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# Life Care Plan Implementation Among Adults with Spinal Cord Injuries

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**Abstract**

A nationwide survey was conducted to assess life care plan implementation in a sample of 55 adults with spinal cord injuries (SCI) for those with or without a favorable settlement or verdict. Areas of inquiry included disability-related goods and services received following life care plan (LCP) development, differences in the purchasing of LCP items and services between those with and without adequate funding, and implementation differences based on demographic factors. Frequency data and chi-square analyses revealed differences in plan implementation for those who received funding to purchase some items in the life care plan when compared to those who did not receive funding. Findings shed further light and empirical validation of LCP implementation rates and items/services purchased by persons with SCI.

**Introduction**

As life care planning is a relatively new field to rehabilitation existing approximately 30 years, there remains a need to demonstrate the efficacy of the plans that life care planners develop. Although life care planning is a flourishing section of the field of rehabilitation, there has been a dearth of research to explore how clients use life care plans following case resolution (Marini & Miller, 2007; Salmons, 2008). While life care planners are in a unique position to create the "big picture" for future needs of the individual with a disability, they rarely know how the LCP is implemented which is a commonly asked question by defense attorneys (Marini & Miller, 2007).

While published life care plan studies have encouraged the use of evidence-based outcome surveys to measure life care planning outcomes (Casuto and Gumpel, 2003; IALCP, 2002; Marini & Miller, 2007; McCollum and Crane, 2001), whether the items outlined in the life care plan were ever implemented remained empirically unsupported in the life care plan literature (Marini & Miller, 2007). To date, four published works have assessed life care plan implementation following plan completion (Casuto & Gumpel, 2003; Marini & Miller, 2007; McCollum & Crane, 2001; Reavis, 2002).

In the first published study, McCollom and Crane (2001) conducted a survey of ten individuals who sustained spinal cord injuries eight to fourteen years prior to the study. Areas

of the LCP were assessed with implementation rates as follows: five of 10 individuals underwent annual comprehensive physician evaluations; 10 of 10 individuals required ongoing use of supplies outlined in the LCP; eight of 10 individuals required wheelchair repairs; three of ten individuals received additional education; 10 of 10 individuals had modified vehicles and drove independently; 10 of 10 individuals completed modifications to their homes; and six of 10 individuals required assistance with personal care. Case management services were needed but not available to eight individuals surveyed.

In 2002, Reavis conducted a retrospective study of one LCP implemented for a female adult with a traumatic brain injury. In this case, the life care planner and case manager continuously followed the client post LCP completion. Ten years after development of the LCP, the plan was still being followed and the client's utilization of resources was consistent with the recommendations in the plan. The client was engaged in activities, experienced infrequent complications and her cognitive status had improved since her initial discharge. Life care planning and case management services were believed to have improved the individual's quality of life.

In related research, Casuto and Gumpel (2003) sought to determine if life care plans accurately recognized care needs and what issues affected LCP use. The authors surveyed families of 22 pediatric LCP clients and concluded that the families who implemented the LCP were actively involved in the development of the LCP, saw plan implementation as their responsibility, and had the education necessary to locate services and resources for their child. Certain components of the LCP were found to be underutilized including recreation, counseling, and use of community resources. The authors concluded that case management services were essential to effective utilization of the plan to improve the child's quality of life (Casuto & Gumpel, 2003).

Finally, Marini and Miller (2007) conducted a pilot study of five adults with spinal cord injuries (SCI) to explore post-settlement LCP implementation. The authors found that 75% of respondents purchased a modified van with lift; 50% built a new accessible home; 75% purchased either full-time or part-time personal attendant care; and 50% purchased lifting devices.

