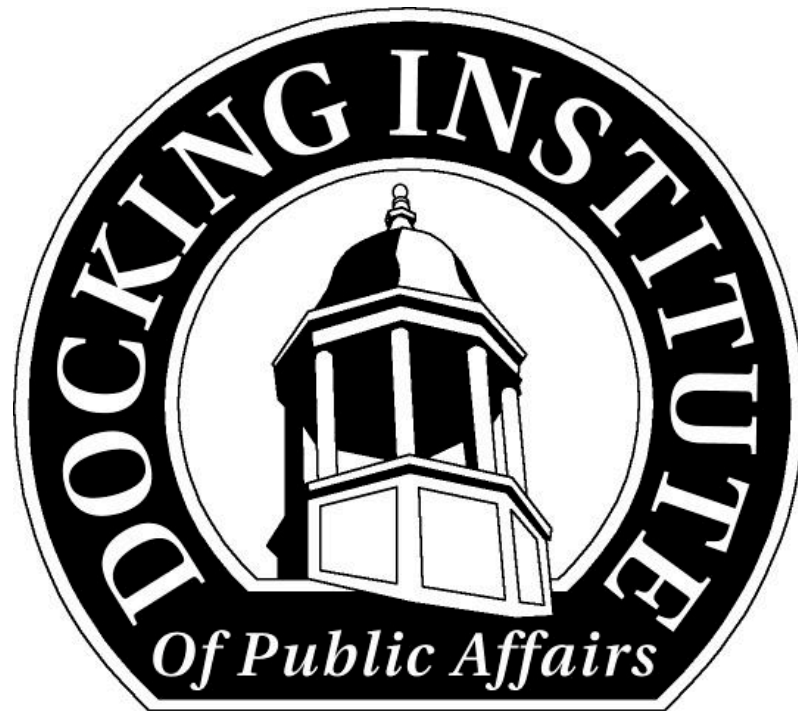
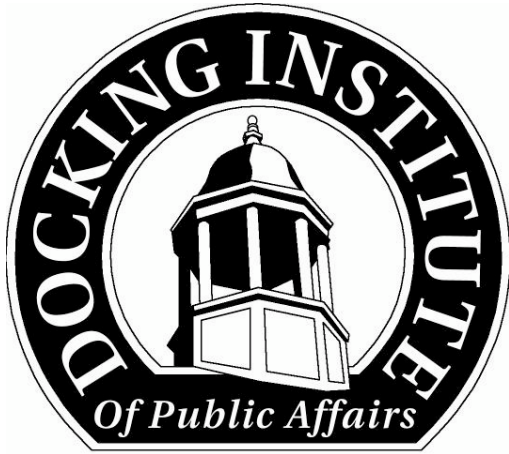


The Economic Impact of Natural Care Giving Among MRDD and PD Waiver Consumers in Kansas



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The staff of the **Docking Institute of Public Affairs** and its **University Center for Survey Research** are dedicated to serving the people of Kansas and surrounding states.

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This research was sponsored by the Kansas Department of Social and Rehabilitation Services, with matching contribution from Fort Hays State University.

This publication was prepared by the Docking Institute of Public Affairs. The statements, findings, and conclusions are those of the authors and do not necessarily reflect the views of the Kansas Department of Social and Rehabilitation Services.

Executive Summary

The Docking Institute of Public Affairs was commissioned to conduct an economic impact analysis of natural care giving among mentally retarded/developmentally disabled (MRDD) and physically disabled (PD) consumers in the state of Kansas. The Institute conducted surveys of caregivers and consumers to answer the study's research questions.

The objectives of the study were to:

- Analyze the socio-demographic profile of natural caregivers.
- Ascertain the previous and current employment history (including salary/wages) of natural caregivers.
- Determine expenses of natural caregivers associated with care giving.
- Examine natural care giving patterns (including time spent, number of caregivers per consumer, etc.).
- Determine the opportunity costs associated with natural care giving.
- Determine the extent to which consumers rely upon natural care givers.
- Examine the personal budgets and expenditures of consumers, including necessary and discretionary items.
- Discern the potential impacts of a reduction in MRDD and PD waiver funding.

The Docking Institute's independent analysis finds that:

- The personal budgets of both consumers with MRDD and consumers with PD show that average income fails to meet average expenses.
- The average monthly income statement for consumers with MRDD shows that total expenses of \$1,175.75 are paid for with \$637.43 of total income plus \$270.96 of estimated average cash value of unpaid assistance plus \$267.37 of unreported assistance.
- The average monthly income statement for consumers with PD shows that total expenses of \$1,309.44 are paid for with \$702.21 of total income plus

\$226.55 of estimated average cash value of unpaid assistance plus \$380.68 of unreported assistance.

- A reduction in MRDD waiver PIL is likely to result in reduced spending on clothing and recreation.
- A reduction in PD waiver PIL is likely to result in reduced spending on clothing, food, and household items.
- Natural caregivers for consumers with MRDD who do not work forego significant income either because they do not earn the income of paid caregivers (\$416 per week on average) or because they do not work (\$570 per week on average in previous employment or \$828 per week on average for those currently employed).
- Natural caregivers for consumers with PD generally have a lower level of educational attainment compared with natural caregivers for consumers with MRDD. Generally, those with less education have fewer job opportunities and lower lifetime earnings. The income opportunities for natural caregivers for consumers with PD range from \$200 per week on average to \$302 per week on average.
- Natural caregivers for consumers with MRDD provide care for a longer time (16.5 years on average) and more hours per week (57 hours on average) compared with natural caregivers for consumers with PD (6.2 years and 55 hours per week on average).

Methods

Survey Methodology

The Docking Institute gathered data on four populations: (1) consumers with mental retardation/developmental disability (MRDD) and (2) these consumers' respective caregivers, and (3) consumers with physical disability (PD) and (4) these consumers' respective caregivers. The Kansas Department of Social and Rehabilitation Services (SRS) randomly selected consumers receiving services through the MRDD and PD waivers from across the state, and provided those lists to the Docking Institute. In all phases of this project the Institute complied with HIPPA regulations in addition to the normal survey research ethic to protect the confidentiality of respondents' information. The list of consumers with MRDD also contained the consumer's respective caregiver, and for those consumers who listed no caregiver, case manager contact information was provided. Caregivers of consumers with MRDD were asked to fill out a questionnaire inquiring about caregiver characteristics. The caregivers were treated as survey informants for consumers with MRDD by providing these caregivers with a questionnaire inquiring about consumer characteristics to be filled out on behalf of the consumer with MRDD. Where no caregiver was associated with a consumer with MRDD, the consumer's case manager was treated as a survey informant for consumers with MRDD. Because SRS lists of PD waiver recipients did not contain any contact information with regard to respective caregivers, the Institute provided to consumers with PD a survey packet to be passed on to their respective caregiver.

This survey administration methodology resulted in surveys targeting five separate units of observation, and Table 1.0 reports final dispositions of these five surveys. All five surveys were conducted in three mailing waves, with the second and third waves being follow up attempts to collect completed questionnaires from non responders to a previous wave. All targeted respondents received a cover letter explaining the reason for the study, the sponsor of the study, instructions for completing and returning the questionnaire, and assurances that the confidentiality

of all individuals would be preserved. The self-administered mail survey included return postage to the Docking Institute.

Table 1.0 clearly shows that response rates were higher among those surveyed in relation to the study of care giving to consumers with MRDD (52%, 52%, and 66%) than among those surveyed in relation to care giving to consumers with PD (38% and 35%). Although the response rate for consumers with PD and caregivers for consumers with PD were relatively low, the patterns revealed by the responses were similar to the patterns associated with consumers with MRDD and caregivers of consumers with MRDD. Another wave of mailed questionnaires would not have been productive. Telephone contact was not used as the survey was quite lengthy and many consumers with PD do not have telephones.

Table 1.0. Survey Dispositions and Response Rates of Five Surveyed Groups

	Consumers with MRDD	Caregivers of MRDD	Case Managers of MRDD	Consumers with PD	Caregivers of PD
Responded	256	251	176	172	158
Refused	8	9	5	5	4
No reply	224	222	85	281	293
Ineligible*	21	27	23	52	55
Response rate**	52%	52%	66%	38%	35%

*Includes situations like undeliverable questionnaires, consumers with no caregivers, care giver/case manager does not have sufficient information to act as informant, no longer receiving waiver services.

** Response rate = responded/(responded + refused + no reply)

Survey Instrument

The Docking Institute and SRS agreed on the survey items used. It was the Institute's responsibility to develop survey items that were technically correct and without bias. Question wording and the design of the survey instrument are the property of the Docking Institute and are not to be used for additional surveys unless

written permission is given by the Director of the Institute. The survey instruments are available from the Docking Institute of Public Affairs.

Introduction

The following analysis is based on survey data provided by natural and paid caregivers, and by consumers themselves. It should be noted that for the natural, or unpaid, caregivers of consumers with physical disability (PD) the number of respondents was rather small. Therefore analysis and conclusions for that subgroup should be considered tentative.

