

A Quantitative Reappraisal of a Qualitative Survey to Assess Reliability and Validity of the Life Care Planning Process

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Abstract. *The professional practice of life care planning requires the practitioner to continually monitor the case specific relevance of the life care plans (LCP) produced. In the course of routine practice validation, one of the authors published the results of a retrospective survey of her pediatric case load (Casuto & Gumpel, 2003). The report of the outcomes of the survey was in the form of a qualitative description. This present study undertook the quantization of particular areas of the qualitative report in order to analytically appraise the accuracy of the descriptive report and further establish intra-planner reliability. This article reports the outcomes of the analysis based on the Therapies and Attendant Care sections of the LCPs surveyed.*

Results

The quantitative analysis found that clients who were receiving therapies were receiving the predicted level of weekly Physical Therapy (PT), Occupational Therapy (OT) and Speech Therapy (ST). However, recommended OT and ST were not well implemented. Likewise, Counseling Services (CS) for the client, the family and/or behavior management were not implemented as recommended in the LCP in many cases. Attendant Care (AC), on the other hand, was implemented consistently at the level recommended in the LCP. These findings, by quantitative analysis, replicated the report of the qualitative survey findings.

Conclusions

The needs of the pediatric client population in this one author's case load were assessed in a consistent, dependable manner and addressed in life care plans which were relevant for the client's anticipated needs. However, the creation of a valid LCP does not assure implementation of the recommendations.

Introduction

The professional practice of life care planning depends upon the consistent, dependable application of the life care planning process by the practitioner in order to both produce a LCP relevant to the individual client and, in the larger view, to validate the utility of life care plan-

ning. The challenges to the process of life care planning as a forensic tool made by the U.S. Supreme Court's rulings in the Daubert case (Countiss, 2002; Countiss & Deutsch, 2002) also require that the stringency of scientific testing and peer reviewed publication of the test results be applied to the methodology used by the life care planner as an expert witness. Definitive research attests to the reliability and validity of the processes used in life care planning practice (Kendall & Deutsch, 2002). The validity of the process as a whole is seen when similar results are produced for clients with similar disabilities in similar environments, but different results when these characteristics differ. A valid LCP must also reasonably address the issues of the disability and contain elements of response to specific recommendations made by relevant specialists. To those utilizing the LCP for financial planning or in a forensic setting, the predictive validity of the instrument is critical. This facet of criterion-related validity asserts that the care recommendations and resultant cost estimates accurately predict the services that the client will need in the future.

Substantiation of reliability is requisite to demonstrating validity. Reliability is evidenced by dependable, consistent results produced by the life care planning process regardless of which life care planner has developed the plan (inter-planner reliability). The reliability of an individual life care planner's work product (intra-planner reliability) is evidenced by dependable, consistent results being generated by a particular practitioner regardless of the referral source, i.e., the defense, the plaintiff, or the court, as in forensic cases. Intra-planner reliability is seen when clients with similar disabilities and situations receive similar LCPs because the recommendations are based on client needs independent of cost, availability of funding, access to care, or referral source.

The validity of the LCP process depends upon the intra-planner reliability of many practitioners' work products. Therefore, establishing and maintaining intra-planner reliability is the professional responsibility of each LCP practitioner. One way a practitioner can assure intra-planner reliability is to follow client outcomes over time, incorporating the feedback information into current practice processes. The retrospective inquiry to the case specific validity of the work product informs the practitioner's future work product, thus maintaining the intra-planner reliability of the life care planning process as the field evolves. "A Retrospective Study of Pediatric Life Care Plan Outcomes: One Life Care Planner's Experience" (Casuto et al., 2003) describes the findings of a survey made in the course of the continuous evaluation process of professional practice. Based on the qualitative information compiled from the surveys, the conclusion was drawn that the LCPs developed "were not consistently implemented" and a recommendation was made that "a case manager is essential to assist the families in identifying services and using the LCP as a tool" (p. 19). The authors wondered whether these perceptions were statistically accurate and whether the needs of the pediatric population had been appropriately anticipated by the LCP process. The purpose of this study was to investigate the reliability and validity of the life care planning process by quantifying the responses from particular areas of the LCPs queried by the survey, and then analyzing the data statistically. The areas of this reappraisal include Physical, Occupational and Speech Therapies, Counseling Services and Attendant Care. Overall, the findings support the reliability of the qualitative findings in these areas.

