Journal of Life Care Planning, Vol. 9, No. 2, (3-14)
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LIFE CARE PLANNING SUMMIT 2010 PROCEEDINGS

by Summit 2010 Co-Chairs
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Introduction

The International Academy of Life Care Planners (IALCP), a section of the International Association of Rehabilitation Professionals (IARP), was honored to host the 2010 Life Care Planning Summit on April 17 and 18, 2010 in Atlanta, Georgia. The Summit was co-sponsored by the Foundation for Life Care Planning Research and the University of Florida.

This biennial event brought together leaders in life care planning from a variety of organizations with a goal of promoting unity. Through a series of round table discussions, life care planners had the opportunity to examine and identify resolutions for hot issues in the field while contributing to the continued evolution of life care planning.

Seventy-one representatives of life care planning training programs, certification programs, and professional associations joined with researchers, practitioners, and support service providers to explore the current state of the field and set future directions for life care planners. The topics discussed at this Summit reflect the changes and maturation occurring in this dynamic field. Although the process of life care planning is not new, a common principle and foundation among all life care planners is to determine consensus and unity in the field, thus leading to the provision of a credible, meaningful, marketable, and defensible service.

Our thanks and appreciation are given to the following colleagues who volunteered to serve as panel members during the general session meetings on Saturday:

- Kathy Adams, RN, home health agency panelist
- Kathie Allison, LCP professionals panelist representing PT
- Huntly Chapman, LCP professionals panelist representing MD

- Carolyn Higdon, LCP professionals panelist representing SLP
- Nancy Mitchell, LCP professionals panelist representing OT
- Ann Neulicht, LCP professionals panelist representing rehab counseling
- Jan Roughan, LCP professionals panelist representing RN
- Carol Walker, LCP professionals panelist representing neuropsychology

Volunteers for the Case Management panel:

- LuRae Ahrendt
- Kathleen Kuntz
- Steve Yuhas

Volunteers who served as recorders during the Round Table discussions:

- Reg Gibbs
- Ann Neulicht
- Bob Taylor

In addition, we are grateful to the following guest panel participants who sacrificed their Saturday morning to provide us with valuable information:

- Matthew Allen (attorney, Hall, Booth, Smith, and Slover, PC)
- Harvey Spiegel (attorney, Henry, Spiegel, Milling, LLP)
- Bill Frazier (trust officer, Sun Trust Bank)
- Mamie Kneller (trust officer, Wells Fargo Bank)
- Samantha Renfro (mother of TBI survivor)

We are doubly grateful to the generous sponsors at Bright Sun Technologies, ABI Mentor, and Elliott & Fitzpatrick. Thank you very much!

Summit participants spent the two day event at nearby Georgia State University and, for the first time in Summit history, participants were introduced to cutting edge technology that tabulated participants' responses in real time by utilizing personal Audience Response Systems from Turning Technologies. Ron Rinaldi was the onsite technician who trained attendees and provided devices to record instant responses throughout the Summit. His assistance was invaluable and truly moved the Summit into the 21st century.

Theme and Goals of Life Care Planning Summit 2010

The broad goals of this year's Summit were to:

- Enable Life Care Planning practitioners to develop improved practice skills
- Establish best practices in the life care planning process
- Enable life care planning organizations to develop priorities for education, research, and services for Life Care Planning professionals

Methodology

This year's Summit integrated technology with the Modified Nominal Group Techniques General Instructions provided by Roger O. Weed, Ph.D. and based on the group consensus technique outlined by Delbecq, Van de Ven, and Gustofson (1975). As instructed, attendees were randomly sorted into three groups and participated through each of the focus group topics. Groups were assigned so that an integrated mix of experience, training and knowledge was assured (nurses, rehabilitation counselors, physicians, occupational therapists, physical therapists, speech/language pathologists, and many others).