Section 1 – A Profile of Natural Caregivers

The focus in this section is on natural, or unpaid, caregivers. Natural caregivers – persons who are family members or friends of a person with a disability and who provide care without remuneration – constitute a significant resource for consumers. Responses from survey informants for consumers with mental retardation developmental disabilities (MRDD) and from consumers with physical disabilities (PD) indicated that more than half of the consumers receive some unpaid care (Table 1.1). The percentages shown in Table 1.1 are of those respondents who answered the relevant questions on the surveys for consumers and for caregivers (for example, N = 360). Just over 1/3 of the consumers in each category received a majority of their care from an unpaid caregiver, The two groups diverged, however, in their likelihood of receiving all their care from natural caregivers. About one out of every eight consumers with MRDD received only unpaid care, almost three times the rate for consumers with PD.

Table 1.1 – Unpaid Care Giving

	Consumers with MRDD (N=360)	Consumers with PD (N=131)
Percentage of consumers receiving unpaid care	51.7%	56.5%
Percentage of consumers receiving more than 50% of their care unpaid	34.2%	34.4%
Percentage of consumers receiving all of their care unpaid	12.2%	4.6%

Although there is considerable variation in the length of time natural caregivers have been involved with their consumers, many respondents indicate

rather high levels of experience. Table 1.2 reveals that half of the caregivers for consumers with PD reported providing care for four years or more. Caregivers for consumers with MRDD were even more tenured, with half of the respondents having more than sixteen and a half years experience. As mentioned above, it should be noted that the number of natural caregivers for PD consumers who responded to the survey was rather small, and so less confidence should be placed in the results.

Table 1.2 – Tenure as an Unpaid Caregiver

	Consumers with MRDD N=184	Consumers with PD N=15
Minimum	.08 years	.08 years
Maximum	68.00 years	15.00 years
Average	16.50 years	6.16 years
Median	14.00 years	4.00 years
Mode	10.00 years	10.00 years

Table 1.3 shows that there was some difference in the educational experience of natural caregivers for consumers with the two types of disabilities. Caregivers of consumers with MRDD were more likely to have graduated from college (48.6%). Of these college graduates 7.7% have an AA degree, 22.1% have a BA degree, and 18.8% have a graduate degree. Only three out of fifteen caregivers for consumers with PD had graduated from college (20%), two people have an AA degree and one person has a graduate degree.

Table 1.3 – Education of Unpaid Caregivers

Consumers with MRDD	N = 181	Percent	Cumulative Percent
Less Than High School Degree	12	6.6%	6.6%
High School Degree	41	22.7%	29.3%
Some College	40	22.1%	51.4%
AA Degree	14	7.7%	59.1%
BA Degree	40	22.1%	81.2%
Graduate Degree	34	18.8%	100.0%

Consumers with PD	N = 15	Percent	Cumulative Percent
Less Than High School Degree	1	6.7%	6.7%
High School Degree	5	33.3%	40.0%
Some College	6	40.0%	80.0%
AA Degree	2	13.3%	93.3%
BA Degree	0	0.0%	93.3%
Graduate Degree	1	6.7%	100.0%

Table 1.4 shows that many caregivers invest substantial amounts of time with their consumer. Half of natural caregivers for consumers with PD report spending at least 32 hours per week with their consumer, while half of those providing care for consumers with MRDD spend more than 38 hours weekly. About half of the caregivers for both types of consumers (50% for consumers with MRDD and 43% for those with PD) indicate that they are with their consumer for at least 40 hours per week.

Most natural caregivers reside with their consumer, likely a reflection of the fact that many of them are family members (Table 1.5). Caregivers for both types of consumers were almost equally likely (61.2% for MRDD vs. 64.3% vs. for PD) to live with their consumer.

Table 1.4 – Hours per Week with Consumer

	Consumers with MRDD N=158	Consumers with PD N=14
Minimum	1	2
Maximum	168	168
Average	57	55
Median	38	32
Mode	168	NA
Percentage spending 40 or more hours weekly with consumer	50%	43%

Table 1.5 – Residence of Unpaid Caregiver

	Consumers with MRDD N=183		Consumers with PD N=14	
Live with consumer	112	61.2%	9	64.3%
Live elsewhere	71	38.8%	5	35.7%

Not surprisingly, Table 1.6 reveals that natural caregivers who reside with their consumer tend to provide much more care than those who do not. For both consumers with MRDD and consumers with PD, resident caregivers reported providing an average of about 80 hours of care per week. Half of caregivers for consumers with MRDD who did not live with the consumer provided less than 3 hours of care weekly, while half of consumers with PD caregivers who lived apart from them provided less than 12.5 hours weekly.

Table 1.6 – Unpaid Caregiver Residence and Hours of Care Provided per Week

	Consumers with MRDD		Consumers with PD	
	Live with consumer N=102	Live elsewhere N=56	Live with consumer N=9	Live elsewhere N=4
Mean	83.29	7.89	78.89	12.25
Median	67.50	3.00	70.00	12.50
Mode	168.00	2.00	N/A	N/A

Despite the hours of care provided by many natural caregivers, many of them are also in the paid labor force (Table 1.7). This is particularly the case for those providing care for consumers with MRDD. In that group, respondents who were

employed outnumbered those who were not by a factor of two to one. Although caregivers for consumers with PD were less likely to work outside the home, the ratio of employed to unemployed was two to three.

Table 1.7 – Unpaid Caregiver Employment

	Consumers with MRDD		Consumers with PD	
	N	%	N	%
Employed outside home	121	66.1%	6	42.9%
Not employed outside home	62	33.9%	8	57.1%

Most caregivers with paid jobs were full-time employees. For both groups, half of those employed outside the home worked 40 hours per week or more (Table 1.8).

Table 1.8 – Unpaid Caregiver Hours Worked Outside Home

	Consumers with MRDD	Consumers with PD
	N= 114	N=5
Mean	38	33
Median	40	40
Mode	40	NA

Table 1.9 reveals that natural caregivers who were also employed continued to provide substantial amounts of care. Among caregivers for consumers with MRDD, half of those with jobs provided more than 34 hours of care per week, and the fact that the mean was 1.5 times that (50 hours) indicates that a number of those caregivers are providing far more hours of care than the median. Those who were caregivers for consumers with PD appeared to provide heroic levels of care, though as in all cases here the possibility that these results are an artifact of the small sample size should be kept in mind. Half of the employed respondents from this group reported spending 76 hours per week or more providing care, while among those who were not employed, half provided at least 22 hours of care.

Table 1.9 – Hours of Care Provided per Week by Employment Status

	Consumers with MRDD		Consumers with PD	
	employed N=104	not employed N=53	employed N=6	not employed N=7
Mean	50	69	83	38
Median	34	35	76	22
Mode	2	168	N/A	N/A

As might be expected, the greater the number of hours caregivers are employed outside the home, the fewer hours of natural care they are able to provide. However, what might not be anticipated is that, at least for caregivers of consumers with MRDD, the statistical association between hours employed outside the home and hours of natural care provided is small in magnitude.¹ In other words, the differences in the hours of care provided by natural caregivers of consumers with MRDD are not explained by the number of hours of employment. For natural caregivers of consumers with PD the number of hours worked seems to have a negative impact on the number of hours of care provided by natural caregivers. However, this may be an artifact of the very small number of respondents who are natural caregivers to consumers with PD.

The average weekly hours of care provided by caregivers of consumers with MRDD who are not employed are quite large (Tables 1.10 and 1.11). About half of them reported having been employed prior to becoming a natural caregiver. Half of these caregivers provide 98 hours of care or more each week. For those caregivers of consumers with MRDD who were not employed before becoming a caregiver, the amount of care provided tended to be smaller. Half of them spend at least 24 hours in care giving each week. Of course, it is impossible for one to work 154 waking hours in a week. However, it is possible that an individual is constantly “on call” for care giving, and it is these types of cases that result in a median value of 154 hours each week. The hours of care provided by the members of these groups suggest that for them the possibility of outside employment was overwhelmed by the demands of care giving.

¹ A discussion of the statistical analysis is in Appendix 1.
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Table 1.10 – Employment Status of Unemployed Unpaid Caregivers Prior to Becoming a Caregiver

	Consumers with MRDD		Consumers with PD	
	N	%	N	%
Employed before becoming caregiver	23	47%	2	50%
Not employed before becoming caregiver	26	53%	2	50%

Table 1.11 – Hours of Care per Week by Prior Employment Status of Unemployed Caregivers

	Consumers with MRDD		Consumers with PD	
	employed	not employed	employed	not employed
	N=21	N=21	N=2	N=1
Mean	95	57	20	2
Median	98	24	20	2
Mode	168	1	N/A	N/A

Table 1.12 shows that natural caregivers for consumers with MRDD who are not employed, but who held jobs prior to care giving, earned about \$9.00 an hour and tended to work full-time. Similarly, caregivers for consumers with PD also tended to be employed full-time, but earned somewhat less, at \$8.50 per hour.