Methods

Design

The methods for the qualitative descriptive survey study, including the survey instrument, have been previously reported (Casuto, et al., 2003). Briefly, the purpose of the antecedent study was "to evaluate reliability of recommendations made by [an] individual life care planner" (p. 14). The specific aim of the study was "to assess effectiveness in identifying care needs, and additional areas which should be addressed in the plans and the issues that impact the families' ability to implement the plans" (p. 14). A telephone survey was administered to 22 pediatric client families that had responded to an initial contact and agreed to participate. All participants resided in California and had been plaintiff cases.

The purpose of the current study was to investigate the accuracy of the earlier descriptive report and to observe intra-planner reliability as well as the case specific relevance of the LCPs. This was done by quantifying the 22 survey responses from particular sections of the LCP and testing the hypotheses that there would be no difference between the predicted level of care in the plan and the level of care being received by the client. The antecedent study was a non-experimental or "descriptive cohort" study aimed at gathering data of interest in the pediatric population being surveyed. The outcomes sought were intended to inform and enhance the reliability of one author's life care planning practice. The design of the study was in the form of a retrospective case review. In comparison, the current study is designed as an analytical retrospection to compare the services predicted in the LCPs against the services being received at the time of the telephone survey. Although the approaches to qualitative and quantitative research designs are different, the reappraisal study was undertaken to examine the results using an alternative approach, to provide a more comprehensive analysis of the data.

Hypotheses

The authors chose the following discrete areas of the LCP for reappraisal: Physical Therapy (PT), Occupational Therapy (OT), Speech Therapy (ST), Counseling Services (CS) and Attendant Care (AC). The hypotheses tested are:

- H1₀: There will be no differences between the Therapies (PT/OT/ST) provided by the LCP and those in use at the time of the survey.
- H2₀: There will be no differences between the CS provided by the LCP and those in use at the time of the survey.
- H3₀: There will be no differences between the AC provided by the LCP and those in use at the time of the survey.

Survey Tools and Measurements

A survey tool specifically developed for this study was employed to compile both the recommendations of the LCP and the services received by the client at the time of the telephone survey (see Appendix A). The function of the new tool was to transcribe the qualitative

responses gathered in the antecedent telephone survey into numerically coded data and display the comparable LCP recommendations in identical fashion. In all cases, the information collected at the time of the original survey was transcribed onto the new survey tool by a staff associate at Rehabilitation Care Coordination who was blinded to the study objectives and without any additional contact with the client. The comparable information as recommended by the LCP was extracted directly from the client's LCP by the staff associate. Both the LCP projections and the implemented services as discovered by the survey were first annualized, then computed for a weekly value for analysis. In this way, services that were only expected or received once per year, such as evaluations, could be included in the final value. Several questions on the new survey (see Appendix A) address information collected on the original telephone survey, but not analyzed for this report.

Each survey was assigned a "study subject ID" number on the cover page which was carried into the footer of each subsequent page of the survey. To assure confidentiality of the clients' private information, the survey forms linked the study subject identifiers to the LCP case identifiers only on the cover page. The case identifying information was necessary to extract the LCP information onto the survey and to transcribe the original telephone survey information onto the new survey. Once these operations were completed, the cover page was dissociated from the survey and stored separately under lock and key as privileged information. The data on the surveys could then be analyzed without reference to the client. Informed consent was not required because this research project was not conducted by a covered entity (Dunn & Chadwick, 1999).

The demographic information generally required by National Institutes of Health (NIH) funded studies was extracted from the original case files and added to the current survey (See questions 1 through 8 on appended survey.) Questions 29 and 32 relate to the therapies (PT, OT, and ST) recommended in the LCP and therapies being received at the time of the survey. The responses to these questions were transformed to annualized sessions per week for analysis. Answers to questions 33 through 36 revealed that so many types of CS were either recommended or utilized that the clients in any one category were too few to yield meaningful comparisons. Therefore, the data on CS were compiled as being recommended or not, and received or not in a 2 by 2 contingency table.