The sample sizes of previous LCP implementation studies were relatively small, the largest of which involved 22 individuals and only clients of the author's caseload. This study attempted to broaden the scope of previous research by surveying clients throughout the United States from the caseloads of multiple life care planners. The purpose of this study was to assess the implementation rates of life care plans developed for adults with spinal cord injuries, to determine what variables contributed to implementation rates, and to see what specific items in the life care plans were purchased. Specifically, the six research questions explored were:

1) What frequency/percentage of individuals with spinal cord injuries (SCI) implements key elements of the Life Care Plan following case resolution independent of funding outcome?
2) Are there frequency/percentage differences in life care plan implementation for those who receive settlement or jury award and those who do not?
3) Are there differences among demographic variables (e.g. geographic area of residence, pre-injury education level, ethnicity, severity of injury) for individuals who implement the life care plan when compared to those who do not implement the plan?
4) Are there differences in LCP implementation by considering case management services, employment, active involvement in developing the LCP, and the impact of

obtaining a settlement?

5) What frequency/percentage of individuals with spinal cord injuries (SCI) implements key elements of the Plan (e.g., therapies, equipment, attendant care, home modifications, transportation) following case resolution independent of funding outcome?
6) Are there frequency/percentage differences in implementation of key elements of the Plan (e.g., therapies, equipment, attendant care, home modifications, and transportation) for those who receive settlement or jury award and those who do not?

**Methodology**

*Respondents*

Research participants were recruited via contacting life care planners throughout the United States. With funding for the solicitation from the Foundation for Life Care Planning Research, the lead author sent out approximately 300 postcards to potential candidates announcing the study and providing instructions on how to complete the survey online. Requests for life care planner referrals were also made through the International Association of Rehabilitation Professional LISTSERV, the 2010 Life Care Planning Summit, the Life Care Planner Forum LISTSERV, the Certified Life Care Planner LISTSERV, the International Academy of Life Care Planners LISTSERV, through advertisement in the Journal of Life Care Planning, and through individual email and telephone contact with life care planners throughout the U.S. The International Commission on Healthcare Certification announced the study on their LISTSERV, offering 10 CLCP CEUs for all life care planners who participated. Life care planners who provided participant contact information were entered into a drawing for a free life care planning conference registration fee of $400.

As a result of these efforts, approximately 614 life care planners were contacted individually by email and/or telephone from October 2010 until March 1, 2011. Of the 614 life care planners contacted, 15 referred a total of 372 possible participants. Approximately 238 of 372 possible participants could not be located. Potential participants were contacted by telephone, email, or mail, depending upon the method of contact information provided by the life care planner. Of the available participants, 11 declined to respond, leaving a sample of 55 adults who agreed to participate. These individuals had sustained spinal cord injuries, engaged in litigation, and in the course of litigation had a LCP developed.

*Instruments*

As there is no commonly used survey to collect LCP data, a LCP survey was developed by the authors to collect demographic and LCP specific information. Survey development included reviewing and adapting three previously developed LCP outcome surveys. All commonly queried items in the previously developed surveys were included in the current survey, including personal assistance, SCI related complications, environmental accessibility, specific health issues, services purchased pre and post LCP development, settlement information, daily activities, and barrier identification. Due to the large number of variables in each LCP, several variables as recommended by Kendall and Deutsch (2002) were selected for measurement. Upon construction of the draft survey, six life care planning experts reviewed the survey to provide suggestions for improvement with the end result of a survey consisting of 37 fixed and open response items. The survey contained six sections including demographics, physical health, pre-LCP assistance, LCP involvement, settlement data and post-LCP assistance.

*Statistical Analysis*

This study employed an ex-post facto research design. Percentages were calculated to report the items received post LCP development. Life care plan implementation was measured via self-report, with respondents estimating the percentage of LCP items (0-100%) implemented. Demographic data was analyzed through a series of chi-square tests, to determine the effect of various demographic variables on LCP implementation. A chi-square test is a measure of association between two or more variables which tests whether a single predictor variable is related to a single criterion variable (Hatcher, 2003). A statistically significant result suggests that the two variables are probably related in the population (Hatcher, 2003). Fisher's exact test was used because of its ability to adjust for a small sample size with fewer than five participants in a cell. Effect sizes were reported in either a phi coefficient if the test was conducted in a 2 x 2 table or a Cramer's V statistic if the table was larger than a 2 x 2 (Aron, Aron & Coups, 2005). Both statistics are essentially correlation coefficients, only with different ranges. For both statistics, numbers close to zero reflect a weak relationship between predictor and criterion variables. Ferguson (2009) indicates that a minimum significant effect size for the social sciences is .2 for a small effect, a moderate effect is .5, and a strong effect is .8.