Table 1.12 – Wages of Unemployed Caregivers with Prior Employment

	Consumers with MRDD		Consumers with PD	
	hours	Wages	hours	wages
	N=21	N=18	N=2	N=2
Mean	38	\$ 10.72	40	\$ 8.50
Median	40	\$ 9.00	40	\$ 8.50
Mode	40	\$ 9.00	40	N/A

Table 1.13 reveals that a majority of caregivers would look for work if they did not have their current responsibilities. Almost two-thirds (62.5%) of those caring for consumers with PD reported that they would seek employment if they were not

caregivers. The percentage among caregivers for consumers with MRDD was even higher (80.8%).

Table 1.13. – Unpaid Caregivers Who Would Seek Employment

	Consumers with MRDD		Consumers with PD	
	N	%	N	%
Currently looking for work	10	19.2%	3	37.5%
Would look for work if not caregiver	42	80.8%	5	62.5%

Caregivers without paid employment indicated that they would use their time in a number of ways if they were not responsible for their consumer (Table 1.14). Those who provided care for consumers with MRDD seemed particularly interested in increasing their participation in volunteer activities, while caregivers for consumers with PD were more interested in employment or in doing more unpaid work at home.

Table 1.14 – How Unpaid Caregivers Would Spend Time If Not a Caregiver

	Consumers with MRDD		Consumers with PD	
	Yes	Percent	Yes	Percent
Work at a paid job	64	28.4%	8	34.8%
Do more unpaid work at home	67	29.8%	8	34.8%
Volunteer for other activities	94	41.8%	7	30.4%

In addition to the effort and the hours involved, natural caregivers incur a variety of other costs. Those who do not reside with their consumers must commute. Table 1.15 shows that while a few commute quite long distances, many caregivers live reasonably near their consumer. Half of caregivers for consumers with MRDD have a commute of 18 minutes or less each day. Half of the caregivers for each group of consumers spend \$40.00 or more commuting each month (Table 1.16).

Table 1.15 – Commuting Time Per Day, Natural Caregivers

	Consumers with MRDD N=70	Consumers with PD N=3
Mean	66 minutes	6 minutes
Median	18 minutes	2 minutes
Mode	5 minutes	NA

Table 1.16 – Cost of Commuting Per Month, Natural Caregivers

	Consumers with MRDD N=32	Consumers with PD N=4
Mean	\$ 70.44	\$ 50.00
Median	\$ 40.00	\$ 40.00
Mode	\$ 40.00	\$ 20.00

Tables 1.17 and 1.18 list other potential costs for natural caregivers. These costs include errands that they may run with or on behalf of their consumer, and outside entertainment they may accompany their consumer to and pay for themselves. Half of caregivers for consumers with MRDD spent \$20.00 or more each month on errands and \$40.00 or more on entertainment. The comparable figures for caregivers of consumers with PD were \$27.50 and \$35.00, respectively.

Table 1.17 – Cost of Errands Per Month

	Consumers with MRDD	Consumers with PD
Number of responses	89	6
Mean	\$ 51.03	\$ 55.83
Median	\$ 25.00	\$ 27.50
Mode	\$ 20.00	\$ 20.00

Table 1.18 – Cost of Entertainment Per Month

	Consumers with MRDD	Consumers with PD
Number of responses	87	4
Mean	\$ 54.08	\$ 36.25
Median	\$ 40.00	\$ 35.00
Mode	\$ 100.00	N/A

An additional cost borne by natural caregivers is important though not easily converted to dollars and cents. Caring for a person with a disability can be stressful,

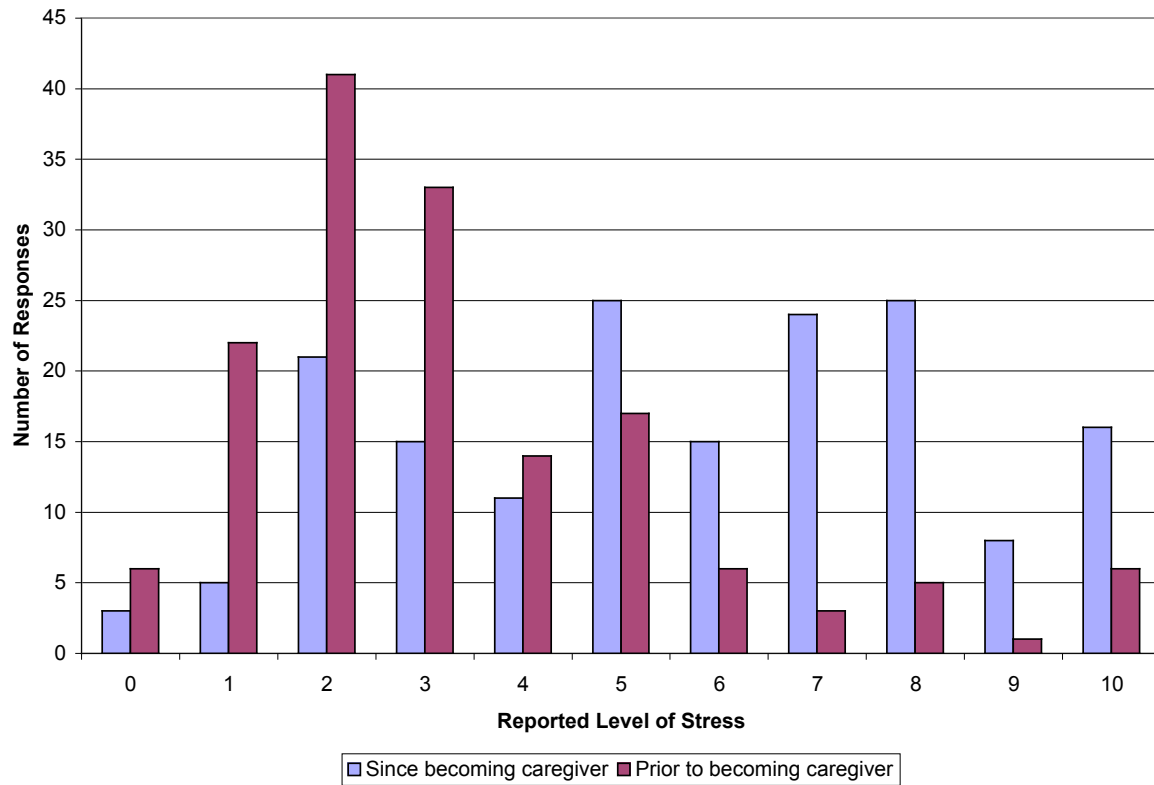
especially for the number of hours of care provided by many respondents. Caregivers were asked to rate their level of stress, both currently and prior to the time they became caregivers, on a ten-point scale. Higher scores reflect higher levels of stress. As can be seen in Table 1.19, caregivers tended to be more likely to report low (categories 1-4) levels of stress prior to becoming a caregiver and were more likely to report high (categories 6-10) levels of stress since becoming a caregiver. On average, the level of stress reported by caregivers for consumers with MRDD increased by 2/3 after becoming a caregiver. Caregivers for consumers with PD reported an increase in stress that was half that size (Table 1.20).

Table 1.19 – Stress and Care Giving, Natural Caregivers

	Consumers with MRDD		Consumers with PD	
	Since becoming caregiver	Prior to becoming caregiver	Since becoming caregiver	Prior to becoming caregiver
No stress	3	6	0	0
1	5	22	0	1
2	21	41	2	3
3	15	33	2	5
4	11	14	0	0
5	25	17	2	3
6	15	6	1	0
7	24	3	2	0
8	25	5	1	0
9	8	1	1	0
Extremely stressed	16	6	1	1

Graphs 1.1 and 1.2 depict the self-estimated stress levels of natural caregivers before becoming a caregiver and afterwards. It is quite clear that there was a shift toward greater levels of stress following becoming a caregiver for a consumer with MRDD. The quantity of data for natural caregivers of consumers with PD limits the certainty that a similar shift occurs among these caregivers.

