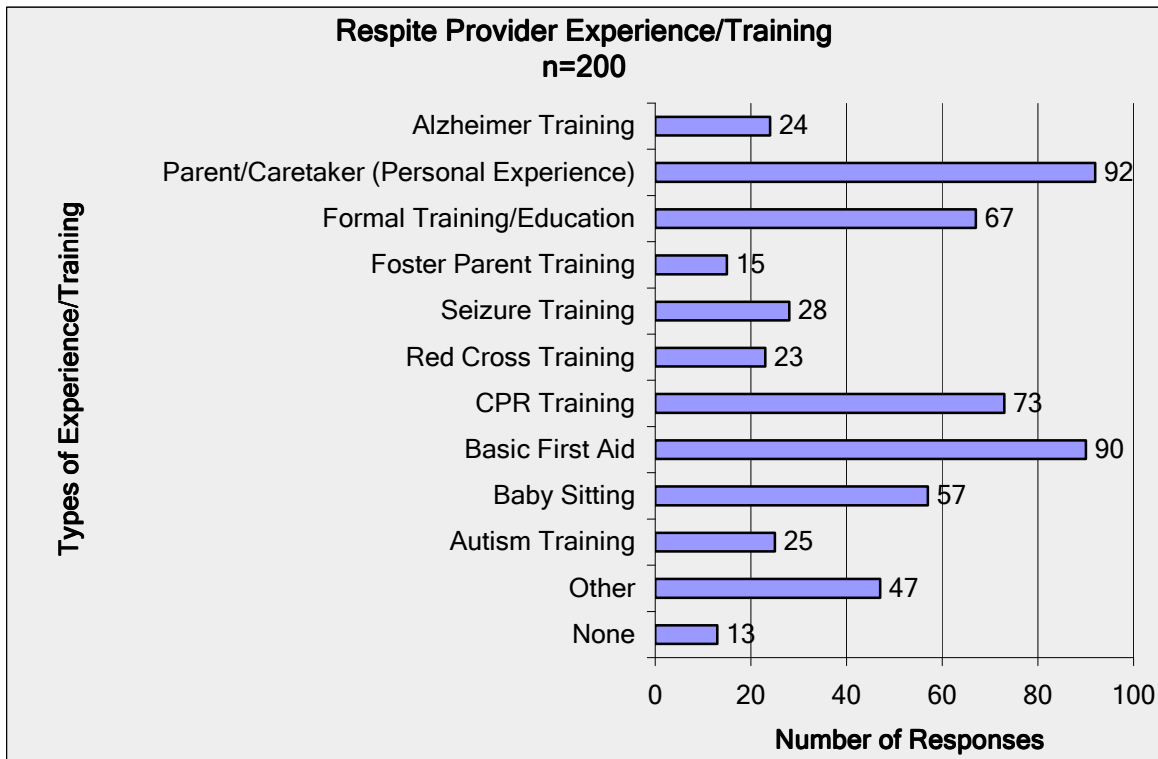


Figure 17: Respite Provider Experience/Training

The caregivers who have used respite services were then asked how their respite services were paid for. Figure 18 illustrates that most of the caregivers had received financial assistance from area agencies (60.8%, n=129) and/or paid out of pocket (54.2%, n=115). Only a handful of respite providers were paid for by insurance companies (2.8%, n=6) or were free of charge (3.3%, n=7). Of the “Other” responses, eleven caregivers identified grants as the source of their respite care funding. The remaining thirteen “Other” responses more explicitly described their payment process for respite care, such as reimbursement methods or the names of specific area agencies.

