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A RETROSPECTIVE STUDY OF PEDIATRIC LIFE CARE PLAN OUTCOMES: ONE LIFE CARE PLANNER'S EXPERIENCE

Doreen Casuto, MRA, RN, CRRN, CCM, CLCP
Leslie Gumpel, BA

Abstract. *This study discusses a retrospective survey of twenty-two pediatric life care plans, completed by one nurse life care planner. Findings demonstrate accuracy in prediction of long-term needs for care, treatment and services, however plan implementation by the parents was inconsistent. Use of case management to implement the life care plan is recommended as a result of the survey.*

Introduction

A life care plan is defined as a "dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized, concise plan for current and future care needs, with associated costs, for individuals who have experienced catastrophic injury or have chronic health care needs" (IALCP, 2000). Many view the life care plan as a tool designed to communicate current and future needs and costs for purposes of litigation. However, many who compile life care documents see the value of the plan as a guide and therefore prepare plans as a tool for the individual and family use. Little research has been published identifying accuracy of life care plans over time (McCollom & Crane, 2001; Sutton, Deutsch, Weed & Berens, 2002).

When a life care plan is prepared for a patient and family, the plan focuses beyond the current needs of the individual and takes into account the disease or disability, as well as the aging process, current health care trends and research. Because the life care plan has a far reaching impact in planning for the care needs of an individual over life, it should be prepared to educate, guide and assist families in planning for, as well as in providing for, these care needs. The life care plan is a dynamic document that adapts to the changing needs of the individual. For this reason, it is recommended, where possible, that life care plans are re-evaluated to assure that individual needs are accurate and recommendations are appropriate.

Some life care planners have the opportunity to implement a life care plan. This provides a unique first hand opportunity to evaluate the effectiveness or outcome of the life care plan in predicting and meeting the individual's care needs. Whether or not the life care planner has such an opportunity, ongoing evaluation of life care plans and their reliability is an important component of practice. This survey was undertaken to assess reliability of life care plans completed by one life care planner.

Methodology

To evaluate reliability of recommendations made by the individual life care planner, this survey was designed to assess effectiveness in identifying care needs, any additional areas which should be addressed in the plans and the issues that impact the families' ability to implement the plans.

A survey tool was developed by the authors to evaluate the effectiveness of completed life care plans. The survey addressed the major recommendations in pediatric plans such as: therapies and frequencies, physicians directing care, hospital and emergency room visits, health care coverage, counseling, recreation and community services, school attendance and care providers. (See Appendix A for complete survey).

Participants identified were families for whom pediatric life care plans had been prepared in plaintiff cases. Staff associates of the authors called selected families and interviewed them using the survey tool. These staff members were familiar with the life care planning process as well as the survey tool itself. Some calls were placed directly to the families, while others were contacted through their attorneys or by mail. Additional child related information was obtained during the survey, to better understand their needs and current issues. Telephone calls were made between August and September of 2002. Cases included both those completed by settlement as well as those that had gone to trial. Thirty-five out of the forty-five cases identified had settled. Of the ten that went to trial, four received awards and six did not. The life care plans were prepared between 1992 and 2002 and involved children/young adults who were between the ages of 1 and 22 years of age when the life care plan was prepared (See Table l).

Of the 45 participants identified, the authors were able to locate current addresses for 38 of the participants. Of the 38 selected for contact, 22 responded. Non-response was associated with attempted contact through attorneys. Also, it was learned that one child had died after life care plan preparation.

Results

Health Care

In all of the twenty-two life care plans, future hospitalization was included and frequency was based upon prior history. In the retrospective study, when asked about hospitalizations, over half of the children had not required hospitalization on a yearly basis. Those children who had been hospitalized had a length of stay averaging from one to two days. The primary causes of admissions were surgery and complications from seizures and asthma.

Over half of those interviewed had no emergency department visits. The other children visited emergency rooms only once a year, with the primary causes being seizures, asthma, broken bones, and post surgical complications. One child had a severe and uncontrolled seizure disorder and went to the emergency room more than fifteen times in a year and had more than three hospitalizations per year, since completion of the life care plan.

While the disabilities among these children varied, the majority of children were followed by pediatricians, family practice physicians, internists, neurologists and orthopedists on a regular basis. Other specialists seen included neurosurgeons, ophthalmologists, endocrinologists and mental health professionals. Those children who had been actively involved with physiatrists at the time of the preparation of the life care plan, continued to follow up on a routine basis. Those children who were not followed by a physiatrist initially,

Table 1

Age Range	Number of Plans	Survey Percentage
1.5 – 5 years	25	45%
6 – 10 years	14	32%
11 – 18 years	8	18%
22 years	1	5%

Types of injuries requiring long-term care may be seen in Table 2.