Graph 1.1 – Stress Levels of Caregivers for Consumers with MRDD



Graph 1.2 – Stress Levels of Caregivers for Consumers with PD

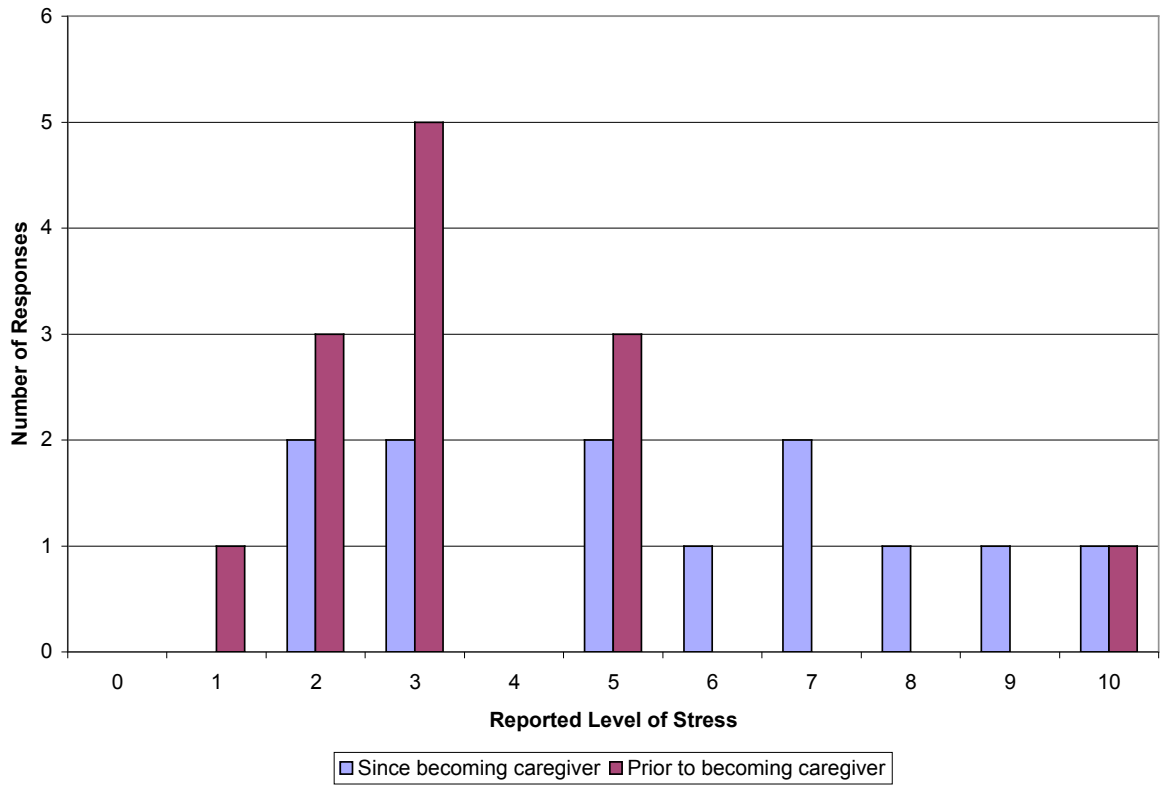


Table 1.20 – Mean Levels of Stress, Prior To and After Becoming a Caregiver

	Consumers with MRDD			Consumers with PD		
	Since becoming caregiver	Prior to becoming caregiver	% change	Since becoming caregiver	Prior to becoming caregiver	% change
Mean stress level	5	3	+67.7%	4	3	+33%

Section 2 – Opportunity Costs for Caregivers of Consumers with MRDD

In this and the following section the focus is on the opportunity costs for all caregivers. Therefore, responses from both natural, or unpaid caregivers and paid caregivers is reported and examined. The following data from the survey of consumers with MRDD provides some insights into the status of the Informant and the amount of time per week that the Informant is with the consumer with MRDD. Table 2.1 represents self-reported informant status. The question allowed, but did not require, multiple responses if the informant fit in more than one category. The category, other, was most often used by parents or other family members.

Table 2.1 – Consumers with MRDD, Informant Status

Guardian	Case Manager	Paid Caregiver	Unpaid Caregiver	Other
207	160	31	46	82

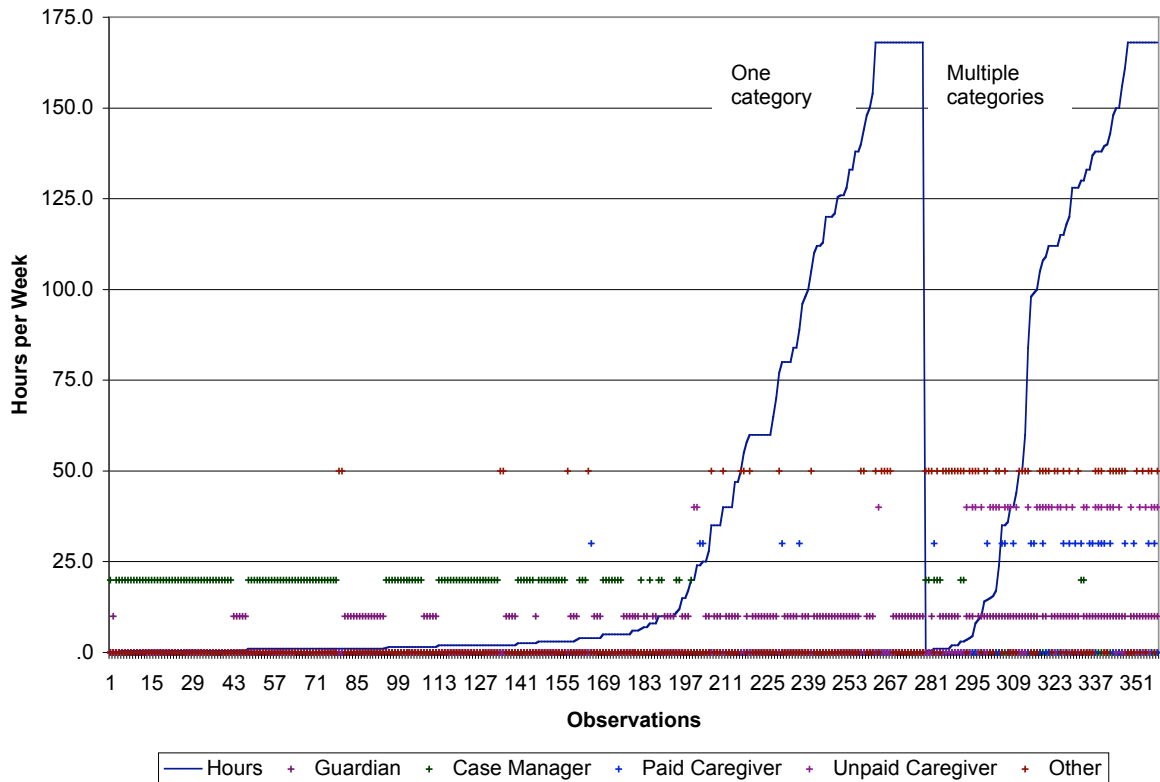
Table 2.2 shows that the distribution of informant time with the consumer with MRDD has a mean value of 42.43 hours per week. However, Graph 2.1 reveals that informant time with consumers with MRDD is not evenly distributed among the various informant status categories. Observations 1 through 279 reflect the hours and status of informants who marked only one informant category. Observations 280 through 358 reflect the hours and informant status of informants who marked more than one informant category. The values (10, 20, 30, 40, and 50) assigned to each informant status category are simply a mechanism to visually separate the data series. Most of the information reported for consumers with MRDD by informants who spend less than 10 hours per week with the consumer comes from case managers. Similarly, most of the information reported for consumers with MRDD by informants who spend more than 40 hours per week with the consumer comes from informants who are guardians (either exclusively or as one of several roles).²

² Appendix 1 contains a more rigorous statistical analysis of the relationships between informant category and hours per week with the consumer with MRDD.

Table 2.2 – Informant Time with Consumer with MRDD per Week

Number of Responses	356
Minimum	0.00
Maximum	168.00
Average (respondents)	42.43
Median	4.00
Mode	1.00

Graph 2.1 - Informant Time with Consumer with MRDD per Week



The following tables are based on the results from 237 valid surveys returned by caregivers of consumers with MRDD. For most of the questions the number of responses was less than 237 as some respondents chose not to answer that particular question.

Table 2.3 shows a distribution of formal educational attainment that is quite similar to the distribution of the general population. The sample of all caregivers for consumers with MRDD reveals slightly lower levels of formal education when

compared with those who are unpaid caregivers (Table 1.3). The opportunity costs associated with care giving are greater for those with higher levels of formal education because education is positively related to lifetime earnings potential.

Table 2.3 – Highest Level of Formal Education (All Caregivers for Consumers with MRDD)

< High School Degree	17	7.3%
High School Degree	59	25.2%
Some College	61	26.1%
AA Degree	16	6.8%
BA Degree	44	18.8%
Graduate Degree	37	15.8%

Table 2.4 provides information about the number of years that caregivers have been giving care to a consumer with MRDD. The average number of years is just over 16 years with a range of 1 month to 68 years. These results for all caregivers are quite similar to those reported in Table 1.2 for unpaid caregivers. The average and median number of years for all caregivers is slightly less than for the unpaid caregivers.

Table 2.4 – Years as a Caregiver (All Caregivers for Consumers with MRDD)

Number of Responses	237
Minimum	0.08
Maximum	68.00
Average (respondents)	16.24
Median	13.83
Mode	10.00

Table 2.5 reveals that consumers with MRDD receive an average 11.84 hours of paid care giving per day and 15.06 hours of unpaid care giving per day. On average consumers with MRDD receive a total of 26.9 hours of care giving per day. The most likely explanation of this apparent impossibility is that care shifts overlap approximately fifteen minutes. So an 8-hour shift with fifteen minutes of overlap at each end is actually 8.5 hours. Three shifts then add up to 25.5 hours per day.