**Results**

*Demographics*

A sample of 55 adults participated in the study. The average age at injury in this sample was 30.6 (SD 14.26). Respondents were 60% male and 40% female. The majority (85%) were White/Caucasian, with 7% African American, 5% Hispanic and 2% Asian. Respondents resided in 18 states throughout the U.S., with over 90% residing in urban geographic locations. Regarding level of spinal cord lesion, seven respondents (13.2%) reported a C2-C4 lesion, 26 (49.1%) reported a C5-T1 injury, 17 (32.1%) reported T2-T12 injury and three (5.7%) reported a L1-L5 level of injury. Cause of injury included motor vehicle accident for 30 respondents (52.6%), on-the-job injury for six (10.5%), sports related injury for five (8.8%), medical mistake for 5 (8.8%), diving for four (7.02%), boating accident for two (3.51%), two with a tumor/mass (3.51%) and one (1.75%) with a severed artery.

At time of injury, 55% of respondents had a high school diploma or less, while approximately 45% had attended some college or above. Regarding pre-injury employment status, 49 respondents (92.45%) were employed or were a student at time of injury, while four (7.54%) were not working or in school. Following the spinal cord injury, 17 respondents (36.17%) were employed or a student at the time of survey completion, while 30 (63.83%) described themselves as unemployed or disabled from employment. Regarding highest level of education completed pre-injury, 15 respondents reported having less than a high school diploma, 14 earned a high school diploma, 14 had some college or vocational/technical school, four were college graduates and eight had completed post-graduate work or a graduate degree. Regarding post-injury education, five respondents (9.62%) reported having less than a high school degree, eight (15.38%) earned a high school diploma, 23 (44.23%) had some college or vocational/ technical training, five (9.62%) earned a college degree, and 11 (21.15%) had completed post-graduate work or a graduate degree. Table 1 reflects demographic data.

Table 1

*Demographic Descriptive Statistics (n=55)*

| Demographic Variable | Response Count | Response Percentage |
|---|---|---|
| **Gender** | | |
| Male | 33 | 60.00% |
| Female | 22 | 40.00% |
| **Ethnicity** | | |
| White/Caucasian | 47 | 85.45% |
| African American | 4 | 7.27% |
| Hispanic/Latino | 3 | 5.45% |
| Asian | 1 | 1.81% |
| **Highest Education Level (post-injury)** | | |
| <High School | 5 | 9.62% |
| HS Graduate | 8 | 15.38% |
| Some College/VoTec | 23 | 44.23% |
| College Graduate | 5 | 9.62% |
| Post Graduate Work/Degree | 11 | 21.15% |

*Life Care Plan Process*

Regarding LCP development, 33 respondents (64.71%) indicated that they were actively involved in the development of their LCP, while 15 (29.41%) indicated that they were not and three respondents (5.88%) did not recall their level of involvement. Twenty-nine respondents (58%) reported receiving a copy of their LCP, while 21 (42%) did not. The majority of respondents 36 (73.47%) did not have access to their LCP at the time of survey completion while 13 respondents (26.53%) did have access to their plan. Five respondents (11.90%) indicated that they remembered the items included in their LCP very well, while 15 (35.71%) indicated that they somewhat remembered the items in their LCP and 22 (52.38%) indicated that they did not recall items in their LCP very well.

