

# Journal of Life Care Planning



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## Editor's Message

*Tanya Rutherford Owen, Ph.D.*

In this issue, I will keep the editor's message very brief, so as to encourage all readers to instead read Cloie Johnson's message as this issue's guest editor. I certainly want to say thank you Anne Savage Veh and Kim Bailey (and many others!) for their work in making the October 2018 IARP conference one of the best that I have attended. For those of you who were unable to attend, we are attempting to include information from some of the conference sessions in this and future issues.

This issue was fast tracked after the October 2018 conference in Charlotte where Cloie Johnson and Jamie Pomeranz presented their Delphi study findings. While those in the room benefited from their recent research, it is our hope that all *Journal of Life Care Planning* readers will now have this information. The goal of this publication is to create a life care planning compendium containing all

Summit proceedings, attendees and *Consensus and Majority Statements* developed over almost two decades of work. I would like to encourage all life care planners, including those who participated in the process and those who did not, to develop a working knowledge of the *2018 Majority and Consensus Statements*. Whether we were first trained as rehabilitation counselors, nurses, physicians, physical therapists, speech therapists, etc., we are all life care planners and these documents were specifically designed to create best practices for **all** life care planners. In writing that this document is the culmination of almost two decades of work, we all owe a great deal of gratitude to Cloie Johnson for her vision for best practices in our field, her tireless work in this direction and, in particular, her view of inclusiveness for our profession.



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## Guest Editor's Message

*Cloie Johnson, M.Ed., ABVE, CCM*

It is an honor and a privilege to be the Guest Editor of this Special Issue on Summits for the *Journal of Life Care Planning (JLCP)*. This edition is a compilation of the efforts of all life care planners since 2000. Over the past 18 years life care planners have worked together to ensure the transdisciplinary specialty practice of life care planning remains strong, active and relevant. As I have previously written, looking back historically to all that we, as life care planners have done, is not only a reflection, but an opportunity. It is an educational tool and a reminder of where we have come from, and a map to where we are going. This special issue holds the dedicated efforts of a multitude of life care planners from a variety of disciplines across a vast geography. The diversity of the participants is indicative of our capacity for cooperation. These efforts mirror the basis of the Summits; collaboration by life care planners, for life care planners about life care planning.

I believe this edition is essential reading for every life care planner. As Dr. Roger Weed has previously reminded us, to be an effective and career-long practitioner, it is critical to understand not only how we became a specialty practice but the trends which have an effect on the contemporary life care planner as a result of changes in health care, current court decisions, and expanding practice horizons. This special issue summarizes the results of the extraordinary efforts of our fellow life care planners over the past eighteen years from all Summits.

Briefly, as previously described, Summits are designed to solicit the active participation of practicing professionals to help define ethics, methodology and standards of practice. (At most conferences the participants are listeners and the speakers impart information whereas at Summits the leaders are listeners and the participants impart information.) Those who educate, research, certify and practice have routinely volunteered their time to collegially come together to look in the mirror at who we are, what we are doing, and where we are going. Attendees have efficiently and effectively helped guide and develop the future of life care planning. Looking at best practices, certifications, court decisions, ethics, methodology and standards of practice across our multidisciplinary practice, the participants have continued to chart the course to more fully understand the methodology and the reality of the consequences of court decisions and other factors derived from various jurisdictions and specialty practice areas.

Reading chronologically the proceedings of each Summit which are reprinted in this edition will ensure the life care planner understands our history and then has the capacity to sustain our professionalism, follow the long-standing tenants and methodology consistent with the multidisciplinary aspect of life care planning. The Summits and their outcomes, tenants and methodology have been reassuringly affirmed in court decisions across the country in both state and federal court jurisdictions as well as adopted by at least 29 other venues (such as Medicare-Set-Aside, family planning, trusts, catastrophic healthcare reserves, workers' compensation claims, among others).

This special issue provides a concise and up close recording of what has historically been achieved in each of the typically biennial Summits since 2000. Life care planners have continued to reflect on the applicability of the Consensus and Majority statements to ensure they maintain relevance, are modified or are eliminated so as to maintain the credibility of the specialty practice, consistent with ongoing research and importantly affirmed by court decisions (for those practitioners who are involved in forensic rehabilitating). I encourage you to continue to be involved in the transdisciplinary practice. This special issue of the *Journal of Life Care Planning* includes:

- The work of an estimated 536 life care planners who took 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
- Proceedings of Life Care Planning Summits conducted in 2000, 2002, 2004, 2006, 2008, 2010 and 2011 (Canada), 2012, 2015 and 2017.
- Letters of Endorsement of the Proceedings from a multitude of organizations involved with the multidisciplinary field of Life Care Planning include:
  - 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)
- The most recent collaboration of life care planners in a Delphi Study resulting in the updated Consensus and Majority Statements.
- A singular repository for all Consensus and Majority Statements created over the course of the 18 year history of the biennial Summits.

I hope you take the time to reflect on the hard work of many, seize the opportunity to participate in future Summits, fully understand historical perspectives and impacts of the Summits, and join other practitioners in sustaining our professionalism in this transdisciplinary specialty practice. I am looking forward to seeing you all at the next life care planning Summit.

**Editor's note:** The following papers were reprinted from previously published articles in earlier issues of the JLCP. The following list of citations provide references to those papers: Weed, R. & Berens, D. (2001). Life Care Planning Summit 2000 Proceedings Athens, GA: Elliott & Fitzpatrick, Inc., 2002 JLCP 1(2) 179-182, JLCP, 2(2), 73-102, 2004 JLCP, 3(2), 109-112, JLCP 3(3) 193-202, 2006 JLCP, 5(1-2), 25-26, 2006 JLCP, 5(3), 57-90, 2008 JLCP, 7(2), 49-60, 2010 JLCP, 9(2), 3-14, 2011 (Canada) JLCP, 10(2), 35-36, 10(3), 3-24, 25-28, 2012 JLCP, 11(2) 3-8, 2015 JLCP 13(4) 27-33, 2017 JLCP 15(3) 19-29.

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# Life Care Planning Consensus and Majority Statements, 2000 - 2018: Are They Still Relevant and Reliable?

## A Delphi Study

*Cloie B. Johnson, MEd*

*Jamie L. Pomeranz, PhD*

*Nichole E. Stetten, PhD*

Beginning in 2000, life care planning Summits have been held at various locations around the country and have reflected collaboration between the diverse associations involved in life care planning (Johnson, 2012; Johnson and Gamez, 2015; Johnson and Gamez, 2017). Summits have been an integral part of the development and evolution of the specialty practice of life care planning. Over time, Summit results have been published, relied upon and utilized by practitioners in their daily work, as a reflection of best practices. The published *Consensus and Majority Statements* serve as reinforcement for the methodology and work of the life care planner. Importantly, Summits and their outcomes are developed by life care planners for life care planners about life care planning.

By the 2017 Summit in Denver, Colorado the specialty practice of life care planning had 102 *Consensus and Majority Statements* derived from life care planning Summits held in 2000, 2002, 2004, 2006, 2008, 2010, 2012 and 2015. At the 2017 Summit, it was further established (below reflect direct quotes):

1. Consensus by the attendees for this Statement: A comprehensive and systematic review of the existing 102 statements through a multi-association process to determine if they are still appropriate and relevant is needed.

Summit participants decided that organizational leadership should initiate action to build upon the work performed in Denver. The goal was to allow practicing life care planners the opportunity to provide input on the existing *Consensus and Majority Statements* and to partake in the systematic review referenced above. Ultimately, the goal was to complete a comprehensive and systematic review of the existing 102 statements through a multiassociation process to determine if they were still appropriate and relevant.

### Methods

#### Participants

The International Academy of Life Care Planners (IALCP), the Life Care Planning Section of the International Association of Rehabilitation Professionals (IARP), led this charge and selected Cloie Johnson as chair. She developed a primary committee made up of life care planners who were representatives from various disciplines and organizations. The primary committee members included: Susan Grisham of the Care Planner Network and past Foundation of Life Care Planning Research (FLCPR) board member; Jody

Masterson, IALCP Chair; Debbe Marcinko, the IALCP representative to the IARP Board; Denise Wrenn the president of the American Association of Nurse Life Care Planners (AANLCP); Evelyn Robert, a board member of the International Commission on Health Care Certification (ICHCC); Jamie Gamez, a 2017 life care planning Summit committee member; and Dr. Jamie Pomeranz, a researcher and educator in the field of life care planning. An invitation was extended to the American Academy of Physician Life Care Planners (AAPLCP), however, the organization declined to participate on the committee.

The primary committee held conference calls and began reviewing the objectives as established at the 2017 Summit by forming two task groups to categorize the statements and draft the foundation for the process. The primary committee then reviewed the categories and foundation and developed a process to conduct a preliminary review of the 102 statements. The primary committee members were presented with previously developed *Consensus and Majority Statements* from Summits dating back to 2000. They were asked to review each statement and vote if they 1) agreed this statement was still appropriate; 2) considered the statement generally valid but should be redefined, combined with another statement or revised; or 3) believed the statement was no longer valid. This process was consistent with the methodology used to review the statements at the 2010 Summit in Atlanta, Georgia (Berens, Johnson, Pomeranz & Preston, 2010). The primary committee reviewed these results during a third call and determined that foundational information, and an understanding of the basis of each statement was necessary to orient all life care planners to the task at hand.

Along the way, the primary committee decided that the survey participants would need to come from various disciplines, hold various certifications and licensures, and belong to various professional associations. Additionally, survey participants would be expected to have an understanding of the *IARP/IALCP Standards of Practice 3rd edition*, as well as the past Summit write-ups since 2000, to ensure a proper foundation of knowledge. A review of *Journal of Life Care Planning* issues 11(1), 11(2) and 13(4) was the best practice of anyone taking the survey to have a proper historical knowledge of the genesis of the *Consensus and Majority Statements*. Additionally, it was agreed that life care planning Summits define best practices and are held by

life care planners and for life care planners, about life care planning.

The primary committee decided that utilizing a similar methodology as used for the review and update of the *Standards of Practice 3rd Edition* was appropriate. This committee recommended that a secondary committee be developed to participate in a “testing” of the study once developed, and prior to being sent out to all life care planners. It was decided that the secondary committee members would include a cross section of active life care planning practitioners willing to volunteer the time required to orient themselves and participate in the process.

The primary committee consulted with academicians to determine the best method to ensure widespread input from those actively participating in the specialty practice of life care planning. Discussions led to a decision that a modified Delphi study would be most appropriate for use with a secondary committee.

### Secondary Committee

Life care planner volunteers were sought for secondary committee participation through list-serve solicitation through IARP, ICHCC, AANLCP and The Care Planner Network, to aid in the development of the instrument to determine if the 102 *Consensus and Majority Statements* from the Summits held since 2000 were still appropriate and relevant. The goal was to have a cross section of actively practicing life care planners from various disciplines and credentials to participate on the secondary committee. The secondary committee was led by Cloie Johnson who tasked Dr. Jamie Pomeranz of the Institute of Rehabilitation Education and Training (IRET) to develop an instrument and assist with review and analysis.

