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The 2012 Life Care Planning Summit: Third Time is a Charm

Editorial by Cloie B. Johnson, MEd - Chair

It was an honor and a privilege to Chair the 2012 Life Care Planning Summit. This was the third Summit I chaired, and it was the most rewarding. This year's Summit was held in Dallas, TX on May 5 & 6, 2012. The evaluations were overwhelmingly positive with good feedback from the attendees. Participants described this Summit as "historic", "best Summit I have attended", and "This is the most professionally stimulating meeting I've attended in years". Other comments included: "I am happy we could come together as a community to define standards and to promote unity in the community", and "My first time at a Summit – sorry I did not attend previous summits – I will attend all in the future".

In this brief editorial, I will attempt to provide an overview of the activities both leading up to and at the Summit. The formal proceedings of the Summit are being drafted by the various volunteers involved, and will be published at a later date. All representative associations and presenters are being asked for their written material as part of this write-up which will be sent to all attendees. Additionally statements will be solicited from all Life Care Planning Associations/Organization for their Endorsement and/or Support. This write up is being presented as a response to the many life care planners who were unable to attend, but anxiously await some feedback as to the outcome. It is not my intent to report complete interactions verbatim, but to provide an overview.

The 2012 LCP Summit was proudly hosted by the International Academy of Life Care Planners (IALCP) and co-sponsored by: International Association of Rehabilitation Professionals (IARP), International Commission on Health Care Certification (ICHCC), University of Florida (U of F), and Foundation for Life Care Planning Research (FLCPR).

The 2012 LCP Summit planning committee is appreciative of the following exhibitors and sponsors: PATE Rehabilitation Hospital, NeuroRestorative, Tanglewood Medical Supplies, Dr. Rodney Isom and Bright Sun Technologies/Reg Gibbs.

The 2012 Life Care Planning Summit was the result of the hard work and efforts of the following committee members: Giovanna Boniface, Elizabeth Davis, Brook Feerick, Susan Riddick-Grisham, Cloie Johnson, Sherry Latham, Karen Preston, Rick Robinson, and Steve Yuhas

We were very appreciative of the following individuals who participated in the Summit:

Steve Cooley, Heidi Fawber, Reg Gibbs, Angie Heitzman, Christine Reid, Evelyn Robert, Joan Schofield, Bob Taylor, and Nancy Zangmeister.

To begin the Summit, a brief overview was presented with an historical review.

The Life Care Planning Summit is a biennial event made up of representatives from professional organizations and training programs, researchers, practitioners, and support service providers, to explore the current state and future directions of the specialty practice of life care planning. Although the process of life care planning and standards of practice have

been established, consensus and unity in the field is a developmental process. Through Summits participants have the opportunity to examine life care planning issues, contribute to the resolutions of these issues, and be involved in the continued evolution of the field.

Since 2000 over 400 life care planners have taken a vested interest in the future and participated in Summits to address cutting edge issues affecting Life Care Plans, Life Care Planning and Life Care Planners. Life Care Planning Summits have been conducted in 2000, 2002, 2004, 2006, 2008, 2010 and 2011 (Canada). Consensus and majority statements affecting the practitioner have been published.

Historically Letters of Support and/or Endorsement of the Summits and/or Proceedings beginning in 2000 have been received from a multitude of organizations involved with the multidisciplinary field of Life Care Planning including:

- American Association of Nurse Life Care Planners (AANLCP),
- American Association of Legal Nurse Consultants (AALNC),
- Care Planner Network,
- Commission on Disability Examiner Certification (CDEC),
- Commission on Health Care Certification (CHCC, currently ICHCC),
- Case Management Society of America (CMSA),
- Foundation for Life Care Planning Research (FLCPR),
- Georgia State University,
- Intelicus,
- International Academy of Life Care Planners (IALCP),
- International Association of Rehabilitation Professionals (IARP),
- IARP-Canada,
- University of Florida,
- Vocational Rehabilitation Association of Canada (VRA)

Educational Conference versus Summit

The differences between Educational Conferences and Summits were explored. The Webinar held in December 2011 through IARP and presented by Dr. Weed is reprinted in part below.

