
ONE-TIME RESPITE CAREGIVER OUTCOMES EVALUATION

FISCAL YEAR 2016

Summary

- Fiscal Year 2016 was the third year one-time respite was provided to a random selection of people on the waiting list.
- Significant decreases in caregiver stress and increase in quality of life were found for FY14 and FY15 recipients.
- FY14 recipients found a significant improvement across all indicators, including quality of life, increased time with spouse, and increased time with other children, among others.
- FY15 also saw a significant increase in quality of life of the caregiver due to the one time respite.
- FY16 found significant increases in quality of life and time spent with family members, as well as a decrease in the amount of stress that the caregiver felt over the care of a family member with disabilities.

Introduction

The 2013 legislative session passed Senate Bill 259, which allows non-lapse funds to be used for one-time respite services for those who are on the waiting list for ongoing services (Section 62A-5-102). From FY14 through FY16, the Division distributed between \$3,000 and \$5,000 to a randomly assigned subset of individuals on the waiting list. The funds differed between fiscal years due to the amount of non-lapse funds. These funds were used for respite services, but could be utilized in any quarter hour increments desired by the family. This service is only in its third year, so in order to properly evaluate the impact of the allotment, regular evaluations must be conducted. This analysis was done to evaluate the impact that these services have on the caregivers both during the services and after the services are complete.

Research Design and Methodology

The purpose of this analysis was to investigate what, if any, impact these one-time respite services had on the caregivers who received them. The ultimate goal is to determine if there is a difference in attitude toward each of the indicators listed in Table 1 between the time they received one-time services and when the one-time services were finished.

Table 1

Indicator	Measure
Spouse	Had enough time to spend with spouse or partner
Children	Had enough time to spend with my other children
Responsibilities	Had enough time for my daily responsibilities
Health	Had enough time for my personal health
Time	Had enough personal time
Quality	Was satisfied with my overall quality of life
Stress	Felt stress over caring for my family member with disabilities

To measure the impact of respite services for families on the waiting list, the Division of Services for People with Disabilities conducted a retrospective survey covering a variety of topics for the caregiver's overall quality of life and available time to spend on various activities. The survey was sent out to each of the caregivers of those who received the one-time services. There were 804 surveys sent out and the Division received completed surveys from 366 families, giving an overall response rate of 45.52%.

Once the results of the survey were received, chi-square analysis was used to determine whether or not there was a significant difference between the time period during-services and the time period post-services. Additionally, as a more descriptive measure, the means for each variable were calculated. This helps to inform of the direction of the change in attitude.

Demographics

Of the primary caregivers who returned the surveys, 93.91%, were the parent of the individual who received the one-time respite services. The other six percent were comprised of grandparents, children, siblings, a landlord and a guardian. Additionally, 82.92% of respondents were married. Of those who were not classified as married, 67.74% reported that they were the only adult caretaker in the household.

Of those that received the services, 54.10% were male and 45.90% were female. Nearly half of the individuals, 49.18%, were under the age of 18 at the time that services began. Another 40.71% were between 18 and 29, and the remaining 9.56% were between 30 and 49. There were only two individuals, comprising 0.55%, receiving services who were over the age of 49. Additionally, all individuals who took part in the one-time respite services were those with intellectual disabilities or related conditions. Just under 44% of participants (43.99%) were people with intellectual disabilities while the remaining 56.01% were people with related conditions.

Survey Design

This survey was designed as a retrospective case study investigating seven different indicators associated with quality of life. The survey includes questions that ask each respondent to score the indicators in the time period that they were receiving the one-time respite services, as well as the time period after respite services had ended. The options given were based on a 5-point Likert Scale ranging from 'strongly disagree' to 'strongly agree.' Using this scale, 'strongly disagree' was given a value of 1, and 'strongly agree' was given a value of 5.

Each survey also contained a number which could be linked back to the consumer's demographic information. This allowed a select few Division research staff to confidentially gather gender, age, and type of disability. This data was used solely for the purpose of descriptive statistics.