The ICHCC offered eight CEUs (including one hour of ethics) for participation in the secondary committee. In order to receive the CEUs, each participant was required to review all of the past Summit write-ups to orient themselves on how each statement was derived and understand the underlying foundation for each *Consensus and Majority Statement*. Initially, 35 volunteers provided their curriculum vitae to participate in the secondary committee. The past Summit write-ups and the first survey were provided to the 35 volunteers and 29 participants completed the survey. These 29 participants were all practicing life care planners who held state and national certifications, were from 16 different states and represented the professions of rehabilitation counseling, case management, nursing, medicine (physician), psychology, and social work. Secondary Committee Participants included Michelle Albers, Dorajane Apuna-Grummer, Barbara Bate, Harold Bialsky, Nancy Bond, Rebecca Busch, Patricia Cline, Dawn Cook, Mariann Cosby, Patricia Costantini, Heidi Fawber, Brook Feerick, Gail Ganata, Harvey Jacobs, Cloie Johnson, Trudy Koslow, Sherry Latham, Amy MacKenzie, Michael Martinez, Jody Masterson, Hector Miranda, Tanya Owen, Dana Penilton,

Jamie Pomeranz, Evelyn Robert, Robert Taylor, Denise Wrenn, and David Zak.

Participants were presented each previously developed *Consensus and Majority Statement* from Summits dating back to 2000. They were asked to indicate if they 1) agreed this statement was still appropriate; 2) considered the statement generally valid but should be redefined, combined with another statement or revised; or 3) believed the statement was no longer valid. If a response was anything other than ‘Agree’, the participant was asked to provide feedback specific to the need to modify or why it may require deletion to assist in the statement modification.

Jamie Pomeranz and Cloie Johnson analyzed the results and found that there was consistency among the responses from the survey seven years prior, which further validated the exploration of the remaining items that did not have clear acceptance. Below is a percentage breakdown of acceptance for each of the statements:

- 33 of the 102 Statements had 75% or greater acceptance
- 74 of the 102 Statements had 60% or greater acceptance
- 87 of the 102 Statements had 51% or greater acceptance

Secondary committee members completed a follow-up survey as an attempt to reach consensus and/or majority agreement of the 15 statements which had not reached majority (51%) consensus in the first survey. The members were provided the choice to either keep, keep with revision, or eliminate the statements. Feedback and clarification of opinions were requested of the secondary committee members.

Dr. Pomeranz and Cloie Johnson reviewed and analyzed the results of the second round. Effort at revision or commentary (including historical education, methodological context or reference) was completed. Following this review and analysis, it was determined, based on the variety of input, that a third round may provide greater clarification and potential consensus. The 15 statements and their qualitative responses were provided for participants to indicate whether to keep, revise or eliminate in a third round to the secondary committee. Typical to the Delphi Method, a third round is necessary if there is a potential to still achieve consensus. Since consensus was not achieved after the second round, the third round was presented and included the qualitative information.

The results revealed majority acceptance for the following revised statements:

- Life Care Planners shall utilize research (including identifying relevant literature to provide a foundation for recommendations, costing for equipment and services, etc.) in life care plan that is reasonable, relevant and appropriate.
- Life Care Planning methods shall be peer-reviewed (formally or informally reviewed by other experts in

the field) at national organization meetings and Summits.

- Life Care Plans shall be developed in the client's/evaluator's best interest.
- Life Care Planners shall utilize standardized procedures and tools for gathering and reporting information and feature standardized forms and formats.
- Life Care Planners will use consistent methodologies to evaluate similar cases.
- Life Care Planners shall properly inject professional expertise.
- Life Care Planners as a whole /or part of the specialty practice of life care planning through ethical practice will contribute to the reliability, validity and accuracy of life care plans.
- Life Care Planners, as a whole and/or part of the specialty practice of life care planning will encourage and participate, if able, in longitudinal studies on life care planning.
- Life Care Planners shall promote and participate in a national organization for life care planners that serves as a collective voice for the field and as a repository for resources.
- Life Care Planners shall keep up to date on best practices in life care planning by completing and encouraging others to participate in continuing education.

### Delphi Analysis

The Delphi is a universally accepted method for obtaining consensus on a multitude of issues and is ideal for obtaining ideas from a diverse group of experts. The method also allows expert input to be refined into a set of variables based on pure expert consensus that is untainted by social pressure or authority figures (Merlin et al, 2017; Robinson, Pomeranz & Young, 2012). Since life care planning is a subspecialty among a wide range of health professions, this method is ideal for determining consensus among such a diverse group of experts. In addition, the Delphi is advantageous as it affords the opportunity to bring together experts from different geographical locations (Merlin et al., 2017). The Delphi method allows researchers to harness this knowledge and experience through a series of carefully constructed rounds to build consensus. Finally, there is less opportunity for opinions to dominate the results since individual participants do not directly interact with each other (Keeney, Hasson & McKenna, 2011; Merlin et al., 2017).

### Participants

Participants were then recruited from multiple life care planning professional organizations. The International Association of Rehabilitation Professionals provided their Forensic Section and Life Care Planning (IALCP Sections), AAPLCP provided their most recent annual conference attendee list, and AANLCP and ICHCC informed their members internally of this opportunity and participants were encouraged to reach out and volunteer. A total of 978 email invitations were sent out requesting participation in the Delphi study to review the 102 *Consensus and Majority Statements*. Participants were asked an initial question, *Are you a practicing life care planner?* If participants responded 'yes' then they were able to continue the survey. If participants answered 'no' then they were told they could not participate and they were subsequently ineligible to participate. Following the initial invitation, 145 life care planners fully completed the survey with an additional 59 participants partially completing it. Seven participants did not receive the invitation due to an incorrect email address or server issues. Thirty-seven people were ineligible because they were not practicing life care planners. Two additional invitations were sent out to those who had not completed or opened the survey. Following the final invitation, 150 respondents completed the survey.

### Demographic Data

Participants (90.1%) responded from 32 states within the United States and 8.9% of the respondents had primary businesses located outside of the United States (See Table 1). Most participants reported backgrounds in rehabilitation counseling (45.64%), followed by nursing (30.87%) (See Table 2). Various certifications were represented in the respondents with licenses and certifications reported in rehabilitation counseling (49.31%), case management (39.61%) and others as shown in Table 3. The highest level of education included a majority (54%) reporting a master's degree (Table 4). Consistent with the recruitment goals, participants were members of multiple organizations with a majority (90.60%) reporting active membership in the International Association of Rehabilitation Professionals (IARP) (See Table 6). There was diversity among participants regarding credentials, with most participants holding the Certified Life Care Planner (CLCP) credential (71.62%) followed by the Certification in Rehabilitation Counseling (CRC) (45.95%) (See Table 6). Finally, participants were asked the number of life care plans completed each year. Responses ranged from never have completed a life care plan (2.03%) to over 40 life care plans completed each year (28.38%) (see Table 7).

Table 1

Where is your primary business located?

<u>Geographic Location</u>	<u>Percent Responses</u>
Outside of the United States	8.90%
Arizona	3.42%
Arkansas	1.37%
California	7.53%
Colorado	4.11%
Connecticut	0.68%
Florida	6.85%
Georgia	3.42%
Hawaii	0.68%
Idaho	0.68%
Illinois	0.68%
Iowa	0.68%
Louisiana	7.53%
Maine	0.68%
Massachusetts	1.37%
Michigan	0.68%
Minnesota	0.68%
Missouri	2.05%
Montana	2.05%
Nebraska	0.68%
New Hampshire	0.68%
New Jersey	4.11%
New Mexico	0.00%
New York	4.11%
North Carolina	2.74%
Ohio	2.05%
Oklahoma	2.05%
Oregon	1.37%
Pennsylvania	4.79%
South Carolina	1.37%
Tennessee	2.74%
Texas	5.48%
Virginia	4.11%
Washington	8.90%
West Virginia	0.68%

Table 2

My primary health care related profession is:

<u>Health Profession</u>	<u>Percent Responses</u>
Counseling	2.01%
Medicine	4.03%
Nursing	30.87%
Occupational Therapy	7.38%
Physical Therapy	0.67%
Psychology	4.70%
Rehabilitation Counseling	45.64%
Social Work	0.67%
Speech Therapy	0.67%
Other (please specify)	3.36%

Table 3

I am licensed at the state level and/or certified at the national level in the following fields of practice (please

<u>License/Certification</u>	<u>Percent Response</u>
Counseling	19.44%
Medicine	3.47%
Nursing	31.94%
Occupational Therapy	7.64%
Physical Therapy	0.69%
Psychology	3.47%
Rehabilitation Counseling	49.31%
Social Work	2.78%
Speech Therapy	0.69%
Case Management	36.81%
Other (please specify)	26.39%

Table 4

What is your highest level of education?

<u>Education</u>	<u>Percent Response</u>
Some college, but no degree	0.00%
2-year college degree	2.03%
4-year college degree	19.59%
Masters Level Graduate-level degree	54.05%
Clinical Doctorate Degree	1.35%
Ph.D.	10.14%
Ed.D.	2.03%
MD	3.38%
DO	0.00%
Other (please specify)	7.43%

Table 5

Please indicate your active membership organizations:

<u>Organization</u>	<u>Percent Response</u>
IARP	90.60%
ICHCC	44.30%
AANLCP	20.13%
AAPLCP	4.70%
Other (please specify)	27.52%

Table 6

*Please check all of your credentials:*

<u>Credential</u>	<u>Percent Response</u>
CRC	45.95%
CCM	35.81%
CLCP	71.62%
CVE	5.41%
CNA	0.00%
LPN	0.00%
RN	30.41%
SLP	0.68%
OT	7.43%
PT	0.68%
CLNC	2.03%
LNCC	4.73%
MSW	0.68%
MSCC	9.46%
CNLCP	14.86%
NCC	2.70%
ABVE	10.14%
CPLCP	1.35%
Other (please specify)	45.27%

Table 7

*Number of life care plans completed each year:*

<u>#Life Care Plans/Year</u>	<u>Percent Response</u>
I have never completed a life care plan	2.03%
1-10	25.00%
11-20	22.30%
21-30	12.84%
31-40	9.46%
Over 40	28.38%

The Delphi process consisted of three rounds with the overall goal of having expert life care planners determine the appropriateness and relevance of the *Consensus and Majority Statements* from the Summits held since 2000. Participants were encouraged to review summaries from previous Summits published within the *Journal of Life Care Planning*.

Participants were asked to review the statements that included additional statements since 2010. These statements were categorized, while maintaining the original numbers (as indicated in parentheses after the statement). Statements that were revised by the secondary committee (see above) were noted with an 'R'. For example, after a statement a participant might have seen (99R). This means that the original statement 99 has been revised. If two statements have been combined, then the statement was denoted with a (11/17R) for example. This meant that statement numbers 11 and 17 were revised and combined.