As with previous Summits, each group had a facilitator (leader) and recorder who used a computer to summarize the data and assist in the utilization of the technology. The personal Audience Response Systems were utilized in the small groups as well as the large group consensus building session. Every attendee participated in discussions on all topic areas. The attendees then re-convened into one large group and the facilitators summarized the comments and noted consensus statements among the groups where applicable. For those topics where consensus was not reached among the roundtable groups, participants had time for additional discussion and the technology was again utilized to record each attendee's "vote" in an effort to achieve consensus statements among the full group.

Threshold for Acceptance

For purposes of the Summit, the following thresholds were established prior to the Summit to determine levels for consensus statements and majority view statements among the participants:

- Unanimous consensus statements are those that were agreed upon by 100% of participants.
- Majority view statements are those that were agreed upon by 75-99% of participants.
- No consensus or majority views are those that did not reach agreement by at least 75% of participants; thereby indicating a need for more discussion and consideration by the group.

Participants

The Life Care Planning Summit 2010 had 71 attendees; however, due to early flight departures and other legitimate reasons, Sunday's final session was comprised of 59 participants (n=59). Demographics of the attendees for Sunday's consensus building group were:

Gender

Male	9
Female	50

Age

Less than 30 years old	1
Age 31 – 40	3
Age 41 – 50	14
Age 51 – 60	28
Age 61 – 70	12
Age 71 +	1

Professional Background

Rehabilitation Counselor	28
Registered Nurse	21
Occupational Therapist	4
Psychologist	3
Physical Therapist	1
Speech Language Pathologist	1
Physician	1

Years Experience as Life Care Planner

0 – 5 years	12
6 – 10 years	11
11 – 15 years	9
16 – 20 years	9
21 – 25 years	13
25 + years	5

Ten attendees reported not being a member of the International Academy of Life Care Planners (IALCP) and nine attendees were not a member of the International Association of Rehabilitation Professionals (IARP).

Topic 1: Best Practices for Establishing Foundation for Necessity: Boundaries for Decision Making

Purpose

Reach consensus on objective methodology for how decisions are made about care items included in a life care plan, focusing on what items a life care planner can put into the plan based on his/her scope of practice versus what items require consultation/recommendation from other experts.

Objectives

- Identify objective criteria and methodology for establishing the scope of practice boundaries for life care planners of various professional backgrounds.
- Understand boundaries for life care plan recommendations for self and other life care planning colleagues.
- Understand how using scope of practice boundaries affects the admissibility and usefulness of life care plans for end-users.

Background

Life care planners come from many disciplines, including registered nurses, rehabilitation counselors, physicians, psychologists, occupational therapists, physical therapists, and speech/language pathologists. Each discipline has its own scope of practice and professionals can recommend and provide certain kinds of treatment interventions based on his/her expertise and scope of practice. All life care planners have clinical practice limits and often must refer or defer to other qualified professionals for treatment interventions/recommendations outside their own discipline and expertise.

Providing a credible, defensible life care plan is vitally important to life care planners.

Topic One discussions were designed to explore the issue of establishing who is qualified to make care recommendations while ensuring that the life care plan is useable, credible, and defensible. The objectives for Topic One were to reach consensus on objective methodology for how decisions are made about care items included in a life care plan, focusing on what items a life care planner can put into the plan based on his/her scope of practice versus what items require consultation/recommendation from other experts.

Presentations

In exploring best practices for establishing foundation, Summit participants heard perspectives from two attorneys (one plaintiff attorney and one defense attorney) who practice in the area of catastrophic injury. Harvey Spiegel and Matthew Allen provided their insight and expertise as trial lawyers in discussing how "who" makes the recommendations in a Life Care Plan affects the admissibility/defensibility of the plan. The attorneys responded to questions regarding implications of a life care planner from a specific discipline making life care plan recommendations based on that discipline's scope of practice without consulting another professional. The attorneys also provided helpful information regarding their personal preferences and opinions based on their experience working with life care planners.