Results

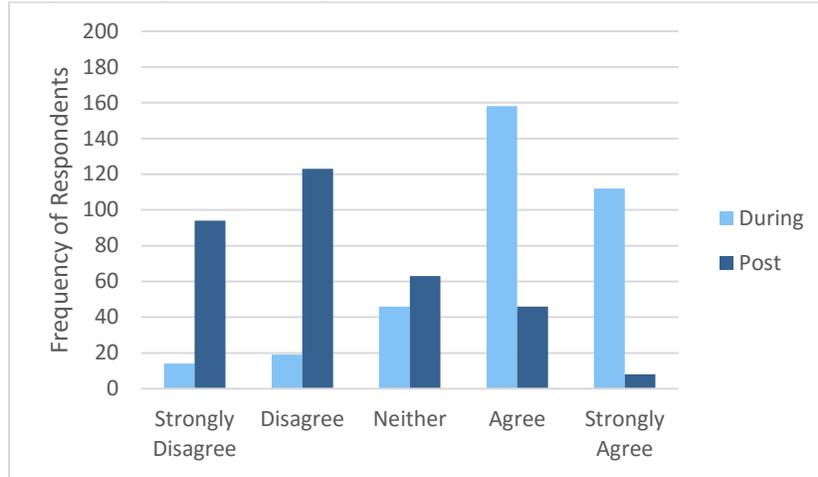
Using chi-square analysis, each indicator was found to have a significant difference from the time period during the one-time service to the time period post services. A summary of the results can be found in Appendix A. Below is an individual analysis of each of the seven variables.

Spouse

Graph 1 shows the frequency of responses to whether or not the caregiver had enough time to spend with their spouse, both during services and after services. The average response during services was 3.95 indicating that the most frequent response was 'agree.' Overall during services, 77.36% of the respondents report that they agree or strongly agree that they had enough time to spend with their spouse. After respite services had ended, the average score was a 2.25 which shows that the average answer was between

'disagree' and 'neither.' After respite services had concluded, 64.97% of respondents indicated that they 'disagree' or 'strongly disagree' that they had enough time with their spouse.

Graph 1. Caregiver had enough time to spend with spouse

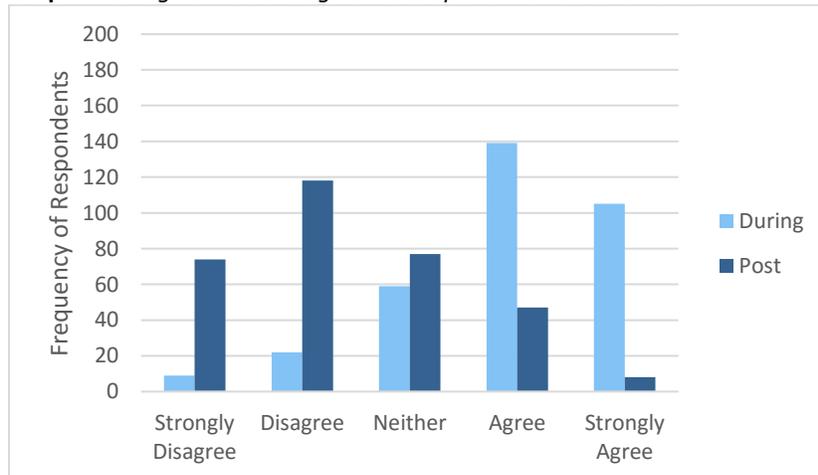


$\chi^2=289.513$ $p<.0001$

Children

Graph 2 shows the frequency of responses to whether or not the caregiver had enough time to spend with their other children, both during services and after services. The average response during services was 3.93 indicating that the most frequent response was 'agree.' Overall during services, 73.05% of the respondents report that they agree or strongly agree that they had enough time to spend with their other children. After respite services had ended, the average score was a 2.37 which shows that the average answer was between 'disagree' and 'neither.' After respite services had concluded 59.26% of respondents indicated that they 'disagree' or 'strongly disagree' that they had enough time with their other children.