*Settlement Information*

Regarding settlement information, 44 respondents (84.62%) in this sample received a court award or settlement, while eight respondents (17.39%) did not. Year of settlement ranged from 1990 to 2011, with the mean number of years of years since settlement of 8.53 (SD = 5.94). Amount of settlements ranged from $30,000 to $4.5 million dollars, with an average settlement/ award reported of $1,653,000 (SD = $1,500,808). Of those who received settlements, 24 respondents (54.55%) did not believe that their settlement was enough to take care of their needs for the balance of their life expectancy, whereas 11 respondents (25%) did. Twelve respondents (27.27%) indicated that they were not sure.

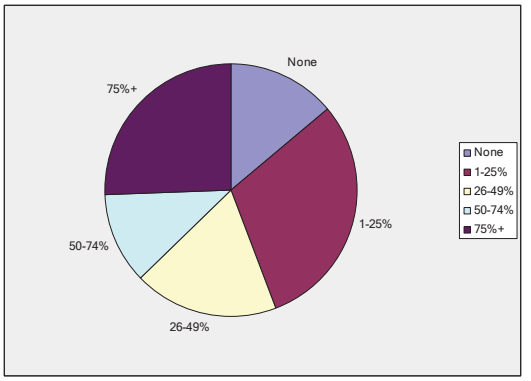
*Life Care Plan Implementation*

The first research question explored was:

1) What frequency/percentage of individuals with spinal cord injuries (SCI) implements key elements of the Life Care Plan following case resolution independent of funding outcome?

Implementation was measured by respondents estimating the percentage of items implemented from their LCP regardless of a favorable settlement/verdict. Five categories were selected for LCP implementation including 1) None 2) 1-25% 3) 26-49% 4) 50-75% and 5) 76%+. Of the total of 43 adults who responded to the question, six respondents implemented none of the items in their plan. Thirteen reported that they implemented one to 25% of items outlined in their LCP. Eight respondents reported that they implemented 26-49% of items outlined in the LCP. Five respondents implemented 50-74% of items outlined in the LCP while eleven implemented over 75% of items outlined in the LCP. Figure 1 reflects this data.

Figure 1: Life care plan implementation (n=43)

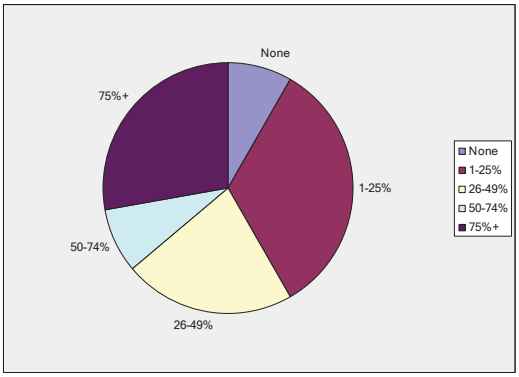


The second research question dealt specifically with the 36 of 43 respondents who did receive a settlement or jury verdict. The research question was:

2) Are there frequency/percentage differences in life care plan implementation for those who receive settlement or jury award and those who do not?

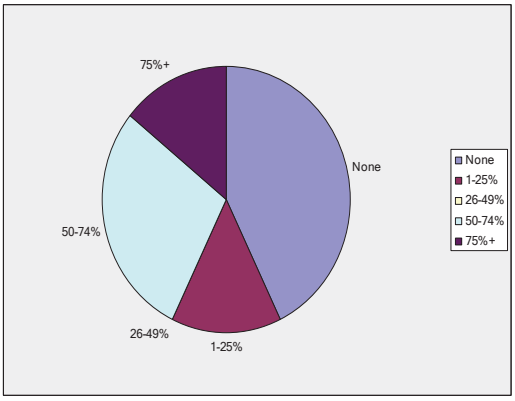
Utilizing this same self-report measure, but extrapolating the data for only those who received a settlement or judgment (n=36), three individuals surveyed implemented none of the items in their plan (8%). Twelve reported that they implemented 1-25% of items outlined in their plan (33%). Eight individuals reported that they implemented 26-49% of items in the plan (22%). Three (8%) individuals implemented 50-74% of items, and 10 (28%) implemented over 75% of items outlined in the LCP. Figure 2 reflects this data.