This general session was followed by a presentation by two trust fund managers who discussed their needs and requirements in using a Life Care Plan in non-litigation situations. Mamie Kneller from Wells Fargo and Bill Frazier from Sun Trust Bank answered questions and provided insight including: 1) What makes a life care plan credible and useable for their purposes; 2) What are the implications of a life care planner making life care plan recommendations outside the planner's scope of practice without consulting another professional, and 3) What are the underlying principles that should be followed by life care planners in determining whether to make independent recommendations or whether to seek other professional opinions. They also provided their personal preferences and opinions based on their experience working with life care planners.

The third presentation for Topic One included professional viewpoints from a panel of multi-disciplinary life care planners consisting of Kathie Allison (Physical Therapist), Huntly Chapman (Physician), Carolyn Higdon (Speech Language Pathologist), Nancy Mitchell (Occupational Therapist), Ann Neulicht (Rehabilitation Counselor), Jan Roughan (Registered Nurse), and Carol Walker (Psychologist), discussing what is within the scope of practice for his/her professional discipline including the content of their training, post-graduate education, clinical specialty, and/or professional experience as a practitioner that gives them the ability to accurately project and include life care planning recommendations. Documents such as practice acts (regulations), professional association scopes of practice, diagnoses manuals, and other authoritative sources that support their ability and their capacity to recommend all aspects of care (e.g., item, frequency, duration, timeframe) also were discussed.

Topic One Consensus Statements

Participants were asked to consider the following statements and to decide to accept, modify, or reject each statement:

1. Life care planners may independently make recommendations for care items that are within their scope of practice to order/prescribe when in clinical practice.
2. Life care planners should obtain recommendations from qualified professionals for care items that the life care planner could not independently order/prescribe in clinical practice.

3. There is not a universal set of recommendations that all life care planners may make; recommendations vary based on the scope of practice of the individual life care planner.
4. Recommendations for care that are included in a life care plan require the same criteria for inclusion regardless of how the life care plan will be used (i.e., litigation or non-litigation).

Of the four target statements for Topic One, the first and second statements reached majority view among the roundtable groups for modification. Shown below is the first target statement as suggested for modification by each of the three roundtable groups:

Suggested Modified Statement # 1

A- Life care planners may independently make recommendations for care items/services that are within their individual professional scope(s) of practice.

B- Life care planners may independently make recommendations for care items within the scope of their practice.

C- Life care planners may independently make recommendations for care items/services that are within their scope of practice.

The above majority view statements were reviewed and discussed by all participants once convened in the general consensus building group session and attendees reached 100% consensus on the statement, modified as follows:

- **Life care planners may independently make recommendations for care items/services that are within their scope of practice. (100% consensus)**

The second target statement also received sufficient input from the three roundtable groups to merit modification and general discussion. Once convened in the general consensus building group, a fourth statement also was added for consideration. The roundtable groups provided the following input:

Suggested Modified Statement # 2

A- Life care planners obtain recommendations from other qualified professionals for care items/services that are outside the scope of practice of the life care planner.

B- Life care planners should obtain recommendations when possible from qualified professionals for care items that are outside their individual professional scope(s) of practice.

C- Life care planners should seek recommendations from other qualified professionals and/or relevant sources for inclusion of care items outside of the life care planner's scope of practice.

D- Life care planners seek recommendations from other qualified professionals and/or relevant sources for inclusion of care items/services outside the individual life care planner's professional scope(s) of practice.

After review and discussion by all participants in the general consensus building group session, the following statement reached 100% consensus by the attendees with the following modification:

- **Life care planners seek recommendations from other qualified professionals and/or relevant sources for inclusion of care items/services outside the individual life care planner's professional scope(s) of practice. (100% consensus)**

The other two statements for Topic One did not reach consensus or a majority view among the attendees and were therefore deleted.

Topic Two: Best Practices for Determining Sources of Attendant Care in the Home

Purpose

Reach consensus on objective methodology for how decisions are made for recommendations about using attendants from agencies or private-hire for care at home.