Graph 2. Caregiver had enough time to spend with other children



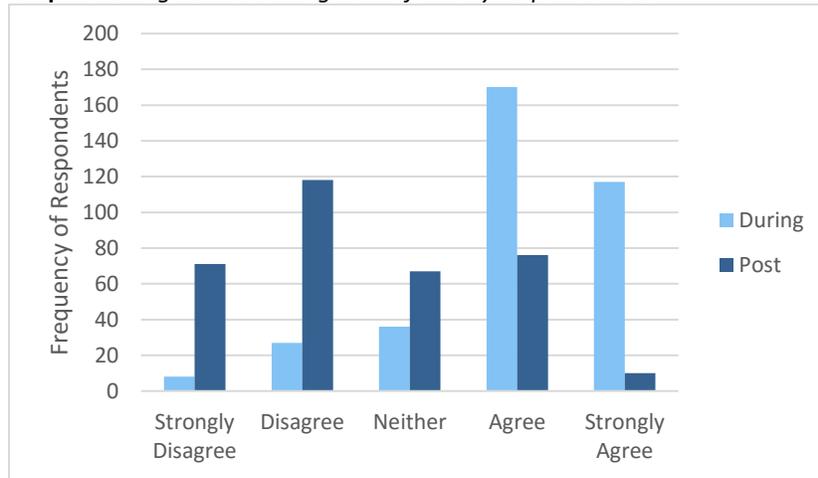
$\chi^2=242.567$ $p<.0001$

Responsibilities

Graph 3 shows the frequency of responses to whether or not the caregiver had enough time to spend on their daily responsibilities, both during services and after services. The average response during services was 4.00 indicating that the most frequent response was 'agree.' Overall during services, 80.17% of the respondents report that they agree or strongly agree that they had enough time for their daily responsibilities. After respite services had ended, the average score was a 2.52 which shows that the average

answer was between 'disagree' and 'neither.' After respite services had concluded, 55.26% of respondents indicated that they disagree or strongly disagree that they had enough time for their daily responsibilities.

Graph 3. Caregiver had enough time for daily responsibilities

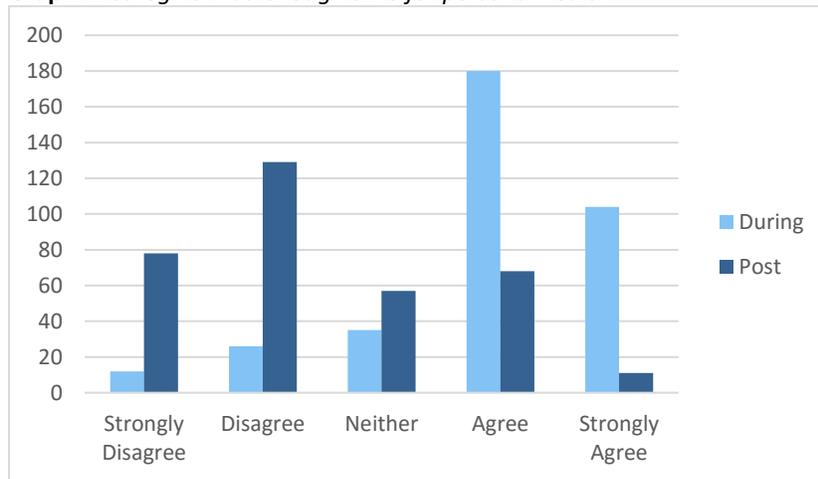


$\chi^2=242.510$ $p<.0001$

Health

Graph 4 shows the frequency of responses to whether or not the caregiver had enough time to spend on their personal health, both during services and after services. The average response during services was 3.95 indicating that the most frequent response was 'agree.' Overall during services, 79.55% of the respondents report that they 'agree' or 'strongly agree' that they had enough time for their personal health. After respite services had ended, the average score was a 2.43 which shows that the average answer was between 'disagree' and 'neither.' After respite services had concluded, 60.35% of respondents indicated that they 'disagree' or 'strongly disagree' that they had enough time for their personal health.