Table 2

Type of Injury	No. of Children	Percentage of Study Group
Birth Injury	7	31%
Brain Injury	3	14%
Spinal Cord Injury	3	14%
Orthopedic Injury	3	14%
Other - Anoxic event, shaken baby syndrome and post meningitis	6	27%

did not initiate this medical care after the recommendation was made in the life care plan.

Of the children surveyed, only one child was not covered by any form of insurance. Fourteen children were covered by private insurance under either their parents' or a grandparents' policy with the remaining six children covered by public insurance, primarily through Medi-Cal. One child had both Medi-Cal and Medicare. In California, Medi-Cal provides health care insurance to California residents who are disabled.

Therapy

In all of the twenty-two life care plans, therapy was included as a recommendation. In the retrospective study, the majority of the children received therapy at school, although 25% received therapy at home, with the rest receiving therapy in a clinic or hospital setting. Twenty-five percent of the children were receiving their therapy through California Children's Services (CCS), a state program that was designed to assist in funding services for children with chronic diseases and/or physical limitations. For those who qualify, CCS provides medical treatment including therapies and surgery, equipment, and medical case management. In order to qualify for CCS, the child must be a California resident under 21 years old. Financial qualifications include that the family income is less that $40,000 or the medical expenses exceed 20% of the family income (CCS Information, February, 2003). Ten percent of the children surveyed received therapy that was funded through insurance and the remainder paid privately for therapy. Ten of the children received occupational therapy one to two times weekly. Fifteen received physical therapy one to four times weekly. Eleven children took part in speech therapy one to five times a week. One child received vision therapy once per week. Only three children in the survey were no longer receiving any therapies and this was due to lack of time (2) or transportation (1).

Counseling

In all of the twenty-two life care plans, counseling was recommended. Counseling services would enable the family to deal with issues surrounding the disability or to cope with the changes they would be experiencing. In the retrospective study, five families used this resource for private counseling and four children attended individual counseling. One child was hospitalized due to emotional adjustment issues. Five children were referred for behavior management, three of whom were funded by Regional Center, a non-profit corporation geared toward providing assistance and resources for people in California with disabilities. Regional Centers are located throughout California with 21 offices servicing the state's individuals who have developmental disabilities and/or mental health impairments. Only one family attended a support meeting through the United Cerebral Palsy organization.

Recreation

In all of the twenty-two life care plans, recreation was included. In the retrospective study, only five children participated in activity programs during the school year or during the summer. Two attended summer camps for children with a disability; one attended a day camp, while the other attended a sleep away camp. Both campers brought private aides to assist them. The child at sleep-away camp brought his sibling as his aide. Another of the children (young adult) surveyed had worked one summer at a camp for deaf children. Two of the children who participated in recreational programs, attended aquatic therapy and equine therapy funded by Regional Center. The fifth child participated in soccer and a Little League baseball program for children with disabilities.

Equipment

In all of the twenty-two life care plans, equipment was recommended. In the retrospective study, when asked about medical equipment, particularly mobility aids, eighteen children used some form of mobility assistance. Eight children had manual wheelchairs, two required power wheelchairs and three were transported in a stroller when in the community. Five children relied on walkers, while only one child used a standing frame. Although positioning equipment had been purchased initially, few families replaced the equipment with growth, since other activities and equipment were felt to meet the children's needs.

Fiduciary

In all of the twenty-two life care plans, fiduciary services were included as necessary future services. In the retrospective study, two children received no monetary compensation from their lawsuit and recommended purchases could not be completed. Twenty cases fell under the jurisdiction of the probate court and financial management of the funds varied. In three of the families, the parents managed the money, while another three received structured settlements with annuities. Four of the families hired an attorney and a bank officer to manage the funds while another four used a fiduciary and an attorney. Only two families used a fiduciary only to administer the funds. Four of the families used attorneys and accountants to manage the funds. Special needs trusts had been established in some of these cases.

Attendant Care

In all of the twenty-two life care plans, attendant care was recommended. In the retrospective study, all the families reported that they provided the majority of care-giving services. Only four families hired private help to supplement the care they were providing their children. One family hired an attendant through an advertisement while the other three families hired the attendants privately through personal contacts. Two of the caregivers were "nannies," one of whom was a live-in. The other provided daily assistance and charged $400-$500 per week. The remaining seventeen families declined outside help and preferred to use assistance from members of their extended family.

Six of the mothers resigned or modified their employment in order to assume responsibility as primary care giver. Four of the mothers receive on-going payment from the settlement that replaces the funds that they would have received if they continued to work. One of the cases is in the process of being set up and the mother is not currently receiving payment. However, this has been recommended in the settlement document. One of the mothers provides transportation for her teenage daughter and is not currently compensated for these services.