In addition to demographic data, participants were asked

to rate their level of agreement with the 102 statements by indicating their recommendation to accept, modify or delete each item. Participants also had the opportunity to comment on each of the 102 statements. Prior to this study and consistent with previous Summits, consensus level was set at 75%, meaning that at least 75% of the participants needed to agree or disagree regarding the current relevance of each statement in order to reach consensus.

All round 1 participants were eligible to participate in round 2. A new email invitation was sent to all eligible participants from round 1 (n=150). Participants received summary quantitative data all the items that did not receive consensus (10 statements). Statements that achieved consensus from the first round (92 statements) were not included in the second round. The experts were then to reevaluate their response after reviewing the summary data from all the participants. Consistent with the Delphi process, participants were instructed to reassess their initial judgements about the statements provided in the previous round. The rationale behind this procedure is through multiple iterations, participants are better able to crystalize their opinions by becoming more insightful and minimizing the effects of noise (Hsu & Stanford, 2007). Summary response data were provided to the participants in the form of a percentage for each possible response to each statement. For example, the first statement was *Life Care Planners shall be limited to the planner's expertise and scope of practice (71)*. The answer choices were:

1. Agree this statement is still appropriate (68% selected this response)
2. Consider generally valid but should be redefined, combined or revised (15.17% selected this response)
3. Believe this statement is no longer valid (15.86% selected this response)

All round 2 participants were eligible to participate in round 3. A new email invitation was sent to all eligible participants from round 2 (n=132). Since consensus was not reached on the 10 items from round 2, participants were asked to reevaluate their responses again, however this time they were asked to review the qualitative data provided from participants in round 1 and round 2. Qualitative data (comments) were presented exactly the way they were provided by participants in previous rounds.

## Results

### Round 1

Respondents (n=139) fully completed the entire survey, with 11 having less than full completion. Consensus was not achieved (75% threshold) for ten of the statements. The statements along with participant responses are included in Table 8.

### Round 2

During the second round, the participants were asked to reevaluate the 10 statements that did not reach majority approval of agreement or disagreement. The statements along

with participant responses are included in Table 8.

**Round 3**

In an effort to be transparent and clear about the process, in the third round, participants were provided the contextual reference to the original statement, the Summit and prompt used where the attendees proposed and agreed upon the statement, as well as Round 1 and 2 results. Participants reviewed these 10 statements with the additional information provided as noted above and voted again. Table 8 depicts the responses across all three rounds.

In summary, there was a majority opinion to delete statements 4 and 6 with greater than 75% agreement. statements 2 and 3 did not have a majority to either delete, revise or endorse as appropriate, so they, therefore, remain intact. Five statements had a majority of greater than 60% to delete, and statement 1 had a 51% majority to delete. Thus, these statements remain intact. A full listing of all updated *Consensus and Majority Statements* as a result of this Delphi study can be found in a separate publication in this same journal.

See Table 8 next page

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Table 8

*Delphi Results for all three rounds:*

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

Original Statement	Summit/Topic	Topic	Response	Round 1	Round 2	Round 3
71	2000/4	Reliability and Validity	Accept	68.00	65.38	20.48
			Modify	15.17	20.00	26.51
			Delete	15.86	14.62	53.01

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

Original Statement	Summit/Topic	Topic	Response	Round 1	Round 2	Round 3
94	2010/2	Private Hire/Agency Procured Service	Accept	68.28	68.46	33.73
			Modify	17.24	17.69	18.07
			Delete	14.48	13.85	48.19

**3. Life care planners shall be involved in research**

Original Statement	Summit/Topic	Topic	Response	Round 1	Round 2	Round 3
83	2002/5	Professional Development	Accept	59.03	46.92	24.39
			Modify	23.61	39.23	36.59
			Delete	17.36	13.85	39.02

**4. Life care planners shall evaluate the cost effectiveness of life care plans.**

Original Statement	Summit/Topic	Topic	Response	Round 1	Round 2	Round 3
88	2004/3	Future of Research in life care planning	Accept	69.72	61.54	13.41
			Modify	16.90	21.54	12.20
			Delete	13.38	16.92	75.90

**5. Life care planners shall explore markets for life care planning outside litigation**

Original Statement	Summit/Topic	Topic	Response	Round 1	Round 2	Round 3
6	2002/2	Marketing life care plan, Developing New Markets for Life care planning and Educating the Public and Other Professionals	Accept	69.01	73.08	13.58
			Modify	17.61	15.38	13.58
			Delete	13.38	11.54	72.89

**6. Life care planning programs shall be promoted widely**

Original Statement	Summit/Topic	Topic	Response	Round 1	Round 2	Round 3
13	2002/1	Continuing Education and Professional Training in Life Care Planning.	Accept	59.44	45.38	12.35
			Modify	16.08	20.77	2.47
			Delete	24.48	33.85	85.19

**7. Life care planner certifications shall be augmented**

Original Statement	Summit/Topic	Topic	Response	Round1	Round 2	Round 3
21	2002/5	Accountability and Standards of Compliance	Accept	50.00	34.61	7.41
			Modify	23.57	36.15	18.51
			Delete	26.43	29.23	74.07

**8. Life care planners shall better define dual roles**

Original Statement	Summit/Topic	Topic	Response	Round1	Round 2	Round 3
45	2002/3	Ethics	Accept	52.78	49.23	13.58
			Modify	21.53	29.23	25.93
			Delete	25.69	21.54	60.49

**9. Life care planners shall draft life care plans under supervision for one year**

Original Statement	Summit/Topic	Topic	Response	Round1	Round 2	Round 3
38	2000/3	Competency	Accept	57.75	53.85	22.22
			Modify	16.90	19.23	9.88
			Delete	25.35	26.92	67.90

**10. Life care planners shall study the reliability, validity and accuracy of life care plans**

Original Statement	Summit/Topic	Topic	Response	Round1	Round 2	Round 3
38	2002/4	Initiate Research and Universal Database	Accept	67.36	68.46	20.99
			Modify	18.06	18.46	14.81
			Delete	14.58	13.08	64.20

### Discussion

At this juncture, the authors respectfully turn these results over to those who coordinate and utilize life care plans, as well as the organizations and associations who lead them. The intent of having a routine life care planning Summit is to remain on the cutting edge of any new developments or issues, as well as to ensure the guiding *Consensus and Majority Statements* of the life care planners, by the life care planners about life care planning remain relevant and reliable. Having conducted this exercise in 2010 and again in 2018, it is our recommendation that ongoing review of the statements becomes a component in the strategic planning for the organizations and associations that provide leadership and education to the specialty practice of life care planning.

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### About the authors:

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Jamie I. Pomeranz, PhD is an Associate Professor at the University of Florida and co-owner of the Institute of Rehabilitation Education & Training. He co-chaired the Life Care Planning Summits in 2008 and 2010. He is the 2010 Recipient of the Patricia McCollum Research Award for Excellence in Life Care Planning Research.

Nichole Stetten, Ph.D. recently completed her Ph.D. in Public Health with a concentration in social and behavioral science. Dr. Stetten's background and experience was utilized in developing the Delphi initial and subsequent round instrument used to collect data for this study.



# Consensus and Majority Statements derived from Life Care Planning Summits held in 2000, 2002, 2004, 2006, 2008, 2010, 2012, 2015 and 2017 and updated via Delphi study in 2018

*Cloie B. Johnson, Jamie L. Pomeranz, & Nichole E. Stetten*

The following statements were created by life care planners at various Summits between 2000 and 2017, and recently updated via Delphi study in 2018. They 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 have knowledge of relevant laws and regulations as well as local and national care standards.
7. Life Care Planners shall understand optimal outcomes achievable for particular injuries.
8. *Revised: Life Care Planners shall promote and participate in a national organization for life care planners that serves as a collective voice for the specialty practice and as a repository for resources.*
9. Life Care Planners shall complete 120 hours of training including courses that focus on disability issues and is specific to life care planning.
10. Life Care Planning programs shall be based on the latest knowledge and practices.
11. Life Care Planning programs shall cover certification-preparation as well as advanced topics and complex issues.
12. Life Care Planning programs shall be offered in accessible geographic locations and electronically.
13. Life Care Planning continuing education units shall be available at an increasing number of forums.
14. Life Care Planning continuing education units shall be available at forums that may not focus solely on life care planning.
15. Life Care Planners shall keep up to date on best practices in life care planning by completing and encouraging others to participate in continuing education.
16. Life Care Planner certification shall render its holder a qualified life care planner, provided that certification is maintained.
17. Life Care Planner certification shall be renewed every five years with the accumulation of 60 continuing education units.
18. Life Care Planners shall be licensed and/or certified in their professional discipline before being certified as a life care planner.
19. The International Commission on Health Care Certification shall apply for National Commission for Certifying Agencies accreditation.
20. Life Care Planners shall hold a certification that has mechanism for complaints and resolution.
21. Life Care Planning certification shall flow from a practitioner-created core curriculum.
22. The Life Care Planning certifying body shall not be proprietary.
23. The Life Care Planning certifying body shall manage and disclose ethical complaints and violations.