There may also be some slight inflation because respondents rounded up. In other words, the average consumer with MRDD requires 24 hour per day care. This is further supported by the total median hours (22.75) of care giving per day for consumers with MRDD.

Table 2.5 – Hours of Assistance/Care Giving Received by Consumer with MRDD per Day

	Paid	Unpaid
Number of Responses	162	151
Minimum	0.00	0.00
Maximum	72.00	96.00
Average (respondents)	11.84	15.06
Median	7.25	15.50
Mode	24.00	24.00

Tables 2.6 and 2.7 provide evidence about the income associated with paid MRDD care giving as an occupation. Based on the 42 responses to this set of questions (out of the 45 people who indicated they were employed as paid caregivers) the average income is \$416.18 per week (36.5 hours times \$11.40 per hour).

Table 2.6 – Currently Employed as a Paid Caregiver for a Consumer with MRDD

Yes	45
No	184

Table 2.7 – Hours Worked per Week, Hourly Wage (Paid Caregivers for Consumers with MRDD)

	Hours	Wage
Number of Responses	42	43
Minimum	3.00	\$ 4.00
Maximum	168.00	\$ 60.00
Average (respondents)	36.50	\$ 11.40
Median	32.50	\$ 8.00
Mode	40.00	\$ 8.00

Tables 2.8 and 2.9 provide estimates of the income associated with all caregivers of consumers with MRDD who have other paid employment. All caregivers of consumers with MRDD who have other paid employment work an average of 36.28 hours per week (based on 138 responses) and earn an average wage of \$22.81 (based on 113 responses). The average weekly income is \$827.58.

Table 2.8 – Other Paid Employment (All Caregivers for Consumers with MRDD)

Yes	141
No	89

Table 2.9 – Hours Worked per Week, Hourly Wage (Other Paid Employment Caregivers for Consumers with MRDD)

	Hours	Wage
Number of Responses	138	113
Minimum	4.00	\$0.00
Maximum	80.00	\$ 600.00
Average (respondents)	36.28	\$ 22.81
Median	40.00	\$ 12.00
Mode	40.00	\$ 11.00

Tables 2.10 and 2.11 provide estimates of the income associated with all caregivers of consumers with MRDD who were previously employed. These previously employed caregivers of consumers with MRDD worked an average of 37.97 hours per week (based on 38 responses) and earned an average wage of \$15.00 (based on 32 responses). The average weekly income was \$569.58.

Table 2.10 – Previously Employed (All Caregivers of Consumers with MRDD)

Yes	37
No	32

Table 2.11 – Hours Worked per Week, Hourly Wage (Previously Employed Caregivers of Consumers with MRDD)

	Hours	Wage
Number of Responses	38	32
Minimum	10.00	\$ 3.25
Maximum	65.00	\$ 150.00
Average (respondents)	37.97	\$ 15.00
Median	40.00	\$ 9.00
Mode	40.00	\$ 9.00

Tables 2.12 and 2.13 indicate that only 15 caregivers of consumers with MRDD are seeking other employment. For those 15 the primary desired attributes of a new job are higher wages and less stress.

Table 2.12 – Seeking Other Employment (All Caregivers of Consumers with MRDD)

Yes	15
No	212

Table 2.13 – Desired Attributes of New Job (All Caregivers of Consumers with MRDD)

	Less Stress	Higher Wages	More Hours	Fewer Hours	Job Security	Better Benefits
Yes	9	13	3	4	10	12
No	2	1	9	6	4	2

Tables 2.14 and 2.15 provide some insight into how caregivers of consumers with MRDD would use their time if not providing care to a consumer with MRDD. Most of those not currently working would seek paid employment (64/89 = 72%). These individuals could earn an average wage of \$11.40 per hour (Table 2.7) as a paid MRDD caregiver. If they earned the average wage of those caregivers who were employed before they became caregivers of consumers with MRDD (Table 2.11), then they would earn \$15.00 per hour. Finally, if they earned the average of those caregivers of consumers with MRDD who are currently employed (Table 2.9),

they would earn \$22.81 per hour. The opportunity cost of the average unpaid caregiver of a consumer with MRDD ranges between \$416 and \$828 per week. The question on which Table 2.15 is based allowed multiple responses. The responses show a preference ordering among the three choices of volunteering, paid work, and unpaid work.

Table 2.14 – Would Seek Employment If Not a Caregiver (All Caregivers of Consumers with MRDD)

Yes	64
No	108

Table 2.15 – How Spend Time If Not a Caregiver (All Caregivers of Consumers with MRDD)

	Paid Work	Unpaid Work	Volunteer
Yes	99	83	111
No	91	93	71

Tables 2.16 through 2.18 reveal the out of pocket expenses of caregivers of consumers with MRDD, as well as, the informal compensation received by caregivers of consumers with MRDD. The question of “informal compensation” was purposefully undefined in an attempt to get some measure of the extent and size of the unrecorded payments to caregivers. The results indicate that informal compensation for caregivers of consumers with MRDD is relatively minor in both extent and size. The out of pocket expenses were generally somewhat greater for all caregivers compared to those of the natural caregivers reported in Tables 1.17 through 1.19. Although the amounts reported in Tables 2.16 through 2.18 seem relatively insignificant, they should be viewed in the context of the total budgets of consumers with MRDD.

Table 2.16 – Caregiver Monthly Expenses (All Caregivers of Consumers with MRDD)

	Commuting To Job		Running Errands		Entertainment	
	Caregiver Dollars per Month	Consumer Dollars per Month	Caregiver Dollars per Month	Consumer Dollars per Month	Caregiver Dollars per Month	Consumer Dollars per Month
Number	40	12	116	19	111	31
Minimum	5.00	0.00	2.00	0.00	5.00	0.00
Maximum	550.00	130.00	400.00	80.00	275.00	175.00
Average	66.03	53.33	54.28	30.16	52.06	40.48
Median	40.00	0.00	30.00	0.00	40.00	0.00
Mode	40.00	0.00	20.00	0.00	100.00	0.00

Table 2.17 – Informal Compensation (All Caregivers of Consumers with MRDD)

Yes	26
No	199

Table 2.18 – Value of Informal Compensation per Month (Caregivers of Consumers with MRDD)

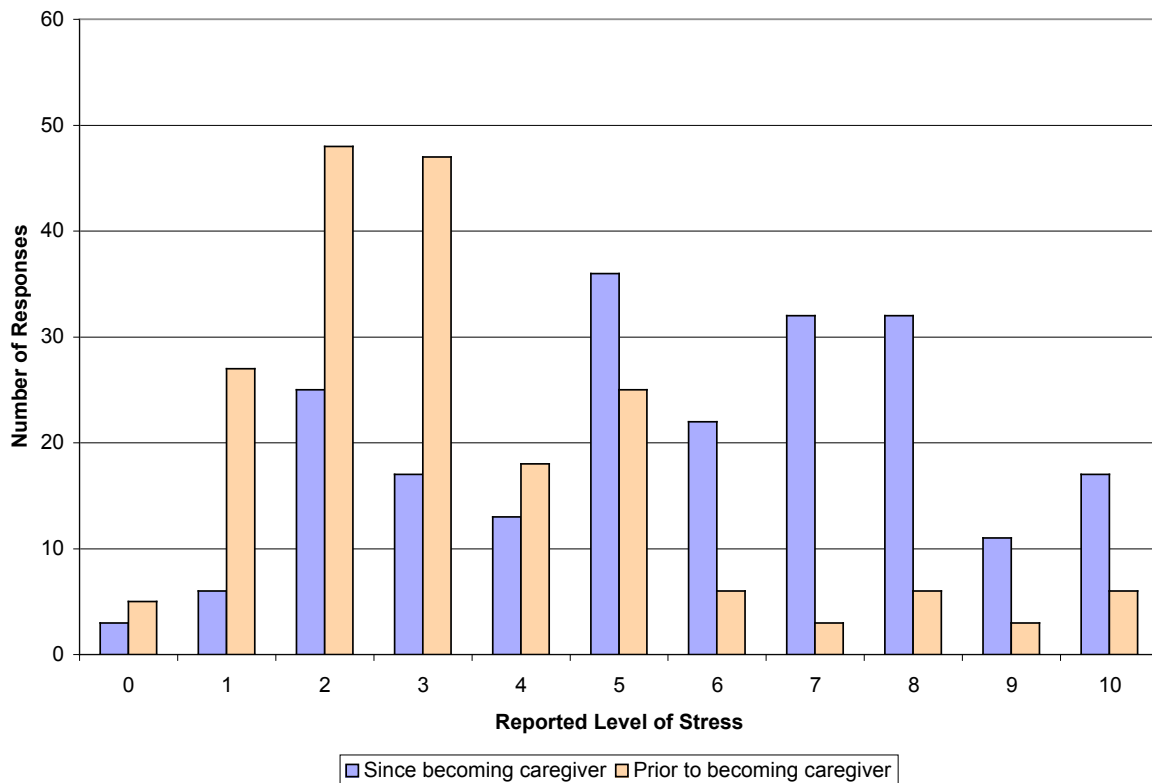
\$1 to \$10	0
\$11 to \$20	13
\$21 to \$30	0
\$31 to \$40	0
\$41 to \$50	0
\$51 to \$75	1
\$76 to \$100	1
> \$100	13

Table 2.19 shows that caregivers of consumers with MRDD have perceived levels of stress that are higher than before they were caregivers of consumers with MRDD. Graph 2.2 provides the same information in a visual manner. As was true of the subset of natural caregivers for consumers with MRDD (Graph 1.1) there is a noticeable shift towards increased levels of stress after becoming a caregiver.