Objectives

- Examine the variables that life care planners must consider when choosing agency-procured or private-hired attendants for home care.
- Understand the risks and benefits of choosing between agency-procured and private-hired attendants for home care.
- Identify objective methodology for making decisions about attendant care at home.

Background

Care at home is often the largest cost item in a life care plan. Therefore, arguments exist in favor of, and against, various home care options. Life care planners need a method to ensure that home care recommendations are credible, reasonable, logical, and defensible.

Presentations

In order to facilitate the discussion for Topic Two, Kathy Adams, RN and co-founder of Accord Services home health care agency, discussed agency considerations, such as regulations and private duty in-home care services for individuals with catastrophic injuries. Ms. Adams was joined by Dan Miears, Accord Services marketing director, and they discussed key national and state regulations that govern home health agency services, the various credentials and/or qualifications required for personal care attendants, knowledge of how state nursing care regulations affect private hire home health care, as well as the benefits of utilizing a home health agency vs. private hire, among other points related to agency care. An interesting comment made by the speakers is that agencies often cannot provide back-up care on short notice when that agency is not the primary provider of attendant care. This is due to the required process for opening a case to service the home health client and locating and training attendants specific to the patient's unique needs.

During the second session of Topic Two, Samantha Renfro, the mother of a 48 year old daughter who experienced traumatic brain injury at age 18, discussed her experience of over 30 years utilizing various home care options. Mrs. Renfro provided her personal experiences of the pros and cons of being a private hire employer versus seeking agency-based home care services from the real-world perspective of both a mother/caregiver/employer and from the experiences of her daughter as a patient/client. Considerations of becoming a private duty employer, providing a comprehensive overview of additional costs and factors, and discussion of responsibilities of being an employer were also paramount to the presentation.

The last session for Topic Two was a panel discussion by experienced case managers and life care planners, including Steve Yuhas, Kathleen Kuntz and LuRae Ahrendt. Each offered discussion as case managers and arrangers of attendant care services on the "Which is Better?" question and they debated and discussed the issue about whether attendants that are from an agency or are privately hired are more reliable, loyal, trustworthy, or a better provider of services for clients with catastrophic disability.

Topic Two Consensus Statements

Participants were asked to consider the following statements and to decide to accept, modify, or reject each statement:

1. Private-hire and agency-procured attendants for home care are both options to be evaluated in every case.

2. Life care planners agree that neither agency-procured attendants for home care nor private-hire attendants for home care are inherently better or worse.
3. Tools need to be developed that reliably screen for the ability to use home care attendants from agencies or private-hire.
4. Life care planners should use objective tools to determine the appropriateness and feasibility of using attendants from agencies or private-hire.
5. A White Paper should be written that provides a practice guideline for decision-making in selecting agency or private-hire home care attendants.
6. The criteria that need to be considered in determining whether to recommend agency or private-hire home care include:
    a. Cognitive abilities of the client/surrogate
    b. Willingness of the client/surrogate
    c. Complexity of tasks to be performed
    d. Predictability of outcome of tasks and need for decision-making by the attendant
    e. Risk to client if tasks are omitted or done incorrectly
    f. Availability of agency staff in the geographic area
    g. Availability of private-hire staff in the geographic area, including needed skill level
    h. Proximity to emergency care and ability of attendant to handle an emergency pending arrival of emergency care
7. Costs for private-hire home care should include all associated costs, which include:
    a. Federal and state taxes and insurances
    b. Workers' compensation or other insurance that covers caregiver injury
    c. Advertising and screening
    d. Case management services if indicated
    e. Room, board, and other incidental costs if indicated

Each break out session carefully reviewed each statement and provided input for acceptance or modification. The results were collected for general discussion on Sunday.