24. Life Care Planning certification exams shall be developed and maintained by an advisory group.
  25. 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.
  26. Standards of Practice terminology shall be reviewed
  27. Standards of Practice terminology shall be defined.
  28. Standards of Practice shall delineate educational requirements for entry into the practice of life care planning.
  29. Standards of Practice shall assert the role and accountability of life care planners
  30. Standards of Practice shall be based on a study defining the role and accountability of life care planners.
  31. Standards of Practice shall allow for individual judgment and expertise.
  32. Standards of Practice shall be utilized in the development of the practice of life care planning.
  33. Standards of Practice shall be applicable to current practices.
  34. Life Care Planners shall accept referrals only in their area of expertise.
  35. Life Care Planners shall maintain objectivity.
  36. Life Care Planners shall maintain strict adherence to confidentiality practices.
  37. Life Care Planners shall renounce inappropriate, distorted or untrue comments about peers.
  38. Life Care Planners shall renounce inappropriate processes and training.
  39. Life Care Planners shall disclose and differentiate between the roles in which they may be called upon to act.
  40. Life Care Planners shall avoid dual relationships when objectivity may be challenged.
  41. Life Care Planners shall establish themselves within their primary field of practice.
  42. Life Care Planners shall objectively place their client's interests before any personal or professional consideration.
  43. Life Care Planners shall adhere to relevant Codes of Ethics.
  44. Life Care Planners shall have access to recourse/corrective action process for ethical violations.
  45. Life Care Plans shall be individualized.
  46. Life Care Plans shall be objective and consistent.
  47. Life Care Plans shall be lifelong and flexible.
  48. Life Care Plans shall be a clear, concise and user-friendly document.
  49. Life Care Plans shall be comprehensive and based on multidisciplinary data.
  50. *Revised: Life Care Planners shall utilize research (including identifying relevant literature to provide a foundation for recommendations, costing for equipment and services, etc.) in Life Care Plan that is reasonable, relevant and appropriate.*
  51. Life Care Planners shall consider the integrity of data.
  52. Life Care Planning shall depend on data collection, analysis and synthesis.
  53. Life Care Planners may request additional data, testing and evaluation if required.
  54. Life Care Planners shall research condition, resources, services and costs.
  55. Life Care Plans shall utilize established procedures.
  56. *Revised: Life Care Planning methods shall be peer reviewed (formally or informally reviewed by other experts in the field) at national organization meetings and Summits.*
  57. *Revised: Life Care Plans shall be developed in the client's/evaluator's best interest.*
  58. Life Care Plans shall include a basis for recommendations.
  59. Life Care Planners shall utilize a reliable, consistent method for reaching conclusions.
  60. Life Care Planners shall utilize adequate medical and other data for opinions.
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61. Life Care Plans shall include an annotated list of requested and reviewed data/sources.
62. *Revised: Life Care Planners shall utilize standardized procedures and tools for gathering and reporting information and feature standardized forms and formats.*
63. *Revised: Life Care Planners will use consistent methodologies to evaluate similar cases.*
64. Life Care Plans shall rely on medical/allied health professional opinions.
65. Life Care Planners shall methodically handle divergent opinions.
66. *Revised: Life Care Planners shall properly inject professional expertise.*
67. Life Care Planners shall utilize credible, evidence-based guidelines.
68. Life Care Planners shall conduct an in-person interview whenever permitted.
69. Life Care Planners shall utilize protocols for cost research.
70. Life Care Planners shall gather geographically relevant & representative prices.
71. Life Care Planners shall utilize protocols for using local versus national resources.
72. Life Care Planners shall follow generally accepted methodology.
73. Differences in clinical judgment can result in different recommendations
74. Life Care Planning databases, templates and software shall have appropriate foundation.
75. Life Care Planning products and processes shall be transparent and consistent.
76. *Revised: Life Care Planners as a whole /or part of the specialty practice of life care planning through ethical practice will contribute to the reliability, validity and accuracy of life care plans.*
77. *Revised: Life Care Planners, as a whole and/or part of the specialty practice of life care planning will encourage and participate, if able, in longitudinal studies on life care planning.*
78. Life Care Planners shall study the impact of life care plans upon quality-of-life.
79. Life Care Planners shall understand and explain research used in a life care plan.
80. Life Care Planners may independently make recommendations for care items/services that are within their scope of practice.
81. 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
82. The cost of private hire home care includes care giver compensation and associated expenses.
83. Life Care Planners shall consider the impact of aging.
84. Review of evidence-based research, review of clinical practice guidelines, medical records, medical and multidisciplinary consultation and evaluation/assessment of evaluatee/family are recognized as best practice sources that provide foundation in life care plans.
85. Best practices for identifying costs in life care plans include:
- a. Verifiable data from appropriately referenced sources
  - b. Costs identified are geographically specific when appropriate and available.
  - c. Non-discounted/market rate prices.
  - d. More than one cost estimate, when appropriate.
86. Life Care Planners will define terminology of our work product(s).
87. Life Care Planners have the option to use support staff under their direction and guidance in completing life care plans.
88. Life Care Planners shall identify conflicts of interest.
89. Life Care Planners shall identify the sources of their recommendations.
90. \*Life Care Planners shall explore markets for life care planning outside litigation.
91. \*Life Care Planner certification standards shall be augmented.
92. \*Life Care Planners shall draft life care plans under supervision for one year.
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93. \*Life Care Planners shall better define dual relationships.
94. \*Life Care Plans shall be limited to the planner's expertise and scope of practice.
95. \*Life Care Planners shall be involved in research.
96. \*When the life care planner includes home care, both private-hire and agency-procured services are options to be considered.

***\*Those statements with an asterisk (\*) did not receive a consensus to maintain, delete or revise.***

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## Life Care Planning Summit 2000

Dallas, Texas  
April 12, 2000

### Introduction

On April 12, 2000, a conference was held specifically to address life care planning topics and issues with the goal of achieving consensus on five focus areas. The conference was sponsored by Intelicus/University of Florida in conjunction with the International Association of Rehabilitation Professionals (IARP), International Academy of Life Care Planners (IALCP), and the Commission on Disability Examiner Certification (CDEC). In addition, the American Association of Legal Nurse Consultants (AALNC) and the Case Management Society of America (CMSA) participated. Each organization was asked to identify a speaker/group facilitator to lead a small focus group.

In order to establish a consistent foundation, the definition of life care planning was distributed as follows:

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.

Source: Combined definition of the University of Florida and Intelicus annual life care planning conference and the American Academy of Nurse Life Care Planners (now known as the International Academy of Life Care Planners) presented at the Forensic Section meeting, NARPPS (now known as the International Association of Rehabilitation Professionals) annual conference, Colorado Springs, CO, and agreed upon April 3, 1998.

For purposes of the Summit, topics and issues were sorted into five focus areas which include:

1. **Professional preparation: Minimum qualifications Education**
    - Experience
    - Certifications
    - Other credentials
  2. **Basic tenets and procedures for completing life care plans:**
    - Records review
    - Medical foundation
    - Expert witness v. consultant
    - Reports and content
    - Economic requirements
  3. **Ethics:**
    - Relevancy of ethics from certifications or licenses not specific to life care planning
    - Maintaining files
-

Documenting contacts for Life Care Plan entries  
 Staying within area of expertise  
 Confidentiality  
 Objectivity

4. **Reliability and validity of the life care plan:**

Based on adequate foundation  
 Opinions referenced in life care planning by credentialed professionals  
 Based on the industry requirements (e.g., personal injury, workers' comp., etc.)  
 Research data

5. **Information dissemination:**

How to make agreed upon standards and procedures readily available to public  
 Publications, association, and certification board web sites  
 Develop a reference list of life care planning and related publications

**Method**

*Speakers*

The participating organizations were asked to nominate a professional who was knowledgeable in the life care planning field who would offer comments to the group at the general session and would also act as facilitator in the focus groups. In addition, in order to achieve proper balance, physicians, plaintiff and defense attorneys, an economist, and other well known rehabilitation and life care planning professionals and authors were invited. The defense attorney and the CDEC Board representative were unable to attend due to poor weather which delayed their flights until too late to actively participate. However, the plaintiff attorney was able to talk with the defense attorney and relevant issues were included. In addition, the CDEC requirements and ethics were distributed to all speakers and attendees prior to the conference.

*Participants*

The attendees (limited to 100 attendees and the speakers) consisted of 102 professionals who were invited from lists of organizations known to include life care planners. Although attendees were generally self-selected, most had demonstrated experience in life care planning and 66 were Certified Life Care Planners (CLCP). Others were highly experienced and/or were actively obtaining training in life care planning. (Note: Although all available attendee reservations were sold, poor weather prevented a few from participation. The attendee list includes only professionals who actually were present for the summit.)

*Procedures*

Prior to the conference, all speakers and attendees were sent a binder which contained relevant information to help reduce the amount of time required to educate the audience. Included in the information was:

Definition of life care planning (see introduction).  
 Ethics and Professional Issues for the Life Care Planner developed by Dr. Roger Weed from a previous annual conference on life care planning.  
 General Considerations for Life Care Planners by Drs. Paul Deutsch and Chris Reid.  
 A Daubert Checklist for the Life Care Planner, by Tyron Elliot, Esq.  
 Daubert, The Emerging Profile, by Tyron Elliot, Esq.

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Daubert and Kumho: Guidelines for the Rehabilitation Consultant, by Dr. Timothy Field.  
 A Rules and Guidelines Checklist by Dr. Randall Thomas.  
 The Commission on Disability Examiner Certification Standards and Examinations  
 Guidelines, by Dr. Robert May.  
 Guidelines for Excellence in Life Care Planning, Draft #3, by Sharon Reavis, Karen  
 Preston and Roger Weed and edited by Patricia McCollom.  
 NARPPS Standards and Ethics (now known as IARP).  
 Code of Ethics and Conduct, by American Association of Legal Nurse Consultants.  
 Miksis v. Howard, 106 F 3d 754 (1997).  
 Davis v. Ford Motor Company, 128 F 3d 631 (1997).

At the Summit, the group was assembled in a general session to explain the procedures  
 and invite the speakers to make opening statements that would serve to help focus  
 attendees on various topics and issues. The initial schedule was planned as follows:

Introduction and purpose — Roger Weed, Ph.D., CRC, CLCP, CCM, CDMS, LPC  
 Keynote speaker for the issues - Paul Deutsch, Ph.D., CRC, LMHC, CLCP  
 Plaintiff attorney perspective — Tyron Elliott, Esq.  
 Defense attorney perspective — Donald Lawson, Esq. (unable to attend due to weather)  
 Medical foundation issues — Richard Bonfiglio, MD and Terry Winkler, MD, CLCP  
 Economic foundation issues — Frederick Raffa, Ph.D.  
 Overview of effects on the industry based on legal research — Timothy Field, Ph.D.  
 Industry comments  
 CLCP Board perspective - Robert May, Rh.D., CRC (unable to attend due to weather)  
 IALCP perspective - Patricia McCollom, MS, RN, CRRN, CDMS, CCM, CLCP  
 NARPPS (now IARP) perspective — Ann Neulicht, Ph.D., CRC, CDMS, CVE, LPC,  
 CLCP, DABVE  
 AALNC perspective — Patty Costantini, RN, M. Ed., CRC, CCM, CLCP, LNCC  
 CMSA perspective — Anne Llewellyn, RN.C., BPSHSA, CCM, CRRN, CEAC  
 Curriculum comments  
 Intelicus - Linda Shaw, Ph.D., CRC  
 University of Florida — Horace Sawyer, Ph.D., CRC

After the general session, numbers were assigned separately to each attendee within their  
 professional discipline so that an integrated mix of experience, training and knowledge was  
 assured. The initial small group session was 45 minutes and sessions thereafter were  
 approximately 30 minutes. Every attendee rotated through all five focus groups and  
 participated in discussions on all topics.

A modified nominal group technique was used within each focus group (except group 4)  
 to gather information in an organized format and to reduce the influence of verbal or assertive  
 participants on the outcome. A summary of the modified nominal group technique follows:

1. Ask the group members to write down their top 3 to 5 suggestions in order of priority
2. Use a flip chart to go around the group and write down suggestions
3. Combine suggestions when possible
4. After the issues are recorded, ask the attendees to "vote" on 3 to 5 of the suggestions  
 listed
5. After the vote, group facilitator assigns 1 to the highest, 2 to the second highest, etc.
6. Facilitator adds up the score for each and the top scoring 3 to 5 recommendations  
 represent the decisions for that group

7. When the large group reconvened, each small group contributed 3 to 5 recommendations. Theoretically, several overlapping recommendations should be made. Time was reserved at the end of the day for additional discussion by and to the panel members from the participants.