For AC questions, the responses were coded as continuous numerical values, e.g., the number of hours of AC per day that would be within the range of 1 to 24 hours per day (See questions 45 and 59 on appended survey.). Additionally, the data was coded in an ordinal fashion, i.e., levels of AC at level 1, 2, 3, or 4 (See questions 52 and 67 on appended survey. When family members provided care, the level of care provided was taken to be that which was predicted by the LCP, excepting 3=RN.). Establishing the method of encoding both pieces of information, i.e., hours of care per day and level of care provided, into a single variable for quantitative analysis was challenging. Using actual costs of care would confound the measurement because the value of currency varies with time in the market economy so that actual projected costs at the time of the LCP would not be comparable with costs for like services at the time the survey is taken. Therefore a standardized measurement that can be used at both times is required. Standardized quantitative units of measurement for LCP needs projections were first used and described in the study, "Reliability of Life Care Plans: A Comparison of Original and Updated Plans" (Sutton, Deutsch, Weed, & Berens, 2002). The measurement device used "dollar costs" for services set at a specific time to calculate the level of service for a specific client at each and every time point included in the study. In this manner, cost fluctuations due to inflation and changes in health care service pricing were normalized for the purpose of

analysis. Thus, the measurement is presented in standardized units of "dollar costs" that allows for measuring costs uniformly across time, rather than the relative dollar values which fluctuate daily in the market economy.

In the present study, costs of each service need were obtained from a database covering one specific U.S. region. Costs were annualized, that is, computed to reflect a one-year service time frame, for the needs projected by the LCP and compared to the annualized costs of services being received by the client as discovered by the telephone survey. (Annualizing the expenses permits services that are anticipated to occur as infrequently as once per year to be factored into the weekly cost.) Thus, both the projected needs and the services being received were computed using the same duration of service period and the same unit of dollar costs.

Statistics Analysis

This study is a preliminary study in that the size of the expected effect is unknown and other studies have not reported information that would allow an estimation of effect size to be made. Therefore the study was not "powered" for determination of sample size. The data for the therapies (PT, OT, ST) and AC were in the form of continuous scale variables as measured at two time points from the same subjects. For this type of data, analysis by two-tailed, paired student's t-tests is appropriate. The level of significance was set at $p < 0.05$, so that the probability of a Type I error is less than 5%. The analysis of CS employed McNemar's test statistic, which is a special case of chi square for a fourfold, 2 by 2 contingency table of paired data. The McNemar statistic is used to evaluate the relationship or independence of paired discrete variables and involves dichotomous measurement (i.e., pass/fail, yes/no, present/absent) which are paired (De Muth, 1999).

Results

Demographics

The ages of the population at the time of the administration of the telephone survey ranged from one to twenty-two years of age. One subject was deceased by the time of the survey. Generally, when the mean \pm the standard error of the mean (SEM) captures the median measure of centrality, the data is deemed to be normally distributed and therefore parametric statistical tests are appropriate. With a mean of 11.4 years and a standard deviation of 5.6 years, the data were seen to be normally distributed in the age frequency distribution histogram (Figure 1).

Figure 2 displays the frequency distribution histogram for the time interval between the production of the LCP and the administration of the survey. The mean was 44.9 months with a range between 3.0 and 109.0 months. The median was 41.0 and the standard deviation was 30.3, which indicates the data is normally distributed.

The distribution of gender/sex within the data set is 15 males, one being deceased at the time of the survey, and 7 females. Study subjects represented the following race categories: 2 Asian, 8 Caucasian, 2 Multi-racial, and 11 unknown or not reported. Ethnicities were comprised of: 5 Hispanic or Latino, 12 not Hispanic or Latino, 5 Unknown (persons not reporting ethnicity). The primary language for the study subjects was English with the exception of 1 subject for whom a translator was employed. For a description of the pediatric client disabilities, see Casuto, et al. (2003).

Physical Therapy had been recommended for 19 of the subjects and 19 were receiving PT

AGE: When Survey Taken

- Number of cases 21
(1 deceased at time of survey)
- Minimum 2.0
- 25% Percentile 7.0
- Median 11.0
- 75% Percentile 15.0
- Maximum 24.0
- Mean 11.4
- Std. Deviation 5.6
- Std. Error 1.2
- 95% CI
- Lower 8.9
- Upper 14.0