Of the seven (7) target consensus statements for Topic Two, the first statement had sufficient interest in modification within the roundtable groups that, once convened in the large consensus building group, participants discussed and worked to reach 100% consensus on the following statement:

- **When the life care planner includes home care, both private-hire and agency-procured services are options to be considered. (100% consensus)**

Original target statements #2, 3, and 4 were deleted based on results of the participants' voting. After much discussion among the large group, statement #5 was merged with statement #6 and then ultimately rejected by the entire group based on the group's consensus to delete the merged statement.

The remaining target Statement #7, sub-sections a. and b. were combined and modified to reach 100% consensus among the participants:

- **The cost of private hire home care includes care giver compensation and associated expenses. (100% consensus)**

Topic Three: Review of Consensus Statements, Majority-View Statements and Results of Life Care Planning Summits 2000 – 2008

Purpose

Review past consensus statements and majority-view statements for continued support,

modification, or deletion. Ensure that consensus statements and majority-view statements, which are published and form expectations for life care planning practice, are accurate, relevant, and appropriate. To require modification or deletion, the statement should:

- Require substantive change to stay within the originally intended meaning, or
- Be deleted if unable to be modified without substantially altering the meaning, or
- Be deleted if it is irrelevant and is no longer required

It was not the intent of the Summit 2010 to rework previous statements for the sake of unsubstantial word preferences if the understanding and meaning of the statement does not require change in order to remain accurate and relevant for today's life care planning practice.

Objectives

- Determine whether statements created at the Summits of 2000, 2002, 2004, 2006, and 2008 are still relevant and appropriate.
- Eliminate obsolete statements that are no longer relevant.
- Establish a process for modifying outdated statements that require change.

Background

Consensus statements, majority view statements and results of the previous decade of Life Care Planning Summits from 2000 – 2008 were reviewed for continued support, modification, or deletion. The task was to explore the current state of the field and set future directions by examining the previously developed consensus statements in the following areas:

- Professional Development
- Education
- Certification
- Standards of Practice
- Ethics
- Methodology and Research

For each statement from prior Summits, current Summit participants responded to the statements indicating Accept, Modify or Delete. To require modification or deletion, Summit participants were instructed that the statement should:

- Require substantive change to stay within the originally intended meaning, or
- Be deleted if unable to be modified without substantially altering the meaning, or
- Be deleted if it is irrelevant and is no longer required

Upon review of over 100 consensus statements from previous Summits, an analysis of the participants' voting was completed. Those items with 75% or greater for Accept were retained; those with 75% or greater for Delete were noted for deletion. Only one statement received 100% consensus as written:

- **Life Care Plans shall be individualized. (100% consensus)**

Further, one statement had a majority of votes to recommend deletion, i.e., “Some aspects of Standards of Practice are too detailed.” For purposes of these proceedings, only those statements that did not receive a majority vote to accept or delete are included below. Due to space limitations, the comprehensive list of all previous Summit statements, including those that were determined for acceptance or deletion, will not be listed here.

The following 43 statements did not receive a majority vote to accept or delete and have been identified by the Summit participants for review for modification. Statements are listed within their respective category:

Professional Development

- Life Care Planners may come from a variety of disciplines, provided they have qualifications including five years’ experience in a primary discipline, complete

supervised time under a qualified life care planner and belong to a life care planning professional association.
- Life Care Planners shall explore markets for life care planning outside litigation.
- Life Care Planners shall promote and participate in a national organization for life care planners that serve as a single voice for the practice of life care planning and as a single repository for life care planning resources.

Education
- Life Care Planning programs shall be promoted widely.
- Life Care Planners shall train themselves and recruit others to instruct educational programs.

Certification
- Life Care Planner certification shall render its holder a qualified life care planner, provided that certification is maintained.
- Life Care Planner certification standards shall be augmented.
- The International Commission on Health Care Certification shall apply for National Commission for Certifying Agencies (NCCA) accreditation.
- Life Care Planning certification shall flow from a practitioner-created core curriculum.
- The Life Care Planning certifying body shall not be proprietary.