Table 2.19 – Level of Stress (All Caregivers of Consumers with MRDD)

	As a Caregiver	Previously
No Stress	3	5
1	6	27
2	25	48
3	17	47
4	13	18
5	36	25
6	22	6
7	32	3
8	32	6
9	11	3
Extremely Stressed	17	6

Graph 2.2 – Stress Levels of All Caregivers for Consumers with MRDD



Section 3 – Opportunity Costs for Caregivers of Consumers with PD

In this section, as in the last, results are reported for all caregivers for consumers with PD. Table 3.1 shows that the highest level of formal education attained by those caregivers of consumers with PD who responded to the survey is strongly skewed toward less education rather than more education. Generally, those with less education have fewer job opportunities and lower lifetime earnings. Therefore, the opportunity costs for caregivers of consumers with PD are lower than the opportunity costs for caregivers of consumers with MRDD.

Table 3.1 – Highest Level of Formal Education for All Caregivers for Consumers with PD

< High School Degree	15
High School Degree	51
Some College	50
AA Degree	7
BA Degree	6
Graduate Degree	1

Table 3.2 shows that the average caregiver of a consumer with PD has provided 6.08 years of assistance/care giving to consumer(s) with PD. This is less than half the number of years for the average MRDD caregiver (16.24 years).

Table 3.2 – Years as a Caregiver for a Consumer with PD

Number of Responses	131
Minimum	0.08
Maximum	37.00
Average (respondents)	6.08
Median	3.25
Mode	10.00

Table 3.3 shows that consumers with PD receive about 50% more unpaid (7.21 hours) assistance/care giving per day as compared with paid (4.88 hours) assistance/care giving. Consumers with PD receive more of their total

assistance/care giving as paid assistance/care giving (60%) when compared to consumers with MRDD (44%).

Table 3.3 – Hours of Assistance/Care Giving Received by Consumers with PD per Day

	Paid	Unpaid
Number of Responses	123	71
Minimum	0.00	0.00
Maximum	24.00	24.50
Average (respondents)	4.88	7.21
Median	4.00	3.00
Mode	2.00	2.00

Tables 3.4 and 3.5 taken together suggest that although caregivers of consumers with PD generally do not live in the same residence as the consumer with PD, they do live in fairly close proximity. The average commute time is less than 13 minutes.

Table 3.4 – Caregiver of a Consumer with PD Lives in Same Residence as Consumer, All Caregivers

Yes	38
No	92

Table 3.5 – Caregiver of a Consumer with PD Commuting Time in Minutes

Number of Responses	88
Minimum	1.00
Maximum	45.00
Average (respondents)	12.82
Median	10.00
Mode	10.00

Table 3.6 and 3.7 provide evidence about the income associated with paid PD care giving as an occupation. Based on 100 complete responses (out of the 111 people who indicated that they were employed as paid caregivers) to this set of

questions the average income is \$199.81 per week (24.79 hours time \$8.06 per hour).

Table 3.6 – Currently Employed as a Paid Caregiver for a Consumer with PD

Yes	111
No	15

Table 3.7 – Hours Worked per Week, Hourly Wage

	Hours per Week	Dollars per Hour
Number of Responses	112	100
Minimum	1.00	\$ 3.13
Maximum	84.00	\$ 17.50
Average (respondents)	24.79	\$ 8.06
Median	22.00	\$ 7.80
Mode	20.00	\$ 7.50

Tables 3.8 and 3.9 provide estimates of the income associated with all caregivers of consumers with PD who have other paid employment. These caregivers of consumers with PD with other paid employment work an average of 28.29 hours per week at a job that pays an average wage of \$9.64 per hour. Their average weekly income from this other job is \$272.72.

Table 3.8 – Other Paid Employment

Yes	58
No	68

Table 3.9 – Hours Worked per Week, Hourly Wage

	Hours per Week	Dollars per Hour
Number of Responses	56	58
Minimum	2.00	\$ 2.00
Maximum	60.00	\$ 30.00
Average (respondents)	28.29	\$ 9.64
Median	30.00	\$ 8.41
Mode	40.00	\$ 8.00

Tables 3.10 and 3.11 provide estimates of the income associated with all caregivers of consumers with PD who were previously employed. These previously employed caregivers of consumers with PD worked an average of 38.24 hours per week (based on 25 responses) and earned an average wage of \$7.91 per hour (based on 24 responses). The average weekly income was \$302.48.

Table 3.10 – Previously Employed

Yes	23
No	24

Table 3.11 – Hours Worked per Week, Hourly Wage (Previously Employed Caregivers of Consumers with PD)

	Hours per Week	Dollars per Hour
Number of Responses	25	24
Minimum	13.00	\$1.65
Maximum	78.00	\$15.00
Average (respondents)	38.24	\$7.91
Median	40.00	\$8.45
Mode	40.00	\$8.50

Table 3.12 shows that 23% of caregivers of consumers with PD are seeking other employment compared with just 7% of caregivers of consumers with MRDD (Table 2.12). However, for both groups the desired attributes of a new job focus on money issues and job security (Tables 3.13 and 2.13).

Table 3.12 – Seeking Other Employment

Yes	28
No	95

Table 3.13 – Desired Attributes of New Job

	Less Stress	Higher Wages	More Hours	Fewer Hours	Job Security	Better Benefits
Yes	8	26	20	1	20	27
No	9	1	4	11	0	1

Tables 3.14 and 3.15 reinforce the conclusion that caregivers of consumers with PD are more likely to seek paid employment when compared with caregivers of consumers with MRDD.

Table 3.14 – Would Seek Employment If Not a Caregiver

Yes	61
No	30

Table 3.15 – How Spend Time If Not a Caregiver

	Paid Work	Unpaid Work	Volunteer
Yes	92	46	40
No	32	49	49

Table 3.16 shows that the average out of pocket expenses of caregivers of consumers with PD are relatively small.

Table 3.16 – All Caregivers, Monthly Expenses

	Commuting To Job		Running Errands		Entertainment	
	Caregiver Dollars	Client Dollars	Caregiver Dollars	Client Dollars	Caregiver Dollars	Client Dollars
Number of Responses	64	2	64	18	40	17
Minimum	2.00	0.00	2.00	0.00	5.00	0.00
Maximum	160.00	228.00	200.00	120.00	150.00	30.00
Average (respondents)	41.63	116.50	32.09	24.83	34.90	17.24
Median	26.00	0.00	20.00	10.00	22.50	7.00
Mode	20.00	0.00	20.00	0.00	20.00	0.00

The amount and value of informal compensation per month for caregivers of consumers with PD is insignificant (Tables 3.17 and 3.18).