Schooling

In twenty-one of the life care plans, an educational advocate was included to assist the families in advocating for their child. The parents were also educated at the initial interview with the family, of the schools' responsibilities to provide attendant care and resources based on the children's care needs. Of those children surveyed, only two had been placed in private schools as a result of the school district's inability to meet the child's needs. None of the families surveyed paid for private schooling. Seven children were provided aides by the school district. Four of these children had a 1:1 aide while the rest had more staff time available in their classrooms. The ratio in the classrooms ranged from 1:3 (1 teacher to 3 students) to 1:10 (1 teacher to 10 students). One child in the survey did not attend school due to his increased susceptibility to upper respiratory tract infections.

Community Services

Twelve of the respondents were no longer using any of the services Regional Centers offered. None of the families had been provided equipment or were participating in the medical waiver which provides additional nursing care and is administered through the Regional Center. There were nine families using respite care with hours ranging from eight to forty hours per month.

Outcomes of the Survey

The focus of the survey was to identify if life care plans completed by one life care planner accurately recognized care needs; to specify the problems or issues that affect the use of the plan; and to define additional areas which need to be included in future life care plans. While the disabilities of those surveyed varied, there were some common trends identified by the survey:

Most of the children did not require hospitalizations on a yearly basis, but those requiring hospitalizations were inpatient one to two days annually. This is significantly different from adults with long-term care needs, who consistently have longer lengths of stay when hospitalized.

Twenty-seven percent of those surveyed visited the emergency room on an annual basis, and this was consistent with expectations included in the life care plans.

Specialized medical care did not occur in frequencies as expected. Those surveyed saw their primary physician or orthopedists more frequently and had the volume of visits per year as projected, but not the specialists as anticipated. The majority of children had been referred to a physiatrist with annual follow up visits recommended, yet only two of those surveyed followed through with this recommendation over the years.

Many of the individuals continued with therapy beyond the expected length of time included in the life care plan and only two received no therapy. An interesting finding was the number of children who used the public school system as their primary resource for therapies. Fifty four percent were receiving therapy at school rather than in a hospital or clinic setting, while twenty-two percent received therapy at home. All of the life care plans identified private therapists either in hospitals or in clinics rather than using public agencies which offer services at no cost.

Community resources outside of therapy were not used by families. They did not appear to understand that the plan should be used in conjunction with available community services, rather than only using private funds. The use of therapy services through schools appears to be recognized by families, but they appeared to need more education regarding the importance of using other community resources before they expended their financial resources.

Families did not consistently use recreational programs. Some appeared to be hesitant to become involved, while others sought out programs on their own. Recreational programs especially during the summer should be encouraged and parents educated about their benefits. Aquatics and equine therapy were the most frequently used programs.

Psychological counseling was another service that appeared to be under utilized. Only five families used counseling while four children attended individual counseling sessions. Two of the teenage girls had disabilities which occurred as a result of an accident during adolescence. As mentioned, one of the girls had to be hospitalized for depression, which was not anticipated in the life care plan. Neither support groups nor resources such as United Cerebral Palsy or Easter Seals were seen as viable resources for the families surveyed.

Those individuals who did not understand how to use the plan as a guide also had difficulty implementing the elements of the life care plan. Although all of the parents had been involved in the preparation of the life care plan, few appeared able to effectively utilize the plan. The court used the plan to assist them with preparing a budget, but few seemed to extract the necessary information to implement the various portions of the plan. The parents who were successful in implementing components of the care plan, were primarily those who saw this as their responsibility and who had the education necessary to search out services and resources for their child. They saw it as their responsibility to become educated to enable them to serve as advocates for their child.

Several of the mothers assumed responsibility for care giving and resigned from their jobs. In taking on this responsibility, some sought out counseling while others attended educational programs regarding services for individuals with disabilities, to assist them in advocating for their child.

Due to the finding that plans were not consistently implemented, it appears that a case manager is essential to assist the families in identifying services and using the life care plan as a tool. The case manager should educate and serve as a facilitator for the parents, assisting them to identify services, resources and agencies that may improve their child's quality of life.

Recommendations

The survey shows the importance of educating families regarding the elements and strategies for the implementation of the life care plan. The families that were not involved, educated about services or assisted in learning to become an advocate for their child were unable to effectively integrate both public and private services to pay for needed care. Parents that were educated and understood how to use the life care plan were able to ensure their child had the necessary resources throughout their life time. Although a life care plan is commonly used as a way to define and summarize damages in personal injury litigation, it should be a living document that helps families plan for, coordinate and manage their children's health care needs and services so they can maximize the potential and improve their quality of life.