Graph 4. Caregiver had enough time for personal health



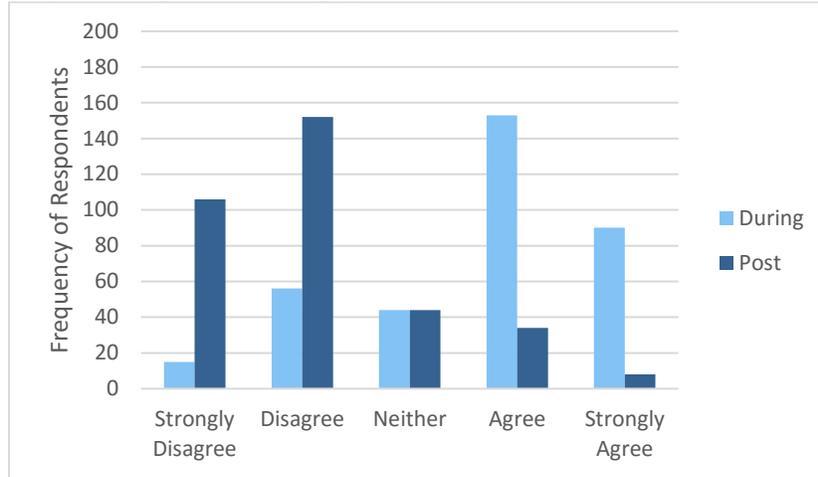
$\chi^2=274.895$ $p<.0001$

Time

Graph 5 shows the frequency of responses to whether or not the caregiver had enough personal time, both during services and after services. The average response during services was 3.69 indicating that the most frequent response was between 'neither' and 'agree.' Overall during services, 67.88% of the respondents report that they 'agree' or 'strongly agree' that they had enough personal time. After respite services had ended, the average score was a 2.09 which shows that the average answer was 'disagree.' After respite

services had concluded, 75.00% of respondents indicated that they ‘disagree’ or ‘strongly disagree’ that they had enough personal time.

Graph 5. Caregiver had enough personal time

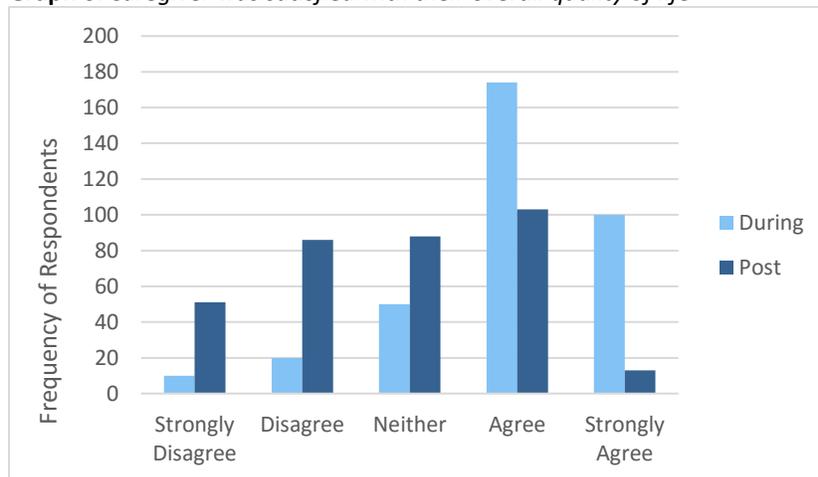


$\chi^2=256.908$ $p<.0001$

Quality

Graph 6 shows the frequency of responses to whether or not the caregiver was satisfied with their overall quality of life, both during services and after services. The average response during services was 3.94 indicating that the most frequent response was ‘agree.’ Overall during services, 77.40% of the respondents report that they ‘agree’ or ‘strongly agree’ that they had enough personal time. After respite services had ended, the average score was a 2.83 which shows that the average answer was between ‘disagree’ and ‘neither.’ Interestingly, just 40.18% of respondents said that they ‘disagree’ or ‘strongly disagree’ that they are satisfied with their overall quality of life after respite services had concluded. The majority of individuals marked ‘neither’ or ‘agree’ with their overall satisfaction with their quality of life.