Educational conferences are typically held annually within ones professional association or by profit or non-profit organizations. There are typically attended in person. Other educational conferences becoming more traditional include Webinars and On-line seminars. Professional association conferences are typically more "cost effective" because speakers typically donate their time/services whereas other conference types typically pay speakers (speaking fees, transportation and other expenses). Leaders are selected to impart information to the attendees. The primary goal of an Educational Conference is to *Impart* information about ethics, standards of practice, clinical practices, disability education, products, supplies, etc to the masses. Educational conferences are designed so that leaders give information to the attendees.

Summits are held to set the stage for a professional practice. Summit attendees provide the information to the leadership. The goal is to *Develop* ethics, standards of practice, standard of care, etc., specifically using the power of the group of attendees (grass roots). Summits are unique in that they are designed so that aggressive, forceful, or overbearing people have limited power. Summits are designed so that people, who are typically in the "background," quiet and less aggressive, have their voices heard. Summits use group dynamics and attempt to achieve consensus or near consensus. And most importantly, Summits typically set the very foundation

for the specialty practice and often are the source for agreed upon standards of practice, standard of care, and ethics. Summit conferences are designed so that attendees give information to leaders.

History

A brief historical review was presented of past Summits which included the following:

- Dallas, TX-April 12, 2000
- Chicago, IL – May 18 - 19, 2002
- Atlanta, GA - April 24 - 25, 2004
- Chicago, IL -May 6 - 7, 2006
- Los Angeles, CA -May 15 – 16, 2008
- Atlanta, GA – April 17 – 18, 2010
- Toronto, ON – June 3 - 4 , 2011

The 2012 Life Care Planning Summit was unique with an "Outside the Box" format. The committee put together a very ambitious agenda. We began with a moderated Town Hall Meeting, conducted a review of Past Consensus and Majority Statements, participated in the nominal group technique Sessions on three hot topic areas, and held an ethics session.

Demographics

We had 74 Life Care Planners register for the Summit and 65 were in attendance. Of those attending:

Profession	Percentage*
Rehabilitation Counselor:	52.31%
Nurse:	44.62%
Occupational Therapist:	3.08%
Psychology:	3.08%
Physician:	1.54%
Special Education	1.54%

*There were attendees with dual professions.

Experience in Life Care Planning:	
< 5 years	12.31%
5-10 years	20.00%
10-15 years	23.08%
> 15 years	44.62%

Gender:	
Males:	23.08%
Females:	76.92%

Town Hall Meeting

We then engaged in a lively Open Dialogue/Town Hall Meeting with representatives from the associations and organizations involved in the multidisciplinary practice.

Representatives included:

Susan Grisham & Christine Reid - FLCPR
Elizabeth Davis, Heidi Fawber & Steve Yuhas - IALCP
Sherry Latham & Evelyn Robert - ICHCC
Nancy Zangmeister & Joan Schofield - AANLCP

Each representative association/organization gave an Introductory Statement. They were asked to provide a brief statement of the current state of the Association and their targeted goals for the foreseeable future (1, 5 and 10 years).

Participants were then requested to provide statements, comments and/or concerns/questions to the representatives. They were limited to one minute and if there was a response given, it was also limited to one minute. At the conclusion each representative was requested to provide closing comments.

A very lively discussion ensued with professionalism and a unanimous desire for unity and cooperation between Associations and Organizations.

The representatives gathered together in the evening after the first day and reported on the second day that they have agreed to have interactive dialogue to ensure the members' needs are met.

Consensus and Majority Statements since 2000.

Past Consensus and Majority Statement were reviewed by the attendees as homework and they were surveyed on the 2000, 2002, 2004, 2006 & 2008 Majority and Consensus Statements which were compiled in 2010.

At the 2010 Summit in Atlanta real time voting was used with the participants for their feedback. The purpose was to review past consensus statements and majority-view statements for continued support, modification, or deletion. The goal was to 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.

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, and those with 75% or greater for Delete were noted for deletion.

