

Community Living Program III Final Evaluation Report

Transitions in Caregiving

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Final analyses on New Hampshire's Community Living Program III, *Transitions in Caregiving*, comprised a research sample of 418 family caregivers. In addition to general demographics, both qualitative and quantitative data were collected and examined in an effort to describe the population that was served and to discuss changes in dependent variables measuring caregiver and care recipient well-being over time. The primary hypothesis of the research study held that interventions of instrumental and emotional support to informal family caregivers would impede research-documented negative effects of caregiving (such as burden and depressive symptoms), even as the health and well-being of care recipients logically and progressively declined over time. The data showed support for the hypothesis, and subsequent analyses considered the following research questions:

RQ1: Did caregiver outcomes vary according to the relationship of the caregiver to the care recipient;

RQ2: Could caregivers' preference for instrumental or emotional supports be predicted from their demographics or from care recipient markers?

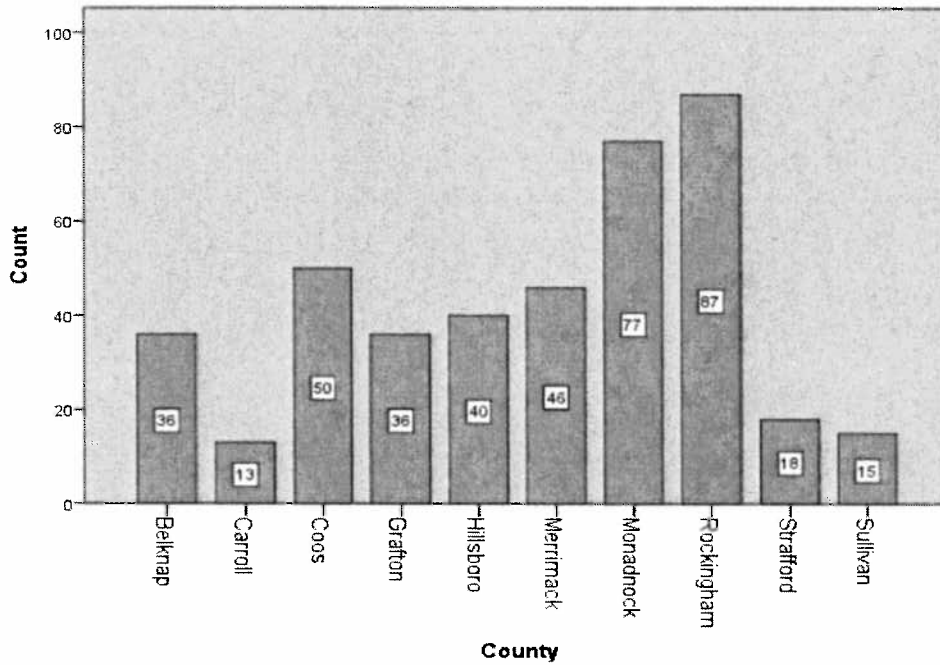
In the next sections of the report, demographic profiles of the caregiver and care recipient are given, followed by descriptions of the research methodology. Finally, analyses supporting the primary hypothesis are described and answers to the research questions are posited. Results from some qualitative analyses are also shared. The concluding sections include a discussion of the findings from programmatic and policy perspectives.

Profile of Participating Caregivers / Care Recipients

Demographics

A total of 418 caregivers participated in this research project through their local ServiceLink Resource Center. Caregivers from every county in the state participated and Chart 1 provides a breakdown by county.

Chart 1. Number of Caregivers Served by County



Categorization by gender is shown in Charts 2 and 3. As can be seen in the charts, the majority of caregivers are female (70.3%) and a slight majority of care recipients are female (56.5%). Age and marital status of the sample are summarized in Table 1. The median age of caregivers in the program was 65, with a range from 25-92. Care recipients' median age was 82, with a range of 46 to 102. The majority of caregivers and care recipients were married.