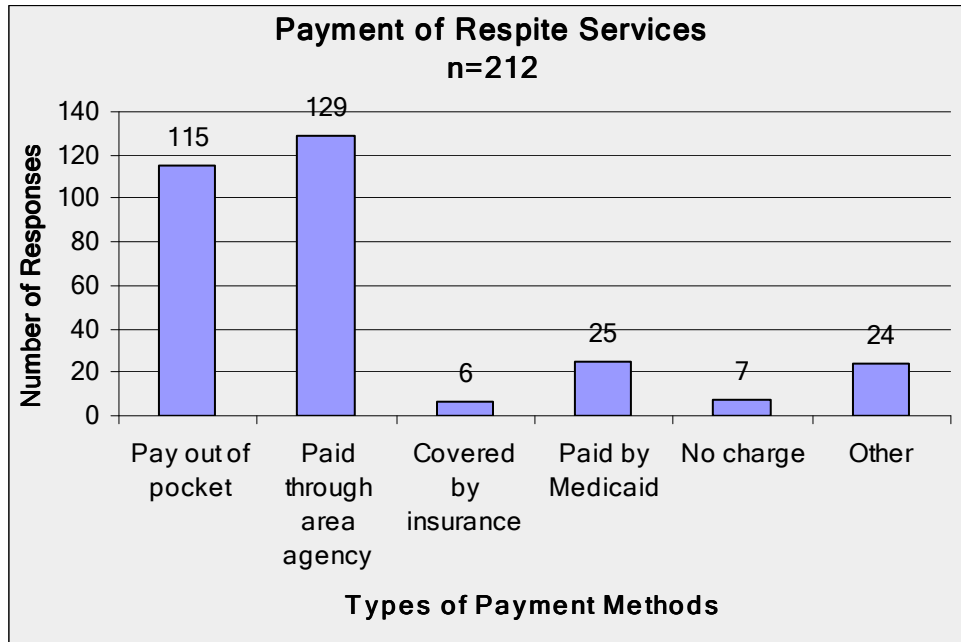


Figure 18: Payment of Respite Services

Regardless of their previous use of respite services, all caregivers who participated in this survey were asked about the barriers they have encountered when considering respite care. As Figure 19 shows, nearly half of the caregivers identified a lack of funds as a barrier in utilizing respite services. The next greatest barrier identified was the respite providers' lack of training/knowledge about the special health care needs of the care recipients. It also appears that high turn over rates do not seem to be a major barrier once caregivers have found a respite provider. However, this could be due to the heavy use of family and friend/neighbor as respite providers (Figure 15). Furthermore, the answer options for this question did not provide a "Not Applicable" category. Therefore, nearly half of the "Other" responses were of this nature, some of which stated that they have experienced no barriers in receiving respite services. The remaining "Other" responses explained in further detail financial hardships, difficulty finding medically trained providers, discomfort and uncooperation of the care recipient, and a general lack of knowledge about resources and providers in their areas.

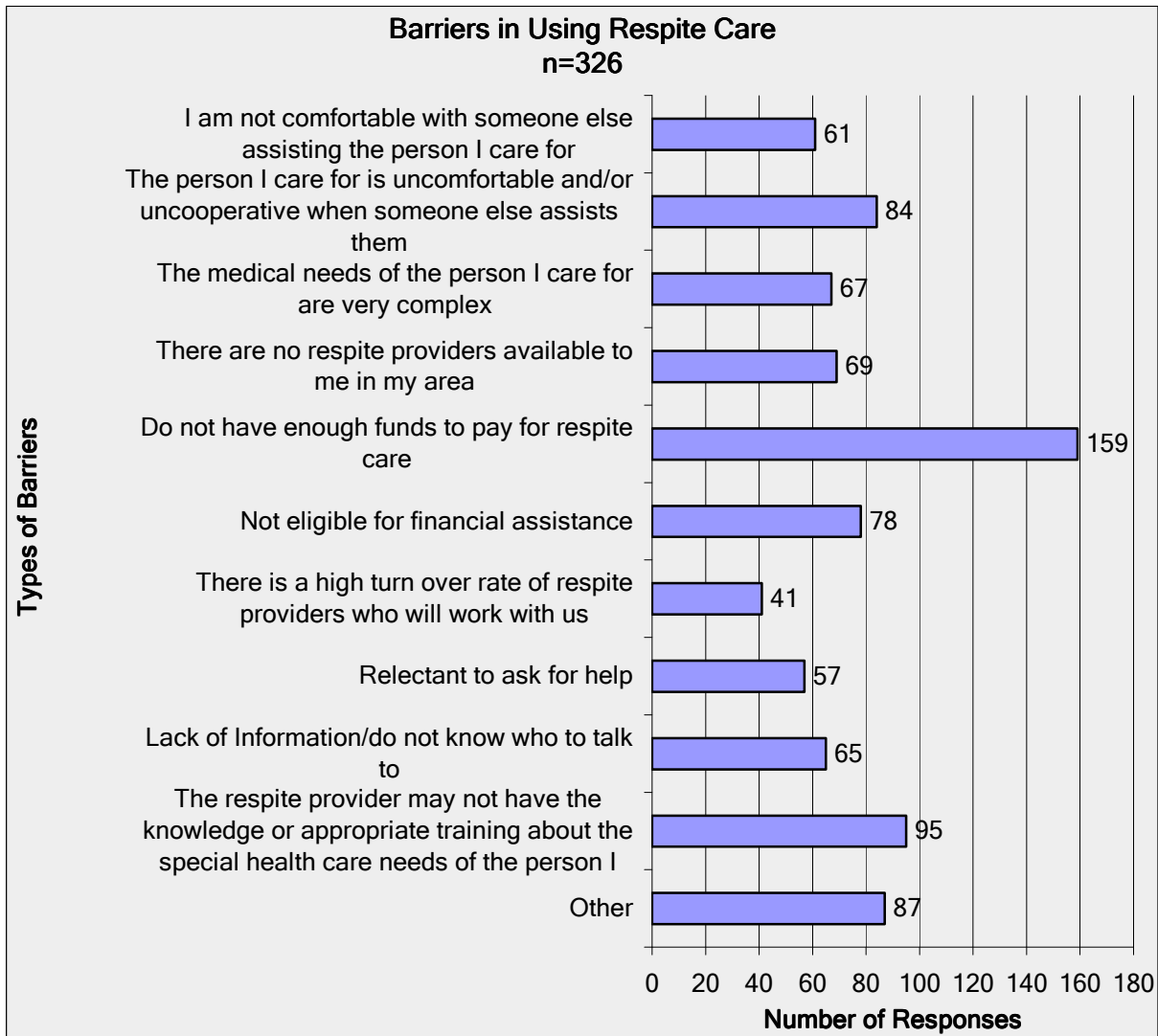


Figure 19: Barriers in Using Respite Care

Respite Care Funding

Part of the Caregiver Needs Assessment also focused on the short term funding available to caregivers and their utilization of these funds. Initially, all of the participating caregivers were asked if they had short term funding available to them for respite care. As Figure 20 shows, roughly a third of every response type (“Yes”, “No”, and “Don’t Know”) was reported. It may be possible that the caregivers that reported “Don’t Know” need more resources and information made available to them about various types of respite care funding options, such as grants through the Alzheimer’s Association, the Veterans Association, and more.