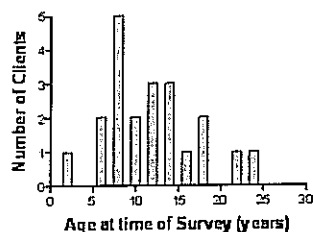


Figure 1

INTERVAL: LCP to Survey

- Number of cases 22
- Minimum 3.0
- 25% Percentile 20.5
- Median 41.0
- 75% Percentile 66.5
- Maximum 109.0
- Mean 44.9
- Std. Deviation 30.3
- Std. Error 6.5
- 95% CI
- Lower 31.5
- Upper 59.3

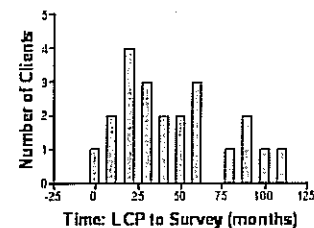


Figure 2

Physical Therapy

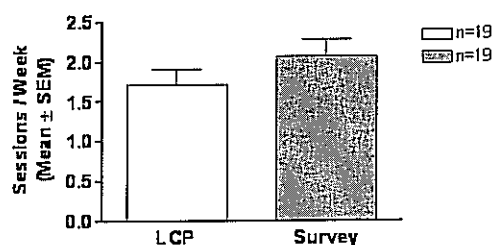


Figure 3

Occupational Therapy

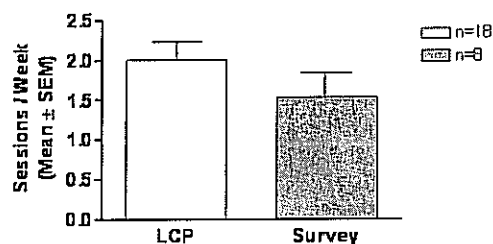


Figure 4

at the time of the survey. The mean number of recommended sessions was 1.72 ± 0.19 and the mean number of sessions being received was 2.06 ± 0.21 per week, annualized. These values were not significantly different by paired t-tests ($p = 0.16$). Figure 3 shows the comparison of the annualized PT sessions per week recommended by the LCP and those being received at the time of the survey.

Occupational Therapy had been recommended for 18 of the subjects, but only 8 subjects were receiving OT at the time of the survey. The mean number of recommended sessions was 2.00 ± 0.24 and the mean number of sessions being received was 1.53 ± 0.31 per week, annualized. These values were not significantly different by paired t-tests ($p = 0.58$). Figure 4 shows the comparison of the annualized OT sessions per week recommended by the LCP and those being received at the time of the survey.

Speech Therapy had been recommended for 16 of the subjects, but only 10 subjects were receiving ST at the time of the survey. The mean number of recommended sessions was 2.08 ± 0.24 and the mean number of sessions being received was 1.95 ± 0.31 per week, annualized. These values were not significantly different by paired t-tests ($p = 0.86$). Figure 5 shows the comparison of the annualized ST sessions per week recommended by the LCP and those being

Speech Therapy

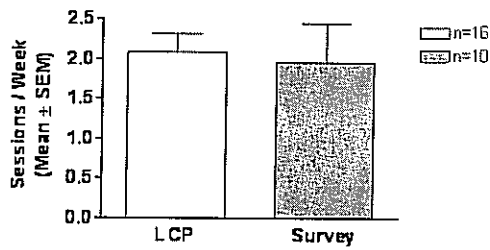


Figure 5

Counseling Services

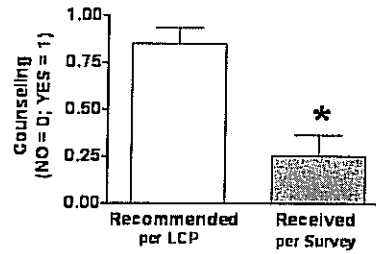


Figure 6

Attendant Care

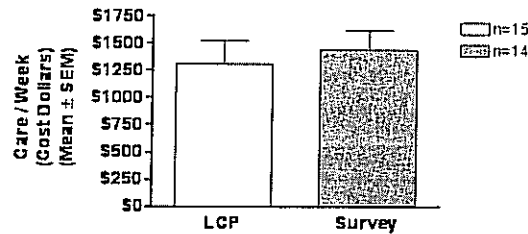


Figure 7

received at the time of the survey.

The data support the acceptance of H_{10} , that there will be no differences between the therapies (PT/OT/ST) provided by the LCP and those in use at the time of the telephone follow-up survey. However, it is important to note that while the therapies were implemented at the level recommended when they were implemented, large percentages of the subjects had not implemented the recommended OT (56%) and ST (37.5%).