Graph 6. Caregiver was satisfied with their overall quality of life



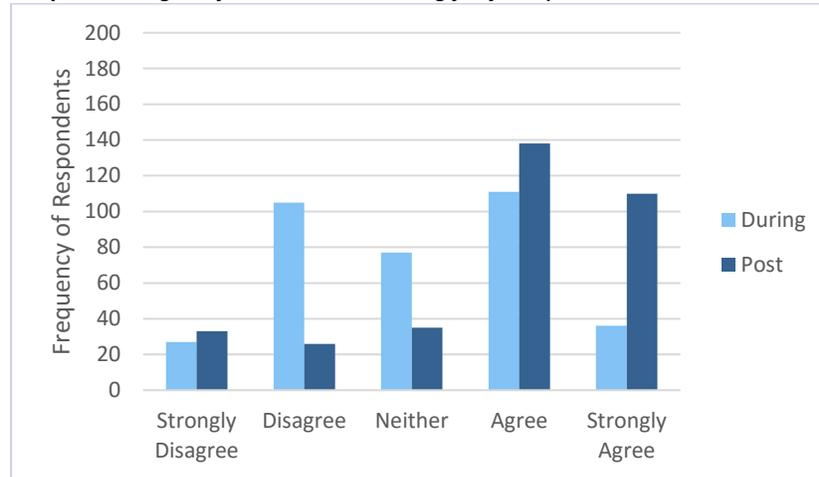
$\chi^2=164.110$ $p<.0001$

Stress

Graph 7 shows the frequency of responses to whether or not the caregiver felt stress over caring for a family member with disabilities, both during services and after services. The average response during services was 3.07 indicating that the most frequent response was ‘neither.’ Overall during services, 37.08% of the respondents report that they ‘disagree’ or ‘strongly disagree’ that they felt stress over the care for their family

member, and 41.29% said that they 'agree' or 'strongly agree' that they felt stress. After respite services had ended, the average score was a 3.78 which shows that the average answer was between 'neither' and 'agree.' After respite services had concluded, 17.25% of respondents said that they 'disagree' or 'strongly disagree' that they felt stress over the care for a family member with disabilities, whereas 72.51% marked that they 'agree' or 'strongly agree' that they felt stress. While the level of stress was primarily distributed across the categories of 'disagree,' 'neither,' and 'agree' during the services, the responses were concentrated between 'agree' and 'strongly agree' after the services ended, indicating that there was a greater amount of stress among caregivers after the services ended than during the one-time respite services.

Graph 7. Caregiver felt stress over caring for family member with disabilities



$\chi^2=104.187$ $p<.0001$

Overall, those who received respite services seem to have an increase in the amount of time spent with their spouse and other children, more time to spend on themselves, and an improved quality of life. Nearly everyone who was involved in this process indicated that they would be interested in receiving respite services again. In total, 96.03% of caregivers would take advantage of this opportunity again, while 2.55% say they would 'maybe/not sure' be interested, and 1.42% say they would not be interested in receiving the service again.

Of those who received the services, 54.09% said that there was an appropriate amount allocated to them for their needs. Another 20.18% marked 'maybe/not sure' if the amount was appropriate, and 25.73% indicated that it was not enough to meet their needs.

The last question on the survey asked caregivers for any other feedback that they have on the respite services. There were four main themes among the responses to the open ended question. The top answers are as follows:

1. The respite services were incredibly helpful, and the family would love to have access to this opportunity again.
2. The paperwork was too cumbersome and there was not enough instruction to help with the process of getting services set up.
3. The services were not only good for the caregiver, but the program gave the individual with disabilities a chance to have social interactions outside the family, which was a positive experience.
4. One of the greatest benefits was being able to spend time with their spouse without having to worry about the care for their child with disabilities. Many marriages have been strained due to stress and care of their family members, but the respite greatly helped those relationships.

Conclusion

Fiscal Year 2016 was the third year that one-time respite services were offered. As it is still in its early years, it is critical to evaluate the impact that this is having on the caregivers to those with disabilities. The purpose of the respite funds are to help alleviate stress and better their quality of life by allowing caregivers to spend more time with their family members as well as increasing personal time. Overall, the respite funds have accomplished this goal. Through the comments, it is clear that there is room for improvement, particularly in assisting with the paperwork and the process of setting up services. Despite those hardships, most caregivers found the respite services to be incredibly helpful for both themselves, and the individual with disabilities who received the services.

Appendix A

Summary chart of survey results

Measure	Mean Score During Services	Most Common Answer During Services'	Mean Score After Services	Most Common Answer After Services	Chi-Square Coefficient	Significance
Had enough time to spend with spouse or partner	3.95	Agree	2.25	Disagree	289.513	p<0.0001
Had enough time to spend with other children	3.93	Agree	2.37	Disagree	242.567	p<0.0001
Had enough time for daily responsibilities	4.00	Agree	2.52	Disagree	242.510	p<0.0001
Had enough time for personal health	3.95	Agree	2.43	Disagree	274.895	p<0.0001
Had enough personal time	3.69	Agree	2.09	Disagree	256.908	p<0.0001
Was satisfied with my overall quality of life	3.94	Agree	2.83	Agree	164.110	p<0.0001
Felt stress over caring for my family member with disabilities	3.07	Agree	3.78	Agree	104.187	p<0.0001