Chart 2. Caregiver Gender

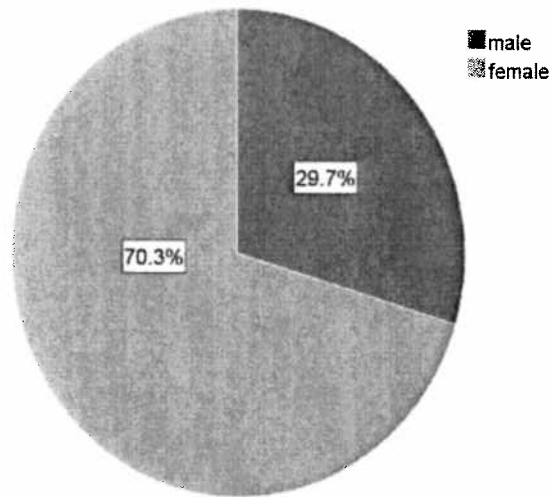


Chart 3. Care Recipient Gender

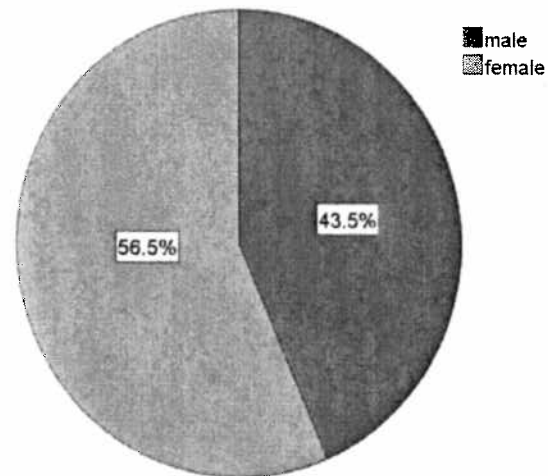


Table 1. Caregiver and Care Recipient Age and Marital Status

	Caregiver	Care Recipient
Age		
Range	25-92 yr	46-102 yr
Average	65 yr	81 yr
Median	65 yr	82 yr
Marital Status		
Married/Partner	82 %	60 %
Single	8 %	1 %
Divorced	6 %	3 %
Widowed	4 %	36 %

Caregivers in the research sample had been in their caregiving role for an average of five and a half years. Individual commitments ranged from two months to 50 years. Caregivers reported that they spent anywhere from one to 24 hours per day providing care, with the average provision being 17.6 hours each day. Most (51%) of the care recipients were the spouse or domestic partners of caregivers.

Wives cared for their husbands in 33% of the cases, while husbands cared for wives in 18%. Adult children caring for the parents comprised another 44% of the sample. Daughters (31%) or daughters-in-law (3%) were the next largest group of relatives who provided care, followed by sons (10%). Other family members made up most of the remaining 5%, and friends and neighbors provided care in just over 1% of cases.

Caregivers lived together with their care recipients in 87% of the research cases, while 6% of care recipients lived alone. Among caregivers, 34% said that the living arrangement was a source of some difficulty. About one quarter of the caregivers had additional informal caregiving responsibilities, either to family members or other individuals. Almost one third (32%) maintained jobs outside the home; about half of these worked full-time, and half worked part-time.

The majority of the caregivers and care recipients fell in a low income tier. Most care recipients (64%) reported annual income between zero and \$20,000. Only a small fraction (2.5%) reported their income as over \$40,000 per year. A summary of information regarding participants' annual income and assets appears in Charts 4, 5, and 6.