Figure 2: Life care plan implementation with funding (n=36)




In contrast, of the seven respondents who did not receive a settlement or jury award, three implemented none of the items in their plan, one reported implementing 1-25% of the items in the plan, two individuals implemented 50-74% of items in their plan, and one implemented over 75% of items outlined in the plan. These results are shown in Figure 3.

Figure 3: Life care plan implementation without funding (n=7)



*Factors Affecting Life Care Plan Implementation*

The third research question explored a wide range of demographic variables regarding any significance they may have in life care plan implementation. Research question number three read:

3) Are there differences among demographic variables (e.g., geographic area of residence, pre-injury education level, ethnicity, severity of injury) for individuals who implement the life care plan when compared to those who do not implement the plan?

Demographic variables were analyzed for their relationship to the percentage of LCP items implemented. The first demographic analysis determined whether there is a relationship between geographic area of residence and degree of LCP implementation. Geographic area of residence was classified as rural (fewer than 2,500 people), urban area (more than 2,500 but fewer than 50,000) or urbanized center (greater than 50,000) (United States Bureau of Census, 2010). Data were analyzed using a chi-square test of independence, which revealed a nonsignificant relationship between geographic area of residence and LCP implementation. Cramer's V was used as the index of effect size, with V = .26, reflecting a recommended minimum effect size (RMPE). Similarly, the demographic variables for education, lesion level, and ethnicity (Caucasian versus non-Caucasian categories) revealed non-significant chi-square's; however, the data did reveal an RMPE of Cramer's V=.24, Cramer's V=.21, and an RMPE of =-.20 using the phi-coefficient for effect size respectively. Gender and age were neither significant in chi-square analysis nor minimum effect size. Numbers of respondents implementing their plans by geography, education level, age, gender, ethnicity and lesion level are shown in Table 3.

Table 3

*Life Care Plan Implementation by Demographic Variable Regardless of Funding (n=43)*

| Demographic Variable | N | <50% Implementation | >50% Implementation |
|---|---|---|---|
| Geography | | | |
| Rural | 3 | 2 | 1 |
| Urban Center | 21 | 16 | 5 |
| Urbanized Area | 18 | 9 | 9 |
| Education (at injury) | | | |
| <High School | 13 | 9 | 4 |
| High School Graduate | 12 | 6 | 6 |
| Some College/VoTec | 9 | 7 | 2 |
| College Graduate | 4 | 2 | 2 |
| Post-Graduate | 4 | 3 | 1 |
| Ethnicity | | | |
| White | 35 | 21 | 14 |
| Non-White | 7 | 6 | 1 |
| Level of Lesion | | | |
| C2-C4 | 4 | 2 | 2 |
| C5-T1 | 22 | 15 | 7 |
| T2-T12 | 11 | 8 | 3 |
| L1-L5 | 2 | 2 | 0 |
| Gender | | | |
| Male | 26 | 18 | 8 |
| Female | 16 | 9 | 7 |
| Age at SCI | | | |
| Under 30 | 24 | 16 | 8 |
| 30+ | 18 | 11 | 7 |

*Life Care Plan Related Variables*

The fourth research question explored four factors that have previously been shown to have some support regarding life care plan implementation. Research question number four was:

4) Are there differences in LCP implementation by considering case management services, employment, active involvement in developing the LCP, and the impact of obtaining a settlement?

This finding involved conducting four chi-square and RMPE analyses regarding the LCP implementation by considering case management services, employment, active involvement in developing the LCP, and the impact of having a settlement. All four analyses showed non-significant results as well as no minimum statistically significant effect size.

*Post Life Care Plan Item and Service Implementation*

The fifth research question more definitively explored key elements generally found within an SCI life care plan as to whether they were/were not implemented regardless of funding outcome. The fifth research question was:

5) What frequency/percentage of individuals with spinal cord injuries (SCI) implements key elements of the Plan (e.g., therapies, equipment, attendant care, home modifications, transportation) following case resolution independent of funding outcome?