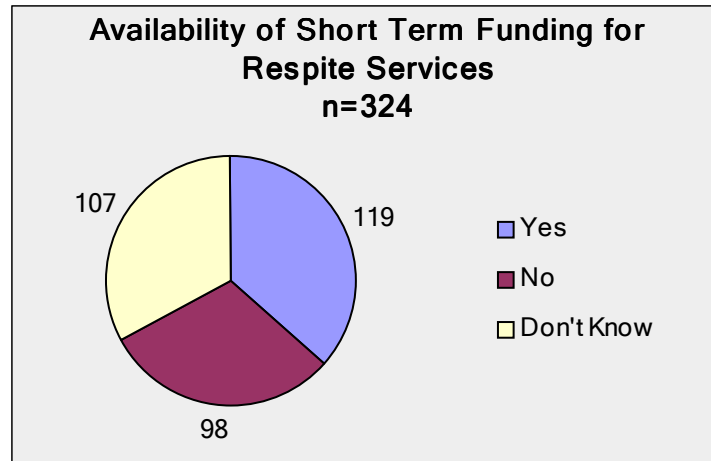


Figure 20: Availability of Short Term Funding for Respite Services

For all of the caregivers that answered “Yes” to having short term funding for respite services available to them, a follow up question asked if they actually use these funds towards respite services. This question was utilized to determine if caregivers actually use the funds towards respite care, if they feel compelled to use these funds towards their care recipients or if caregivers are reluctant to ask for help (Figure 19), or some other reasons. Of the 119 caregivers with short term funding (answered “Yes” in Figure 20), nearly 90% (n=107) of them reported using these funds towards respite care (Table 9).

Use of Short Term Funding	
n=119	
Yes	107
No	12

Table 9: Use of Short Term Funding

The remaining 12 caregivers who reported not using their available short term funding for respite care towards these services were then asked why. Figure 21 reveals that the lack of respite care providers, discomfort using respite providers (by both the care recipient and caregiver), and reluctance to ask for help were all noted as reasons towards not using the funds. For the “Other” category, caregivers elaborated on their care recipient’s unwillingness to cooperate with non-family respite providers, the lack of respite providers in their area, and difficulty in filing all of the appropriate paperwork in a timely fashion.

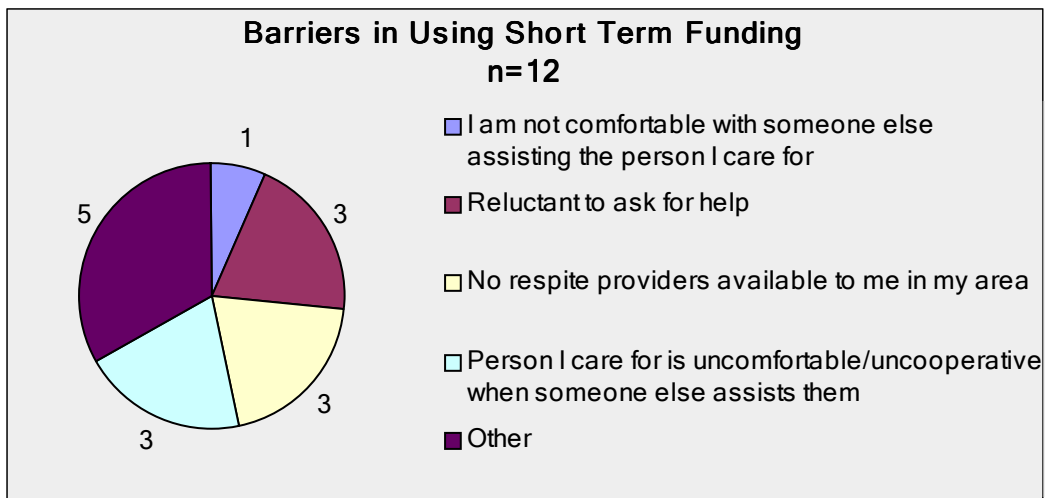


Figure 21: Barriers in Using Short Term Funding

Conclusion

Through the invaluable feedback from caregivers in this survey, the Caregiver Needs Assessment has enabled the NH DHHS to recognize the distribution of caregivers within the state and their overall needs. This evaluation summary provides a snapshot into the needs and preferences of NH caregivers regarding the types of services they utilize, gaps in these services and their preferences in respite care. With this information, the NH DHHS and the Lifespan Respite Coalition aims to direct future energy and resources into efficiently accommodating caregivers into where they have indicated their greatest needs.