Table 3.17 – Informal Compensation

Yes	10
No	118

Table 3.18 – Value of Informal Compensation per Month

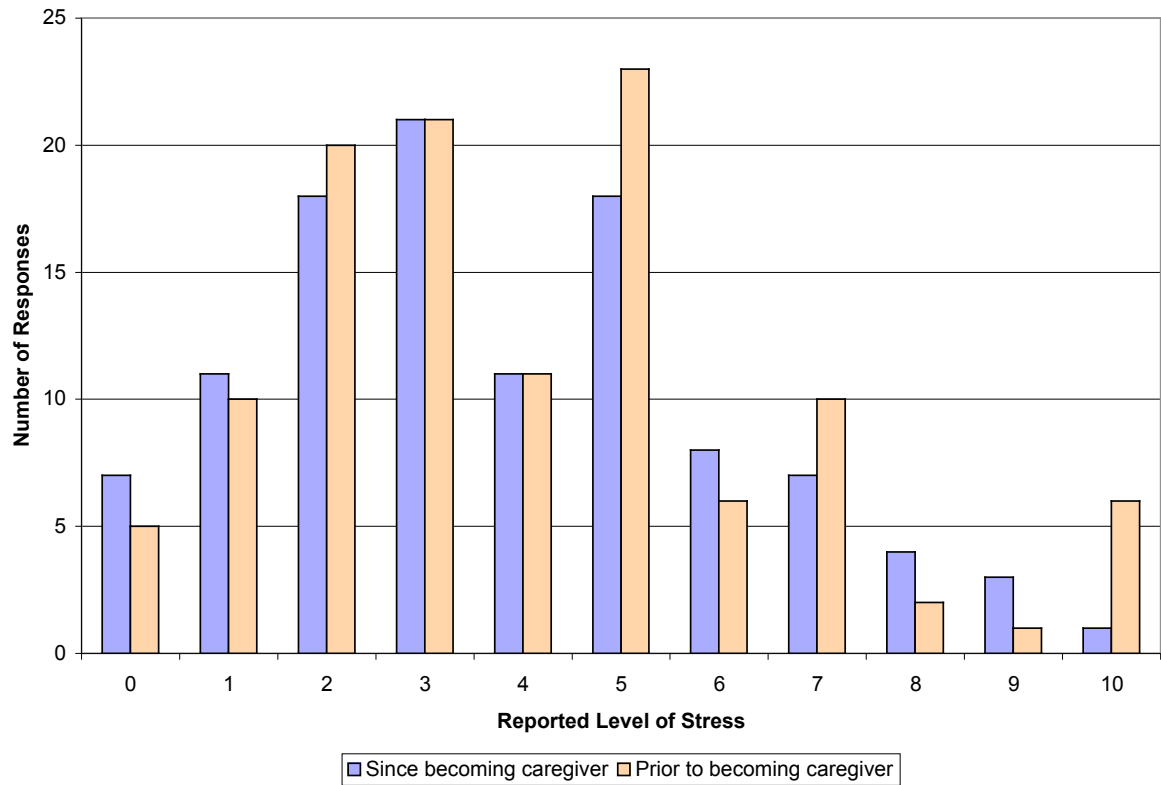
\$1 to \$10	6
\$11 to \$20	3
\$21 to \$30	1
\$31 to \$40	0
\$41 to \$50	0
\$51 to \$75	0
\$76 to \$100	0
> \$100	3

Table 3.19 (and Graph 3.1) reveal that caregivers for consumers with PD report similar levels of stress before and after becoming a caregiver. This confirms what seemed to be the case for natural caregivers for consumers with PD (Graph 1.2)

Table 3.19 – Level of Stress

	Caregiver	Previously
No Stress	7	5
1	11	10
2	18	20
3	21	21
4	11	11
5	18	23
6	8	6
7	7	10
8	4	2
9	3	1
Extremely Stressed	1	6

Graph 3.1 – Reported Levels of Stress, All Caregivers for Consumers with PD



Section 4 – An examination of the personal budgets and expenditures of consumers (PD and MRDD).

The following tables show the average allocation of expenditures for consumers with MRDD by broad categories. There is no significance to the order of the categories. These are basic categories that are common to personal budgets..

Table 4.1 shows that consumers with MRDD spend their income on shelter, food, services, and medical expenditures in that order. It also shows that expenses exceed income by \$267 in unreported assistance on average. When the value of unpaid assistance is included the shortfall increases to \$538.33 (270.96 + 267.37).

Table 4.1 – Average Monthly Income Statement Consumers with MRDD

Income Related Information		
Not Working at Paid Employment		177
Full Time Paid Employment		61
Half Time Paid Employment		154
Average Hours Working		22.6
Average Hourly Wage	\$	4.87
Average Income from Working	\$	477.69
Average Total Income (All)	\$	637.43
Estimated Average Cash Value of Unpaid Assistance	\$	270.96
Total Income plus Cash Value of Unpaid Assistance	\$	908.39
Expense Related Information		
Medical Expenditures		
Medical Services	\$	39.36
Prescription Drugs	\$	37.41
Medical Devices	\$	29.88
Non-Prescription Drugs	\$	10.93
Total Medical Expenditures	\$	117.58
Have Private Health Insurance		24%
Food		
Restaurants/Fast Food	\$	62.82
Supermarkets/Convenience Stores	\$	159.98
Total Food Expenditures	\$	222.80
Clothing and Footwear		
Clothing and Footwear	\$	29.76
Total Clothing and Footwear	\$	29.76
		2.5%

Household Items

Health and Beauty Aids	\$ 32.55	
Non-Food Household Supplies	\$ 30.29	
Total Household Items	<u>\$ 62.83</u>	5.3%

Home Furnishings

Furniture and Accessories	\$ 13.58	
Appliances and Electronics	\$ 15.37	
Total Home Furnishings	<u>\$ 28.96</u>	2.5%

Services

Personal Services	\$ 55.69	
Household Services	\$ 49.59	
Other Services	\$ 77.59	
Total Services	<u>\$ 182.87</u>	15.6%

Rental and Utility Expenses

Rent	\$ 288.85	
Natural Gas*	\$ 28.92	
Electricity*	\$ 27.72	
Water, Sewer, and Trash*	\$ 11.17	
Telephone	\$ 30.21	
Television (Cable or Satellite)	\$ 20.03	
Total Rental and Utility Expenses	<u>\$ 406.90</u>	34.6%
*Adjusted for those included in Rent		

Non-Medical Insurance

Life Insurance	\$ 11.98	
Renter's/Homeowner's Insurance	\$ 17.72	
Other Insurance	\$ 31.06	
Total Non-Medical Insurance	<u>\$ 60.76</u>	5.2%

Donations

Charitable Contributions	\$ 12.96	
Total Donations	<u>\$ 12.96</u>	1.1%

Recreation

Recreational and Entertainment Goods	\$ 25.20	
Recreational and Entertainment Services	\$ 25.13	
Total Recreation	<u>\$ 50.33</u>	4.3%

Total Average Monthly Expenses	\$1,175.75	100.0%
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Total Income plus Cash Value of Unpaid Assistance	\$ 908.39	77.3%
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Unreported Assistance	\$ 267.37	22.7%
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Table 4.2 shows that consumers with PD spend their income on shelter, food, services, insurance, and medical expenditures in that order. It also shows that expenses exceed income by \$380 of unreported assistance on average. When the value of unpaid assistance is included the shortfall increases to \$607.23 (226.55 + 380.68).

Table 4.2 – Average Monthly Income Statement Consumers with PD

Income Related Information		
Not Working at Paid Employment	115	
Full Time Paid Employment	1	
Half Time Paid Employment	1	
Average Hours Working		
Average Hourly Wage		
Average Income from Working		
Average Total Income (All)	\$ 702.21	
Estimated Average Cash Value of Unpaid Assistance	\$ 226.55	
Total Income plus Cash Value of Unpaid Assistance	\$ 928.76	
Expense Related Information		
Medical Expenditures		
Medical Services	\$ 41.97	
Prescription Drugs	\$ 26.79	
Medical Devices	\$ 20.84	
Non-Prescription Drugs	\$ 16.35	
Total Medical Expenditures	\$ 105.94	8.1%
Have Private Health Insurance	10%	
Food		
Restaurants/Fast Food	\$ 84.96	
Supermarkets/Convenience Stores	\$ 216.64	
Total Food Expenditures	\$ 301.59	23.0%
Clothing and Footwear		
Clothing and Footwear	\$ 16.13	
Total Clothing and Footwear	\$ 16.13	1.2%
Household Items		
Health and Beauty Aids	\$ 26.15	
Non-Food Household Supplies	\$ 29.68	
Total Household Items	\$ 55.82	4.3%

Home Furnishings

Furniture and Accessories	\$ 12.84	
Appliances and Electronics	\$ 20.49	
Total Home Furnishings	\$ 33.34	2.5%

Services

Personal Services	\$ 39.02	
Household Services	\$ 41.33	
Other Services	\$ 69.48	
Total Services	\$ 149.83	11.4%

Rental and Utility Expenses

Rent	\$ 210.34	
Natural Gas*	\$ 71.65	
Electricity*	\$ 63.76	
Water, Sewer, and Trash*	\$ 21.51	
Telephone	\$ 52.74	
Television (Cable or Satellite)	\$ 38.73	
Total Rental and Utility Expenses	\$ 458.73	35.0%

*Adjusted for those included in Rent

Non-Medical Insurance

Life Insurance	\$ 30.98	
Renter's/Homeowner's Insurance	\$ 56.48	
Other Insurance	\$ 31.74	
Total Non-Medical Insurance	\$ 119.20	9.1%

Donations

Charitable Contributions	\$ 16.43	
Total Donations	\$ 16.43	1.3%

Recreation

Recreational and Entertainment Goods	\$ 28.61	
Recreational and Entertainment Services	\$ 23.82	
Total Recreation	\$ 52.43	4.0%

Total Average Monthly Expenses	\$1,309.44	100.0%
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Total Income plus Cash Value of Unpaid Assistance	\$ 928.76	70.9%
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Unreported Assistance	\$ 380.68	29.1%
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Section 5 – An Examination of the Potential Impacts of a Reduction in MRDD and PD Waiver Consumer’s Protected Income Level (PIL)

Another objective of the present study is to discern the potential impacts of a reduction in MRDD and PD waiver PIL including such things as: whether consumption patterns would be altered and how; whether natural caregivers/relatives would absorb costs; whether institutionalization is a possibility; whether capacity to handle unexpected expenses changes, *et cetera*.