Respondents were queried about specific goods and services purchased following LCP development. Regarding services most frequently purchased or used following LCP development, the most frequently consumed services included urology visits, general practitioner visits, physical therapy, counseling, case management, occupational therapy, physiatry visits, and nutritional counseling. The most commonly purchased items after LCP development included van/ vehicle with modifications, bed/mattress system, power wheelchair/ scooter, manual wheelchair, home modifications, hoyer or other lifts, and exercise equipment. Thirteen individuals reported obtaining new, accessible housing, while three respondents reported receiving none of the above items.

*Funding versus No Funding*

The sixth and final research question again involved items and services generally found in an SCI life care plan, and in this instance, compared those who received a favorable settlement or verdict versus those who did not. The specific research question was:

6) Are there frequency/percentage differences in implementation of key elements of the Plan for those who receive settlement or jury award and those who do not?

When only data pertaining to those who received a settlement were examined, the following items were found to be the most frequently purchased items: van/vehicle with modifications, bed/mattress system, power wheelchair/scooter, manual wheelchair, home modifications, hoyer or other lifts, and exercise equipment. Eleven individuals reported obtaining new, accessible housing. One respondent reported receiving none of the above items. The most frequently consumed services included urology visits, general practitioner visits, physical therapy, counseling, case management, occupational therapy, physiatry visits, and nutritional counseling. Comparison of items and services received with and without funding is shown in Table 4 and 5.

Table 4

*Post LCP Summary of Services Received With and Without Funding*

| LCP Item | Post-LCP w/funding (%) (n=45) | Post LCP without funding(%) (n=8) |
|---|---|---|
| Counseling Services | 11 (24.44%) | 0 (0%) |
| General Practice Visits | 26 (57.78%) | 6 (75%) |
| PT Services | 18 (40%) | 3 (37.50%) |
| Physiatry Visits | 6 (13.33%) | 2 (25%) |
| OT Services | 6 (13.33%) | 2 (25%) |
| Urology Visits | 30 (66.67%) | 6 (75%) |
| Nutritional Counseling | 3 (6.67%) | 1 (12.50%) |
| Case Management | 8 (17.78%) | 1 (12.50%) |
| Yearly E.R.Visits | 11 (24.44%) | 2 (25%) |
| Manual Wheelchair | 19 (42.22%) | 4 (50%) |
| Power Wheelchair | 21 (46.67%) | 6 (75%) |
| Hoyer/ other lifts | 15 (33.33%) | 4 (50%) |
| Exercise equipment | 12 (26.67%) | 1 (12.50%) |
| Bed/Mattress system | 22 (48.89%) | 6 (75%) |
| None of these | 1 (2.22%) | 2 (25%) |

Table 5

*Post Life Care Plan Items Received with and without Funding*

| Life Care Plan Item | Post-LCP-funding (%) | | Post-LCP-without funding (%) | |
|---|---|---|---|---|
| | N | Implementation | N | Implementation |
| New Accessible Housing | 45 | 11 (24.44%) | 8 | 2 (25%) |
| Home Modifications | 45 | 15 (33.33%) | 8 | 4 (50%) |
| Widened doors | 45 | 0 | 8 | 0 |
| Ramps | 45 | 1 (2.22%) | 8 | 1 (12.50%) |
| Accessible bathroom | 45 | 10 (22.22%) | 8 | 3 (37.50%) |
| Access entire house | 45 | 7 (15.56%) | 8 | 0 |
| Specialized devices | 45 | 7 (15.56%) | 8 | 0 |
| Van/Vehicle Modifications | 45 | 37 (82.22%) | 8 | 7 (87.50%) |