Only one statement received 100% consensus, i.e., "Life Care Plans shall be individualized,"

And one statement had a majority of votes to recommend deletion, i.e., "Some aspects of

Standards of Practice are too detailed."

As part of the 2012 Summit, the attendees completed homework and reviewed 43 statements that did not receive a majority vote to accept or delete and have been identified by the Summit participants for review for modification.

The 2012 Summit Attendees were asked for input to verify the results as two years have passed since that original process occurred. 22 statements received a majority vote to "Accept", one statement received a majority to "Revise" and no statements received majority to "Delete". There were no statements with an overwhelming majority to change, therefore all other statements remain relevant.

Four statements received zero deletion recommendations. The group chose to attempt to revise the following statement: Life Care Planners shall utilize protocols for handling the impact of aging.

The reworked statement receiving consensus was "Life Care Planners shall consider the impact of aging."

The Summit attendees agreed that all Consensus and Majority Statements will be routinely reviewed for relevance, and all Consensus and Majority Statements will be reprinted and published. These are republished for reference at the end of this write-up.

Roundtable discussions on three "Hot Topics"

The Summit attendees then received a brief overview of the three hot topics in Life Care Planning. The areas of focus included Definitions of Life Care Plans and Terminology, Best practices for Costing and Best Practices for Foundations in Life Care Plans.

Each attendee was then randomly assigned a number and rotated through all focus group topics. Numbers are assigned separately to professional disciplines so that an integrated mix of experience, training and knowledge is assured (rehabilitation counselors, nurses, therapists, etc..)

Topic 1 - Best Practices for Establishing Foundation for Life Care Plans was facilitated by Robert Taylor and Reg Gibbs recorded. The purpose was to reach consensus on objective resources included in a life care plan.

Topic 2 - Best Practices for Providing Costs within Life Care Plans was facilitated by Rick Robinson and recorded by Heidi Fawber. The purpose was to reach consensus on objective resources when placing costs in a life care plan.

Topic 3 - Definitions and Terms specific to Life Care Planning – Minimum Life Care Plan, Medical Cost Projections, Life Care Plans are these all the same? was facilitated by Karen Preston and Giovanna Boniface recorded. The purpose was to reach consensus on acceptable terminology used to develop Life Care Plans.

The modified nominal group technique was again utilized. The groups reconvened the following day to review the results and develop Majority and/or Consensus statements.

Topic 1 provided consistent responses within the category and the entire group agreed on the following Consensus statement:

Review of evidence based research, review of clinical practice guidelines, medical records, medical and multidisciplinary consultation, and evaluation/assessment of evaluee/family are recognized as best practice sources that provide foundation in Life Care Plans.

Topic 2 results were reported and a group Consensus was developed regarding the following:

Best practices for identifying costs in Life Care Plans include:

1. Verifiable data from appropriately referenced sources
2. Costs identified are geographically specific when appropriate and available.
3. Non-discounted/market rate prices.
4. More than one cost estimate, when appropriate.

(Footnote – when appropriate requires further discussion and definition – in the interim the term "appropriate" is for the practitioner to define and defend)

The results of Topic 3 were reviewed and the groups had similar theses in two areas; statements regarding protection and control of the field, concepts about defining other products and what they are (methodology), and statements about Life Care Planner skills and business practice.

One consensus statement was created by the group:

- Life care planners will define terminology of our work product(s).
- Further the attendees requested the leadership consider the matter of terminology including "mini" or "minimal" life care plan and contact attorneys and others as appropriate

Ethics

The final aspect of the 2012 Summit included an Open Dialogue/Ethics Session to Develop Consensus/Majority Statements and Framework for the Practitioner. This session was moderated by Christine Reid, PhD.

In follow up to the homework in which each attendee was asked to review the IALCP Standards of Practice, the ICHCC Code of Ethics, and the Code of Ethics for each license and organization for which they belongs.

The attendees were then asked to report their observation of the differences between the various Code of Ethics and then what they believe could/should be done with the differences.