Counseling Services had been recommended for 20 of the clients, but only 3 of those clients were receiving CS. At the time of the survey 14 subjects for whom CS had been recommended were not receiving CS. Of the 4 clients for whom CS was not predicted by the LCP, one subject was receiving CS. The data is coded as nominal with discrete values of 0 = no CS and 1 = CS as predicted by the LCP or as discovered by the Survey.

These tallies are displayed in Table 1 as the fourfold, 2 X 2 contingency table to which the

Table 1

Recommended by LCP	Discovered by Survey	Discovered by Survey
	Yes = 4	No = 17
Yes = 20	a = 3	b = 14
No = 1	c = 1	d = 3

McNemar test statistic was applied.

The calculated McNemar test statistic for the data is 11.27. That value is less than the critical value at $p < 0.05$ of 3.84. Therefore the H_2 , that there will be no differences between the CS anticipated by the LCP and those in use at the time of the telephone follow-up survey, can be rejected. Paired measurements for the two time periods are displayed in Figure 6. The significant difference at $p, 0.05$ is marked by "**".

Attendant Care had been recommended for 15 of the subjects. At the time of the survey, 13 subjects (86.7%) were receiving AC. The mean dollar cost of the annualized weekly AC was $\$1,309.00 \pm \211.60 and the mean dollar cost being received was $\$1,438.00 \pm \173.70 per week, annualized. These values were not significantly different by paired t-tests ($p = 0.87$). The data support the acceptance of H_3 , that there will be no difference between AC projected by the LCP and AC provided at the time of the survey. Figure 7 shows the comparison of the annualized AC per week recommended by the LCP and AC being received at the time of the survey.

Discussion

The descriptive report of the telephone survey assessed the therapies, PT/OT/ST, predominantly as a group, noting how many children were receiving special types of therapies. The observation was made that many children were receiving therapy in the school setting and their therapy seemed to continue beyond the duration expected by the LCP. The analysis of the data in the present study attests that PT was well implemented and implemented at the frequency recommended by the LCP. While OT and ST were also implemented at the recommended levels when implemented, these special therapies were not well utilized. Although CS were recommended universally in this population, the cohort study remarked on the under utilization of CS by the clients. This finding was substantiated by the quantitative analysis. Like CS, AC was recommended in the LCP for every subject in this study. The telephone survey qualitative report focused on the families of the clients providing the majority of AC. The analysis of the reports of AC, whether provided by outside help or the family, supported the LCP's valid assessment of the level and amount of AC needed by the client.

In summary, the quantitative reappraisal supported the findings observed in the descriptive report of the telephone survey and further delineated those observations.

Limitations of the Study

The telephone survey discovered the services currently being received; whereas, the LCP was prepared for anticipated needs of the client. The survey information may be reflecting resource-driven implementation of services and not unmet needs or even noncompliance. For the CS, it is not clear whether the needs were over-estimated by the LCP; were being received, but not acknowledged by the client; or were frankly unmet because the client was noncompliant due to the stigmatization of CS, or lacked resources to access CS. On the other hand, the time of the resource use may not be concurrent with the survey window, i.e., counseling may have been utilized in years prior to the survey or alternatively may yet be utilized in future years. Future studies might be better served by assessing the current needs rather than the current level of services being received. When the LCP is forecasting client needs, the follow up must verify the client's needs or the question of unmet needs vs. over estimation of needs by the LCP will remain open.

Conclusions, Significance and Future Directions

In summary, we can conclude from this analysis of the data that the earlier descriptive report of the telephone survey findings was made with a high degree of fidelity with respect to the LCP sections on the therapies (PT/OT/ST), counseling services and attendant care. Furthermore, the needs of this pediatric client population were consistently and dependably assessed by the LCPs written by one of the authors, thus attesting to intra-planner reliability. However, as seen in this report, a LCP that is relevant for a specific client does not assure implementation of the recommendations.

The LCP is not only a forensic tool, it is also an evaluation and education tool for rehabilitation of the client (McCullom & Weed, 2002). Follow up with the client is necessary to insure implementation. Through implementation, the "LCP will accomplish its mission: ...to decrease the frequency and severity of medical complications for a particular [client], avoiding case management by crisis intervention, and improving the [client's] overall quality of life" (Kendall, et al., 2002, p. 158-159). Likewise the specialty case management tool of life care planning will continue to be available to clients only as continuing research investigates the reliability, validity and relevancy to each specific client's case of the life care planning process. Because the validity of the LCP process depends upon the reliability of many practitioners' production of LCPs relevant to each specific client's case, continuing research is a mandate to the professional life care planner.