Standards of Practice
- Standards of Practice terminology shall be reviewed.
- Standards of Practice shall be based on a study defining the role and accountability of life care planners.
- Some aspects of Standards of Practice are too detailed (2004).
- Standards of Practice shall be unitized in the development of the practice of life care planning.

Ethics
- Life Care Planners shall accept referrals only in their area of expertise.
- Life Care Planners shall draft life care plans under supervision for one year.
- Life Care Planners shall renounce inappropriate processes and training.
- Life Care Planners shall disclose and differentiate between the roles in which they may be called upon to act.
- Life Care Planners shall better define dual relationships.
- Life Care Planners shall establish themselves within their primary field of practice.
- Life Care Planners shall objectively place their client's interests before any personal or professional consideration.

Methodology
- Life Care Plans shall be lifelong and flexible.
- Life Care Plans shall utilize research for recommendations.
- Life Care Planning shall depend on data collection, analysis and synthesis.
- Life Care Plans shall be developed in the client's best interest.
- Life Care Plans shall include an annotated list of requested and reviewed data/sources.
- Life Care Plans shall feature standardized forms and formats.
- Life Care Plans shall be consistent across similar cases.
- Life Care Plans shall rely on medical/allied health professional opinions.
- Life Care Plans shall be limited to the planner's expertise and scope of practice.
- Life Care Planners shall methodically handle divergent opinions.
- Life Care Planners shall properly inject personal expertise.

- Life Care Planners shall utilize protocols for cost research.
- Life Care Planners shall utilize protocols for using local versus national resources.
- Life Care Planners shall utilize protocols for handling the impact of aging.
- Life Care Planning databases, templates and software shall have appropriate foundation.
- Life Care Planners shall be involved in research.
- Life Care Planners shall include research in life care plans.
- Life Care Planners shall study the reliability, validity and accuracy of life care plans.
- Life Care Planners shall assess the reliability, validity and accuracy of data and methods.
- Life Care Planners shall conduct longitudinal studies.
- Life Care Planners shall evaluate the cost-effectiveness of life care plans.
- Life Care Planners shall study the impact of life care plans upon quality-of-life.

Discussion

Following the presentation of consensus statements, Summit participants voted and a discussion ensued regarding not only the statements that require modifying, but what should be the process for modifying and updating them. The International Symposium of Life Care Planners (IALCP) has offered to lead the process of Summit statement modification. The ideas generated by the Summit attendees to modify the statements included forming a multidisciplinary task force and utilizing a work group at the upcoming International Symposium for Life Care Planning (ISLCP) in September 2010 to provide follow-through and continuity in the process. This work group would be charged with developing the process of analyzing the statements identified as needing modification during the Life Care Planning Summit 2010. The objective of the work group would be to review and understand the proceedings of the past five Life Care Planning Summits, the process utilized in the development of statements from the past five Summits, create a methodological design of the analysis of the relevancy of the Summit statements requiring modification as noted by the Life Care Planning Summit 2010, and present a plan of action to modify the statements as necessary by the Task Force.

Summary

The Life Care Planning Summit 2010 marked the culmination of a decade's worth of Summits spanning the years 2000-2010. This year's Summit provided a productive and positive experience with a lively, passionate, and energetic group of attendees. According to Summit participants, use of the personal Audience Response System technology made the process of consensus building easier and allowed the group to stay focused on the objectives. The use of this technology resulted in less time and frustration to work through the process of reviewing, developing, modifying, and reaching consensus among the participants. Another positive change for this year's Summit was the focus on two primary topics, which allowed greater time and more in-depth discussion and consideration of ideas before the consensus statements were developed. The result was that consensus statements were reached that addressed the topics. The changes that were incorporated into the format of the Life Care Planning Summit 2010 lay a foundation for stronger Summits in the future. Where will you be in 2012?

Reference

Delbecq, A.L., Van de Ven, A.H., & Gustafson, D.H. (1975). *Group techniques for program planning: A guide to nominal and delphi processes.* Glenview, IL: Scott Foresman and Company.

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