After a lively discussion, the following Consensus statement was created:

Life Care Planners recommend the Life Care Planning Professional Associations and Life Care Planning certifying bodies, including but not limited to: IARP, IALCP, AANLCP, ICHCC, and CNLCP, jointly work toward a unified code of ethics for the practice of Life Care Planning.

After a whirlwind weekend in Dallas, I believe the multidisciplinary practice of Life Care Planning is alive, well and stronger than ever. On we go!

Cloie B. Johnson, MEd is the Past Chair of the International Academy of Life Care Planners, International Association of Rehabilitation Professionals and the Chair of the Life Care Planning Summits held in 2010, 2011 (Canada) and 2012. *Thank you to Susan Grisham and Steve Yuhas for their editing assistance.*

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Consensus and Majority Statements derived from Life Care Planning Summits held in 2000, 2002, 2004, 2006, 2008, 2010 and 2012

Compiled by Karen Preston and Cloie Johnson

The following statements were created by Life Care Planners at various Summits between 2000 and 2012, and are relevant and applicable to all life care planners:

1. 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.

2. Life Care Planners shall seek out mentor relationships, educating students and unaffiliated professionals about life care planning training, education, experience, special knowledge and required credentials.

3. Life Care Planners shall disseminate information regarding their area of practice through electronic collaboration, Web sites, peer-reviewed journals, books, conferences and symposia and professional associations.

4. Life Care Planning research shall be reviewed by peers through an objective and "blind" process that addresses methodology.

5. Life Care Planners shall understand the definition of reliability and consistently practice in such a manner.

6. Life Care Planners shall explore markets for life care planning outside litigation.

7. Life Care Planners shall have knowledge of relevant laws and regulations as well as local and national care standards.

8. Life Care Planners shall understand optimal outcomes achievable for particular injuries.

9. 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.

10. Life Care Planners shall complete 120 hours of training including courses that focus on

disability issues and is specific to life care planning.

11. Life Care Planning programs shall be based on the latest knowledge and practices.

12. Life Care Planning programs shall cover certification-preparation as well as advanced topics and complex issues.

13. Life Care Planning programs shall be promoted widely

14. Life Care Planning programs shall be offered in accessible geographic locations and electronically.

15. Life Care Planning continuing education units shall be available at an increasing number of forums.

16. Life Care Planning continuing education units shall be available at forums that may not focus solely on life care planning.

17. Life Care Planners shall train themselves and recruit others to instruct educational programs.

18. Life Care Planner certification shall render its holder a qualified life care planner, provided that certification is maintained.

19. Life Care Planner certification shall be renewed every five years with the accumulation of 60 continuing education units.

20. Life Care Planners shall be licensed and/or certified in their professional discipline before being certified as a life care planner.

21. Life Care Planner certification standards shall be augmented.

22. The International Commission on Health Care Certification shall apply for National Commission for Certifying Agencies accreditation.

23. Life Care Planners shall hold a certification that has mechanism for complaints and resolution.

24. Life Care Planning certification shall flow from a practitioner-created core curriculum.

25. The Life Care Planning certifying body shall not be proprietary.

26. The Life Care Planning certifying body shall manage and disclose ethical complaints and violations.

27. Life Care Planning certification exams shall be developed and maintained by an advisory group.

28. Life Care Planning certification exams shall be administered by an autonomous entity independent of any organization that provides life care planning training and/or education.

29. Standards of Practice terminology shall be reviewed

30. Standards of Practice terminology shall be defined.

31. Standards of Practice shall delineate educational requirements for entry into the practice of life care planning.

32. Standards of Practice shall assert the role and accountability of life care planners

33. Standards of Practice shall be based on a study defining the role and accountability of life care planners.

34. Standards of Practice shall allow for individual judgment and expertise.

35. Standards of Practice shall be utilized in the development of the practice of life care planning.

36. Standards of Practice shall be applicable to current practices.

37. Life Care Planners shall accept referrals only in their area of expertise.

38. Life Care Planners shall draft life care plans under supervision for one year.

39. Life Care Planners shall maintain objectivity.

40. Life Care Planners shall maintain strict adherence to confidentiality practices.

41. Life Care Planners shall renounce inappropriate, distorted or untrue comments about peers.

42. Life Care Planners shall renounce inappropriate processes and training.

43. Life Care Planners shall disclose and differentiate between the roles in which they may be called upon to act.

44. Life Care Planners shall avoid dual relationships when objectivity may be challenged.

45. Life Care Planners shall better define dual relationships.

46. Life Care Planners shall establish themselves within their primary field of practice.

47. Life Care Planners shall objectively place their client's interests before any personal or professional consideration.

48. Life Care Planners shall adhere to relevant Codes of Ethics.

49. Life Care Planners shall have access to recourse/corrective action process for Ethical violations.

50. Life Care Plans shall be individualized.

51. Life Care Plans shall be objective and consistent.

52. Life Care Plans shall be lifelong and flexible.

53. Life Care Plans shall be a clear, concise and user-friendly document.

54. Life Care Plans shall be comprehensive and based on multidisciplinary data.

55. Life Care Plans shall utilize research for recommendations.

56. Life Care Planners shall consider the integrity of data.

57. Life Care Planning shall depend on data collection, analysis and synthesis.

58. Life Care Planners may request additional data, testing and evaluation if required.

59. Life Care Planners shall research condition, resources, services and costs.

60. Life Care Plans shall utilize established procedures.

61. Life Care Planning procedures shall be peer or organizationally reviewed.

62. Life Care Plans shall be developed in the client's best interest.

63. Life Care Plans shall include a basis for recommendations.

64. Life Care Planners shall utilize a reliable, consistent method for reaching conclusions.

65. Life Care Planners shall utilize adequate medical and other data for opinions.

66. Life Care Plans shall include an annotated list of requested and reviewed data/sources.

67. Life Care Planners shall utilize standardized procedures and tools for gathering and reporting information.

68. Life Care Plans shall feature standardized forms and formats.

69. Life Care Plans shall be consistent across similar cases.

70. Life Care Plans shall rely on medical/allied health professional opinions.

71. Life Care Plans shall be limited to the planner's expertise and scope of practice.

72. Life Care Planners shall methodically handle divergent opinions.

73. Life Care Planners shall properly inject personal expertise.

74. Life Care Planners shall utilize credible, evidence-based guidelines.

75. Life Care Planners shall conduct an in-person interview whenever permitted.

76. Life Care Planners shall utilize protocols for cost research.

77. Life Care Planners shall gather geographically relevant & representative prices.

78. Life Care Planners shall utilize protocols for using local versus national resources.

79. Life Care Planners shall follow generally accepted methodology.
80. Differences in clinical judgment can result in different recommendations

81. Life Care Planning databases, templates and software shall have appropriate foundation.

82. Life Care Planning products and processes shall be transparent and consistent.

83. Life Care Planners shall be involved in research.

84. Life Care Planners shall include research in life care plans.

85. Life Care Planners shall study the reliability, validity and accuracy of life care plans.

86. Life Care Planners shall assess the reliability, validity and accuracy of data and methods.

87. Life Care Planners shall conduct longitudinal studies.

88. Life Care Planners shall evaluate the cost-effectiveness of life care plans.

89. Life Care Planners shall study the impact of life care plans upon quality-of-life.

90. Life Care Planners shall understand and explain research used in a life care plan.

91. Life Care Planners shall utilize research that is reasonable, relevant and appropriate.

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

93. 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

94. When the life care planner includes home care, both private-hire and agency-procured services are options to be considered.

95. The cost of private hire home care includes care giver compensation and associated expenses.

96. Life Care Planners shall consider the impact of aging.

97. Review of evidence based research, review of clinical practice guidelines, medical records, medical and multidisciplinary consultation, and evaluation/assessment of evaluee/family are recognized as best practice sources that provide foundation in Life Care Plans.

98. Best practices for identifying costs in Life Care Plans include:
- Verifiable data from appropriately referenced sources
- Costs identified are geographically specific when appropriate and available.
- Non-discounted/market rate prices.
- More than one cost estimate, when appropriate.

99. Life care planners will define terminology of our work product(s).