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Appendix A

Survey of Pediatric Life Care Plan Outcomes

Appendix A

Survey of Pediatric Life Care Plan Outcomes

The following interview is confidential. Do not indicate the subject's name or note any personal identifiers on the sheets. The goal of this interview is to obtain information regarding the pediatric patients for whom Life Care Plans were prepared by a lone life care planner, Doreen Casuto, MRA, RN, CRRN, CCM, CLCP

COVER PAGE

Interviewer code: _____ (4 digits)

Patient's Name: _____

Study Subject ID: _____ (4 digits) [Enter number in footer of document]

Date of Life Care Plan: _____ (mm/yyyy)

Date Interview Conducted: _____ (mm/yyyy)

Time Begun: _____ (hh:mm)

Time Ended: _____ (hh:mm)

v.9

Study Subject ID: _____ (4 digits)

1

DEMOGRAPHIC CHARACTERISTICS

The first questions are about your background.

- 1) What is your age? _____ Years
- 2) What is your gender? [*Circle one*] MALE = 1 FEMALE = 2
- 3) What is your racial heritage? [*Circle one*]

1 = American Indian/Alaskan Native	5 = Caucasian/White
2 = Asian	6 = Multi-racial
3 = Native Hawaiian or Other Pacific Islander	7 = Unknown or not reported
4 = Black or African American	

- 4) What is your ethnic cultural heritage? [*Circle one*]

1 = Hispanic or Latino	2 = Not Hispanic or Latino
3 = Unknown (persons not reporting ethnicity)	

- 5) What is your primary language? [*Circle one*]

1 = English	3 = Chinese	5 = Swahili	7 = Other (please specify)
2 = Spanish	4 = Arabic	6 = Haitian Creole	

- 6) Do you understand spoken English? [*Circle one*]

0 = NO 1 = YES

- 7) Was a translator employed in administering this survey? [*Circle one*]

0 = NO 1 = YES

- 8) What was the last grade you completed in school: _____ [*Enter code from chart below.*]

- 1 = [$<$ 12 years – less than high school graduate/G.E.D.]
 2 = [12 years – high school graduate/G.E.D., but no college]
 3 = [$>$ 12 – 15 years – some college or technical training, but no Baccalaureate degree]
 4 = [16 years – Baccalaureate/undergraduate degree]
 5 = [$>$ 16 years – Post graduate education]

MEDICAL STATUS

[Take the information for questions 9 – 12 from the Life Care Plan.]

9) Year of accident/illness/injury: _____

10) Age at time of accident/illness/injury: _____

[Age in years; 999 = at birth; 0 = under 1 yr old]

11) State of patient's residence: _____

12) Medical Diagnosis: _____

Medical and Case Management

The following questions are about your medical history since your accident/illness/injury.

13) When is the most recent time you had a complete evaluation for your accident/illness/injury?

0 = Never _____ = Year of evaluation

14) How often has a case manager been consulted within the past 12 months?

0 = Never _____ = Number of consultation with a case manager

_____ = Number of hours in each consultation

v.9

Study Subject ID: _____ (4 digits)

3

15) In the past year, how often have the following medical providers been consulted?

[Circle all that apply and write in number of visits in the past year.]

Physician's Specialty:	Number of visits:	Physician's Specialty:	Number of visits:
1 = Primary care / family or general practitioner; Internist		6 = Psychiatrist	
2 = Cardiologist		7 = Pulmonologist	
3 = Dentist		8 = Neurologist	
4 = Endocrinologist		9 = Urologist	
5 = Orthopedist		10 = Other	

16) If "Other" doctors are consulted, what is their specialty?

17) Can you make routine visits with your doctors or do you have a gatekeeper?

[Circle one]

1 = Can make routine visits

2 = Must go through a gatekeeper

18) What types of doctors require referrals?

Hospitalizations, ER visits and Medications

These questions are specifically about hospital or emergency room care you may have received and about your medications.

19) Within the past 12 months have any illnesses or injuries resulted in a visit to the emergency room?