Chart 4. Caregiver Annual Income Range

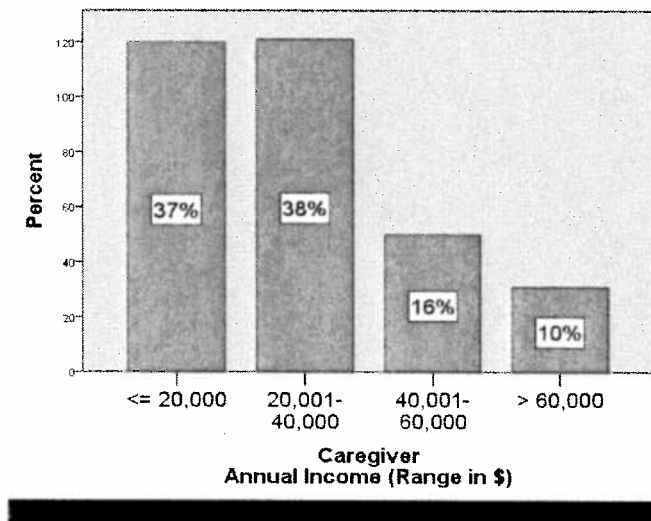


Chart 5. Care Recipient Annual Income Range

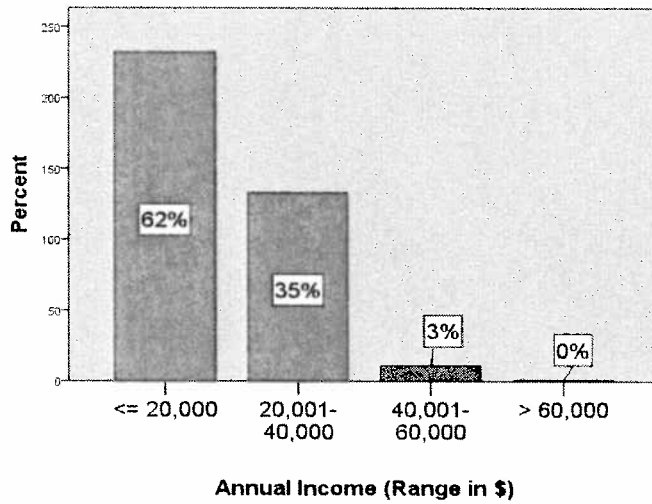
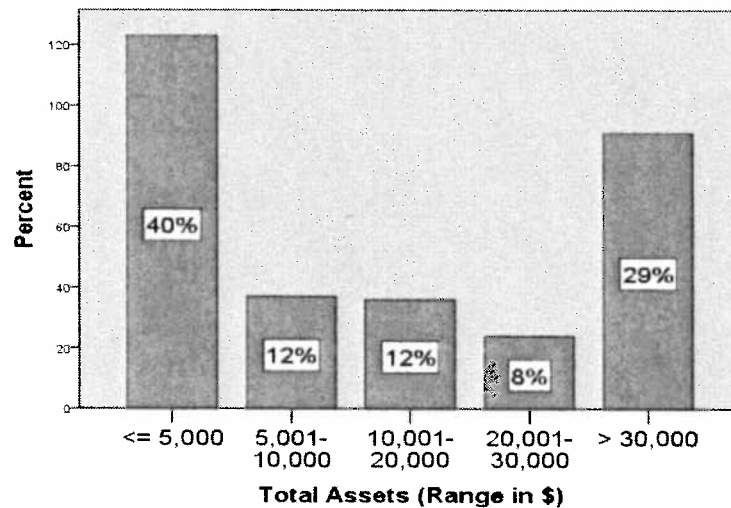


Chart 6. Care Recipient Financial Assets Range



Methods

Intervention

Caregivers (from the sample of 418) were assessed by Caregiver Specialists from local ServiceLink Resource Centers, first at an initial home visit and again six months later, to determine their levels of caregiver burden, depressive symptoms, and mental and physical well-being. Interventions

delivered by Caregiver Specialists included service referrals, small discretionary grants of Title IIIe funds, caregiver educational programs, and emotional support and counseling to informal family caregivers. Through these interventions, it was hypothesized that research-documented negative effects of caregiving might remain stable, or be improved, even though the health and well-being of care recipients might logically be expected to decline over time.

Measures

An initial snapshot of caregivers who entered the program was generated using results of the Zarit Burden Interview, the Center for Epidemiologic Studies Depression Scale, and the SF-12 Health Survey, among other measures. Analysis of caregiver data from first-time assessments showed that 79% experienced mild to severe burden as a result of their caregiving roles, with more than a quarter falling into categories of “moderate” or “severe” burden. Clinically significant levels of depressive symptoms were reported by 40% of caregivers. Table 2 shows information from the scales on depressive symptoms and burden.

Table 2. Percentage of Caregivers Experiencing Burden and/or Depressive Symptoms

	Zarit Burden Interview	Center for Epidemiologic Studies Depression Scale
Little or none	20.6 %	60.7 %
Mild to moderate	49.3 %	23.0 %
Moderate to severe	27.8 %	16.3 %
Severe	2.4 %	***

***Only 3, as opposed to 4, categories are generally distinguished for levels of depressive symptoms.

Mental and physical well-being were measured with the SF-12 Health Survey. The Survey is scored in relation to US population norms by age group. Generally, caregivers in our program fell below the average, at statistically significant levels, for all age groups on the Mental Component Summary (MCS) of the SF-12 Survey. The older the caregivers, the smaller the difference scores between the

sample and the population mean, indicating that the younger the caregiver, the greater the threat to his/her mental well-being. Regarding physical well-being, caregivers were not significantly different from the average for their age groups on the Physical Component Summary (PCS) except for those under age 55, who reported lower levels of physical health than same-age population counterparts. Scores from the PCS and the MCS did not correlate significantly with one another. Table 3 shows the difference scores from population average by age group and the corresponding statistical analyses.

Table 3. Caregivers' Difference from Same-Age Population Means on Mental and Physical Well-Being

Caregiver Age	Mental Component Summary	Physical Component Summary
Under 55	-8.1 ^a	-4.3 ^b
55 – 64	-8.3 ^c	ns
65 – 74	-5.3 ^d	ns
75 and up	-3.3 ^e	ns

^a $t_{88} = -5.88, p < .001$, ns = not statistically different from population average

^b $t_{88} = -3.42, p < .01$

^c $t_{115} = -7.75, p < .001$

^d $t_{101} = -5.25, p < .001$

^e $t_{105} = -3.31, p < .01$

Statistically significant correlations were found among scores on well-being (both physical and mental) and symptoms of burden and/or depression among the 418 caregivers. As expected, correlations were strong among mental well-being (MCS), depressive symptoms (CES-D), and caregiver burden (ZBI). Higher scores on ZBI and CES-D correlated with lower scores on MCS, indicating that greater burden and stronger depressive symptoms corresponded with poorer mental health outcomes. Lower levels of physical well-being were also correlated with depressive symptoms, suggesting that those caregivers with diminished physical health had greater susceptibility to depression. The strength and nature of the correlations (analyzed with Pearson r) are depicted in Table 4.

Table 4. Correlations among Burden, Depressive Symptoms, and Well-Being

	Zarit	CES-D	MCS	PCS
Zarit	1			
CES-D	.55**	1		
MCS	-.39**	-.45**	1	
PCS	-.09	-.16*	-.06	1

* $p < .05$

** $p < .01$

Results

Hypothesis Testing

Results from caregivers who provided both initial and six-month follow-up data showed support for the hypothesis that programmatic interventions help to prevent decreases in caregiver well-being and quality of life over time. Two caveats, however, must be noted. First, the researchers acknowledge that six months is but of a fraction of the time that most of the program's caregivers have been providing for their care recipients; recall that caregivers have been in their role for an average of five years, and the range in the sample goes up to 50 years. Second, a limitation of the Transitions in Caregiving research design is its quasi-experimental nature. That the findings are consistent with the hypothesis suggests a possible relation between the intervention and caregiver outcomes, but the design cannot rule out other possible explanations. A carefully constructed control group would be necessary to do so.

Despite these limitations, it is promising to note that even a short time of organized support corresponded to stability in levels of caregivers' burden, depressive symptoms, and mental and physical well-being, even as the care recipients to whom they are committed showed significant declines in activities of daily living (ADLs) over the same six-month period. The means for each of the dependent measures at initial and follow-up assessment are presented in Table 5, as is the number of ADLs with which care recipients required "extensive assistance" or were "dependent" on the caregiver. Of the

means reported below, only the care recipients' needs with activities of daily living differed to a statistically significant degree.

Table 5. Mean Scores on Well-Being, Depression, and Burden at Initial and Follow-up Assessment

	n	Initial Assessment	Six-month Follow-up
Zarit Burden Interview	243	32.85 (13.36)	33.20 (14.81)
CES-D Depressive Symptoms	239	13.76 (10.74)	13.88 (10.58)
Mental CS	242	44.76 (11.10)	44.26 (10.94)
Physical CS	242	43.92 (11.79)	44.31 (12.18)
# of "dependent" Activities of Daily Living	182	3.85	4.23 ^a

Mean (Standard Deviation)

^a $t_{181} = -2.42, p < .05$

Research Question 1: Did caregiver outcomes vary according to the relationship of the caregiver to the care recipient?

Spousal caregivers represented 51% (n = 211) of the initial sample, and adult child caregivers comprised 44% (n = 181). Analyses performed to consider the differences between the two groups returned statistically significant findings for the Zarit Burden Interview and the Mental Component Summary of the SF-12. An explanation of these differences is given in the next paragraphs. A descriptive comparison of the groups is shown in Table 6.

Table 6. Spousal Caregivers Compared with Adult Child Caregivers

	Spousal Caregivers		Adult Child Caregivers	
Age	74		56	
Gender	Female	64%	Female	77%
	Male	36%	Male	23%
Caring for	Wife	37%	Mother	78%
	Husband	63%	Father	22%
Hours/day providing care	19.2		15.7	
Years providing care	6.3		4.7	

Although spousal caregivers are older, have been providing care longer, and provide care for more hours each day than their adult child counterparts, they also suffer less caregiving burden than the younger group. Caregiver burden was found to differ significantly among the groups at the time of initial assessment ($t_{392} = -2.91, p < .01$) and at the 6-month follow-up ($t_{227} = -2.44, p < .05$). As expected given the correlation among the two scales, mental well-being, as measured with the SF-12 MCS, was also significantly lower among the adult child caregivers at initial assessment ($t_{366} = 3.44, p < .001$). Importantly, there was no difference between the groups in cognitive capacity of the care recipients or the number of ADLs requiring extensive assistance.

The descriptive statistics in Table 8 accord with common sense, given the nature of the spousal relationship. Some explanation of the difference in their experience of burden may be found in other differences that were found between the two groups, namely, employment status, other caregiving responsibilities, and income / out-of-pocket expenses.

With an average age of 56 years, most adult child caregivers are still members of the primary work force. In fact, 53% of our sample of adult children work outside the home (as compared to 11% of spousal caregivers), and more than half of those (55%) work full-time. In addition to employment status,

many adult child caregivers (44%) report additional caregiving responsibilities above and beyond their parent(s). Only 10% of spousal caregivers in the sample have caregiving roles besides their husbands/wives.

Data regarding income and out-of-pocket expenses associated with caregiving paint an interesting picture. As a whole, the adult children earn statistically significantly more money per year than the spousal caregivers (\$20,000 – \$40,000 as opposed to less than \$20,000, respectively). Conversely, spousal caregivers report higher levels of out-of-pocket spending than adult children, but it is the latter group who find this spending more problematic: 75% of spousal caregivers incur costs from their caregiving role, as do 54% of adult children; 30% of spouses report these expenses to be problematic, as do 36% of adult children. Why is it that adult children earn more, spend less, and find it more problematic to do so?

While no statistical evidence is available to answer the question directly, reason suggests life stage and the nuclear versus extended family as possible explanations. Couples generally share finances, while adult children have formed their own nuclear family, in many cases, and caregiving for an aging parent presents itself as an extra demand and cost (regardless of the willingness to help or the closeness of the relationship). The greater presence of additional caregiving responsibilities among adult child caregivers and their greater likelihood of employment also suggest more duties to juggle and, thus, a greater burden and lower levels of mental / emotional well-being.

Research Question 2: Could caregivers' preference for instrumental or emotional supports be predicted from their demographics or from care recipient markers?

At the six month follow-up assessment, caregivers were asked to state the most helpful aspect of the Transitions in Caregiving intervention. Responses, given by 236 participants, were then coded by two researchers into three categories: instrumental supports, emotional supports, and other.

Instrumental supports included such things as respite care, funds for modifications or supplies, and referral to specific services. Instrumental supports were named as “most helpful” by 152 caregivers.

Emotional supports included one-on-one visits or telephone conversations with the Caregiver Specialist and comments such as, “knowing there was someone I could talk to;” “knowing someone cared;” “knowing that I wasn’t alone.” Emotional supports were named as “most helpful” by 78 caregivers. Six participants’ answers did not fit either category and were coded as other and withheld from the analyses that are next described.

A first glance at the data suggests that spousal caregivers are more likely than adult children to appreciate emotional support, while adult children cite preferences for instrumental supports more often than spouses. The difference, however, was not statistically significant. Only one variable was found to significantly predict whether participants would find instrumental or emotional supports more helpful: care recipients’ cognitive ability, as measured with the Short Portable Mental Status Questionnaire (SPMSQ). Table 7 shows that caregivers whose loved ones suffer more cognitive impairment (higher scores on the SPMSQ) were significantly more likely to name instrumental supports as the most helpful part of Transitions in Caregiving.

Table 7. Support Type Preference, Relationship, and Care Recipient Mental Status

	Spousal Caregiver	Adult Child Caregiver	Care Recipient SPMSQ Mean Score**
Instrumental Support	44%	53%	5.37
Emotional Support	51%	41%	4.53

** $t_{194} = 3.29, p = .001$

Qualitative Analyses: Strengths and Rewards

Caregivers in the research sample are often able to articulate personal strengths they bring to their caregiving role and the rewards that they take away from the experience. Some common themes emerge in the strengths and rewards they describe; those cited most frequently appear in Table 8.

Table 8. Strengths and Rewards Emerging from the Caregiver Role

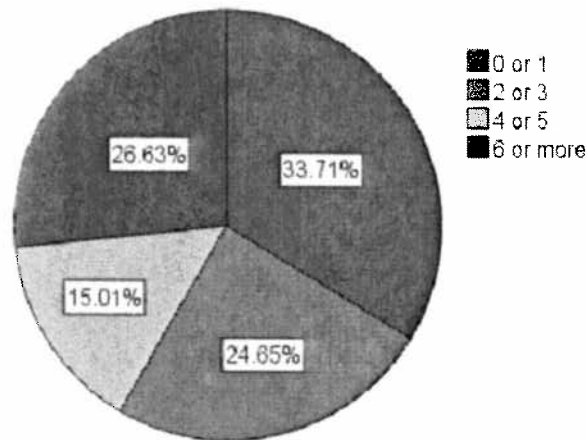
Strengths Brought to Caregiver Role	
33%	Warmth, compassion, love
32%	Organization, resourcefulness, relevant skills
25%	Patience, perseverance, stamina
11%	Dependability, loyalty, consistency

Rewards Emerging from Caregiver Role	
34%	The love caregiver and care recipient share, relationship benefits
25%	Keep care recipient at home, out of institution
25%	Quality of life, quality of care given to care recipient
19%	Duty fulfilled, personally satisfying
16%	To see the care recipient laugh, smile, be happy or grateful

Activities of Daily Living and Mental Status of Care Recipients

As shown in the previous section, care recipients' ability to independently perform activities of daily living declined significantly from the initial assessment to the six-month follow-up. A wide majority of care recipients (66.3% at initial visit and 70.3% six months later) require extensive assistance or are fully dependent on caregivers' help with two or more ADLs. In New Hampshire, this level of need is consistent with eligibility for admission to a nursing home facility. Chart 7 shows the percentage of care recipients requiring the highest levels of assistance with increasing numbers of ADLs.

Chart 7. Number of ADLs Care Recipients Cannot Perform Independently



Beyond physical needs, a large proportion of care recipients (69%) suffer cognitive impairments resulting from dementia or other causes, as indicated by scores on the Short Portable Mental Status Questionnaire. Indeed, these challenges are reflected in caregivers' primary reported concerns about care recipients' safety: the top two worries involved a) falls, balance, and mobility, and b) wandering and forgetfulness leading to personal endangerment. The amount of overlap between physical and cognitive challenges is presented in Table 9.

Table 9. Percent of Care Recipients with Cognitive Impairment Who Meet or Do Not Meet Nursing Home Level of Care for Dependence with ADLs

	Status of Cognitive Impairment			
	None	Mild	Moderate	Severe
0 or 1 ADL	33%	19%	23%	25%
2 or more ADLs (nursing home level of care)	27%	17%	22%	35%

Nursing Home Eligibility and Spend Down to Medicaid

In July, 2010, the NH Bureau of Elderly and Adult Services published updated Medicaid rates for typical and atypical care at the state's nursing home facilities. Whereas the average for a private payer was

estimated to be \$8000 per month (BEAS calculates the per diem at \$262.99 * 30.24 = monthly rate), the Medicaid rate for typical care institutions (with high-cost outliers removed) averaged just over \$4000 per month. Comparing these figures to data regarding care recipients' income and assets, we can estimate how long it would take for them to spend down to Medicaid. Table 10 shows the length of time to spend down assets using both the private payer and the Medicaid rate averages. The more conservative calculations, those using the Medicaid rate, indicate that almost three-quarters of the care recipients in the sample would spend down to Medicaid within eight months of entering a typical NH nursing home. The fact that more than 97% of care recipients have income of \$40,000 per year or less means that only 3% would be able to afford the monthly Medicaid rate without assistance for more than six or seven months, maximum, after eliminating their assets.

Table 10. Percent of Care Recipients Who Would Spend Down to Medicaid in Given Number of Months

Asset level	% of care recipients	# of months at private payer rate	# of months at Medicaid rate
<= \$5000	40%	0	<2
\$ 5,001 – 10,000	12%	<2	<3
\$10,001 – 20,000	12%	<3	≤5
\$20,001 – 30,000	8%	<4	<8
> \$30,000	29%	-	-

Conclusion

Caregiver Commitment and the Value of Committing to Caregivers

Despite evidence of caregiver burden, depressive symptoms, other threats to well-being, and the plethora of hours and years devoted to caregiving; the sample of 418 caregivers is strongly committed to their role in keeping their care recipients at home, in the community. When asked whether they perceived there to be a chance their care recipient might enter a nursing home in the

coming six months, caregivers responded resoundingly (74%) that there was “absolutely not” a chance of institutionalization; 23% felt it was “possible,” and only 2% said it was “very likely” their care recipient would enter a nursing home in the near future.

The value to our state and counties of providing a minimal amount of caregiver support is demonstrated through the data generated with funds from the Community Living Program grant. The data show the high level of need exhibited by the majority of our sample’s care recipients and the levels of caregiver burden, depressive symptoms and other health outcomes experienced by their caregivers. Despite this high level of need, the results indicate the stabilizing effect that modest levels of support and assistance can have on caregivers as the caregivers in this sample did not report an increase in feelings of burden or depression over time as their family member’s condition worsened. This data supports the presumption that a small amount of funding can realize significant savings in projected Medicaid costs by delaying or diverting admission to nursing homes.

Family caregivers appreciate support that allows them respite to rejuvenate, to remain employed, to care for their children or grandchildren, or simply to continue in their role as caregiver. They appreciate help defraying the cost of supplies and maintenance that allow them to meet their care recipients’ increasing needs. Moreover, they appreciate the support that allows them to keep their aging and ailing family members at home, where they can enjoy the continued rewards of those relationships. Commitment of resources to programs that sustain the work of family and informal caregivers ensures that these unpaid caregivers can, in turn, uphold and maintain the commitment they choose to make to their family member.