Table 5.1 shows that a one-time \$100 increase in spending by consumers with MRDD is most likely to be spent on clothing (31%), recreation (19%), food (16%), or other (11%) in that order. The question on which the table is based allowed each respondent to allocate the \$100 according to his/her own preferences. The number column shows these preferences. The dollars reported in the total column are for each category across all respondents (Total = Average X Number).

Table 5.1 – One-time \$100 Increase Spending Choices, Consumers with MRDD

	Average	Number	Total	Percent
Food	\$ 36.13	119	\$4,300	16%
Clothing	\$ 48.02	169	\$8,115	31%
Household	\$ 30.18	57	\$1,720	7%
Furnishings	\$ 37.19	48	\$1,785	7%
Services	\$ 49.82	28	\$1,395	5%
Rent/Utility	\$ 38.10	21	\$ 800	3%
Recreation	\$ 38.82	131	\$5,085	19%
Donations	\$ 16.25	16	\$ 260	1%
Other	\$ 56.82	49	\$2,784	11%

Likewise, table 5.2 shows that a monthly increase of \$100 would be spent on the same items in the same order. The purpose in discerning how additional funds would be spent by or for consumers with MRDD is to understand the preferences of those consumers for different categories of goods and services. These categories may represent the more controllable categories from the perspective of the consumer with MRDD or their financial agent.

Table 5.2 – Monthly \$100 Increase Spending Choices, Consumers with MRDD

	Average	Number	Total	Percent
Food	\$ 33.41	156	\$ 5,212	21%
Clothing	\$ 36.10	178	\$ 6,425	25%
Household	\$ 22.54	67	\$ 1,510	6%
Furnishings	\$ 27.00	45	\$ 1,215	5%
Services	\$ 37.44	45	\$ 1,685	7%
Rent/Utility	\$ 41.67	24	\$ 1,000	4%
Recreation	\$ 33.76	158	\$ 5,334	21%
Donations	\$ 17.78	18	\$ 320	1%
Other	\$ 45.16	57	\$ 2,574	10%

Table 5.3 provides insight into how consumers with MRDD would adjust their spending to accommodate a \$100 per month decrease in spending. As before the question allowed multiple choices in an attempt to determine the preferences of the consumers with MRDD or their agents. The numbers represent the total number of times each category was selected. Recreation (25%) and clothing (23%) are the most likely areas for adjustment. Food, household, and furnishings are also areas of adjustment for consumers with MRDD.

Table 5.3 – Monthly \$100 Decrease Spending Choices, Consumers with MRDD

	Number	Percent
Food	155	14%
Clothing	259	23%
Household	143	13%
Furnishings	136	12%
Utility	52	5%
Donations	64	6%
Recreation	274	25%
Other	27	2%

Table 5.4 shows that consumers with MRDD would pay for an unexpected \$100 expense through a wide variety of means. The top choices were reduction in recreation and third party support. Again, it is important to note that the personal budgets of the consumers with MRDD reported in the previous section show that very little is spent on some of the areas that are targeted for reduction by respondents in this section.

Table 5.4 – How Pay for an Unexpected \$100 Expense, Consumers with MRDD

	Number	Percent
Savings	105	10%
Work More	55	5%
Reduce Food	106	10%
Reduce Clothing	148	14%
Reduce Household	106	10%
Reduce Furnishings	88	8%
Reduce Utility	35	3%
Reduce Donations	48	4%
Reduce Recreation	181	17%
Third Party Support	174	16%
Other	45	4%

Table 5.5 shows that consumers with PD would spend a \$100 one-time increase on food (24%), rent/utility (21%), or clothing (17%), in that order. The question on which the table is based allowed each respondent to allocate the \$100 according to his/her own preferences. The number column shows these preferences. The dollars reported in the total column are for each category across all respondents (Total = Average X Number).

Table 5.5 – One-time \$100 Increase Spending Choices, Consumers with PD

	Average	Number	Total	Percent
Food	\$ 48.03	163	\$ 7,829	24%
Clothing	\$ 41.34	137	\$ 5,678	17%
Household	\$ 25.77	78	\$ 2,004	6%
Furnishings	\$ 37.50	64	\$ 2,381	7%
Services	\$ 57.63	65	\$ 3,724	11%
Rent/Utility	\$ 68.06	101	\$ 6,877	21%
Recreation	\$ 31.70	59	\$ 1,861	6%
Donations	\$ 19.64	34	\$ 661	2%
Other	\$ 37.81	54	\$ 2,035	6%

For an ongoing monthly increase of \$100 (Table 5.6) the consumers with PD indicated that they would spend the funds on food (30%), rent/utility (18%), or clothing (16%).

Table 5.6 – Monthly \$100 Increase Spending Choices, Consumers with PD

	Average	Number	Total	Percent
Food	\$ 41.67	165	\$ 6,861	30%
Clothing	\$ 31.13	115	\$ 3,584	16%
Household	\$ 23.51	91	\$ 2,128	9%
Furnishings	\$ 27.61	51	\$ 1,397	6%
Services	\$ 28.82	46	\$ 1,321	6%
Rent/Utility	\$ 42.14	98	\$ 4,136	18%
Recreation	\$ 21.72	51	\$ 1,102	5%
Donations	\$ 15.65	39	\$ 605	3%
Other	\$ 34.09	56	\$ 1,912	8%

Table 5.7 shows the areas that consumers with PD would cut spending if faced with an ongoing \$100 monthly decrease in income. Clothing, food, and household expenses top the list, followed by other, furnishings, and utility.

Table 5.7 – Monthly \$100 Decrease Spending Choices, Consumers with PD

	Number	Percent
Food	95	19%
Clothing	99	20%
Household	80	16%
Furnishings	52	10%
Utility	45	9%
Donations	37	7%
Recreation	26	5%
Other	62	13%

Table 5.8 shows that consumers with PD would pay for an unexpected \$100 expense by reducing food, clothing, or household expenditures. These reductions in basic categories may represent a better understanding of the personal budgeting process among consumers with PD when compared to consumers with MRDD. Again, for both groups of consumers it is important to remember that the personal budgets in section 4 showed an unreported funding gap (expenses exceeding income) of between \$267 for consumers with MRDD and \$381 for consumers with PD. It is beyond the scope of the present work to determine the exact nature of this gap, but clearly additional expenses or loss in income would be expected to further widen the gap.

Table 5.8 – How Pay for an Unexpected \$100 Expense, Consumers with PD

	Number	Percent
Savings	12	2%
Work More	3	1%
Reduce Food	85	18%
Reduce Clothing	80	16%
Reduce Household	71	15%
Reduce Furnishings	44	9%
Reduce Utility	38	8%
Reduce Donations	49	10%
Reduce Recreation	27	6%
Third Party Support	47	10%
Other	29	6%

Appendix 1

As might be expected, the greater the number of hours caregivers are employed outside the home, the fewer hours of natural care they provide (Table A1.1). However, what might not be anticipated is that, at least for caregivers of consumers with MRDD, the association between hours employed outside the home and hours of natural care provided is small in magnitude, with a Pearson r value of only $-.20$. This means that only about 4% of the differences in the hours of care provided by natural caregivers of consumers with MRDD can be explained by the number of hours of employment. For natural caregivers of consumers with PD, the relationship is much stronger ($-.83$), but again, this may be an artifact of the very small number of respondents who are natural caregivers to consumers with PD.

Table A1.1 – Pearson r Association Between Hours of Work and Hours of Care

	Consumers with MRDD	Consumers with PD
Correlation	$-.20$	$-.83$

Regression analysis, Table A1.2, shows that 35% of the variation in time informants spent with consumers with MRDD per week was explained by the dummy variables for informant categories. The coefficient for the category, guardian, was not statistically significant. However, the intercept (59.78) (which includes the category, other) and the coefficients for the remaining categories were all statistically significant. The coefficient for case manager was strongly negative (-56.75) which indicates that case managers, as a group, spend little time with consumers. The coefficient for paid and unpaid caregivers was strongly positive (35.68 and 33.41 respectively).

Table A1.2 – Hours per Week by Informant Category

<i>Regression Statistics</i>				
Multiple R				0.59962762
R Square				0.35955328
Adjusted R Square				0.3522961
Standard Error				47.346665
Observations				358
	<i>Coefficients</i>	<i>Standard Error</i>	<i>t Stat</i>	<i>P-value</i>
Intercept	59.7828562	8.35427422	7.15596049	4.8399E-12
Guardian	-1.2771334	8.79270179	-0.1452493	0.88459697
Case Manager	-56.749892	9.09346261	-6.2407352	1.2483E-09
Paid Caregiver	35.6834771	9.68530911	3.68428893	0.00026531
Unpaid Caregiver	33.4085755	8.20889913	4.06979973	5.81E-05