0 = NO _____ = Number of visits

20) Why was the visit necessary and if it resulted in admission to the hospital, how long was the stay? [*Probe for cause of ER visits*]

Diagnosis:	Number of days (0 = not admitted):

21) Within the past 12 months have any other illnesses or injuries necessitated hospitalization?

0 = NO _____ = Number of visits

22) Why was hospitalization necessary and how many days long was the stay?

Diagnosis:	Number of days in the hospital:

23) Within the last 12 months, have any illnesses or injuries necessitated additional care or treatment or surgery?

Diagnosis/surgical procedure:	Days of treatment:

24) What medications are currently being taken?

25) Have the medications changed significantly since the onset of the disability?

0 = NO Changes

1 = Changes made as described below

Describe changes in medications since the onset of disability

26) What kind of health care covers the patient's medical expenses? [Circle all that apply]

0 = No health care coverage	4 = private ins through State/uninsurable
1 = private ins through an employer	5 = public health care/Medi-care
2 = private ins through family member	6 = other
3 = private ins through self purchase	

**Physical Therapy (PT)/Occupational Therapy (OT)/
Speech Therapy (SP)**

These questions are specifically about any therapy that the LCP recommended.

27) What type of therapy setting was recommended? [*Circle one*]

1 = Hospital setting	4 = Home setting
2 = Clinic setting	5 = Other setting
3 = School setting	999 = No therapy received

[If no therapy was recommended, skip to question 33.]

28) If therapy was recommended, who was to for it? [*Circle all that apply*]

1 = Private pay	2 = Medi-Care, Medic-Aid, or Medi-Cal
3 = Private Insurance	4 = CCS
5 = Regional Center	6 = Other

29) What frequency of the therapies was recommended by the LCP?

	Per Week	Per Month	Per Year
PT			
OT			
SP			

These questions are specifically about any therapy that you may have received.

30) Has there been any therapy and if so in what type of setting? [*Circle one*]

1 = Hospital setting	4 = Home setting
2 = Clinic setting	5 = Other setting
3 = School setting	999 = No therapy received

[If no therapy has been received, skip to question 33.]

31) If therapy has been received, who paid for it? **[Circle all that apply]**

1 = Private pay	2 = Medi-Care, Medic-Aid, or Medi-Cal
3 = Private Insurance	4 = CCS
5 = Regional Center	6 = Other

32) What is the frequency of the therapies?

	Per Week	Per Month	Per Year
PT			
OT			
SP			

Counseling Services (CS)

These questions are about counseling service that was recommended in the LCP.

33) Were counseling services recommended by the LCP? **[Circle all that apply]**

0 = NO; go to question 35	2 = YES, Family/Spouse
1 = YES, Self	3 = Behavior Management

34) What kind of provider of counseling services was recommended by the LCP?
[Circle one]

1 = Psychological Agency 2 = Private Counselor 3 = Informal Support Group

These questions are about any counseling service that you have used.

35) Has the patient or the family utilized counseling services? **[Circle all that apply]**

0 = NO; go to question 37	2 = YES, Family/Spouse
1 = YES, Self	3 = Behavior Management

36) If services have been used, who provided them? **[Circle one]**

1 = Psychological Agency 2 = Private Counselor 3 = Informal Support Group

RESIDENTIAL STATUS AND PERSONAL CARE

The next questions are about the patients living and personal care arrangements.

Living Arrangement

37) Does the patient live at home? [*Circle one*]

0 = No	1 = Yes, alone	2 = Yes, with a parent
3 = Yes, with a spouse or significant other	4 = Yes, with a guardian or relative other than a parent	

38) Does the patient live in a residential facility? [*Circle one*]

0 = NO 1 = YES

[If patient does not live in a residential facility, skip to question 42.]

39) If so, which one _____

40) Have they always been at this facility? [*Circle one*]

0 = NO 1 = YES

41) If NO, in what other facilities have they lived?

42) Are there plans to move the patient to a residential facility? [*Circle one*]

0 = NO 1 = YES

[If '0 = NO', skip to question 45.]

43) If so, which one? _____

44) When is the move planned? _____

Personal Care Arrangements as Recommended by the LCP

45) How many hours of personal care and assistance were recommended each day? This includes assistance with dressing, eating, bathing, cooking, administering medications, community outings, and all other activities that need to be accomplished in a day.