At the end of the conference day, attendees were re-assembled into one large group and the facilitators summarized the comments and consensus was noted. Overall, a significant amount of consensus was reached on multiple topics. In other areas, there was a majority view.

Following the Summit, a draft of the proceedings was sent to all attendees, speakers and participating organizations and their comments solicited. Corrections and clarification were obtained from the participants and incorporated as appropriate into the proceedings.

Finally, a second "prepublication draft" incorporating the second edited version which represented consensus and majority views was distributed to participating organizations for endorsement and final comment. This document is a culmination of the efforts of many individuals and representative organizations that have contributed and endorsed the contents contained in this report.

## **Results**

The following sections represent a summary of the results of each focus group.

# **FOCUS TOPIC 1: PROFESSIONAL PREPARATION**

*Group Facilitator: Horace Sawyer, Ph.D., CRC  
Recorder: Ann Wallace, MS, CRC, CDMS, MFCT*

## **Overall Observations**

Qualified life care planners must demonstrate a level of competence combining education, professional preparation, and experience. The greatest strength and primary challenge of life care planning is the interdisciplinary nature of service delivery and qualified professionals preparing life care plans from different disciplines.

In life care planning, certification came before standards of practice which is rare among service delivery strategies.

Life care planning is not a profession, but comprised of different qualified professionals providing the same specific area of expertise and consultation (i.e., specialty within a profession).

Qualification standards are needed that are professionally appropriate for life care planning without being exclusionary.

## **Priority Areas**

### *Education*

#### *Majority View*

Minimal level of education at the Bachelors Degree level (one group expressed concerns that a professional with a BA does not have the necessary skills)

If professional entry level is higher, i.e. Masters Degree, this higher level is required  
Professional degree above the bachelor level required if appropriate, i.e., physician

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*Experience**Majority View*

Essential to have a combination of experience and education

Minimum of five years experience in a rehabilitation and health related field prior to being qualified for life care planning

*Certification**Majority View*

Eventual requirement for certification in an area related to life care planning to be recognized as a qualified life care planner

In addition, certified and/or licensed in own profession with established ethical standards

*Professional Training**Majority View*

Completion of professional training in life care planning and specific to the primary areas of developing, defending, and managing a life care plan

The present 120 hours of specialty training is acceptable

*Additional Qualifications**Majority View*

Completion of supervised period of time (internship, mentorship, practicum, etc.) under the supervision of a qualified life care planner required prior to being regarded qualified for life care planning

During this supervisory period, required completion of several life care plans, in collaboration with supervisor/mentor, that would be peer-reviewed. (Editor's note: suggest minimum 5 life care plans).

## **FOCUS TOPIC 2: BASIC TENETS AND PROCEDURES**

*Group facilitators: Ann Neulicht, Ph.D., CRC, CDMS, CVE, LPC, CLCP, DABVE  
and Patty Costantini, RN, M.Ed., CCM, CRC, CLCP, LNCC (also recorder)*

**TENETS****Priority Areas**

**A Life Care Plan is Individualized to Reflect Specific Needs and Promote Optimal Health, Function and Autonomy**

## Consensus

Specific to an individual, disability, and geographic area

Promotes maximum function/optimizes residual functional capacity

Maximizes independence in a safe and least restrictive environment

Provides a framework/roadmap for implementation of optimal level of care

Includes proactive recommendations to prevent/decrease complications

Functional for the client

Reflects the whole person/client

Considers person/family-centered needs and preferences  
Restores quality of life to pre-injury expectations as much as possible

**A Life Care Plan is Objective and Consistent**

Consensus

Opinions are supported by relevant, available data and research  
Conclusions are based on medical, vocational and rehabilitation needs/case specific data  
Recommendations are medically/vocationally reasonable and appropriate, probable, necessary and prudent  
Utilizes unbiased and established procedures

**A Life Care Plan is a Lifelong and Flexible Document**

Consensus

A dynamic tool that changes with the client's needs (disability related and developmental)  
Provides a logical/cyclic progression of services projected over the client's life expectancy  
Reflects a work in progress (e.g. covers client's life span)  
Usable (e.g. able to be implemented)

**A Life Care Plan is Comprehensive and Based on Multidisciplinary Data**

Consensus

Answers questions  
Discusses consequences of a catastrophic impairment/disability  
Provides collaborative recommendations to address medical, vocational, psychological, rehabilitation and education services as well as functional needs

**PROCEDURES**

**Priority Areas**

**Completion of an Assessment that includes Collection, Analysis and Synthesis of all Available and Relevant Data**

Consensus

To the fullest extent possible, conduct an inclusive data collection process to obtain available and relevant records (including those of the client, treating professionals and other relevant providers)  
Conduct a comprehensive interview with the client, his/her family and/or significant other(s), if possible  
Communicate with all relevant professionals/experts actively involved in client's care, if possible

**Request Additional Testing, Evaluation, or Data, if Needed**

Consensus

Address gaps in records and/or recommendations  
Obtain recommendations that are within the expertise of the provider  
Render opinions that are within the expertise of the life care planner

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### **Research Medical Condition, Resources, and Services to Outline Reasonable and Appropriate Recommendations and Associated Costs**

#### Consensus

- Contact verifiable, reliable and credible sources
- Review/utilize current literature, research and data to provide a foundation for opinions, conclusions and recommendations
- Address reasonable desires/preferences of the client and/or family
- Ask appropriate questions of all relevant providers
- Assess relevant costs
- Provide fair and representative costs relevant to the geographic area or region

### **Maintain Consistent System of Data Collection/Analysis, Record Keeping and Reporting**

#### Consensus

- Create a systematic diagnosis-based record keeping process for standardized data collection
- Utilize a standardized format to insure a comprehensive and objective life care plan
- Provide conclusions/recommendations supported by evidence within the life care plan and consistent with case records/documentation and other relevant information

## **FOCUS TOPIC 3: ETHICS**

*Group facilitators: Patricia McCollom, RN, MS, CRRN, CDMS, CCM, CLCP and Linda R. Shaw, Ph.D., CRC*

#### **Overall Observations**

As the professional specialization of life care planning has evolved, the need to promote ethical practice among life care planners has taken on increasing prominence. Participants were grouped together and nine (9) major themes were identified that encompass the majority of the comments. The consensus on these nine themes are described below and the general number of responses within each theme are shown in parentheses (totals do not correspond precisely to the number of total concerns identified as some may have been included within multiple themes):

#### **Priority Areas**

##### **Competency (41)**

#### Consensus

- All life care planners must accept referrals only in the areas of their competency
- All life care planners must be educated in the process of life care planning based on each industry's standards and published procedures
- Aspiring life care planners with less than one year of experience should be supervised by life care planners with at least two years experience

##### **Objectivity (43)**

#### Consensus

- Essential for life care planners to remain objective in their assessments and development

of life care plans despite pressures to construct a plan that is helpful to either plaintiff or defense legal positions

Need to adequately address objectivity in curriculum/training arenas

Life care planning industry needs to provide a mechanism for recourse and corrective action, possibly through a certification-related disciplinary process, when life care planners fail to exercise their obligation to professional objectivity

Life care planners must be certified or licensed in their area of expertise (not necessarily certified as a life care planner/CLCP) that provides a mechanism for ethics complaint resolution

### **Confidentiality Breaches (22)**

Consensus

Life care planners must be educated about confidentiality requirements and legalities

Life care planners must adhere to confidentiality practices when providing services and maintaining records

### **Lack of Consistency in the Life Care Planning Process (12)**

Consensus

Life care planners must use established procedures

"Enhancements" or significant changes in procedures should be subject to peer or organizational review by professionals who are experts in the field

Life care planners should belong to an organization that reviews life care planning topics and issues, as well as offers continuing education specifically related to the industry

### **Rules of Conduct Among Life Care Planners (11)**

Consensus

Life care planners shall refrain from inappropriate, distorted or untrue comments about colleagues and/or the process or training programs available for life care planners

Lack of Research Basis for Recommendations/Conclusions (11) Consensus

It is essential for life care planners to remain objective in their assessments

Life care planners must be certified in their area of expertise that also provides a mechanism for ethics complaint resolution

Life care planners should belong to an organization that reviews life care planning topics and issues, as well as offers continuing education specifically related to the industry

### **Individualizing Life Care Plans to Patient/Family Issues (10)**

Consensus

Life care plans are to be individualized to the client and his/her disability

Life care plans are to be developed in the client's best interest and have a foundation for inclusion of recommendations (i.e., medical foundation based on research and opinions of treating professionals within their own area of expertise v. own experience/opinions)

### **Lack of Consensus Regarding Life Care Planning Certification (8)**

Consensus

Life care planners should belong to an organization and/or be certified in an area that incorporates ethics and procedures specific to life care planning

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## Dual Relationships (7)

### Consensus

Life care planners who are qualified to provide a variety of services or act in several roles must disclose to the client and referral sources what role they are assuming and when/if roles shift

Life care planners must avoid dual relationships, including but not limited to, pre-existing personal relationships with clients, sexual contact with clients, accepting referrals from sources where objectivity can be challenged (such as dating or being married to the referral source), etc.

### Summary of Ethics Discussions

Themes generally fell into three groups in the frequency with which they were voiced:

<b>High Frequency Themes (41-43):</b>	Competency Objectivity
<b>Medium Frequency Themes (22):</b>	Confidentiality Breaches
<b>Lower Frequency Themes (7-12):</b>	Lack of Consistency in Life Care Planning Process Rules of Conduct among Life Care Planners Lack of Research Basis for Recommendations/Conclusions Individualizing the Life Care Plan to Patient/Family Issues Lack of Consensus regarding Certification Dual Relationships

### Breakdown of Participants' Comments Regarding Ethics

1. Persons without clinical skills (insufficient experience) competency, understanding the disability itself, practice with lack of experience (#34) \*\*41\*\*
2. Lack of research base \*\*11\*\*
3. Lack of consistency in process of doing LCP/procedures \*\*12\*\*
4. Need for emphasis on role of LCP/professional disclosure/role as educator \*\*3\*\*
5. Individual consensus re: standards, stakeholders (#6, 10, 29)
6. Lack of consensus regarding certification (#5, 10, 29) \*\*\*\*\* holding out as "better than" uncertified, do we all need to be certified? \*\*7\*\*
7. Continuity among various standards/ethics \*\*2\*\*
8. Advocacy vs. reporter (#21) role clarified \*\*2\*\*
9. Pressures to "help the case"/OBJECTIVITY (#28) \*\*43\*\*
10. Need for all to "buy in" to one credentialing process (certification) (#5, 6, 29)
11. Lack of emphasis in university programs on LCP (competence) \*\*2\*\*
12. Need to operationalize ethical task standards—competency based terms \*\*3\*\*
13. Referencing no or non-existent databases/misrepresenting data
14. Not collecting sufficient data to form valid opinions \*\*2\*\*
15. Plans do not reflect consumer values/independent needs (#22) \*\*3\*\*
16. Rules of conduct among LCPlanners (e.g., not disparaging, objectivity) \*\*11\*\*
17. Consistency in maintaining files/disposing of files \*\*4\*\*
18. Confidentiality breaches, including contact with treating professionals without consent of person with disability or others (#33) \*\*22\*\*