The survey does not represent a randomized or scientific study. It documents results from a selected population and is a review of the work of one professional. The findings demonstrate the value of retrospective review, to determine accuracy of individual work and issues that may impact plan implementation. Further surveys should be completed to compare outcomes across practitioners and geographical areas. Limiting variables to comparison of children with like disabilities may be of help in future studies, to quantify frequencies of medical follow-up and services for given populations.

References to funding of life care plans are not included in this survey report, due to confidentiality of settlement outcomes. Financial outcomes of settlement often are not made available to life care planners.

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About the Authors

Doreen Casuto, *MRA, RN, CRRN, CCM*, CLCP, received a BSN from the American University of Washington, DC in 1970 and a Master's degree in Rehabilitation Administration from the University of San Francisco in 1984. She has 30 years experience in the field of rehabilitation nursing, education, consultation and 14 years as an independent case manager and life care planner working with catastrophically injured children and adults.

Leslie Gumpel, *BA*, graduated from Brandeis University in 2002 and has worked with Rehabilitation Care Coordination as a research assistant and assistant case manager.

Appendix A

Pediatric Life Care Plan Survey

1. How many times have you been hospitalized per year? _____ & number of days ____
   Cause:

2. How many ER visits per year? _____ times and cause :

3. Are your medications different from your initial Life Care Plan? __________

PT/OT/SP Therapy

1. Have you had any therapy in a hospital, clinic, or private setting? _______________

2. How do you pay for your therapy? Private pay_____ CCS_______Ins.________

3. What is the overall frequency per year of your therapies?
   PT_____ OT_____ SP_____

Community Services

1. Regional Center: ______ Equipment - What type ____________
______ Respite Care - How often and what duration? _______
______ Medical Waiver _____ Sliding Scale

2. CCS: _____

3. School: _____ Public school
______ Private with public placement
______ Private without public placement
______Therapy at school PT/OT/SP
______ Completed school
______ Diploma
______ Certificate of completion
______ Aide at school Ratio: ___ 1:1 ____Other ______Hours available

4. Activity/Transitional Programs
What programs are you involved in? ___________
What is your cost to participate in the program? __________,
How many hours a day do you participate? ____________
Days a week___________________
Do you need transportation? ________ Do you need an aide? __________

5. Employment
Do you have regular employment?__________
Structured/Supported employment__________
How many hours a day do you work? _______ How many days a week? _________
Do you need transportation? __________
Do you receive pay? _________________

6. Health Care
Do you have private health care?_______ Through an employer _____________
Through State uninsurable ____________
Through parent/grandparent ___________
Through self purchase____________
Do you have public health care?_________ Through Medi-care _______
Through Medi-Cal ________
Both _____

7. MD'S
What types of doctors do you use? ________Ped/ IM / FP
________ Renal
________ Orthopedist
________ Neurologist
________ Others:
Who serves as Primary? _____________
Can you make routine visits with your doctors or do you have a gatekeeper?
____
What type of doctors do you have routine visits with?
____
What type of doctors require referrals? ________________________________

8. Recreational Activities: ____ with disabled – Sharp/Casa Colina
_______ with non- disabled – Scouts, YMCA
______ sports activities – Swimming Club, wrestling, softball league
_______ organizations/programs
______ ABI, BIF
______ SCI, Women's Group
______ Abilities Expos
______ Educational Program-Child
______ Health: Aquatics/Fitness
______ Child ______ Cost
___________________ Which program

9. Mobility: _______ Local
_______ Manual
_______ Power
_______ Standing/Wheelchair
_______ Advances- glide/gobot

_________ Community
______ Power
______ Rental
______ Car/Van: ______ Purchase or _____ Lease
______ Frequency of Abilities Expo _____ Miles _____ years attended

10. Home ______ Purchased new home with modifications
______ Modifications/ improvements made in existing home
______ Types of modifications_______________________________________
______ Average cost of modifications

11. Financial Management _______ Parents ______ Bond
_______ Fiduciary _______ Attorney and Fiduciary
_______ Minors Compromise with request
_______ Bank Management (Trust Department)
_______ Structured Settlement

12. Counseling _______ Family
_______ Child
_______ Behavior Management
_______ Agency
_______ Regional Center
_______ Children’s Hospital
_______ Private

13. Care Providers ______ Family
______ Private hire
______ Word of Mouth
______ Ads
______ from Agency
______ Agency: ________________ one or several
______ Training: ________ Private ________Public ________ VA
______ Length of employment

______ Salaried ___________ Range
_____ New ______ Long term employment
______ Benefits
_______ Vacation ______ Sick Leave ______ Insurance
_______ Workers’ Compensation

Information obtained by: Date: