LIFE CARE PLANNING FOR INDIVIDUALS WITH SPINAL CORD INJURIES: OUTCOMES AND CONSIDERATIONS

DISSERTATION

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

By

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The Ohio State University
2007

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Life care planning is a specialty area of practice that relies upon a multidisciplinary approach to case analysis and comprehensive plan development. This area evolved as a tool of case management and has applications within a variety of industries and disciplines including private and government health insurance, disability management, home and facility-based health care, vocational rehabilitation, psychological counseling, durable medical equipment and assistive technology, and personal injury litigation. Life care planning methodology utilizes evidence-based standards of care, clinical practice guidelines, published research, and recommendations from members of a client’s treatment team to identify long-term medical and rehabilitation needs for individuals with catastrophic injuries and chronic health conditions. Plan recommendations are based upon the unique needs of each individual and their anticipated needs over time. Associated costs of all plan recommendations are based upon the fees charged by service providers and vendors within the individual’s local community or geographic region, and they are projected over the course of his or her life expectancy.
The purpose of the present study was to describe the outcomes experienced by individuals with spinal cord injuries for whom life care plans were developed. An exploratory qualitative case study approach involving semi-structured, in-depth interviews allowed investigators to describe emergent themes and to assess the consistency between current self-reported needs and those that were projected in each participant’s life care plan. Seven individuals participated in the study.

Themes that emerged from participant interview included: the importance of maintaining independence, health, pre-injury goals, and a positive outlook; fear of future health problems and further physical limitations; frustration with the health insurance claims process; the need for case management support; and the role of professionals in litigated cases.

In considering the consistency between current and projected needs, plan recommendations regarding personal assistance were not applicable in three cases because the participants are not yet of the age when such services were projected to begin. In three cases, participants reported requiring fewer hours of personal assistance than was projected in their life care plans. In one case, the participant receives 24 hour attendant care and has so since the time of the injury. The continued need for such care was accurately projected in the life care plan.

With regard to medical care, each plan demonstrated areas where projections were consistent with current needs and areas where projections were
inconsistent. Interpretation of these findings is limited by the lack of access to each participant’s recent medical and rehabilitation records, and the inability to interview the primary care physicians who are currently directing their medical care.

Given the emergent themes, post-injury outcomes, and unexpected findings revealed in the present study, an educational initiative focused upon informing clients of the value and utility of their individualized life care plan appears necessary. Investigators discuss the implications of the findings, challenges in conducting research within the specialty, and suggest directions for future research.
DEDICATION

This dissertation is dedicated to my family.

First, this is dedicated to my parents, Pamela and Stephen Allison. My love and respect for them is beyond what can be communicated in words, but I hope to live my life as they have modeled; with generosity, persistence, humility, strength of character, faith, trust in the meaningfulness of challenges, delight in accomplishments, and unwavering dedication to our family.

This is also to my sister, Amy, and to my nephew, Vincent. Amy is a trusting, tolerant, patient, and loving individual who has confronted daunting obstacles with amazing courage. I admire her ability to persevere through trying situations with a forgiving heart. She is an extraordinary sister, mother, and friend. Vincent came into our lives on May 10, 2006 and has been blessing every day since. His spirit, enthusiasm, and joy remind me of all that is wondrous and magical in the world.

My family has been a constant source of support and encouragement. For that, I am truly grateful.
I offer my sincere gratitude to the members of my dissertation committee; Dr. Joe Wheaton, Dr. Darcy Granello, and Dr. Bruce Growick. Throughout my program of study at OSU, they were among the primary professors who facilitated my educational growth and influenced my professional development. Their encouragement and feedback throughout the dissertation process was invaluable. Their dedication to my academic and career goals continues to be gratefully appreciated.

I also want to thank the individuals who volunteered to be part of this study. They were willing to share details of their lives that will help life care planners and other professionals gain greater insights regarding their medical, personal care, and health-related needs. Moreover, their willingness to discuss the issues that are of importance to them may help to shape future research that will improve the provision of services, accuracy of plan projections, and utility of life care plans over time. It was a pleasure to speak with each of these participants and I am glad that I had an opportunity to gain some experience in this method of data collection.
This research study was funded by a grant from the Foundation for Life Care Planning Research, and I am honored to have been selected as a fellowship recipient. I want to acknowledge the generous contributions made to the Foundation by life care planners and other interested parties. The Foundation supports the research efforts of those who are interested in expanding upon the existing body of literature and is particularly supportive of student work within the specialty.
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FIELD OF STUDY

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CHAPTER 1
INTRODUCTION

For many years, rehabilitation and case management professionals have developed comprehensive plans to describe the needs and define the goals of their clients. Rehabilitation and case management plans are utilized in a wide range of disciplines and are generally accepted as valuable tools in communicating shared expectations among members of the treatment team, payors, families, and the individuals receiving services (Weed & Field, 2001). A comprehensive plan allows for consistency and continuity among various providers who may be supporting an individual in pursuit of his or her educational, vocational, personal, and health-related goals. Such plans provide a framework for integrating services and resources, making treatment or therapeutic decisions, and observing changes in functional limitations over time.

Life care planning is a relatively new subspecialty that has experienced tremendous growth in the last 25 years. This growth is due, in part, to the utilization of life care plans within the rehabilitation, insurance, and legal professions. More significantly, life care plans may be growing in popularity
because they are viewed as valuable tools in managing the long-term needs of individuals with catastrophic injuries and chronic illnesses.

**Historical Background**

Although the term “life care plan” may be unfamiliar to some professionals, the methodology employed throughout the plan development process is similar to the methods used by case managers, rehabilitation counselors, therapists, and others who are responsible for planning for an individual’s long-term needs following an injury. The tenets and methodologies of life care planning emerged from a combination of case management practices and catastrophic disability research in the mid-1970s. Historically, this area of practice has been described as having evolved from three distinct disciplines; experimental analysis of behavior, developmental psychology, and case management (Deutsch, 2002; Deutsch & Reid, 2003).

During the 1970s, experimental behavior analysis was an emerging area of study in the field of psychology (Deutsch & Reid, 2003). This subspecialty combines the underlying principles of experimental and clinical psychology in order to scientifically study behavior and the mechanisms of behavior change (Deutsch, 2002; Deutsch & Reid, 2003). In doing so, researchers attempt to define how and why individuals react to specific situations in specific ways. Inherent in this area of study are the principles of learning theory and behavioral psychology,
which rely upon the counting and charting of discrete behaviors in order to
document changes over time (Deutsch & Reid, 2003). Complex behaviors are
deconstructed into specific actions that can be quantitatively measured and
analyzed in relation to the presentation of various stimuli, or as an individual reacts
to given situations (Deutsch & Reid, 2003). The techniques that drive behavior
analysis are also critical elements of life care planning. Planners must be able to
identify the short-term and long-term goals and acute needs of patients, and then
clearly communicate these details to all parties involved in the case (Deutsch, 2002;
Deutsch & Reid, 2003). Just as behavior charts serve as documentation of behavior
change over time, life care plans serve to comprehensively account for the medical,
care, and rehabilitation needs of individuals with catastrophic injuries.

Developmental psychology involves the study of social, cognitive, and
physical changes that occur throughout the life span (Deutsch, 2002; Deutsch &
Reid, 2003). This area of study has defined several critical periods in human
development that, in part, determine future attitudes, behaviors, relationships, and
sense of wellbeing. Developmental psychology attempts to identify the effects of
aging by conducting longitudinal and cross-sectional research and recognizes that
the human life cycle is comprised of many phases, not just childhood and
adolescence (Deutsch & Reid, 2003). This focus on the human life cycle and phase
changes throughout the aging process provides a philosophical basis for life care
planning (Deutsch, 2002; Deutsch & Reid, 2003). A comprehensive plan provides
continuity of care while accounting for the client-specific characteristics that will interact with the effects of disability over time.

Case management also emerged as an area of applied study in the early 1970s (Deutsch & Reid, 2003). At that time, founding professionals within the specialty of life care planning were providing case management support and guidance to young children and adults with disabilities and their families (Deutsch & Reid, 2003). These professionals recognized a deficiency in the choice of tools available to them when presenting complex, long-term care and rehabilitation plans to clients, their families, and practitioners from other disciplines (Deutsch & Reid, 2003). In the early stages of its history, founding practitioners were conducting research with children who had cerebral palsy (Deutsch & Sawyer, 1985; Deutsch & Reid, 2003). When reviewing the recommendations for future care with families, it was difficult to adequately communicate the information because of the overwhelming complexity of the children’s needs. Parents, therapists, educators, physicians, and others involved in the child's care needed a structured, systematic reference tool that summarized the recommendations and provided a roadmap to follow in the future. Over time, the framework for the life care plan evolved. The practices and basic principles inherent within rehabilitation counseling, rehabilitation nursing, rehabilitation psychology, and case management culminated in the establishment of the tenets, standards, and methodologies of life care planning (Deutsch, 2002; Deutsch & Reid, 2003). These professionals recognized
the importance of integrated, coordinated services for those with long-term medical and rehabilitation needs (Deutsch & Reid, 2003).

Life care plans provided the necessary format for presenting comprehensive, yet exceptionally detailed information regarding the manifold needs of patients with catastrophic injuries (Deutsch, 2002; Deutsch & Reid, 2003). Using life care plans as tools of case management, professionals were able to more efficiently communicate with clients and their families, to offer assistance, and to suggest effective, proactive strategies for maximizing long-term health and wellbeing (Deutsch & Reid, 2003). The life care plan became a document that allowed practitioners to clearly identify the critical periods of need as children progressed through the developmental phases of the life cycle and as adults experienced similar phase changes over time. This, combined with the amassing knowledge bases and practice methodologies in the aforementioned areas, guided the evolution of life care planning and enabled its application to a diverse population of individuals with varying levels of disability.

Life Care Planning in Publication

The term “life care plan” first appeared in the literature in 1981 with the publication of the multi-volume legal text, Damages in Tort Actions (Deutsch & Raffa, 1981). Life care plans were discussed within the context of civil litigation as a means of determining the economic damages in personal injury, medical
malpractice, and other civil cases. The authors of the text described a methodology for developing a detailed analysis of an individual’s future medical care needs, psychological counseling, social and recreational support, necessary services, and equipment and assistive technology needs through life expectancy. Life care plans provided a format by which to represent these diverse needs in a logical, easily interpretable manner. From its inception, Deutsch and Raffa (1981) described life care planning as a consistent methodology for comprehensively analyzing an individual’s current and future needs resulting from the onset of a catastrophic injury through to the end of his or her life expectancy. They clarified that consistency in the methodology used to develop an individualized plan meant that the process of identifying needs remained the same from case to case; not that the same services should be provided to all individuals with similar injuries or chronic illnesses (Deutsch & Raffa, 1981). Two components of this description deserve additional discussion; the concepts of a consistent methodology and needs-driven recommendations.

In order to most effectively and accurately analyze the needs of clients, life care planners must employ a consistent approach to the task (Deutsch & Raffa, 1981). Life care planners deliberately and systematically organize, evaluate, and interpret client-specific information according to the principles and practices established within the specialty. When client data is systematically collected and managed, each detail of his or her circumstance may be identified and appropriate
recommendations may be made. Consistency in practice methodology helps to ensure that planners holistically consider the future needs of clients as they age with injuries or chronic illnesses that will result in greater functional limitations over time. Similarly, consistency in methodology helps to ensure that the planner maintains objectivity across cases.

When a consistent case analysis and plan development methodology is followed, research regarding client outcomes may be used as a resource in projecting probable future needs. From the specialty of experimental behavior analysis, life care planning borrowed the concept of critically evaluating the components of a client’s current situation as one means of identifying long-term needs (Deutsch & Reid, 2003). Based upon these current and anticipated needs, planners are able to access evidence-based rehabilitation research and to collaborate with members of the client’s treatment team to specify appropriate long-term recommendations. One of the basic principles of life care planning is that recommendations within a plan must be founded upon established medical and rehabilitation outcomes as documented within research literature and as supported by members of the client’s treatment team (Deutsch & Raffa, 1981; Deutsch & Reid, 2003).

The concept of needs-based recommendations is a fundamental principle of life care planning. Private health insurance policy guidelines, government insurance program allocations, and other collateral sources of funding are not
considered when identifying client needs and citing recommendations within a life care plan. Projections are based upon medical and rehabilitation foundations and the anticipated needs of clients throughout life expectancy. This approach allows planners to comprehensively outline anticipated needs and to recommend appropriate support services and items that will allow clients to achieve as much functional independence as possible, to accomplish their long-term goals, and to enjoy a satisfying, rewarding quality of life. Plans that are based upon funding considerations may endanger the health and wellbeing of clients who require more care, equipment, or support services than specific funding resources allow.

Realistically, funding and resource limitations must be considered, but the life care planning literature clearly explains the importance of not allowing such factors to influence the type, duration, or frequency of services that are identified within a client’s plan (Deutsch & Reid, 2003). Recommendations should be based upon the anticipated future needs of a client, regardless of the source of payment. During the plan implementation phase, case managers may work collaboratively with professionals from numerous disciplines and community agencies to creatively resolve funding issues and to identify collateral sources of support. Plan implementation is most effectively accomplished through a team approach, with consideration given to all possible avenues of funding (Deutsch & Reid, 2003). The application of a consistent methodology that outlines needs-based recommendations is a fundamental concept that guides the development of a life
care plan. Additional principles and tenets will be thoroughly discussed in Chapter 2 as the majority of currently published literature in this area directly addresses the guiding concepts within this specialty area of practice.

Current Definition of Life Care Planning

The current definition of a life care plan was adopted at the 1998 International Association of Rehabilitation Professionals (formerly the National Association of Rehabilitation Professionals in the Private Sector) and is as follows (International Academy of Life Care Planners, 2006):

A Life Care Plan is 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 needs with associated costs for individuals who have experienced catastrophic injury or have chronic health care needs. (p. 123)

The description of a life care plan as being dynamic communicates the notion that there is a potential for modifications as the needs of clients and their families change over time. This implies that recommendations are based upon what is known about the client at the time that a plan is developed and acknowledges that circumstances may necessitate future revision. The definition also explains that recommendations are based upon the unique experiences, environment, co-morbidities, age, vocational goals, and other specific needs
affecting the client and his or her family. In specifying that the life care plan is a document based upon standards of practice, the definition underscores the importance of maintaining a consistent methodology, ethical practice, and professional competency within the specialty area. The definition further specifies that plan projections are identified through comprehensive assessment, data analysis, and research. By definition, the process of life care planning requires a holistic consideration of all aspects of a client’s current situation so that plan projections accurately reflect the entirety of his or her anticipated needs through life expectancy.

The life care plan is a complex document, designed to meet the specific long-term needs related to all aspects involved in managing injuries and chronic illnesses over time. As a dynamic document, Weed and Field (2001) offer the following examples of catastrophic injuries that may necessitate the development of a life care plan: Spinal cord injury, traumatic brain injury, severe burns, amputations, organ transplantation, and congenital abnormalities. Conditions such as diabetes, multiple sclerosis, stroke, and cardiopulmonary diseases are chronic, disabling conditions that may also be considered catastrophic in their affect on individuals and families.

The planning process is multidisciplinary and includes professionals from seemingly disparate fields such as economics, education, allied-health, medical technologies, supported and assisted living, nursing, engineering, biomechanics,
psychology, dietary and nutrition, pharmacology, law, family services, and others who may be called upon to offer advice or support for an individual coping with a life altering illness or injury (Deutsch & Reid, 2003). Each profession perceives issues in the case from a unique perspective, offers distinctive skills, and can propose recommendations in the best long-term interests of an individual and his or her family.

Because of the complexity of the medical issues involved in catastrophic cases, the wide-ranging needs of clients, and the need to complete a detailed analysis, the process of formulating a life care plan is truly a collaborative effort. The decisions considered by life care planners and the consultation team have far-reaching implications. The process of developing a life care plan has been compared to playing three-dimensional chess where each move influences the configuration of the entire game, from many angles, and from many viewpoints (Deutsch, 2002). Similarly, a multidimensional perspective is necessary in order to identify the interactive effects of plan recommendations. A team, comprised of all relevant disciplines, must be involved in the planning process so that the recommended goods and services accurately represent the needs of the client over time.
Standards and Certification in Life Care Planning

With its foundation in psychology and rehabilitation case management, life care planning attracts board certified professionals from diverse fields of practice, including rehabilitation counseling, allied health, rehabilitation nursing, rehabilitation psychology, physiatry and medicine, vocational rehabilitation, social work, special education, and other fields. In order to be eligible for certification, a professional must have achieved certification or licensure in his or her primary discipline. The Commission on Health Care Certification (CHCC), which is the national organization responsible for certifying life care planners, also requires that candidates complete a minimum of 120 hours of post-graduate or post-specialty degree training specific to life care planning (Commission on Health Care Certification, 2003). The International Academy of Life Care Planners (IALCP) was formed in 1996 as the first professional organization within this specialty area (McCollom & Weed, 2002). Since then, IALCP has led in the effort to establish standards of practice and to promote professional development through continuing education. In addition to demonstrating competency, life care planners are obligated to maintain ethical standards of practice and to uphold the principles of client autonomy, beneficence, nonmaleficence, and justice (Blackwell, 1999).

To the greatest extent possible, autonomy in all aspects of an individual’s life should be considered the goal when making treatment, personal assistance, equipment, and other recommendations within the life care plan.
Recommendations should facilitate independence and reflect the preferences of the client and the family when such options exist. Psychological adjustment to catastrophic injury may be most effectively facilitated when a plan reflects appropriate aids for independent functioning, personal assistance, mobility, community involvement, and other activities that allow an individual a sense of choice, control, and self-reliance (Blackwell, 1999). The principle of autonomy applies not only to recommendations within the life care plan itself, but also to the role of the client in the plan development process. To the greatest extent possible, clients are included throughout the development of the life care plan so that they are able to voice preferences, to make informed choices, and to be active participants in charting their future needs. Informed consent is an essential component of autonomy. At no time during the planning process should clients be left without explanation as to the intentions of the planner. Rather, planners must clearly explain their role and function, limitations of confidentiality, purpose of the plan, methodology involved in the planning process, and the value of the completed plan (Blackwell, 1999).

Beneficence is demonstrated throughout the planning process because all recommendations are intended for the long-term health and wellbeing of the client. Preventative measures are included in the plan to ensure the best possible care and to avoid complications. A planner seeks to maximize an individual’s potential and to minimize complications by proposing recommendations in the best interest of
the client. Although there are acute medical situations and complications that cannot be foreseen when developing a life care plan, the goal of this process is to minimize such occurrences (Deutsch & Reid, 2003). When reacting to a crisis, the client, family, and involved professionals often do not have an opportunity to judiciously consider the viability of various intervention options, but must take immediate action to resolve a threatening situation.

Nonmaleficence may seem an obvious principle in this discussion, but the concept also encompasses the harm inflicted as a result of professional incompetence (Blackwell, 1999; Weed & Berens, 2004). A life care planner must demonstrate the technical and communication skills necessary to develop a comprehensive, meaningful document that will remain relevant and useful over time. Otherwise, an individual may endure harm caused by errors, omissions, or negligence if planners fail to adhere to the published standards of practice and methodological guidelines. Professional competency also includes having an awareness of cultural, religious, geographic, and other personal characteristics that may influence compliance with specific recommendations within the life care plan (Weed & Berens, 2004).

Lastly, a life care planner must engage in practices that promote the just treatment of individuals with disabilities. A planner must be able to fairly assess the functional limitations resulting from injury or illness and to accurately identify the needs of the individual when determining necessary goods and services.
Particularly in forensic cases, the principle of justice obligates planners to objectively and adequately represent the needs of a client, regardless of whether their professional fees are being paid by plaintiff or defense counsel. The contents of the life care plan are not to be influenced by the objectives of legal representatives involved in a litigated case.

Because of the diversity of professional backgrounds, credentials, and experience represented by life care planners, the standards and ethical guidelines governing this specialty area are applicable to numerous practice settings. Weed (2002a) cites the following environments in which life care plans are frequently utilized to project care needs and future costs: Personal injury litigation, managed health care organizations, worker’s compensation, hospitals and rehabilitation facilities, state rehabilitation bureaus, private rehabilitation agencies, insurance carriers, estate planners, elder care management, and other practice settings that promote the long-term health and wellbeing of individuals with disabilities, catastrophic injuries, or chronic illnesses. Life care planners who choose to become nationally board certified may come into the specialty with expertise in various disciplines, but are obligated to protect the interests of clients by adhering to the accepted standards of practice (Weed, 2002a).
Importance of the Study

The Foundation for Life Care Planning Research was established in 2000 for the purpose of supporting research efforts in life care planning (Deutsch, 2003). The Foundation is comprised of board members who are leaders in the specialty and have published extensively in this area. The mission of the Foundation is to provide financial and consultation support to individuals pursuing research in life care planning (Deutsch, 2003). Given the current status of the specialty and the utility of life care planning in various practice settings, the Foundation has identified the need for reliability and validity research as being of critical importance (Deutsch, 2003). Because the tenets and methodologies are well-established in the literature, the specialty has naturally evolved to a stage where research efforts may be effectively devoted toward establishing the reliability and validity of the techniques employed throughout the plan development process. As a tool utilized within the forensic area, an additional catalyst for this effort has resulted from the outcome of the Daubert v. Merrell Dow Pharmaceuticals, Inc. case.

In 1993 the U.S. Supreme Court established rigid standards for admitting expert testimony into evidence with its ruling in the Daubert v. Merrell Dow Pharmaceuticals, Inc. case (Countiss & Deutsch, 2002). Countiss and Deutsch (2002) explain that the Daubert ruling established the following basic considerations for determining whether scientific testimony from an expert can be
admitted in evidence: Whether the theory or technique utilized by the expert can be, or has been, tested; the extent to which the theory or technique relies upon the subjective interpretation of the expert; whether the theory or technique has been subjected to peer review or publication; whether the rate, or potential rate, of error is known; the degree of general acceptance of the theory or technique within the field; and the non-judicial purposes to which the theory or technique may apply. Although these guidelines are currently applicable only in federal courts, it is expected that many states will also adopt these rigorous standards of admissibility (Countiss & Deutsch, 2002).

The Daubert ruling impacts all expert witnesses who provide testimony. The ruling compels professionals to demonstrate the validity of the methodology that was used to formulate the opinions and recommendations relative to the specific case being heard. The Daubert ruling presents a particularly important challenge for life care planners. Because life care planning is a relatively new area of practice when compared to the fields of psychology and case management, it is imperative that the reliability and validity of its methodology are thoroughly documented through research. Referencing the Daubert guidelines, Countiss and Deutsch (2002) analyzed each of the six factors that the ruling set forth as they relate to life care planning. The following discussion summarizes their analysis (Countiss & Deutsch, 2002).
The first consideration outlined by the *Daubert* ruling involves the extent to which life care planning has been empirically tested. Rather than a theory, Countiss and Deutsch (2002) explain that life care planning is a tool used by rehabilitation professionals to document the needs of an individual with a catastrophic injury or chronic illness. Life care plans have evolved as a case management tool used to methodically evaluate all of an individual’s care, rehabilitation, vocational, psychological, and social needs through his or her life expectancy. The recommendations contained in a life care plan are based upon the characteristics of the client, family, nature of the injury or illness, residual functioning, and other relevant factors. Although life care planning is not a theory, research within the specialty is possible; particularly with regard to the extent to which an individual’s comprehensive needs were projected by plan recommendations. Research efforts can ascertain whether projections were consistent with medical and case management standards of practice and whether they adequately accounted for clients’ needs over time. Countiss and Deutsch (2002) assert that investigations of this type are valuable and informative, but are not the type of research associated with scientific disciplines as referred to in the *Daubert* ruling.

The second *Daubert* question considers the extent to which life care planning relies upon the subjective interpretation of the expert. As is true in many other disciplines, Countiss and Deutsch (2002) explain that life care planning relies
upon the professional judgment of the practitioner when citing recommendations within a plan. However, there are published standards of practice in the field of life care planning, medical and rehabilitation foundations regarding specific disabilities, clinical practice guidelines, and standards of care that inform the decision-making process. Characteristics of the individual (e.g., gender, age, cultural background, family structure, etc.) and the functional limitations imposed by the injury are taken into account in order to identify necessary goods and services. Even with evidence-based research that supports plan recommendations, there is a great deal of variety and exceptionality that must be considered when analyzing the current and future needs of a client. The presence of a catastrophic injury or chronic illness introduces variables that may complicate the analysis of an individual’s needs. Such considerations require life care planners to rely upon professional judgment in order to develop a life care plan that is meaningful and relevant to the client.

Third, the *Daubert* ruling asks whether life care planning has been subjected to peer review or publication. Countiss and Deutsch (2002) note that, as the field grows, there are increasing opportunities for peer communication, debate, and publication. Representatives from national organizations such as the Commission on Health Care Certification, the American Association of Legal Nurse Consultants, the Case Management Society of America, the Life Care Planning division of the International Association for Rehabilitation Professionals,
and other groups have worked collaboratively to analyze and revise standards of practice in life care planning (Countiss and Deutsch, 2002). The *Journal of Life Care Planning* was first published in 2002 and serves as a resource for practitioners and researchers (McCollom, 2002f). In addition, numerous references have been published in textbooks, peer reviewed journals, and general interest periodicals that are referenced by professionals in rehabilitation counseling, rehabilitation psychology, nursing, allied health, case management, and other areas of practice. Publication is expected to expand as more professionals become involved in life care planning and recognize the applicability of its methodology across various practice settings.

The fourth question considered by the *Daubert* guidelines asks whether the rate, or potential rate, of error in life care planning is known. Countiss and Deutsch (2002) explain that there is no rate of error associated with the process of life care planning itself, but potential error exists as a function of the level of skill and knowledge demonstrated by an individual life care planner. Unlike psychometric instruments having a standard rate of error, the validity of a life care plan depends upon the competency of the planner and upon his or her ability to develop a comprehensive plan according to the methodology accepted by other professionals in the specialty. Although differences in professional opinion exist, life care planners employ a consistent methodology in order to project the future needs of an individual and the family.
The *Daubert* ruling also considers whether life care planning is generally accepted as a specialty area of practice. Countiss and Deutsch (2002) surveyed the 87 Council of Rehabilitation Education accredited universities in the United States that offered graduate programs in rehabilitation counseling at that time. Of the 42 respondents, 83% (or 35 schools) indicated that case management courses were part of their core curriculum. Life care planning was a component of 54% of the programs, and 21% of the respondents indicated that at least one faculty member was actively involved in developing life care plans in private consultation. At that time, four universities offered graduate training in life care planning and the following organizations provided continuing education credits for certified life care planners: The Rehabilitation Psychology division of the American Psychological Association, the American Rehabilitation Counseling Association, and the National Rehabilitation Counseling Association (Countiss and Deutsch, 2002). General acceptance is further demonstrated by the fact that life care planning is endorsed and sponsored by the following professional organizations: The International Association of Rehabilitation Professionals, the Life Care Planning division of the International Association of Rehabilitation Professionals, the Commission on Health Care Certification, the American Association of Legal Nurse Consultants, and the Case Management Society of America (Countiss and Deutsch, 2002).

Countiss and Deutsch (2002) also note that life care planning has received increased attention from the federal government and professionals practicing in the
area of worker’s compensation. Since 2001 the Centers for Medicare and Medicaid Services (CMS) has been aggressively pursing worker’s compensation settlement cases to ensure that the interests of CMS have been fairly considered at the time of a compensatory award to an injured party (Haines & Campbell, 2000). Briefly, an individual receiving a worker’s compensation settlement of more than $250,000 and who is a Medicare beneficiary (or will be within six months) must establish a Medicare Set-Aside fund in order to pay for those goods and services that are normally covered by Medicare (Haines & Campbell, 2000). The existence of a life care plan is one piece of documentation accepted by CMS as substantiation of the individual’s need for long-term care and rehabilitation. The federal government recognizes the utility of life care planning in projecting an individual’s future consumption of Medicare allowable resources. Although a life care plan and a Medicare Set-Aside projection are two very different documents, the federal government accepts a life care plan as a document that comprehensively outlines an individual’s future needs (Haines & Campbell, 2000).

Finally, the Daubert ruling considers the non-judicial purposes to which life care planning may apply. Countiss and Deutsch (2002) explain that life care planning originated as a case management tool and continues to evolve as a distinct, well-defined specialty area of practice. Life care planning may be applied to many fields of care including inpatient acute rehabilitation programs, outpatient rehabilitation programs, independent living programs, elder care management,
worker’s compensation casework, and other areas. The methodology employed by life care planners is applicable to all levels of catastrophic injury and chronic illness, regardless of an individual’s medical diagnosis. Many rehabilitation programs employ life care planners as members of their comprehensive care teams. Life care planners work in a variety of settings, and practitioners may choose to work exclusively in non-litigated casework. Life care planning may be applied to both litigated and non-litigated cases with equal veracity. Because courts have become more cautious in the types of testimony that will be admitted into evidence, research within the specialty is critical in establishing that the prescribed methodology is a philosophically sound, reliable, and valid means of projecting the needs of clients with catastrophic injuries or chronic illnesses.

The present study attempts to add to the existing body of knowledge by describing the outcomes experienced by seven individuals for whom life care plans were developed. In-depth telephone interviews revealed several themes that participants identified as being of importance to them. The present study also evaluated the consistency demonstrated between participants’ current self-report needs and those anticipated in their individualized life care plan. A literature review, description of the research methodology, summaries of each interview, and discussion regarding the findings of this study are presented in the following chapters.
Evaluating the effectiveness of long-term rehabilitation planning is a critical measure of a service provider’s ability to accurately identify appropriate recommendations that support the independence and wellbeing of individuals with permanent disabilities and chronic health conditions. Professionals in areas such as psychology, mental health counseling, and psychotherapy (Goldfried & Wolfe, 1998; Clement, 1996; Speer & Newman, 1996), case management (Dalaronde, 2002), rehabilitation and disability management (Callahan & Barisa, 2005; Heinemann, 2005; McAweeney, & Crewe, 2000; Rogers & Holm, 1994), and other fields recognize the importance of outcome measures as a means of informing and improving case assessment and planning methodologies. A practitioner is often left to wonder whether the long-term recommendations made for a client were, in fact, truly effective, accurate, adequate, and properly funded as the needs of the client changed over time.

Not only are these questions critical in terms of assessing quality of care and standards of practice, but practitioners in a variety of fields are experiencing a
demand for increased accountability, more stringent accreditation expectations, more ambitious professional certification and licensure standards, and greater scrutiny of client outcomes (Press, 2004; Schnelker & Rumrill, 2001). Practitioners recognize that their professional work will be critically evaluated by various stakeholders and must be prepared to justify the practices and methodologies utilized throughout the case identification, assessment, planning, and long-term evaluation processes (Goldfried & Wolfe, 1998; McAweeney & Crewe, 2000). Practitioners in rehabilitation and health care professions are facing numerous service delivery challenges as private and government insurance benefit reimbursement guidelines for medical treatment, rehabilitation, length of stay in care facilities, and other covered areas become more time-limited and tightly controlled (McGettigan, 2003). In order to maintain funding, accreditation, and status as qualified service providers, practitioners are required to justify their practice methodologies to third party payers, state regulatory agencies, and federal accreditation organizations (McAweeney & Crewe, 2000; Weeks, 2002). Without such evidence, the possibility exists that practice guidelines and standards will be imposed by third parties through coverage restrictions and other benefit limitations (Goldfried & Wolfe, 1998). Recent consumer-driven efforts have further compelled the health care industry to produce evidence of quality, efficacy, and cost-effective practices (Bloche, 2006).
As a subspecialty of case management, life care planning methodology is also subject to intense scrutiny, particularly as its applicability within the legal arena and insurance industry becomes more widespread. The specialty has a well-established core of tenets and methodologies that have been documented within the professional literature (Blackwell, Krause, Winkler, & Stiens, 2001; Dahlberg, 2002; Deutsch, 1990, 2002; Deutsch, Allison, Cimino-Ferguson, 2005; Deutsch, Allison, & Reid, 2003; Deutsch & Raffa, 1981; Deutsch & Sawyer, 1985; McCollom, 2000a, 2002c, 2002g; McCollom & Weed, 2002; Riddick-Grisham, 2004a, 2004b; Weed, 2002a, 2002b, 2004b; Weed & Field, 2001). The application of life care planning principles in adult and pediatric catastrophic cases is prevalent in the literature and includes those involving spinal cord injury (Blackwell et al., 2001; Kitchen, 1992; Livingstone, 2005; Winkler, 1996; Winkler & Deming, 2004; Winkler & Weed, 1999, 2004a), acquired brain injury (Deutsch & Sawyer, 1997b; Guercio, Sanders, & Dixon, 2005; Jackson, 2003; McDonnell, 2002; Ripley & Weed, 2004; Savage, Klingbeil, & Fawber, 2004; Sherer, Madison, & Hannay, 2000; Young & Weed, 1999), burn injury (Brown & Helm, 1999; Brown, Helm, & Weed, 2004; Sheridan & Fox, 2004), amputation (Deutsch & Sawyer, 2000; Meier, 1999, 2004, 2005; Meier & Weed, 2004), organ transplantation (Bagwell, Nichols, & Weed, 2004; Brown, 2005; Lane & Weed, 1999; Smith-Fields, Chrobak, Danner-Koptik, Shores, & Cepulionis, 2004) and other chronic health conditions. As practitioners face the challenges brought about by an increasingly complex
health care system and greater involvement in litigated cases, current efforts within
the specialty are focused upon further refining practice methodologies,
incorporating current disability-specific research findings, and extending the
principles of life care planning into new areas of practice.

Seminal Publications

The notion that life care planning is firmly rooted within the broad field of
rehabilitation services can be attributed to the publication of the first resource that
outlined the methodology of case analysis; *Damages in Tort Actions* (Deutsch &
Raffa, 1981). Originally, one volume of this multi-volume series was co-authored
by Dr. Paul Deutsch, a rehabilitation counselor, and Dr. Frederick Raffa, an
economist. These authors were experienced legal consultants and had produced
extensive research in the areas of catastrophic disability assessment, case
management, damages in personal injury cases, and damages in wrongful death
cases (Deutsch & Raffa, 1981). The volume included chapters that addressed
topics related to expert witness testimony, rehabilitation evaluation, issues of
relevance to catastrophic injury assessment, evaluation of economic losses,
projection of future costs, diminution of earning capacity, and courtroom
considerations unique to rehabilitation professionals and economists. The volume
also included case examples of catastrophic, non-catastrophic, and wrongful death
cases.
As may be apparent from the title of this series, the readership was comprised primarily of attorneys with specialized practices in personal injury and wrongful death. Life care plans were, and continue to be, identified as valuable tools within the litigated arena. Because the long-term needs of individuals with catastrophic injuries or chronic illnesses are identified and associated costs are compiled, the document provides a basis for calculating the economic damages in personal injury cases (Barker, 1999; Caragonne & Male, 2003; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; McCollom, 2002c; Powell, 2003; Weed, 1995b). Topics relevant to life care plan development were discussed within the context of rehabilitation counseling and the rehabilitation plan. The primary principles of practice described within this text clearly drew upon the established methodologies of case management and rehabilitation counseling as the authors described the assessment and plan development processes.

These principles were reinforced and expanded upon with the publication of *A Guide to Rehabilitation* in 1985 (Deutsch & Sawyer, 1985). This text further elaborated upon the technical aspects of life care planning, case assessment, and the role of the planner within the forensic arena. Life care planners and the rehabilitation community were the intended audience for this text, and case development methodology was detailed. Medical, vocational, and psychosocial considerations relevant to specific catastrophic injuries and chronic illnesses were discussed, and case examples illustrated how recommendations could be integrated
into a comprehensive, yet concise, life care plan. Similar to *Damages in Tort Actions*, this publication clearly referenced the accepted practices within rehabilitation services and described the specialty of life care planning as a tool of case management.

As evidence of its utility, relevance, accessibility, and value, *A Guide to Rehabilitation* continues to be a primary professional resource for life care planners with frequent updates addressing contemporary issues, innovations, and data sources (Blackwell et al., 2001; Neulicht, Riddick-Grisham, Hinton, Constantini, Thomas, & Goodrich, 2002; Smolarski, 1997; Weed, 2002a). Although specific considerations and technologies may have changed over the years, the fundamental practice methodology outlined in the original texts has remained virtually unchanged.

Life care planning is an effective means by which to communicate with clients, families, rehabilitation professionals, disability case managers, and others who may be involved in providing long-term support. As the standards and methods have gained acceptance outside of the general rehabilitation circle, insurance carriers, workers’ compensation judges, circuit court judges, federal court judges, attorneys, and others have called upon life care planners as experts in long-term disability management. Courts have sought the specialized knowledge of life care planners so that they, and juries, are better able to understand the long-term effects of catastrophic injuries and the associated economic damages of such cases.
Within the legal arena and beyond, life care planning has experienced tremendous growth and is recognized as a valuable means of disability analysis (Boling & Wolf, 2003; Countiss, 2002; Countiss & Deutsch, 2002; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Knouse, 2003; Weed, 2004b, 2004c). This is due, in large part, to the rigor with which standards of practice and case analysis methodologies are applied to individualized plan development.

Principles of Life Care Planning Practice

Since the concept of life care planning was first described in the professional literature in the 1980s (Deutsch & Raffa, 1981; Deutsch & Sawyer, 1985), a review of subsequent publications reveals that most of the work falls within the following broad categories: Principles and methodologies of the practice, standards of practice, forensic applications, and current trends. The basic principles of life care planning methodology have been consistently described by authors from various professional backgrounds as the specialty has evolved over time. The volume of subsequent publications represents the multidisciplinary nature of the specialty and the applicability of life care planning principles in various practice settings. Further, these publications document the professional dialog that has occurred over the past two decades and demonstrate a general acceptance of life care planning methodology among practitioners within the specialty (Barker, 1999; Blackwell, Millington, & Guglielmo, 1999; Caragonne &
Male, 2003; Gibson, 2000; Harrell, Bagwell, & Coupland, 1997; Knouse, 2003; Rice, Hicks, & Wiehe, 2000; Sherer, et al., 2000; Stolte-Upman, 2003; Voogt, 1996; Weed, 2002a). The principles of this practice area are well-established within the literature and describe the characteristics that make life care planning unique among rehabilitation and health related areas. A life care plan is a tool of case management, relies upon a consistent methodology, is based upon the distinctive needs of the individual client, requires collaboration with a multidisciplinary team, and is founded upon medical evidence and rehabilitation principles.

*Tool of Case Management*

The notion that life care planning is a tool of case management is fundamental to the manner in which practitioners approach case analysis and plan development (Blackwell et al., 2001; Boling & Wolf, 2003; Demoratz, 2004; Deutsch, 1990, 2002; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Deutsch, Kendall, Raffa, Daninhirsch, & Cimino-Ferguson, 2005; Harrell, et al., 1997; McCollom, 2000a, 2002b, 2002c, 2005; Preston, 2003; Rice, et al., 2000; Roughan, 2001; Stolte-Upman, 2003; Toran, 1999; Weed, 1995b, 2004b; Weed & Field, 2001). A life care plan facilitates the case management process by specifying timelines for necessary interventions, anticipated support services, associated costs, vendors and service providers within the client’s community, and empirical documentation that provides the foundation for recommendations.
(Deutsch, 1990; Deutsch, Allison, et al., 2005; Deutsch & Reid, 2003; Rice, et al., 2000). Similar to the methodology involved in developing a case management plan, life care planning involves gathering and integrating client information from various sources, assessing the needs of the client, developing a comprehensive plan based upon the client’s unique circumstances, and evaluating the appropriateness of recommendations as needs evolve over time (Barker, 1999; Deutsch, 1990; Deutsch & Reid, 2003; Kuntz, 2005; Rice, et al., 2000). Plan recommendations are based upon the unique goals, abilities, and challenges of each client.

A Consistent Methodology

Since the original definition of a life care plan was proposed by Deutsch and Raffa (1981), consistency in case analysis and development has been a cornerstone of practice (Deutsch, 1990; Deutsch, Allison, & Kendall, 2003; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Deutsch, Allison, et al., 2005; McCollom, 2005; Sunday & Arnold, 2004; Weed, 1995b; Weed & Field, 2001). This concept applies to all aspects of case development as well as business practices. Deutsch and Reid (2003) note that adherence to the published principles and standards of practice helps to ensure internal reliability of plan recommendations by systematically working through the analytical process in each case. Although plan recommendations may vary depending upon the needs of each client, the methodology with which they are formulated and the decision making process utilized to identify appropriate items and services is uniform. Adherence to a
consistent methodology also allows the planner to establish professional credibility as an objective evaluator and to maintain ethical obligations.

Needs Based Recommendations

One aspect of life care planning that distinguishes it from some case management models is the emphasis on the needs of the client, rather than available funding, collateral resources, vendors, services, or similar considerations (Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Deutsch, Allison, et. al, 2005; McCollom, 2005; Rice, et al., 2000). In a life care plan, medical, therapeutic, vocational, and other rehabilitative services are recommended based upon the client’s current and anticipated needs throughout life expectancy. However, case management models utilized within the workers’ compensation and insurance arena, typically limit services to those provided under a subscriber’s group health plan or set of injury-specific protocols. Services may be available only under certain conditions, may be restricted to a specific number of visits, or may be provided only by certain vendors or contractors. During the life care plan development process, such considerations do not influence the nature, frequency, or duration of the recommendations made for a client. If vendors or service providers are not available within the client’s immediate geographic area, travel costs are built into the plan to ensure accessibility.
The life care planner does not typically negotiate with vendors and service providers for discounted rates, nor does the planner rely upon government programs, such as Medicare, to pay for items recommended in the plan. Such negotiation and consideration of collateral resources may occur when the plan is implemented, but they are not relied upon when developing the plan. This is one of the primary philosophical differences between the life care planning and the case management process. The role of the life care planner and the role of the case manager are distinctly different from one another (Blackwell, 1999; Boling & Wolf, 2003; Cimino-Ferguson, 2005; Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch, McCollom, Weed, & Berens, 2003; Deutsch & Reid, 2003; McCollom, 2005; Rice, et al., 2000; Weed, 1990, 1992, 1995a; Weed & Berens, 2004).

Multidisciplinary Collaboration

The concept of a multidisciplinary team approach to case analysis and plan development is common to rehabilitation, medical, and other allied health professions (Deutsch & Reid, 2003; McCollom, 2005; Weed, 2004b; Weed & Field, 2001). Planning for the long-term medical and rehabilitation needs of individuals with catastrophic injuries requires the specialized knowledge of a multidisciplinary team. The importance of this team approach is well-established in the literature and is a cornerstone concept throughout the Standards of Practice for Life Care Planners published by the International Academy of Life Care
Consultation with members of the client’s current treatment team is crucial in understanding his or her present level of functioning, potential level of functioning, and anticipated rehabilitation outcomes based upon an analysis of specific strengths, challenges, goals, potential complications and residual disabilities (Deutsch, 1990; Deutsch & Reid, 2003; Weed & Field, 2001). Input from treating physicians and consulting physiatrists is mandatory in establishing a medical foundation for recommendations involving laboratory tests, surgical interventions, therapeutic interventions, frequency and duration of routine office visits, and prescription and non-prescription medications. Such recommendations may also have implications for the type of supplies, equipment, personal care, and other needs identified in the plan (Deutsch, 1990; Deutsch & Reid, 2003). Likewise, recommendations from current or consulting therapists, vocational
rehabilitation consultants, and other professionals are critical in identifying necessary evaluations, therapy, assistive technology, aids for independent living, home furnishings, vehicle modifications, and other items.

Life care planners rely upon the professional opinions of members of the multidisciplinary team to establish the foundations for plan recommendations and to avoid making assertions that are beyond their scope of practice. The multidisciplinary team approach allows the specific needs of each individual to be considered holistically and, based upon the known long-term outcomes of the specific injury or illness, recommendations are customized to meet anticipated needs. The importance of various members of the multidisciplinary team in both adult and pediatric cases has been well-documented in the life care planning literature. Depending upon the needs of the client, team members may include an audiologist (Gladstone, Higdon, & Weed, 1999; Higdon, 2004a; Higdon, Higdon, & Gladstone, 2004), educational consultant (David & Sears, 2004; England, 2004), home care provider (Gunter & Matteson, 2004), neurologist (Pearl, 2004), neuropsychologist (Bryant & McLean, 2004; Evans, 1999, 2004; Taylor, Kreutzer, Livingston, & Riddick, 2004), nurse specialist (Frame, 2004; Riddick-Grisham, 2004b; Riddick-Grisham & Weed, 1999; Sluis-Powers, 1994), nutritionist (Isaacs, 2004), occupational therapist (Lack, 2004; McCaigue, 1999, 2004), pediatric care manager (Phillips & Bond, 2004), pediatrician (Accardo & Accardo, 2004), physical therapist (Peddle, 1999, 2004; Ricardo & Good, 2004; Watkins, 1999),

Medical and Rehabilitation Foundations

It is through multidisciplinary collaboration and documentation of evidence-based practices that life care planners establish the medical and rehabilitation foundations within an individualized plan. Such evidence is critical. Not only does it provide clients and their families with specific support for recommendations, but it is essential in establishing the integrity of the plan and assuring admissibility as evidence in litigated cases (Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Gunn, 1994; Gunn & Gunn, 1999, 2004; Vierling, 2002; Weed & Field, 2001). The planner is responsible for developing a cohesive, comprehensive, integrated plan that appropriately meets the unique future needs of the individual for whom it was created. In addition to contributions from the multidisciplinary team, practitioners rely upon clinical practice guidelines, established standards of care, and published research to identify appropriate
recommendations based upon the specific needs of the individual for whom the plan is developed (Deutsch & Reid, 2003; Deutsch, Allison, et al., 2005; McCollom, 2005; Riddick-Grisham, 2006). A well written life care plan reflects both the collective knowledge of the multidisciplinary team and data drawn from relevant published research (Evans, 1996).

The importance of the contributions of the multidisciplinary team cannot be overstated. The professional judgments of those who have an established clinical history with the client are typically highly regarded by jurors in litigated cases and are critical in establishing the medical and rehabilitation foundations for the life care plan (Slovenko, 2004). These foundations are also established through documentation of published data, clinical outcomes, and evidence-based research. These evidence-based resources may include standards of care and standards of care and practice, clinical practice guidelines, and relevant published research (Deutsch, Allison, et al., 2005; Deutsch, Allison, & Kendall, 2003; Deutsch, Allison, & Reid, 2003; Kitchen, 2002; McCollom, 2002c, 2005; Riddick-Grisham, 2006).

Standards

Standards of care are client-focused and describe desired treatment and/or rehabilitation outcomes for individuals with specific clinical diagnoses (Preston, 2002). Quality assurance teams in hospitals and other institutions often evaluate
these standards, and utilize them as a means of improving patient care and satisfaction. Standards of care are useful to life care planners because they provide guidance in identifying the long-term care needs, recommended interventions, and expected outcomes. Standards of care may be established within medical and rehabilitation specialties, or through agencies such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) that assess the quality of care provided by health organizations in the United States (Joint Commission on Accreditation of Healthcare Organizations, 2006). Information, standards, safety guidelines, and research produced by JCAHO can help planners to establish the necessary foundations for recommendations involving preventative care and maintenance (Deming, 2006). Standards of practice typically identify the methodologies and procedures followed by professionals in arriving upon clinical judgments and long-term management recommendations. Life care planners often refer to standards of practice and standards of care to more accurately project future needs, to better understand the typical progression and course of treatment, to more effectively communicate with members of the multidisciplinary team, and to proactively plan for anticipated changes throughout life expectancy.

Clinical Practice Guidelines

Clinical practice guidelines are statements regarding appropriate care for specific clinical diagnoses and are derived through a formal process involving the evaluation of scientific evidence. Practice guidelines assist physicians and other
practitioners in the decision making process. These guidelines are an important source of support for recommendations within a life care plan because they often provide a framework for identifying the long-term needs of an individual based upon current levels of function (Deutsch, Allison, & Kendall, 2003; Preston, 2002; McCollom & Allison, 2004). For example, the Consortium for Spinal Cord Medicine, which is sponsored by the Paralyzed Veterans of America, publishes evidence-based clinical practice guidelines regarding bladder management, preservation of upper limb function, respiratory management, neurogenic bowel management, management of autonomic dysreflexia, pressure ulcer prevention, thromboembolism prevention, and other issues (Paralyzed Veterans of America, 2006). These guidelines may assist planners in identifying comprehensive, preventative care that accounts for both current and anticipated changes throughout the aging process. Particularly helpful are clinical practice guidelines that describe the probable physiological, psychological, and functional consequences of a specific disability or chronic condition, and identify recommendations for maximizing client outcomes. The Standards of Practice for Life Care Planners cites standards of care and clinical practice guidelines from reliable sources as being one of the foundations of plan development research (International Academy of Life Care Planners, 2006).

Research published in peer reviewed journals can also provide evidence-based support for recommendations contained in a life care plan. Although these
articles have been peer-reviewed, the planner cannot presume that the research findings are applicable to specific clients or that the conclusions drawn by the authors are entirely correct. When considering evidence-based support for the life care plan, an attempt is made to identify several relevant research studies that yield similar results, replicated studies, longitudinal studies, and other methodologies that demonstrate the vigor of a particular intervention or treatment recommendation (Deutsch, Allison, & Kendall, 2003). Such documentation contributes to the credibility of the plan, and helps to educate all parties as to the reasons for inclusion of various items in the plan. The Standards of Practice for Life Care Planners state that a review of relevant literature from reliable sources is one of the foundations of plan development research (International Academy of Life Care Planners, 2006).

Life care planners refer to all available resources when analyzing a case and determining appropriate recommendations. Whether the retaining attorney represents the plaintiff or defendant in a case, their orientation is irrelevant in the review of evidence-based literature. Planners do not attempt to identify only those guidelines and research studies that support the position of the retaining counsel, but must objectively evaluate the veracity and relevance of existing data as it applies to the injured individual. Regardless of the data source, the planner must carefully evaluate the population from which the data was derived and analyze the validity and reliability of the methodology used to develop the standard, guideline,
or research study. Recommendations founded upon faulty data may fail to meet critical needs, misappropriate resources, and ultimately be of little value to clients (Evans, 1996). Limitations of an existing body of research must be identified and references to evidence-based sources within the life care plan must be relevant to the case. Always, the planner approaches each client as an individual and works to understand his or her unique circumstances in relation to what is reported in the research literature (Deutsch, Allison, & Kendall, 2003; Deutsch & Reid, 2003; Evans, 1999; Kitchen, 2002; McCollom, 2005; Weed, 1995b).

Vocational Considerations

The life care planning process is also reflective of the methodologies established in the area of vocational counseling and rehabilitation. Vocational counselors routinely attempt to project return-to-work success based upon personal history, positive attributes, and challenges (Field, 2002; Weed & Field, 2001). In litigated cases, economic damages resulting from a reduced or complete loss of access to the labor market due to injury can be quantified by vocational professionals and economists (Deutsch & Reid, 2003; Weed, 1996, 2004c, Whitmore, 1996). The extent to which an injury results in a diminished or complete loss of earning capacity is determined through an extensive evaluation process that is typically conducted by a qualified vocational rehabilitation expert (Neulicht & Berens, 2005; Raffa & Wells, 1994; Weed, 1996, 2004c). The vocational analysis process consists of specific methodologies that have been
established within the field of vocational rehabilitation and consultants consider pre-injury, injury-specific, and post-injury factors in formulating recommendations (Blackwell, et al., 1999; Choppa, Johnson, Fountaine, Shafer, Jayne, Grimes, & Field, 2004; Weed, 1996; Weed & Field, 2001). These considerations may include the client’s educational background and employment history, the residual abilities and functional limitations that result from the injury, age at injury, transferability of skills, motivation to return to work, access to the labor market, placeability, earning capacity, and other factors (Neulicht & Berens, 2005; Blackwell, et al., 1999; Choppa, et al., 2004; Deutsch & Reid, 2003; Field, 2002; Weed, 1996, 2004a, 2004c; Weed & Field, 2001).

Unless uniquely qualified to complete vocational analyses, evaluate earning capacity, and independently include recommendations relative to work, life care planners consult with a vocational rehabilitation experts to ensure the multidimensional integrity of the plan, to account for necessary supports, and to avoid recommending duplicative services (Deutsch & Reid, 2003; Deutsch, Allison, & Reid, 2003; Field, 2002; Neulicht & Berens, 2005; Weed, 1996, 2002a, 2004c). For example, if an individual is expected to return to part-time employment for 8-10 years post-injury, the number of hours of home health care should be consequently reduced to reflect those hours when the individual will be working outside of the home. Based upon the pre-injury vocational projections and the post-injury vocational projections outlined in the assessment report, the
economist is able to calculate the difference in lifetime earnings and other factors that may need to be considered in quantifying diminution of earning capacity (Raffa & Wells, 1994).

The Case Analysis and Plan Development Process

Although the specific case workflow may vary among life care planners, the following explanation regarding the methodology of case analysis is similar across practice settings. However, notable exceptions exist when planners are retained by defense counsel because there is often limited access to client records, independent client evaluations, or client interviews (Weed, 1999). This case analysis methodology has been documented throughout the professional literature within the specialty (Barker, 1999; Dahlberg, 2002; Deutsch, 1990; Deutsch & Reid, 2003; Deutsch, Allison, et al., 2005; Voogt, 1996; Weed, 1995b, 1999, 2001, 2002a, 2004a).

Review of Records

First, a thorough review of all relevant client records is essential in understanding the history of the case, progress made since injury, and possible recommendations noted by professionals who have specialized, first-hand knowledge (Dahlberg, 2002; Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Weed, 2002a, 2004b). In litigated cases, medical and rehabilitation records can be requested from the referring attorney who may already
have them as part of their own case development process or can subpoena them from the members of the treatment team. In non-litigated cases, the client typically must contact their physicians, therapists, and treatment facilities and follow the protocols for making a formal request for these records.

The Standards of Practice for Life Care Planners state that one of the fundamental functions of a planner is to assess client data and information from numerous sources, including the client, family members, and others who may offer relevant insights (International Academy of Life Care Planners, 2006). Sources that should be reviewed include the client’s medical records, reports and diagnostics generated by allied health professionals, financial, educational, vocational records, and other information of relevance in the case (International Academy of Life Care Planners, 2006). Not only does this provide the planner with a holistic perspective, but it allows for identification of appropriate support services that will help to restore maximum vocational, psychosocial, and rehabilitation potential. The planner will be expected to justify all recommendations and to explain the necessity of each. By thoroughly understanding a client’s pre-injury disposition as well as his or her current situation, the planner is better able to communicate with the multidisciplinary team and to develop a plan that appropriately addresses the client’s unique strengths and challenges.
Client Interview

The client interview constitutes one of the most critical aspects of case analysis because it allows the planner to gather the case history from first-person report and to clarify any discrepancies that exist within the records reviewed (Dahlberg, 2002; Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Weed, 2002a, 2004b). The importance of gathering information from the client and collaborating with them to develop a relevant life care plan is stated in the *Standards of Practice for Life Care Planners* (International Academy of Life Care Planners, 2006). The client interview gives the planner an opportunity to ask detailed questions, to precisely understand the client’s functional strengths and challenges, and to gain insights regarding the client’s psychosocial health (Deutsch & Reid, 2003; Kitchen, 2002). It also gives the client an opportunity to thoroughly explain his or her circumstances, to communicate goals and interests, and to provide concrete examples that will better assist the planner in identifying the limitations imposed by the injury or illness (Kitchen, 2002).

Throughout this process, a substantial amount of time is spent describing physical limitations and in specifying how such limitations impact upon the client’s ability to complete activities of daily living independently (Deutsch & Reid, 2003; Kitchen, 2002). Such information will help the planner to educate others involved in the case, and will provide a foundation for identifying appropriate recommendations regarding therapy, aids for independent functioning, home
furnishings, transportation, vocational goals, and other items specified in the plan (Kitchen, 2002). In addition, the planner is able to more accurately assess the personal impact of the injury or illness upon the lifestyle and psychosocial health of the client, and to project how it may evolve throughout the aging process (Kitchen, 2002; Mitchell, 2004a, 2004b). The ethnic and cultural background of the client may influence his or her adjustment to long-term disability, values and beliefs regarding personal attendant and home health care, and perceptions of medical treatment and therapeutic interventions (Munoz & Hemmila, 2004). Such orientations are critically important considerations in developing a relevant, useful plan.

A semi-structured interview format allows for a consistent method of collecting necessary information across cases while providing flexibility for follow-up questions that further clarify client responses (Kitchen, 2002; Deutsch & Reid, 2003; Deutsch, Allison, & Reid, 2003). Most planners summarize the information provided during the client interview into a narrative report that accompanies the life care plan. When reviewing the plan, readers should be able to identify a clear connection between the information provided by the client during the interview and the recommendations contained in the plan (Kitchen, 2002). The interview process serves not only to elicit information from the client, but also establishes the planner as a partner in developing a plan that is based upon recommendations of personal relevance (Deutsch, 1990). The planner should thoroughly discuss his or her role
in the case and should describe their qualifications, work experience, and methodology in developing plan recommendations (Deutsch, 1990; Deutsch & Reid, 2003; International Academy of Life Care Planners, 2006).

**Plan Development**

As discussed earlier in this chapter, the medical and rehabilitation foundations for each of the recommendations cited in the life care plan are established through consultation with members of the treatment team and a review of clinical practice guidelines, standards of practice, and relevant research (Barker & Saulino, 2004; Dahlberg, 2002; Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Weed, 2002a, 2004b; Weed & Field, 2001). When all records have been reviewed, the client interview completed, and consultation with the multidisciplinary team has been accomplished, the practitioner begins to develop the life care plan. As a case management tool and educational document, the categories within a life care plan facilitate the implementation process by presenting complex needs in a logical, structured manner. Comprehensive life care plans facilitate the provision of an integrated continuum of care that addresses the changing needs of an individual as they age with a disability (Blackwell et al., 2001; Deutsch, 1990; Deutsch & Reid, 2003; Deutsch, Allison, & Reid, 2003; Mitchell, 2004a, 2004b; Turner, Taylor, Rubin, & May, 2000; Weed, 2004b; Weed & Field, 2001). The methodology involved in life care plan development is clearly reliant upon the principles of practice established within the field of rehabilitation.
The goal of a life care plan is to, to the greatest extent possible, restore an individual’s level of functional independence, health, and quality of life to what was expected had the injury or chronic illness not occurred (Brethauer & Brethauer, 2003; Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; International Academy of Life Care Planners, 2006). To this end, the planner considers recommendations that will maximize medical and rehabilitation potentialities.

Categories of Plan Recommendations

A review of the life care planning literature indicates that there are common categories of recommendations that may be considered when developing a life care plan, though not all are relevant for each client (Barker & Saulino, 2004; Blackwell et al., 2001; Deutsch, 1990; Deutsch, Allison, & Reid, 2004; Deutsch & Raffa, 1981; Deutsch & Reid, 2003; Deutsch & Sawyer, 1985; Riddick-Grisham, 2004b; Smolarski, 1997; Weed, 1995b, 2001, 2002a, 2004b). Categories that are not relevant to the needs of the individual for whom the plan is being developed are simply eliminated from the life care plan. The life care plan template proposed by Deutsch and Sawyer (1985) is provided in Appendix A. Each recommendation includes specific information regarding initiation and suspension dates, the frequency of the service or replacement schedule of the item, duration of the service or use of the item, the base cost of the service or item, and the name of the professional who recommended the service or item. Such information assists the
economist in calculating the overall cost of the plan and facilitates the implementation of the plan (Weed, 1995b, 2002a). Where helpful, recommendations may also include footnotes that provide additional clarification, explanation, or documentation (Deutsch, Allison, & Reid, 2003; Weed, 2004a). Such specificity facilitates plan implementation, and allows for more precise economic analyses. The multidimensionality of life care planning is evident when the complex, lifelong needs of clients with catastrophic and chronic illnesses are documented comprehensively, and the implications of specific recommendations are considered in relation to all other components of the plan.

*Projected Evaluations*

All projected evaluations to be completed over the client’s life expectancy are identified in the life care plan. This section of the plan typically does not include evaluations conducted by physicians, but focuses on non-medical assessments that are not reflected in subsequent plan categories (Weed, 1995b, 2002a). These evaluations may include, but are not limited to, physical therapy, occupational therapy, recreational therapy, psychology, neuropsychology, developmental psychology, audiology, assistive technology, nutrition, behavioral psychology, recreational therapy, speech therapy, vocational rehabilitation, or other areas. Evaluations are often coordinated with recommended therapies so that treatment plans can be developed and periodic re-evaluations can be completed.
Projected Therapeutic Modalities

Physical therapy, occupational therapy, psychological counseling, and other therapeutic services are specifically identified in the life care plan. Such therapies may be deemed necessary on a long-term or on a periodic basis, depending upon the needs of the client. For example, periodic supervised therapy may be recommended as a client ages to address the anticipated effects of the natural aging process upon the residual functional ability resulting from an injury. As has been established within the field of rehabilitation, therapeutic programs can be critically important to assisting an individual to adjust to the effects of their disability because they include a strong educational component and because of the positive impact upon self-confidence, well-being, and sense of purpose (Weed & Field, 2001).

Diagnostic/Educational Testing

Depending upon the needs of the client, the life care plan may include a category that specifies educational testing services such as vocational assessment and training, special education recommendations, supplemental tutoring and individualized support, and post-secondary or continuing professional education. In pediatric life care plans, this may include recommendations for psychoeducational testing to qualify the child for special education services, classroom accommodations, or curriculum modifications (England, 2004).
adult life care plans, this category most often includes recommendations that support vocational goals (Field, 2002; Weed, 2002a). Vocational counseling support for an adult with a disability is often necessary, particularly when he or she is no longer able to perform the essential functions of their pre-injury job (Neulicht & Berens, 2004). Recommendations such as retraining, worksite accommodations, assistive technologies, job placement assistance, vocational counseling and other interventions may be cited within this category. When reasonable to do so, it is important to recognize vocational rehabilitation as a means of returning the individual to gainful employment. When a return to full-time work is not possible due to the nature of an individual’s disability, it is equally important to consider vocational alternatives such as part-time work, volunteer opportunities, or other forms of purposeful activity. As established with the rehabilitation literature, work has therapeutic, psychological, and social value (Blackwell, et al., 1999; Deutsch & Reid, 2003; Field, 2002; Weed & Field, 2001). The life care plan recognizes this value and, to the greatest extent possible, incorporates recommendations leading to participation to the workforce (Blackwell, et al., 1999; Deutsch & Reid, 2003; Field, 2002; Hill, 2004a; Weed, 2004c; Weed & Field, 2001).

Wheelchair Needs

Depending upon the extent of the mobility limitations imposed by the individual’s disability, the category dedicated to wheelchair needs can cover a broad range of wheelchair types suited for their unique usage needs. For
individuals with spinal cord injuries, the identification of appropriate wheelchairs for use in a variety of environments is essential to facilitating community integration and maximizing independence (Blackwell et al., 2001; Mitchell, 2005).

Physical therapists, physiatrists, and other qualified members of the multidisciplinary team play a critical role in identifying current and future needs regarding wheelchair needs. In addition to basic power and manual wheelchairs, specialized models such as athletic, pediatric, power scooters, and shower wheelchairs may be appropriate considerations for certain individuals. Clients may require the availability of a manual wheelchair for use as a backup in situations when the power wheelchair is not available, such as when routine maintenance is being performed. In some cases, the use of a wheelchair on an intermittent basis may be recommended at a point in the future when the natural aging process interacts with an individual’s disability or when degenerative changes are anticipated.

Wheelchair prescriptions are based upon the individual's age, body type, height and weight, level of function, level of activity, environment, lifestyle and other considerations (Amsterdam, 2004a, 2004b; Kreutz, 2002; Mitchell, 2005; Weed, 2002a). Typically, such prescriptions are written by an individual’s physiatrist, physical therapist, or other qualified professional (Kreutz, 2002). Recommendations within this category have implications for other projections made within the life care plan such as therapy, home furnishings, and medical care.
For example, because extended use of a manual wheelchair may cause significant deterioration in the shoulder joints and upper extremities, consequences of such use must be considered. Preventative measures are identified within the plan to preserve the most function and independence as possible (Blackwell et al., 2001; Kreutz, 2002). Potential complications resulting from extended wheelchair use, such as repetitive motion and similar secondary injuries, are outlined in the life care plan.

Wheelchair Accessories and Maintenance

The wheelchair accessories and maintenance portion of the plan reflect the current and anticipated needs of the client. Items such as wheelchair gloves, lap boards, carry pouches, safety belts, and transfer boards may be included in this category. Wheelchair aids enhance independence, allow the individual to work and engage in recreational activities comfortably, and to interact with other people from a seated position. Recommendations for appropriate wheelchair cushions, which can be quite expensive, are essential in reducing pressure, preventing skin breakdown, and maintaining proper positioning in both manual and electric wheelchairs (Amsterdam, 2004a, 2004b; Blackwell et al., 2001; Kreutz, 2002; Mitchell, 2005). Wheelchair batteries are also included in this category and replacement schedules depend upon the specifications of the wheelchair, the extent of daily use, the charge-life of required batteries, and other considerations (Amsterdam, 2004a, 2004b). Planners must also consider the frequency of
wheelchair maintenance and replacement over the life span of the client. Typically, annual maintenance is recommended in order to ensure proper function and safety of the wheelchair (Amsterdam, 2004a, 2004b; Winkler, 1996). Maintenance costs generally begin the year after the purchase of a new wheelchair because most necessary repairs and adjustments are covered by the manufacturer’s limited warranty (Amsterdam, 2002, 2004a, 2004b; Blackwell et al., 2001; Winkler, 1996). Typical replacement schedules may be available from the manufacturer for those whose usage is within the average range. However, through consultation with a client’s physical therapist or other members of the multidisciplinary team, typical replacement schedules may be accelerated to account for physical growth in pediatric cases, wheelchair use by highly active adults, wear resulting from use in a rural environment, and other usage patterns that warrant more frequent replacement (Amsterdam, 2002, 2004a, 2004b; Weed, 2002a). Conversely, typical replacement schedules may be decelerated over the life span as, for example, secondary injuries are expected to negatively impact independent mobility.

Orthopedics and Prosthetics

The orthopedics and prosthetics category identifies upper and lower extremity supports that may include such items as upper arm or forearm splints, prostheses, braces, foot-ankle orthoses, and other devices. Orthopedic equipment such as standing tables, support cushions, body support systems, workplace modifications, specialty exercise equipment, and other items that may facilitate
home-based therapy are also specified within the life care plan. These recommendations are often suggested by professionals such as occupational therapists, physical therapists, or physiatrists who have knowledge of the current therapeutic needs of the individual and can identify anticipated future needs. These items assist clients in improving and maintaining independence, and in accomplishing daily tasks more efficiently. Long-term medical and rehabilitation prognoses may heavily influence the devices recommended for a client as he or she ages.

*Home Furnishings and Accessories*

Items such as handheld shower heads, lift recliners, specialty beds, low-pressure mattresses, pneumatic lifts, and levered door handles allow for greater independence, and prevention of complications and potential injury. In cases where substantial assistance from caregivers is necessary, these home furnishings and accessories may facilitate transfers, dressing, bathing, eating, and other daily tasks. To the greatest extent possible, items in this category allow an individual to live safely within the home environment, effectively accomplish routine tasks, and facilitate caregiving (Blackwell et al., 2001).

*Aids for Independent Function*

Aids for independent function that can be used to enhance independence include such items as long-handled reachers, kitchen tools, book holders, walker
trolleys, mouth sticks, canes, walkers, and a host of other items. Assistive
technology, augmentative and alternative communication, adapted equipment, and
other items that allow a client to more effectively interact with others and access
the environment may be included in this category (Bristow & Pickering, 1995;
Herr, 1996; Hill, 2004a; King, 2004). Vocational and therapeutic goals may
instigate the need to include specialty items for use in the community, on the
worksite, in the classroom, or in other situations. There are many items that may
be identified as being beneficial for clients with mobility, range of motion, balance,
endurance, and similar functional difficulties. Items within this category may be
used in a variety of settings and for a variety of purposes. An environmental
control unit, for example, allows an individual to control the room temperature,
electric appliances and telephones, computer systems, door locks, and other devices
in his or her environment. These devices may range from simple remote control
units to more elaborate voice-activated computer-based systems (Bristow &
Pickering, 1995; Hill, 2004a; Moreo, 1997; Weed, 2002a). Clients who are able to
use such devices effectively may feel more in control, confident in their ability to
function independently, and may require less support from caregivers, thus
reducing the overall cost of personal assistance within the life care plan.

Medications

Prescription and over the counter nonprescription medications related to the
injury or chronic illness that will be used long-term are cited in the life care plan.
Medications used to treat acute symptoms or illnesses are not typically included unless there is a basis for determining the duration of use (Dahlberg, 2002; Weed, 2002a). For example, a client with a history of urinary tract infections may require antibiotics periodically. When a medical foundation for such episodes can be established, medications used for specified periods of time may be cited (Weed, 2002a). Planners must gather supportive evidence from treating physicians regarding the continued use of medications in order to cite them in a client’s life care plan (Barker & Saulino, 2004; Dahlberg, 2002; Lane & Weed, 1999; Oakes, 2004; Weed, 2002a). The effects of an injury or chronic illness may impact pre-existing conditions resulting in increased dosages or necessitating a change to a more expensive medication. When these increases can be accurately calculated and verified to be the result of the present injury, the offset cost may be included in the life care plan. The medical foundations for recommendations within this category are best established by physicians who are currently treating the client.

Supplies

All necessary supply needs associated with the injury are categorized and may include such items as catheters, gauze pads, diapers, support hose, feeding tubes, and other items. Although the client is able to specify the type and quantity of items that he or she is currently using, recommendations from members of the multidisciplinary team regarding anticipated use help to ensure that future needs are adequately identified. Similar to medication recommendations, clients who are
expected to undergo surgery or other medical procedures may require periodic use of certain supplies. When a medical foundation for such episodes can be established, these items may be specified in the plan.

Home Care and Facility Care

In cases requiring home care, attendant care, or facility care services, the majority of the total cost of the life care plan is typically derived from this single category (Brown & Smith, 2004; Dahlberg, 2002; Gamboa & Hanak, 1991; Kitchen, 2002; Pomeranz, Shaw, Sawyer, & Velozo, 2006). This is particularly true for clients who have high-level spinal cord injuries or other conditions that require intensive routine medical care and total assistance in activities of daily living (Harrell & Krause, 2002). In addition to the anticipated number of annual hours of care, planners also specify the type of personal care and assistance that will be required throughout a client’s life span. This may include medical care provided by a registered nurse or home health aide, or assistance with activities of daily living, household chores, transportation, and other routine tasks provided by an attendant or companion.

The amount and type of care that is recommended in the life care plan is dependent upon a number of factors including the client’s current level of independence and ability to safely accomplish activities of daily living, physical and mobility limitations, short-term and long-term vocational goals, community integration and transportation needs, anticipated medical and rehabilitation status,
ability to react to crisis situations, and other considerations (Fischer, 2004; Guercio, et al., 2005; Sandel, Isom, & Koch, 2003). The Nurse Practice Act or Home Health Practices Act within the client’s state of residence, state regulations, and local home health policies dictate the types of services that can be performed by nurse’s aides and registered nurses within the home setting (Dahlberg, 2002; Deutsch, Allison, & Reid, 2003; Kitchen, 2002; Lane & Weed, 1999; Riddick-Grisham, 2004b; Riddick-Grisham & Weed, 1999). For example, in many states, certified nurse’s aides cannot perform any type of invasive procedure such as a catheter change or administration of intravenous medications. Therefore, the cost of obtaining a registered nurse to perform these tasks must be calculated into the life care plan.

Care recommendations are dictated only by the needs of the client. Family members and volunteers are not assumed to be long-term caregivers, even if such care is being received at the time of the initial case analysis (Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Kitchen, 2002). Planners must assume that no family or volunteer care is available to a client because it is not possible to guarantee the availability of this resource throughout an individual’s life span. Even if family members elect to provide this care, their services have an economic value that should be calculated into the overall cost of the life care plan (Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Kitchen, 2002). Further, most adults within the general population of the United States do
not expect to be cared for by family members and, were it not for the injury or illness, clients would not have typically required this support.

Although caregiving by parents and the extended family is expected through the developmental years in pediatric cases, the intensity and duration of this care naturally decreases as children age and become more independent. In pediatric cases, a gradual increase of external support services should be cited in the life care plan to reflect this natural occurrence. During the developmental years, respite care for families is often included in life care plans and is supported by a body of literature that documents the physical and psychosocial hardships of those serving as long-term caregivers for children and adults with catastrophic injuries (Sherman, 1995). Such services allow parents and siblings to spend time outside of the home without worrying about the safety and well-being of the young client. Respite care services help to relieve some of the stress felt by families attempting to maintain a balance between their caregiving responsibilities and their obligations in the workplace, home, and community.

Case management support is often recommended in complex cases, when cognitive or other issues may interfere with the client’s ability to efficiently coordinate necessary services, or when it is believed that periodic follow-up will enhance outcomes (Brethauer & Brethauer, 2003; Dahlberg, 2002; Deutsch & Reid, 2003). Case management services may also be valuable as a means of educating the client and family regarding the disability, identifying compensatory strategies
for accomplishing routine tasks, accessing community resources, and planning for future needs (Blackwell et al., 2001; Guercio, et al., 2005; Jackson, 2003; Redmond, 2004). Accurate recommendations regarding long-term care are critical in adequately preparing for functional changes over time, appropriating sufficient funding, and ensuring quality of life. Input from members of the multidisciplinary team, desires of the client and his or her family, anticipated personal assistance needs throughout the aging process, and other considerations guide the planner in developing recommendations within this category.

*Future Routine Medical Care*

Routine medical care recommendations require collaboration and input from current treating physicians and other members of the multidisciplinary team so that adequate medical foundations can be established. All routine medical follow-up, including specialty physician visits, dental visits, annual evaluations, x-rays, blood tests, and other necessary medical care, is specified. Unless the planner is a physician, he or she is not qualified to order specific tests or to make specific diagnoses. However, standards of care, clinical practice guidelines, and published research may guide the planner in outlining a comprehensive projection of future medical needs (Blackwell et al., 2001; Deutsch & Reid, 2003). For example, certain prescription medications require periodic laboratory testing to ensure proper metabolism. If such prescriptions were recommended by the treating physician, the planner may include projections regarding periodic laboratory testing. The
planner plays an active, contributing role throughout the plan development process. In litigated cases, the planner will be expected to justify and explain the purpose of each recommendation cited. Consequently, the planner must be cautious not to make assertions beyond his or her scope of practice, but must be able to provide support for all of the recommendations contained within the life care plan (Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003, International Academy of Life Care Planners, 2006).

*Future Aggressive Medical Care*

Recommendations with the category of aggressive future medical care or surgical intervention are typically provided by treating physicians. Such recommendations may include plastic surgery to repair skin breakdown, the placement of an intrathecal Baclofen pump, the implantation of an electrical stimulation device, or similar invasive procedures (Weed, 2002a). In most instances, only medical professionals are qualified to project the need for surgery or aggressive treatment and, particularly in litigated cases, planners must clearly establish the foundation for such recommendations.

Once a specific procedure is identified, the planner can then document the associated costs including, hospital charges, surgical and anesthesiology fees, or any other related charges. Projections involving future surgeries or other invasive procedures can potentially impact those within several other categories. For example, planners must also consider whether additional personal assistance,
therapy, routine medical follow-up, aids for independence, supplies, medications, and other items or services may be necessary for a specified period of time. Only those procedures that are within reasonable medical probability are calculated into the life care plan. If the procedure does not meet the threshold of probability, the associated costs may be specified for information purposes, only, so that the planner can educate all parties regarding possible future needs. This notation communicates that additional aggressive procedures may be necessary, but cannot be reliably projected.

*Transportation*

Transportation needs, including all necessary vehicle adaptations, transportation services, handicapped parking permit fees, emergency roadside assistance, and other related items may be included in this category. Depending upon the needs of the individual, items may range from relatively simple adaptations such as a spinner knob placed on a steering wheel, to more complex van adaptations for wheelchair stowage (Pierce, 1999; Weed & Engelhart, 2005). In most cases, the life care plan addresses only those needs resulting from the onset of injury, so an offset for the cost of accommodations is typically calculated (Deutsch & Reid, 2003). For example, when outlining the costs associated with an adapted van, planners may offset the total cost with the average cost of an automobile if the client would likely have owned an automobile pre-injury.

Physical therapists and other professionals specializing in mobility and
accessibility often perform evaluations that assist the multidisciplinary team in identifying appropriate adapted transportation equipment (McCaigue, 2004; Pierce, 1999). The items within this category promote independence, facilitate community involvement, and allow an individual to participate in vocational, educational, social, and other meaningful activities outside of the home. Active, personally rewarding involvement in activities of interest improves quality of life and is a cornerstone principle of rehabilitation (Deutsch & Reid, 2003; Dijkers, 1996; Kemp, Adkins, & Thompson, 2004; Pierce, 1999; Stiens, Kirshblum, Groah, McKinley, & Gittler, 2002; Vogel, Klass, Lubicky, & Anderson, 1998; Westgren & Levi, 1998).

**Architectural Renovations**

Architectural renovations and home adaptations made necessary by the onset of disability are specified in the life care plan. Recommendations may include roll-in showers, modifications in the kitchen and bath, widened doorways, entry/exit ramps, elevators or stair lifts for access to second and third floors, storage space for specialized equipment, and other renovations that will allow clients to safely and efficiently access all areas of their home (Moreo, 1997; Weed, 2002a). Professionals with specialized knowledge of both architectural modifications and accessibility can perform an evaluation of the client’s home, and provide the multidisciplinary team with critical information that may impact other categories within the plan (Moreo, 1997; Weed, 2002a).
Leisure and Recreation

Recommendations cited within this category include items and services that allow clients to engage in avocational interests, to express creativity, and to maximize independence and enjoyment of recreational activities. For example, a recommendation may include an allowance for an attendant to accompany a client to athletic events, subscriptions to disability-related magazines (e.g., New Mobility, Ability), adaptive toys for children, specialty sporting equipment, and other items. Because of the social nature of leisure activities, involvement is often therapeutic and allows clients to interact with others, to build relationships based upon common interests, to pursue pre-injury avocations, and to develop a self-identity beyond their disability (Blackwell et al., 2001; Deutsch & Reid, 2003). In addition to the social benefits, leisure activities help to maintain physical strength, endurance, and overall health (Weed, 1991). Items and activities recommended within this category may require the support of a physical therapist, or occupational therapist, periodic evaluations, or other services that should be reflected in other sections of the plan.

Potential Complications

Although the costs associated with potential complications cannot be calculated into the life care plan, it is important that such possibilities are identified as a means of educating all parties involved in the case (Deutsch, Allison, & Reid,
Depending upon the specific injury, clients may be at greater risk for infections, the development of secondary conditions, orthopedic overuse injuries, psychological disorders, and other conditions. Such complications may evolve and, if not efficiently remedied, can result in irreversible damage that may further debilitate and inhibit the client from attaining his or her rehabilitation goals. Weed (2002a) notes that clients who do not receive adequate care, or fail to comply with the preventative recommendations reflected in the plan, may incur increased costs due to complications that could have been avoided. As an educational tool, the objective of the life care plan is to prevent, or to at least minimize, potential complications by recommending goods and services that accommodate anticipated changes over time (Blackwell et al., 2001; Deutsch & Reid, 2003; Harrell, et al., 1997; McCollom, 2002c; Weed, 2002a; Winkler, 2002). However, it is recognized that some complications simply cannot be foreseen or precluded. The identification of potential complications helps to ensure proactive vigilance for signs and symptoms of conditions that may be of significant harm to the client.

Report Format

Because life care planners originate from various professional backgrounds, there is no standard format for report presentation (Riddick-Grisham, 2006; Thomas, 1999, 2004; Weed, 2001, 2002a). Most practitioners choose to develop a narrative report that accompanies the life care and specifies the case analysis
methodology used to identify plan recommendations, including details regarding the client interview, review of records, consultation with the multidisciplinary team, and other documentation that provides the foundation for the plan. In an effort to educate and facilitate implementation, the evidence provided in the narrative report should clearly link to plan recommendations, and justify the inclusion of specific services and items. The narrative report discusses the unique elements of the case and demonstrates the methodology through which recommendations were identified.

Most planners present recommendations in a tabular format, as illustrated in Appendix A, though various presentation styles exist (Riddick-Grisham, 2006; Weed, 2002a). The contents, rather than the format, are most important. Depending upon the qualifications of the life care planner, some plans will include a category containing vocational or educational needs based upon the recommendations provided by a vocational rehabilitation consultant. Others may include a vocational assessment and a comprehensive vocational or educational plan completed by the life care planner. In either case, the recommended services and supports are identified (e.g., job coaching, tuition, vocational evaluation, textbooks, etc.), associated costs are calculated, and these items are integrated into the overall cost projection (Weed, 2001, 2002a).
Cost Calculation

Once specific recommendations are identified, all associated costs are researched and cited in the life care plan. The overall cost of plan recommendations is of primary interest to those who use life care plans as a basis for establishing the economic damages in forensic cases and for those who are responsible for overseeing the distribution of case funds (Smolarski, 1997). Fiduciaries, case managers, clients, family members, and others who forecast the long-term financial stability of assets need to know the present and projected future costs of each recommended service or item cited in the plan.

Because the calculation of growth trends in various industries and the reduction of these costs to present value requires the specialized skill of economists, life care planners typically provide only the current cost of all recommendations in the plan. Planners conduct extensive research within the client’s local and regional residential area to obtain accurate costs based upon what is charged by the vendors and service providers who are most likely to actually provide support to him or her (Albee, 2003; Busch, 2002; Deutsch & Reid, 2003; Harrell, et al., 1997; Kitchen & Brown, 2004; McCollom, 2002c; Rosenblatt, 2002; Smolarski, 1997). A review of the market within the client’s geographic region allows the planner to create a summative source list that, in addition to the costs quoted, also contains the name and contact information for each vendor or service provider contacted. Such documentation is required in litigated cases, but also
facilitates plan implementation in non-litigated cases. Typically, multiple vendors and service providers are contacted so that a range of costs can be cited in the plan (Deutsch & Reid, 2003; Kitchen, 1999b; Kitchen & Brown, 2004; Weed, 2002a). Exceptionally high and low costs are eliminated so that the plan reflects the actual cost of goods and services to be incurred.

There are several specific considerations involved in identifying costs that have been documented within the life care planning literature. These considerations include private versus agency home health care recommendations, the applicability of collateral resources, offsetting costs for pre-existing needs, the role of the economist, and the calculation of life expectancy. Each of these issues can substantially impact the overall cost of an individual’s life care plan.

*Private Versus Agency Home Health Care*

In most cases, life care plans include only the costs charged by home health agencies in a client’s local area rather than those charged by privately hired attendants. Although privately hired attendant care may appear to be less expensive when hourly rates are compared to those charged by agencies, there are additional costs that make this option as expensive, or more expensive, than hiring care through a home health agency (Dahlberg, 2002; Deutsch & Reid, 2003; Thomas & Kitchen, 1996, 1997; Weed, 2002a).
In addition to the difficulty in initiating and managing services, the expense incurred with payroll and employment taxes, liability and Workers’ Compensation insurance, employee benefits, bonding agreements, costs associated with interviewing and hiring attendants, and other expenses must all be considered (Dahlberg, 2002; Harrell & Krause, 2002; Thomas & Kitchen, 1996, 1997; Weed, 2002a). Further, additional case management support is often necessary in order to manage the complexity of tasks such as coordinating and monitoring the quality of care, selecting appropriate candidates, maintaining financial records, ensuring continuity of care when a professional requests vacation time or becomes ill, and accommodating unplanned absences (Deutsch & Reid, 2003; Thomas & Kitchen, 1996, 1997). Home health care provided through local agencies are obligated to abide by state regulations and standards, a designated scope of practice, and reimbursement guidelines that help to maintain the quality and reliability of care provided to consumers (Harrell & Krause, 2002). When home health agencies are contracted for services, there is an implied level of consumer protection that safeguards clients against violations of care standards.

Collateral Resources

An important principle of life care planning methodology involves the issue of collateral resources. Collateral resources may include a number of community services (e.g., volunteer organizations), government programs (e.g., Medicare, Medicaid), private sources (e.g., health insurance groups), and negotiated rates for
long-term contracts that provide resources at a less costly rate than if purchased at market value. For two reasons, such resources are not typically considered when recommendations are being identified and the life care plan is being developed. First, the long-term availability of these resources cannot be guaranteed. Second, recommendations are based upon the client’s needs, not upon the services that happen to be provided through collateral resources; a concept that is fundamental to life care planning methodology. Rules regarding eligibility, program benefits, coverage for specific items and services, reimbursement rates, and other plan characteristics change frequently (Ehlert & Rubin, 2004). For example, Vierling (2004) notes that even a confirmed diagnosis of a catastrophic injury does not automatically qualify an individual for accommodations under the Americans with Disabilities Act. This legislation is being further refined as cases are brought into court and decisions are made based upon interpretations of the law as it is written (Vierling, 2004).

The life care planning literature consistently emphasizes that budgetary issues, including the availability of collateral resources, should not impact the type or duration of care or rehabilitation that is recommended (Deutsch, 1990; Deutsch, Allison, & Reid, 2004; Deutsch & Reid, 2003; Deutsch & Sawyer, 1985; Riddick-Grisham, 2004b; Vierling, 2005; Weed, 2004a). Provision is made for all of the client’s needs without relying upon services that may not be in available in the future. However, rules regarding the admissibility of collateral resources in
litigated cases vary from state to state (Brown & Smith, 2004; Elliott, 1997, 2004; Gunn & Gunn, 1999, 2004; Stern, 2004; Weed, 2004a). In some instances, the life care planner may be asked to identify appropriate collateral resources and to discuss the extent of such services available to the client. Such circumstances do not alter the methodology employed by a life care planner in identifying necessary items and services. The unique needs of each client are assessed, collaboration with the multidisciplinary team occurs, and the medical and rehabilitation foundations for each recommendation are established. But, when mandated by the court, collateral resources may then be identified as the means through which some of the client’s needs may be fulfilled.

There is an exception to this principle. In cases involving a child or young adult, services provided through the school system under the Individuals with Disabilities Education Act (IDEA) may be cited in the life care plan (Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Neulicht & Berens, 2004). The specialty is in agreement that this is the only collateral source that should be considered because the continued existence of IDEA can be confidently relied upon as a viable source of educational services and funding. In some cases, the provisions of IDEA alone are not sufficient in meeting the needs of the child or young adult, so supplementary services during the school year and summer months may be recommended.
Once the implementation phase of the process begins, planners may collaborate with the client, family, case manager, and other professionals to identify collateral sources of funding. In most cases, life care plans are implemented with the assistance of case managers, by clients, or by family members. Case managers often work collaboratively with professionals from numerous specialty areas, and community agencies to creatively resolve funding issues and identify collateral sources of support. Just as is true throughout the plan development process, plan implementation is most effectively accomplished through a team approach, with consideration given to all possible avenues of funding.

Cost Offsetting

Another important cost consideration involves cost offsetting and it is most often accomplished through consultation with the professionals who are completing the economic analyses of life care plans. Cost offsets most commonly occur in litigated cases because the damages directly resulting from the client’s injury must be specifically identified and accurately quantified. Only those costs necessitated by the onset of injury are included in the overall economic damages analyses (Busch, 2002; Caragonne & Male, 2003; Dahlberg, 2002; Deutsch & Reid, 2003; Powell, 2003; Weed, 2004c). Offsets are frequently noted in the category of transportation needs, for example, because most people purchase automobiles from their earned wages. When the case involves wage loss reimbursement, the cost of a basic automobile has already been calculated into the damages total. If a modified
van is necessary due to the client’s injury, the total cost of a van will be offset by the average cost of an automobile. Similarly, if vehicle modifications are necessary due to the client’s injury, only the cost of adaptations will be reflected in the life care plan.

Role of the Economist

An economist relies upon the categories specified in a life care plan to group similar goods and services when performing long-term cost analyses. Each of these elements has a unique growth trend that is projected over the period of time specified by the planner, and then reduced to present value so that the actual cost of the plan can be determined (Busch, 2002; Caragonne & Male, 2003; Deutsch, 1990; Deutsch & Reid, 2003; Dillman, 1994, 1999, 2004; Ireland & Rizzardi-Pearson, 2004; Raffa & Wells, 1994). The duration, frequency, and applicable replacement schedules specified by the life care planner allows the economist to more precisely calculate the overall cost of the plan (Dillman, 1994, 1999, 2004; Ireland & Rizzardi-Pearson, 2004; Raffa & Wells, 1994; Weed, 2002a). Using the base costs provided by the planner as a foundation for the analyses, the economist is able to calculate the total cost of goods and services through a client’s life expectancy and then reduce the figure to present day value (Busch, 2002; Caragonne & Male, 2003; Deutsch & Reid, 2003; Dillman, 1994, 1999, 2004; Gamboa & Hanak, 1991; Ireland & Rizzardi-Pearson, 2004; Raffa &
Wells, 1994). This analysis provides those involved in the case with a single figure that reflects the total present day value of all recommendations in the life care plan.

When wage loss results from the injury and a vocational plan has been developed, economists are also able to factor vocational recommendations into the overall damages figure. In litigated cases, this figure represents, at least in part, the economic damages resulting from the injury sustained by the client. Pain and suffering and punitive damages are not addressed by the life care plan but are separate elements of a litigated case.

*Life Expectancy*

The determination of life expectancy is considered to be beyond the scope of practice of the life care planner unless he or she is also a physiatrist or similarly qualified medical practitioner (Caragonne & Male, 2003; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003). Because the life care plan includes recommendations throughout life expectancy and may be used as a basis for settlement and financing, an accurate projection is critical in assuring that the plan is adequately funded and does not overestimate long-term costs (DeVivo, 2002; Krause, 2002). Rather than a precise prediction, life expectancy is based upon a statistical average of a group of similar individuals (Katz, 2003; Plioplys, 2004). Physicians rely upon published data tables, such as those produced by the National Spinal Cord Injury Statistical Center or the National Center for Health Statistics,
and factors such as age, current lifestyle, level of injury, degree of impairment, and premorbid health status to assign life expectancy (DeVivo, 2002; Katz, 2003; Krause, 2002; Plioplys, 2004). In some cases, a normal life expectancy may be assigned; in others, a reduced life expectancy may result from the client’s illness or injury.

The issue of life expectancy is particularly important in litigated cases involving catastrophic injury. In order to receive adequate compensation to cover the long-term cost of care and rehabilitation, it is generally in the plaintiff’s favor to learn that a normal life expectancy is anticipated, despite the effects of injury. Conversely, when faced with the possibility of exposure for costs of care and rehabilitation throughout a plaintiff’s normal life expectancy, to learn that a reduced life expectancy is anticipated based upon the catastrophic impact of an injury is generally preferred by defendants (Kessler, 2004).

Training, Certification, and Standards of Practice

As a multidisciplinary specialty, life care planning is practiced by individuals from diverse professional backgrounds. Planners are typically certified or licensure in a primary field of practice such as rehabilitation counseling, case management, rehabilitation nursing, physical or occupational therapy, vocational rehabilitation, physiatry, or other health related areas (Deutsch, 2002; Deutsch & Reid, 2003; May, 1999, 2002b; 2002c; Sherer, et al., 2000; Weed, 2004b). Although it is not currently mandated, many professionals choose to pursue board
certification in life care planning upon completion of a comprehensive training program. The first educational meeting that provided training in life care planning was held in the late 1980s (Deutsch & Reid, 2003; Deutsch, Weed, McCollom, & Grisham, 2006; Weed, 2004). Since that time, several comprehensive training programs have been developed in response to growing interest in this specialty area of practice.

Training Programs

Currently, there are five primary training programs available to professionals interested in obtaining the requisite hours of post-graduate or post-specialty degree training toward certification in life care planning. Each offers a unique professional development experience, though the program offered by the American Association of Nurse Life Care Planners (AANLCP) is open only to registered nurses. Participants who complete this program may seek certification through the American Association of Nurse Life Care Planning Certification Board (AANLCP). In order to sit for the examination, candidates must have obtained a minimum of either 61 direct contact hours from an approved life care planning program or documentation of 500 hours of life care planning experience within the immediate two year period prior to application for certification and obtain a passing score on the written examination (American Association of Nurse Life Care Planners, 2007). The AANLCP confers the Certified Nurse Life Care Planner (CNCLP) credential that was first awarded in 1998. Since that time, more than 370
nurses have acquired this designation (American Association of Nurse Life Care Planners, 2007).

Kaplan University provides exclusively Web-based coursework while Capitol University Law School, MediPro Seminars, and the University of Florida provide training through a combination of onsite and distance education modules. These programs are open to certified or licensed nurses, rehabilitation and vocational counselors, case managers and social workers, physical and occupational therapists, and other professionals who meet the eligibility requirements to sit for certification through the Commission Health Care Certification (May, 1999; 2002b; May & Lubinskas, 2004; May, Turner, Taylor & Rubin, 2000a).

Certification

The Commission on Health Care Certification (CHCC), originally known as the Commission on Disability Examiner Certification (CDEC), is the agency that confers the Certified Life Care Planner (CLCP) credential. The first CLCP credential was awarded by CDEC in 1996 (May, 2002a, 2002b; May & Lubinskas, 2004; May, Turner, Taylor, & Rubin, 2000b). Since then, more than 725 professionals have earned this distinction (Commission on Health Care Certification, 2006). In addition to possessing primary certification in a qualified health-related field, candidates must complete a minimum of 120 hours of training in life care planning, successfully complete a peer reviewed life care plan or one
year of supervision with a CLCP, and attain a passing score on the written certification examination (May, 1999, 2002b; May & Lubinskas, 2004; May, et al., 2000b). CHCC requires training programs to incorporate the following knowledge areas into their curricula: An orientation toward life care planning as a tool of case management, assessment of rehabilitation potential, medical and rehabilitation aspects of disability, plan development methodology, roles and responsibilities in consultation, and other professional and business-related issues involved in life care planning practice (May, 1999, 2002b, 2002c; May & Lubinskas, 2004).

Given the rate at which medical and rehabilitation technologies develop, continuing professional development is critical. Ongoing professional development is required by both certification agencies for credential renewal and is recognized in the standards of practice as an essential function of life care planning (International Academy of Life Care Planners, 2006; May, 1999, 2002b, 2002c; May & Lubinskas, 2004). Opportunities for advanced practice training are offered by a number of organizations and include online, onsite, and distance learning formats. Annual conferences such as the American Association of Nurse Life Care Planners Annual Educational Conference and the International Conference on Life Care Planning specifically address the issues of relevance to practicing life care planners. Topics such as ethical practice, standards of care and clinical practice guidelines, research outcomes in life care planning and specific disability areas, deposition and testimony, legal considerations, and others directly inform the case analysis and
plan development processes. Professional activities such as presenting sessions at regional and national conferences, relevant committee work, writing test items for certification examinations, publishing articles or texts, and other experiences that enhance knowledge and practice may be applied toward credential renewal and further enhance the skills of practitioners (American Association of Nurse Life Care Planners, 2007; Commission on Health Care Certification, 2006).

**Standards of Practice**

Discussions regarding the specific curricular and professional training standards that should be required for life care planners are ongoing as practice expectations become more complex (Berens, 2006; Isom & Marini, 2002; Isom, Marini, & Reid, 2003; McCollom, 2006). The *Standards of Practice for Life Care Planners* published by the International Academy of Life Care Planners (IALCP) offer guidance by identifying the educational, preparatory, and requisite skills that should be demonstrated by candidates seeking the CLCP credential (International Academy of Life Care Planners, 2006). These standards were not established as a means of specifying certification eligibility criteria, but as a description of the expectations of practice so that training programs may sufficiently prepare practitioners and certification can be validated (Preston, 2002).

The IALCP recognizes the qualifications of professionals from fields such as nursing, rehabilitation counseling, medicine, psychology, and physical,
occupation, or speech therapy, and other health related areas. The standards state that candidates should meet the educational criteria established within their primary field of practice, which may include the attainment of an advanced degree, licensure, or other credential (International Academy of Life Care Planners, 2006). Further, the standards state that candidates should have completed an accredited program in a professional health care field, and that their professional licensure or certification should be active (International Academy of Life Care Planners, 2006). The standards also specify that candidates should be expected to demonstrate that their primary discipline provides adequate educational experiences in human anatomy and physiology, pathophysiology, the health care delivery system, the role and function of various health care professionals, and use of clinical practice guidelines and standards of care (International Academy of Life Care Planners, 2006).

The standards identify several complex specialized skills that are necessary in plan development. These skills include the ability to work autonomously, attend to details, research and gather information, analyze data, synthesize large volumes of information, demonstrate clear verbal and written communication skills, maintain positive working relationships and collegial networks, and exhibit a professional demeanor and appearance (International Academy of Life Care Planners, 2006). Rather than proposed as objectives of the training programs, these
specialized skills are identified as a means of defining the attributes that will be necessary in developing cohesive, comprehensive life care plans.

These standards are consistent with those established by CHCC in the development and ongoing review of the CLCP certification examination. In collaboration with professional organizations and information gleaned from a role and function study conducted in 2000, CHCC has identified several broad categories of competencies that are essential in the practice of life care planning (Turner, et al., 2000). These competencies were incorporated into the fourth revision of the certification examination that was released in July 2002 and include the following broad areas of practice: Knowledge of medical interventions and potential complications associated with specific catastrophic injuries, legislative issues, measurement and statistics, psychological issues, and general terms and definitions and miscellaneous items (May & Lubinskas, 2004; McKinley, 2004a).

Certification in life care planning connotes a level of expertise and dedication to continuous development that distinguishes professionals as having acquired advanced, specialized skills. May (2002b) notes that this does not, however, guarantee that the services provided by a certified planner are of higher quality than those who do not possess the CLCP credential. Rather, certification provides a measure of professional accountability to the established code of ethics and standards of practice and a measure of credibility for consumers who are the recipients of life care planning services (May, 2002a, 2002b; May, et al., 2000b).
The training and certification processes prepares planners to integrate research literature, clinical practice guidelines, and data obtained from members of the multidisciplinary team into a plan that addresses the long-term needs of individuals across the continuum of care. As Weed (2002b) notes, the acquisition of an advanced degree and certification does not signify that a professional possesses the specialized skills and knowledge necessary to effectively analyze a case and to develop an appropriate life care plan. Certification simply identifies a qualified professional as having met the minimum required competencies and knowledge sets within an area of practice (May & Lubinskas, 2004; Toran, 1999).

Professional development, experience, and active scholarship over a period of time distinguish accomplished life care planners from those who are novices within the specialty. As the specialty continues to evolve, training programs and certification standards will be revised to reflect current practice and, consequently, to enhance the competence and professionalism attained through advanced study (May, 2002b; McKinley, 2004b).

The IALCP, which began as the American Academy of Nurse Life Care Planners, has led the effort to create a definition and to develop the standards of practice for life care planning (Deutsch & Reid, 2003; McCollom, 2002c; Weed, 2004b). The IALCP first published the Standards of Practice for Life Care Planners in 2000 and have since worked collaboratively with their membership to peer review and create standards that accurately reflect the practice (McCollom,
The most recent standards of practice were published in the Journal of Life Care Planning in 2006 (Fick & Preston, 2006; International Academy of Life Care Planners, 2006; McCollom, 2006).

Standards of practice inform the life care planning process by specifying the roles and functions, ethical obligations, and minimum competencies that should be possessed by professionals within a field of practice (McCollom, 2002g, 2006; Preston, 2002). These are based upon the skills, knowledge, and activities that are identified by members of the practice area and are defined as being critical professional competencies (Preston, 2002). Performance evaluations, certification examination content, other measures often rely upon these standards as a baseline for appraising the skill and expertise of a professional. As such, standards that accurately reflect the experience of life care planners are essential to their credibility and relevance in practice.

In addition to the elements that have been cited elsewhere in this chapter, the Standards of Practice for Life Care Planners identify the specific roles and functions of the life care planner. Broadly stated, these functions include assessment, plan development research, data analysis, planning, collaboration, facilitation, evaluation, and testimony (International Academy of Life Care Planners, 2006). Assessment involves systematic and comprehensive collection of data regarding a client’s medical, health, biopsychosocial, financial, educational, and vocational status (International Academy of Life Care Planners, 2006).
Information that is not available, or to which the planner is denied access, should be noted in the plan (International Academy of Life Care Planners, 2006). Doing so identifies the resources that were not considered during the case analysis and plan development process.

Plan development research includes identification of recommendations and associated costs through a consistent, valid process (International Academy of Life Care Planners, 2006). Plan recommendations should be based upon collaboration with other professionals, personal clinical experience, and current standards of care, clinical practice guidelines, and published literature that are collected from reliable sources (International Academy of Life Care Planners, 2006). When care issues are involved, recommendations should be reflective of considerations such as indications and contraindications for such care, facility admission criteria, availability of care, program goals and outcomes, duration of care, and the ability of the client to appropriately access services (International Academy of Life Care Planners, 2006). Cost research should be based upon sources that are reasonably available to the client and should include options for multiple vendors or service providers, when possible (International Academy of Life Care Planners, 2006).

Data analysis involves a through evaluation of client needs, review of recommendations for consistency with established standards of care, and determination regarding the need for additional client assessments, documentation or information, or expert opinions (International Academy of Life Care Planners,
Planning requires adherence to a consistent method for presenting recommendations, associated costs, and supporting documentation in the life care plan (International Academy of Life Care Planners, 2006). Planning is based upon the unique needs of each client and a consistent method for determining which recommendations should be included and excluded from the plan (International Academy of Life Care Planners, 2006).

The standards state that collaboration includes developing positive relationships with all parties involved in each case, seeking additional expert opinions when necessary, and sharing pertinent information for the purpose of developing recommendations and opinions (International Academy of Life Care Planners, 2006). Similarly, facilitation involves objectively assisting others in reaching agreements regarding plan content, and educating others regarding the life care planning process (International Academy of Life Care Planners, 2006). Evaluation of the final plan should include a review for internal consistency, comprehensiveness, and consistency with standards of care (International Academy of Life Care Planners, 2006).

In addition, evaluation involves educating other parties involved in the case to ensure that all aspects of the plan are clearly understood and interpreted (International Academy of Life Care Planners, 2006). Finally, the standards specify that, if the planner engages in forensic testimony, he or she may act as a consultant regarding recommendations and costs and may provide sworn testimony.
(International Academy of Life Care Planners, 2006). In doing so, the planner must maintain records of all research and supporting documentation upon which the recommendations of each life care plan were developed (International Academy of Life Care Planners, 2006). The scope of practice is broadly defined within the standards and states that life care planning is a collaborative process that involves the client, family, care providers, and all relevant parties in the coordination, assessment, evaluation, and monitoring of necessary services (International Academy of Life Care Planners, 2006).

The performance standards outlined by the IALCP state that planners must practice in an ethical manner and critically review published guidelines and research literature to support plan recommendations with appropriate research findings from relevant sources (International Academy of Life Care Planners, 2006). Further, the standards specify that planners should attempt to actively participate in research that will enhance client outcomes and contribute to the field of knowledge (International Academy of Life Care Planners, 2006). Continuing education within both the primary area of certification or licensure and in current trends in life care planning is also specified as a necessity.

In addition to the competencies identified in the Standards of Practice for Life Care Planners, several specialized skills and professional competencies are documented in the literature. For example, knowledge of the long-term medical and rehabilitation implications of various injuries and chronic illnesses is an
essential competency in life care planning and is consistently identified as a core competency in both the standards of practice and in the professional literature (Blackwell et al., 2001; Deutsch & Reid, 2003; International Academy of Life Care Planners, 2006; Kuntz, 2005; McCollom, 2006; Winkler, 2002). Weed (2001, 2002b) specified the following essential competencies: Knowing what questions to ask of members of the multidisciplinary team and service providers, knowing how the medical system works and how to access relevant information, knowing which specialists should be consulted for recommendations, knowing how to research information about specific medical conditions and associated costs, knowing when information provided by others involved in the case is credible and adequate, and the ability to offer opinions based upon professional experience.

Forensic Applications

Approximately 11,000 new cases of spinal cord injury occur annually (National Spinal Cord Injury Statistical Center, 2006b). Some of these cases are caused by the negligence of others that results in personal injury litigation. Life care plans have been utilized in such cases as a method of identifying and quantifying the life-long economic impact of injuries and illnesses. Prosecuting attorneys not only have to establish that the accused party is guilty of wrongdoing and liable for damages, but must also specify how their client was impacted and represent the entirety of his or her damages in monetary terms (Elliott, 1995, 1999, 2004; Weed, 2004a). The life care plan helps attorneys to establish a client’s

Defense attorneys may also retain a life care planner to dispute the extent of necessary support and resulting compensation owed to the injured party. The defense team seeks to limit proposed damages, and frequently reviews the life care plan prepared at the request of the plaintiff attorney for instances of overreaching, exaggeration, duplications, inflation of costs, and other weaknesses (Gunn & Gunn, 1999, 2004; Stern, 2004). Defense teams evaluate plan recommendations in terms of whether they are reasonable, necessary, and the associated costs are properly calculated (Brown & Smith, 2004). Assuming that the life care planners retained by the plaintiff and defense teams are ethical and comply with the established methodology, the plan recommendations should be similar in representing the future needs of the individual seeking damages (Deutsch & Reid, 2003; Kessler, 2004). Theoretically this is true, but in practice, human factors such as greed, incompetence, misplaced loyalties, or simple professional disagreements may
influence the accuracy and objectivity of plan recommendations (Weed, 2004c). Such discrepancies provide a basis for lengthy arguments on both sides of the case.

Life care plans that are developed for the purpose of quantifying economic damages in personal injury, medical malpractice, or similar tort cases are based upon what is known at the time that the case is evaluated and what is reasonably expected to occur in the future. Recommendations are founded upon evidence in the relevant research literature, current clinical practice guidelines, accepted standards of practice, and the professional judgment of members of the multidisciplinary team who have direct knowledge of the client. In litigated cases, life care planners are retained by attorneys to objectively evaluate the current and future needs of clients resulting from the onset of injury (Deutsch, 1990; Deutsch & Reid, 2003; Shepherd & Pittman, 1995; Voogt, 1996; Weed, 2004c; Weed & Field, 2001). Although only a small percentage of medical malpractice and personal injury cases actually go to trial, the life care planner must be prepared to follow the protocols and procedures involved in providing expert testimony (Sunday & Arnold, 2004).

The credibility of the planner and the reliability of the methodology used to develop recommendations is of critical importance in determining whether the life care plan, and accompanying testimony, will be admissible as evidence in a case (Choppa, et al., 2004; Countiss & Deutsch, 2002; Deutsch, 1990; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003; Feldbaum, 1998; Shepherd &

Because the content of the plan and testimony must be viewed to be non-biased and based upon established medical and rehabilitation foundations, planners do not engage in therapeutic, counseling, or case management relationships with clients (Dahlberg, 2002; Deutsch, 1990). To do so may be interpreted as having developed opinions based upon subjective, rather than objective, professional judgments. Consequently, the methodology of case analysis and plan development must be sufficiently discriminative to identify relevant indicators of probable future needs throughout the case analysis process and to incorporate necessary medical care, rehabilitation and therapy, vocational guidance, equipment, supplies, and other supports that will be necessary throughout the client’s life span (Choppa, et al., 2004; Marini & Harper, 2006; Weed, 1999). Elliott (2004) notes that jurors and other decision makers who review the life care plan naturally interpret it through their own experiences and personal knowledge. Recommendations that appear to be unreasonable or inappropriate may prompt doubts about the veracity of the planner and of the entire life care plan (Deutsch & Reid, 2003; Elliott, 1999, 2004;

Proper explanation and documentation will provide face validity, and will assist all parties involved in the case to appreciate why certain items and services are recommended. The plan must accurately represent all of a client’s needs through life expectancy because the compensation awarded in the settlement is typically the only opportunity given to the plaintiff to present his or her case. Post-settlement, the planner cannot request a retrial to seek supplementary compensation if additional information is learned or if certain items were not cited in the plan (Kitchen, 2002; Vierling, 2002; Weed, 1999, 2001).

The implications of the *Daubert v. Merrell Dow Pharmaceuticals, Inc.* case were discussed in Chapter 1 and clearly illustrate the importance of developing life care plans based upon the established methodology and standards of practice within the specialty (Countiss, 2002; Countiss & Deutsch, 2002; Deutsch, 1990, 2004; Deutsch, Allison, & Reid, 2003; Deutsch, McCollo, et al., 2003; Deutsch & Reid, 2003; Feldbaum, 1998; Knouse, 2003; Marini & Harper, 2006; McCollo, 2002b; Neulicht, 2006; Taylor, 2004; Weed, 1999, 2004c). In addition, the professional qualifications of the planner are highly scrutinized and, if proven to be unqualified, the testimony of the planner will not be permitted to be presented at trial (Brown & Smith, 2004; Deutsch, McCollo, et al., 2003; Gunn & Gunn, 1999, 2004; Stern, 2004). Until the *Daubert* decision in 1993, testifying experts were subject to the
standards established in the *Frye v. United States* case that allowed testimony if it was determined that the expert had knowledge and information that would assist jurors in deciding appropriate case outcomes (Countiss & Deutsch, 2002; Feldbaum, 1998; Weed, 2004c). This was based upon an assumption that the expert had complied with case evaluation methodologies and practices that were generally accepted within the field (Weed, 2004c). The *Daubert* decision substantially altered the standards for admissibility of scientific evidence in many jurisdictions.

As discussed in Chapter 1, experts testifying in states that operate under the *Daubert* ruling are now required to provide documentation that the methodologies employed in formulating their opinions and recommendations are peer reviewed, published within the professional literature, credible and reliable, generally accepted by peers, and effective in non-judicial situations (Countiss, 2002; Countiss & Deutsch, 2002; Deutsch, 2004; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003; Gibson, 2000; Marini & Harper, 2006; Taylor, 2004; Vierling, 2002; Weed, 1999, 2004a, 2004c). The *Kumho Tire v. Patrick Carmichael* decision in 1999 extended these criteria to the non-scientific testimony admitted in some states; this includes the testimony provided by life care planners (Countiss & Deutsch, 2002; Deutsch, McCollom, et al., 2003; Weed, 2004a, 2004c). Because rules regarding admissibility of evidence and expert testimony vary from state to state, life care planners who practice in multiple regions of the

The role of the life care planner within the forensic arena has been consistently documented within the literature. The role of the life care planner is described as that of an educator, not an advocate (Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003; Sunday & Arnold, 2004; Taylor, 2004). Although this concept may appear at odds with the basic professional philosophy held by those in the health and rehabilitation professions, it simply distinguishes the unique function served by planners who are asked to provide objective opinions within the realm of litigation (Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003). Judges, juries, attorneys, insurance administrators, and others rely upon life care planners as educators and to clearly communicate the nature of a client’s injury or illness, residual functional limitations, psychosocial and vocational impact of the resulting disability, and expected outcomes over his or her life expectancy (Deutsch, 1990; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003; Weed, 1990, 1992, 1999, 2001). This explanation demonstrates the extent to which the life of the client has been impacted by the injury or illness. If a defense attorney is able to establish that the planner is functioning within the role of advocate, rather than educator, the jury may be convinced that the recommended items and services
were identified for the convenience and enjoyment of the client, rather than as necessities (Gunn, 1994; Gunn & Gunn, 1999, 2004).

Ethical practice is assumed to be the intention of rehabilitation and health care professionals who specialize in life care planning. The ability to objectively and continuously self-evaluate ethical behavior is critical in protecting the welfare of clients, providing appropriate service, and maintaining an exemplary professional reputation. As a specialty within the field of case management, there are several ethical foundations to which life care planners are expected to adhere that were discussed in Chapter 1. These foundations are common within health care and rehabilitation practice areas and include a commitment to client autonomy, beneficence, nonmaleficence, and justice (Blackwell, 1999; Reavis, 2002b; Weed & Berens, 2004). The standards of practice clearly state that life care planners must practice in an ethical manner that is consistent with the standards established both in their primary disciplines and within the specialty (International Academy of Life Care Planners, 2006). In addition to these ideals, a review of the life care planning literature reveals that there are specific ethical standards that practitioners are expected to uphold in the course of providing services and collaborating with other professionals. These include disclosure of the limits of confidentiality and the role of the life care planner, avoidance of dual relationships, and maintaining professional competency.
Confidentiality must be maintained and strictly protected (Blackwell, 1999; Deutsch, 2004; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003; International Academy of Life Care Planners, 2006; Weed, 1995a). Throughout the case analysis and plan development process, the planner may generate electronic or printed files, receive documentation from members of the multidisciplinary team, and review private health, employment, educational, and other personal records. Assessment data, laboratory results and physician interpretations, counseling notes, therapy summaries and other sensitive documentation may become part of the client’s file. Moreover, records with little or no relevance to the case that pre-date the injury may be forwarded by care providers and others who have some knowledge of the client. For example, in comprehensively evaluating the case, a client’s lifestyle, health issues, past substance abuse, criminal record, or other transgressions may be revealed. Although such information may have implications for anticipated compliance with plan recommendations or potential complications, planners must be prepared for the possibility that unflattering information may be used by the opposing attorney to discredit or prejudice a jury against the client based upon his or her past actions.

Life care planners are ethically obligated to take extraordinary precautions to protect client information while it is in their possession (International Academy of Life Care Planners, 2006). However, in litigated cases confidentiality between the life care planner and the client is effectively nonexistent, though this varies.
from state to state (Weed & Berens, 2004). In fulfilling the role of expert witness, the life care planner is obligated to reveal all foundations upon which recommendations were based, including the information provided by clients (Gunn, 1994; Gunn & Gunn, 1999, 2004; Weed & Berens, 2004). As noted in the standards of practice, life care planners do not have the same confidentiality privileges as clients have with their attorneys (International Academy of Life Care Planners, 2006). For this reason, planners must thoroughly discuss their role and function with clients. This may include providing an explanation of the case analysis and plan development processes, disclosing any actual or potential conflicts of interest, and describing how the life care plan may be used in court (Blackwell, 1999; Cimino-Ferguson, 2005; Deutsch, 1990, 2004; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003; International Academy of Life Care Planners, 2006; Weed & Berens, 2004). Client consent is required before the medical records can be reviewed, a personal interview is conducted, or communication with other professionals occurs. The planner should work with the client to ensure that he or she has clear expectations of the planner’s role in the case (Deutsch, 1990; Deutsch, McCollom, et al., 2003; Weed & Berens, 2004).

Dual relationships, or those that establish the planner in multiple roles, should be avoided and are prohibited in the standards of practice (Blackwell, 1999; Cimino-Ferguson, 2005; Deutsch, 1990, 2004; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003; International Academy of Life Care Planners, 2006; Weed
Plans developed for family, friends, colleagues, or similar relations may skew the objectivity, or the perceived objectivity, of the planner and add a personal dimension to recommendations that may affect judgment. Similarly, planners should refrain from developing close personal relationships with referral sources, particularly attorneys (Cimino-Ferguson, 2005; Weed & Berens, 2004). Such familiarity may challenge a planner’s objectivity and may be used to discredit the life care plan. The concept of dual relationships may also apply to life care plans written by current treaters, therapists, case managers, and others (Slovenko, 2004). Although the information provided may be based upon direct observation and an intimate understanding of the circumstances of the case, it may also be perceived as being biased in favor of the client (Slovenko, 2004). In litigated cases, a planner is not serving the needs of a client or fulfilling their role as an expert witness if they are perceived to be providing subjective testimony. Planners advocate for the needs of clients by educating the parties involved, by making well-founded recommendations, and by explaining the long-term ramifications resulting from injury.

Even post-settlement, a life care planner must carefully consider the ethical implications of serving as a case manager because her or she may be perceived to have gained personal financial benefit from recommending these support services (Gunn & Gunn, 1999, 2004). The role of case manager and life care planner are viewed within the specialty to be separate and distinct (Blackwell, 1999; Boling &
Wolf, 2003; Cimino-Ferguson, 2005; Deutsch, 1990; Deutsch, Allison, & Reid, 2003; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003; McCollom, 2005; Rice, et al., 2000; Weed, 1990, 1992, 1995a; Weed & Berens, 2004). Self-referral, even to facilities or programs with which the planner is affiliated, can be detrimental and may seriously compromise the planner’s credibility (Gunn & Gunn, 1999, 2004).

Life care planners must clearly delineate their scope of practice and avoid making assertions that are beyond their professional range of competence (Blackwell, 1999; Deutsch, 1990, 2004; Deutsch, McCollom, et al., 2003; Deutsch & Reid, 2003; International Academy of Life Care Planners, 2006; McCollom, 2005; Reavis, 2002b). It is unethical for a life care planner to make recommendations in areas in which he or she no expertise or formal training, and will result in disqualification as an expert witness if such instances are discovered (Deutsch, McCollom, et al., 2003; Weed, 1990, 1992, 1995a, 2002b; Weed & Berens, 2004). However, identifying whether or not an ethical transgression may have occurred is somewhat complicated by the fact that the scope of an individual planner’s practice depends upon his or her educational background, knowledge, and work experience and it is broadly defined by the standards of practice (Sunday & Arnold, 2004). There is no specific, universally applicable standard regarding the scope of practice of all life care planners because the specialty is comprised of professionals from various backgrounds and with various credentials (Sunday &
Arnold, 2004). For example, it would be inappropriate for a rehabilitation nurse with no specific training in vocational assessment to develop the vocational plan and recommendations regarding future career goals. Likewise, it would be inappropriate for a vocational counselor with no specific training as a physical therapist to identify seating and positioning recommendations. Recommendations regarding surgical interventions, vocational and educational development, health and strength maintenance, routine medical follow-up and other needs must be supported by qualified professionals. Many standardized assessments and physical examinations can only be conducted and interpreted by those with the proper credentials. A planner who fails to consult with members of the multidisciplinary team and asserts that his or her own clinical experience, alone, is sufficient basis for plan recommendations fails to comply with the standards of practice and may jeopardize their credibility as an expert witness (Deutsch, 1990; Deutsch, McCollom, et al., 2003; Weed, 2002b; Weed & Berens, 2004). Consequently, the welfare of the client may be harmed through inaccurate recommendations or through exclusion of the life care plan as an evidentiary document in the case. Life care planners must be aware of their professional limitations and consult with others who are properly credentialed when issues are beyond their scope of practice.

Life care planners have an obligation to maintain professional competency (Blackwell, 1999; Deutsch, 2004; Deutsch, McCollom, et al., 2003; Deutsch &
Reid, 2003; International Academy of Life Care Planners, 2006; McCollom, 2005; Reavis, 2002b; Weed, 1990, 1992, 1995a). Recommendations should be supported with medical evidence, research, and sound principles of rehabilitation science. Documentation should accompany all aspects of the life care plan and should be available for review by other professionals. Life care planners must rely upon credible research in developing life care plans and should attempt to add to the knowledge base within the specialty by contributing to the existing research and maintaining active participation in continuing professional development activities (International Academy of Life Care Planners, 2006).

The Commission on Health Care Certification (CHCC), the certifying agency for the Certified Life Care Planner (CLCP) credential, has also established a Code of Professional Ethics. These principles include an obligation to comply with the moral and legal standards involved in each specific case, to respect the integrity and protect the welfare of clients, to advocate in the best interest of clients, to facilitate relationships with other professionals, disclose fee schedules and fairly charge for services rendered, to maintain confidentiality, appropriately utilize assessments, engage in research activities, to competently practice, and to respect and recognize the limitations of the CLCP credential (Commission on Health Care Certification, 2006). Life care planners demonstrate their commitment to these principles by earning the CLCP credential and adhering to them in practice.
Litigated cases present particularly complex ethical challenges. The adversarial legal system allows both the defendant and the plaintiff to put forth their best arguments and evidence in presenting their cases (Slovenko, 2004). Maintaining professional objectivity when confronting the desires of the retaining counsel may influence ethical behavior and perceptions. In litigated cases where attorneys vehemently advocate for their clients, Weed (2004c) explains that planners may become convinced of the veracity of the legal argument that may, consequently, compromise their ability to objectively evaluate a case. Also, attorneys may selectively provide documentation and information that supports their legal argument and directly shapes the material that is evaluated by the planner; and consequently, the recommendations contained in the life care plan (Weed, 2004c). Further, planners must critically review their business practices to ensure that retainer agreements include proper language and protections, that testimony is not provided on a contingency basis, that no perceived conflicts of interest exist, and that necessary precautions are taken to avoid violations of accepted legal protocols (Slovenko, 2004; Weed, 1995a).

There are multiple layers of ethical implications inherent throughout the case analysis and plan development process (Savage, 2004). Given the complexities of catastrophic injury cases, planners are obligated to uphold the standard of practice that have been established within the specialty and to approach decision making in an ethical, objective manner (Deutsch, McCollom, et al., 2003;
McCollom, 2005; Reavis, 2002b). Planners must continually evaluate the ethical ramifications of their recommendations, business practices, methodology, and interactions with colleagues, clients, families, and legal representatives. Planners occupy a powerful position in litigated cases because their work product is used as the basis for compensation for future injury-related expenses. Decisions regarding specific recommendations and interventions, medical and home health care, quality of life, safety and preventative measures, allocation of limited resources, recognition of the client’s wishes, and many other issues may profoundly impact the amount of compensation awarded and efficiency of plan implementation (Savage, 2004).

Current Trends

Since the first life care planning Summit was held in 2000, these biennial events have become one of the primary venues where planners discuss issues of relevance to the practice (Weed & Berens, 2000). This forum serves as an opportunity to exchange ideas and information regarding current challenges as the specialty continues to grow and evolve. A review of the Summit proceeding summaries indicates that common topics of importance as identified by practitioners within the specialty include issues related to standards of practice (Berens, 2004; Deutsch & Allison, 2002), peer review (Riddick-Grisham, 2006), case analysis and plan development methodology (Berens, 2002; Berens, 2006; Deutsch & Allison, 2002; McCollom, 2000a, 2004b; Riddick-Grisham, 2006),
litigation and considerations related to the *Daubert* decision (Berens, 2006; McCollom, 2000a; Riddick-Grisham, 2006), malpractice and ethical concerns (Berens, 2002, 2006; McCollom, 2000a; Riddick-Grisham, 2003, 2006; Weed & Berens, 2000), professional development and mentoring (Berens, 2002; Berens, 2004; Deutsch & Allison, 2002; McCollom, 2000a, 2004b; Riddick-Grisham, 2003, 2006), and research in life care planning (Berens, 2004; Riddick-Grisham, 2003, 2006; Weed & Berens, 2000). Issues of relevance to the specialty are also discussed at national and regional life care planning conferences, within professional life care planning organizations, in the *Journal of Life Care Planning*, and in other publications (Weed, 2004b).

The specialty of life care planning continues to evolve as the established methodologies are applied to more diverse populations of individuals whose lives are impacted by catastrophic injuries and chronic illnesses that result in long-term disabilities. The principles of life care planning have been applied to geriatric and elder care cases (McCollom, 2000a, 2002b, 2002c, 2004a; Smolarski, 1997; Stolte-Upman, 2003; Weed, 2004b), pediatric cases (Deming, 2006; Higdon, 2005; Riddick-Grisham, 2004a; Toran, 1999; Weed, 1995b), and in facility discharge planning (McCollom, 2002b, 2002c; Neulicht, et al., 2002; Oakes, 1992; Sherer, et al., 2000; Toran, 1999; Weed, 2004b). Life care planning principles have been applied to adult and pediatric cases involving a variety of disabilities and conditions including reflex sympathetic dystrophy and chronic pain (Apuna, 2001;

In addition to diversified populations, life care planning is becoming more widely recognized as a valuable tool in establishing insurance and Medicare Set-Aside reserves (Allison, McCollom, & Deutsch, 2004; Dahlberg, 2002; Manley, 2003; McCollom, 2002b, 2002c; Toran, 1999; Weed, 1995b, 2004b), and managing estate and special needs trust funds (McCollom, 2002b, 2002c; Smolarski, 1997; Weed, 2004b). Changes in relevant legislation, medical advances, rehabilitation trends, funding resources, and other developments that affect these special
populations may also have consequential implications for the considerations made throughout the case analysis and planning processes.

Research in Life Care Planning

The development of a body of research literature within a specialty area of practice evolves over time and through multiple research endeavors that contribute to the field of knowledge in cumulative, incremental steps (Rumrill & Fitzgerald, 2001). With the fundamental principles of life care planning established, with adequate case databases for exploration, and with increasingly stringent demands upon expert witnesses in litigated cases, research in life care planning emerged in the 2000s. In 2002, Kendall and Deutsch published an article that outlined the need for empirical research within the specialty and provided an overview of basic methodological, design, and analysis concepts. Specifically, the article emphasized the need for ongoing studies that explore the reliability and validity of life care planning methodology. In addition to ensuring that plans reflect the actual needs of individuals with catastrophic injuries, the authors noted that such research is necessary if life care planning is going to continue to be accepted within the forensic arena as a valid method of identifying long-term needs in litigated cases. Equally important, establishing the reliability and validity of life care planning methodology as a case management tool helps to ensure that individuals with catastrophic injuries receive the appropriate services, equipment, and support to proactively maximize potential rehabilitation, medical improvement, and quality of
life (Kendall & Deutsch, 2002). For more than a decade practitioners have examined outcomes within their own caseloads and have described the methods used to determine the accuracy of plan projections and of overall client satisfaction (Casuto & Gumpel, 2003; Kendall & Casuto, 2005; McCollom & Crane, 2001; Patterson, Murphy, & Masterson., 2004; Reavis, 2002a; Sutton, Deutsch, Weed, & Berens, 2002).

Currently, life care planning does not appear to be facing the research versus practice gap that exists in some fields (Clement, 1996; Goldfried & Wolfe, 1998). Goldfried and Wolfe (1998) note that the gap between research and practice can create two distinct, and sometimes antagonistic, entities within a single field of study if researchers fail to remain mindful of the primary consumers of their work. Life care planning may be spared this dilemma, due to the fact that practitioners are expected to justify recommendations based upon research findings, including those reported in clinical practice guidelines and standards of practice. Particularly in litigated cases, planners must demonstrate adequate medical and rehabilitation foundations for all items that they have included, and excluded, from life care plans.

The majority of the research studies that have been published to date have been conducted by practitioners alone or in partnership with colleagues who have specific expertise in research design and statistical analysis (Casuto & Gumpel, 2003; Deutsch, et al., 2006; Kendall & Casuto, 2005; McCollom & Crane, 2001;
Marini & Harper, 2006; Patterson, et al., 2004; Pomeranz, et al., 2006; Sutton, et al., 2002; Turner, et al., 2000). Studies have been described in a manner that appears to identify the life care planning community as the target audience. This allows the research to be accessible, relevant, and meaningful to practitioners. Such care in communication is critical in initiating a professional dialog and in ensuring that research findings are considered and implemented, as appropriate. Largely driven by the *Daubert* decision, questions regarding the reliability and validity of the life care planning process have been topics of interest at Summit meetings, professional conferences, and in publications (Deutsch, McCollom, et al., 2003; May, 2002c; McCollom, 2002e). With relatively few research-based publications currently available within the specialty of life care planning, a thorough review of each of the existing studies is warranted. These studies guided the design and instrumentation of the present study and provide a foundation for future research.

*Job Functions*

The first empirical study involving life care planning pre-dated the Kendall and Deutsch (2002) article, but did not involve an exploration of the reliability and validity of the specialty. It was published in 2000 and sought to more clearly define the job functions associated with life care plan development (Turner, et al., 2000). Researchers developed a preliminary list of 75 job tasks based upon a review of existing literature within the specialty. This list was reviewed by a panel
of 11 experts who reviewed it for content validity and identified 19 items for deletion. The remaining 56-item list became the Life Care Planning Job Task Inventory (JTI) that was mailed to 992 individuals identified through national organizations and life care planning training program rosters.

Respondents were asked to rate each item on a six-point scale according to the percentage of cases requiring the described task. A total of 239 questionnaires (25%) were returned for analysis. Following a statistical factor analysis, three job functions were revealed to account for 31.7% of the total variance and were deemed to be associated with the life care plan development; assessing a client’s medical and independent living service needs, vocational assessment, and consultant services to the legal system.

Researchers concluded that these findings were consistent with job functions that had been described within the non-empirical professional literature. Given the results, researchers asserted that this evidence can be used as a basis for preservice training curricula and continuing professional development. Further, this information may contribute to evidence-based CLCP certification examination criteria, credentialing requirements, and to the creation of a standard job description.
Accuracy Over Time

McCollom and Crane (2001) conducted a descriptive study involving 10 individuals with spinal cord injuries who were part of their life care planning practice caseload. The researchers developed a questionnaire instrument and obtained responses through self-report telephone interviews with participants. Results were reported as percentages of the sample. Demographically, the sample included 10 participants; 3 females and 7 males who ranged in age from 23 years to 77 years. Five participants were injured 8 years prior to the publication of the study, 4 participants were injured 7 years prior, and 1 participant was injured 14 years prior. Life care plans were completed three to six years prior to the publication the study. Participants were asked to respond to 11 questions.

Researchers asked participants to indicate whether they had completed comprehensive annual spinal cord evaluations and how frequently they were seen by a physician. Recommendations for comprehensive annual spinal cord evaluations were present in all of the participants’ life care plans. Five participants had completed comprehensive annual evaluations and 5 consulted with a family physician on an as-needed basis. One participant stated that he must obtain approval from his workers’ compensation insurance company prior to any physician visit, and another consulted with his physical medicine and rehabilitation specialist twice per year. Additional information was not provided by the researchers.
All of the participants indicated that they had experienced complications since the development of their life care plans. All life care plans indicated that the clients were at greater risk for urinary tract infection, deep vein thrombosis, and skin breakdown as a consequence of spinal cord injury. The most frequently reported complications were urinary tract infection and chronic pain, though the number of individuals who experienced each of these conditions was not specified by the researchers. In addition, 4 participants reported experiencing skin breakdown; the severity and duration of which was not specified. All of the life care plans suggested that individuals were at greater risk for hospitalization due to complications. Six of the participants reported that they had been hospitalized due to complications, though specific diagnoses were not indicated. Two participants reported that they had been hospitalized annually for the past 3 years, but specific diagnoses were not indicated.

The life care plans of all participants specified the prescription medication being used at the time of plan development. All participants reported that they continued to require multiple prescription medications, though information regarding the specific medications being used was not provided by the researchers. Five participants required Baclofen for spasticity control and 1 required a morphine pump for chronic pain control. Similarly, the life care plans of all participants specified the disposable supplies being used at the time of plan development. All participants reported that these supplies continued to be necessary, though
information regarding the specific supplies being used was not reported by the researchers. Annual wheelchair maintenance was recommended in each of the life care plans. Eight participants indicated that their wheelchairs had required repair in the prior 12 month period and 1 participant had purchased a new wheelchair since the plan had been developed. Six participants noted problems with wheelchair maintenance, but specific difficulties were not described by the researchers.

Although specific services were not specified by the researchers, they indicated that all life care plans contained recommendations for vocational rehabilitation support. One participant was working full-time, 1 worked part-time, and the remaining 8 participants were not working at the time of the study. Three individuals had completed additional educational training and 1 participant was in a full-time educational program at the time the survey was conducted, though the specific information about these educational programs was not provided by the researchers.

All life care plans contained recommendations for vehicle modifications and all participants reported that they independently operated modified vehicles; 5 of which had vans with wheelchair lifts. All plans included recommendations for home accessibility, and participants reported that they had completed home modifications. Specific examples of these necessary renovations were not provided by the researchers. Lastly, all of the life care plans recommended the need for some level of personal care, but specific information regarding the type and number
of weekly hours of assistance was not provided by the researchers. Six individuals required personal assistance; 3 of which received this care from their spouses. Researchers did not specify the source of personal assistance for the 3 remaining individuals. Researchers noted that the participants who reported that they did not require personal assistance were less than 30 years of age at the time the survey was conducted.

The researchers concluded that there was a “clear consistency” between the needs that were projected in the original life care plans and those reported by study participants. They noted that participants who completed comprehensive annual spinal cord evaluations reported fewer complications than those who consulted with physicians on an as-needed basis. Researchers also noted that all of the participants expressed a need for assistance in coordinating services and managing supplies. Although case management support was not available to 8 of the participants, reasons for unavailability were not specified.

*Life Care Planning Methodology*

Sutton, et al., (2002) conducted a retrospective, quantitative research study that explored the reliability of life care plans. The caseloads of two life care planners were combined, and 65 cases representing individuals with various injuries were reviewed. In each case, recommendations regarding home health care and routine medical care in updated plans were compared to those specified in
clients’ original plans. Details concerning the circumstances that necessitated plan updates were not provided by the researchers. Researchers used the costs of recommended services as a measure of agreement between the original and the updated plans. To create an equitable means of comparing plans that reflected costs based upon the market rates at the time of plan development, costs for recommended services in the original and in the updated plans were calibrated. These costs were converted to the rates charged for the specified services in 2002; the year the study was conducted. By controlling for inflation, market fluctuations, and changes in the values of goods and services, the researchers asserted that cost could be used as a unit of measurement and a means of comparison between plans. Chi-square analyses of difference between the original and updated plans were not significant at the .05 level. Researchers concluded that this suggested that the plan recommendations analyzed in the sample were reliable over time.

*Pediatric Outcomes*

Casuto and Gumpel (2003) conducted a retrospective descriptive study involving 22 participants who required pediatric life care plans. Participants were selected from the researchers’ own professional database of plaintiff cases. The purpose of the study was to evaluate the accuracy of recommendations regarding personal care needs, to identify additional areas that should be addressed in pediatric life care plans, and to explore the factors that influence the ability of the family to fully implement the plan as written. Researchers indicated that 45
potential participants were identified, but the specific selection criteria used to extract them from the researchers’ database were not discussed. Of these, 38 case histories contained valid contact information.

Demographically, at the time of injury the majority of participants were between the ages of 1.5 and 5 years (45%), or 6 to 10 years of age (32%). Eighteen percent were 11 to 18 years of age and 5% were 19 to 22 years of age. The majority of participants had birth injuries (31%) or injuries classified as “other,” (e.g., anoxic event, shaken baby syndrome, post-meningitis) (27%). Fourteen percent were brain injured, 14% were spinal cord injured, and 14% had orthopedic injuries. Life care plans were developed 1 to 11 years prior to the publication of the study. Researchers did not specify whether the survey data was collected from parents, from children who were able to speak on their own behalf, or from both sources. The questionnaire was developed by the researchers, and participants’ responses were collected by telephone interview. Participants were asked to respond to questions regarding health care, therapy, counseling, recreation, equipment, fiduciary services, attendant care, schooling, and community services.

In terms of health care, researchers explained that “over half” of the participants had not required hospitalization on a yearly basis, but those who were hospitalized averaged a length of stay from one to two days. The primary causes of hospitalizations were surgery and complications resulting from seizures and asthma. Researchers noted that “over half” of the participants had not visited the
emergency room, and the remaining individuals had visited only once per year due to seizures, asthma, broken bones, and post-surgical complications. The researchers did not specify a timeframe during which these visits occurred (e.g., the prior 12-month period, since the plan was developed, other). One child visited the emergency room more than 15 times and was hospitalized more than 3 times in a year due to a severe, uncontrolled seizure disorder.

The researchers noted that “most” children consulted with pediatricians, family practice physicians, internists, neurologists, and orthopedists on a regular basis, though participants also indicated that specialists, including neurosurgeons, ophthalmologists, endocrinologists, and mental health professionals, were visited. Those who were consulting with physiatrists at the time that the plan was developed to continued to do so. Those who were not seeing a physiatrist at the time that the plan was developed did not subsequently seek such care. Fourteen children were covered under a family member’s medical insurance policy and the remainder were covered by public insurance programs. Only 1 participant was not covered by any form of insurance.

All 22 life care plans contained recommendations for various types of therapy; the specific types of which were not provided by the researchers. Ten children received occupational therapy one or two times per week, 15 received physical therapy one to four times per week, 11 received speech therapy one to five times per week, and 1 child received vision therapy one time per week. Three
children did not receive any therapy and this was due to lack of time or lack of transportation. Researchers reported that 25% of the sample received therapy at home and the remainder received therapy in a clinic or hospital setting. In 25% of the cases, therapy was funded through a public benefit program; California Children’s Services. Ten percent of the participants funded therapy through health insurance plans, and the remainder paid for services privately. Psychological counseling was recommended in all 22 life care plans. Five participants indicated that their families received private psychological counseling and 4 children received individual counseling. One family attended a support group through United Cerebral Palsy. Though specifics are not provided, the researchers also noted that 1 participant had been hospitalized due to “emotional adjustment issues” and 5 children were referred for behavior management intervention.

Recommendations involving recreational activities were included in all 22 life care plans; the specific recommendations are not provided by the researchers. Five participants were involved in activity programs during the school year or during the summer; 1 participated in aquatic therapy, and 1 participated in equine therapy. Two attended summer camps for children with disabilities and each had private aides with them; one of which was a sibling. Equipment was recommended in all 22 life care plans; specifics of which were not provided by the researchers. Eighteen children were found to rely upon some form of mobility assistance. Eight used manual wheelchairs, 2 used power wheelchairs, 5 used walkers, and 3 were
transported in strollers. One child used a standing frame and, although positioning equipment had been purchased initially, researchers reported that “few” families replaced this equipment as their children grew. Respondents indicated that recreational activities and equipment currently in use appeared to meet the children’s needs, though details regarding adequacy and appropriateness were not provided by the researchers.

Fiduciary services were recommended in all 22 life care plans, though only 2 respondents indicated that they used a fiduciary exclusively to administer funds. Two individuals received no monetary compensation from their lawsuits. Parents managed the settlement proceeds in 3 cases, 3 received structured settlements, 4 retained an attorney and bank officer to administer funds, 4 relied upon the combined services of a fiduciary and an attorney, and 4 relied upon the combined services of an accountant and an attorney to manage funds. The researchers noted that special needs trusts had been established in “some” of these cases.

Though specific types (e.g., registered nurse, nurse aide, etc.) and number of hours of care per week are not specified by the researchers, attendant care was recommended in all 22 life care plans. All families indicated that they provide a majority of personal assistance and care. Only four families hired individuals to provide additional attendant care and two of these were identified as nannies; one of whom lived with the family. Six mothers assumed the role of primary care giver
and four received compensation from settlement funds that replace their salaries had they continued to work.

An educational advocate was recommended in 21 of the life care plans. Two children were placed in private schools due to the local school districts’ inability to meet the children’s needs. Seven children worked with classroom aides who were provided by the school and 1 child did not attend school due to increased risk for upper respiratory infections. The researchers did not specify whether any of the participants were working with educational advocates at the time the study was conducted.

In terms of community services, nine families relied upon respite care that ranged from 8 to 40 hours per month. Researchers noted that 12 participants were no longer using services provided by regional service centers, but whether these services were being utilized at the time of plan development, the specific services that may have been utilized, and the purpose of these regional centers was not described.

Researchers identified some of the trends revealed by the survey. First, they noted that most children did not require annual hospitalization and that, for those who did, only a one to two day stay was required. Second, they reported that 27% of participants required annual visits to the emergency room and noted that this was consistent with the recommendations contained in the life care plans.
Third, researchers stated that they were surprised to learn that the medical specialists recommended in life care plans were not being utilized by participants. Although the number of annual visits to a medical provider was accurate, the type of specialist being consulted with was not. Participants reported consulting with primary care physicians and orthopedists more frequently than anticipated by the original plans. Researchers further noted that annual consultations with a physiatrist was recommended in “the majority” of cases, yet only 2 respondents indicated that this was occurring at the time of the study. Fourth, therapy was found to extend beyond the recommended duration, though specific information regarding this issue was not provided by the researchers. Although all of the life care plans included provisions for private therapy in clinic and hospital settings, 54% of respondents indicated that the public school system was the primary service provider, and only 22% reported that they received therapy at home.

Researchers noted that, with the exception of therapy provided by the public school system, the availability and value of community resources did not appear to be recognized by respondents. They suggested that families may benefit from additional information and education regarding the importance of seeking community resources prior to utilizing private funds for services. Similarly, researchers noted that families did not take advantage of recreational programs and that psychological counseling was underutilized by participants. Again, researchers
suggested that additional education and information may be necessary in order to emphasize the importance of such services.

Researchers concluded that the support of a case manager appeared to be critical in assisting families to refer to the life care plan as a means of identifying necessary goods and services over time. They noted that few parents appeared to be able to effectively implement the life care plan and to apply the recommendations contained in it. They observed that the parents who were most successful in implementation took ownership of the task, had the necessary education to seek appropriate, quality services, and were strong advocates for their children.

Based upon the results of the study, the researchers reiterated their assertion that families need to be specifically educated regarding the utility a life care plan as a means of managing the long-term needs of children with various disabilities. They suggested that additional surveys conducted with multiple practitioners, over a more diverse geographic area, and with children having the same disability, may add to what is known regarding frequency of medical follow-up and services for specific populations. The researchers stated that the purpose of the study was to evaluate outcomes in pediatric clients for whom life care plans had been developed. It did not seek to quantify the accuracy of recommendations, per se, but sought to explore the progress, status, and actual service utilization patterns of clients within a single practitioner’s caseload. The researchers did not provide a thorough review
of specific recommendations contained in the original life care plans, but noted
generally where consistencies (e.g., the number of projected annual emergency
room visits) and discrepancies existed (e.g., the type of annual medical specialist
visits). In 2005, a follow-up study was conducted and data collected from three
specific plan areas described in this original study were statistically analyzed;
therapies, psychological counseling services, and attendant care (Kendall & Casuto,
2005).

*Pediatric Outcomes Quantified*

In 2005, Kendall and Casuto (2005) revisited the qualitative data that had
been previously collected from one of the researchers’ own caseload of 22 pediatric
life care plans that had been developed in plaintiff cases and published in the
*Journal of Life Care Planning*. The intent of the 2005 study was to quantify the
findings pertaining to therapies, counseling services, and attendant care reported in
the descriptive survey conducted by Casuto and Gumpel in 2003. Specifically, the
researchers sought to quantify the accuracy of the recommendations contained in
the original pediatric life care plans by determining the extent to which
recommended services were actually being received by study participants at the
time they were interviewed in 2003.

Researchers numerically coded the data gathered in the 2003 study and used
the same identification system to numerically code the recommendations contained
in each participant’s life care plan. For the purpose of analyses, researchers converted the number of therapies reportedly received by participants to annualized weekly sessions. When examining the data pertaining to counseling services, researchers found that too many specific types of were recommended and reported to obtain sufficient responses within any single category of to yield meaningful results. Therefore, counseling services were coded dichotomously as recommended or not recommended, and received or not received. They were analyzed within a 2 x 2 contingency table. When examining the data pertaining to attendant care services, the number of hours of care per day that were recommended and reportedly received were coded it as continuous numerical values. The data was further converted into standardized units of “dollar costs” based upon the technique utilized in a previous quantitative study conducted by Sutton, et al., (2002). This technique eliminated the impact of inflation and market fluctuations that confound comparisons of costs of services over time. By applying a standard cost per hour to both the recommended and the actual attendant care needs reported by participants, researchers were able to compare differences by using cost of services as a unit of measure. The researchers annualized the costs reflected in the original life plans and those reported by participants.

Researchers also expanded upon the demographic information presented in the 2003 study. The mean age of participants at the time that the 2003 survey was completed was 11.4 years with a standard deviation of 5.6 years; a normal
distribution was obtained. The mean interval between the time the plan was
developed and the 2003 study was 44.9 months with a range from 3.0 and 109.0
months. With a median of 41.0 months and standard deviation of 30.0, a normal
distribution was obtained. Fifteen males and 7 females participated in the 2003
survey. Of these, 5 were of Hispanic or Latino heritage, 12 were non-Hispanic or
non-Latino, and the ethnicity of 5 participants was unknown.

Physical therapy was recommended in 19 life care plans, and 19
participants reported that they were receiving it when the 2003 study was
conducted. The life care plans recommended an average of 1.72 ± 0.19 sessions
per week, and participants reported receiving 2.06 ± 0.21 sessions per week,
annualized. Paired t-test analyses revealed no statistical significance (p = 0.16)
between the recommended and the actual number of physical therapy sessions.
Occupational therapy had been recommended in 18 life care plans, and 8
participants reported that they were receiving it when the 2003 study was
conducted. The life care plans recommended an average of 2.00 ± 0.24 sessions
per week, and participants reported receiving 1.53 ± 0.31 sessions per week,
annualized. Paired t-test analyses revealed no statistical significance (p = 0.58)
between the recommended and the actual number of occupational therapy sessions.
Speech therapy was recommended in 16 life care plans, and 10 participants
reported that they were receiving it when the 2003 study was conducted. The life
care plans recommended an average of 2.08 ± 0.24 sessions per week, and
participants reported receiving $1.95 \pm 0.31$ sessions per week, annualized. Paired t-test analyses revealed no statistical significance ($p = 0.86$) between the recommended and the actual number of speech therapy sessions. Although there were no statistically significant differences between the projected and actual numbers of sessions of therapy per week, 56% of the participants failed to implement occupational therapy, and 37.5% failed to implement speech therapy as recommended.

Psychological counseling services were recommended in 20 life care plans, and 3 participants were receiving it when the 2003 study was conducted. In one case, an individual was receiving counseling services that were not projected in the life care plan. A McNemar test was applied to the data, resulting in a value of 11.27. As this was less than the critical value of 3.84 (at $p < 0.05$), researchers concluded that statistical significance was achieved and the null hypothesis of no difference was rejected. Attendant care was recommended in 15 life care plans, and 13 participants reported that they were receiving it when the 2003 study was conducted. The life care plans recommended a mean cost of weekly care at $1,309.00 \pm 211.60$ per week, and participants reported requiring $1,420.00 \pm 173.70$ per week, annualized. Paired t-test analyses revealed no statistical significance ($p = 0.87$) between the recommended and the actual number of attendant care hours.
Researchers concluded that the statistical analyses confirmed the observations stated by the researchers in the original 2003 study. They reiterated their assertion that psychological counseling services were underutilized by the participants. In discussing the limitations of the study, the researchers noted that the responses obtained during the 2003 survey have been influenced by a number of factors that were unexplored. For example, they noted that possible causes of underutilization of counseling services (e.g., services were unnecessarily prescribed by the life care planner, clients did not comply with recommendations due to the stigmatization of mental health counseling, etc.) could not be determined based solely upon the information collected in the 2003 study. Researchers suggested that future studies may need to be designed so that an individual’s needs, rather than the current level of services received, are reported.

*Technology and Life Care Planning*

Deutsch, Kendall, et al., (2005) examined seven categories of recommendations that were included in 50 life care plans developed for children with cerebral palsy. These categories included wheelchair needs, orthotics and prosthetics, home furnishings and accessories, aids for independent function, medications, supplies, and future aggressive medical treatment. The researchers stated that the purpose of the study was to explore the economic impact of technological advancements over time by comparing cost projections made in life care plans that were developed between 1986 and 1991 (referred to as Era I) and
those developed between 2002 and 2004 (referred to as Era II). For each of the
seven categories, researchers hypothesized that there would be no difference
between Era I and Era II costs.

Researchers explained that cases were randomly selected from a database
maintained by the Foundation for Life Care Planning Research. Inclusion criteria
specified plans that were originally developed for children diagnosed with cerebral
palsy between 1 and 8 years of age, and those developed during the timeframes of
interest (Era I or Era II). All Era I life care plans were contributed to the database
by a single practitioner. Era II life care plans were contributed by multiple
practitioners. The researchers note that all contributors were, “…known to adhere
to the published standards of practice in the field of life care planning” (Deutsch,
Kendall, et al., 2005, p. 164). Researchers explained that an initial search of the
database revealed that 46 plans matched the established inclusion criteria and were
developed during Era I, but only 23 met the criteria and were developed during Era
II. To arrive upon an equitable balance, 27 plans developed during Era I were
randomly selected and all 23 plans developed during Era II were included in the
study.

Researchers extracted and totaled the costs of all recommendations included
in the seven plan categories of interest. Only those items that were identified as
requiring purchase or replacement after the individual was 18 years of age were
included in the analysis. For the purposes of comparison, all costs, regardless of
the year that the plan was originally developed, were converted by an economist to 2004 dollars based upon Consumer Price Index rates.

The decision regarding whether to rely upon parametric versus non-parametric statistical analyses was complicated by the fact that prior data about population size and distribution did not exist. Therefore, all data sets were tested for normality using either the D’Agostino & Pearson omnibus normality test or the Kolmogorov Smirnov test in data sets consisting of five or fewer cases. Instances that revealed normality in both data sets (i.e., Era I and Era II data sets) were analyzed using unpaired student’s t-tests. Instances in which normality was not revealed in both data sets were analyzed using the Mann-Whitney U test for nonparametric unpaired data. All analyses were completed using a two-tailed p value and, unless otherwise noted, an alpha level of p < 0.05 was selected. No values were excluded as outliers.

Data sets within the category of wheelchair needs were not normally distributed and were analyzed using the Mann-Whitney U test. Results indicated that there was a significant difference between Era I costs (2,925 ± 102.9, n = 20) and Era II costs (4,908 ± 418.3, n = 19) at p < 0.001. Data sets within the category of orthotics and prosthetics were not normally distributed and were analyzed using the Mann-Whitney U test. Results indicated that there was no significant difference between Era I costs (1,591 ± 568.4, n = 10) and Era II costs (4,908 ± 418.3, n = 19). Data sets within the category of home furnishings and accessories
were normally distributed and were analyzed using the student’s unpaired t-test. Results indicated that there was a significant difference between Era I costs (3,119 ± 450.1, n = 24) and Era II costs (8,823 ± 2,032, n = 22) at p < 0.01. Data sets within the category of aids for independent function were not normally distributed and were analyzed using the Mann-Whitney U test. Results indicated that there was not a significant difference between Era I costs (7,406 ± 4,703, n = 11) and Era II costs (3,593 ± 637.7, n = 22). Researchers note that, although not statistically significant, a review of the plotted data reveals that a single, exceptionally high value existed in the Era I data set. Data sets within the category of medications were not normally distributed and were analyzed using the Mann-Whitney U test. Results indicated that there was a significant difference between Era I costs (1,074 ± 208.6, n = 17) and Era II costs (5,479 ± 1,244, n = 21) at p < 0.01. Data sets within the category of supplies were not normally distributed and were analyzed using the Mann-Whitney U test. Results indicated that there was a significant difference between Era I costs (2,964 ± 1,324, n = 17) and Era II costs (9,725 ± 2,750, n = 17). Lastly, data sets within the category of aggressive future medical care were normally distributed and were analyzed using the student’s unpaired t-test. Results indicated that there was not a significant difference between Era I costs (30,810 ± 12,590, n = 5) and Era II costs (49,870 ± 8,897, n = 19). Within this category, follow-up analyses were conducted with all 50 cases involved in the study, including those which contained zero values or recommendations for
aggressive future medical care. These data sets were not normally distributed and were analyzed using the Mann-Whitney U test. Results indicated that there was a significant difference between Era I costs ($5,705 \pm 3,166, n = 27$) and Era II costs ($41,193 \pm 8,351, n = 23$) at $p < 0.0001$.

In their discussion, the researchers summarized that an overall, statistically significant difference exists between Era I and Era II costs in most of the categories that were analyzed. Practically, this means that, even when adjusted for standard inflation and other market rate differences that occur over time, individuals may not have adequate funding to replace the equipment that was recommended in plans that were developed between 1986 and 1991. The researchers propose that this difference may be attributed to advancements in equipment materials (e.g., lightweight titanium manual wheelchair material) and in technologies that could not have been anticipated by practitioners developing plans during Era I.

Researchers acknowledge that this was a pilot study and included only individuals with cerebral palsy, but suggested that planners and economists may either have to consider using an adjusted growth rate when calculating long-term replacement values, or consider designating a type of technology fund to offset the costs of technologies that become available post plan development. Researchers noted that in only one case had replacement costs actually decreased over time. This reduction was found within the category of aids for independent function, but further details were not provided. The researchers concluded that this study serves
to raise questions regarding the adequacy of cost projections based upon traditional Consumer Price Index calculations. They stressed the importance of additional research in this area, with greater numbers, and with participants having other types of injuries.

*Medical Equipment Replacement Values*

Marini and Harper (2006) conducted a study involving 101 professionals who specialized in assistive technology and durable medical equipment. Inclusion criteria required that participants represented geographically diverse regions of the United States, and were identified as either being certified assistive technology practitioners by the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), or had acquired at least 2 years of work experience and were currently working as assistive technology suppliers. Researchers identified potential participants by searching telephone directories for certified RESNA practitioners working in medical supply companies within each of the 50 states. The goal of the researchers was to obtain participation by four practitioners from each state (for a total of 200 participants), but only 135 agreed to participate, and 101 actually completed a usable survey. Participants were offered $5 for their responses. In cases where questionnaires had not been returned within two weeks (17%), a second questionnaire was mailed.
Initially, the questionnaire was sent to assistive technology and durable medical equipment professionals with more than 10 years of experience for feedback and to establish content validity. Based upon this feedback, the researchers finalized a 16-item questionnaire to elicit participant responses regarding equipment replacement and component replacement rates for various assistive technology devices and durable medical equipment (e.g., wheeled walkers, power scooters, environmental control units, etc.). Questionnaire instructions directed respondents to assume typical daily use of the specified equipment. Items that the practitioner did not have experience with, or feel comfortable indicating a response, were to be left unanswered. Researchers analyzed responses using frequency counts. Median scores and ranges were calculated for each item identified on the questionnaire. Researchers explained that median scores, rather than mean scores, were selected because medians are less influenced by outliers and most effectively represent the central values indicated by respondents.

Researchers concluded that in over 90% of cases, inter-rater consistency among practitioners was “fairly consistent.” Researchers detailed the aggregate responses regarding replacement and maintenance timeframes, as well as estimated costs for each of the assistive technology and durable equipment items presented in the questionnaire. Researchers concluded that there were no clinically significant differences between recommendations made for those living in the northern or
southern states, though wheelchair tires in the southern states rated a slightly longer life expectancy than those in the northern states. No specific statistical data was provided by the researchers. The researchers further concluded that the results of the study were consistent with the replacement and maintenance recommendations currently included in life care plans, but the basis for this claim was not elaborated upon. The researchers proposed that data collected from assistive technology and durable medical equipment specialists can be used by life care planners as a point of comparison, but cautioned that consideration of individual characteristics (e.g., weight, usage patterns, type of disability, etc.) and local market costs must guide specific plan recommendations.

**Personal Attendant Care**

Pomeranz, et al., (2006) conducted a study for the purpose of identifying the specific activities that life care planners should consider when recommending personal attendant care for individuals with spinal cord injury. They recruited 25 life care planners who participated in all three phases of a Delphi study. Consensus among participants regarding 164 activities was obtained after three rounds. Researchers utilized a purposeful sampling approach to select 100 potential participants from a group of approximately 500 professionals who completed a life care planning national board certification program and had worked as life care planners for at least 3 years.
Following the methodology consistent with a Delphi study, participants completed a series of questionnaires. Questionnaires were developed using the Quask Form Artist software program and were made available to participants online. The first questionnaire contained open-ended prompts that were developed by the researchers based upon a review of the relevant literature and were alpha tested with four life care planners who were affiliated with the University of Florida.

During the first round, 198 activities were identified by participants as being relevant considerations when recommending personal attendant care. During the second round, these activities were listed, and participants were asked to indicate their degree of agreement with each item by rating it on a Likert scale (1 = strongly disagree, 2 = disagree, 3 = agree, and 4 = strongly agree). Mean and interquartile ranges were calculated. For 87% of the activities, respondents demonstrated a high level of agreement as 173 of the 198 items fell within an interquartile range of 1 or below. During the third round, participants were asked to reconsider the 198 items presented during the second round and, again, median and interquartile ranges were calculated. Researchers report that median scores for 15 of the items changed; 183 (92%) remained unchanged. There were 196 activities that scored within an interquartile range of 1 or less that demonstrated a high level of agreement (99%) among participants. These activities included various activities of daily living (e.g., dressing, grooming), housekeeping (e.g.,
dusting, ironing), home and yard maintenance (e.g., lawn mowing, emptying garbage), work and educational activities (e.g., dictation, note taking), leisure activities (e.g., camping, hunting), and transportation (e.g., running errands, going to the movies). Results of the third round also identified 34 activities (e.g., waxing furniture, pool maintenance) that received scores which led researchers to conclude that they should be excluded from consideration when determining personal attendant care.

Researchers noted that possible gender bias may have contributed to study findings since 87% of the participants were female and the home maintenance type of activities that were excluded may be more commonly performed by males. Another possible contributor to results may be that a majority of participants (77.4%) were nurses, who by training, may be more attuned to personal care needs. A third possible explanation may have been that planners did not ascribe the need for personal attendant care in order to accomplish the household and maintenance-oriented tasks identified within the questionnaire. Finally, researchers noted that participants may have placed some activities within another category of the life care plan (e.g., home maintenance), rather than view them as responsibilities that fell within the realm of personal attendant care.

The researchers identified the method of data analysis as one limitation of the study. They documented the use of the Delphi technique in the general research literature, but noted that participants may not have been familiar with this
methodology; despite the inclusion of a detailed instructional example. Researchers suggested that the activities identified by study participant as being important considerations may be developed into a checklist and used as a basis for discussing personal attendant care needs with clients throughout the planning process.

**Conclusion**

The value of the body of literature that has developed within the specialty of life care planning over the past decades cannot be understated. Rumrill and Fitzgerald (2001) note that narrative literature reviews and other forms of publication stimulate new theories and models, analyze controversial issues, introduce best practices, and elicit dialog among practitioners regarding issues of relevance to the field of study. Given this rich body of work upon which to build, and the multidimensionality of the specialty, researchers are able to pursue innumerable avenues of inquiry of substantial interest to life care planners.

Researchers and practitioners within the specialty of life care planning have called for an increased emphasis on empirical research in order to validate the methodologies utilized in developing plans to account for medical, rehabilitation, and personal care needs throughout life expectancy (Deutsch, McCollom, et al., 2003; Deutsch, Allison, & Reid, 2003; Deutsch & Reid, 2003; Kendall & Deutsch, 2002; Knouse, 2003; Marini & Harper, 2006; May, 2002c; Weed, 2004a, 2004b).
Not only is such research essential in validating the case management applications of the specialty, but it is particularly critical given the stringent guidelines regarding admissibility of expert testimony in litigated cases under the Daubert ruling. Summative statements regarding what is known and unknown about the validity of life care planning methodology cannot yet be made due to the paucity of existing research (Neulicht, et al., 2002). However, the studies that have been conducted provide a basis for further exploration and represent important initial steps toward the development of a rich body of research literature. The Foundation for Life Care Planning Research was established in 2002 for the purpose of supporting graduate students, practitioners, and others who are interested in conducting research within the specialty (Deutsch, 2003; Weed, 2004b). This organization is working to raise funds to support grant fellowships and to build a case database to be used in future research endeavors.

The Present Study

A review of existing empirical research within the specialty of life care planning provides a foundation for the present study’s purpose, research design, and importance. Because of the cumulative cost involved, research regarding personal assistance and routine medical care is of particular importance in assuring that adequate funding is allocated for a client’s future needs (Brown & Smith, 2004; Dahlberg, 2002; Gamboa & Hanak, 1991; Kitchen, 2002; Pomeranz et al., 2006). Existing studies reveal that life care planners identify the assessment of
medical and independent living service needs as one of the three primary job functions of practitioners (Turner et al., 2000). Elements from existing studies have been incorporated into the design as a means of building upon current knowledge and developing a research methodology that could be duplicated by practitioners in the future. Of specific relevance to the present study is the research conducted by Casuto and Gumpel (2003), McCollom and Crane (2001), Pomeranz, et al., (2006), and Sutton et al., (2002). These studies helped to shape the research methodology and questionnaire instrument utilized in the present study.

Spinal cord injury was selected as the target population within the present study because life care planners have identified it, along with acquired brain injury, as being one of the two conditions predominately represented within their practices (Turner, et al., 2000). Also, because of the relationship between level of injury and resulting functional limitations, outcomes experienced by clients with spinal cord injuries typically follow a more predictable course than other catastrophic injuries. Research data, clinical practice guidelines, and other resources regarding long-term outcomes have been established in the medical and rehabilitation literature, and are referenced by life care planners when developing recommendations. Finally, issues regarding personal assistance and routine medical care projections are of interest within the specialty, and are of relevance when life care planning for clients with spinal cord injuries.
A sample drawn from a single source is typically a less-preferred method of data collection than selecting potential participants from a database of cases contributed by many practitioners. In this study, however, the sample is being drawn from the recognized originator of this specialty area of practice. This practitioner developed the tenets and methodologies of life care planning, first published in this area of practice, led the first training seminars for health care professionals seeking national board certification, and has published research in this area. The researchers involved in the present study recognize the limitations in generalizing findings to plans developed by other practitioners, to other clients, and perhaps in other practice settings. However, establishing research foundations within the specialty is a critical component in providing quality services to clients and to promoting the growth of research in this area. Researchers believe that the findings of the present study will contribute to the development of increasingly refined practice methodologies and outcome measures. The accuracy of plan recommendations depends upon the expertise, knowledge, experience, and methodology applied to the case analysis and planning processes. By utilizing life care plans that were developed by a recognized authority within the specialty, inaccurate projections due to such factors as professional incompetence or lack of adherence to published methodologies are substantially reduced.

Schnelker and Rumrill (2001) note that objectives-oriented rehabilitation program evaluation models that assess outcomes by identifying discrepancies
between actual performance and program objectives may oversimplify relationships and fail to explore reasons for discrepancies. Researchers in the present study have attempted to address this problem by utilizing a qualitative, case study approach involving semi-structured telephone interviews with participants. This allowed participants to voice their perceptions, experiences, and feelings relative to the questions of interest within the study. Insights and information shared by participants may be useful in hypothesizing explanations for inconsistencies between reported and projected needs, and in advancing the body of knowledge regarding the lived experiences of individuals with spinal cord injuries for whom life care plans were developed. Quantifying outcomes is a complicated proposition and requires multiple research efforts to establish data trends (Delaronde, 2002). Ultimately, the goal of evaluating the effectiveness of practices and methodologies in rehabilitation is to improve quality of life and to promote independence for individuals with disabilities (Schnelker & Rumrill, 2001; Weed & Field, 2001). To that end, the present study seeks to advance the body of research literature in life care planning by describing the outcomes experienced by clients and by evaluating the consistency of these outcomes against those projected in each individualized life care plan.
CHAPTER 3
METHODOLOGY

The purpose of this study was to describe the outcomes experienced by
individuals with spinal cord injuries for whom life care plans were developed. In
addition, researchers were interested in assessing how accurately each participant’s
individualized life care plan projected his or her current need for personal
assistance and consultation with general and specialty physicians. Specifically, the
research questions of interest were: (a) What are the routine medical follow-up and
personal assistance needs of individuals with spinal cord injuries post plan
development, and (b) How well did each participant’s life care plan anticipate his
or her current needs? The goal of this study was to add knowledge of value and
relevance to the existing body of research literature, and to provide insights to
assist life care planners in developing recommendations that are of maximum long-
term benefit to clients.
The present study utilized an exploratory case study approach involving semi-structured, in-depth interviews with a purposive sample of individuals for whom life care plans were developed. Through the lived experiences and current needs reported by participants, the accuracy of projections made within each individual’s life care plan was considered. Where inconsistencies between reported and projected needs existed, researchers were interested in formulating possible explanations and suggesting directions for future study. Understanding the current needs and outcomes experienced by participants is important to the specialty because such insight has implications for the life care planning process and the methodology applied in formulating recommendations.

As evidenced by the literature review, there has not yet been a standardized outcome assessment instrument developed within the specialty of life care planning to evaluate the long-term accuracy of plan projections. The present study adds to the body of literature by describing the experiences of participants in relation to the anticipated outcomes reflected in their individualized life care plans. Where variations from the plans exist, researchers sought to identify factors that may have influenced the type and frequency of services that were reportedly currently necessary. Personal assistance and follow-up physician visit recommendations were selected as focal areas of this study because they typically represent the most expensive components of an individual’s life care plan. Consequently, more
information about the needs and experiences of clients within these specific areas may assist practitioners in developing plans that are adequate and realistic.

Qualitative Design

The purpose of this study is well-suited for a purely qualitative research approach and, specifically, to a case study strategy. Qualitative methodologies are particularly useful when researchers are conducting initial explorations, developing theories, or generating hypotheses (Devers, 1999; Patton, 1999; Pope & Mays, 1995; Sofaer, 1999), moving toward explanations (Sofaer, 1999), enhancing the understanding of the context of events (Sofaer, 1999, 2002); understanding cases in detail (Patton, 1999), examining meaning in context (Patton, 1999), identifying the most effective means of implementing evidence-based findings into practice (Shortell, 1999), capturing changes in a dynamic environment (Patton, 1999), and when topics of interest are highly context and case dependent (Patton, 1999). As Patton (1999) notes, this approach is distinguished from quantitative research which is useful in generalizing from a sample to a population, when testing hypotheses, and when making systematic comparisons of standardized criteria. Data obtained from the present study enhances the specialty’s understanding of the experiences of participants over time, and how these outcomes relate to those anticipated within each individualized life care plan. Further, the data may inform future quantitative studies by identifying themes that are of importance to the participants, providing possible explanations for cases that yielded unexpected
findings, and generating future research questions (Rundall, Devers, & Sofaer, 1999).

In the present study, the range of possible outcomes was not fully known. A qualitative approach allowed complex questions to be explored and described so that researchers could consider multiple factors that may have impacted the accuracy of recommendations within each participant’s life care plan (Sofaer, 1999). Likewise, a case study approach was a valuable methodology to employ because broad questions were being addressed within the complex circumstances surrounding each participant’s post plan development experience (Keen & Packwood, 1995). This approach, in combination with the use of a semi-structured questionnaire, allowed researchers to ask follow-up questions, to seek clarification, and to ask participants to elaborate upon responses throughout the interview. Participants may have shared a greater depth of information with researchers than would have been gathered had other data collection methods been employed.

In describing the experiences of participants and considering the accuracy of plan recommendations, researchers recognized that a number of complicating or intervening factors may have influenced reported outcomes; many of which were beyond the ability of the planner to foresee at the time the plan was developed. For example, researchers anticipated that the current needs reported by participants may be dependent upon whether adequate funding awarded through the legal process, whether funds were appropriately managed, whether participants and caregivers
adhered to the preventative health measures included in the plan, whether recommendations from treating physicians and consulting professionals were adequate and appropriate, whether secondary injuries were sustained after the plan was developed, whether beneficial new technologies or medications had been developed, and a myriad of other issues that may have shaped each participant’s current circumstances over the years since the plans were developed.

Semi-structured interviews were appropriately utilized in the present study because researchers were interested in exploring two particular aspects of each participant’s life care plan, current personal assistance and physician consultation needs, and understood that responses would likely yield complex interrelationships among multiple contributing circumstances. Semi-structured interviews allowed participants to thoroughly describe their experiences relative to a specific series of questions posed by researchers (Keen & Packwood, 1995; Morse & Field, 1995; Nagy Hesse-Biber & Leavy, 2006). Further, the flexibility of open-ended and spontaneous follow-up questions encouraged participants to expand upon responses within the context of a more natural, conversational interview than may have been possible utilizing a purely quantitative design (Legard, Keegan, & Ward, 2003).

A qualitative approach allowed researchers to describe the extent of agreement between reported and projected needs and, where possible, to suggest possible explanations for inconsistencies. Discrepancies between projected and
reported needs are of utmost importance to practitioners who are interested in validating the methodology applied to life care plan development. By exploring the real-world outcomes reported by individuals for whom life care plans were developed, recommendation considerations may be refined to more accurately reflect the lived experience of clients. Flyvbjerg (2006) emphasizes the importance and value of this type of knowledge when researchers seek to understand a population or area of study that has not been extensively explored.

A fundamental assumption in life care planning is that specific plan recommendations cannot be generalized to all members of a group of individuals with the same injury, diagnosis, or medical condition. If this were possible, the need for life care planners, consultation with members of the treatment team, and detailed case analyses would be eliminated and, based upon select client characteristics (e.g., level of injury, age), a standard plan of care could be identified for use as the basis for economic valuation of the case. As described in the previous chapters, life care planning methodology is based upon a holistic, case study approach throughout each phase of the plan development process. Clients and family members are actively involved in this process and are asked to contribute information that will assist planners in identifying relevant support services, future medical care and rehabilitation needs, equipment and supplies, and other items. The methodology utilized in the present study closely resembles that which is applied to the case analysis process in life care planning. The importance
of the client’s experience, perspective, long-term goals, and personal preferences is
recognized in both life care planning methodology and in life care planning
research.

Participants

Selection Procedure

The potential participant pool was drawn from a comprehensive database of
client records retained by a single life care planner dating from the early 1980s.
Only litigated cases in which the practitioner was retained by plaintiff counsel were
utilized for this study due to legal protocols that restrict contact with injured parties
when retained by defense counsel. The database was queried for all spinal cord
injury cases in which a life care plan was developed 5 or more years prior the
commencement of the study (in the year 2001 or earlier); 271 cases were retrieved.
The researchers chose a minimum of 5 years post plan development for inclusion in
this study because this timeframe may provide for a more rigorous assessment of
the accuracy of plans than would a relatively shorter post plan development period.
This timeframe captured some of the phase changes that are accounted for in the
life care plans as the natural aging process impacts functional limitations and
general health.

From this group of 271 cases, 134 individuals who were at least 18 years of
age (in the year 2006) and who sustained no simultaneous secondary trauma (e.g.,
brain injury) at the time of injury were selected. Individuals with whom contact would not be possible were eliminated; 3 were living outside of the United States at the time of the evaluation, 26 had no current mailing address, and 8 were known to be deceased. Consequently, 97 individuals comprise the potential participant pool.

An introductory letter was sent as a means of establishing contact with the 97 potential participants. Of these, 38 were returned as undeliverable. A recruitment packet was sent to the remaining 59 potential participants and 12 of these were returned as undeliverable. Five volunteers returned the necessary consent paperwork for participation. Follow-up letters were sent to 47 non-respondents and two additional volunteers returned the necessary consent paperwork for participation.

**Demographic Information**

Demographic information reflective of the potential participant pool is presented in Appendix B. Demographics were comparable in terms of quadriplegic (47%) and paraplegic (53%) levels of injury, though males (70%) were more predominantly represented than females (30%). Caucasians (84%) represented the majority of the potential participant pool. The life care plans dated from 1987 through 2001. Therefore, the length of time since plans were developed ranged from 6 years to 20 years prior to the commencement of the present study. Dates of injury ranged from 1977 through 1999. Therefore, the length of time since onset of
injury ranged from 8 years to 30 years prior to the commencement of the present study. The age at onset of injury ranged from less than 1 year to 76 years of age. At the commencement of the study in 2007, the current age of potential participants ranged from 23 years to 89 years. Nine of the potential participants were 70 years of age or older. Southern states, including Alabama, Arkansas, Florida, and Georgia, were heavily represented (71%) within this sample pool. The majority (63%) of potential participants were residing in Florida at the time their life care plans were developed.

**Instrumentation**

Initially, researchers considered mailing a questionnaire to participants, but informal feedback received from a small group of individuals with spinal cord injuries (n=4) indicated that detailed written responses would be more time consuming to complete, may be physically challenging for some individuals, may yield incomplete responses, and may result in inaccurate interpretations of the information provided. It was determined that a telephone interview would allow for probing, explanation, and clarification of questions and responses. The nature of the questions required participants to reflect upon past service utilization and current needs. The flexibility afforded through telephone interviews allowed researchers to elicit descriptive responses that enhanced the accuracy of reported needs and, consequently, led to a more complete understanding of clients’ post plan development experiences. This approach is also consistent with prior life care
planning research that utilized telephone interviews as a means of data collection (Casuto & Gumpel, 2003; McCollom, & Crane, 2001). As a means of establishing the content validity of the questionnaire, researchers also sought feedback from a recognized leader, researcher, and educator within the specialty of life care planning. The primary questions were found to adequately reflect the study’s research objectives.

All participants were asked to respond to the primary questions, but probes posed by the researchers varied depending upon the information shared by participants. Follow-up questions allowed them an opportunity to elaborate, to provide examples, and to clarify meaning. The questionnaire encompassed four broad areas of relevance to the study; demographic information, general health and related factors (including lifestyle, coordination of care, and subsequent injury or illness), personal assistance, and physician consultation (general and specialty) (refer to Appendix C to review the questionnaire). Researchers used a telephone script (Appendix D) as a guide and recorded all responses offered throughout each interview.

Nature of the Injury

The first two items on the questionnaire asked participants to specify the nature of the spinal cord injury by reporting the level of injury (e.g., T6, C7), whether the injury was complete or incomplete, and the cause of the injury (e.g., motor vehicle accident, sports-related injury). Such information assisted
researchers in establishing relationships between the nature of the injury, general health status, personal assistance needs, physician visits, and subsequent injuries and illnesses. The nature of the injury is an important prognostic characteristic, particularly as described within the outcomes-based research literature relative to functional independence and routine medical care.

*Residence*

Questions 3 and 4 asked participants to report their current living situation (e.g., home, apartment, condominium, rehabilitation facility, skilled nursing care facility, or other), and whether they are living with others (e.g., family, friend, roommate, attendant or home health aide, registered nurse, or other). Probes included questions regarding accessibility and home modifications, marital status, number of children in the family, and others as appropriate. This information was helpful to researchers in considering the availability of needed support services and possible relevance to personal assistance and medical care.

*Health Status*

Questions 5, 6, and 7 asked participants to reflect upon their general health status, personal assistance needs, and physician visits over the past five years. Regarding general health status, participants were asked to specify whether it has improved, declined, or remained about the same. Regarding personal assistance needs, participants were asked to indicate whether they have required more, less, or
about the same number of hours of personal assistance from others each week. Regarding physician visits, respondents were asked to state whether they have required more, fewer, or about the same number of visits per year. Respondents who indicated that there has been a change in status were asked to explain the probable causes. Researchers used this information in considering relationships between participants’ perceptions of their general health status, the number of hours of personal assistance received each week, and the number of physician visits required each year.

*Lifestyle*

Questions 8, 9, and 10 addressed three lifestyle characteristics that may have an adverse impact upon post spinal cord injury rehabilitation; alcohol, cigarette, and recreational drug consumption. Participants were asked to specify, on average, the number of alcoholic beverages they consume and the number of cigarettes they smoke on a daily basis. They were also asked to specify, whether or not they consume any recreational, non-prescription drugs. Probes included questions regarding other lifestyle choices that impact general health positively or negatively. In addition to providing insights regarding the accuracy of life care plan recommendations, lifestyle characteristics were considered in relation to participants’ current health status, visits to the emergency room, hospitalizations, subsequent illnesses or injuries, and other items reflected in the questionnaire.
Question 11 asked participants to discuss the activities within their typical routines that require assistance from other individuals. The researchers clearly stated that, initially, only the activities for which the participant is actually receiving assistance should be identified. This question yielded three data points; a list of the specific activities that require assistance, the amount of time necessary to thoroughly and safely complete the activity, and the provider of this assistance. The specific activities requiring personal assistance are not identified in the life care plan, but this specificity was necessary in order to prompt participants to reflect upon and accurately report their needs. Although the question, “How many hours of personal assistance do you require each week?” may appear to be straightforward, it is actually very complex. Accurate responses required participants to recall the specific activities that they are unable to complete independently and to report how long it takes to complete each task with assistance.

Personal assistance was defined as any form of help needed to complete a specified activity. This ranged from minimal stand-by assistance to total assistance in activities of daily living such as bathing, grooming, dressing, eating, and other tasks. In addition, assistance needed in transportation, community outings, worksites, and other settings were explored with each participant. In order to make the analysis of this data more informative, researchers prompted participants to consider the personal care required within each the following categories: Grooming
and bathing tasks, household activities, community outings, and other activities. Grooming and bathing tasks included activities such as dressing, hair styling, trimming nails and facial hair, and personal hygiene. Household tasks included activities such as cleaning, doing laundry, cooking, paying bills, and sorting mail. Community outings included activities such as provision of transportation to and from shopping areas, social activities, and other events outside of the home. Other tasks, such as taking medications or making appointments, comprised the fourth category.

Question 12 asked participants to report whether they are receiving the amount of personal assistance that they truly need. If a participant responded affirmatively, the researchers continued to question 14. For those stating they were not receiving the amount of weekly personal assistance that is necessary, the researchers continued to question 13 that asked participants to describe the activities requiring additional assistance and to estimate the additional amount of time necessary to complete the task. For each task, participants were asked to discuss why this additional assistance is necessary and why it is not currently received. Activities were explored within the four primary task areas established in question 11 (i.e., grooming and bathing tasks, household activities, community outings, and other activities).

Probes included a number of questions regarding service utilization and access, transportation needs, vocational status, social activities and community
participation, acquisition of information about services and tools that may enhance independence, and others as appropriate. Discussion regarding personal assistance was an essential element of this questionnaire and in understanding the experiences of participants. Although adequate funding, availability of healthcare professionals, and other factors may prevent individuals from accessing needed assistance, the necessity for such care may exist. Therefore, the perspective of the participant and possible barriers to needed assistance must be taken into account when considering responses in relation to the recommendations made in the life care plan.

Case Management and Medical Evaluations

Questions 14, 15, and 16 explored each participant’s history with services providing preventative interventions, education, and coordination of care. Specifically, participants were asked to discuss whether they have completed annual comprehensive spinal cord injury evaluations, whether they require assistance in scheduling appointments, whether they receive case management support, and whether they refer to their individualized life care plan as a guide to care. Responses to these questions were of value when considering relationships between each participant’s general health, personal assistance needs, physician visits, and post plan development injuries or illnesses. Probes included questions regarding the services found to be most useful, least useful, necessary in the past, anticipated in the future, and others as appropriate. Information regarding
participants’ actual service utilization is of particular interest to practitioners
because plan recommendations are based upon the assumption that preventative,
proactive measures will substantially reduce complications.

**Physician Visits**

To consider the accuracy of projected physician visits, question 17 asked
participants to discuss their history of physician visits within the prior 12-month
period and to indicate the reason for these visits. Although only routine and injury-
related visits are specified each participant’s life care plan, unforeseen
complications and other instances requiring medical care may impact a client’s
general health status and the need for personal assistance. To facilitate the data
analysis process, responses were identified as routine (e.g., annual checkup),
unrelated to the spinal cord injury (e.g., bee sting), related to the spinal cord injury
(e.g., urinary tract infection), or undetermined (e.g., recent frequent migraine
headaches). Probes included questions regarding accessibility of medical services,
coordination of care, quality of care, past and current methods of acquiring medical
information, and others as appropriate. Responses to these questions allowed
researchers to explore the accuracy of the recommendations included in each
participant’s life care plan and to consider why discrepancies may exist between
what was projected and what is currently necessary.
Subsequent Injury or Illness

Questions 18, 19, and 20 were critical in determining whether individuals have sustained a subsequent injury (e.g., orthopedic injury) or developed a condition over time (e.g., diabetes) that may significantly impact reported needs, and consequently, the accuracy of the life care plan projections. Question 18 asked participants to describe any illnesses or injuries within the prior 12-month period that resulted in the need to seek medical care through a hospital emergency room or urgent care facility. In cases where such visits were necessary, participants were asked to indicate the diagnosis or to explain the reason for the visit. Participants were asked whether the incident resulted in hospitalization and to report their length of stay. Question 19 asked participants to discuss any direct hospital admissions that may have occurred within the prior 12-month period, the diagnosis or reason for hospitalization, to indicate the source of the referral (e.g., primary care physician, specialist), and to report their length of stay. Information regarding recent injuries and illnesses may influence participants’ perception of their general health, current personal assistance needs, and frequency of specialty physician visits.

Question 20 asked participants to reflect upon their medical history since the development of the life care plan and to discuss any notable injuries or illnesses that have occurred. Researchers prompted participants to specify the diagnoses, approximate year of each incident, length of time that additional care was needed,
and, if it is currently ongoing, the anticipated length of time that additional care will continue. Subsequent injuries or illnesses that occurred post plan development may substantially impact the accuracy of the recommendations reflected in the life care plan as well as the current general health, personal assistance needs, and physician visits reported by participants.

Depending upon comorbid factors, research indicates that common complications for individuals with spinal cord injuries include, but are not limited to, the following: decubitus ulcer, skin breakdown, urinary tract infection, cardiovascular difficulties, pulmonary complications, joint deterioration, autonomic dysreflexia, heterotopic ossification, spasticity, osteoporosis, contractures, chronic pain, deep vein thrombosis, and fractures (Blackwell, et al., 2001). Although complications may significantly affect an individual’s long-term course of treatment and rehabilitation outcomes, such instances cannot be reasonably projected within the life care plan. Information regarding the post plan development experiences of participants may contribute to the existing body of knowledge regarding complications and outcomes over time. To facilitate the data analysis process, responses regarding diagnoses may be classified as unrelated to the spinal cord injury, related to the spinal cord injury, or undetermined. Lastly, participants were asked to identify any new technologies, equipment, medications, or items that they are currently using but were unavailable at the time their plan was developed. Responses provided researchers with insight regarding items that
participants found were of benefit to them. Participants were then asked to share their final thoughts, elaborate upon any issues that were previously discussed, or to raise issues that may be of relevance in evaluating the accuracy of plan recommendations. The final thoughts shared by participants reinforced the themes that emerged from each interview and allowed them to conclude the session by discussing the issues that they felt were most important for the researchers to understand.

**Procedure**

Due to the response rate, researchers revised the design of this study from a mixed-methodology to a purely qualitative approach to allow for more in-depth, meaningful interviews with volunteers. All study participants received an introductory letter, recruitment packet, and a follow-up letter that described the modified data collection procedure. Participants were asked to re-consent after reviewing the modified procedure.

*Introductory Letter*

Potential participants were sent an introductory letter that explained the purpose of the study and noted that a more comprehensive recruitment packet would follow (Appendix E). The letter was printed on departmental letterhead, and included contact information for the researchers. Potential participants were invited to contact the co-investigator with questions or to discuss concerns. As
noted earlier, a substantial number of introductory letters were returned as undeliverable and those cases were removed from the database.

*Recruitment Packet*

Three weeks after the introductory letter was sent, potential participants were sent a recruitment packet that included the following materials: A cover letter (Appendix F), a consent form required by the university entitled “Authorization to Use Personal Health Information in Research” (Appendix G), a consent form required by the university entitled “Consent for Participation in Social and Behavioral Research” (Appendix H), a telephone call preference form (Appendix I), and a list of the primary questions contained on the questionnaire (Appendix J). Individuals wishing to participate in the study were asked to complete the telephone call preference form (Appendix I) and to sign the consent forms (Appendices G and H) as is consistent with the guidelines for research involving human subjects as dictated by the Institutional Review Board of The Ohio State University.

Because the consent forms required signatures and needed to be returned to researchers, extra copies were included so that participants could retain them for future reference. The cover letter and the consent forms were printed on OSU departmental letterhead and a stamped return envelope addressed to the co-investigator was included. Mailing materials included 8 1/2” x 11” catalog style
mailing envelopes, address labels, and business-sized addressed and stamped return envelopes.

Follow-up Letter

Four weeks after the recruitment packets were sent, a final letter was sent to non-respondents (Appendix K). This letter reiterated the importance of study, the value of their contribution, and welcomed recipients to contact the co-investigator with any questions or concerns.

Revised Consent Letter

Researchers sent a letter to all consenting participants that explained the reason for the shift in methodology, and noted that the time necessary to complete the telephone interview had increased from 20-25 minutes to approximately 90 minutes (Appendix L). In recognition of the additional time commitment, participants were informed that they would each receive a stipend of $50.00 upon completion of the interview. They were asked to either sign the re-consent forms or to decline participation and return them to the co-investigator using the enclosed addressed, stamped envelope. Participants were invited to contact the co-investigator with any questions or concerns.

Telephone Interview

Following the telephone script as a guideline, researchers conducted the telephone interview while simultaneously documenting responses on an electronic
copy of the questionnaire that was created as a Microsoft Word form. Researchers used a hands-free receiver and microphone so that responses could be typed directly into the form fields as information is discussed. The length of the interviews ranged from 75 minutes to 110 minutes and all were completed in a single session. Immediately following each interview, participants were sent a copy of the response form that was completed by the researcher throughout the session. A cover letter (Appendix M) instructed participants to carefully review the document for accuracy and to make corrections as necessary. Participants were also welcomed to add more detail, clarify remarks, further elaborate upon items, or to otherwise comment. Participants were advised that they could return the revised document to the co-investigator in the addressed, stamped envelope enclosed with the letter, could send an e-mail message to the co-investigator, or could telephone the co-investigator to discuss necessary edits.

Data Analysis

As noted previously, the purpose of this study was to describe the outcomes experienced by participants, and to assess the accuracy with which their individualized life care plans had projected their current needs regarding personal assistance and consultation with general and specialty physicians. In cases where inconsistencies between projected and reported needs existed, researchers were interested in proposing possible explanations and suggesting directions for future study.
In case study research, analysis typically builds upon a descriptive narrative and is directed toward examination of the overall patterns that exist within individual cases, interrelationships among concepts, and broad categories that emerge relative to the topic being explored (Kohn, 1997; Stake, 1995, 2006; Yin, 2003). Eisenhardt (2002) notes that, although there is no standard format for analyzing case study data, researchers may begin by summarizing the information obtained from participants into a case narrative and, where beneficial, presenting information in summative tables. Through detailed descriptions, researchers become thoroughly conversant with the details and unique patterns that emerge from each case (Eisenhardt, 2002; Stake, 1995, 2006; Yin, 2003). Stake (1995) describes the process of qualitative analysis as one that is focused upon an instance, or case study, and requires the researcher to pull it apart, then to reconstruct it for meaning. Similarly, Nagy Hesse-Biber and Leavy (2006) emphasize the importance of initially establishing a thorough description of the data, then continually reflecting upon it as themes emerge, disconfirming information is considered, and conclusions are drawn. Such attention to the narrative description help to ensure that interpretations are rooted within the data, rather than inadvertently imposed by researchers (Spencer, Richie, & O’Connor, 2003).

Analytical Approach

The analytical process employed in the present study incorporates the aforementioned strategies and is based upon Yin’s (2003) approach to case study
analysis. Yin (2003) suggests that researchers select a general analytic strategy as well as a specific mode of analysis that reflects the purpose of the study and the data set. In general, the purpose, research design, procedure, questionnaire, and other elements of the present study were based upon the theoretical proposition that the methodology applied to life care plan development produces accurate recommendations regarding personal assistance and physician consultations. Yin (2003) notes that such theoretical propositions allow researchers to narrow the focus of analysis, to identify alternate explanations, and to describe existing relationships within the case study.

The specific mode of analysis applied in the present study involves, what Yin (2003) refers to as, pattern matching. This can be accomplished by considering the information provided by each participant and comparing their reported needs to those projected in their individualized life care plan. Through the pattern matching process, both consistencies and inconsistencies between reported and projected needs that can be identified and, ultimately, used to evaluate the theoretical proposition as it applies to each specific case. This approach allowed researchers to describe the outcomes experienced by participants, to evaluate the accuracy of recommendations within each life care plan, to identify confounding factors that may impact the accuracy of plan projections, and to consider themes that emerged within each case. An analysis guide was used in pattern matching and identification of emerging themes (Appendix N). These patterns and themes, when
considered in relation to the recommendations contained in the participant’s life care plan, enabled researchers to examine the accuracy of projected needs and to suggest areas for further exploration. Conclusions and interpretation of findings are presented in Chapter 5.

*Minimizing Threats*

Whereas threats to internal and external validity, reliability, and generalizability are typically controlled in quantitative studies through the application of specific research design elements, randomization, and statistical analyses, qualitative researchers attempt to minimize threats to the trustworthiness of their findings by addressing issues of credibility, transferability, dependability, and researcher bias (Hanley-Maxwell, Al Hano, & Skivington, 2007; Ohman, 2005). Credibility in qualitative research is comparable to the concept of internal validity in quantitative research and refers to the accuracy with which researchers represent the perspectives of participants (Devers, 1999; Hanley-Maxwell, et al., 2007; Nagy Hesse-Biber & Leavy, 2006; Ohman, 2005). Credibility can be addressed in a number of ways (e.g., through triangulation of data sources and methods, prolonged engagement), but was most appropriately achieved in the present study through member checking and peer debriefing.

Member checking enhanced the credibility of the data collection process because it allowed participants to verify that researchers had correctly recorded the information provided and gives them an opportunity to clarify meaning (Creswell,
1994; Ohman, 2005; Patton, 1999; Stake, 2006). As noted in the Procedure section, participants were sent a copy of the response forms that were completed by the researcher throughout each telephone interview. They were asked to carefully review the document for accuracy, to make corrections as necessary, and to elaborate further upon any issues they wished. Peer debriefing involves sharing the results of a study with colleagues and seeking feedback regarding the reasonableness of conclusions (Ohman, 2005; Patton, 1999). In the present study, collaboration between the principle investigator, the dissertation committee, and the co-investigator allowed for close scrutiny of the relationship between participant responses, emergent themes, and the conclusions drawn. Further, each interview was thoroughly summarized and recommendations contained in each life care plan were included within the appendices so that readers may also consider the credibility of the conclusions drawn by the researchers. Member checking and peer debriefing substantially minimized threats to credibility within the present study because researchers fully disclosed the primary source information that provided the foundation for conclusions.

Transferability, also referred to as applicability, of findings within qualitative research is comparable to the concept of external validity in quantitative research (Ohman, 2005). Typically, the goal of qualitative research is not generalizability of results to a population, but applicability of findings to similar cases, settings, or situations (Devers, 1999; Hanley-Maxwell, et al., 2007).
Applicability of findings can be enhanced when researchers provide thorough, detailed descriptions that facilitate a comprehensive understanding of study participants, their lived experiences, and their unique perspectives (Devers, 1999; Hanley-Maxwell, et al., 2007). This depth of description of each participant and their reported outcomes is reflected in Chapter 4 of the present study. Such detailed summaries allow readers to consider similarities, differences, and the unique post-injury experiences of a small, but diverse, group of individuals.

In the present study, transferability of findings is limited by involving only participants with spinal cord injuries, collecting data from just 7 participants, and working from the case file of a single practitioner. However, the specialty is seeking to establish a foundation of research literature that is based upon actual client outcomes, and the experiences of those who participated in the present study provide insights of value to future researchers who may explore similar cases. The goal of research in life care planning is not to develop a set of standard recommendations that are applicable to all individuals with specific types of spinal cord injuries, but it is to understand the real-world outcomes experienced by those who have participated in the life care planning process. The highly individualized nature of the planning process is reflected in the detailed narrative provided by researchers in describing each case included in the present study.

Dependability is similar to the concept of consistency and reliability in quantitative research, and relates to the extent to which similar findings may be
obtained if study procedures were replicated as described and if factors that may have influenced the results are taken into consideration (Devers, 1999). Researcher bias is a threat to trustworthiness and addresses the researcher’s ability to remain neutral when considering data so that findings are based upon the experiences reported by participants, rather than biases or preconceptions imposed by the researcher (Devers, 1999). Threats to dependability and researcher bias may be minimized through the development of an audit trail. Audit trails are recommended as a means of describing how specific themes and concepts contributed to the interpretation of the data and, ultimately, upon the conclusions drawn (Devers, 1999; Hanley-Maxell, et al., 2007). In the present study, an audit trail minimized threats to dependability and researcher bias because it was created and made available to the reader through the extensive descriptions included in the Methodology, Results and Discussion sections of this dissertation project. Such transparency allows the reader to consider the credibility, transferability, dependability and bias of the researchers by reviewing the audit trail and to authenticate the conclusions drawn.

Conclusion

Although the number of responses to the initial request for participants was far fewer than expected, researchers were able to continue investigating the primary topic of interest by shifting from a mixed-methodology approach to a qualitative approach. The purpose of this study was to describe the outcomes experienced by
individuals with spinal cord injuries for whom life care plans were developed. In addition, researchers were interested in assessing how accurately each participant’s individualized life care plan projected his or her current need for personal assistance and consultation with general and specialty physicians. The goal was to add knowledge of value and relevance to the existing body of research literature, and to provide insights to assist life care planners in developing recommendations that are of maximum long-term benefit to clients.

A qualitative approach allowed researchers to describe the extent of agreement between reported needs and projected needs and, where they existed, to suggest possible explanations for inconsistencies. Discrepancies between projected and reported needs are of utmost importance to practitioners as the specialty seeks to empirically validate the methodology applied to life care plan development. This study was designed in reference to the existing research literature within the specialty. The data obtained may enhance future studies by providing insights regarding relevant themes, possible explanations for cases that yielded unexpected findings, and generating research questions for further exploration.
CHAPTER 4
RESULTS

Summaries of the data collected during the in-depth telephone interviews with the 7 study participants are presented in this chapter. All demographic data presented in the chapter was self-reported, although date of injury, date of life care plan development, age at injury, and similar information was contained in the life care plan. All personal information taken from each participant’s life care plan was verified during the interview. The length of the interviews ranged from 75 minutes to 110 minutes, and all were completed in a single session over the telephone. Data collection occurred during the months of May and June in 2007. All references to current needs, current age, years since injury, and similar notations are measured from this point in time. A comparison of current self-reported needs and life care plan projections is presented, and emergent themes are discussed at the end of each case study.
Case One: Jim

Demographic Information

In April 1984 at the age of 19 years, this male sustained a C5-6 incomplete spinal cord injury as the result of a work-related motor vehicle accident. His life care plan was developed in 1990, 6 years following the onset of injury. Jim (not his real name) is currently 42 years of age and it has been 23 years since the injury occurred; 17 years have passed since his life care plan was developed. He was not married and did not have children at the time of the injury, and this has not changed. Jim was working at the time of the injury, but did not return. He earned a bachelor’s degree and master’s degree in political science subsequent to the injury and had planned to teach. From 1994 to 2004, he owned and operated a retail business, a video store and newsstand, but over time the business climate changed and problems with employees prompted him to sell it. Currently, he is not planning to return to work. He explained that he is financially secure and does not need to rely upon income earned from working a full-time or part-time job.

Jim shares a house with his parents and is able to access all rooms in the home. Following in the injury, an addition to the home was built to increase the shared living space and the living area, bedroom, den, and bathroom most frequently used by Jim. Exterior ramps to the front and back doors of the home and an elevator to the second floor were installed.
General Health and Lifestyle

Over the past 5 years, Jim believes that his general health had declined, but it has substantially improved over the past year following the removal of a non-functioning kidney in February 2006. He has required about the same number of hours of personal assistance each week since the injury. However, due to the recent nephrectomy, he has required more physician visits in recent years than in past years. Jim also attributes the increased frequency of physician visits to the natural aging process and to his attempt to become more attentive to his general health. Jim consumes no alcohol, cigarettes, or recreational drugs. He believes that lack of exercise and excess weight are lifestyle habits that may be negatively contributing to his current general health, but he is not currently following any specific weight management program.

Personal Assistance

Jim privately hires personal attendants for 56 hours each week and his parents supplement with assistance as necessary. He estimates that his parents provide an additional 10-15 hours of assistance each week with grocery shopping, running errands, and other activities that occur during times when an attendant is not available. Jim requires assistance with nearly all activities of daily living including dressing, showering and personal hygiene, nail care, completing a bowel and bladder program (which requires approximately 30 minutes, four times each
day), medication set-up, turning in bed at night (which requires approximately 30 minutes, twice per night) light cooking, and general household chores. Attendants also assist with range of motion and other exercises. When supplies are set-up by an attendant, he is able to accomplish some activities of daily living independently including brushing his teeth and hair, shaving, eating, washing his face, reading, and using a modified computer keyboard. His primary means of locomotion is a power wheelchair, and he is able to operate it independently. In total, Jim estimates that his morning routine requires approximately 2 to 2 ½ hours each morning and his evening routine requires approximately 1 hour.

Jim manages his own finances, with occasional assistance from his mother who performs all writing tasks on his behalf. Jim works with an accountant to manage his long-term financial plan, make investments, complete annual tax return statements, and manage his employee records. Currently, he coordinates his care among seven attendants, and he stated that this has worked well for him. Because he had control over the hiring process, he works with attendants who are knowledgeable, respectful, and diligent in performing their duties. He has not had any problems with no-shows nor been left without care for an extended period of time. If this were to happen, his parents are nearby and could offer assistance as necessary. While in college, Jim worked with attendants that were provided through a home health care agency, but since then the attendants have been
privately hired. A payroll company issues paychecks and tracks information necessary for taxes, and an accountant oversees this process.

The only concern that Jim expressed about the personal assistance that he is currently receiving involves the anticipated loss of his primary attendant and those who are currently working with him. He has had to replace several staff members over the years, and it has been fairly easy to find replacements because the person leaving can generally recommend a suitable colleague. However, he gets along well with his current attendants. Jim believes that his care is sufficient and adequate for his needs at this time. If additional assistance is needed in the future, he has the funds to be able to increase the number of hours of care that he is receiving. Jim explained that he prefers to privately hire attendants because he is able to select them personally and is not expected to commit to a minimum number of hours per week as may be required through an agency.

Jim drives a modified van with a ramp, hand controls, and modified break and gas. The van is also equipped with various switches (e.g., turn signals, power window switches, windshield wipers, etc.) that are easily accessible. Within a few months after his injury, he participated in a driving course and selected customized equipment with the assistance of occupational therapists and others who offered recommendations. He noted that he bought a new van about one year after the injury and replaced it with another new van about 3 years ago. He worked with an occupational therapist and driving specialist in his town to detail the specifications
for the modifications. Jim found the local dealer to be very helpful and estimates that he spent an additional $500-$750 for the modifications that were necessary. A local mechanic is able to service the van when necessary, and major equipment is under a lifetime warranty through the dealership.

The ability to drive independently was, and remains, very important to Jim. Prior to the injury, he felt that driving allowed him greater independence, opportunities for socializing, and the ability to engage in leisure activities. Jim continues to feel this way and values the sense of freedom that results from the ability to drive. Because he was 19 years old at the time of the injury, he was preparing to attend college and was looking forward to the experience. Driving allowed him to recapture some of the mobility and independence that the injury had claimed and it gave him another means of socializing with peers. He commented, “Maybe it’s because I was a young male, but I didn’t want anyone to treat me differently after I was injured. I was set on doing things by myself as much as possible, and I sure didn’t want my parents to be wheeling me around town with my friends. I was lucky to have a group of friends who were accepting; they are still my friends now.”

Jim is very active in the community and has lived in the same town for most of his life. The town’s population is approximately 40,000 and Jim has an extensive social network of friends and family whom he has known for many years. When prompted, he did not identify any current barriers to social or leisure
activities, but noted that he does encounter difficulty when trying to shoot pool in some establishments where there is not ample room to maneuver his wheelchair around the tables. He is able to access local grocery stores, drugstores, shopping malls, restaurants, movie theaters, and other retail areas in the community that are open to the general public. When prompted, Jim was not able to identify any public areas that are inaccessible.

**Medical Evaluations and Case Management**

Jim does not recall ever having completed a comprehensive spinal cord injury evaluation and does not believe that such an evaluation is necessary because he regularly consults with his primary care physician. He is not currently receiving any case management support, but did when he was initially discharged from the hospital. Case management support was provided by the hospital and assisted in coordinating services through a statewide nonprofit agency. This agency provided a variety of independent living services including self care, nutrition, self-advocacy, peer counseling, health education, and other skills. Jim was involved in the independent living program for approximately 6 weeks and, although he has not done so, he is able to access the facility as a resource at any time. Case management support was terminated upon completion of the independent living program. Jim does not believe that such support would be helpful to him now because he has found ways to compensate for his limitations and knows the resources that are available because he is a long-term resident of his community.
When prompted, he could not identify any services that would be of value to him currently, but noted that soon after injury, he would have benefited from having additional guidance in recruiting, selecting, and training attendants. Jim noted that, initially, he was not sure about what to expect in terms of his own level of independence in the home and community, nor what he would be eventually capable of accomplishing independently, so it was difficult to determine the specific qualities and qualifications of applicants that were necessary. Jim has not referred to the life care plan that was developed for him, neither in past nor in recent years, but believes that it was helpful in resolving the legal case, and the life care planner provided trial testimony.

**Physician Visits**

Jim schedules his own physician appointments and pays for visits through Medicare. He has not encountered any restrictions regarding the frequency of visits, consultation or lab fee payment, or similar issues that may impact receipt of care. In approximately the last 4 years, Jim has visited his primary care physician annually. Prior to that, he was not seeing his physician as consistently as he is currently, and he estimated that he visited once every 5 to 6 years. He noted that it was not due to any external limitations, but that he was feeling healthy, and did not believe that there was a need to schedule appointments. Jim described his relationship with his primary care physician as “very good,” but noted that the physician has no expertise in spinal cord injury. Jim does not want to change to a
physician with expertise in this area because the physician actively refers him to specialists when necessary. According to his insurance plan, referrals to specialists must be facilitated through the primary care physician. Jim believes that he is receiving adequate care, information, and education from his physician. Jim stated that his primary source of health-related information was derived from the training he received during rehabilitation.

Since 1985, he has visited a urologist annually and within the last 5 years, has scheduled quarterly visits. The increased frequency is due to problems related to kidney function and the need for more consistent monitoring. As noted, Jim underwent a nephrectomy in 2006. He consulted with a podiatrist two or three times per year between 1984 and 1987, but his attendants now provide his nail care. He does not visit a dentist any more frequently than is recommended for the general population; two times each year. Jim has scheduled a preliminary consultation with a sleep specialist because he suspects that he has sleep apnea and that a CPAP device may be necessary. He believes that the condition is related to the spinal cord injury because of his decreased respiratory capacity, limited mobility, excess weight, and perhaps the effects of aging.

When asked to consider where his health ranked in terms of all of the other concerns of his life, Jim stated that it ranked 8 on a 10 point scale, with 10 being the most important issue. He noted that this fluctuates over time, but because he is
currently having difficulty sleeping and has recently recovered from surgery, his health is one of his primary concerns, overall.

Subsequent Injury or Illness

Within the last 12 to 18 months, Jim has visited the emergency room twice due to kidney problems. One of these visits resulted in a hospital admission of seven days. A nephrectomy in 2006 resulted from blunt trauma which occurred at the time of injury, and Jim remained hospitalized for 10 days. Over the years, numerous infections were treated with antibiotics until the decision was made to remove the non-functioning kidney. The only other hospitalization occurred in 1998 when Jim was treated for influenza and his length of stay was three days. Jim reported that he has fully recovered from each of these incidents, and no additional personal assistance or medical follow-up is required.

Currently, his primary health concerns include urinary tract infections which occur approximately four times per year and have become more frequent over the past 3 years. Until recently, kidney infections were problematic, but have not been an issue since the nephrectomy. Jim noted that something is triggering autonomic dysreflexia on approximately a daily basis, though the cause is not yet known. Initially, symptoms appear as though the bladder is full or as suggestive of a kidney infection. However, this is not necessarily the case, and Jim believes that
it may soon be diagnosed as neurogenic bladder. Since the injury, he has not had any broken bones, decubitus ulcers, or skin breakdown.

New Technologies

Jim uses a personal home computer for correspondence, reading, accessing the Internet, and entertainment. He used a personal computer while attending college, and notes that he occasionally searches the Internet for health-related information. He is also taking a new medication, Lyrica, which is helping to reduce instances of autonomic dysreflexia. The medication is prescribed through the primary care physician and requires no additional follow-up or lab work.

Concluding Thoughts

Jim suggested that a central resource for adaptive equipment, assistive technology, and simple workarounds would be helpful for individuals with spinal cord (and similar) injuries. He has developed many items that are customized to his needs (e.g., modified reachers, supports for shooting pool) and a clearinghouse for these kinds of simple, do-it-yourself items that are not available in catalogs would be very helpful. Such a clearinghouse could serve as a resource for exchanging ideas, problem-solving unique needs and functional limitations, and learning about new items that may be available for purchase.
Analysis

A comparison between Jim’s current self-reported needs and the life care plan projections is presented in Appendix O.

Personal Assistance

The life care plan that was developed for Jim recommended that he would live in private residence, and require attendant care services for 16 hours per day from the time of the injury through life expectancy and LPN nursing care for 8 hours per day from the time of the injury through life expectancy. Weekly interior and exterior home maintenance services were recommended through life expectancy.

Consistent with the life care plan projection, Jim reported that he is living in a private residence. The type of personal assistance that was projected in the plan is also consistent with what Jim reported as being necessary. Jim requires support with nearly every activity of daily living and hires attendants to provide these services. Attendant care was recommended in the life care plan, along with LPN nursing assistance to perform his bowel and bladder program and to set-up his medications. Due to the invasive nature of catheterization, most state nurse practice acts require that such procedures be completed by an LPN or an RN.

The number of hours of personal assistance projected in the life care plan is inconsistent with what Jim reported as being necessary. Jim hires attendants for 56
hours per week and his parents provide an estimated 10-15 hours of assistance per week. The estimated 66-71 hours per week of assistance that Jim is currently receiving is substantially less than the 168 projected in the life care plan. Because Jim lives with his parents, he is not responsible for completing interior and exterior home maintenance, so this recommendation is not currently applicable. However, if Jim were not living with his parents, such services would be required.

**Physician Visits**

The life care plan recommended that Jim would require annual inpatient and outpatient spinal cord injury evaluations, and general physician visits through life expectancy. The plan also recommended biannual visits with a urologist to maintain urological care, and a nephrologist for routine assessments. Visits to a podiatrist for routine assessment were projected three to four times per year, and an outpatient clinical evaluation for a functional electrical stimulation program was recommended.

Consistent with this life care plan, Jim reported that he is currently consulting with his primary care physician on an annual basis. Jim noted that the increased frequency of urology visits is due to a history of issues with kidney function and a recent nephrectomy. Although the plan recommended visits with both a urologist and a nephrologist, Jim reported that his urologist has managed the condition and has not referred him for further specialized care. The plan indicated
that two visits per year to the urologist and two visits per year to the nephrologist would be necessary. Jim consults with a urologist four times per year and, given the advice of his urologist, these reported needs are consistent with plan recommendations.

Inconsistent with plan recommendations, Jim is not currently visiting a podiatrist for nail care, though there is a need for such care and it is currently being provided by an attendant. Inconsistent with plan recommendations, Jim did not report having completed annual inpatient and outpatient spinal cord injury evaluations, or an outpatient clinical evaluation for a functional electrical stimulation program as recommended in the life care plan. He also noted that he has scheduled a consultation with a sleep specialist because he suspects that he has developed sleep apnea. Although this recommendation was not cited in the life care plan, it is not a condition that would ordinarily be anticipated as a complication of spinal cord injury nor projected as a future need.

**Emergent Themes**

There are three primary themes that emerged from the interview that are of particular interest to life care planners. First, Jim appears to be more independent and require fewer hours of personal assistance than was projected in his plan. He is able to independently operate his power wheelchair and drive a vehicle, he manages his own finances, he hires his own attendant care staff, and he is active in
the community. Although he requires assistance in accomplishing personal care, turning in bed at night, and routine household tasks, Jim is able to pursue social and recreational activities without the assistance of attendants. He stressed that maintaining his independence has always been an important goal, perhaps because of his age at injury, but also because of his determination to find ways to compensate for his physical limitations. Jim earned two academic degrees and managed his own retail business post-injury. He explained that he feels comfortable living in his small town and that he is able to participate in community events and activities to the extent that he desires.

When utilized as a document within a personal injury case, the life care planner must be able to substantiate all recommendations by providing medical and rehabilitation foundations. Plan recommendations regarding personal assistance were based upon an assessment of Jim’s functional ability and needs at the time of the evaluation. Given his level of injury and the extent of Jim’s needs in completing activities of daily living and routine self-care tasks, the extent of his independence in the community and in academic and vocational pursuits may not have been reasonably projected at the time that the plan was developed. Although the methodology applied to the development of a life care plan recognizes the unique abilities of individuals, future recommendations are based upon research and input from members of the treatment team regarding what the average individual with a specific level of injury may be expected to require through life
expectancy. Unless there is substantive documentation to the contrary, recommendations that extend beyond established medical and rehabilitation guidelines may be difficult to justify within the context of a litigated personal injury case.

The second theme that emerged is that Jim perceives his health as being an important issue, though he noted that the degree of his concern fluctuates over time depending upon his current state of health. Among all of the other concerns in his life, Jim ranked his health at an 8 on a 10 point scale, with 10 being the most important issue. He noted that his overall health had declined until 2006 when his kidney was removed, but it has since improved. He reports that he is consistently consulting with his primary care physician and urologist, and he intends to continue doing so in the future. Throughout the interview, Jim commented about his interest in maintaining his health and his belief that preventative care is important as he ages. He acknowledged that some of his lifestyle choices may be contributing to some of his current health problems (e.g., sleep apnea), but he is not participating in any specific diet or exercise regimen. Until about 4 years ago, he had inconsistently consulted with his primary care physician because he was feeling healthy and did not believe that there was a need to schedule routine assessments. Jim has since visited his primary care physician on a regular basis, and relies upon the physician for referrals to specialists as necessary. It appears that Jim has not been referred for a comprehensive spinal cord injury evaluation and, when asked
whether he believed that he would benefit from such an assessment, he denied that it would be of value because he consistently consults with his primary care physician.

Plan recommendations regarding future physician visits were based upon an assessment of Jim’s needs at the time of the evaluation, a review of the medical records, and input from members of his treatment team. As such, these prospective recommendations are preventative in nature, tend to be conservative, and are suggested as a means of monitoring an individual’s health status over time. The plan provided for routine physician visits, but for a period of years, Jim did not consult with his primary care physician because he was feeling healthy and had no medical complaints. It is not possible to determine whether any of his current health concerns may have been reduced or eliminated had he consistently scheduled routine follow-up consultations. Further, his insurance plan requires that referrals to specialists are initiated through the primary care physician, so perhaps consultations with a nephrologist or a podiatrist have not been deemed necessary by his primary care physician in recent years. As a tool of case management, a life care plan will project frequencies and types of specialty physician visits that are aligned with clinical practice guidelines and the expertise of members of the treatment team. These professionals have an intimate knowledge of the individual and the outcomes experienced by those with similar levels of injury, functional abilities, and rehabilitation goals.
The third theme that emerged involves case management support. Although these services were not recommended in the life care plan, it appears as though periodic meetings with a case manager could have been of value soon after discharge from the rehabilitation facility and in the years since. Jim stated that he would have benefited from having additional guidance in recruiting, selecting, and training attendants. In addition, while in college a case manager may have been able to suggest assistive technologies, campus and community services, and other resources that could have enhanced his educational experience. Later, a case manager may have assisted with tasks such as locating qualified attendants, coordinating preventative health care, and providing informational resources regarding spinal cord injury. Jim successfully earned academic degrees, operated a retail business, and managed his attendant care, but case management support may have introduced him to additional tools and resources that would have been of value.

It is interesting to note that, although Jim ranked health issues as a high concern, his primary source of health related information was the training he received during rehabilitation approximately 23 years ago, even though he has access to the resources available on the Internet. Further, although he denied his need for case management services and has not accessed the rehabilitation facility as a resource, he expressed an interest in learning more about the resources available to individuals with spinal cord injuries. He specifically mentioned his
interest in identifying new adaptive equipment, assistive technology, and other resources that directly coincide with the scope of expertise of case managers. It is possible that Jim did not report having a need for periodic case management because he is unfamiliar with the range of services that are available.

Case Two: Teresa

Demographic Information

In April 1994 at the age of 45 years, this female sustained a T2 complete spinal cord injury as the result of a motor vehicle accident. Her life care plan was developed in 1995, 19 months following the onset of injury. Teresa (not her real name) is currently 58 years of age and it has been 13 years since the injury occurred; approximately 12 years have passed since her life care plan was developed. She was divorced at the time of the injury and is not currently married. She had one 22 year old daughter at the time of the injury and had no additional children subsequently. Teresa was working as a coordinating producer at a local ABC television affiliate at the time of the injury, but has not returned to work at any point since the injury.

Teresa is currently living in her own home with live-in attendants, and she is able to access all rooms in the home. Following in the injury, modifications to the home were made, including increased living space, widened doorframes, an elevator to the second floor, and exterior ramps. The master bathroom was
renovated to include a roll-in shower and accessible sink and storage space. Closets in the master bedroom were redesigned to improve accessibility and an awning was installed over her car port.

*General Health and Lifestyle*

Over the past 5 years, Teresa believes that her general health has declined. She was diagnosed with sepsis resulting from a urinary tract infection in 2000, but has fully recovered with no residual difficulties. She then lost the use of her dominant right arm in 2005 due to heterotopic ossification and an attempted surgical intervention that caused permanent damage to her limb. Teresa reports that these recent events have likely had a negative impact on her general health because of the limitations that resulted. Teresa has required about the same number of hours of assistance per week, but has had full-time live-in assistance since the time of the injury. Although she has not required additional time, she has become more reliant upon attendants to assist with tasks that she was able to accomplish with little support in the past. Over the past 5 years, she has required fewer doctor visits. Despite the aforementioned health concerns, she feels healthier than she has been in 13 years because she is taking a low grade antibiotic daily to prevent urinary tract infections. This has been a successful prophylactic strategy that as produced no negative side effects. Teresa consumes no alcohol, cigarettes, or recreational drugs. When prompted, she did not identify any lifestyle habits that may be positively or negatively contributing to her general health.
**Personal Assistance**

Since the injury occurred, Teresa has privately hired a staff of attendants, and someone is with her 24 hours per day. Currently, she has a staff of five who rotate in 8 hour shifts. An attendant assists in all aspects of personal care including bowel and bladder programs, personal hygiene and showering, hair styling, and brushing teeth. Attendents also assist with dressing, medication set-up, general housework, writing, laundry, cooking, and other daily tasks. She relies on an attendant to properly position her in the wheelchair, on the couch, in her bed, and while riding in her van. Teresa estimates that her morning routine is completed in approximately 3 to 4 hours and her evening routine is completed in approximately 2 to 3 hours. Teresa pays a lawn company for weekly service and hires skilled craftsmen for interior and exterior home maintenance as necessary.

Because she no longer has functional use of her right arm, Teresa is not able to transfer herself to and from her wheelchair, propel a manual wheelchair, write legibly, self-catheterize, lift items weighing more than two or three pounds with her left arm, or complete other routine tasks without assistance. She is gaining strength and flexibility in her left arm and hand, but she is not able to accomplish tasks as efficiently as when she used to use her right arm and hand. Teresa noted that she is very cautious about preserving the remaining function in her left shoulder, and avoids activities that may compromise the use of her left arm and hand. In addition to being an inconvenience, Teresa noted that the loss of her right arm has also had a
substantial psychological impact. She explained that the lack of independence and the awareness of her increasing limitations have caused her to become periodically depressed.

Teresa works with an accountant to manage her general finances, and pays the attendants by personal check each week. The attendants work as independent contractors, so no taxes are withheld and no benefits are paid. Initially, there was frequent staff turn-over, but Teresa notes that there has been none within the past 5 years. There are home health agencies in the area, but she likes to choose her own attendants and wants to keep costs reasonable. Teresa does not have any concerns about the quality or amount of assistance that she is currently receiving.

Teresa does not drive, but has a modified van with a ramp and wheelchair tie downs. The van was purchased new in 1994, has had few mechanical problems, and has only 53,000 miles. Although the van is 13 years old, Teresa noted that it is in good condition, and she intends to keep it for as long as possible. About 5 years ago the wheelchair ties were replaced at a cost of approximately $80 and a component of the ramp was replaced at a cost of approximately $35. The van can be repaired about 20 miles from Teresa’s residence. Her insurance policy covers anyone who may be driving if an accident should occur, and she has a handicapped parking permit.
When prompted, Teresa did not identify any current barriers to social or leisure activities in the community, but noted that he does encounter difficulty when trying to visit friends and family members in their homes. She has a portable ramp that she can use to access front or side doors of most homes, but often many interior rooms are inaccessible. On occasion, people have had to lift her wheelchair into the home when the span of the exterior stairs (more than five or six steps) is beyond that of the portable ramp. Bathrooms are particularly problematic because guest bathrooms are typically smaller than master bathrooms and most will not accommodate a wheelchair. Teresa explained that she makes a conscious effort to void her bladder before leaving to visit a residence and is careful not to eat or drink too much while away from home. Teresa noted that she makes an effort to visit friends and family in their homes so that they are not continually inconvenienced by having to drive to her home, and because she does not want to feel isolated or reclusive. She enjoys visiting other people and believes that it is important to make the effort to maintain an active social life. When prompted, she was not able to identify any public areas that are inaccessible.

Medical Evaluations and Case Management

Teresa does not recall ever having completed a comprehensive spinal cord injury evaluation and does not believe that such an evaluation is necessary because her primary care physician conducts thorough annual examinations. She is not currently receiving any case management support and does not believe that it
would be of value at this time. She is a member of a statewide spinal cord injury commission and feels confident in her own ability to coordinate her medical care.

When prompted, she could not identify any services that would be of value to her currently, but noted that the psychological counseling and comprehensive rehabilitation program that she participated in soon after injury were very helpful. Upon discharge from the hospital, she completed a 6 week transitional living program at a nationally recognized rehabilitation and research facility. For a period of approximately 4 weeks following discharge, a coordinator periodically contacted her by telephone to assess her progress and respond to questions. Teresa has not referred to the life care plan that was developed for her, neither in past nor in recent years, but believes that it was helpful in resolving the legal case. She commented that she did remember reviewing it, but is not certain how it was utilized by the attorney in her case.

*Physician Visits*

Teresa schedules her own physician appointments and pays for visits through Medicare. She has not encountered any restrictions regarding the frequency of visits, consultation or lab fee payment, or similar issues that may impact receipt of care. She consults with her primary care physician approximately three times per year and has been doing so consistently since the injury. Depending upon her health concerns, there have been periods of time when she has gone as
frequently as six or seven times per year, or as infrequently as once per year.

Teresa described her relationship with his primary care physician as “good” and noted that she feels comfortable talking with him about all aspects of her medical care. According to her insurance plan, referrals to specialists must be facilitated through the primary care physician. She believes that her physician has experience in treating individuals with spinal cord injury, and noted that he and her pharmacist are her primary sources of health related information. She believes that she is receiving adequate care, is consulting with her physician as frequently as she would like, and has no limitations when scheduling appointments.

She has consulted with a urologist sporadically since the injury, but estimates that in the last 5 years she has seen him twice per year. Teresa does not consult with a podiatrist, but has regular manicures and pedicures at a nail salon. She does not visit a dentist any more frequently than is recommended for the general population; two times each year.

When asked to consider where her health ranked in terms of all of the other concerns of her life, Teresa stated that it ranked 8 on a 10 point scale, with 10 being the most important issue. She explained that the loss of the use of her dominant right arm has had a substantial impact on her ability to accomplish daily tasks independently, and has caused her to feel less in control of her environment, leisure time, and health. Her left arm is weaker and less flexible than her right arm, and her lack of fine motor coordination is a distinct deficit.
Subsequent Injury or Illness

Within the last 12 months, Teresa has not visited the emergency room or been admitted to the hospital. Approximately 1 year after the spinal cord injury, she developed a decubitus ulcer which required surgery, and she was in the hospital for approximately 1 week. For a period of approximately 18 months between 1998 and 1999 she had had difficulty with autonomic dysreflexia, but it was believed to be related to skin breakdown and catheter placement. Since that time, she has not experienced symptoms that required emergency medical attention. As noted earlier, she was diagnosed with sepsis resulting from a urinary tract infection in 2000 and recovered fully. She lost the functional use of her dominant right arm and hand in 2005 after undergoing an unsuccessful invasive procedure involving her right shoulder. Due to heterotopic ossification and complications of an attempted intervention, the range of motion, strength, and general functioning of her dominant arm and hand has decreased over a period of approximately 1 year. The intervention was attempted as a means of improving functioning, but a complication during the procedure resulted in the complete loss of function in her dominant arm and hand. Teresa was told by her physician that heterotopic ossification is a condition that is frequently associated with spinal cord injuries, and perhaps a genetic predisposition, and that it was aggravated by overuse of her shoulders in propelling her manual wheelchair, transferring to and from her
wheelchair, and in completing other routine activities. She has been told that there is nothing that can be done to reverse her current situation.

Teresa noted that, although the surgical physician explained the risks involved in the procedure, this incident has caused her to become distrustful of medical professionals and fearful of having to undergo future procedures. She explained, “I went into the surgery center hoping that this would help me to be able to do more for myself, but left being able to do even less than what I did right after the accident. I try not to blame the doctor, but I just can’t help being angry at someone. And, they tell me that I’ll just have to learn to deal with it; that nothing can be done to improve it. I didn’t have much to begin with, now I have even less. It’s very depressing.” Teresa noted that the outcome of the procedure has been devastating because of the permanency of the situation. She remarked, “I have no hope that things will get better with time. They will only get worse.” Teresa explained that she is very protective of her left arm and hand, and is very cautious about using them repetitively. She recognizes that she may have fallen into a cycle of dependency and may rely upon her attendants more than necessary. She explained that that she does not attempt to complete tasks that she could probably accomplish with minimal assistance because she is fearful of jeopardizing the function of her left arm and hand.

Currently, Teresa’s primary health concerns are urinary tract infections and heterotopic ossification in her right hip that was identified approximately 18
months ago. One year ago, she began taking a new daily low dose antibiotic which has reduced the occurrence of urinary tract infections from approximately once every 2 months to once every 6 months. The medication is prescribed through her primary care physician and appears to have no adverse side effects. She is now using packaged sterilized catheters which are also helping to prevent infections. Previously, she was using a type of catheter that had to be manually sterilized before use.

Teresa is most concerned about the possible consequences of heterotopic ossification that may further limit her ability to accomplish daily tasks with assistance and may limit her ability to actively participate in activities outside of her home. She understands that routine tasks such as bathing and transferring to and from her wheelchair will require even greater care. Ultimately, she is concerned that the progression of symptoms related to heterotopic ossification will prevent her from leaving her home and participating in community activities. She adamantly stated that she does not want to become a “homebound recluse.”

New Technologies

When prompted, Teresa was not able to identify any new technologies that is currently using, but she did note that she now relies upon a power wheelchair as her primary means of locomotion in her home and in the community. She purchased it, along with customized seat cushions for optimum positioning, after
she lost the use of her right arm. A physical therapist associated with the surgical facility where the procedure was done assisted in developing an appropriate prescription and submitting paperwork to Medicare. Teresa is able to access the physical therapy department at this facility when future adjustments, repairs, or replacements are necessary.

Concluding Thoughts

Teresa notes that there are individuals with the same level of injury who are more independent than she is, but attributes this difference to the loss of function in her right arm and to heterotopic ossification. The loss of function in her right arm has substantially impacted her ability to complete daily tasks without assistance and she has concerns about additional limitations that may result from the heterotopic ossification in the future. Given the results of the attempted intervention involving her shoulder, Teresa is fearful of consenting to future invasive procedures that may be suggested by her treating physicians.

Analysis

A comparison between Teresa’s current self-reported needs and the life care plan projections is presented in Appendix P.

Personal Assistance

The life care plan that was developed for Teresa recommended that she would live in a private residence and require live-in attendant care services from
the time of the injury through life expectancy. However, if she were unable to
regain her ability to independently catheterize, a live-in LPN would be required to
perform the invasive procedure. Weekly interior and exterior home maintenance
services were recommended through life expectancy.

The type of personal assistance and number of hours per week of care
projected in the life care plan are consistent with what Teresa reported as being
currently necessary. Also consistent with plan recommendations, Teresa lives in a
private residence. Attendant care was recommended in the life care plan, along
with LPN nursing assistance to perform her bowel and bladder program and to set-
up her medications. Due to the invasive nature of catheterization, most state nurse
practice acts require that such procedures be completed by an LPN or an RN.
Consistent with the recommendations in the life care plan, Teresa pays a lawn
company for weekly service and hires skilled craftsmen for interior and exterior
home maintenance as necessary.

*Physician Visits*

The life care plan that was developed for Teresa recommended that she
would require annual inpatient and outpatient spinal cord injury evaluations to
monitor her status and suggest adjustments in care. The plan also recommended
visits with a general physician for routine assessment and a urologist to monitor her
urological system twice per year. Visits with a physiatrist to monitor for decubitus
ulcers and heterotopic ossification were recommended three to four times per year. Visits with a podiatrist for foot and nail care were recommended four times per year. An evaluation with a psychiatrist to determine the need for psychotropic medication was also projected.

Consistent with plan recommendations, Teresa visits a urologist biannually. The plan projected general physician visits to occur biannually, but she is currently consulting with him three times per year. Inconsistent with plan recommendations, Teresa did not report having completed annual inpatient and outpatient spinal cord injury evaluations, physiatrist visits, podiatrist visits, or a psychiatric evaluation. Because her insurance plan requires that referrals to specialists are initiated through the primary care physician, consultations with these specialists may not have been deemed necessary in recent years. However, there is a need for nail care and it is currently being provided by a pedicurist. Further, since Teresa has experienced greater restrictions in her functional independence, has expressed her psychological difficulty in adjusting to this challenge, and is concerned about future physical limitations due to heterotopic ossification, recommendations regarding comprehensive spinal cord injury and psychiatric evaluations appear to be appropriate.
Emergent Themes

There are two primary themes that emerged from the interview that are of particular interest to life care planners. First, the loss of function in Teresa’s dominant right arm and hand has had a substantial impact on her ability to accomplish daily tasks independently and on her psychological wellbeing. Although she has required live-in attendant care since the injury, she noted that she is now unable to accomplish daily tasks without assistance. Although Teresa is able to use her left arm to accomplish some tasks, it lacks the strength, range of motion, and fine motor coordination that her right arm had. In a broader sense, this has caused her to feel less in control of her environment, leisure time, and overall health. She admitted to periodic depression and feelings of distrust toward medical professionals.

Teresa has required live-in attendant care since the time of the injury, as was accurately projected in the life care plan. However, the plan could not have reasonably anticipated the loss of function that resulted from the attempted medical intervention. In this case, the type of care required or number of hours of assistance needed each week is not impacted, but this outcome has affected Teresa psychologically. Although she did not report that she is currently pursuing psychological counseling, the one-time psychiatric evaluation recommended in her life care plan appears to be appropriate given her difficulty in adjusting to increased physical limitations.
The second theme that emerged from the interview is Teresa’s concern regarding the long-term impact of heterotopic ossification on her ability to function and on her general health. This concern is affecting the way in which she approaches daily tasks and thinks about her future. She appears to perceive a direct relationship between having developed heterotopic ossification and her current inability to use her right arm and hand, rather than to identify the outcome as being the result of a complication that occurred during the surgical procedure. This attribution may reinforce her fears regarding imminent future difficulties. Teresa explained that she is concerned about preserving her current level of functioning, particularly in her left arm and hand, and noted that she avoids attempting activities that may compromise her abilities in any way.

One of the central principles of life care planning is that the occurrence of complications associated with spinal cord injuries, and residual difficulties resulting from them, cannot be accurately projected. For educational purposes, many practitioners include information regarding complications in the life care plan, but the relevant costs are not included in the final economic valuation of the plan. Heterotopic ossification is a recognized complication associated with spinal cord injuries and no specific recommendations with regard to this condition were made in Teresa’s plan. However, the plan did recommend annual comprehensive spinal cord injury evaluations and consistent consultations with a physiatrist. These consultations would provide for periodic assessment and monitoring of her...
physical condition, identification of aids for independent living, practical suggestions for caregivers, and discussions regarding relevant health information.

Case Three: Robert

Demographic Information

In April 1996 at the age of 43 years, this male sustained a T11, T12, L1 complete spinal cord injury as the result of a work-related injury when he fell from a height of approximately 28 feet. His life care plan was developed in 1998, 2 years following the onset of injury. Robert (not his real name) is currently 53 years of age and it has been 11 years since the injury occurred; 9 years have passed since his life care plan was developed. Robert was engaged at the time of the injury and is currently married. He had one daughter who was 17 years old when the injury occurred. He is not currently working and did not return to work after the injury.

Currently, Robert shares a house with his wife, and he is able to access all rooms in the home. He was building his current home at the time that the injury occurred and modified the floor plans to include necessary accommodations. Exterior ramps to the front door and back patio were added, doorways were widened, the master bathroom was reconfigured so that he could transfer easily from a wheelchair to the toilet and from a wheelchair to a built-in shower seat. Master bedroom closet shelves were lowered and additional lower unit storage
space was added in the master bathroom, kitchen, living rooms, and garage. With the exception of the bedrooms, there is tile floor throughout the home.

General Health and Lifestyle

Over the past 5 years, Robert’s general health has improved. He is not sure why, but believes that this can be attributed to his lifestyle. He stays physically active, maintains a healthy diet, does not smoke cigarettes, drink alcohol, or consume recreational drugs. Over the past 5 years, he has required about the same number of hours of assistance per week, but has visited his primary care physician more frequently. Robert explained that this is not due to any specific health concerns, but because approximately 18 months ago his health insurance policy changed and Medicare allows him frequent visits. Previously, he had consulted with his primary care physician once or twice per year.

Personal Assistance

Robert does not hire any attendant care, but estimates that he requires 35-42 hours of assistance each week. His wife assists with personal hygiene, cooking, laundry, and other daily activities as necessary. He is able to self-catheterize, complete his bowel program, brush his hair and teeth, dress, eat, and perform most other activities that can be accomplished from a seated or supported standing position. Robert’s wife completes the yard work and other general home maintenance tasks. He hires skilled craftsmen when interior and exterior home
repairs are necessary, but noted that these are tasks that he would have completed himself prior to the injury. His primary means of locomotion is a manual wheelchair, and he is able to support himself and ambulate for short distances using a pair of crutches. Robert noted that he has been fortunate that he has not been in a situation where his wife was not able to assist for a prolonged period of time, but he believes that his neighbors and his daughter would help if necessary. He notes that he does not have any concerns about the type or amount of personal assistance that he is currently receiving.

Robert drives a truck with a modified steering system, throttle, and brake. He participated in a driving course soon after the injury and has had no difficulties operating a vehicle, but notes that he can only drive for approximately 1 hour before needing to get out of the truck and stretch. Sitting for prolonged periods of time causes discomfort, joint stiffness, and aching in the lower back. When prompted, Robert did not identify any barriers to his participation in community, social, or leisure activities.

Medical Evaluations and Case Management

Robert does not recall ever having completed a comprehensive spinal cord injury evaluation and does not believe that such an evaluation is necessary because he consults with his primary care physician every other month. He is not currently receiving any case management support and does not believe that it would be of
value to him. He noted that the psychological counseling he received while in rehabilitation following the injury was helpful, and he appreciated having an opportunity to participate in both individual and group sessions. Robert felt that the support and encouragement gained through counseling helped him to adjust to his limitations, evaluate his priorities, and define his own goals. The self-directed nature of the counseling process fit well with his personality.

However, his experience in working with insurance company case managers has been negative. He explained that he has worked with approximately five insurance companies since the injury occurred and commented, “They tried to plan my life for me. They were trying to make decisions for me; when and how I should do things. I don’t like being told what to do, particularly by people who don’t even know me. But, they seemed to have only one way of doing things, whether it was right for me, or not. They didn’t know how to work with me or how to do what I needed to have done so that I could go on living my life the way that I wanted to.” For example, one insurance company denied approval for a specific wheelchair model that was recommended and endorsed by four of the members of his treatment team, including his primary care physician. Robert wanted this wheelchair because it would allow him to be more independent and, even with the written support of is physicians and therapists, the insurance company deemed that it was not a medical necessity and denied payment. Robert explained that this was a particularly frustrating experience because it seemed that the insurance company
protocols were designed to limit his independence, were based upon guidelines that were not applicable to him, and were structured to save the company money. This instance occurred approximately 2 years after his injury and, combined with similar incidents, has left Robert with a negative impression of the value of case management.

Robert noted that he is a very determined, independent person, and he was offended by some of the professionals involved in his rehabilitation and in his legal case who underestimated what he would be capable of accomplishing after his injury. He recalled that several members of his rehabilitation treatment team discouraged him from setting goals of returning to work, walking with crutches, scuba diving, operating machinery, and pursuing similar interests involving physical activity. Robert explained that he insisted upon being as independent as possible and believes that individuals with spinal cord injuries should be encouraged to set challenging goals, rather than to accept the lowered expectations proposed by professionals. He offered an example of this tendency when he shared the recommendations of vocational evaluator who had been retained by his attorney to assess his ability to return to work after the injury. The evaluator concluded that he could not return to his position as a carpenter and could not be retrained to perform any job, either within his field of expertise, or beyond it. Robert was both disappointed and furious upon reading this evaluator’s report. His attorney explained how these results may impact his personal injury case and that,
ultimately, such conclusions may be beneficial within the context of the lawsuit. By stating that Robert was not capable of returning to work, the economic damages in the case increased substantially. Robert understood the attorney’s perspective, but did not agree with the analysis provided by the evaluator. He very much sought to maintain as much independence as possible and felt that the conclusion did not accurately reflect what he was capable of accomplishing. He noted that his current financial situation is such that he does not have to work in order to maintain his preferred lifestyle, but believes that he could have returned to work as a productive, efficient member of a construction-related sales, management, or supervisory team. He noted, “I’ve always been an active person; sitting still just isn’t for me. Even though I don’t have a job, I’m out working in the barn and in the fields every day. We have a lot of land to keep track of, so there is always something that needs to be done.” Robert summarized his feelings by saying that soon after his injury he became skeptical of the motives of some professionals and resented those who seemed not to take is own goals and desires into consideration.

Robert has been an active advocate and resource for other individuals with spinal cord injuries and regularly talks with others soon after their injuries occur. He frequently travels to rehabilitation units, describes his experiences, and encourages others to actively seek ways to continue to do the things that they enjoy. By sharing his story, Robert believes that he offers hope and a positive message to others who may be having difficulty adjusting to the reality of their injuries. He
feels strongly about the need to maintain involvement in activities that were of interest prior to the injury and encourages others to find ways to continue participating, despite the challenges that may be involved.

Robert could not identify any services or resources that he felt would be of benefit to him currently. He has not referred back to the life care plan that was developed, neither in recent nor in past years, but believes that it was helpful in resolving the legal case. He is not certain how it was specifically utilized by the attorney in his case.

Physician Visits

Robert schedules his own physician appointments and pays for visits through Medicare. He has not encountered any restrictions regarding the frequency of visits, consultation or lab fee payment, or similar issues that may impact receipt of care. He consults with his primary care physician every other month, but believes that annual visits would be adequate. His physician prescribes antibiotics when bladder infections occur (two to three times per year) and also provides urology care. He does not consult with any other medical specialists and does not visit a dentist any more frequently than is recommended for the general population; two times each year. Robert noted that, according to his insurance plan, referrals to specialists must be facilitated through the primary care physician. He described his relationship with his primary care physician as “excellent,” and he has had the same
physician since the injury. He believes that he is receiving adequate care, is consulting with him as frequently as he would like, and has no limitations when scheduling appointments.

Robert has developed arched feet since his injury and consults with an orthopedist one to two times each year. He tried several ankle-foot orthoses in the past, but they were not durable, and he broke his right foot twice while wearing them. He was being fitted for his ninth pair in 2002 when he asked about the possibility of trying shoes that are specifically designed for individuals with polio. Robert’s wife had seen someone wearing them and wondered whether they may be appropriate. These shoes have worked very well for Robert and each pair lasts for 2 to 3 years. He noted that his primary source of health-related information is his wife because she regularly locates valuable resources through the Internet.

When asked to consider where his health ranked in terms of all of the other concerns of his life, Robert stated that it ranked 6 on a 10 point scale, with 10 being the most important issue. He explained that he is feeling healthy, is able to do nearly everything that he would like to do, and does not think about his health often. He noted that his may change when he begins to experience some of the more physically limiting effects of the aging process.
Subsequent Injury or Illness

Within the last 12 months, Robert has not visited the emergency room or been admitted to the hospital. Since the injury, he has broken his right foot twice, sustained a serious sunburn, and had hernia repair surgery in 2003. None of these instances resulted in any long-term need for additional personal assistance or medical follow-up, but he did note that he is making a conscious effort to be more careful when ambulating with crutches to avoid falls.

Currently, Robert’s primary health concern is maintaining his present level of health, his independence, and living to 75 years of age or older. His feet have become markedly arched since the injury, and this makes walking distances of more than approximately one-half of a mile and standing for more than 30 minutes difficult. Robert uses a manual wheelchair for prolonged outings. He has also developed heterotopic ossification which has not been particularly problematic to date, but he is aware of the need to avoid activities that may result in accidental falls, broken bones, and fractures.

New Technologies

When prompted, Robert noted that he was not aware of any new technologies that he is currently using that were developed since his injury, but noted that he is interested in participating in clinical trials if researchers begin recruiting individuals to undergo spinal fusion surgery or similar medical
procedures. He is certain that medical technology will improve to the extent that individuals with spinal cord and other injuries will have the ability to regain nearly full functioning.

Concluding Thoughts

Robert firmly stated that physicians, therapists, evaluators, and other health care professionals should not take hope away from those who are recently injured. “These people are telling you that you don’t have a life anymore. Don’t tell people that their old life is completely gone. That’s what got me so aggravated; when people told me that I couldn’t do things anymore.” Robert explained that he is able to accomplish tasks that doctors told him would not be possible. For example, he is walking with crutches, but was told soon after the injury that he would not regain this ability. Robert believes that he has been able to surpass the physicians’ initial prognoses because he was determined to continue participating in the activities that he enjoyed, was in good physical condition at the time of the injury, and challenged himself to achieve increasingly complex physical goals. He believes that his abilities exceed those of other individuals with the same level of spinal cord injury because of this strong desire to remain physically active. Robert opined that if other individuals were given the resources and support to remain physically active, they, too, might be more independent than physicians and therapists expect.
Analysis

A comparison between Robert’s current self-reported needs and the life care plan projections is presented in Appendix Q.

Personal Assistance

The life care plan that was developed for Robert projected that he would live in a private residence and recommended that he would require attendant care services for 8 hours per day from the time of the injury through age 59 years, and then live-in attendant care from age 60 years through life expectancy. Weekly house cleaning services and interior and exterior home maintenance services were recommended through life expectancy. Four to 6 hours per month of case management support was projected.

Robert is not yet 60 years old, so the recommendation for live-in attendant care noted in the life care plan cannot be assessed for consistency with his current needs. Currently, the type of personal assistance that Robert requires is consistent with the recommendations made in the life care plan, and he does live in a private residence. He is independent in completing his bowel and bladder program and medication set-up and administration and would not otherwise require skilled nursing care. Although he does not hire attendant care, he reported that his wife provides approximately 35-42 hours of assistance each week. The number of hours of assistance that Robert reported as being necessary is inconsistent with the 56
hours per week of attendant care recommended in the life care plan. Robert’s wife completes household chores and lawn maintenance, and he hires skilled craftsmen when interior and exterior home repairs are necessary. The need for assistance with these tasks is consistent with plan recommendations. Robert is not currently receiving case management support and does not believe that such support is necessary. This is inconsistent with the recommendation for case management services that was made in the life care plan.

Physician Visits

The life care plan that was developed for Robert recommended that he would require outpatient spinal cord injury evaluations twice per year from the time of the injury through age 49 years. Annual inpatient and outpatient spinal cord injury evaluations were recommended from age 50 years through life expectancy. Annual visits with an orthopedic surgeon to monitor the injury and spinal fusion and with a gastroenterologist monitor reflux were projected. Biannual visits with a general physician for routine assessment, a physiatrist to monitor for issues associated with the injury and to assess rehabilitation needs, and a urologist to monitor the urological system were recommended. The plan projected three to four visits per year with a psychiatrist to assess the need for antidepressant medication and follow-up care, if prescribed.
Robert’s current health care regimen is inconsistent with the recommendations for physician visits cited in the life care plan. He did not report having completed annual inpatient and outpatient spinal cord injury evaluations, or to be currently consulting with an orthopedic surgeon, gastroenterologist, physiatrist, urologist, or psychiatrist. Robert’s insurance plan requires that referrals to specialists are initiated through the primary care physician, so perhaps these specialty consultations have not been deemed necessary by his primary care physician in recent years. Robert has not taken any antidepressant medication since the injury, so the recommendation regarding psychiatry consultations is not applicable. He consults with an orthopedist one to two times each year for monitoring and prescription of foot-ankle orthoses, but this need was not projected in the life care plan.

Consistent with the plan, he does consult with a general physician but, with visits every other month, this appears to exceed the frequency projected in the life care plan. However, Robert explained that the frequency of visits is not due to any specific health concerns, but because of allowances in his Medicare insurance policy and because his general physician also performs urology care. Robert estimated that his general physician prescribes antibiotics for urinary tract infections two to three times per year and, until approximately 18 months ago, he had consulted with his general physician once or twice per year. Based upon this
information, two to three urology visits per year and one to two general physician visits per year is consistent with projections made in his life care plan.

Emergent Themes

There are two primary themes that emerged from the interview that are of particular interest to life care planners. First, Robert repeatedly discussed his desire to remain as independent and physically active as possible. He noted that his current level of independence exceeded what was projected by health care professionals after the injury, and he attributes this to the fact that he was determined to continue participating in the activities that he enjoyed, was in good physical condition at the time of the injury, and has continually challenged himself to achieve increasingly complex physical goals. At the time of his injury, he was working in a physically demanding occupation as a carpenter and noted that he has always led an active lifestyle. Robert believes that his abilities may exceed those of other individuals with the same level of spinal cord injury because of this strong desire to remain physically active and to pursue his interests.

As applied within the context of a legal case, the medical and rehabilitation foundations for plan projections must be supported by applicable data. Although the methodology applied to the development of a life care plan recognizes the unique needs of individuals, future recommendations are based upon research and input from members of the treatment team regarding what the average individual
with a specific level of injury may be expected to require through life expectancy. Actual individual outcomes may vary from this aggregated profile but, as a prospective document, exceptions cannot be substantiated unless there is sufficient medical or rehabilitation foundation to justify inclusion or exclusion of typically required services. The fact that Robert’s current degree of functional independence surpasses what was anticipated based upon his level of injury is beyond the ability of the life care plan to reasonably project.

The second theme that emerged from the interview involves the role and impact of some of the professionals who have been involved in his legal case and rehabilitation. Robert perceived that some of the health care professionals he encountered after his injury discouraged him from setting challenging personal goals and from resuming participation in the activities that he enjoyed. Rather than perceiving these professionals as allies and information resources, he found the preponderance of their guidance to be limiting and irrelevant. Consequently, Robert does not hold a high opinion regarding the value of case management services, but he does have a positive working relationship with his primary care physician. Robert also discussed his commitment to talking with other individuals with spinal cord injuries about the importance of finding ways to re-engage in activities that are personally fulfilling. Because this has been such a vital issue for him since his injury, he explained that he is pleased to be able to help others who may be having difficulty adjusting to their new way of life.
This theme is relevant to life care planners because, while individual differences must be recognized and play an important role in determining recommendations, projections must also be based upon probabilities reflected in outcome data so that they can be defended within the legal arena. Clients need to understand how plan projections were arrived upon. Otherwise, the document may appear to be a generic set of recommendations, rather than a carefully researched, well-founded, individualized guide for planning for future needs. As rehabilitation and health care professionals, planners also have a responsibility to educate clients regarding the life care planning process, the methodologies relied upon to formulate recommendations, and the practical utility of the plan in managing the short and long-term effects of the injury. Reviewing the detailed analyses and projections contained in a life care plan can be an overwhelming experience for a client who is not prepared to apply the information in a meaningful way. As discussed in Chapter 1, informed consent includes a professional obligation to thoroughly explain the role and function of the planner, how recommendations are derived, and the value of the plan beyond litigation.

Case Four: Lynne

Demographic Information

In August 1990 at the age of 31 years, this female sustained a T6 incomplete spinal cord injury as the result of a motor vehicle accident. Her life
care plan was developed in 1991, 1 year following the onset of injury. Lynne (not her real name) is currently 49 years of age and it has been 17 years since the injury occurred; 16 years have passed since his life care plan was developed. She was married at the time, then later divorced. She remarried a man with paraplegia and is now a widow. She lost her husband five years ago due to cancer and continues to mourn his passing. Lynne has three stepchildren; two of whom, along with two step-grandchildren, live within 90 miles of her home. She was working as a secretary a hospital at the time of the injury and is currently working as a church secretary.

Lynn lives in a house that she shares with her father. The home was remodeled before she moved in, approximately 5 years ago. A hall bathroom and adjacent bedrooms were modified, new kitchen countertops and sink were installed, and her shower was made accessible. She self-transfers to a shower bench. Because her late husband was also paraplegic, they were able to find an apartment complex where new units were being built. The builder designed an accessible apartment for them with tile floors, lowered cabinets, widened doorways, and eliminated the cabinets from under sinks in the master bathroom.

*General Health and Lifestyle*

Over the past 5 years, Lynne believes that her general health has stayed about the same, and she has required about the same number of hours of assistance
per week. However, she has consulted with her primary care physician more frequently and attributes this to the aging process. She noted that there have been no major changes in her health, but she is aware that she does not have the level of endurance and stamina that she once did. She is also aware of the changes that are expected to occur as a female with a spinal cord injury and is beginning to experience menopausal symptoms. Lynne also commented that the emotional impact of losing her husband five years ago may be indirectly negatively impacting her overall health. Further, he was quite ill for a period of approximately one year and Lynne believes that this has made her more aware of the importance of seeking preventative health care. She consumes no alcohol, cigarettes, or recreational drugs and noted that she would like to exercise more frequently as a means of improving her overall health.

**Personal Assistance**

Lynne is independent in all aspects of self-care and activities of daily living. She is able to self-catheterize and to self-transfer to and from her wheelchair. A manual wheelchair is her primary mode of locomotion. With appropriate accommodations and simple compensatory devices, she does not currently require any assistance in completing activities of daily living, participating in community events, or engaging in leisure activities. Her office building is accessible, she is able to position her wheelchair under a standard desk, and can reach her computer, telephone, file cabinets, and other equipment with no difficulty. She has no
concerns about the need for personal assistance at this time, but noted that there are local agencies, friends, and family who would offer support if necessary.

She drives a Toyota minivan with a fold-out wheelchair ramp. The van lowers to ground-level and is equipped with power seats. She transfers from the wheelchair to the driver’s seat and uses hand controls for steering. Approximately 6 months after her injury, she participated in a driving course and worked with an occupational therapist to identify appropriate modifications. In the past, she has had full-size vans with lifts, hand controls, and power seats, but noted that her current van is easier and more economical to drive. She has only had to have the wheelchair ramp repaired one time, and it was under warranty. Her local Toyota dealership was able to make the repair in less than one day. When prompted, Lynne did not report any barriers to her participation in social or community activities.

Medical Evaluations and Case Management

Lynne does not recall ever having had a comprehensive spinal cord injury evaluation and does not believe that such an evaluation would be of benefit. She noted that she consults regularly with her primary care physician and mentioned that there are few spinal cord injury rehabilitation facilities in her local geographic area. She is not currently receiving any case management support and does not believe that it would be of value at this time. However, such support may have
been valuable during rehabilitation and while transitioning back into her daily routine. Specifically, Lynne explained that she would like to have had more information about the state and federal benefit programs that she may have been eligible to receive. For example, she did not apply for disability benefits initially because she believed that she would not be eligible after returning to work. Whether or not she would have met the eligibility requirements for this particular program, guidance in these types of matters would have been very helpful.

When prompted, Lynne was not able to identify any services that she believes that she would benefit from currently, but noted that she has been very fortunate and has always had what she needed. She commented, “When you’re first injured, you want to be around others with injuries, but then you get busy with life. I’ve been lucky to have all of the equipment and medical care that I need and the support that I get from my friends and family makes my life much easier.” Lynne tries to maintain a positive outlook and pushes herself to remain in close contact with friends and family, despite occasional bouts with mild depression. The social relationships that she has formed remind her of all that she has to be grateful for and help her to keep daily trials in perspective. She noted that a social group for individuals with spinal cord injury would possibly be of interest, but she is not sure whether there are many others in her local community who would participate. She would like to have a resource for sharing information and experiences, but noted that, with a full-time job, she would not likely be able to
actively participate in a social group on a regular basis. Lynne has not referred back to the life care plan that was developed, neither in recent nor in past years, but believes that it was helpful in resolving her legal case.

*Physician Visits*

Lynne schedules her own physician appointments and pays for visits through Medicare. She has not encountered any restrictions regarding the frequency of visits, consultation or lab fee payment, or similar issues that may impact receipt of care. For several years, Lynne did not consult with a primary care physician at all, but within the past 5 years, she has consistently made appointments approximately two times per year. She has developed carpal tunnel syndrome in both wrists, and her late husband’s health problems prompted her to become more vigilant regarding her own health. She described her relationship with her primary care physician as “good” and noted that referrals to specialists must be facilitated through the primary care physician. She feels that she is receiving adequate care, is consulting with him as frequently as she would like, and has no limitations when scheduling appointments. In addition to her general physician, Lynne also consults with a physiatrist twice per year. The physiatrist prescribes Baclofen for lower back spasms and monitors her overall health. She also consults with a urologist two times per year to monitor renal function. She does not visit a dentist any more frequently than is recommended for the general population; two times each year. Lynne noted that her primary source of health-related information is the Internet.
When asked to consider where her health ranked in terms of all of the other concerns of her life, Lynne stated that it ranked 8 on a 10 point scale, with 10 being the most important issue. She wants to be more active and make some lifestyle changes that will positively impact her health. She also noted that she is emotionally depressed due to the death of her husband 5 years ago and of her mother soon afterward. She commented, “At least I was fortunate enough to have had the chance to know him and we really did adore one another. He was one of the best things that ever happened to me, so I shouldn’t mourn his passing. But, that kind of love is not easy to come by and I miss the feeling of security and the companionship that we shared.” Lynne stressed that she is grateful to have the support and friendship of her father, but she did not expect that she would be living with him at this stage in her life. She was depressed immediately following the injury and for several months following the subsequent divorce from her first husband, but was overjoyed when she dated, then married, her second husband. They had a wonderful life and she felt truly happy for the 9 years that they were together. Lynne explained that she would like to build her own house, but it is emotionally difficult to think about re-establishing herself in a new home and leaving her father. She commented, “We kind of take care of one another. I’ve lost my husband, he’s lost his wife and both of us appreciate having someone else there to talk to. We are very close, but this is not how I expected things to be; I’m sure that he didn’t either.”
Subsequent Injury or Illness

Within the last 12 months, Lynne has not visited the emergency room or been admitted to the hospital. Since the injury, she had her gall bladder removed (she was not admitted to the hospital after the procedure), broke a bone in one of her toes when her foot slid off of the foot plate of her wheelchair (no cast was placed), and she has developed carpal tunnel syndrome. In 2005, she experienced symptoms of dysreflexia, reported to the emergency room, and discovered that it was caused by a urinary tract infection. These symptoms were experienced on a subsequent occasion, and the cause was again identified as a urinary tract infection.

Currently, Lynne’s primary health concerns include increased limitations caused by carpal tunnel in both wrists and diminished function, strength, and range of motion in her shoulders. Eventually, she expects that she will need to have carpal tunnel surgery but dreads it because she knows that she will be very limited in her ability to care for herself throughout the recovery period. She has a close friend who is willing to stay with her until she is able to resume her normal activities. Lynne is concerned about maintaining her health and noted that she is not concerned about any major issues, but is not certain whether she would recognize minor signs and symptoms that may quickly escalate into more serious conditions. Although there are no obvious problems, she wants maintain consistent consultations with her primary care physician so that her overall health can be closely monitored. She has had no skin breakdown because she does have some
sensitivity to pressure since her injury is incomplete. Lynne noted that urinary tract infections occur less than once per year and in the last 5 years she has required antibiotic medication only once or twice.

New Technologies

When prompted, Lynne was not aware of any new technologies that she is currently using that were not available at the time of her injury.

Concluding Thoughts

Lynne again stated that she believes that she is very fortunate and that she likely has more support than other people in similar situations. At the time of her injury she was working as a secretary in a hospital and received a great deal of support from her coworkers. She did not require any worksite accommodations, but was able to take a leave of absence for several weeks while in rehabilitation and was given the opportunity to work flexible hours so that she could attend medical appointments. Although she did not work closely with a case manager, Lynne believes that she gleaned a great deal of information and resources through informal exchanges with coworkers who were experienced in coordinating health care services. Since the injury, Lynne has tried to stay active so that she is able to remain as independent as possible in the future.
Analysis

A comparison between Lynne’s current self-reported needs and the life care plan projections is presented in Appendix R.

*Personal Assistance*

The life care plan that was developed for Lynne projected that she would require live-in attendant care in a private residence beginning between the ages of 50 and 60 years through life expectancy. Weekly house cleaning services were recommended from the time of injury through life expectancy.

Lynne is not yet 50 years old, so the recommendation for live-in attendant care noted in the life care plan cannot be assessed for consistency with her current needs. Currently, she lives in a private residence and is fully independent in all aspects of self-care and activities of daily living, is able to drive a vehicle, and requires few worksite accommodations. She does not hire any attendant care, nor does she rely upon family or friends for personal assistance. The recommendation regarding weekly house cleaning services is inconsistent with her current needs as Lynne reported that she accomplishes these tasks independently.

*Physician Visits*

The life care plan that was developed for Lynne recommended that she would require annual inpatient and outpatient spinal cord injury evaluations.
General physician and urologist visits were recommended one to two times per year for routine medical care.

Consistent with the recommendations made in the life care plan, Lynne reported that she visits a general physician and a urologist two times per year. She reported that she has never completed an inpatient or an outpatient spinal cord injury evaluation, which is inconsistent with plan recommendations. Because her insurance plan requires that referrals for specialized services are initiated through the primary care physician, perhaps comprehensive spinal cord injury evaluations have not been deemed necessary by her primary care physician. Lynne visits a physiatrist two times per year, but this need was not projected in her life care plan.

Emergent Themes

There are two primary themes that emerged from the interview that are of particular interest to life care planners. First, Lynne explained that maintaining her health has become an important issue, particularly as she begins to experience some of the effects of the aging process. Among all of the other concerns in her life, Lynne ranked her health at an 8 on a 10 point scale, with 10 being the most important issue in her life. Although Lynn is not currently concerned about any specific health issues, she is not certain that she would recognize minor symptoms that may quickly escalate into more serious conditions. For this reason, she intends to maintain consistent consultations with her primary care physician so that her
overall health can be closely monitored. Lynne also explained that her husband had been seriously ill for a period of time before his death and she believes that this has made her more aware of the importance of seeking preventative health care.

This theme does not directly relate to the study’s research questions but is of interest to life care planners because it reinforces the need to consider the impact of the aging process on spinal cord injuries, functional abilities, and psychological wellbeing. Further, this theme illustrates the need to educate clients regarding the importance of routine medical care as a means of identifying issues in the initial stages of development, rather than as more serious conditions.

The second theme that emerged from the interview involves Lynne’s sense of gratitude, despite the grief that she continues to feel after her husband’s death. Throughout the interview, Lynne commented about how fortunate she was to be in good health, to be independent, to have a job that she enjoys, to have close family and friends, and to share a home with her father. She did discuss her feelings of depression and grief over the loss of her husband, but also described the positive experiences that she shared with him. Lynne noted that she works to maintain a positive outlook and pushes herself to remain in close contact with friends and family. Although it is difficult at times, these relationships remind her of all that she has to be grateful for and help her to keep daily trials in perspective.

This theme does not directly relate to the project research questions, but is of valuable to life care planners because it reinforces the notion that clients gain
confidence and satisfaction when they have access to the resources necessary to resume their pre-injury goals, activities, and lifestyles. Although the role of the life care planner is not that of case manager, plan recommendations should reflect a consideration of the equipment, training, services, and other items necessary to achieve personal goals and to maintain a satisfying quality of life. The ability of a life care planner to directly affect the psychological wellbeing of a client may be limited, but recommendations for psychological counseling and other support services may assist in the development of critical adjustment skills and behaviors that will enhance quality of life and of interpersonal relationships.

Case Five: Edward

Demographic Information

In February 1988 at the age of 16 years, this male sustained a T12 complete spinal cord injury as the result of a motor vehicle malfunction while driving. His life care plan was developed in 1989, 1 year following the onset of injury. Edward (not his real name) is currently 36 years of age and it has been 19 years since the injury occurred; 18 years have passed since his life care plan was developed. He was not married and did not have children at the time of the injury, but is currently married and adopted a daughter as a newborn in 2000. He was in high school at the time of the injury and is currently working as an accountant in his family-owned and operated residential construction business.
Edward shares a house with his wife and daughter, and he is able to access all rooms in the home. The home has an open floor plan, but doorways were widened and two walls in the master bathroom were removed to allow for access to the toilet and bath areas. Floor-level cabinetry in the master bathroom and kitchen were removed to allow for wheelchair access, the island work space in the kitchen was lowered, and shelving in storage closets throughout the home and in the garage have been lowered. Two exterior ramps allow access through the front and back patio doors. When considering homes to purchase, he sought floor plans that were adequate and would require few modifications.

General Health and Lifestyle

Over the past 5 years, Edward believes that his general health has stayed about the same, and he has required about the same number of hours of personal assistance per week. He noted that he has consulted with his primary care physician more frequently over the past 5 years, primarily because he is taking the initiative to address minor problems before they become more serious. He noted that he has no major difficulties, but has begun to experience more minor health complaints than in previous years. He attributes this to the natural aging process and suspects that his health may not be as good as it could have been if he had addressed minor health issues more proactively in previous years. Edward also noted that his current physician is the best that he has ever had. He is comfortable consulting with him and does not hesitate to make appointments as necessary.
Edward does not consume alcohol, cigarettes, or recreational drugs, but noted that there are lifestyle habits that may be negatively contributing to his health; specifically, a tendency to neglect a healthy diet, inconsistent exercise, and lack of physical activity. He is approximately 30 pounds overweight.

**Personal Assistance**

Edward does not currently require any attendant care, and his wife assists occasionally with minor tasks, as needed. He is entirely independent in all self-care and activities of daily living and, with the exception of heavy home maintenance, he is also independent in all household tasks such as laundry, dusting, and light cooking. Edward uses a manual wheelchair as his primary mode of locomotion, but is able to ambulate with crutches for short distances.

He drives a Pontiac mini-van with hand controls and noted that it can be serviced by a local mechanic, if needed. There is no wheelchair lift or ramp, and he folds the wheelchair for stowage when driving. He completed a driving course soon after the injury. When prompted, he did not report having any barriers to his participation in community, social, or leisure activities.

**Medical Evaluations and Case Management**

Edward does not recall ever having completed a comprehensive spinal cord injury evaluation and does not believe that such an evaluation is necessary because he has remained in good health since the injury. He is not currently receiving any
case management support and does not believe that it would be of value to him because he feels comfortable managing his own care. However, this support may have been helpful soon after the injury, particularly in coordinating health care, medical follow-up, rehabilitation, and other services.

Edward explained that the most important source of support after the injury was provided by his family. He explained that his parents were stable, financially secure, and encouraging. Because of this, Edward believes that he had many more opportunities than some of his peers, and he was fortunate to have a large social network that facilitated his adjustment. His friends and family did not dwell on the injury, but moved forward in a positive way. He commented, “The best thing about the events afterward was that my family’s expectations didn’t change.” Edward explained that he went on a mission trip after the injury and expected that he would have a family of his own, work, achieve goals, and live his life as he had planned prior the injury. Edward reiterated the importance of his family’s support and believes that he was able to accept the challenges following his injury because the event was not treated as though it precluded him from having a fulfilling, healthy future. He summarized by commenting, “I didn’t expect any less of myself.” Edward was not able to identify any services that would be of value to him currently, but did note that he refers to the Internet as an information resource and talks with others about health and lifestyle issues.
Edward is an accountant and explained that few worksite accommodations are necessary. The office building is fully accessible, and there are no stairs. The men’s bathroom door was reversed so that it swings outward and can accommodate his wheelchair. Edward noted that this was not necessary because he has a pair of crutches that he can use for walking short distances, but it was an accommodation that was easily completed. He has not referred back to the life care plan that was developed, neither in recent nor in past years, and is unsure how it was utilized in the legal case.

Physician Visits

Edward schedules his own physician appointments and pays for visits through a private insurance company that is available through his employer. He has a PPO policy and consults with his primary care physician every other month. He has not encountered any restrictions regarding the frequency of visits, consultation or lab fee payment, or similar issues that may impact receipt of care. He described his relationship with his primary care physician as “excellent” and believes that he is open and knowledgeable. His insurance plan allows him to make appointments with specialists without a direct referral from his primary care physician, though visits must be pre-approved by the carrier. He has not attempted to consult with any specialists without a referral to date. Edward believes that he is receiving adequate care and education and can consult as often as necessary. His physician is his primary source of health related information. He consults with a
urologist one or two times per year, but does not see any other specialists on a regular basis. Edward does not visit a dentist any more frequently than is recommended for the general population; two times each year.

Edward explained that his insurance policy changed about 2 years ago and he had been a member of an HMO. It was a terrible experience. He had to work through an insurance representative to get approval for scheduling appointments and receiving treatment. In one instance, such approval took 4 weeks and was a substantial disincentive for consulting with a physician for minor or preventative concerns. He commented, “I know that their job is to weed out the people who don’t really need to be seen, but most people’s problems are real. When you have to go through so many hoops, you get discouraged. Most people will just give up. The insurance company dictated who I should see and how often I should visit.” Edward noted that these problems are not present in all HMO plans, because he had an HMO policy while living in another state and had a very positive experience. Most all of his physicians were part of the approved network, and he did not have difficulty receiving timely approval for claims.

When asked to consider where his health ranked in terms of all of the other concerns of his life, Edward stated that it ranked 4 on a 10 point scale, with 10 being the most important issue in his life. He explained that there are so many other concerns that currently take priority, such as his daughter, work, his wife, maintaining his household, his aging parents, and other issues. He does not focus
on health issues unless he recognizes that there is a problem or has a scheduled physician appointment. He noted that he should probably focus on his health to a greater extent, but has noticed that health issues are becoming more important to him as he gets older. Since he has been in good health to this point, he believes that he has gotten into the habit of taking it for granted.

Subsequent Injury or Illness

Within the last 12 months, Edward has not visited the emergency room or been admitted to the hospital. Since the injury, he required an appendectomy in 2005 which was not related to the spinal cord injury and sought treatment for two spider bites in 2000. Treatment for the spider bites required intravenous antibiotics on the first occasion and a course of prescription medication on the second occasion. There were no long-term effects.

Currently, Edward’s primary health concerns are calluses that develop on back of his heels and escalate into sores. This has been a recurrent problem and may be related to the shoes he is wearing. He is also concerned about chronic pain management and has been given a referral for a neurology consultation. He has shooting pains from his buttocks through his lower back that occur 20 to 30 times per hour. He has been taking medication, which has helped to reduce the frequency and intensity of the pain, but he has noticed that the chronic nature of this problem has resulted in some psychological consequences. He explained that he has
become short-tempered, depressed, pessimistic, and less interested in pursuing activities that he once enjoyed. These feelings are not debilitating, but Edward does not want to allow them to become more pervasive or habitual, and he plans to follow-up with a neurologist as soon as possible.

New Technologies

For the past 3 months, Edward has been taking Tramadol for chronic pain, and it has worked well with no side effects. He was not aware of any other technologies that he is currently using that were not available at the time of his injury.

Concluding Thoughts

Since he has developed a trusting, positive relationship with his primary care physician, Edward explained that he is less hesitant to confront health concerns as they arise. This, in combination with the relative ease with which he is able to schedule visits through his insurance company, has prompted him to become more diligent about seeking preventative care, consistently consulting with his physician, and monitoring his lifestyle. Edward recently enrolled in the generic prescription drug program through Walmart, and this has resulted in substantial savings. Before enrolling, he was spending $85-90 each month for medication, but is now spending $10-12 per month. He noted that he learned of this discount program by accident and wondered why his physician did not suggest it. Although
he trusts his physician’s medical advice, he continues to have misgivings about the business of medicine that seems to capitalize on maintaining individuals in patient roles. He commented, “I know how pharmaceutical, insurance companies, and doctors make money and I sometimes wonder whether people with disabilities are just being used to build their wealth. I know that we may use more of the health resources than other people do, but the whole system seems to be rigged against those of us with disabilities.”

Analysis

A comparison between Edward’s current self-reported needs and the life care plan projections is presented in Appendix S.

*Personal Assistance*

The life care plan that was developed for Edward projected that he would require live-in attendant care services in a private residence beginning between the ages of 55 and 65 years through life expectancy. Weekly interior and exterior home maintenance services were recommended through life expectancy.

Edward is not yet 55 years old, so the recommendation for live-in attendant care noted in the life care plan cannot be assessed for consistency with his current needs. Currently, he reports that he lives in a private residence and is fully independent in all aspects of self-care and activities of daily living, is able to drive a vehicle, and requires few worksite accommodations. He does not hire any
attendant care, nor does he rely upon family or friends for personal assistance. The recommendation regarding weekly house cleaning services is inconsistent with his current needs as Edward reports that he is able to accomplish these tasks independently.

Physician Visits

The life care plan that was developed for Edward recommended that he would require annual inpatient and outpatient spinal cord injury evaluations and general physician visits for routine medical care. The plan also recommended visits with a urologist for routine monitoring two to three times per year, in addition to the urological assessments completed during the annual spinal cord injury evaluations.

Consistent with the recommendations made in the life care plan, Edward consults with a urologist one to two times per year. Whereas the life care plan projected annual visits with a general physician, Edwards consults with him six times per year. He noted that he has consulted with his primary care physician more frequently over the past 5 years, primarily because he is taking the initiative to address minor problems before they become more serious. Edward also noted that plans to consult with a neurologist regarding chronic pain. This need was not projected in his life care plan.
Emergent Themes

There are three primary themes that emerged from the interview that are of particular interest to life care planners. First, Edward expressed his frustration in working with insurance companies that required pre-approval for physician visits and other services. He noted that working through the approval process was a substantial disincentive for consulting with a physician when minor or preventative concerns arose. In addition to delaying the immediate need for medical care, Edward noted that this process may cause individuals to simply stop seeking preventative care until a major incident occurs or an issue is clearly evident. The recommendations cited in a life care plan are formulated to prevent, or markedly reduce, emergency situations from arising. Such crises often leave individuals with few treatment options, the need to take drastic measures in order to reverse the pathogenesis or symptoms, increased recovery costs, increased susceptibility to recurrence or to the development of secondary conditions, or put them at risk for sustaining permanent damage to affected body systems.

This theme is not directly related to the life care planning process because the planner cannot control the type of insurance plan selected, but it does highlight the need for clients to fully understand the reasons why specific types and frequencies of medical consultations have been recommended. Such information may encourage clients to more vigorously pursue the medical care that they require, despite obstacles, in an effort to maintain overall health and functional
independence to the degree possible. The planner can offer information about the primary similarities and differences between types of insurance plans, prepare them for common challenges, and provide resources for further exploration. However, in litigated cases, such advice is complicated by the fact that costs associated with plan recommendations are based upon the assumption that they will be paid from the proceeds of the lawsuit. The plan cites private pay rates for all routine consultations, evaluations, and invasive procedures because the development process does not take collateral resources into consideration when recommendations are identified. There is no guarantee that the client will receive the necessary settlement funding to purchase all of the items and services outlined in the life care plan. Regardless of the payment source, life care planners can assist clients in managing their own health care by providing them with information, educating them regarding their long-term needs, and emphasizing the value of preventative, routine medical care.

The second theme that emerged from the interview involves the importance of maintaining pre-injury goals. Edward explained that his family was the most critical source of support after his injury, and they encouraged him to pursue the plans that he had made prior to the injury. Consequently, Edward expected that he would have a family of his own, work, and lead a fulfilling life despite his injury. This expectation, the opportunities that his family was able to provide, and a large social network of friends, allowed Edward to resume activities of interest and to
pursue his long-term goals. Throughout the interview, Edward commented about the importance of his parent’s involvement and of their attitude immediately following the injury and in subsequent years. Because he was just 16 years of age when the injury occurred, the reaction of his parents has had a lasting impact upon his self-confidence, sense of purpose, and personal achievements.

This theme is not directly related to the project research questions, but is an important aspect of planning for the successful psychological adjustment of clients following injury. Family counseling and other resources are sometimes included in life care plans developed for young people because the value of this support system is recognized as being a critical factor in facilitating adjustment. Particularly when injury occurs at a young age, the entire family system is affected by the realities of daily care and assistance, shifts in roles and responsibilities, changes in relationships among siblings, health and medical issues, rehabilitation efforts, and other modifications that can cause distress. Support services may also be recommended during transition phases, such as graduating from high school, beginning a job search, starting college, moving from the family home, and during other periods of time when the family unit is impacted. The importance of family support cannot be overstated and, where applicable, planners may include family-focused recommendations as a means of promoting a positive adjustment following injury.
The third theme that emerged from the interview was that Edward is currently making a concentrated effort to attend to health issues and to seek medical care when minor issues are recognized. Since he has developed a trusting, positive relationship with his primary care physician, Edward explained that he is less hesitant to confront health concerns. This, in combination with the relative ease with which he is able to schedule visits through his current insurance company, has prompted him to become more diligent about seeking preventative care, consistently consulting with his physician, and monitoring his lifestyle. Although Edward ranks his health at 4 on a 10 point scale, with 10 being the most important issue. Throughout the interview he noted that he wants to maintain his current level of health and independence and intends to consistently consult with his primary care physician.

This theme is not directly related to the project research questions, but it is of interest to life care planners because it suggests that concerns regarding health fluctuate over time as various health issues arise and depending upon the attention that other life circumstances require. This theme illustrates the need to educate clients regarding the importance of routine medical care as a means of identifying issues in the initial stages of development, rather than as more serious conditions.
Case Six: Bonnie

Demographic Information

In April 1989 at the age of 43 years, this female sustained a T10 complete spinal cord injury as the result of a motor vehicle accident. Her life care plan was developed in 1996, 7 years following the onset of injury. Bonnie (not her real name) is currently 61 years of age and it has been 18 years since the injury occurred; 11 years have passed since her life care plan was developed. Bonnie was married at the time of the injury, but was in the process of divorcing her husband. She did not live with her husband at the time, and their divorce was final within approximately 6 months after the injury. She did not remarry. Bonnie had twin daughters who were 9 years old when she was injured, and a friend cared for them while she was participating in a 6 week inpatient rehabilitation program. She was not working at the time of the injury, but she returned to work for 3 months as a secretary at a local roofing company in 1998. Bonnie had a heart attack and did not return to work subsequently. The heart attack may have been prompted by a blood clot that formed when her leg was in a cast following a fall.

Bonnie is currently living alone in a house that she owns, and she is able to access all rooms in the home. It is the same house that she owned at the time of the injury. Following in the injury, an exterior ramp from her back porch to the back...
door was installed and additional storage areas were built at lower levels in her kitchen, bathroom, bedroom, and den.

General Health and Lifestyle

Over the past 5 years, Bonnie believes that her general health has stayed about the same, she has required about the same number of hours of assistance per week, and has required about the same number of physician visits. She consumes no alcohol, cigarettes, or recreational drugs. When prompted, she could not identify any lifestyle habits that may be contributing to her general health, either positively or negatively.

Personal Assistance

Bonnie is independent in all areas of self-care and activities of daily living, and she does not hire any attendant or home health care. She uses a manual wheelchair as her primary mode of locomotion, and she is able to accomplish a supported stand and pivot. Her nephew lives within three miles of her home, and he maintains her lawn, performs general home maintenance, runs errands occasionally (e.g., grocery shopping), and helps to complete various housekeeping tasks when necessary. Bonnie estimates that her nephew assists her 5 to 7 hours per week, in addition to the time required to complete lawn and home maintenance. In 1997, she hired an individual for approximately 6 hours per week to assist with house cleaning, laundry, and similar tasks through a local home health care agency.
Six months later, the agency went out of business, and she did not seek a replacement because she returned to work soon afterward.

Although she is currently able to do housework independently, Bonnie noted that it would be nice to have help. As she ages, routine tasks such as laundry and vacuuming have become more difficult, but she feels that she would like to continue performing these tasks for as long as she is able. She commented, “I know that it doesn’t make much sense, but somehow knowing that I am able to do these things myself gives me some way to be productive during the day. I don’t especially like doing housework, but I feel good that I can still do it on my own. I don’t want to pay someone else to do these things until I really need the help.” She does not have any difficulties in completing self-care tasks, dressing, grooming, or similar activities, but noted that it does take her longer to prepare in the morning, and she sometimes has trouble buttoning clothing and manipulating small fasteners. She attributes this to the aging process and noted that she may need to be evaluated for new prescription eyeglasses. Bonnie is somewhat concerned about how she will be able to accomplish general housework, errands, and personal care activities in the future, but she noted that when her needs escalate, there are local agencies who could provide support, and she does have the means to pay for such services.

Bonnie drives a two-door 1996 Oldsmobile vehicle with hand controls. She folds her wheelchair and stows it in the back seat while driving. She noted that she is able to accomplish this independently, but lifting her wheelchair into and out of
the vehicle is challenging. When prompted, Bonnie did not note any barriers to her participation in community, social, or leisure activities.

*Medical Evaluations and Case Management*

Bonnie does not recall ever having had a comprehensive spinal cord injury evaluation and does not believe that such an evaluation would be beneficial to her at this time because she feels healthy, even though she notices that some tasks require more time to complete than they once did. She surmised that this is part of the aging process and does not believe that a comprehensive evaluation would provide her with any more information than what she already knows. Bonnie is not currently receiving any case management support and does not believe that it would be of value at this time. However, she believes that this would have been helpful soon after the injury occurred and while she was transitioning home from the rehabilitation facility, particularly relative to coordination of medical care and therapy, application of compensatory strategies learned during rehabilitation, and identification of reliable information resources in the local community. When prompted, she could not identify any services that she felt would be of benefit to her currently.

Bonnie had a positive rehabilitation experience, and the information she learned has been useful since that time. Particularly helpful were the instructions pertaining to proper skin care, medical information about spinal cord injury, and
strategies for efficiently accomplishing activities of daily living. However, during the final 2 weeks of the residential program, she was moved to the end of the hall on the unit and received no assistance completing in any daily living activities and, in preparation for discharge, was expected to be fully independent. This transition was not introduced gradually enough for her, and she did not feel prepared to suddenly be independent. She was discharged with no case management support and had 9 year old twin daughters to care for at home. A friend lived with her for approximately 6 months until she was able to transition back to her home routine. Bonnie explained, “I learned a lot during rehab, but I didn’t feel like I was ready to take care of myself and my kids, plus everything else, when I got home. This was a big change and I just didn’t know how I was going to carry on once I healed and things started to get back to normal. In my case, I didn’t really have a husband who was there for me, so if it wasn’t for my friend, I don’t know what I would have done. You’re left on your own.” Bonnie explained that she did not seek case management support upon her return home because her friend had volunteered to assist her and because she did not want to pay for these services. She was concerned about her financial situation and did not view case management as a necessity. Bonnie noted that, with her divorce and personal injury case in progress, medical concerns, caregiving responsibilities, and other priorities, making contact with a case manager was not as important as attending to the immediate issues that existed. She has not referred back to the life care plan that was developed, neither
in recent nor in past years, and is unsure whether it was helpful in resolving the legal case.

**Physician Visits**

Bonnie schedules her own physician appointments and pays for visits through Medicare. She has not encountered any restrictions regarding the frequency of visits, consultation or lab fee payment, or similar issues that may impact receipt of care. She has consistently consulted with her primary care physician four times per year for routine follow-up visits. She described her relationship with his primary care physician as “good” and believes that she is receiving adequate care, is consulting with him as frequently as she would like, and has no limitations when scheduling appointments. According to her insurance plan, referrals to specialists must be facilitated through the primary care physician. When such referrals have been necessary in the past, her primary care physician was able to facilitate them, and Medicare has not denied any of her claims. She noted that her primary sources of health-related information are her physician and pharmacist.

Bonnie consults with a urologist annually and met with a neurologist two or three times soon after the injury. She sought an evaluation because she was experiencing lower back pain, and she was given prescription medication that was minimally effective. She has not visited a neurologist since. Bonnie received
psychological counseling during rehabilitation, but not afterward. She consulted with a cardiologist following a heart attack in 1998, but has not had an appointment with him since 2000 and does not anticipate consulting with him in the future. Bonnie does not visit a dentist any more frequently than is recommended for the general population; two times each year.

When asked to consider where her health ranked in terms of all of the other concerns of her life, Bonnie stated that it ranked 7 on a 10 point scale, with 10 being the most important issue. She commented, “I’ve got more to think about than my health but, knock wood, I’ve been healthy lately, so it’s not something that I’m worried about right now. As I get older, though, I do notice that I’m slowing down and that some things are harder to do than they used to be.”

Subsequent Injury or Illness

Within the last 12 months, Bonnie has not visited the emergency room or been admitted to the hospital. Since the injury, she had surgery on her left knee in 1994, and again on her left leg in 1995 resulting from falls from her wheelchair. She fell again in 1997 and broke her left leg. In 1998, Bonnie had a heart attack which may have been caused by clot that formed when her leg was in a cast in 1997. In 2002, she was hospitalized for approximately 1 week due to dehydration.

Bonnie explained that she has broken her left leg at least two times since her heart attack in 1998, but refuses to go to the emergency room or to seek
medical care. She fears that, if a cast is placed, she will be at risk for another heart attack, or something similar, and that she will develop ulcers on her heels. Bonnie stated, “The treatment is worse than the injury, and there is no way that I want to do anything that may make things even worse.” She noted that she has experienced no side effects or consequences of not having sought medical attention for her broken leg. She has lower back pain, but notes that it is not severe and she does not take prescription medication for it. When necessary, she takes Tylenol. Bonnie’s primary health concerns are osteoporosis and irritable bowel syndrome. She takes Actonel and calcium for osteoporosis, and her irritable bowel condition is fairly well controlled through diet.

New Technologies

When prompted, Bonnie did not identify any new technologies that she is currently using that were not available at the time of her injury.

Concluding Thoughts

Bonnie is not hesitant to seek routine medical care from her physician, but she is very fearful of being submitted to treatments that may actually cause her more harm than the original complaint. For example, the probability that her heart attack was precipitated by the placement of a leg cast has caused her to be reluctant to seek medical attention, even when such attention may be necessary and recommended. She explained that she has become more careful when engaging in
any physical activities because her primary care physician recently told her that if she should break a hip, she will have to be put into a body cast. This, she explained, would be unbearable.

Analysis

A comparison between Bonnie’s current self-reported needs and the life care plan projections is presented in Appendix T.

Personal Assistance

The life care plan that was developed for Bonnie recommended that she would require attendant care services in a private residence for 4 to 6 hours per day from the time of the injury through age 64 years, and then live-in attendant services from age 65 years through life expectancy. Two to 4 hours per month of case management support and weekly interior and exterior home maintenance services were recommended through life expectancy.

Bonnie is not yet 65 years old, so the recommendation for live-in attendant care noted in the life care plan cannot be assessed for consistency with her current needs. Currently, Bonnie’s personal assistance needs are inconsistent with the recommendations made in the life care plan, though she does live in a private residence. She is independent in all areas of self-care and activities of daily living. She does not hire any attendant care and is able to operate a vehicle independently. Consistent with the plan recommendations regarding home maintenance, Bonnie’s
nephew maintains the lawn and completes minor home repairs as necessary. Her
nephew also assists her on occasion by running errands and completing various
household chores. The 5 to 7 hours per week of assistance that her nephew
provides differs substantially from the 28 to 32 hours of assistance per week that
was projected in the life care plan. Inconsistent with the plan, Bonnie is not
currently receiving case management services and does not believe that such
support is necessary. However, she noted that case management services may have
been valuable following the injury, during rehabilitation, and as she transitioned
back into her daily routine.

Physician Visits

The life care plan that was developed for Bonnie recommended that she
would require annual outpatient spinal cord injury evaluations and annual visits
with an orthopedic surgeon to evaluate for orthopedic injuries and monitor care
through life expectancy. The plan recommended biannual visits with a general
physician for routine medical care, a physiatrist to monitor for issues associated
with the spinal cord injury, and a urologist to monitor the urological system. Also,
three to four visits per year with a psychiatrist to monitor psychotropic medication
use, and six to eight visits per year with a podiatrist for nail care were
recommended.
Bonnie’s current health care regimen is inconsistent with the recommendations for physician visits cited in the life care plan. She did not report having completed annual outpatient spinal cord injury evaluations, or to be currently consulting with an orthopedic surgeon, physiatrist, podiatrist, or psychiatrist. Bonnie’s insurance plan requires that referrals to specialists are initiated through the primary care physician, so perhaps consultations within these specialties have not been deemed necessary by her primary care physician. She is not taking any antidepressant or other psychotropic medications, but noted that she did for a period of approximately 2 years following the injury. Consistent with the plan, she does consult with a general physician but, with visits four times per year, this exceeds the frequency projected in the life care. Similarly, she does consult with a urologist, but on an annual basis, rather than biannually as projected in the life care plan.

Emergent Themes

There are two primary themes that emerged from the interview that are of particular interest to life care planners. First, Bonnie described feeling as though the transition between rehabilitation and her discharge home was not gradual enough to fully prepare her for the realities of coping with the physical and psychological adjustment following her injury while simultaneously resuming her parenting and household responsibilities. She explained that case management services would have been helpful to her when she returned home, particularly
relative to coordination of medical care and therapy, application of compensatory strategies learned during rehabilitation, and identification of reliable information resources in the local community. Bonnie’s concerns following discharge were compounded by the fact that she had two young children at the time and was in the process of divorcing her husband.

Case management was recommended in Bonnie’s life care plan through life expectancy, though the plan was not developed until 7 years after her injury. At that point, Bonnie would have already transitioned from the rehabilitation facility back into her home. Bonnie reported that case management support is not a current need, but she did express that it was a need following discharge from her rehabilitation program. Bonnie explained that she did not seek case management support because she was concerned about her financial situation and had other priorities to attend to when she returned home. This instance illustrates the importance of including case management support in life care plans, particularly in situations where the physical and psychological wellbeing of an individual may be impacted by factors beyond those directly related to the injury. Further, such support may be critical in maintaining the stability of the family unit, particularly when young children are involved. It is not possible to determine whether case management support may have improved outcomes related to personal care or medical follow-up, but Bonnie noted that these services would have been helpful as she transitioned home from her rehabilitation program. Given her current views
regarding medical care, a knowledgeable case manager may be a valuable resource regarding treatment options, the importance of preventative efforts, and other health related information.

The second theme that emerged from the interview involves Bonnie’s fear of the possibility of future invasive treatment. She attributes her heart attack in 1998 to a blood clot that formed when her left leg was placed in a cast as the result of a broken bone. Bonnie reported that she has broken her left leg at least two times since her heart attack, but she refuses to go to the emergency room or to see medical care. She fears that, if a cast is placed, she will be at risk for another heart attack, or something similar. For Bonnie, the risks involved in seeking treatment outweigh the perceived benefits of having her broken bone reset. Even so, Bonnie reports that she does consult with her primary care physician four times per year and with a urologist annually. She is not opposed to maintaining routine consultations. She is more cautious when engaging in physical activities because she wants to preserve the level of functioning that she now has and wants to remain as independent as possible. In addition, she fears that additional broken bones, specifically, a broken hip bone, will necessitate the placement of a full body cast. Bonnie noted that such immobilization and loss of independence would be devastating to her. This, combined with the fear of the possibility of subsequent medical issues, causes her to avoid seeking medical attention for issues that she believes may require invasive or extensive treatment.
One of the guiding tenets of life care planning states that complications cannot typically be accurately projected. As such, known complications relative to spinal cord injuries may be noted and described for educational purposes, but associated costs are not calculated into the overall economic projection. Bonnie’s history of broken leg bones, her heart attack, hospitalization for dehydration, and concern regarding irritable bowel syndrome are not recognized as common complications directly related to spinal cord injuries and would not have been discussed within her plan. Osteoporosis and similar bone-related conditions are complications that are known to develop as a result of a spinal cord injury, but could not have been reasonably projected at the time that the life care plan was developed. Bonnie’s willingness to seek routine medical care is compatible with the proactive nature of the life care plan, but her avoidance of recommended invasive treatment could jeopardize her health in the future. Her primary care physician have discussed this issue with Bonnie but, ultimately, she controls the course of treatment that she is most comfortable in pursuing.

Case Seven: Evelyn

Demographic Information

In October 1988 at the age of 18 years, this female sustained a T6-8 complete spinal cord injury as the result of a moped accident. Her life care plan was developed in 1992, 4 years following the onset of injury. Evelyn (not her real
name) is currently 37 years of age and it has been 19 years since the injury occurred; 15 years have passed since her life care plan was developed. She was not married at the time of the injury, but is currently married. She did not have children prior to the injury, but now has a one year old daughter. She was not working at the time, but earned three four-year college degrees (a bachelor’s degree in French, a master’s degree in Art History, and a master’s degree in Museum Education) following the injury. She has held various positions in art museums, art galleries, and nonprofit organizations. Most recently, she worked as a program manager for the American Association of Museums until June 2007.

Evelyn is currently living in a condominium with her husband and daughter. She is able to access all rooms in the condominium, and it is on the second floor of a four-story building. There is an accessible elevator from the below-ground parking garage into the building. Since the injury, she has lived in various cities (and abroad) and has been able to select apartments that are accessible, even while attending college and living in campus housing.

*General Health and Lifestyle*

Over the past 5 years, Evelyn believes that her general health has declined. Although there have been no serious issues, she has had some minor concerns and she noted that she feels that her confidence in her health has declined. These minor instances, the pregnancy and the birth of her daughter, and the fact that she is
getting older has prompted her to become more focused on her overall health. Consequently, the number of annual physician visits has also increased, although reasons for such are not specifically related to complications associated with her spinal cord injury. Over the past 5 years, she has required about the same number of hours of assistance per week, though she has been fully independent in all self-care tasks and activities of daily living since the injury.

Evelyn consumes no alcohol, cigarettes, or recreational drugs and, when prompted, could not identify any specific lifestyle habits that may be positively or negatively contributing to her general health. It has been difficult to attend to her own needs over the last year while also working full-time and caring for her infant daughter. She recently resigned from her job because she was not able to adjust her work schedule so that she could attend physical therapy, medical appointments, and other health-related meetings during the day. She noted that this is a significant issue for individuals with chronic health problems and permanent disabilities because employers may not be willing to make work schedule accommodations and, ultimately, an individual’s earning power may be substantially diminished. She stressed that she and her husband are fortunate enough to be able to remain financially stable on one income, but knows that this is not the case for all individuals with spinal cord injuries.
**Personal Assistance**

She is fully independent in self-care and all aspects of daily living. Evelyn’s husband assists as necessary, but she does not hire any attendant care. She uses a manual wheelchair as her primary mode of locomotion. Evelyn stated that it would be nice to have a personal assistant for 3 to 5 hours per week who could complete some of the routine household tasks (e.g., grocery shopping, house cleaning, running errands, etc.), but noted that this is primarily because she is getting older and is also taking care of her daughter. Evelyn hires a nanny who is available for childcare 8 hours per day.

Evelyn did not require any worksite accommodations, but did have difficulty attending health-related appointments given her inflexible work schedule. After the birth of her daughter 1 year ago, she returned after an 8 week maternity leave, but was not able to continue working full-time while managing her personal responsibilities at home. She would like to find a part-time job that will afford her more flexibility while her daughter is young.

Evelyn drives a station wagon with hand controls and dissembles the wheelchair for stowage. She had a brief driver’s education session while in rehabilitation. Generally, she does not have any difficulty accessing public areas, but noted that she occasionally encounters older buildings and residences that are difficult to access without assistance. Several years ago, Evelyn worked for a historical society and would sometimes be required to visit older, historically
significant homes that had not been retrofitted to comply with modern accessibility codes.

*Medical Evaluations and Case Management*

She does not recall having completed a comprehensive spinal cord injury evaluation since she participated in a residential rehabilitation program after her injury. However, in 2005 her primary care physician referred her to a physiatrist who specializes in spinal cord injury, and she has met with him twice. She is not experiencing any difficulties at this time, but wants to establish herself as a patient so that she can more closely monitor changes in her health in the future. She did not receive case management support following her injury, nor is she currently. However, she believes that such support would be of value to her because she is concerned about maintaining her health and is aware that there are specific complications related to spinal cord injury that, left undiagnosed, could result in substantial, long-term consequences. Aside from case management support, Evelyn did not identify any additional services that would be of benefit to her currently.

Evelyn explained that she has had difficulty when working with insurance companies to approve claims for necessary equipment. She often spends money out of her own pocket to avoid having to wait through the claims process. The lack of customer service offered by the insurance companies that she has dealt with over
the years has been particularly frustrating. For example, she is currently waiting for a new wheelchair back that was ordered 4 months ago, and she has not heard anything about the claim from her insurance company. Now, she will have to call the company to follow-up on the claim and will either have to wait for a response if they are able to locate her original claim, file a duplicate claim if they are unable to locate the original, or file an appeal if the claim has been denied without her knowledge.

Evenlyn explained that, because she is a strong self-advocate, she is typically able to get what she needs, but she worries about the experience of others who do not have the information necessary to obtain essential equipment and services. She also noted that it is particularly frustrating to have to work through an intermediary when ordering medical equipment. She believes that she knows what she needs and resents being treated as though the insurance company knows what is best for her. She commented, “The insurance companies have rules that they have to follow, but they do not take the knowledge and the intelligence of the policy holder into account. I’ve been a paraplegic for many, many years and I know what is going to work best for me. I know when a part on my wheelchair needs to be replaced. Rather than just accept my word for it, they send an evaluator to my home to verify that it is, indeed, necessary. Of course, these people have to come during the work day and can only give you a general time period, like between one o’clock and five o’clock, so you have to take time off from work to
wait for them to tell you what you already knew. It is very frustrating and that’s an example of why I just could not continue to work full-time right now.”

Lack of choice in equipment and suppliers is another issue that has presented difficulty for Evelyn. Approved vendors are selected by the insurance company, so when they complete an assessment, they typically only promote the equipment that their company sells. Therefore, there is no way for the consumer to compare the quality and utility of products across brands. Evelyn stated that this, in combination with the length of time and convoluted process involved in getting an insurance claim approved, is a significant barrier to obtaining appropriate, high quality medical equipment. She noted that a case manager may be very helpful in navigating the insurance system and in identifying equipment and services that would be of benefit. Evelyn has not referred back to the life care plan that was developed and did not realize that one had been written during her legal case.

**Physician Visits**

Evelyn schedules her own physician appointments and they are paid for through a private insurance policy available through her husband’s employer. She has not encountered any restrictions regarding the frequency of visits, consultation or lab fee payment, or similar issues that may impact receipt of care. From approximately 1995 through 2001, she did not have a primary care physician, but for the past 5 years she has been consulting with him three to four times per year.
She described her relationship with her primary care physician as “okay,” but noted that the physician does not have expertise in the area of spinal cord injury. She believes that she is receiving adequate care, is consulting with him as frequently as she would like, and has no limitations when scheduling appointments. However, in addition to the general care she is receiving from the primary care physician, she believes that she also needs to consult with a spinal cord injury specialist who can monitor her health and proactively address any changes that may occur over time. Her insurance plan allows her to schedule appointments with specialists without a direct referral from a primary care physician, though visits must be pre-approved by the carrier.

She stated that she is receiving adequate care because she is advocating for it and has adequate insurance coverage. She is not, however, receiving the kind of health care management and coordination of services that she feels she needs. For example, she would like to be able to work with someone who was able to verify that she is consulting with appropriate specialists, to recommend new or different equipment that may better suit her needs, to be certain that the recommendations made by physicians are compatible with one other, to ensure that she is receiving holistic care, and to act as a general resource. She noted that her primary source of health-related information is her physician and the Internet.

Since 2005, Evelyn has consulted with a physiatrist one to two times per year. He cannot be designated as her primary care physician, but she will continue
to have, at minimum, annual consultations. She has not consulted with a urologist since the injury, but her physiatrist has recommended that she do so. When asked to consider where her health ranked in terms of all of the other concerns of her life, Evelyn stated that it ranked 9 on a 10 point scale, with 10 being the most important issue. She commented, “Because, ultimately, having good health means that I can take care of the other things. I need to be more conscious of my health and, now that I have quit my job, it will be easier for me to do physical therapy and to make appointments as I need to.”

Subsequent Injury or Illness

Within the last 12 months, she has visited the emergency room three times with symptoms resembling autonomic dysreflexia. These symptoms resolved and, upon evaluation, it was found that they are related to bowel activity. With the exception of giving birth, she has not been admitted to the hospital. There were no complications during her pregnancy or associated with her daughter’s birth. Evelyn’s daughter was born of normal weight and in good health at delivery.

Since the injury, Evelyn has not experienced any complications related to the spinal cord injury, but noted that she develops a urinary tract infection approximately once per year. In 1989 she had surgery to replace a rod in her spine, then the rod was subsequently shorted in 1997. She gave birth 1 year ago, developed an inner ear condition similar to vertigo between 2000 and 2004, and
developed a fistula in 2006 which was deemed to be unrelated to the spinal cord injury. Evelyn’s inner ear condition has resolved, and there were no long-term repercussions from any of these instances.

Evelyn noted that her primary health concern is a basic fear of what may be developing that she is unaware of, or not taking adequate precautions to prevent from escalating into serious issues. The fact her fistula was initially, and for a period of several months, misdiagnosed as a pressure sore contributes to her health concerns and to her fear that she may develop a condition which will be overlooked by physicians. This instance has reinforced her belief that she needs to pursue regular consultations with a physiatrist who specializes in spinal cord injury.

New Technologies

Evelyn bought a Parastep system, a functional neuromuscular stimulation system, in approximately 2000 and will soon be using it more frequently when she resumes physical therapy. She experienced some peripheral benefits (e.g., increased stamina, improved breathing) when she was exercising with it more consistently a couple of years ago. She needs to have assistance while using it and plans to work with a physical therapist two to three times per week. Also, Evelyn orders supplies through the Internet and is using a patch as a substitute for Detrol and Ditropan to control bladder spasms. It is not as effective as Detrol, but there are no side effects.
Concluding Thoughts

Evelyn reiterated the need for individuals with spinal cord injuries to be educated about their rights and to be strong self-advocates. She credits some of her early therapists and professionals who assisted her throughout the rehabilitation process with giving her the information and strategies that she needed to be able to accomplish her personal and career goals. However, she feels strongly that changes in the current insurance policy and claims process are necessary. She explained, “Things are complicated enough without having to battle an insurance company for equipment that you are entitled to. I sometimes wonder whether my health and general level of functioning may be better or worse, depending on the insurance company that my employer, or my husband’s employer, happens to have. I’ll never know, but I wonder whether there are things out there that may make my life easier that I’ll never hear about because they are not an approved part of my insurance plan. Then, I worry about whether I’m really getting good medical care. Again, how would I know?”

Analysis

A comparison between Evelyn’s current self-reported needs and the life care plan projections is presented in Appendix U.
**Personal Assistance**

The life care plan that was developed for Evelyn recommended that she would require live-in attendant care services in a private residence beginning between the ages of 50 and 60 years. Weekly house cleaning services were recommended from the age of injury through life expectancy.

Evelyn is not yet 50 years old, so the recommendation for live-in attendant care noted in the life care plan cannot be assessed for consistency with her current needs. Currently, she reports that she lives in a private residence, is fully independent in all aspects of self-care and activities of daily living, and is able to drive a vehicle. She requires no environmental worksite accommodations, but noted that she needs to have a flexible work schedule in order to attend health-related appointments. She does not hire any attendant care, nor does she rely upon family or friends for personal assistance. The plan recommendation regarding weekly house cleaning services is inconsistent with Evelyn’s current needs as she stated that she is able to accomplish household tasks. However, she did note that 3 to 5 hours of assistance with these routine tasks would be helpful.

**Physician Visits**

The life care plan that was developed for Evelyn recommended that she would require annual outpatient spinal cord injury evaluations from the time of the injury through life expectancy, and then annual inpatient spinal cord injury
evaluations beginning at age 40 through life expectancy. One to two general physician visits and urologist visits for routine medical care per year were recommended.

Evelyn has not completed outpatient spinal cord injury evaluations, which is inconsistent with the recommendation made in the life care plan. She does consult with a general physician but, with three to four reported visits per year, this is more frequently than projected in the life care plan. Evelyn is not currently consulting with a urologist, but noted that her general physician has recommended that she do so. This is consistent with the urology recommendation made in the life care plan. She has recently begun consulting with a physiatrist one to two times per year, but this need was not projected in the life care plan.

Emergent Themes

There are two primary themes that emerged from the interview that are of particular interest to life care planners. First, Evelyn described the frustration of working with insurance companies to approve claims for necessary equipment. She often spends money out of her own pocket to avoid having to wait through the claims process and noted that the lack of customer service offered by the insurance companies is particularly counterproductive. Evelyn described herself as a strong self-advocate and noted that she is typically able to get what she needs, but resents being treated as though the insurance company knows what is best for her. She
also expressed disappointment regarding the lack of choice in equipment and suppliers because the approved vendors are selected by the insurance company. When an equipment assessment is completed, the vendor typically promotes only those items that their company sells. Therefore, there is no way for the consumer to compare the quality and utility of products that may be available from a variety of vendors. Evelyn stated that this, in combination with the length of time and convoluted process involved in getting an insurance claim approved, is a significant barrier to obtaining appropriate, high quality medical equipment. She noted that a case manager may be very helpful in navigating the insurance system and in identifying equipment and services that would be of benefit.

This theme is not directly related to the life care planning process because the planner cannot control the type of insurance plan selected by clients. However, planners can help to educate clients regarding the primary similarities and differences among types of insurance, prepare them for common challenges, and provide resources for further exploration. A knowledgeable case manager may also be a valuable resource for individuals who or are long-term users of equipment, assistive technology, or aides for independent functioning. As Evelyn noted, clients may only be presented with a limited range of equipment if they are relying upon their insurance provider to purchase necessary items. Depending upon specific policy restrictions, alternate equipment may be approved if adequate
justification for its purchase can be documented, but this process is time-consuming and not always intuitive to the client.

The second theme that emerged involves Evelyn’s desire to become more focused on her overall health. Although she has experienced no major health issues since her injury, recent minor instances, the pregnancy and the birth of her daughter, and her age have prompted Evelyn to take an increased interest in her physical health. Evelyn noted that her primary health concern is a basic fear that she may be developing a condition that she is unaware of, or not taking adequate precautions to prevent from escalating into serious issues. In relation to all of the other concerns in her life, Evelyn stated that her health ranked 9 on a 10 point scale, with 10 being the most important issue. She mentioned that it was difficult to attend to her own needs over the last year while working full-time and caring for her infant daughter. She recently resigned from her job because she was not able to adjust her work schedule so that she could attend physical therapy, medical appointments, and other health-related meetings during the day.

She intends to begin a regular Parastep system exercise regimen with the guidance of a physical therapist. In addition, Evelyn has started consulting with a physiatrist. Although she is not experiencing any difficulties at this time, Evelyn wants to establish herself as a patient so that she can more closely monitor changes in her health as she ages and proactively address issues as they arise. As noted with regard to equipment issues, she believes that case management support would also
be of value to her in managing her health. Evelyn is concerned about maintaining her present level of functioning and is aware that there are specific complications related to spinal cord injury that, left undiagnosed, could result in substantial, long-term consequences.

This theme is of relevance to the life care planning process because recommendations within this category are founded upon input from members of the treatment team, clinical practice guidelines, and research findings. The frequency of visits and specialties specified in the plan are meant to provide individuals with adequate care to monitor for changes in status over time and to prevent, or substantially reduce, occurrences of serious illness. Evelyn noted that she has taken steps to focus more specifically on maintaining her health and, consequently, these goals are more closely aligned with the guiding principles of the life care planning process. She is seeing a general physician more frequently than was projected plan, has initiated consultations with a physiatrist, intends to begin an exercise regimen, and believes that case management services may be beneficial in managing her health. Life care planners can educate clients regarding the value of preventative, routine medical care by clearly describing the reason for each recommendation. With this understanding, clients may be more apt to refer to and comply with the recommendations made in the life care plan.
Summary

The purpose of this study is to consider how accurately each participant’s individualized life care plan projected his or her current need for personal assistance and consultation with general and specialty physicians. Further, researchers are interested in understanding the lived experiences of study participants and in exploring emerging themes that may have relevance to the life care planning process. In addition to collecting data relevant to personal assistance and physician consultations, the interview process was designed to gather information regarding outcomes and other factors that may impact these two categories of the life care plan. Each of the case studies reveals areas where life care plan projections were both consistent and inconsistent with current needs as reported by the participants. Chapter 5 will discuss the relevance of these findings, of emergent themes, and of other issues impacting the methodology and processes applied to the life care planning process.
CHAPTER 5
DISCUSSION

The present study represents an initial attempt to better understand and describe the lived experiences of individuals with spinal cord injuries for whom life care plans were developed. At the center of the present investigation, researchers were interested in comparing each participant’s self-reported needs to those projected in their individualized life care plans within two specific categories; personal assistance and routine medical care. With just 7 study participants, it is not possible to assert summative conclusions regarding the reliability or validity of life care planning methodology, but the information gathered will be helpful in building an understanding of the post-injury experiences of individuals with spinal cord injuries, enhancing service delivery, and developing future research studies. The design of the present study allowed researchers to engage in authentic conversations with participants while considering how well their life care plans projected their current needs.
The co-investigator is a certified life care planner and completed a mentorship with the practitioner whose case load was utilized in the present study. Given this professional background, it is recognized that, if bias exists, this researcher may have unintentionally represented the current needs reported by participants as being more consistent with those projected in the life care plan than was actually true. In an effort to minimize this threat to the internal validity of the study, this issue was addressed throughout the data collection and analyses processes. The co-investigator actively assessed the accuracy with which case study summaries were described, enlisted the assistance of the participants to ensure that data was correctly recorded during the interview, and considered rival explanations for the conclusions reached. Further, in Chapter 4, researchers disclosed the primary source information that provides the foundation for the conclusions reached. Each interview was summarized and comparisons between each participant’s reported needs to those projected in their life care plans were provided to the reader in the document tables. Having access to this source information, readers have the ability to consider the credibility of the conclusions drawn by the researchers.

Summary of Findings

All of the findings summarized in the following section were self-reported by the participants as part of the interview process. The researchers did not conduct any observations, verify the participants’ accounts against those of close
family members, or engage in any other form of data triangulation as a means of evaluating the accuracy of the information provided.

Demographics

Demographic information is summarized in Appendix V. Seven individuals with spinal cord injuries participated in the present study; 4 participants were female, 3 participants were male. Levels of injury included one at C5-6, five between T2 and T12, and one at L1-T11. Five injuries were complete; two were incomplete. Five injuries resulted from motor vehicle accidents, one from a moped accident, and one from a work-related fall from a height of approximately 28 feet. Age at injury range from 16 years to 45 years and the length of time since the life care plan was developed range from 11 years to 23 years. The current ages of participants ranged from 36 years to 61 years.

One of the participants was married at the time of the injury, and 1 was in the midst of a divorce. Since then, 1 participant divorced, and 3 are currently married. Two participants had children at the time of the injury and 2 had children post-injury. All of the participants currently live in a private residence, and 5 live in a home with family members. One participant has 24 hour attendant care, and 1 participant lives alone, but a family member is within three miles of her home. Five participants returned to work at some point after the injury, and 2 earned post-
secondary degrees. Six participants are able to drive independently with vehicle modifications, and 1 owns a vehicle that can be driven by attendants.

General Post-injury Outcomes

All participants reported that they are currently receiving adequate personal assistance and medical care. In cases where more personal assistance hours were recommended in the plan than participants indicated was currently necessary, participants did not indicate that lack of funding for such assistance was the reason for this discrepancy. They noted that additional hours of assistance were not necessary. All participants reported having some form of health insurance. Five participants are insured through Medicare, and 2 receive medical care benefits through an employer sponsored program. None of the participants reported the need to see a dentist any more frequently than recommended for the general population; two times per year.

When asked about the status of their general health over the past 5 years, 3 participants indicated that it has stayed about the same, 3 indicated that it has declined, and 1 indicated that it had improved subsequent to the removal of a non-functioning kidney. All participants indicated that there has been no change in the number of personal assistance hours per week required over the past 5 years. Five participants indicated that the number of physician visits required per year has increased over the past 5 years; 1 indicated that the number remained the same, and
indicated that the number has decreased. None of the participants reported using non-prescription drugs, alcohol, or cigarettes; even on an occasional basis.

Three participants noted that lack of exercise and an unhealthy diet may be negatively impacting their current general health. Of these, 1 participant believed that her health may be further impacted by her emotional state subsequent to the death of her husband and mother. One participant attributed his good health to the fact that he stays physically active and maintains a healthy diet. When prompted, 3 participants were not able to identify any specific lifestyle habits that may be positively or negatively impacting their general health. When asked to consider where their health ranked in terms of all of the other concerns of their lives, responses ranged from 4 to 9 on a 10 point scale, with 10 being the most important issue. Although it was recommended in two life care plans, none of the participants are currently receiving case management support. None of the participants have referred back to their life care plan since it was developed.

When asked to describe their relationship with their primary care physician, 2 participants indicated that it was “excellent,” 1 indicated that it was “very good,” 3 indicted that it was “good,” and 1 described it as “okay.” Two participants explained that they did not believe that their primary physician had specific training or extensive experience in managing the outcomes and complications associated with spinal cord injury. The remainder felt comfortable discussing injury-related issues with their physician, and 1 participant noted that he has consulted with the
same physician since the injury occurred. The participants’ primary sources of health-related information included their primary care physicians, pharmacists, the Internet, and the training that they received during rehabilitation.

Regarding subsequent injuries or illnesses, 3 participants have experienced autonomic dysreflexia, 5 participants have experienced recurring urinary tract infections, and 2 participants have developed heterotopic ossification since their life care plans were developed. Other injuries and illnesses included: sepsis, the loss of use of dominant arm following an unsuccessful surgical intervention, a broken foot resulting from a fall, serious sunburn, arched feet, a broken toe due to the foot slipping from the wheelchair rest, the development of carpal tunnel as the result of overuse, spider bites, a heart attack that may have been caused by a clot that formed when the participant’s foot was in a cast, the development of an inner ear condition similar to vertigo, and a fistula.

The current primary health concerns reported by participants included: urinary tract infection, autonomic dysreflexia, heterotopic ossification, chronic lower back pain with accompanying psychological difficulties, the possibility of having developed a neurogenic bladder, calluses that develop on back of the heels and escalate into sores, and the development of carpal tunnel syndrome that has resulted in diminished function, strength, and range of motion in the shoulders, arms, and hands. Two participants noted that they are not concerned about any major issues in particular, but they are not certain whether they would recognize the
minor signs and symptoms that may quickly progress into more serious conditions. They worried that they may be developing an unrecognized condition and not taking adequate precautions to prevent it from progressing into a more serious issue. One participant expressed concerns about being subjected to treatments that may actually cause more discomfort and long-term functional limitations than the original complaint.

Reported hospitalizations were due to: a nephrectomy, a cholecystectomy, an appendectomy, hernia repair surgery, spinal surgeries, knee surgery resulting from a fall from wheelchair, decubitus ulcer, dehydration, and influenza. Regarding the use of new medical or assistive technologies, 4 participants reported use of personal home computer for accessing health-related and other information, 3 participants are taking new medications that appear to be effective, 1 participant is now using a power rather than a manual wheelchair, and 1 participant is using a Parastep system as part of an exercise program.

At the end of the interview, participants were asked to share their concluding thoughts. The issues that were mentioned included: the need for a centralized, consumer-friendly resource for a variety of information regarding spinal cord injuries, concerns about future limitations resulting from heterotopic ossification and other conditions, and the need for professionals to be sensitive to the post-injury goals of clients. Participants also stressed the importance of staying active, of developing a positive relationship with their primary care physician for
prevention and early detection of health issues, and of connecting with a network of supportive, knowledgeable individuals who can offer assistance. Insurance issues related to the claims approval process and of the business of medicine, in general, were also identified by 3 participants as being problematic. These participants expressed the need for individuals with spinal cord injuries to be educated about their rights and to be strong self-advocates.

Comparison of Reported and Projected Needs

In three cases, plan recommendations regarding personal assistance were not applicable because the participants are not yet of the age when such services were projected to begin. In three cases, participants reported requiring fewer hours of personal assistance than was projected in their life care plans. In one case, the participant receives 24 hour attendant care and has so since the time of the injury. The continued need for such care was accurately projected in the life care plan.

Caution should be exercised in interpreting these findings because recommendations relative to personal assistance are based upon the assumption that an individual will have no resources for personal care in the future, including family members, volunteers, or collateral funding to purchase services within the open market. Although family members may chose to provide this support, planners must ensure that adequate funding is calculated into the overall cost of the plan because the long-term availability of appropriate care cannot be guaranteed and is essential to the health and well-being of the client. In addition, support
provided by family members may not necessarily be focused toward direct physical assistance with personal care activities, but may include tasks such as personal financial management, running errands, shopping, cooking, attending to housekeeping chores, home and lawn maintenance, transportation, and similar activities that would otherwise require attendant services. Within the context of a family unit, certain responsibilities may be naturally divided according to the relative strengths and interests of family members. It is possible that the time necessary to complete these delegated responsibilities may not be recognized by participants, yet the need for such assistance exists and would have been accounted for within the life care plan.

With regard to medical care, each plan demonstrated areas where projections were consistent with current needs and areas where projections were inconsistent. Interpretation of these findings is limited by the lack of access to each participant’s recent medical and rehabilitation records, and the inability to interview the primary care physicians who are currently directing their medical care. In the present study, it is not possible to determine how specific post-injury events may have impacted the accuracy of each participant’s life care plan over time. For example, several participants indicated that they consulted with their primary care physicians only when they had specific complaints or concerns, but not for routine well visits. Perhaps this tendency is common among members of the general population as well as individuals who have no post-injury medical
concerns, such as diabetes or high blood pressure, which require frequent monitoring. However, one of the primary principles of life care plan development involves the provision of preventative services as a means of preventing, or substantially reducing, the occurrence of complications. The importance of periodic monitoring and assessment may not be recognized by the clients, but these preventative measures are integral components of comprehensive life care plans that identify services that will help to maintain health, functional independence, and quality of life over time.

Emergent Themes

There are several themes that emerged from the interviews with study participants. Although some of these themes were common to more than one participant, attempts to quantify or to compare them across cases may lead to erroneous conclusions due to the number of cases accessed in the present study. Theses themes are of interest to life care planners because they represent real-world experiences, concerns, and outcomes reported by clients.

Themes related to the importance of maintaining independence, health, pre-injury goals, and a positive outlook emerged as being primary concerns that were present throughout several of the interviews with participants. They explained the importance of maintaining as much independence as possible, of finding ways to compensate for physical limitations that may challenge their ability to complete
routine daily tasks or to participate in social events, of seeking preventative medical care, and of not allowing their injury to prevent them from pursuing their pre-injury goals and interests. Specifically, the importance of independence was an emergent theme in two case studies. Participants commented that being able to drive, interact in community events and social activities, engage in hobbies, and even to complete routine household tasks without assistance provided a sense of accomplishment, purpose, and self-worth.

The importance of maintaining optimum health was an emergent theme in four case studies. Participants noted that they have paid closer attention to their health in recent years, particularly as some have begun to experience some of the general effects of the aging process. In addition to maintaining the physical ability to accomplish specific activities, participants noted that preserving their health allowed them to be more independent in personal care and household tasks, active in the community, and capable of working toward achieving personal goals. One participant noted, “… ultimately, having good health means that I can take care of the other things.” Preventative care, well visits with the primary care physician, and early detection were mentioned as means by which participants were attempting to proactively reduce or eliminate major health issues from arising. Participants recognized that complications could potentially have a detrimental impact on independent functioning and quality of life.
The importance of maintaining pre-injury goals was an emergent theme in one case study, though several participants also expressed the importance of pursuing their pre-injury goals, despite the obstacles that may have to be overcome. Family support, high personal expectations, and determination were mentioned as being critical factors in achieving success. Regarding his post-injury experience, one participant commented, “The best thing about the events afterward was that my family’s expectations didn’t change.” Another participant noted, “Maybe it’s because I was a young male, but I didn’t want anyone to treat me differently after I was injured. I was set on doing things by myself as much as possible, and I sure didn’t want my parents to be wheeling me around town with my friends. I was lucky to have a group of friends who were accepting; they are still my friends now.”

Similarly, fear of future health problems and further physical limitations emerged as being primary concerns that were present throughout two participant interviews. Each of these individuals experienced, or perceived that they had experienced, negative outcomes resulting from medical interventions. One participant stated, “The treatment is worse than the injury, and there is no way that I want to do anything that may make things even worse.” Consequently, she is not hesitant to seek routine medical care from her physician, but is very fearful of recommended treatments that may actually cause her more harm than the original complaint.
Another participant lost the use of her dominant right arm due to heterotopic ossification and an attempted surgical intervention that caused permanent damage to her limb. She noted that she has become more reliant upon attendants to assist with tasks that she was able to accomplish with little support in the past. For example, she is no longer able to transfer herself to and from her wheelchair, propel a manual wheelchair, write legibly, self-catheterize, lift items weighing more than two or three pounds with her left arm, or complete other routine tasks without assistance. In addition to being an inconvenience, she noted that the loss of her right arm has also had a substantial psychological impact and admitted to periodic depression. She commented, “I have no hope that things will get better with time. They will only get worse.”

The importance of maintaining a positive outlook and sense of gratitude emerged as a theme in one case study. Despite the grief that she continues to feel after the death of her husband 5 years ago, throughout the interview, this participant commented about how fortunate she was to be in good health, to be independent, to have a job that she enjoys, to have supportive family and friends, and to share a home with her father. She noted that she works to maintain a positive outlook and pushes herself to remain in close contact with friends and family. Although it is difficult at times, these relationships remind her of all that she has to be grateful for and help her to keep daily trials in perspective.
Themes involving frustration with the health insurance claims process, the need for case management support, and the role of professionals in litigated cases also emerged as being primary concerns that were present throughout several of the interviews with participants. Frustration with the health insurance claims process was an emergent theme in two case studies. They explained that, in their experience, the health insurance claims approval process employed by some companies was a substantial disincentive for consulting with physicians when minor or preventative concerns arose. In addition to delaying the immediate need for medical care, participants noted that this process may cause individuals to simply stop seeking preventative care until a major incident occurs or until a relatively minor issue escalates into a critical concern. They also explained that, because they were familiar with the system and were strong self-advocates, they are typically able to get what they need. However, they worry about the experience of others who do not have the information or assertiveness necessary to obtain essential equipment and medical services. Regarding equipment, one participant noted that she often spends money out of her own pocket to avoid having to wait through the claims pre-approval process, and to eliminate the need to schedule consultations with an intermediary equipment vendor selected by the carrier. She also noted that the lack of customer service offered by insurance companies has been particularly frustrating.
The ability to access necessary health care is an essential component of maintaining quality of life. Although he reported having negative experiences with the health insurance system in the past, one participant reported that he is satisfied with his current health insurance carrier and commented that, in addition to having developed a positive relationship with his primary care physician, the relative ease with which he is able to schedule routine visits has prompted him to more diligently seek preventative care, consistently consult with his physician, and to monitor his lifestyle more closely. Health insurance coverage and management issues may have a far greater influence upon a client’s post-injury health and willingness to adhere the recommended course of care than is currently recognized. Consequently, this issue may need to be further explored when researchers attempt to compare self-reported needs to those projected in individualized life care plans.

In two case studies, the need for case management support emerged as a primary theme, though this issue was also of importance in several other cases. One participant stated that he would have benefited from having additional guidance in recruiting, selecting, and training attendants. And while in college, a case manager may have been able to suggest assistive technologies, campus and community services, and other resources that could have enhanced his educational experience. Later, a case manager may have assisted with tasks such as locating qualified attendants, coordinating preventative health care, and providing information resources regarding spinal cord injury. Currently, although he denied
his need for case management services, he expressed an interest in identifying new adaptive equipment, assistive technology, and other resources that directly coincide with the scope of expertise of case managers.

Another participant reported that she was discharged from the rehabilitation facility with no case management support and had 9 year old twin daughters to care for at home. She explained, “I learned a lot during rehab, but I didn’t feel like I was ready to take care of myself and my kids, plus everything else, when I got home. This was a big change and I just didn’t know how I was going to carry on once I healed and things started to get back to normal. In my case, I didn’t really have a husband who was there for me, so if it wasn’t for my friend, I don’t know what I would have done. You’re left on your own.” She noted that she did not seek case management support upon her return home because her friend had volunteered to assist her, and because he was concerned about her financial situation. She did not want to pay for these services because she did not view case management support as a necessity, in addition to her other financial obligations. She was in the midst of a divorce and a personal injury case, had medical concerns, and was attempting to resume her caregiving responsibilities. Compared to the other priorities in her life at the time, making contact with and paying fees to a case manager was not as important as attending to the immediate issues that existed.

Although it was not one of the primary themes that emerged during the interview, another participant believed that case management support would be of
value to her because she is concerned about maintaining her health. She is aware that there are specific complications related to spinal cord injury that, left undiagnosed, could result in substantial, long-term consequences. She stated that she is receiving adequate care because of her self-advocacy efforts and because she has adequate insurance coverage, but is not receiving the kind of health care management and coordination of services that she feels she needs. An additional participant noted that post-injury, she would like to have had more information about the state and federal benefit programs that she may have been eligible to receive.

In one case study, the role and impact of some of the professionals who have been involved in the participant’s legal case and rehabilitation emerged as a primary theme. He explained that he is a very determined, independent person and he was offended by some of the professionals involved in his rehabilitation and in his legal case who underestimated what he would be capable of accomplishing after his injury. He recalled that several members of his rehabilitation treatment team discouraged him from setting goals of returning to work, walking with crutches, scuba diving, operating machinery, and pursuing similar interests involving physical activity. He insisted upon being as independent as possible and believes that individuals with spinal cord injuries should be encouraged to set challenging goals, rather than to accept the lowered expectations proposed by professionals. He firmly stated that physicians, therapists, evaluators, and other health care
professionals, should not take hope away from those who are recently injured. He commented, “These people are telling you that you don’t have a life anymore. Don’t tell people that their old life is completely gone. That’s what got me so aggravated; when people told me that I couldn’t do things anymore.”

For life care planners, these emergent themes not only encapsulate the concerns of the participants in the present study, but also reinforce the guiding principles upon which the planning process is founded. Broadly stated, the goal of a life care plan is to comprehensively identify future needs, to facilitate the delivery of necessary equipment and services that maximize a client’s psychosocial, rehabilitation, vocational, and medical recovery potential, and to enhance quality of life. To various degrees, each of the emergent themes revealed in the present study relates to this overarching goal, and demonstrate that the concerns and experiences reported by participants are closely aligned with the primary aim of life care planning. Further, these themes demonstrate a close correspondence between the real-world concerns of clients and the methodology utilized by planners in identifying appropriate recommendations and establishing necessary foundations.

Although the planner is not able to control events beyond the process involved in the development of each client’s individualized plan, the importance of including recommendations that maximize independence, maintain optimum health, and assist clients in achieving pre-injury goals is evident. Further, these emergent themes reinforce the importance of developing cooperative relationships
with clients and members of the multidisciplinary team, offering explanations regarding specific plan recommendations, making certain that clients have access to case management support, and ensuring psychological wellbeing by considering how social support systems and community involvement can be facilitated.

**Unexpected Findings**

Unexpectedly, none of the 7 participants reported that they had completed annual comprehensive spinal cord injury evaluations, as was recommended in each plan, and none reported having referred back to their life care plan since it had been developed. These findings represent an important opportunity for client education through debriefing sessions after individualized plans have been developed. Such sessions allow planners to fully explain how current and future needs were identified, which agencies and vendors within their local regions are potential service providers, how associated costs were calculated, and how the research literature, clinical practice guidelines, standards of care, and feedback from members of the treatment team were used as foundations for recommendations. This finding indicates that life care planners must work to more effectively educate clients regarding the value of preventative, routine medical care. Planners must clearly describe how such efforts may reduce future complications and enhance independence, overall health, and quality of life.
Perhaps the life care plan is not referred to as a resource and recommendations are not followed because clients view it as a document that is associated with litigation and developed only to aid the attorney in establishing the economic damages associated with their cases. Perhaps some clients are not comfortable contemplating the realities of their future personal assistance and medical care needs. Perhaps one or a series of events occurred after plan development, and the recommendations no longer appear to be accurate or relevant. Perhaps the course of care recommended by clients’ current primary care physicians differs from that projected in their life care plans. There are likely to be many reasons why life care plans are not used as long-term resources, but if clients do not understand the recommendations and how they were arrived upon, they will not understand its value.

Evaluating Consistency

Researchers in the present study were interested in comparing participant’s self-reported needs to those projected in their individualized life care plans within two specific categories; personal assistance and routine medical care. Analyzing the consistency between reported and projected needs is one way to assist the specialty of life care planning in establishing the reliability and validity of the methodology applied to the case analysis and development processes. Although quantifying consistencies and discrepancies is a relatively straight-forward
proposition, identifying the causes for various degrees of agreement is a more complex task.

**Medical and Rehabilitation Foundations**

Projections contained in a life care plan reflect the recommendations of members of the client’s current treatment team, published guidelines and standards, and the planner’s assessment of future needs. In order to justify the projections, planners must be able to demonstrate that medical and rehabilitation foundations support each item that is recommended. The planner relies upon the professional expertise of members of the treatment team and evidenced-based outcomes research to substantiate the contents of the life care plan. Adjustments are made based upon the unique features of each case, but all items must be justifiable and based upon medical and rehabilitation foundations.

As applied within the context of a legal case, the medical and rehabilitation foundations for plan projections must be supported by applicable data. Although the methodology applied to the development of a life care plan recognizes the unique needs of individuals, future recommendations are primarily based upon what the average individual with a specific level of injury may be expected to require through life expectancy. Actual individual outcomes may vary from this aggregated profile but, as a prospective document, exceptions cannot be substantiated unless there is sufficient medical or rehabilitation justification to
include or exclude services that are typically required by individuals with specific levels of injury and characteristics. Even with careful attention to the population described in research studies, the lived experience of an individual may not closely correspond to future expectations based upon the literature. This is not necessarily due to planner error, but is a reality of projecting future needs based upon evidence-based outcomes. In the present study, 3 of the 4 participants for whom personal assistance recommendations were applicable reported that they required less assistance than was projected in their life care plans. Based upon their self-report, it appears that the level of independence currently demonstrated by these participants exceeds what would be expected based upon the relevant research data available at the time the plan was developed. The reasons for this discrepancy is an issue that may be explored further in future research studies.

Health Insurance Guidelines

Discrepancies between reported and projected needs may be due to insurance policy guidelines and restrictions that regulate the personal assistance and medical care received by clients. In the present study, 5 of the 7 participants were covered by Medicare policies and rely upon their primary care physician to make referrals to specialists as necessary. Life care planners cannot influence whether routine evaluations by those specializing in spinal cord injury, urology, and other areas are made by primary care physicians. Even though such referrals may be components of applicable clinical practice guidelines and other standards,
the onus rests with the primary care physician to initiate and maintain these referrals.

For researchers, this means that consideration may need to be given to the role of the primary care physician and function of health insurance coverage guidelines when considering the degree of consistency that exists between reported and projected needs. Researchers must exercise caution when assuming that primary care physicians are proactively addressing the needs of patients with disabilities. There may be disincentives for physicians who make referrals to specialists for routine monitoring and assessment, particularly in private health insurance groups or health management organizations, if such activity is analyzed as a cost-control component of physician efficiency rankings that are established by some insurance carriers (Robinson, 2006). In other words, if a physician’s efficiency ranking within an insurance carrier scheme, and ultimately their reimbursement potential, may be impacted by the number of referrals made to specialists, physicians may refrain from referring patients for routine assessments. Instead, such assessments may be reserved for patients with a higher probability of being diagnosed with a specific condition.

Similarly, the type of health insurance carried by clients may influence the referral practices, course of treatment, or clinical decisions made by physicians (Meyers, Mishori, McCann, Delgado, O’Malley, & Fryer, 2006). Given several options, physicians may select the course of treatment that coincides with the one
most highly endorsed by the patient’s insurance carrier. Whether motivated by a concern for their personal benefit or for the benefit of the patient, such decisions may facilitate the physician’s payment, eliminate the need to submit additional supporting documentation, and enable patients to avoid the claim denial and appeals processes (Meyers, et al., 2006).

It is also possible that some primary care physicians are unfamiliar with the clinical practice guidelines and standards of care relative to individuals with spinal cord injuries. They may be unaware of the need for periodic comprehensive assessment, overlook symptoms of common complications, or fail to employ a holistic approach in managing the individual’s course of care. For example, two of the participants in the present study described symptoms indicative of depression or substantial adjustment difficulties. Psychological counseling would seem an appropriate intervention, yet neither participant is currently receiving such support. It is not known whether the participants have shared these symptoms with their primary care physicians, but psychological health should be one component of a comprehensive course of care.

Recommendations made in a life care plan are designed to prevent, or substantially reduce, the occurrence of crisis situations that arise after conditions have escalated and require immediate intervention. This approach is founded upon medical and rehabilitation principles, but may be at odds with what some clients experience when working within the current health care system. None of the
participants in the present study reported having completed a comprehensive spinal cord injury evaluation in recent years. One possible explanation for this may involve issues related to insurance coverage. Unless a client presents with symptoms of a more complex medical concern that are assuredly included in their health insurance coverage plan, primary care physicians may not make referrals for routine comprehensive evaluations as a preventative measure.

On the other side of this issue, costs associated with plan recommendations are based upon the assumption that they will be paid from the proceeds of the lawsuit. The plan cites private pay rates for all routine consultations, evaluations, and invasive procedures because collateral resources are not typically taken into consideration when recommendations are identified. However, there is no guarantee that the client will receive the necessary settlement funding to purchase all of the items and services outlined in the life care plan; nor is there a systematic surveillance method to verify that settlement funds are, in fact, spent as allocated for future medical and rehabilitation costs. Life care planners cannot control the type of insurance plan that a client may have, but they can work with clients to ensure that they fully understand the reasons why specific types and frequencies of medical consultations have been recommended. Such information may encourage clients to more vigorously pursue the medical care that they require, despite obstacles, in an effort to maintain overall health and functional independence.
In the present study, participants were not asked to detail their interactions with their primary care physicians regarding referrals, but were simply asked whether they were required to have a referral in order to consult with a specialist. Each of the 5 participants who receive Medicare are required to have a referral for specialist consultations. The other 2 participants have private insurance and are able to make appointments with specialists without a referral from their primary care physicians, but these must be pre-approved by the carrier. The influence of health insurance guidelines and the course of treatment recommended by clients’ primary care physicians are issues that require additional consideration by researchers interested in comparing current needs to those projected in individualized life care plans.

Self-Report

Research designs in rehabilitation and the social sciences routinely rely upon self-reported data with the understanding that some information may be more objectively reliable and valid than others, and that it may fluctuate over time (Burns, Moskowitz, Ash, Kane, Finch, & Bak, 1992; Feldman & Lynch, 1988; Mabe & West, 1982; Street, 1992). In the present study, 3 of the 4 participants for whom personal assistance recommendations were applicable reported that they required less assistance than was projected in their life care plans. It appears that the level of independence currently demonstrated by these participants exceeds what would be expected based upon the relevant research data at the time that the
plan was developed. However, recommendations are based upon the assumption that the client will not have access to any family members, friends, or volunteers to assist as necessary. In each of the three cases where this inconsistency exists, the client lives with, or near, family members who regularly provide additional assistance as needed.

Cook and Campbell (1979) note that participants tend to interpret their own behavior and needs in ways that reflect positively on themselves. It is possible that participants overstated their ability to perform routine tasks independently and understated the number of hours of assistance that they receive from family members in order to appear less dependent upon others. Researchers are not suggesting that participants would have done this intentionally, but the amount of incidental assistance that is actually given by others when completing routine daily tasks and engaging in cooperative activities may not be recognized by the participants. They may have inaccurately reported their current needs due to misperceptions about their own abilities, a desire to appear more independent, or to provide responses that they believed would most closely match researchers’ expectations.

Another aspect of this issue to consider involves the possible influence that the existence of a personal injury case may have had on participant’s input throughout the life care plan development process. The researchers in the present study are not suggesting that participants intentionally misrepresented their needs.
while working with members of their treatment team or the life care planner, but within the context of litigation, clients may have inadvertently exaggerated their needs in order to create a perception of greater disability and need for support care and services. This phenomenon has been considered in cases involving worker’s compensation and other situations involving compensable injuries, and is an issue that requires further exploration within the context of life care planning (Aronoff, Mandel, Genovese, Maitz, Dorto, Klimek, & Staats, 2007; Mendelson & Mendelson, 2004). One possible incentive for clients to create this perception is that more complex cases typically necessitate the inclusion of additional assistance, medical care, equipment, aids for independent functioning, periodic evaluations, and other services that, ultimately, increase the overall cost of the plan and result in higher economic damages. Attorneys representing plaintiffs in personal injury cases must comprehensively demonstrate a client’s degree of disability and economic losses in order to justify the damages sought. As a tool that delineates all future medical and rehabilitation needs, the life care plan often serves as a basis for the computation of economic damages from which settlement funds are derived. Logically, clients who require more frequent or more skilled levels of care and services will typically have more costly life care plans, and require larger settlement amounts to adequately compensate for future needs.
Adherence to Recommendations

Measuring and improving patient adherence to a physician recommended course of care is an issue discussed frequently in health-related research, particularly as it relates to chronic conditions that require consistent monitoring, lifestyle modifications, and pharmacological management (DiMatteo, 2004; Konradi & Lyon, 2000; Osterberg & Balschke, 2005). The development of a valid, well-documented, and individualized life care plan does not assure that the recommendations will be implemented or that the client will adhere to them over time. For example, none of the participants in the present study completed comprehensive spinal cord injury evaluations, as was recommended in each of their plans, nor referred back to their life care plan post-development. It is not possible to determine whether adherence with this recommendation may have prevented the subsequent illnesses and injuries that were reported by participants, but the importance of maintaining functional independence and optimum health emerged as themes within the present study.

Non-adherence to health-related recommendations is an issue that complicates case management and impacts the provision of preventative care. Although there are often significant time constraints limiting a professional’s ability to consistently follow-up with clients, the importance of understanding why some do not adhere to recommended services is critical in ensuring continuity of care and appropriate intervention (Mullahy, 2005). As suggested by Mullahy
there are many difficulties that clients may be confronted with that may result in non-compliance. These difficulties include navigating the health care system, meeting required insurance co-payments or deductibles, overcoming communication or comprehension barriers, making successful psychological adjustment to long-term disability or chronic illness, stress, and other obstacles (Mullahy, 2005). In addition to client-specific factors, characteristics that are unique to medical facilities and clinics may also play a role in promoting, or discouraging, adherence to the recommended course of care (Ramsey, Cheadle, Neighbor, Gore, Temple, Staiger, Goldberg, 2001).

Life care planners formulate recommendations based upon the assumption that all preventative measures will be adhered to so that complications, decreased functional independence, and decline in overall health can be avoided. However, when considering the consistency between reported and projected needs, non-adherence to preventative recommendations may negatively impact the evaluation of the accuracy of a life care plan. Differences that exist between reported and projected needs may arise because a client is not following the recommendations contained in the life care plan, rather than the need for specified care and services does not exist. Clients may choose to accept the advice of their current health care providers just as they may choose to adhere to the projections cited in the life care plan. For example, a life care plan may state that a general practitioner visit is required two times per year, but the client reports that she only goes once every two
years because she has felt healthy in recent years. This would result in a difference between the number of reported and projected visits, but the client may need to consult with her physician two times per year to monitor for changes over time, to maintain optimum health, and to identify problematic situations before they escalate into more serious conditions. Similarly, although it is recommended that the average adult with no specific dental problems should have their teeth professionally cleaned and examined two times per year, many within the general population do not comply with this guideline. The standard of care is not erroneous, but the degree of adherence to the standard varies between individuals.

Individualized recommendations involving medical care are developed in collaboration with members of the clients’ treatment team and are based upon medical and rehabilitation foundations. Well visits with a primary care physician may be perceived by the client as being unnecessary, but if the continuity of care is not maintained over time, complications may result. Whether clients choose to comply with all plan recommendations is beyond the scope of planners’ role and function, though planners can explain the value of periodic case management support and educate clients regarding the importance of adhering to them. The fact that a client does not comply with the recommendations outlined in his or her life care plan should not necessary lead researchers to conclude that the plan is inaccurate or that the methodology applied to the development of the plan is invalid.
In the present study, participants reported their actual service utilization patterns, not what has been recommended by their primary care physicians, therapists, or other healthcare professionals. The results reflect the frequencies and types of services that the participants are actually seeking, not necessary what is recommended by health care professionals. Therefore, even though participants did not report having accessed specialty care and other medical services as specified in their individualized life care plan, the need for such consultation may be valid and necessary as a component of a comprehensive health maintenance program.

Participants were not asked to discuss whether their primary care physicians had suggested additional medical care or whether they had chosen to comply with these recommendations. Future research exploring clients’ adherence to recommended medical follow-up and rehabilitation services may provide additional insight that will help to distinguish discrepancies resulting from methodological issues from those resulting from non-compliance with a proactive, preventative plan of care.

In addition to medical care, the issue of compliance may also impact the consistency between reported and projected personal assistance needs. In the present study, 3 of the 4 participants for whom personal assistance recommendations were applicable reported that they required less assistance than was projected in their life care plans. Even though participants reported that they are able to independently perform self-care and household tasks, repetitive or strenuous activity could contribute to joint, muscle, and other problems over time.
Particularly for paraplegic individuals who self-propel manual wheelchairs, accomplish transfers, and otherwise tax the upper body with weight-bearing tasks, efforts must be taken to preserve such functioning by avoiding tasks that may compromise strength, endurance, flexibility, and, ultimately, the ability to engage in activities that enhance quality of life. For some individuals, however, the ability to perform routine household tasks is a personal measure of their quality of life and they want to continue to care for themselves and their households for as long as they are able to do so. In such cases, plan recommendations suggesting that more personal assistance is needed than is currently reported are not necessarily inaccurate, but the consistency between reported and projected needs may be impacted by the client’s desire to perform certain tasks without assistance.

*Planner Error*

In the present study, it is not possible to identify whether planner error may account for some degree of inconsistency between reported and projected needs. However, all cases were drawn from the case load of the founder of this specialty area of practice and were deemed by the researchers to be one of the most reliable sources of data by virtue of the planner’s years of experience, publications, educational efforts, and numerous professional contributions to the field. The issue of planner error is a complicating factor in studies that compare reported needs to those outlined in a life care plan because there is no practical way to accurately and systematically verify that the plan development methodologies were adhered to as
described within the professional literature. In these initial studies conducted within the specialty, it is difficult to differentiate between possible methodological flaws that can be attributed to the life care planning process versus those that may be attributable to practitioner error.

The issue of professional error is present in nearly all outcomes oriented studies that compare expected results to those reported by clients. For example, a physician may misinterpret laboratory or therapeutic assessments and base care recommendations upon an expected result that is not, in fact, realistic. If this physician’s recommendations were subject to the review employed in the present study, researchers would discover inconsistencies between what the physician projected and what the client reported. Fortunately for the client who consults regularly with the physician, such errors may be identified relatively quickly as disconfirming data prompts the physician to reconsider the recommended course of care. Just as we would not conclude that the entire educational system is flawed simply because a teacher fails to appropriately implement effective instructional techniques, the validity of the life care planning process cannot be determined based upon the performance of a small group of practitioners or upon a small number of studies. There are inexperienced, mediocre, and highly competent professionals in all fields of practice.

The competency of a life care planner is difficult to measure, but may be a factor to be considered when conducting research that explores the validity of the
methodology applied to plan development. For the life care planner practicing within the litigated arena, ongoing contact with the client is not typically possible. This reality limits a planner’s ability to either formally or informally evaluate whether their projections proved accurate, were appropriately implemented, or were used as the basis for future case management support. Although it may not be possible to quantify professional error, the possibility of such should be recognized by researchers.

Unanticipated Events

One of the basic tenets of life care planning acknowledges the fact that future complications and advances in technology cannot be accurately projected. Even with the best of medical and personal care, secondary injuries such as fractures, infections, and head injuries may occur as the result of unpredictable events. Falls, motor vehicle accidents, and unrelated conditions may cause additional complications that result in long-term effects. Technological advances have the potential to either improve or to complicate a client’s lifestyle. Likewise, such advances may either increase or decrease the resources allocated and the cost of recommendations cited in a life care plan.

Projections are based upon what is known about a client at the time of the evaluation, the conditions under which adequate assistance and preventative care will be provided, and the presumption that the client will adhere to all of the
personal assistance and medical care recommendations. The multidimensional nature of a life care plan is such that, a change within one category of the plan may impact the recommendations within other categories of the plan. For example, if a client were to be involved in a motor vehicle accident, there may be a need for increased personal assistance and medical follow-up, either short-term or for an extended period of time.

Clients who have experienced complications that cannot be anticipated by planners may report needing more assistance and care than was projected in the life care plan. This would result in an inconsistency between the reported and projected needs, but distinguishing between those due to the spinal cord injury and those related to subsequent complications may be difficult. Further, although the impact of aging is taken into account throughout the plan development process, the cumulative, interactive effects of several complicating illnesses and injuries on subsequent health cannot be accurately projected. Complications that are known to occur more frequently in individuals with spinal cord injuries can be noted for educational purposes in the life care plan but, unless there is an established history and documentation from members of the treatment team, associated costs due to complications are not typically factored into the overall plan.

This is an issue that is present in nearly all outcomes oriented studies that compare expected results to those reported by clients. Unknown and uncontrolled events occurring post plan development will be present within nearly every
available potential participant pool. For example, in the present study participants reported developing carpal tunnel syndrome, the loss of function in the dominant arm, arched feet, and depression following the death of a spouse. Although these events do not appear to explain the inconsistencies between all reported and projected needs, it is possible that they may indirectly impact personal assistance and routine medical care. Professionals who work with clients to develop prospective plans of care cannot account for events involving changes in technology, treatment protocols and standards, or complications resulting from future events, drug interactions, or secondary conditions that may have developed even in the absence of a specific injury. This presents a challenge for researchers who are evaluating the consistency between reported and projected needs.

Implications

Literature in Life Care Planning

Elements from existing studies conducted within the specialty of life care planning have been incorporated into the design of the present study. Researchers referred to these studies as a means of building upon current knowledge and developing a research design and methodology that could realistically be duplicated by practitioners in the future. Of specific relevance were the studies conducted by Casuto and Gumpel (2003), and McCollom and Crane (2001). These studies helped to shape the research design, methodology, and survey instrument utilized in
the present study. In these studies, telephone interviews were conducted by life care planners who developed their own questionnaire instruments using a single practitioner’s case file as the basis for participant recruitment. Participants were asked to describe their current needs within several categories in an effort to assess the accuracy of the projections cited in their life care plans.

Casuto and Gumpel (2003) conducted a retrospective descriptive study involving 22 participants with various injuries who required pediatric life care plans. As such, their findings were not relevant to those of the present study, but the research methodology was similar. The purpose of their study was to evaluate the accuracy of recommendations regarding care needs, to identify additional areas that should be addressed in pediatric life care plans, and to explore the factors that influence the ability of the family to fully implement the plan as written. Participants were asked to respond to questions regarding health care, therapy, counseling, recreation, equipment, fiduciary services, attendant care, schooling, and community services. Many of these questions were beyond the scope of the present study, but the comprehensiveness of the questionnaire implies that the researchers recognized the multidimensional nature of potential outcomes.

The design, questionnaire instrument, and participant selection criteria applied within the present study was modeled after that which was utilized in the McCollom and Crane (2001) study. The study involved 10 adult clients with spinal cord injuries for whom life care plans had been developed. The questionnaire
utilized by McCollom and Crane (2001) queried participants about their experiences within a number of plan categories, including those relative to personal assistance and routine medical care. Some of the findings may be compared to those reported in the present study, but caution should be exercised as each study involved only a few number of participants, and specific comparisons to the original projections in the life care plans in the McCollom and Crane (2001) study were not provided.

Whereas the present study revealed that none of the 7 participants had completed the recommended annual spinal cord injury evaluations, 5 of the 10 participants in the McCollom and Crane (2001) study indicated that they had. Urinary tract infections, chronic pain, and skin breakdown were the most frequently reported complications in the McCollom and Crane (2001) study. Similarly, these and other complications were reported by participants in the present study.

Regarding personal care, all 10 of the life care plans in the McCollom and Crane (2001) study recommended the need for some level of support, though specific information regarding the type and number of hours per week of care was not provided by the researchers. Six individuals reported that they required personal assistance; 3 of which received this care from their spouses. The source of personal assistance for the remaining individuals was not specified. McCollom and Crane (2001) noted that the 3 participants who reported that they did not require personal assistance were under the age of 30 years.
In the present study, all 7 of the life care plans recommended the need for some level of personal assistance at various points within the client’s life span. Of the 4 for whom the need for personal assistance was projected as a current need, all reported requiring assistance with specific tasks. However, 3 of the participants reported requiring substantially less time than was projected in their plans, and 1 participant had been receiving 24 hour attendant care since the time of the injury. While case management support was not a central element in either study, some of the participants in each reported a need for assistance in coordinating their health care and services, accessing new resources, and ensuring continuity of care, in general.

The research conducted by Sutton et al., (2002) and Pomeranz et al., (2006) were also of value in designing the present research study because they addressed issues of relevance to personal assistance and routine medical are recommendations. Sutton et al., (2002) conducted a retrospective, quantitative research study that explored the reliability of life care plans. The caseloads of two life care planners were combined and 65 cases representing individuals with various injuries were reviewed. In each case, recommendations regarding home health care and routine medical care in updated plans were compared to those specified in client’s original plans. Chi-square analyses of difference between original and updated plans were not significant at the .05 level, which suggests that plan recommendations were reliable over time.
This finding represents an attempt to better understand the degree accuracy regarding personal assistance and medical care recommendations, as does the present study. However, the research design approaches differed substantially from one another. Whereas Sutton et al., (2002) compared recommendations in each client’s original life care plan to an updated plan, researchers in the present study interviewed past clients and asked detailed follow-up questions in order to better understand reported outcomes. Due to the number of participants in the present study, however, the statistical significance of inconsistencies between the reported and projected needs of participants cannot be determined.

Likewise, the Pomeranz et al., (2006) study was of relevance to the present study because it represents an attempt to better understand the personal care needs of clients as perceived by life care planners. Although the research approach and purpose differed substantially from the present study, Pomeranz et al., (2006) described 164 specific activities that were identified by the life care planners as being important considerations when formulating recommendations regarding attendant care for clients with spinal cord injuries. These included various activities of daily living (e.g., dressing, grooming), housekeeping (e.g., dusting, ironing), home and yard maintenance (e.g., lawn mowing, emptying garbage), work and educational activities (e.g., dictation, note taking), leisure activities (e.g., camping, hunting), and transportation (e.g., running errands, going to the movies).
Although the research approaches, participant demographics, and purposes differed substantially from the present study, each contributes to the existing literature by considering how the accuracy of plan projections may be improved. Whereas the Pomeranz et al., (2006) study was developed to assess the importance that life care planners attributed to various activities when formulating recommendations for personal assistance, the present study sought to determine whether these needs were accurately anticipated by comparing those reported by participants to those projected within each participant’s life care plan.

**Contributions of the Present Study**

The present study contributes to the existing body of literature by describing the current personal assistance and medical care needs of 7 individuals for whom life care plans were developed. Each of the existing studies that have been published within the research literature contributes data that helps to further clarify outcomes and to generate future research questions. The present study contributes to the existing body of research knowledge regarding the consistency between reported and projected needs, and identifies themes that are of primary concern to the participants. In addition to gaining a greater understanding of the actual outcomes experienced by individuals, this study allows life care planners to learn more about the concerns of clients as they live, work, and age with spinal cord injuries. Conclusions regarding the need for additional client education, follow-up support, case management, and some form of continuing service to clients are
shared by the present study, the Casuto and Gumpel (2003) study, and the McCollom and Crane (2001) study.

The present study also serves as a template for future research efforts that explore the outcomes experienced by clients. It provides a means of both evaluating the accuracy of plan projections, while qualitatively analyzing the unique circumstances of each participant’s case. In order for quantitative data to be meaningful and relevant to the practice of life care planning, researchers must also integrate qualitative analyses into methodologies to explain how results may be influenced by each participant’s current care needs, health status, therapeutic efforts, vocational goals, family responsibilities, and a host of other client-specific factors. Determining the validity of plan recommendations over time is not a straight-forward prospect and cannot be adequately described through statistical analysis alone. Qualitative case studies allow researchers to better understand the obstacles and successes that clients experience over time. This understanding may lead to new planning methodologies and foundations to support recommendations that will more appropriately address the unique needs of clients.

Limitations

Generalizability

Given that the present study involves a small, self-selected group of participants, findings cannot be generalized. The themes that emerged from the
interviews and the comparisons between reported and projected needs in each life care plan are not sufficient in number to draw any conclusions regarding the issues of importance to individuals with spinal cord injuries, or of the validity of the methodology applied to the life care planning process. The present study serves as an initial attempt to better understand the lived experiences of participants and to ascertain whether their individualized plan projections accurately anticipated their current personal assistance and routine medical care needs. Results may be useful in developing future research studies, but should not be interpreted as conclusive, applicable to other individuals with spinal cord injuries, or indicative of the validity of the life care planning process. Because of the few number of participants comprising this study cohort, comparisons across cases should be undertaken cautiously. Further, a self-report format was utilized in the present study and, as discussed previously in this chapter, this method of data collection can elicit problematic responses. Although the self-report format is common in the social sciences, the inherent flaws are acknowledged by the researchers.

All individuals who volunteered to be part of the present study were interviewed. Beyond demographics, researchers are not able to determine how the participants may differ from other members of the potential participant pool. Therefore, the participant group may have experienced post-plan phenomenon that are substantially different from those who did not volunteer.
Single Case Load

Another limitation of the present study is that only one practitioner’s case load was used as the basis for participant recruitment. However, this allowed the researchers to eliminate possible variations between planners that may have been attributable to years of experience, professional training, compliance in practice with the published methodology, and other factors. While the threat of planner error exists in the present study, the case load utilized is that of a recognized leader, educator, and researcher within the specialty who has published extensively in this area of practice. The methodology applied to the plan development process in each of these cases can be relied upon to be as close to what is described within the professional literature as any other practitioner’s case load. Although the utilization of just one practitioner’s case load is a limitation, if it can be assumed that the practitioner systematically approached each case as is detailed in the professional literature, it also functions as a means of equalizing the planner-specific factors that may complicate studies involving multiple practitioners.

Control

Researchers were able to identify emerging themes throughout each interview, but could not control for factors that may have impacted the accuracy of each participant’s life care plan recommendations regarding personal assistance and routine medical care. First, it is not possible to determine whether participants had
adhered to all of the recommendations specified in their life care plans over time, although none of the participants reported that they had referred back to it since it had been developed. Adherence to the preventative recommendations within the life care plans cannot be established. Second, the interviews revealed that the participants’ primary care physician directs their care and, in 5 of the 7 cases, is responsible for making referrals to specialists as necessary. Researchers cannot assume that each participant’s primary care provider is managing their care based upon the established clinical guidelines and standards, so cannot determine how closely plan projections coincide with the course of treatment prescribed by physicians.

Directions for Future Research

Research within the specialty of life care planning is in its infancy, and there are many avenues of future study that would benefit the specialty and the clients served. Any information that advances the practice of life care planning with knowledge relevant to any aspect of the methodology or planning process, client outcomes, funding issues associated with care and services, long-term case management, resource utilization, professional preparation and development, and other facets of the specialty is of value. Because of the increasingly stringent guidelines to which expert witnesses in litigated cases are being held, research exploring the reliability and validity of the methodology applied to the life care
planning process is of particular importance in ensuring that the current and future needs of injured clients are adequately represented.

_Consistency of Projections Compared to Guidelines_

Since recommendations must be substantiated by medical and rehabilitation foundations, investigations regarding the degree of consistency between life care plan projections and the established clinical practice guidelines, standards of care, and research literature would be of value. Investigations that compare plan recommendations to the established standards and guidelines may be more closely aligned with the measures used within the legal arena to evaluate plan validity. The methodology applied to the development of a life care plan should lead to the production of a document that is consistent with the published medical and rehabilitation outcomes for individuals with similar needs. Research comparing life care plans to the published medical and rehabilitation guidelines could serve as another approach to establishing the reliability and validity of the methodology. Similarly, while engaged in this effort, researchers may be able to better define the demographics, types of injury, rehabilitation experiences, personality traits, or other personal characteristics that distinguish the outcomes of some individuals from the aggregate described within the existing research literature. Such information may help to build a foundation of knowledge that justifies exceptions to the guidelines and support the individualization of life care plans.
The Context of Planning

Theoretically, when comparing the methodology involved in developing plans within the litigated arena and those developed for other purposes, there should be no difference in the planner’s approach to formulating recommendations. In practice, however, some differences may exist that have yet to be explored. Plans developed within the context of litigation should not reflect the underlying goals of the retaining party. As discussed in Chapter 2, the role of a life care planner in litigated cases is that of expert witness and educator. Planners have a professional ethical obligation to maintain objectivity throughout the case analysis and plan development processes.

Research regarding the influence that the context of a case may have upon the recommendations contained in a life care plan has not yet been conducted. Comparisons between cases completed for litigation versus those completed for case management purposes, and those completed in plaintiff versus defense cases may reveal differences in methodology, recommended services, associated costs, or other aspects of the plan. Within-case and across-case analyses may be helpful in determining whether such differences exist, describing the extent of these differences, and identifying whether differences are necessarily due to the context within which certain plans are being developed. For example, one primary difference between cases developed in defense cases is that planners are not consistently able to complete a clinical interview with the client, or to review all
pertinent medical, psychological, educational, vocational, and other records. Such instances are due to the legal rules and guidelines governing the availability of evidence and other case materials. Comparisons between the plans developed under such conditions versus those developed in situations where planners were able to access all available documentation may reveal substantial differences in the final plan document. Ultimately, this knowledge may allow planners to more convincingly educate all parties involved in litigated cases regarding the importance of obtaining access to all case-related materials for the benefit of the client.

*Longitudinal Studies*

Longitudinal research in life care planning is difficult because of the dual role assumed when a life care planner simultaneously acts as a case manager or a researcher. However, as discussed in Chapter 2, some planners believe that a shift in roles is acceptable once cases have been settled, and there are no longer any financial or professional obligations to the retaining party. The specialty of life care planning could benefit from longitudinal data regarding the lived experiences of clients with various injuries and diagnoses over time. Such research could help to describe the circumstances that result in the need to update plans, how plans are being utilized by clients and consulting professionals, the duration of the relevancy of plans beyond their dates of completion, and other data that may improve the planning process and better serve clients.
Replication of Existing Studies

The outcome oriented studies that currently exist within the life care planning literature involve relatively small, narrowly selected samples that are not able to be generalized beyond the participants. The specialty could benefit from replications of existing studies with more participants, involving multiple practitioners, and inclusive of a range of injury types. Perhaps researchers working in cooperation could identify an existing study to use as the model for a broader, multi-site exploration of an issue involving clients at various stages of the post-plan development process. Such studies may yield data that could be aggregated and statistically analyzed or used in qualitative studies to describe post-plan development experiences and trends.

Of particular interest may be studies that triangulate data from multiple sources as a means of identifying. In the present study, for example, a comparison of the information provided by participants, family members, and treating physicians may have revealed insights regarding the extent of consistency among each of these data sources as well as with the projected needs cited in the individualized life care plans. In another example, the present study could be expanded upon to explore the issue of fallibility in self-reporting or self-perception by asking participants to indicate the number of hours of personal assistance that they currently require, and then compare responses to a written or video log of the actual assistance that they received. This may reveal some insights regarding the
participants’ perceptions of the amount of personal assistance that they require while also providing researchers with a more objective measure for comparison with the plan projections.

Challenges in Life Care Planning Research

There are some substantial challenges when conducting research within the specialty of life care planning, some of which have been discussed in this chapter. One of the challenges involves the accessibility of a representative sample of cases from which to recruit research participants. The complexities involved in conducting research (e.g., time commitment, expense, knowledge, access to published research, etc.) may prohibit practitioners from becoming involved in this endeavor, particularly when managing active cases. Even if not acting in the role of a researcher, the prospect of having the outcomes of one’s own professional work critiqued and evaluated may cause practitioners to be reluctant to participate in outcomes oriented research projects. Opening one’s professional database to the scrutiny of empirical research is a daunting prospect, regardless of the number of years in practice. While veteran practitioners may have developed greater competence in their ability to develop comprehensive and accurate plans, empirically testing this assumption may be viewed as potentially threatening to their professional reputations as case managers and expert witnesses, and may be perceived as being potentially threatening to their personal sense of confidence, purpose, and worth. Professional competence may not be objectively self-assessed
in this specialty area of practice, though planners may develop a general sense of their ability through years of experience as expert witnesses, presenting trial testimony, maintaining appropriate credentials and required professional development hours, and through informal interactions with past clients. One of the possible reasons why research in the area of life care planning is so sparse may have to do with the fact that professionals are reluctant to open themselves up to the possibility that analyses may reveal discrepancies between what the practitioner projected and what study participants report as being currently necessary. However, at this point in the evolution of research in this area, practitioner error is just one possible explanation for such discrepancies and, in fact, a certain degree of inconsistency can be expected when exploring the innumerable and unforeseeable circumstances that may arise in the lives of clients after plans have been developed. Given that there are relatively few certified life care planners in the United States, this concern may substantially limit the number of cases available to researchers. Combined with the fact that clients do not typically inform planners when relocation occurs and that researchers are often restricted from contacting clients represented by the opposing party in litigated cases, making contact with and recruiting a demographically diverse, representative sample of participants is difficult.

Another research challenge is created when researchers attempt to isolate certain categories of the life care plan for study. Due to the comprehensiveness of
the planning process and interdependency among plan categories, survey research will be challenged to draw precise conclusions while simultaneously accounting for all possible explanations for given outcomes. For example, in the present study, the development of a survey that adequately described the lived experiences of participants, while also addressing the central research questions, proved to be a complex task. Researchers recognized that reported changes in needs within one category of a plan may consequently have caused changes within other categories. Further, it was recognized that one post-plan development injury, illness, or peripheral event (e.g., the client moved to a new community, a new medication or technology becomes available, etc.) may have impacted the relevance or adequacy of recommendations within multiple components of the plan. Over time, the cumulative effect of even just a few relatively minor changes in status, may substantially impact the accuracy of the recommendations originally contained within the life care plan.

Another research challenge includes ethical concerns about the impact of dual roles when life care planners also serve as case managers or researchers. Although there may be some risks regarding loss of professional objectivity or potential conflicts of interest, the inability to act in these roles may substantially limit a practitioner’s access past clients, and to evaluate the effectiveness and accuracy of the recommendations contained in their plans. At this point in its evolution, the type of research that may be most helpful to practitioners are studies
conducted by colleagues with knowledge of the specialty and its forensic applications, experience in a variety of clinical settings, and the research skills necessary to continue developing a relevant body of literature.

Other challenges involve circumstances that are beyond the control of the planner and cannot be foreseen at the time of plan development. For example, in litigated cases plans may not be fully funded and individuals may decide not to follow certain recommendations, or to follow them inconsistently, in order to conserve spending. Also, study participants can be asked whether or not they are following the recommended plan, but this compliance cannot be directly observed unless there are specific research design strategies implemented to assess such behavior. Changes may occur in other fields of study and practice over time that may influence what members of a client’s current treatment team recommends. Advances in medicine, rehabilitation programs, assistive devices, and other technologies may substantially impact the lifestyle and health of clients after plans have been developed. Likewise, standards of care and clinical practice guidelines may change over time as more is learned about the most effective courses of treatment and rehabilitation.

Even when attempting to simplify the research questions and objectives, studies within this specialty may be problematic. For example, if an attempt were made to compare an individual practitioner’s degree of consistency between plans developed for same type of injury, difficulties would arise because clients require
different types of support, levels of assistance, and medical care depending upon
their needs at the time of evaluation and their anticipated needs. Further
complicating such research, plans developed in defense cases (where the injured
individual was the plaintiff), often cannot be revisited for research purposes due to
limitations imposed as a result of litigation. Although the basic tenets and
methodologies have remained the same since the inception of the specialty, the
tools through which the planner applies these methodologies have changed over the
years. For example, the widespread availability and utilization of online databases,
research literature, clinical practice guidelines, and professional networking allows
the present-day planner to access state-of-the-art references. In combination with
qualitative information, statistical data collected from national surveys,
administrative records, and matched data sets can assist the planner in establishing
the foundations for recommendations that most appropriately meet client needs
(Bruyere & Houtenville, 2006). For example, consider the information sources that
are currently available regarding spinal cord injury. The volume and sophistication
of data that can be readily accessed by life care planners has increased substantially
since the inception of the National Spinal Cord Injury Statistical Center (NSCISC)
in 1975. Today, data of more than 109,277 individuals who have been treated at
one of the 16 Model Spinal Cord Injury Systems facilities regarding demographics,
life expectancy, complications, service utilization, functional gains, and a host of
additional information is published annually by the NSCISC (National Spinal Cord
Injury Statistical Center, 2006a). The data collected and analyzed from this source informs the development of clinical practice guidelines and treatment protocols utilized by professionals in the medical community. Contemporary planners gain the benefit of this data, and of the knowledge resulting from other longitudinal studies and data collection sources that help to establish the medical and rehabilitation foundations for plans.

There is a fundamental conundrum that faces researchers when documenting outcomes following life care plan development, and then attempting to correlate these outcomes with the recommendations contained in the plan; to what causes can inconsistencies be attributed? Inconsistencies may result from clients’ lack of understanding, non-compliance, or commitment to maintaining optimum health; faulty recommendations made by members of the treatment team at the time the plan was developed; inaccuracies in the published clinical practice guidelines and standards of care; inexperience or ineptitude of the life care planner, unforeseen medical complications or advancements in technology, pharmacology, and other areas; lack of funding to support recommended services; from other factors; or from a combination of several factors. Perhaps the most effective research approach will be one in which participants are closely followed over time from the point that each plan is developed, beyond the resolution of litigation, and at consistent intervals throughout life expectancy. Recognizing the obvious limitations imposed by time and financial resources, thorough longitudinal case
study analyses that describe the lived experiences of clients would substantially enrich the existing body of research within the specialty and provide foundations for specific plan recommendations of benefit to clients.

Conclusion

The purpose of the present study was to describe the outcomes experienced by individuals with spinal cord injuries for whom life care plans were developed. In addition, researchers were interested in assessing how accurately each participant’s individualized life care plan projected his or her current need for personal assistance and consultation with general and specialty physicians. The goal was to add knowledge of value and relevance to the existing body of research literature, and to provide insights to assist life care planners in developing recommendations that are of maximum long-term benefit to clients.

Plan recommendations are based upon an evaluation of a client’s current needs and their anticipated needs throughout the life expectancy based upon applicable clinical practice guidelines, standards of care, published research literature, and collaboration with members of the client’s treatment team. These sources provide the most reliable foundations for plan recommendations that are currently available to practitioners. Individual preferences, goals, economic circumstances, psychological wellbeing, social networks and interpersonal relationships, secondary medical conditions, the effects of aging, and numerous other factors likely impact client outcomes. However, unless there is sufficient
documentation and evidentiary support for making recommendations that vary from what is reported within the literature, life care plans typically conservatively project needs according to the aggregate, evidence-based data found in the literature. Understanding how and why variances from this data occur will be a long-term research endeavor within the specialty of life care planning.

*Anticipating the Future*

It is not realistic to believe that there will be a one-to-one correspondence between actual and projected needs, but the acceptable degree of discrepancy and evaluation rubric for determining the extent to which inconsistencies exist has yet to be defined within the life care planning community. As discussed in Chapter 2, the *Daubert* ruling poses greater challenges for expert witnesses, represents a more restrictive stance regarding the admissibility of evidence, and has prompted the specialty of life care planning to more thoroughly consider the reliability and validity of the methodology applied to the case analysis and plan development processes. The intrinsic rate of error within this methodology has not been determined statistically through empirical research, nor has the specialty defined for itself what an acceptable rate of error is, given expected individual variances over time. Even stated in broad terms, the specialty has yet to identify what constitutes a minor versus a major discrepancy between the needs and service utilization patterns reported by clients, and those that were projected by the planner. Some inconsistencies may be more detrimental to the client, some may result in
significantly higher or lower costs, and some may have relatively little effect. Once
identified, the field is further challenged to determine the causes of discrepancies.
The multidimensional nature of the planning process, the autonomy of the
individual, the unpredictability of random events and secondary health concerns,
and the demands present within the forensic arena demonstrate that this is an
important, but difficult, issue to resolve.

Life care planning combines the science of rehabilitation medicine with the
art of anticipating future needs based upon individual characteristics. As a science,
cases are systematically analyzed, current needs are identified through a specific set
of questions and processes, and recommendations are developed referencing a
consistent, deliberate methodology, regardless of the retaining party’s interests. As
an art, clients are recognized as having unique personal attributes and cases are
viewed in the entirety as having unique circumstances and that should be reflected
in plan recommendations. The specialty is challenged to bridge the practice of
science and art by developing foundationally sound, evidence-based plans that also
account for the individualized needs, abilities, and goals of each client.

The findings of the present study demonstrate the need for further research
regarding the long-term applicability of recommendations that purport to account
for the needs of an individual throughout his or her life expectancy. The fact that
none of the participants referred to their plans post development, and the
discrepancies revealed between the projected and the actual needs reported by
study participants raise questions about the capacity of life care plans to accurately anticipate the multitude of factors that may potentially impact the health and well-being of an individual over time. Certainly, life care plans serve a purpose in delineating probable comprehensive future needs and establishing a basis for the economic damages associated with the onset of injury. However, the long-term accuracy of these prospective documents is questionable and warrants further research. Although the definition of a life care plan specifically describes it as a “dynamic document,” the specialty has yet to implement a process for ensuring that they remain relevant to the changing needs of clients over time.

Research regarding the accuracy of life care plans over time is critical in understanding the capacity of the methodology to identify future needs, longevity of recommendations within various categories of the plan, and establishing guidelines for follow-up consultation and comprehensive plan revision. The specialty needs to identify those critical periods of time, subsequent medical developments, rehabilitation events, or other circumstances that necessitate reevaluation. Clients may be more likely to utilize the life care plan as a guideline for future services and support if it is revisited during these critical periods to ensure that recommendations remain relevant to their changing needs. In their role as expert witnesses, life care planners are often asked by opposing counsel, often sarcastically, to explain how they are uniquely qualified to predict the future. In addition to educating involved parties regarding the methodology applied to the
development of a life care plan, the planner’s credibility may be further enhanced if the limitations of long-term projections are able to be discussed. Research findings may allow planners to provide evidence for the need for periodic reevaluation; evidence which may justify the inclusion of follow-up evaluations into the overall cost of the original life care plan. Reevaluations should not be perceived as a negative aspect of the methodology, but as an acknowledgement of the realities of long-term planning for future needs.

Although important, perhaps research questions that seek to compare actual outcomes reported by clients with those projected in their life care plan are not indicative of the reliability and validity of the methodology applied to the life care planning process. Rather, as suggested previously in this chapter, the reliability and validity of life care planning methodology may be better evaluated by comparing plan recommendations with those reflected in relevant standards of care, clinical practice guidelines, and research literature. In addition to the contributions made by members of the client’s treatment team, these are the foundations upon which projections are developed. Consistency between plan recommendations and these foundations would demonstrate that the methodology relies upon the most objective, state-of-the-art sources available at the time of plan development.

In essence, the validity of individual plan recommendations is evaluated throughout the cross-examination process. Opposing attorneys question experts regarding the foundations for their recommendations and attempt to discover
conflicts of evidence, gaps in knowledge, or errors in professional judgment that
would invalidate plan projections. Plans that are not based upon valid,
authoritative resources or supporting evidence cannot be successfully defended and
may be summarily discredited. When competently developed, life care plans
utilized within the context of litigation are essential documents that assist in
educating all involved parties regarding the nature of an injury and the myriad of
needs associated with long-term management. There is typically just a single
window of opportunity within which to present the merits of a case and to
substantiate the economic impact of an event that resulted in injury. The specialty
of life care planning can address questions regarding validity and client outcomes
by producing further empirical research that addresses these issues.

Educational Initiative

Given the emergent themes, post-injury outcomes, and unexpected findings
revealed in the present study, an educational initiative focused upon informing
clients of the value and utility of their individualized life care plan appears
necessary. Being mindful of issues related to dual roles, planners have an
opportunity to educate clients by meeting with them after their plan has been
developed and informing them of its value as a tool for long-term injury
management. Such sessions would allow planners to fully explain how current and
future needs were identified, which agencies and vendors within their local regions
are potential service providers, how associated costs were calculated, and how the
foundations for recommendations were determined. Life care planners need to educate clients regarding the value of preventative, routine medical care by clearly describing how such efforts may reduce future complications and enhance independence, overall health, and quality of life.

Similarly, planners must emphasize the value of periodic case management support to ensure coordination of care, access to necessary services, long-term disability management, and implementation of life care plan recommendations. If changes in a plan are necessary over time due to medical complications or other unforeseen circumstances, knowledgeable case managers can revise recommendations to maintain the cohesion and relevance of the original document. By definition, a life care plan is dynamic. Planners recognize that circumstances change at multiple levels over time and base future projections upon what is known at the time of plan development. Life care planners can assist clients in managing their own health care by providing them with information and resources, encouraging them to seek periodic case management support, educating them regarding their long-term needs, and emphasizing the value of preventative, routine medical care.

Debriefing sessions may also include discussions regarding some of the most likely obstacles and challenges that can be anticipated, how the aging process may impact functional independence, fertility and childcare issues, vocational goals, home modifications, assistive technologies, transportation issues, and many
other topics of relevance to the client. By describing the life care plan as a customized blueprint for future needs that is applicable beyond the client’s legal case, such discussions may encourage clients to value the plan as a resource for future reference. Finally, clients must be given an opportunity to ask questions and to request clarification. Practitioners must not assume that clients will understand how to best utilize the life care plan or that they know what each of the recommendations entails. The complexity of a life care plan may be overwhelming and planners must ensure that all questions regarding its utility and implementation are thoroughly answered.

**Final Thoughts**

This study represents one attempt to further define and identify outcomes following life care plan development. Much of the success of a plan depends upon the effectiveness with which the individual implements all recommendations, experiences subsequent medical complications, adjusts to disability, obtains adequate financial resources, has access to necessary health care and personal assistance, and, generally, progresses as would be expected based upon applicable prospective data. The reliability and validity of the methodology applied to life care planning is important to explore because the accuracy and adequacy of recommendations may directly impact the settlement funds received by clients, if utilized within the context of litigation. Beyond that setting, a life care plan represents an individual’s anticipated needs, based upon what is known about the
typical progression of their injury and their unique personal attributes. A standardized life care plan for all individuals with spinal cord injuries will not adequately account for the individual differences that make a plan truly customized to meet the diversity of client needs over time. The development of such plans is not the goal of research related to the reliability and validity of the methodology involved in life care planning. Rather, research regarding reliability and validity is focused upon understanding client outcomes and attempting to better define the reasons why inconsistencies between reported needs and expected needs exist. Ultimately, such knowledge will benefit clients and their families as life care planning methodology adapts in response to the real-world experiences of individuals for whom plans were developed.
REFERENCES


Devers, K. (1999). How will we know ‘good’ qualitative research when we see it? Beginning the dialogue in health services research. *Health Services Research, 34*(5), 1153-1188.


Fischer, J. (2004). Reliance on objective functional testing to identify an individual’s needs for home support services. Journal of Life Care Planning, 3(1), 29-34.


APPENDIX A

LIFE CARE PLAN TEMPLATE
## Life Care Plan for Jim Smith

**Category:** Routine Medical Care

<table>
<thead>
<tr>
<th>Item or Service</th>
<th>Outpatient SCI Evaluation</th>
<th>General Physician</th>
<th>Urologist</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age and Year</strong></td>
<td>Begin at age 30 (2007), through life expectancy</td>
<td>Begin at age 30 (2007), through life expectancy</td>
<td>Begin at age 30 (2007), though life expectancy</td>
</tr>
<tr>
<td><strong>Frequency or Replacement</strong></td>
<td>1x/year</td>
<td>6x/year</td>
<td>4x/year</td>
</tr>
<tr>
<td><strong>Purpose</strong></td>
<td>Monitor health status and assess treatment plan</td>
<td>Routine health assessment</td>
<td>Evaluation of urological functioning</td>
</tr>
<tr>
<td><strong>Cost</strong></td>
<td>$850-$1,000</td>
<td>$75-$90 per visit</td>
<td>$85-$95 per visit</td>
</tr>
<tr>
<td><strong>Recommended by</strong></td>
<td>Dr. Saltz, treating general physician</td>
<td>Dr. Saltz, treating general physician</td>
<td>Dr. Basse, treating urologist</td>
</tr>
</tbody>
</table>
APPENDIX B

POTENTIAL PARTICIPANT DEMOGRAPHICS
## Demographic Summary of the Potential Participant Pool

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Quadriplegia</th>
<th>Paraplegia</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>34</td>
<td>34</td>
<td>68 (70%)</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
<td>17</td>
<td>29 (30%)</td>
</tr>
<tr>
<td>Total</td>
<td>46 (47%)</td>
<td>51 (53%)</td>
<td>97</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>39</td>
<td>42</td>
<td>81 (84%)</td>
</tr>
<tr>
<td>African-American</td>
<td>4</td>
<td>4</td>
<td>8 (8%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>3</td>
<td>3</td>
<td>6 (6%)</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>2</td>
<td>2 (2%)</td>
</tr>
</tbody>
</table>
APPENDIX C

QUESTIONNAIRE
Questionnaire

Participant Code: ____________________________

NATURE OF THE INJURY

1. What is the level of your spinal cord injury? __________
   Is your injury complete or incomplete? □ Complete □ Incomplete

2. How did the injury occur? __________________________________________

RESIDENCE

3. Where are you currently living?
   □ House
   □ Apartment or condominium
   □ Rehabilitation, group home, or supported living facility
   □ Skilled nursing care facility
   □ Other (Specify): ____________________________

4. With whom do you live?
   □ Alone
   □ Family, friend(s), or roommate(s)
   □ Attendant or nurse’s aide
   □ RN or LPN
   □ Other (Specify): ____________________________

Possible probes: Are you able to access all rooms in your home? - Outdoors? What types of modification have you made to your home since your injury? Are there modifications that you need to make to your home in the future? Do you live with a spouse? Do you live with children? - How many? What are their ages? Were you married at the time of the injury? Did you have children at the time of the injury?

HEALTH STATUS

5. Over the last five years, has your general health improved, declined, or stayed about the same?
   □ Improved □ Declined □ Same

If improved or declined, ask: Why? ________________________________________________

6. Over the last five years, have you required more personal assistance and care from others, less personal care, or about the same number of hours of care each week?
   □ More □ Less □ Same

If more or less, ask: Why? ____________________________________________

7. Over the last five years, have you required more doctor visits, fewer doctor visits, or about the same number of doctor visits per year?
   □ More □ Fewer □ Same

If more or less, ask Why? ____________________________________________
LIFESTYLE

8. On average, how many alcoholic beverages do you consume on a daily basis? ______

9. On average, how many cigarettes do you smoke on a daily basis? ______

10. Aside from prescription medications, do you consume any recreational drugs?
    - [ ] Yes
    - [ ] No

Possible probes: What are some of your other habits that may impact your general health, either positively or negatively?

PERSONAL ASSISTANCE

11. Think about your typical day and your typical week. What activities do you need help to complete? Who assists you and how much time do you spend on each activity? (Note: If the answer is not obvious, ask: How often do you need help with this activity? Daily, weekly, monthly, or yearly? Code D, W, M, or Y.)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Family, friend or unpaid volunteer</th>
<th>Nurse’s aide</th>
<th>RN or LPN</th>
<th>Other</th>
<th>How often is help needed? D/W/M/Y</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowel and/or bladder program</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication set-up</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication administration (e.g., IV medicine, blending medication with food/liquid)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Turning in bed at night and/or weight shifting during the day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

12. Are you getting the amount of help you need to perform the activities we just discussed?
    - [ ] Yes (If yes, skip to question 14)
    - [ ] No (If no, continue to the next question)

13. What type of assistance do you need, about how much additional time is needed, and why do you need this additional help? (Record in chart 13a)
13a. If you need this additional help, why are you not currently receiving it? (Record in chart 13a)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Amount of time</th>
<th>Why is this additional help needed?</th>
<th>Why are you not receiving this help?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Possible probes: Was there ever a time when you needed more personal assistance than you were receiving? – How did you solve this problem? Tell me about your transportation needs. Do you drive? What vehicle modifications do you currently have? Do you anticipate needing additional modifications in the future? Do you need transportation to work? What are your general job duties? What types of accommodations do you currently require at work? What are the current barriers to your participation in social or community activities? When you were first injured, how did you learn to accomplish personal care and other daily activities? Now, how do you keep informed about new tools or techniques for accomplishing personal care and other daily activities? What do you believe to be the primary influences on the personal care that you currently need?

CASE MANAGEMENT AND MEDICAL EVALUATIONS

14. When did you last have a comprehensive spinal cord injury evaluation? Date: ________________
   If never, ask: Do you believe you need one? □ No (If no, continue to the next question)
   □ Yes (If yes, ask: Why?) ____________________________

15. Who plans and schedules your doctor visits? (If case manager is not mentioned, ask: Have you ever worked with a case manager in the past? □ No (If no, continue to the next question) □ Yes (If yes, ask: Why did you stop working with a case manager?) _______________________
   □ Self
   □ RN or LPN
   □ Family member, unpaid friend or volunteer
   □ Other: ____________________
   □ Case manager

16. Do you refer to the life care plan that was developed for you? □ Yes     □ No
   If yes, ask: How often; weekly, monthly, yearly? ______________________
   For what purposes? ______________________
   If no, ask: Why not? ______________________

Possible probes: Where did you have your last comprehensive evaluation? Was the visit helpful? Do you believe that future evaluations may be useful? When you were first injured, what services were most helpful to you? –Least helpful? Looking back, are there other services that you feel would have been valuable to you? Now, what services do you find most helpful? What additional services would be helpful?
PHYSICIAN VISITS

17. Within the past 12 months, how many times have you visited a doctor? Were these visits routine, unrelated to the spinal cord injury, related to the spinal cord injury, or not possible to classify?

<table>
<thead>
<tr>
<th>Specialists</th>
<th>Number of Visits</th>
<th>Purpose (Specify number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Provider, General Practitioner, Internist,</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
<tr>
<td>Physiatrist, Physical Medicine &amp; Rehabilitation Doctor</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
<tr>
<td>Urologist</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
<tr>
<td>Podiatrist</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
<tr>
<td>Dentist</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
<tr>
<td>Orthopedist</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
<tr>
<td>Neurologist</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
<tr>
<td>Cardiologist</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>□ Routine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>□ Unrelated to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Related to SCI</td>
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<tr>
<td></td>
<td></td>
<td>□ Undetermined</td>
</tr>
</tbody>
</table>
Possible probes: What limitations do you have when scheduling physician visits? - Are you able to schedule your physician visits as you wish, or do you need to work with an insurance representative or case manager to do so? How do you pay for your visits? Are you consulting with physicians as often as you would like? Do you feel that you are receiving adequate care? Do you feel that you are receiving adequate education and information from physicians? Tell me about your relationship with your primary care physician. How could your medical care be improved? When you were first injured, how did you learn about the medical aspects of your injury? Now, how do you keep informed about the medical aspects of your injury?

SUBSEQUENT INJURY/ILLNESS

18. Within the last 12 months, have you had any illnesses or injuries that caused you to visit the emergency room or an urgent care facility? □ No (If no, skip to number 19) □ Yes (If yes, ask: What was the diagnosis or reason for the visit? Was the diagnosis related to the spinal cord injury, unrelated to the spinal cord injury, or is it not possible to classify? Record in chart 18a)

18a. Did any of these visits result in admission to the hospital? □ No (If no, skip to number 19) □ Yes (If yes, ask: For how many days were you hospitalized? Record in chart)

<table>
<thead>
<tr>
<th>Reason for Visit</th>
<th>Admitted to Hospital?</th>
<th>Days in Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Unrelated to SCI □ Related to SCI □ Undetermined</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>□ Unrelated to SCI □ Related to SCI □ Undetermined</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
<tr>
<td>□ Unrelated to SCI □ Related to SCI □ Undetermined</td>
<td>□ Yes □ No</td>
<td></td>
</tr>
</tbody>
</table>

19. Other than hospital admissions through the emergency room, within the last 12 months have you been hospitalized? □ No (If no, continue to next question) □ Yes (If yes, ask: What was the reason, how many days did you stay, and who referred you? Was the diagnosis related to the spinal cord injury, unrelated to the spinal cord injury, or is it not possible to classify? Record in chart)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Days in Hospital</th>
<th>Referred by</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Unrelated to SCI □ Related to SCI □ Undetermined</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
20. Since your life care plan was developed, have you had any injuries or illnesses that required additional medical care or personal assistance?  
☐ No (If no, end the survey)  ☐ Yes (If yes, ask: What was the diagnosis and in approximately what year did the difficulty occur? Was the diagnosis related to the spinal cord injury, unrelated to the spinal cord injury, or is it not possible to classify? Record in chart 20a)

20a. How long did you need this additional care and, if you continue to need it today, how long do you think it will continue? (Record in chart 20a)

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Approx. Year of Occurrence</th>
<th>Length of Additional Care</th>
<th>Anticipated Duration of Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Unrelated to SCI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Related to SCI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Undetermined</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Unrelated to SCI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Related to SCI</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>☐ Undetermined</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Possible probes: Do you think that there is any relationship between your lifestyle and the injuries or illnesses that you have had over the past year? Do you think that there is any relationship between the personal assistance that you are receiving and your overall health? What do you believe are the primary influences on the medical care that you currently need?

New technologies:

Concluding thoughts:
APPENDIX D

TELEPHONE SCRIPT
Telephone Script

Hello [PARTICIPANT’S NAME]. This is Lori Allison calling and, if you recall, you agreed to participate in a research project regarding your life care plan. You indicated that you would prefer a call in the [MORNING, AFTERNOON OR EVENING, AS APPLICABLE]. Am I calling at a convenient time? [IF SO, PROCEED WITH SURVEY. IF NOT, ARRANGE ANOTHER DAY AND/OR TIME.]

I will ask you several questions about your current needs and will be happy to repeat or clarify any questions that you may not understand. Please let me know if I can provide you with additional explanation because it is important to answer these questions as accurately as possible. Do you have any questions before we begin? [IF SO, RESPOND TO QUESTIONS. IF NOT, PROCEED WITH SURVEY AND RECORD ANSWERS]

NATURE OF THE INJURY

1. What is the level of your spinal cord injury? [RECORD RESPONSE] Is the injury complete or incomplete? [RECORD RESPONSE]
2. How did the injury occur? [RECORD RESPONSE]

RESIDENCE

3. Where are you currently living? [RECORD RESPONSE]
4. With whom do you live? [RECORD RESPONSE]

Possible probes: Are you able to access all rooms in your home? - Outdoors? What types of modification have you made to your home since your injury? Are there modifications that you need to make to your home in the future? Do you live with a spouse? Do you live with children? - How many? What are their ages? Were you married at the time of the injury? Did you have children at the time of the injury?

HEALTH STATUS

5. Over the last five years, has your general health improved, declined, or stayed about the same? [RECORD RESPONSE]
6. Over the last five years, have you required more personal assistance and care from others, less personal care, or about the same number of hours of care each week? [RECORD RESPONSE]
7. Over the last five years, have you required more doctor visits, fewer doctor visits, or about the same number of doctor visits per year? [RECORD RESPONSE]

LIFESTYLE

8. On average, how many alcoholic beverages do you consume on a daily basis? [RECORD RESPONSE]
9. On average, how many cigarettes do you smoke on a daily basis? [RECORD RESPONSE]
10. Aside from prescription medications, do you consume any recreational drugs? [RECORD RESPONSE]

Possible probes: What are some of your other habits that may impact your general health, either positively or negatively?

PERSONAL ASSISTANCE

11. Think about your typical day and your typical week. What activities do you need help to complete? Who assists you and how much time do you spend on each activity? [RECORD RESPONSE OR PROMPT IF NECESSARY. IF THE ANSWER IS NOT OBVIOUS, ASK] How often do you need help with this activity? Daily, weekly, monthly, or yearly? [RECORD RESPONSE. CONTINUE TO NUMBER 12 IF NO PROMPT IS NEEDED]

PROMPT 1: Do you require assistance with any of the following tasks?
- Completing a bowel and/or bladder program? [RECORD RESPONSE]
- Setting up medications? [RECORD RESPONSE]
- Taking medications such as IV medicines, or blending medications with food or liquid? [RECORD RESPONSE]
- Do you need help turning in bed at night or weight shifting during the day? [RECORD RESPONSE]
PROMPT 2: Consider the average number of hours of assistance you receive during a typical week in these areas: Grooming and Bathing tasks such as dressing and personal hygiene? [PAUSE FOR RESPONSE] Who provides this assistance? [RECORD TIME UNDER APPROPRIATE PROVIDERS] Completing Household Tasks such as cleaning, doing laundry, cooking, paying bills, and sorting mail? [PAUSE FOR RESPONSE] Who provides this assistance? [RECORD TIME UNDER APPROPRIATE PROVIDERS]. Going on Community Outings including transportation to and from shopping areas, social activities, and other events outside of your home? [PAUSE FOR RESPONSE] Who provides this assistance? [RECORD TIME UNDER APPROPRIATE PROVIDERS]. Do you need assistance for Other tasks such as taking medications or making appointments? [PAUSE FOR RESPONSE] Who provides this assistance? [RECORD TIME UNDER APPROPRIATE PROVIDERS]

12. Are you getting the amount of help you need to perform the activities we just discussed? [RECORD RESPONSE. IF YES, THE RESEARCHER WILL CONTINUE TO QUESTION 14. IF NO, THE RESEARCHER WILL CONTINUE TO NUMBER 13]

13. What type of assistance do you need, about how much additional time is needed, and why do you need this additional help? [RECORD RESPONSE IN CHART 13a]

13a. If you need this additional help, why are you not currently receiving it? [RECORD RESPONSE IN CHART 13a]

Possible probes: Was there ever a time when you needed more personal assistance than you were receiving? – How did you solve this problem? Tell me about your transportation needs. Do you drive? What vehicle modifications do you currently have? Do you anticipate needing additional modifications in the future? Do you need transportation to work? What are your general job duties? What types of accommodations do you currently require at work? What are the current barriers to your participation in social or community activities? When you were first injured, how did you learn to accomplish personal care and other daily activities? Now, how do you keep informed about new tools or techniques for accomplishing personal care and other daily activities? What do you believe to be the primary influences on the personal care that you currently need?

Check point: We are about half-way through the interview, [PARTICIPANT’S NAME]. Would you like to continue, or would you prefer that I call you back on another day? [IF THE PARTICIPANT WOULD LIKE TO CONTINUE, DO SO. IF NOT, SPECIFY A DATE AND TIME TO RESUME THE INTERVIEW.]
14. When did you last have a comprehensive spinal cord injury evaluation? [RECORD RESPONSE. IF NEVER, ASK] Do you believe that you need one? [RECORD RESPONSE. IF NO, CONTINUE TO NEXT QUESTION. IF YES, ASK ] Why?

15. Who plans and schedules your doctor visits? [RECORD RESPONSE. PROMPT IF CASE MANAGER IS NOT MENTIONED]

   PROMPT: Have you worked with a case manager in the past? [RECORD RESPONSE. IF NO, CONTINUE TO NEXT QUESTION. IF YES, ASK]
   Why did you stop working with a case manager? [RECORD RESPONSE]

16. Do you refer to the life care plan that was developed for you? [RECORD RESPONSE. IF NO, ASK: Why not? IF YES, ASK: How often; weekly, monthly yearly? RECORD RESPONSE THEN ASK: For what purposes? RECORD RESPONSE]

   Possible probes: Where did you have your last comprehensive evaluation? Was the visit helpful? Do you believe that future evaluations may be useful? When you were first injured, what services were most helpful to you? –Least helpful? Looking back, are there other services that you feel would have been valuable to you? Now, what services do you find most helpful? What additional services would be helpful?

PHYSICIAN VISITS

17. Within the past 12 months, how often have you visited a doctor? [RECORD RESPONSE, OR PROMPT FROM LIST OF SPECIALISTS] Were these visits routine, related to the spinal cord injury, unrelated to the spinal cord injury, or is it not possible to classify some of these visits? [RECORD RESPONSE]

   PROMPT: Have you visited any of the following specialists? Primary Care Provider, General Practitioner, or Internist; Physiatrist or Physical Medicine and Rehabilitation Doctor; Urologist; Podiatrist; Dentist; Orthopedist; Neurologist; Psychiatrist; Cardiologist; Other

   Possible probes: What limitations do you have when scheduling physician visits? Are you able to schedule your physician visits as you wish, or do you need to work with an insurance representative or case manager to do so? How do you pay for your visits? Are you consulting with physicians as often as you would like? Do you feel that you are receiving adequate care? Do you feel that you are receiving adequate education and information from physicians? Tell me about your relationship with your primary care physician. Do you visit a dentist any more frequently than is recommended for the general population – two times per year? How could your medical care be improved? When you were first injured, how did you learn about the medical aspects of your injury? Currently, how do you keep informed about the medical aspects of your injury?
SUBSEQUENT INJURY/ILLNESS

18. Within the last 12 months, have you had any illnesses or injuries that caused you to visit the emergency room or an urgent care facility? [RECORD RESPONSE. IF NO, SKIP TO QUESTION 19. IF YES, ASK] What was the diagnosis or reason for the visit? Was the diagnosis related to the spinal cord injury, unrelated to the spinal cord injury, or is it not possible to classify? [RECORD RESPONSE IN CHART 1]

18a. Did any of these visits result in admission to the hospital? [IF NO, SKIP TO QUESTION 19. IF YES, ASK] For how many days were you hospitalized? [RECORD RESPONSE IN CHART 18a]

19. Other than hospital admissions through the emergency room, within the last 12 months have you been hospitalized? [IF NO, SKIP TO QUESTION 20. IF YES, ASK] What was the reason, how many days did you stay, and who referred you? Was the diagnosis related to the spinal cord injury, unrelated to the spinal cord injury, or is it not possible to classify? [RECORD RESPONSES]

20. Since your life care plan was developed, have you had any injuries or illnesses that required additional medical care or personal assistance? [RECORD RESPONSE. IF NO, CONTINUE TO FINAL THOUGHTS. IF YES, ASK] What were your diagnoses and approximately when did the difficulty occur? Was the diagnosis related to the spinal cord injury, unrelated to the spinal cord injury, or is it not possible to classify? [RECORD RESPONSES IN CHART 20a AND CONTINUE TO FINAL THOUGHTS.]

Possible probes: Do you think that there is any relationship between your lifestyle and the injuries or illnesses that you have had over the past year? Do you think that there is any relationship between the personal assistance that you are receiving and your overall health? What do you believe are the primary influences on the medical care that you currently need?

20a. How long did you need this additional care and, if you continue to need it today, how long do you think it will continue? [RECORD RESPONSES IN CHART 20a AND CONTINUE TO NEW TECHNOLOGY.]

New technology: Are there any new technologies, equipment, medications or other items that you are using now that were not available at the time of your injury? [RECORD RESPONSES AND CONTINUE TO FINAL THOUGHTS.]
Final thoughts: As you reflect upon our discussion, are there any issues that you feel are important for me to consider as I describe your experiences and assess how well your current needs were projected in your life care plan? [RECORD RESPONSES AND CONTINUE TO CONCLUDING STATEMENT.]

CONCLUDING STATEMENT

I’ve finished with my questions. Would you like to review any of your responses or discuss anything related to the questionnaire? [IF SO, REVIEW SPECIFIC QUESTIONS OF INTEREST TO THE PARTICIPANT] Thank you for your time, [PARTICIPANT’S NAME], and for your willingness to participate in this study. [IF APPLICABLE: Your interview contact form indicates that you would like to receive a summary of the results of this study when it is completed. I will be certain to send this to you at the conclusion of the project.] I will send you a copy of your responses so that you can make any corrections that may be necessary. If you would like to add information as you review the summary, you are welcome to do so. It was a pleasure to talk with you and I appreciate your time. Thank you again and good-bye.
APPENDIX E

INTRODUCTORY LETTER
Dear <Name>:

My name is Lori Allison and I would like to invite you to participate in an important research study. I am a doctoral candidate at The Ohio State University and am doing research in the area of life care planning.

I worked at Paul M. Deutsch & Associates in Oviedo, Florida as a certified life care planner and understand that you had a life care plan developed several years ago. I am interested in learning whether that plan has accurately projected your current needs. I would like to speak with you on the telephone about the personal assistance and physician visits that you now require. You do not need a copy of your plan in order to participate.

My advisor, Dr. Joe Wheaton, and I will soon be sending you a packet of paperwork. This packet includes more information about the study and several forms for you to sign and return. It also includes a list of the questions that I will be asking so that you know what to expect and can think about your answers. You can also tell me the days and times that are best to call.

Please consider participating in this study. You have an opportunity to help life care planners in making recommendations that truly represent the needs of people with spinal cord injuries. If you have any questions or would like to discuss this opportunity, please feel free to contact Lori Allison at 407-415-3242 or atloriallison1000@yahoo.com.

Sincerely,

Lori A. Allison, MA, CLCP, CCM, MSCC
The Ohio State University, Columbus, OH
APPENDIX F

RECRUITMENT LETTER
Dear <Name>:

We would like to invite you to participate in a research project designed to evaluate the methodology of life care planning for individuals with spinal cord injuries and to give you an opportunity to win $100.00, as well!

**The Purpose of the Study**

Lori Allison is a doctoral candidate at The Ohio State University working under the supervision of Dr. Joe Wheaton. Prior to beginning her research, Lori worked at Paul M. Deutsch & Associates and became a certified life care planner. For her dissertation project, she is interested in learning whether the life care plan that was developed for you after your spinal cord injury has accurately projected your current care needs. Specifically, she is interested interviewing you over the telephone regarding the personal assistance and physician visits that you now require. By comparing your current needs to those projected in your original plan, the validity of life care planning methodology can be explored. You do not have to have a copy of your plan in order to participate!

**Why is This Study Important?**

This is a very exciting study because it is one of the first to evaluate the accuracy of long-term recommendations in life care plans. You have an opportunity to assist the specialty in assessing its ability to make recommendations that truly represent the needs of people with spinal cord injuries. Most importantly, you have an opportunity to improve future life care plans by providing critical information. We intend to publish the results of this study so that other planners may learn from the experience of study participants.

**Confidentiality**

Your responses to each question will be kept strictly confidential. Once Lori has spoken with you on the telephone, your responses to the questionnaire and your original life care plan will be identified only by a random code. Your name will not appear on these documents or on any other material related to the project. All telephone interviews will be conducted from a private office and no recording audio recording devices will be used.
Participation in the Study
To participate in this study, simply sign, date and return the forms that are printed on yellow paper in the self-addressed, stamped envelope. Please return the following forms:

- Consent For Participation in Social and Behavioral Research
- Authorization to Use Personal Health Information in Research
- Telephone Interview Contact

We have made an extra copy of each of the forms so that you will have them for your records. We have also enclosed a copy of the questions that will be asked so that you know exactly what to expect when Lori calls. Please read these questions and think about your answers. The telephone questionnaire will take approximately 20-25 minutes and will not involve any long distance charges to you. Participation in this study is voluntary and you may withdraw at any time with no penalty, even after speaking with Lori on the telephone.

Please return your signed forms as quickly as possible! As a way of thanking you for your time and effort, your name will be entered into a lottery drawing for $100.00 as soon as we receive your packet of signed forms and complete the telephone interview.

If you would like to speak with us about this project, do not hesitate to contact Dr. Joe Wheaton at 614-292-8313 (or via e-mail at wheaton3@osu.edu) or Lori Allison at 407-415-3242 (or via e-mail at loriallison1000@yahoo.com). Thank you for your time. We are looking forward to talking with you!

Sincerely,

Joe E. Wheaton, Ph.D.
The Ohio State University, Columbus, OH

Lori A. Allison, MA, CLCP
The Ohio State University, Columbus, OH
APPENDIX G

AUTHORIZATION TO USE PERSONAL HEALTH INFORMATION
Title of the Study: Validity in Life Care Planning for Individuals with Spinal Cord Injuries
OSU Protocol Number: 2005B0130
Principal Investigator: Dr. Joe E. Wheaton

Participant Name: ____________________________

Before researchers use or share any health information about you as part of this study, The Ohio State University is required to obtain your authorization. This helps explain to you how this information will be used or shared with others involved in the study.

- The Ohio State University and its hospitals, clinics, health-care providers and researchers are required to protect the privacy of your health information.

- If you agree to take part in this study your health information will remain strictly confidential and will be accessed by the researchers, only. Your name will be removed from your life care plan and all related documentation will bear only a random code as a means of identification.

- Results of this study will be shared with practitioners in the specialty of life care planning and other rehabilitation related areas through publications, conference presentations, and professional workshops. At no time will the names of participants be identified.

Please read the information carefully before signing this form. Please ask if you have any questions about this authorization, the University’s Notice of Privacy Practices or the study before signing this form.

Those Who May Use, Share and Receive Your Information as Part of This Study

- Only the two project researchers, Dr. Joe E. Wheaton and Ms. Lori A. Allison, will use, share and/or receive your personal health information as contained in your original life care plan and reported during the telephone interview.

- Immediately following the telephone interview, your name will be removed from all documents and referenced by a random subject code, only.

Initials/Date: ________________
• At the conclusion of the study, results may be shared with practicing life care planners and other rehabilitation professionals through publication and/or presentations such as:
  • Publication in the *Journal of Life Care Planning*
  • Presentation at the annual International Conference for Life Care Planning

Authorization Period

• This authorization will not expire unless you change your mind and revoke it in writing.
• Your personal information will be identified only by random subject code (not by your name) immediately following the telephone interview, but the information provided during the study may be analyzed for many years and it is not possible to know when this will be complete.

Signing the Authorization

• You have the right to refuse to sign this authorization. Your health care outside of the study, payment for your health care, and your health care benefits will not be affected if you choose not to sign this form.
• If you sign this authorization, you may change your mind at any time. Researchers may continue to use information collected up until the time that you formally changed your mind. If you change your mind, your authorization must be revoked in writing. To revoke your authorization, please write to: Dr. Joe E. Wheaton, The Ohio State University, 356D Arps Hall, 1945 N. High Street, Columbus, OH 43210.

Contact for Questions

• If you have any questions relating to the research, please contact Dr. Joe E. Wheaton, The Ohio State University, 356D Arps Hall, 1945 N. High Street, Columbus, OH 43210.

Signature

I have read (or someone has read to me) this form and have been able to ask questions. All of my questions about this form have been answered to my satisfaction. By signing below, I permit Dr. Joe E. Wheaton and Ms. Lori A. Allison to use and share my personal health information for this study. I will be given a copy of this signed form.

Signature

(Participant or Legally Authorized Representative)

Name: __________________________________________________

(Print name above) (If legal representative, also print relationship to participant.)

Date _________________ Time ___________ AM / PM

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APPENDIX H

CONSENT FOR PARTICIPATION
CONSENT FOR PARTICIPATION IN RESEARCH

I consent to participate in the research project entitled: Validation of Life Care Planning Methodology for Individuals with Spinal Cord Injury

I have received a letter from Lori A. Allison of The Ohio State University that explains the purpose of the study, the procedures to be followed, and the amount of time that I am expected to commit. My responses will remain confidential and will only be identified by a subject code once they have been submitted to Ms. Allison. The possible benefits of the study have been described and I understand that the results will be published in a professional journal.

I acknowledge that I have been given Ms. Allison’s contact information and have been encouraged to call her at 407-415-3424 if I have questions regarding any aspect of my participation in the study. In addition, if I have questions about my rights as a research participant, I can call the Office of Research Risks Protection at The Ohio State University at (614) 688-4792.

I understand that I am free to withdraw consent at any time and to discontinue participation at any point throughout the study and there will be no penalty. I understand that Ms. Allison will use information contained in my original life care plan and my responses to the study questionnaire as a basis for evaluating life care planning methodology.

Finally, I acknowledge that I have read this form or have had it read to me. I fully understand the consent agreement and sign it freely and voluntarily. A copy has been provided to me for future reference.

Date: ___________________________  Signed: ___________________________

Signed: ____________________________________________  <Name of Participant>

Signed: ____________________________________________  Lori A. Allison, MA, CLCP, CCM, MSCC

Signed: ____________________________________________  Dr. Joe Wheaton, Ph.D., Doctoral Advisor
The Ohio State University, Columbus, OH
APPENDIX I

TELEPHONE CALL PREFERENCE
Telephone Call Preference

1. When would you like to be contacted? Please check all that apply.

   Morning (9:00 a.m. - 12:00 p.m.) □
   Afternoon (12:00 p.m.-6:00 p.m.) □
   Evening (6:00 p.m.-9:00 p.m.) □

2. What day of the week do you prefer? Please check all that apply.

   Sunday □  Monday □  Tuesday □  Wednesday □
   Thursday □  Friday □  Saturday □

3. What telephone number would you like me to call? Feel free to provide more than one telephone number.

   ________________________________
   ________________________________

4. When the study is completed, would you like to receive a summary of the results?

   Yes □  No □

5. Would you be interested in participating in other research projects related to life care planning?

   Yes □  No □  Maybe □

Thank you for your willingness to participate in this exciting study!

If you have any questions, please feel free to contact:
Dr. Joe Wheaton at 614-292-8313 (or via e-mail at wheaton3.osu.edu) or Lori Allison at 407-415-3242 (or via e-mail at loriallison1000@yahoo.com).
APPENDIX J

LIST OF QUESTIONS
Primary Questions That Will Be Asked During the Telephone Interview

Please read each of these questions and carefully consider your responses. You do not need to return this form to me! I have given you this list so that you can review the types of questions that I will ask and so that you can think about your answers before I talk with you on the telephone. If you have any difficulty, please feel free to contact Lori Allison at 407-415-3242 or via e-mail at loriallison1000@yahoo.com

1. What is the level of your spinal cord injury? Is your injury complete or incomplete?

2. How did the injury occur?

3. Where are you currently living?

4. With whom do you live?

5. Over the last five years, has your general health improved, declined, or stayed about the same?

6. Over the last five years, have you required more personal assistance and care from others, less personal care, or about the same number of hours of care each week?

7. Over the last five years, have you required more doctor visits, fewer doctor visits, or about the same number of doctor visits per year?

8. On average, how many alcoholic beverages do you consume on a daily basis?

9. On average, how many cigarettes do you smoke on a daily basis?

10. Aside from prescription medications, do you consume any recreational drugs?

11. Think about your typical day and your typical week. What activities do you need help to complete? Who assists you and how much time do they spend on each activity? This includes assistance with dressing, eating, bathing, cooking, taking medications, community outings, doing laundry, grocery shopping, and all other activities that you need help in accomplishing. Please think about all of the care and assistance that is provided by family members, registered nurses, home health aides, and others.

12. Are you getting the amount of help you need to perform the activities that you identified in Question 11?
13. If applicable: If you responded “No” to Question 12, what type of assistance do you need, about how much additional time is needed, and why do you need this additional help? If you need additional help, why are you not currently receiving it?

14. When did you last have a comprehensive spinal cord injury evaluation?

15. Who plans and schedules your doctor visits, therapies, care and other medical appointments?

16. Do you refer to the life care plan that was developed for you?

17. Within the past 12 months, how many times have you visited a doctor? The list below may help you to recall your recent visits:

- Primary Care Provider, General Practitioner, Internist
- Physiatrist or Physical Medicine and Rehabilitation Doctor
- Urologist
- Orthopedist
- Podiatrist
- Dentist
- Neurologist
- Psychiatrist
- Cardiologist
- Other

18. Within the last 12 months, have you had any illnesses or injuries that caused you to visit the emergency room?

19. Other than hospital admissions through the emergency room, within the last 12 months have you been hospitalized?

20. Since your life care plan was developed, have you had any injuries or illnesses that required additional medical care or personal assistance?
APPENDIX K

FOLLOW-UP LETTER
Dear <Name>:

Several weeks ago, I mailed a packet of information to you regarding a study that is focused upon life care planning for individuals with spinal cord injuries. Would you please consider participating in this study?

I welcome you to mail your signed consent forms by March 15, 2007. If you need another packet of materials, please feel free to contact me and I will be happy to send one immediately.

Your involvement in this project, and others like it, is invaluable. Only a limited number of people have been invited to participate in this study. You have an opportunity to assist life care planners in making recommendations that truly represent the needs of people with spinal cord injuries. Most importantly, you have an opportunity to improve future life care plans by providing critical information about your personal experiences. As a way of thanking you for your time and effort, your name will be entered into a lottery drawing for $100.00 as soon as I receive your packet of signed forms and complete the telephone interview.

If you would like to speak with me about this project, do not hesitate to call: 407-415-3242 or to send an e-mail message: loriallison1000@yahoo.com.

Thank you for your time. I am looking forward to talking with you!

Sincerely,

Lori A. Allison, MA, CLCP, CCM, MSCC
The Ohio State University, Columbus, OH
APPENDIX L

LETTER TO PARTICIPANTS
Dear <Name>:

Thank you for your willingness to participate in my research study which is focused upon life care planning for individuals with spinal cord injuries. I am looking forward to talking with you soon.

Because there were fewer volunteers than I had anticipated, there is now an opportunity to have a more in-depth discussion regarding the primary questions of interest. Rather than a period of 20-25 minutes, I am seeking your permission to extend our conversation to approximately 60-90 minutes. This will allow us to talk in greater detail about your experience since your life care plan was developed. The primary interview questions will still be based upon those included in the original information packet and does not have to be completed in one session. In recognition of your time and effort, I will send you a $50.00 stipend at the conclusion of the interview.

Due to these changes, I have enclosed another set of consent forms for your signature. If you are no longer interested in participating, simply write “No Thanks” on the signature line. Please return the forms in the enclosed stamped, addressed envelope.

Your participation is valuable and may result in meaningful improvements in life care planning for individuals with spinal cord injuries. I hope that you remain interested in participating in this study and welcome you to contact me if you have any questions or concerns at 407-415-3242 or via e-mail at loriallison1000@yahoo.com.

Sincerely,

Lori A. Allison, MA, CLCP, CCM, MSCC
The Ohio State University, Columbus, OH
APPENDIX M

MEMBER CHECK LETTER
Dear <Name>:

Thank you for your time in completing the recent telephone interview. Enclosed, you will find a copy of the notes that I took during the session for your review. Please feel free to make corrections, to clarify responses, or to add information if you would like to offer further explanation.

You are welcome to call, email, or make notations on the printed copy and return the document to me in the addressed, stamped envelope which is enclosed.

It was a pleasure to talk with you and I sincerely appreciate your willingness to share your experiences. Because of your generosity, the specialty of life care planning will gain valuable insights that will benefit other individuals with spinal cord injuries in the future.

If you should have any questions or comments, please do not hesitate to contact me.

I wish you the best and thank you for making this project possible.

Sincerely,

Lori A. Allison, MA, CLCP, CCM, MSCC
The Ohio State University, Columbus, OH
Case Analysis Guide

Upon completion of a narrative summary of the information provided by study participants, researchers considered the emerging themes and relationships between the nature of the injury and demographics, general health, personal assistance, and physician visits. The following questions guided this analysis:

Nature of the Injury and Demographics (Questions 1-4)
1. Did the LCP accurately project the client’s residential situation (home/facility)?
2. What factors may account for discrepancies between projected and reported residential status?

General Health and Coordination of Care (Questions 5-10, 14-16)
1. What is the relationship between the client’s general health, the need for personal assistance, and the frequency of physician visits over the past five year period?
2. What is the relationship between the client’s lifestyle, the need for personal assistance, and the frequency of physician visits?
3. What is the relationship between the client’s general health, case management support, and LCP utilization?
4. What is the relationship between the need for personal assistance, the frequency of physician visits, and case management support and LCP utilization?

Personal Assistance (Questions 11-13a)
1. Did the LCP accurately project the type of assistance that would be required (e.g., nurse, HHA)?
2. Did the LCP accurately project the number of hours of personal assistance would be required?
3. What factors may account for discrepancies between projected and reported personal assistance needs?

Physician Visits and Medical Care (Questions 17-20a)
1. Did the LCP accurately project the type of specialty phys visits that would be required?
2. Did the LCP accurately project the number of specialty phys visits that would be required?
3. What factors may account for discrepancies between projected and reported physician visits?

Emergent Themes
1. Based upon the patterns that were identified, what are the primary themes that emerged from the interview?
2. What were the issues of importance to the participants?
3. When asked to share their final thoughts, which issues did participants choose to discuss?
4. How do these emergent themes relate to the methodology involved in developing a life care plan?
### Case 1, Jim: Comparison Between Projected and Current Needs

<table>
<thead>
<tr>
<th>Life Care Plan Projections</th>
<th>Current Self-Reported Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant and LPN care, 168 hours per week in a private residence</td>
<td>Attendant and family care, 66-71 hours per week in a private residence</td>
</tr>
<tr>
<td>Weekly interior/exterior home maintenance</td>
<td>Not applicable (lives with parents), but would be necessary if living alone</td>
</tr>
<tr>
<td>Inpatient and outpatient spinal cord injury evaluations, annual</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>General physician, annual</td>
<td>General physician, annual</td>
</tr>
<tr>
<td>Urologist, biannual</td>
<td>Urologist, 4 times per year</td>
</tr>
<tr>
<td>Nephrologist, biannual</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Podiatrist, 3-4 visits per year</td>
<td>Nail care provided by attendant</td>
</tr>
<tr>
<td>Outpatient clinical evaluation for an FES program, one time only</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Not projected</td>
<td>Sleep specialist consultation for possible sleep apnea</td>
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</table>
APPENDIX P

CASE STUDY: TERESA
### Case 2, Teresa: Comparison Between Projected and Current Needs

<table>
<thead>
<tr>
<th>Life Care Plan Projections</th>
<th>Current Self-Reported Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live-in attendant care, 24 hours per day in a private residence</td>
<td>Live-in attendant care, 24 hours per day in a private residence</td>
</tr>
<tr>
<td>Weekly interior/exterior home maintenance</td>
<td>Weekly lawn service, hires professionals for interior/exterior maintenance</td>
</tr>
<tr>
<td>Inpatient and outpatient spinal cord injury evaluations, annual visits</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>General physician, biannual visits</td>
<td>General physician, 3 times per year</td>
</tr>
<tr>
<td>Urologist, biannual visits</td>
<td>Urologist, biannual visits</td>
</tr>
<tr>
<td>Physiatrist, 3-4 visits per year</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Podiatrist, 4 visits per year</td>
<td>Nail care provided by a pedicurist</td>
</tr>
<tr>
<td>Psychiatrist evaluation, one time only</td>
<td>Not reported as a current need</td>
</tr>
</tbody>
</table>
APPENDIX Q

CASE STUDY: ROBERT
## Case 3, Robert: Comparison Between Projected and Current Needs

<table>
<thead>
<tr>
<th>Life Care Plan Projections</th>
<th>Current Self-Reported Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant care, 56 hours per week in a private residence</td>
<td>Family care, 35-42 hours per week in a private residence</td>
</tr>
<tr>
<td>Weekly house cleaning and interior/exterior home maintenance</td>
<td>House cleaning, lawn maintenance completed by wife; interior/exterior home maintenance by a professional</td>
</tr>
<tr>
<td>Case management support, 4-6 hours per month</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>General physician, biannual visits</td>
<td>General physician, 6 visits per year</td>
</tr>
<tr>
<td>Inpatient and outpatient spinal cord injury evaluations, annual visits</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Orthopedic surgeon, gastroenterologist, annual visits</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Physiatrist, urologist biannual visits</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Psychiatrist, 3-4 visits per year</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Not projected</td>
<td>Orthopedist, 1-2 visits per year</td>
</tr>
</tbody>
</table>
### Case 4, Lynne: Comparison Between Projected and Current Needs

<table>
<thead>
<tr>
<th>Life Care Plan Projections</th>
<th>Current Self-Reported Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live-in attendant care, 24 hours per day beginning between 50 and 60 years of age in a private residence</td>
<td>Not applicable (not yet 50 years of age)</td>
</tr>
<tr>
<td>Weekly house cleaning services</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Inpatient and outpatient spinal cord injury evaluations, annual visits</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>General physician, 1-2 visits per year</td>
<td>General physician, biannual visits</td>
</tr>
<tr>
<td>Urologist, 1-2 visits per year</td>
<td>Urologist, biannual visits</td>
</tr>
<tr>
<td>Not projected</td>
<td>Physiatrist, biannual visits</td>
</tr>
</tbody>
</table>
APPENDIX S

CASE STUDY: EDWARD
### Case 5, Edward: Comparison Between Projected and Current Needs

<table>
<thead>
<tr>
<th>Life Care Plan Projections</th>
<th>Current Self-Reported Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live-in attendant care, 24 hours per day, beginning between 55 and 65 years of age in a private residence</td>
<td>Not applicable (not yet 55 years of age)</td>
</tr>
<tr>
<td>Weekly interior/exterior home maintenance</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Inpatient and outpatient spinal cord injury evaluations, annual</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>General physician, annual</td>
<td>General physician, 6 times per year</td>
</tr>
<tr>
<td>Urologist, 2-3 times per year</td>
<td>Urologist, 1-2 times per year</td>
</tr>
<tr>
<td>Not projected</td>
<td>Neurology consultation, pending</td>
</tr>
</tbody>
</table>
APPENDIX T

CASE STUDY: BONNIE
<table>
<thead>
<tr>
<th>Life Care Plan Projections</th>
<th>Current Self-Reported Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant care, 28-42 hours per week, in a private residence</td>
<td>Nephew assists 5-7 hours per week, in a private residence</td>
</tr>
<tr>
<td>Weekly interior/exterior home maintenance</td>
<td>Interior/exterior maintenance completed by nephew</td>
</tr>
<tr>
<td>Case management, 2-4 hours per month</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Outpatient spinal cord injury evaluations, annual visits</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>General physician, biannual visits</td>
<td>General physician, 4 visits per year</td>
</tr>
<tr>
<td>Urologist, biannual visits</td>
<td>Urologist, annual visits</td>
</tr>
<tr>
<td>Physiatrist and orthopedic surgeon, biannual visits</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Psychiatrist, 3-4 visits per year</td>
<td>During rehabilitation only</td>
</tr>
<tr>
<td>Podiatrist, 6-8 visits per year</td>
<td>Not reported as a current need</td>
</tr>
</tbody>
</table>
### Case 7, Evelyn: Comparison Between Projected and Current Needs

<table>
<thead>
<tr>
<th>Life Care Plan Projections</th>
<th>Current Self-Reported Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live-in attendant care, 24 hours per day between 50 and 60 years of age in a private residence</td>
<td>Not applicable (not yet 50 years of age)</td>
</tr>
<tr>
<td>Weekly house cleaning services</td>
<td>Not reported as a need, although she believes it would be useful</td>
</tr>
<tr>
<td>Not projected</td>
<td>Case management services</td>
</tr>
<tr>
<td>Outpatient spinal cord injury evaluations, annual visits</td>
<td>Not reported as a current need</td>
</tr>
<tr>
<td>Inpatient spinal cord injury evaluations, annual visits, beginning at 40 years of age</td>
<td>Not applicable (not yet 40 years of age)</td>
</tr>
<tr>
<td>General physician, 1-2 visits per year</td>
<td>General physician, 3-4 visits per year</td>
</tr>
<tr>
<td>Urologist, 1-2 visits per year</td>
<td>Not reported as a need, but recommended by general physician</td>
</tr>
<tr>
<td>Not projected</td>
<td>Psychiatrist, 1-2 visits per year</td>
</tr>
</tbody>
</table>
APPENDIX V

DEMOGRAPHIC SUMMARY
Demographic Summary

<table>
<thead>
<tr>
<th>Case</th>
<th>Sex</th>
<th>Injury</th>
<th>Cause</th>
<th>Age at Injury</th>
<th>Years Since Injury</th>
<th>Years Since Plan Was Developed</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Jim</td>
<td>Male</td>
<td>C6-5</td>
<td>19 years</td>
<td>23 years</td>
<td>17 years</td>
</tr>
<tr>
<td>2</td>
<td>Teresa</td>
<td>Female</td>
<td>T2</td>
<td>45 years</td>
<td>13 years</td>
<td>12 years</td>
</tr>
<tr>
<td>3</td>
<td>Robert</td>
<td>Male</td>
<td>L1-T11</td>
<td>43 years</td>
<td>11 years</td>
<td>9 years</td>
</tr>
<tr>
<td>4</td>
<td>Lynne</td>
<td>Female</td>
<td>T6</td>
<td>31 years</td>
<td>17 years</td>
<td>16 years</td>
</tr>
<tr>
<td>5</td>
<td>Edward</td>
<td>Male</td>
<td>T12</td>
<td>16 years</td>
<td>19 years</td>
<td>18 years</td>
</tr>
<tr>
<td>6</td>
<td>Bonnie</td>
<td>Female</td>
<td>T10</td>
<td>43 years</td>
<td>18 years</td>
<td>11 years</td>
</tr>
<tr>
<td>7</td>
<td>Evelyn</td>
<td>Female</td>
<td>T6-8</td>
<td>18 years</td>
<td>19 years</td>
<td>15 years</td>
</tr>
</tbody>
</table>

Note. Data collection occurred during the months of May and June in 2007. All references to current needs, current age, years since injury, and similar notations are measured from this point in time.

*Motor vehicle accident (MVA)*
APPENDIX W

IRB APPROVAL NOTICE
Office of Responsible Research Practices
300 Research Foundation
1960 Kenny Road
Columbus, OH 43210-1063
Phone (614) 688-8457
Fax (614) 688-0366
www.orrp.osu.edu

November 13, 2006

Protocol Number: 2005B0130

Protocol Title: VALIDITY IN LIFE CARE PLANNING FOR INDIVIDUALS WITH SPINAL CORD INJURIES, Joe Wheaton, Lori Allison, PAES

Request to amend the protocol dated 10/26/06—Revise survey, letter, data form.
Type of Review: Amendment--expedited
Date of Approval: November 9, 2006
IRB Staff Contact: Cheri Pettrey
(614) 292-0526
Pettey.6@osu.edu

Dear Dr. Wheaton,
The Behavioral and Social Sciences IRB APPROVED the above referenced amendment BY EXPEDITED REVIEW.

Note that if applicable, informed consent (and HIPAA research authorization) must be obtained from subjects or their legally authorized representatives and documented prior to research involvement. The IRB-approved consent form and process must be used. Changes in the research (e.g., recruitment procedures, advertisements, enrollment numbers, etc.) or informed consent process must be approved by the IRB before they are implemented (except where necessary to eliminate apparent immediate hazards to subjects).

It is the responsibility of the investigator to promptly report to the IRB any serious, unexpected and related adverse events or potential unanticipated problems involving risks to subjects or others.

This approval is issued under The Ohio State University’s OHRP Federalwide Assurance #00006378. All forms and procedures can be found on the ORRP website – www.orrp.osu.edu. Please feel free to contact the IRB staff contact listed above with any questions or concerns.

Thomas Nygren, PhD, Chair
Behavioral and Social Sciences Institutional Review Board
Behavioral and Social Sciences Institutional Review Board