**Discussion**

This study represents the largest and most comprehensive life care plan implementation study to date and provides further empirical validation on the topic concerning persons with SCI. Several key observations and findings are noteworthy of discussion. First is the fact that regardless of available funding, these respondents and many other individuals with SCI all have future medical needs that persons without such a disability require. Of the 43 individuals who reported implementing some aspects of their life care plan regardless of funding, 86% indicated having implemented/purchased relevant items and services of the plan. Similarly, of the 36 respondents who received a favorable settlement or verdict, 92% implemented/purchased relevant items and services of their life care plan. In both instances, over one-third of respondents reported implementing over 50% of their life care plan. In contrast, three of the seven (43%) of those who did not receive any funding reported having implemented no aspects of their life care plan. It is evident from this analysis that receiving funding for disability related items validates that these participants did indeed purchase more items and services in their life care plan than those without funding.

A second factor suggested by the current findings is that for several of the seven individuals who did not receive a settlement or verdict, they still have to purchase some items and services, but do so by relying upon collateral sources. When individually looking at the seven specific respondent surveys, the most commonly cited source of payment included state department of vocational rehabilitation services, Veterans' Administration, Medicare, and state SCI programs. Several respondents indicated that disability related goods and services were purchased by family members and some were received through charitable donations. Although in most states, it is not permissible in tort litigation for life care planners to discuss collateral sources; in reality, when eligible or available, some persons with SCI must come to rely upon whatever limited and/or restricted other funding sources are available. Some of these services; however, are geared to income, have long waiting lists, are restricted or time-limited, and are vulnerable to cutbacks during economic downturns.

Separately, in this particular study, it is noteworthy that 55% of awarded respondents believed they did not receive sufficient settlement funding to provide for a lifetime of SCI related needs, and an additional 27% expressed uncertainty about the adequacy of their settlement. Therefore, the perception that over 80% of the respondents in this sample expressed concern that their disability related needs may not meet their long-term financial needs may have lead to reluctance in purchasing all items recommended in the plan. In follow-up phone interviews, some respondents commented that while they believed their condition would not lead to a shortened life expectancy, they feared that their financial resources would not last to their life expectancy. Given that attorney's fees are deducted from settlements or awards designed to cover a lifetime of disability related goods and services, their assessment of funding shortage may be a valid one.

In summarizing Table 5 regarding services received with and without funding, a cursory review may suggest that those without funding consumed some disability-related goods and services at higher rates than those with funding. The ability of the respondents in the no funding group to obtain medical necessities such as a wheelchairs, specialized beds, and/or lifting devices appears to be likely due to adequate government or private insurance as this group reported these fall-back collateral sources. In fact, some items and services appear to be consumed at a higher percentage by those in the no funding group. This is attributable to the unequal sample size for the two groups, as the no funding group had only eight respondents, compared to the 45 respondents in the funding group. Interestingly, several

items/services that may otherwise be viewed as a convenience or luxury (counseling, case management, and exercise equipment) were purchased with greater frequency by those having received a settlement or verdict. For example, none of the no-funding group purchased counseling services, whereas approximately 25% of the funding group did purchase such services.

*"Big Ticket" Items Purchased*

In-depth questions were also posed to respondents about two key areas of the LCP; home modifications and transportation. Hammel (2004) found the availability of resources (including attendant care, transportation and adequate income) to be at the foundation of quality of life, with these items affording individuals with spinal cord injuries the opportunity for increased independence and improved community participation.

Noticeable differences in LCP implementation became evident when comparing home modifications received by those who did and did not receive LCP funding. Thirteen respondents in this sample reported obtaining new accessible housing. Of this group, 85% of respondents were in the group with funding (settlement or verdict). Nineteen respondents received home modifications after their LCP was developed. Seventy-nine percent of those who received post-LCP home modification were in the group with funding. Seven individuals reported modifying their home for whole- house access. All of those individuals were in the group with settlement/verdict funding as well. None of the respondents in the no-funding group reported modifying their home to include whole-house access, specialized devices such as ceiling lifts, or storm provisions. For those who did not receive funding, the highest level of home modification received included an accessible bathroom. It is evident from this data that individuals in this sample made the necessary home modifications (e.g., wider doors, ramps to entrance) to return home. However, for many individuals who are without adequate funding, they may continue to have limited access to much of their primary residence, even years after their injury.