_____ = Number of hours of personal care recommended each day (on average)

46) Were any family members considered to provide care for the patient?
[Circle all that apply]

0 = No family care	1 = Parent	2 = Spouse	3 = Grandparent
4 = Sibling	5 = Child	6 = Friend	7 = Other

[If "0 = No family care", skip to question 51.]

47) Was the family to be reimbursed for their care giving? [Circle one]

0 = NO 1 = YES 2 = Partial only

[If "0 = NO", skip to question 51.]

48) If YES, was reimbursement recommended on an hourly basis? [Circle one]

0 = NO 1 = YES

49) If YES, how many hours per week were recommended for compensation?

_____ = Number of hours of personal care COMPENSATED per week

50) Was their salary recommended for replacement? [Circle one]

0 = NO 1 = YES 2 = Partial only

51) Who else was recommended to provide personal care? [Circle all that apply]

0 = No one else	1 = Home health agency	2 = Private hire attendant
3 = Volunteers	4 = Self	5 = other

[If "0 = No one else", skip to question 59.]

52) If a private attendant was recommended, what level of care was being recommended by the LCP?

1 = nurse's aid	2 = LPN	3 = RN	4 = Other
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53) Where was the attendant care recommended to be provided?

1 = in the patient's home	2 = In the residential facility	3 = Other
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54) If the care was recommended to be provided in a residential facility, was this care in addition to that provided by the facility?

0 = NO 1 = YES

55) How many hours per week were recommended for the attendant employment?

56) How was the attendant to be compensated? [*Circle one*]

0 = No compensation	1 = Salaried	2 = hourly wage
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57) What was the recommended dollar amount of compensation?

\$ _____

58) What benefits were recommended to be provided? [*Circle all that apply*]

0 = No benefits provided	1 = vacation time	2 = sick leave
3 = insurance	4 = worker's compensation	5 = other

Personal Care Arrangements as Discovered by the Survey

59) On average, how many hours of personal care and assistance are required each day? This includes assistance with dressing, eating, bathing, cooking, administering medications, community outings, and all other activities that need to be accomplished in a day.

_____ = Number of hours of personal care **NEEDED** each day (on average)

60) Of these hours of necessary personal care, how many hours do you (or your insurance carrier) pay for?

_____ = Number of hours of personal care PAID FOR each day (on average)

61) Do any family members provide care for the patient? [*Circle all that apply*]

0 = No family care	1 = Parent	2 = Spouse	3 = Grandparent
4 = Sibling	5 = Child	6 = Friend	7 = Other

[If "0 = No family care", skip to question 66.]

62) Is the family being reimbursed for their care giving? [*Circle one*]

0 = NO 1 = YES 2 = Partial only

[If "0 = NO", skip to question 66.]

63) If YES, is reimbursement on an hourly basis? [*Circle one*]

0 = NO 1 = YES

64) If YES, how many hours per week are compensated?

_____ = Number of hours of personal care COMPENSATED per week

65) Has their salary been replaced? [*Circle one*]

0 = NO 1 = YES 2 = Partial only

66) Who else provides personal care? [*Circle all that apply*]

0 = No one else	1 = Home health agency	2 = Private hire attendant
3 = Volunteers	4 = Self	5 = other

[If "0 = No one else", survey is complete.]

67) If a private attendant is currently employed, what level of care is being provided?

1 = nurse's aid	2 = LPN	3 = RN	4 = Other
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68) Where is the attendant care being provided?

1 = in the patient's home	2 = In the residential facility	3 = Other
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69) If the care is being provided in a residential facility, is this care in addition to that provided by the facility?

0 = NO 1 = YES

70) How were these attendants discovered? [*Circle all that apply*]

1 = Ads	2 = Word of mouth	3 = Agency	4 = Other
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71) If private attendants have provided care, who trained them? [*Circle one*]

0 = No training 2 = Private 3 = Public 4 = VA

72) How long has an attendant been employed? _____

73) How many hours per week is the attendant employed? _____

74) How is the attendant compensated? [*Circle one*]

0 = No compensation	1 = Salaried	2 = hourly wage
---------------------	--------------	-----------------

75) What is the dollar amount of compensation? _____

76) What benefits are provided? [*Circle all that apply*]

0 = No benefits provided	1 = vacation time	2 = sick leave
3 = insurance	4 = worker's compensation	5 = other