19. Acceptable and published research procedures/validity/citing invalid research \*\*3\*\*
20. LCP individualized to patient/family needs/issues \*\*8\*\*
21. Dual relationship: e.g. LCP and case manager, impact on objectivity (#8) \*\*7\*\*
22. Medical necessity vs. quality of life (#15)
23. Infighting of organizations \*\*3\*\*
24. Equal access to data/information
25. Need to engage in interdisciplinary model while acting within scope of practice
26. Content of LCP must have defined outcome/rationale \*\*2\*\*
27. Must be valid basis for recommendations: fiscal responsibility \*\*2\*\*
28. Honest and competent evaluation — do not inflate/undershoot figures (#9) \*\*5\*\*
29. Raising the bar/setting agreed upon standards (#10, 6, 5) \*\*3\*\*
30. Consistency in standards across various practice arenas ( e.g. litigation, w.c., etc.)
31. Business practices/accepting contingency payment/referral agreements, etc. \*\*4\*\*
32. Releasing notes/work product (#33)
33. Confidentiality of caseload/specific name in deposition/non-Federal Rule 26 (#18, 32)
34. Staying within your discipline's standards of practice (#1) \*\*2\*\*
35. Doing "canned" LCPs \*\*3\*\*
36. Untruthful/manipulating data
37. Confidentiality of names/sanitized LCPs
38. Reviewing value statement/CDEC
39. Qualifications to do plan
40. Conflict of interest identification \*\*4\*\*
41. Failure to give credit for research data
42. Comprehensive rather than selective approach
43. Discounting LCPs for reduced life expectancy

*Note:* Numbers in parentheses represent other items related to this item. Numbers within double asterisks (\*\*) represent the number of participants who mentioned this concern. Those items for which there is no number in double asterisks were mentioned only once.

## **FOCUS TOPIC 4: RELIABILITY AND VALIDITY**

*Group facilitator: Tyron Elliott, Esq., with assistance from  
Richard Bonfiglio, MD; Paul Deutsch, Ph.D., CRC, LMHC, CLCP  
and Chris Reid, Ph.D., CRC, CLCP*

*Recorder: Mary Barros-Bailey, MA, CRC, CDMS, OWCP, NCC, CLCP*

(Editor's note: This group was generally structured differently in that they did not hand out cards for each participant and instead brainstormed on applying the concepts to life care planning).

### **Priority Areas**

#### **Reliability**

##### Consensus

Must use a reliable, dependable, and consistent method of drawing conclusions

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- Must have an adequate amount of medical and other data to form opinion(s)
- Must include list of sources requested and a list of data reviewed
- Must include list of responses received and date of response so an outside source can understand what questions were asked, how data was collected, date of response, and results
- Need to know and understand the definition of reliability as related to opinions - Must utilize consistent and standardized procedures for completing life care plans
- Standardized formats based upon published and generally accepted procedures are necessary (may include checklists and forms)
- Appropriate to rely upon medical and allied health professional opinions in developing the life care plan
- Must stay within life care planner's area of expertise
- Although life care plans are individualized, it is important for the life care planner to be able to verify that he/she approaches each case similarly and that the plans for similar cases are relatively consistent

### **Validity**

#### **Consensus**

When sufficient database is available, the life care planner will utilize existing research with regard to recommendations included in the plan. Examples may include life expectancy, need for therapies, treatment recommendations, replacement schedules of equipment, etc.

Justification for valid entries in a life care plan may vary from state to state and jurisdiction to jurisdiction. The life care planner must be knowledgeable with regard to legal rules.

### **Working definitions and guidelines**

Face Validity: Explaining the logical basis of steps helps to document face validity.

- a. Does the plan appear to be what it is?
- b. Is there an "analytical fit" or "reasonable man, reasonable woman, or reasonable person" standard?
- c. Does the plan look like it is doing what it is intended to do?

Content Validity: It is the life care planner's responsibility to make the content of the life care plan valid to the particular client.

- a. Based on the legal standards for each case which may vary by state, the life care planner must insure that all relevant needs are included and eliminate all unnecessary items
  - b. Consideration of different ranges of care:
    1. minimum care;
    2. "reasonable person" care;
    3. "Saks Fifth Avenue" care
  - c. Consideration of pre-existing factors:
    1. How to account or not account for it?
    2. How complete is the medical history?
    3. How do you package the "whole person" in the life care plan (including pre-existing conditions)?
    4. Determination may vary by jurisdiction
  - d. Consideration of conflicts of medical opinions
  - e. Awareness/knowledge about proper medical foundation and basis for plan and disability
  - f. Having appropriate opinions from appropriate disciplines is important
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- g. Valid data means having entire file/records and an adequate amount of baseline and medical data
- h. Should know the disability sufficiently to understand what medical professionals and which disciplines are needed
- i. Consideration of complications that are contingencies
- j. Differentiating between what is probable v. what is possible
- k. Provide medical foundation through physicians and/or research as the starting point, not the ending point
- l. Cannot cost out future technology or "possibilities"
- m. Revert back to the life care planner's role as educator
- n. Be able to demonstrate on an item-by-item basis the rationale for each item and conclusion
- o. Provide substantiation and documentation for each recommendation
- p. Obtain physician approval of recommendations within their area of expertise (i.e., physician sign-off of plan v. own opinion). Federal rules do not require sign-off on every life care plan although this may be different from state to state.
- q. Life care planner needs to be cognizant when something is outside his/her area of expertise

**Criterion Validity:** When the life care planner relies on an opinion, he/she adds criterion validity.

- a. Concurrent Validity: Doing a research and literature review to determine appropriate information that exists in the current published literature
- b. Predictive Validity: Providing opinions on individual caseload experience; being able to show follow-through; knowing follow up studies to look at basis over time

**Process Validity:** As a result of the life care planning process, the client more likely than not will ...

- a. Achieve longer life
  - b. Achieve greater quality of life
  - c. Maximize functional capabilities
  - d. Minimize complications
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## FOCUS TOPIC 5: INFORMATION DISSEMINATION

*Group Facilitators: Tim Field, Ph.D. and  
Anne Llewellyn, RN.C, BPSHSA, CCM, CRRN, CEAC*

Priority Areas

Ways to Distribute and Disseminate Summit Information and/or Product  
Consensus

Activity/Method	Group 1	Group 2	Group 3	Group 4	Group 5
1. List Serve	10				
2. Info. Coord. Group	6				
3. Super Web/Net	15	17		13	1 1
4. Prof. Journals		19	10	11	15
5. Distance Learning		6			
6. Peer Reviews			8		
7. Manuals (updated)			8		
8. Book emails				10	
<u>9. Member Organization</u>					1 i

### Summary in rank order of preference:

1. Super web/net (56)
2. Professional journals (55)
3. Member organizations (11)
4. List serves on the Internet (10)
5. Book emails (10)
6. Updated manuals (8)
7. Peer reviews (8)
8. Information coordination group (6)
9. Distance learning (6)
10. Develop Reference List of Appropriate and Peer-Reviewed Life Care Planning Publications

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**INTELICUS**  
A University of Florida Partnership

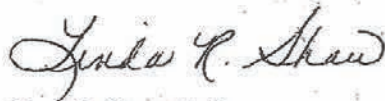
October 25, 2000

Roger O. Weed, Ph.D.  
Georgia State University  
Department of Counseling and Psychological Services  
9<sup>th</sup> Floor, college of Education  
Atlanta, GA 30303-3083

Dear Dr. Weed:

On behalf of Intelicus, I would like to endorse the Proceedings of the Life Care Planning Summit, held in Dallas on April 12, 2000. We are pleased to have been a part of this important effort and hope that it will serve as a foundation document to guide the future development of Life Care Planning education, research and practice.

Sincerely,



Linda R. Shaw, Ph.D.  
Life Care Planning Faculty and Curriculum Chair

**IALCP**

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International Academy of Life Care Planners 114 N.W. 5th St. Ankeny, Ia. 50021 (800) 531-5146 Fax (515) 965-1286

October 5, 2000

**TO:** Roger Weed, PhD, CRC, CCM, CLCP

**FROM:** Patricia McCollom, RN, MS, CRRN, CDMS, CCM, CLCP  
Chief Executive Officer  
International Academy of Life Care Planners

**RE:** Proceedings of the Life Care Planning Summit 2000

The International Academy of Life Care Planners is grateful to have had the opportunity to participate in the sponsorship, development and presentation of the Life Care Planning Summit 2000.

The proceedings have been reviewed and input provided from the Academy members who attended. Further, initial findings were presented at the Academy's CMSA Pre-Conference Symposium, June 2000, and input was solicited from the more than 100 in attendance.

The outcome of the Life Care Planning Summit 2000 is one of challenge and excitement! Clearly those attending shared common concern for the professionalism, education, ethics and knowledge of life care planning practitioners. The proceedings offer to practitioners a foundation for future dialogue and a blueprint for education needs.

Let us go forward together with these proceedings, which support the IALCP's Standards of Practice for Life Care Planners, to promote ongoing discussion and advanced practice educational offerings.

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UNIVERSITY OF  
FLORIDA

College of Health Professions  
Department of Rehabilitation Counseling

PO Box 100175  
Gainesville Florida 32610-0175  
Tel.: (352) 395-0745  
Fax: (352) 395-0744

November 1, 2000

Roger Weed, Ph.D.  
Georgia State University  
Department of Counseling and Psychological Services  
6<sup>th</sup> Floor, College of Education  
Atlanta, GA 30303-3083

Dear Dr. Weed,

I recently had an opportunity to review the draft of the conference proceedings from the Life Care Planning Summit held in Dallas, Texas on April 12, 2000. As a representative of the University of Florida, I fully endorse the concept of developing the consensus of life care planners from various areas of the country. I anticipate that these proceedings will facilitate a more positive and collaborative approach to the practice of life care planning.

I am glad our University was actively involved in this important summit in life care planning and appreciate the collaboration with you, as well as your commitment to this effort.

Sincerely,

A handwritten signature in cursive script that reads "Horace W. Sawyer".

Horace W. Sawyer, Ed.D., CRC  
Professor and Chair



American Association of Legal Nurse Consultants  
4700 W. Lake Avenue, Glenview, IL 60025-1485  
Toll free phone 877/402-2562 • Fax 877/734-8668

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October 31, 2000

Roger Weed, PhD CRC CCM CLCP  
Weed and Associates Inc.  
PO Box 2133  
Duluth, GA 30096

Dear Dr. Weed:

The American Association of Legal Nurse Consultants is grateful to have had the opportunity to participate in Life Care Planning Summit 2000.

We have reviewed the proceedings and are pleased to offer our endorsement. The proceedings represent a significant step in the evolution of the practice of Life Care Planning.

AALNC looks forward to ongoing dialog and future collaboration with other leaders in the field of Life Care Planning.