In addition to home modifications, respondents described their purchase of disability related van or vehicle modifications. Inclusion of transportation in the LCP may contribute to the effectiveness of the entire plan as accessible transportation enables community participation, and increases one's ability to attend medical appointments, work and social engagements (Weed, 1999; Weed & Berens, 2010). In this sample, 37 of 45 (82.22%) respondents in the funding group reported receiving a van or vehicle modifications compared to 7 of 8 in the no funding group (87.50%). While the source of funding of this particular item was not queried, some individuals reported receiving assistance through the Veterans' Affairs, Department of Rehabilitation Services, and SCI programs all of which commonly provide modified vehicles.

*Barriers to Implementation*

Respondents were also queried about barriers to obtaining necessary disability-related goods and services. Only six of 44 respondents who received a settlement/verdict reported that they could not afford the items, compared to four of seven respondents who did not receive funding. Five of 51 respondents noted that the item or service was unavailable in their geographic area. Seven of 51 respondents indicated that they did not know whom to contact to obtain the recommended item or service. Four of 51 did not understand the function or purpose of the item/service. Thirteen of 51 respondents indicated that they believed that they no longer needed the item/service that were initially recommended. When given opportunities

to explain barriers, respondents noted an intermediate party that was responsible for dispensing funds for services (e.g. trust or workers' compensation carrier), some of whom noted reluctance by the parties to do so.

*Limitations*

Due to the unique set of factors associated with spinal cord injuries, LCP implementation rates in this study may not be generalizable to other LCP populations including those with traumatic brain injury, amputation, or developmental disabilities. Additionally, information collected in this study was primarily collected by mail, telephone and internet surveying. It is possible that different results may have been elicited with in-person interviews. Life care plan implementation rates were collected via self-report format and the LCP was rarely available for review at the time of survey completion. In fact, 73% of participants did not have access to the plan at the time of survey completion. For some, the LCP was developed up to 20 years ago and participants had difficulty recalling what was in the plan. In this sample, 52% of respondents indicated that they did not recall items in the plan very well.

Another limitation pertains to the fact that although the survey was reviewed and subsequently modified after receiving input from six experienced life care planners, the LCP survey adapted from other field tested surveys was not field tested itself. Additionally, although the present study possessed the largest sample size than previous similar studies, this sample included adults from only 2% of life care planner caseloads. This small sample, especially for those who did not receive a settlement/verdict may partially explain the lack of statistically significant associations of life care plan implementation factors. Chi square testing is limited in its effectiveness to detect between group differences with small sample sizes, and may be influenced by samples that are too small or non-randomly distributed (Ferguson, 2009). Finally, we were unable to delineate what percentage of an individual's settlement/verdict was due to combining future earning capacity loss versus future medical care needs. Although not having a direct impact on the settlement amount, it is possible that some of the 73% of participants who did not have access to or perhaps remember little from their life care plan really did not know enough to quantify what percentage of their future medical care needs were actually implemented, therefore, leading to an underestimation in results.

**Summary**

This study differed from previous LCP follow-up studies as it included respondents from the caseloads of 15 life care planners throughout the United States. Considering the small sample size which contributed to the lack of statistically significant findings, both groups continued to consume disability related items and services generally found in life care plans developed with persons with SCI. However, some of the items and services implemented were significantly different when respondents were provided the funds necessary to obtain the recommended goods. Life care planners should be cognizant of the fact that all of the services typically found for this population in life care plans were indeed purchased much of the time; however, those who did not receive a favorable settlement or verdict and those with a perceived inadequate settlement ultimately ended up relying upon collateral sources to meet their needs. Future research should explore life care plan implementation with other populations such as those with head injuries and amputations as well as to what extent collateral sources may or may not meet some or all their future needs.

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