Sincerely,

Jeannie Autry, BS RN LNCC  
President

cc: Patricia A. Costantini, MEd RN LNCC  
Past President

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**International Association of Rehabilitation Professionals**

October 23, 2000

On behalf of the International Association of Rehabilitation Professionals, I am pleased to write that IARP endorses the Life Care Planning Summit 2000 Proceedings without reservation. The Summit was a special opportunity for professionals in the field to discuss and delineate best practices for Life Care Planning. The Proceedings profile our high standards and effectively lay the groundwork for future deliberation of training and service delivery issues.

Roger and Debbie, we thank you for taking the lead in this historic endeavor, actively involving IARP in all phases of the Summit as well as pulling together the information in such a professional manner.

Best Regards,

A handwritten signature in black ink, which appears to read "Ann T. Neulicht". The signature is written in a cursive, flowing style.

Ann T. Neulicht, PhD, CLCP, CRC, CVE, CDMS, LPC, DABVE  
International Association of Rehabilitation Professionals Representative

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**Commission on Disability  
Examiner Certification**

V. Robert May III, Rh.D.  
Administrator

Commissioners November 28, 2000

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Vocational Evaluation

Hiram Sawyer, Ed.D.  
Life Care Planning

Darrell Taylor, Ph.D.  
University Studies

Roger Weed, Ph.D.  
Georgia State University  
Department of Counseling and Psychological Services  
6th Floor, College of Education  
Atlanta, GA 30303-3083

Dear Dr. Weed:

I want to commend you on your efforts to establish practice standards in the specialty rehabilitation area of life care planning. There is no doubt that your efforts to organize and to provide structure to a multitude of professionals who have an interest in life care plan service delivery will only strengthen the quality of service and assist this Commission in regulating those who choose to become certified in life care planning. We fully endorse your leadership and we look forward to contributing to your efforts however you may wish our involvement to be.

Again, thank you for your kind consideration of this Commission and I look forward to working with you on this monumental project.

Sincerely yours,

V. Robert May III, Rh.D., CDE II  
Executive Administrator



November 27, 2000

To: Roger Weed, PhD, CRC, CCM CLCP

From: Jeanne Boling, MSN, CRRN, CDMS, CCM-48  
Executive Director  
Case Management Society of America

Re: Proceedings of the Life Care Planning Summit 2000

Case Management Society of America is pleased to have been involved in the Life Care Planning Summit 2000 and to have been integral in the development of the consensus statements contained within the LCP Summit 2000 Proceedings. CMSA supports the process of peer review of the Proceedings content by the LCP Summit 2000 participants and others in pre-conference seminars at both CMSA's Annual Conference and the Medical Case Management Convention.

The building of significant dialogue among industry professionals toward consensus is a critical first step in the development of Life Care Planning. CMSA applauds the industry leaders spearheading this development and looks forward to continued efforts and discussion.



## **Summary of the Life Care Planning Summit 2002**

*Debbie Berens, CRC, CCM, CLCP*

### **Introduction**

Were YOU there? Did YOU see the group of the industry's leading life care planning professionals assembled in one conference hall? Did YOU hear the volumes of creative and thought-provoking discussions? The Life Care Planning Summit 2002 was held on May 19, 2002 in Oak Brook, Illinois with 120 professionals in attendance. This one-day Summit focused on the areas of Standards of Practice and Certification and followed the Life Care Planning Advanced Practice Program also held in Oak Brook on May 18, 2002. Chaired by Susan Riddick-Grisham and sponsored by Intelicus/University of Florida, the Summit drew support and participation from key professional organizations in life care planning including the International Academy of Life Care Planners (IALCP), International Association of Rehabilitation Professionals (IARP), American Association of Legal Nurse Consultants (AALNC) and Commission on Health Care Certification, CHCC (formerly known as Commission on Disability Examiner Certification, CDEC). The Summit also was supported by academic institutions including Georgia State University and Virginia Commonwealth University. Other highly qualified and experienced life care planners donated their time and dedication to the Summit as organizers, speakers, facilitators and recorders for the roundtable discussions.

### **Process**

As a natural outgrowth of the Life Care Planning Summit held in 2000, this year's Summit was structured in a similar way. An introductory session was held in the morning for the entire group which included presentations on Standards of Practice by Karen Preston (look for her article elsewhere in this Journal), Ethics by Roger Weed, Changes in the Industry by Paul Deutsch and Certification by Bob May. The group was then assembled into 10 smaller groups, with an attempt to have representation within each group of the various backgrounds, education, training, experience and knowledge of the life care planning professionals who were present. Following a modified nominal group technique, the 10 groups then rotated through roundtable discussions on five (5) topic areas of focus thought to be integral to the current practice of life care planning:

- 1) Scope of Practice/Specialty Skills
  - 2) Life Care Plan Methodology and Functions
-

- 3) Ethics
- 4) Professional Development and
- 5) The Future of Life Care Planning.

Every participant rotated through the five roundtables and each roundtable had approximately 30-40 minutes to discuss the specific topic and generate comments from the participants. The small size of the roundtables enabled individual participation from each member. Groups were then asked to prioritize the most important issues pertaining to the topic area. Consensus among the roundtables was then determined based on the priority order of the issues. Because there were two (2) roundtable groups for each of the five (5) topic areas, at the completion of all roundtable discussions, facilitators within each topic area culled the data, combined results and determined those areas in which consensus was reached or a high level of agreement was obtained within the particular topic. This information was then presented back to the entire group in the afternoon session so participants could learn of the consensus or priority areas which grew out of the roundtable discussions.

If this sounds like a monumental task to accomplish in an eight hour day, it was. But true to our profession, participants were intellectually and physically "charged up" for the task and fully participated in the process. The Summit consisted of representation from a wide variety of life care planning professionals both from the US and Canada who hold an incredible amount of years of wisdom and experience. Where else can you find the true pioneers of life care planning, Paul Deutsch and Roger Weed, in the same room along with the movers and shakers and future leaders in the industry? The "electricity" and intellectual discussion generated by the participants and facilitated by the roundtable facilitators was outstanding!

### **Historical Basis**

A summary of the Life Care Planning Summit 2002 would not be complete without summarizing the historical base that has led to the present day Summit. Technically, Summit 2002 comprised the third Life Care Planning Summit that has been held. The first Summit, held in December 1997, was at the direction and conception of Roger Weed and included representatives from Intelicus/University of Florida, CHCC (then the Commission on Disability Examiner Certification) and IALCP (then the American Academy of Nurse Life Care Planners). This small group gathered for a one day Summit in Atlanta, Georgia to discuss the status of life care planning (in 1997). Outcomes identified by the group included promotion of the practice of life care planning as well as utilization of qualified life care planners to provide life care planning and related services, exploration of a common definition of life care plan, education regarding alternate uses for life care plans, identification of common concerns and variances among life care planning professionals/organizations, establishment of a hierarchy of needs, development of acceptable research methodologies consistent with Federal Rule of Evidence 702 (remember Daubert was just a "baby" to the life care planning industry in 1997), collaboration among professionals and organizations that represent life care planners, and initiation of action items to achieve the outcomes. Common concerns expressed by the group included the meaning of certification, development of standards of practice, ethical practice, and potential fragmentation of life care planners within the life care planning industry. Consensus was reached at the first Summit that life care planning is transdisciplinary and therefore there was a need to work on national collaboration, even to the extent of forming a separate, single organization for life care planners. Educational programs on a national level

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to further promote collaboration as well as include advanced practice sessions also was considered a consensus area by participants in the first Summit.

Now advance forward to the Life Care Planning Summit 2000 held in Dallas, Texas. Summit 2000 most likely is remembered by many life care planners and, in fact, was attended by many of the Summit 2002 participants. Chaired by Roger Weed, this Summit also was sponsored by Intelicus/University of Florida in conjunction with IALCP, IARP and CDEC and had many of the same participating experts. The modified nominal group technique was employed with this group for the first time and roundtable discussions were held in similar manner to the Summit 2002 roundtables. The five (5) focus areas identified in 2000 included:

- 1) Professional Preparation
- 2) Basic Tenets and Procedures for Completing Life Care Plans
- 3) Ethics
- 4) Reliability and Validity of the Life Care Plan and
- 5) Information Dissemination.

With 100 participants in attendance (full capacity), consensus was achieved in many of the priority areas and on issues where consensus was unable to be achieved, a majority view was established. Another outcome of Summit 2000 was development of a bibliography of appropriate and peer-reviewed life care planning and related publications. Participants at the Summit were asked to contribute applicable references for the bibliography and a list of 148 references was developed. That list continues to grow and, at the time of the Summit 2002, had approximately 177 references (Weed, R., Berens, D., Deutsch, P. 2002). For a full summary of the Life Care Planning Summit 2000, the reader is referred to the Life Care Planning Summit 2000 Proceedings, Weed, R. & Berens, D. (Eds.), (2001), printed by Elliott & Fitzpatrick, Inc. (800/843-4977).

### **Conclusion**

An historical review of the Life Care Planning Summits is helpful in identifying similarities over time and areas where there has been accomplishment and progression of the practice as well as areas of continued development. It is obvious that a lot has been accomplished as a result of the Summits and that life care planning professionals who have participated in any or all of the Summits can be proud of the contributions they have made that, in turn, have helped shape our practice and determined the direction for our industry based on the collective input. It is interesting to note that one common theme or thread throughout all of the Summits has been the need for collaboration among professionals and organizations that represent life care planners. Another common area of focus has been continued promotion and enforcement of ethical practice among life care planners and consistency within our industry on the methodology employed by life care planners in developing life care plans. The Summits have been a proactive attempt by leaders in life care planning to establish that consistency and collaboration among the practice of life care planning.

Promoted as a way to provide a forum for discussion among life care planners to "have a significant voice in the development of life care planning education, research and practice," the Life Care Planning Summit 2002 offered more than that to its participants. Summit 2002 allowed participants to discuss issues important to them and relevant to the practice of life care planning, including standards of practice, ethics and certification, among other topic areas.

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Although final results from the Summit 2002 roundtable discussions have not yet been fully analyzed, plans are to have a draft of the results (i.e., consensus areas or majority view areas among the five topic areas) reviewed by participants of the Summit and opportunity given for comment. Once comments are received from the participants, a second draft will be sent to appropriate organizations for review and comment. The ultimate outcome is a concise document of published proceedings from the Life Care Planning Summit 2002. It is anticipated that the proceedings will further define our practice and pave the path for future directions within life care planning. Now don't YOU want to be a part of that?

### References

Weed, R. & Berens, D. (Eds.). (2001). *Life Care Planning Summit 2000 Proceedings*. Sponsored by Intelicus, International Academy of Life Care Planners, International Association of Rehabilitation Professionals and the Commission on Disability Examiner Certification, April 12, 2000, Dallas, TX. Athens, GA: Elliott & Fitzpatrick, Inc.

Weed, R., Berens, D. & Deutsch, P. (2002). Bibliography of life care planning and related publications, *Journal of Life Care Planning*, 1(1), 73-84.

### Biography

Debbie Berens, MS, CRC, CCM, CLCP, is a rehabilitation consultant and life care planner in private practice in Atlanta, Georgia. Her experience as a vocational rehabilitation counselor and case manager in the areas of workers' compensation, short and long-term disability, Social Security, Veterans Affairs job placement, general liability and personal injury forms the foundation for her consulting practice that specializes in assessment, research and development of life care/future care plans for children and adults with catastrophic injuries and disabilities. Debbie is a part-time instructor in the graduate Rehabilitation Counseling program at Georgia State University as well as adjunct faculty with the Intelicus nationwide training program in Life Care Planning for Advanced Catastrophic Case Management. In July 2001, she completed a five year term as Commissioner on the national Commission on Rehabilitation Counselor Certification (CRCC) where she was actively involved as a member of the Ethics Committee responsible for revising the Professional Code of Ethics for Rehabilitation Counselors and also served as chair of the Standards and Credentials Committee. She is active in both state and national rehabilitation organizations and is a past-president of the Professional Rehabilitation Specialists of Georgia, the state chapter of the International Association of Rehabilitation Professionals (IARP). She has participated both as an organizer and attendee in all three of the Life Care Planning Summits and has contributed over the years to writings and publications in the field of rehabilitation and life care planning. She is a current member of the National Coalition of Life Care Planners Task Force as well as serves on the Editorial Board of the *Journal of Life Care Planning*.

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## Life Care Planning Summit 2002

*Susan Riddick-Grisham, RN, CCM, CLCP*  
*Program Chair*

### Introduction

Life care planning has become a valuable and necessary component of catastrophic case management and rehabilitation. Over the past 20 years, there has been significant growth in this transdisciplinary specialized field of practice. As the field has grown, professionals involved in the practice of life care planning have participated in the development of standards.

On April 12, 2000, life care planners from across the United States came together to participate in the first national life care planning summit. This professional summit provided a forum for in-depth discussion pertaining to five topic areas: Professional Preparation, Basic Tenets and Procedures for completing life care plans, Ethics, Reliability and Validity of the life care plan, and Information Dissemination. Out of this historic endeavor, a consensus document was published to guide the future development of life care planning, education, research and practice.

Continuing the ongoing progress in life care planning education, standards development, professionalism, and research, an online national survey of life care planners was conducted in November 2001. Results of the survey were peer-reviewed and published, along with the survey instrument, in an article titled *Life Care Planning Survey 2001: Process, Methods and Protocols* (*Journal of Life Care Planning*, 2002, 1(2), 97-148). The results specifically described the current state of life care planning practice along with protocols/procedures used by life care planners.

On May 19, 2002, 120 life care planners came to together for the second national life care planning summit. Building on all of the significant accomplishments of the April 2000 meeting, **Summit 2002** again created a forum for discussion among professionals about issues which impact the field of life care planning.

The Summit was sponsored by Intelicus/University of Florida in conjunction with the International Association of Rehabilitation Professionals (IARP), International Academy of Life Care Planners (IALCP), and the Commission on Health Care Certification (CHCC).

In preparation for this professional meeting, an educational committee worked to identify five focus areas to be addressed in the roundtable discussions. This committee consisted of Susan Riddick-Grisham, program Chair, Debbie Berens, Paul M. Deutsch, Tim Field, Patricia McCollom and Roger Weed.

The five topic areas and objectives included:

1. Life Care Plan Methodology/Functions - to explore life care plan methodology as outlined in the IALCP Standards of Practice and to determine if revisions are needed to better reflect changes in the field.

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2. Professional Development - to explore professional development of the life care planner.
3. Scope of Practice/Specialty Skills - to explore the current requirements for becoming qualified and/or certified as a life care planner.
4. Ethics - to explore ethics involved in the practice of life care planning.
5. Future of Life Care Planning - to explore future developments, issues, and trends in life care planning.

### **Method**

To better prepare attendees for the program, relevant materials were assembled and sent to all registered participants in advance of the Summit. Materials consisted of:

1. IALCP Standards of Practice
2. Code of Ethics for Rehabilitation Counselors
3. CHCC Guidelines

Facilitators and recorders for the roundtable discussions were identified by the program Chair. They consisted of qualified individuals from the supporting organizations as well as other experienced life care planning professionals. Due to the size of the number of participants, each topic area had two roundtables.

Prior to the Summit the attendees participated in a day long educational program focused on advanced practice issues. Presentations covered issues such as research methodology for life care planners, evidence-based guidelines, care management applications and factors in assessing medical equipment choices.

The Summit convened with a keynote presentation on the meaning and value of standards. In preparation for the roundtable discussions, each attendee was assigned a number within their professional discipline so that an integrated mix of experience, training and knowledge was assured. The small group sessions were 30 minutes each and every attendee participated in discussions on all topic areas. The method for soliciting information from the group was a modified nominal group technique.

At the end of the day, the attendees were reassembled into one large group. A brief summary of the results of each topic area was presented by one of the facilitators for each topic area.

A thorough analysis of the findings was later completed by each of the facilitators and provided to the program Chair. A comment noted by each of the facilitators, and many of the attendees, was the suggestion for the next Summit to either allow more time within the roundtables for greater substantive discussions or limit the size of the roundtable groups. Another observation made by some participants was the apparent variable application of the nominal group techniques by the roundtable facilitators. Understandably, these observations created the need for closer inspection of results published when analyzing data. Given these considerations, the summary of the results published on the following pages is accurate and adequately represents the views of the life care planning professionals who participated in Summit 2002.

After the Summit results were documented, a draft of the proceedings was developed and sent to key individuals within the sponsoring organizations and life care planning industry for review and comment. Based on feedback, the proceedings were revised as appropriate and the final step was to solicit endorsement of the proceedings from the sponsoring organizations as well as to ensure their support to the continued study, research and validation of life care planning.

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## Results

The following sections represent a summary of the results of the focus groups. For purposes of this document, the following terms are defined:

1. Areas of Consensus means that all attendees present agreed to the areas as reported and associated with the bullet point.
2. Areas of Discussion means that an attendee or attendees present offered suggestions or recommendations that did not have unanimous support. In some cases, most attendees agreed and in others, the point could be an individual's suggestion with little group support.

FOCUS AREA:	<b>Life Care Plan Methodology/Functions</b>
Group Facilitators:	Terry Winkler, MD, CLCP Karen Preston, MS, RN, CRRN, PHN
Recorders:	Amy Sutton, RN, BSN, MA Lynn Esko, CRC, LMHC, CCM, CLCP

The charge given this group was to explore life care plan methodology as outlined in the IALCP Standards of Practice and to determine if revisions are needed to better reflect changes in the field. Scope of discussion would include areas relating to data collection, assessment, planning, plan research, facilitation, evaluation and testimony. Further, that the group, individually and collectively, establish priorities for these areas.

## Overall Premises

Qualified life care planners must demonstrate a level of competence combining education, professional preparation, and experience. As this area of specialized practice grows it is essential that there is a consistency of practice across all disciplines entering the field. The IALCP Standards of Practice represent the parameters of responsibility for which life care planners are accountable.

## Areas of Consensus

To create a foundation for life care plan content there needs to be:

1. Integrity of data- delineating what data was gathered, from what resources including research and literature.
  2. A method to handle divergent opinions between experts or between experts and the literature.
  3. A method to properly interject personal expertise.
  4. Use of credible evidence-based guidelines.
  5. Having access to conduct an in-person interview can enhance the life care planning process.
  6. Standard tools for gathering and reporting information.
  7. Protocols for doing cost research.
  8. Protocols for handling "the impact of aging" aspects in a life care plan.
  9. Guides outlining when to use local versus national resources.
  10. Collaboration.
-

There needs to be a review of all terminology used to describe methodology of life care planning as stated in the IALCP Standards.

The life care planner should understand the difference between local standards for treatment and management of care versus the national standard (Centers of Excellence).

The life care planner should understand the optimal outcomes achievable to each injured person.

### **Priority Areas**

#### *Priority #1: Life Care Plan Methodology/ IALCP Standards*

##### **Areas of Discussion:**

1. Life care planners should utilize a peer review process.
2. Life care planners should seek other experts' input as needed or as appropriate to augment one's experience.
3. Should the life care plan include a section discussing the client's perspective?
4. The Standards do not reflect the value of doing a face-to-face interview with the client.
5. Further discussion needs to be conducted to evaluate the use of the words "thorough" and "complete" as stated in the IALCP Standards.
6. Standards should be general.
7. Need to differentiate between standards of practice and standards of methodology.
8. Need for total review and rewrite of the Standards.
9. The language in the Standards should be "request for" such items as medical records and in-person interview along with "seeks other experts' input as needed or as appropriate to augment one's experience."
10. Written standards should not be so narrow as to limit the life care planner's ability to practice.
11. Should there be standard templates for gathering data?
12. Indiscriminate use of medical literature with no understanding of its validity or applicability.
13. Should financial information be obtained from the client and then used in the life care plan?

#### *Priority #2: Qualifications*

##### **Areas of Discussion:**

1. Re-evaluation of grandfathering (CHCC). (Editor's Note: CHCC does not allow grandfathering).
  2. Review of existing requirements and raising standards for CHCC credentialing.
  3. State licensure requirements for nurses doing life care plans.
  4. Experience with collaborative teamwork. What should that include?
  5. Five (5) years case management experience require for certification.
  6. Bachelor of Science requirement for nurses and Masters degree for other health disciplines to qualify for training.
  7. Ongoing peer review for maintenance of certification.
  8. Active licensure and certification in primary field of practice.
  9. Many life care planning training issues need to be addressed.
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*Priority #3: Life Care Plan Critique*

**Areas of Discussion:**

1. A critique should address the methodology of the life care planner.
2. A critique should be a professional review, based on objectivity.

**FOCUS AREA:**                    **Professional Development**  
**Group Facilitators:**        Paul Deutsch, Ph.D., CRC, LMHC, CLCP  
   Tim Field, Ph.D  
**Recorders:**                    Dan Bagwell, RN, CLCP  
   V. Robert May, Rh.D. CDE

The charge given this group was to explore professional development of the life care planner. Scope of discussion would include areas relating to training and education, certification and research. Further, that the group, individually and collectively, establish priorities for these areas.

**Overall Premises**

Professionals in various health care fields, including nursing, medicine, rehabilitation counseling, social work, physical and occupational therapy are involved in developing life care plans. As this specialized field of practice continues to grow and develop it is of specific purpose that a coordinated effort with standardized approaches be promoted. Education of new and experienced life care planners is an essential part of continuing professional development. The community of life care planners is now looking for more advanced educational opportunities along with ways to be involved in life care plan certification and research.

**Priority Areas**

*Priority Area #1: CHCC compliance with or under accountability to the NCCA.*

**Areas of Consensus:**

1. The field of life care planners should monitor the formal application to NCCA.
2. CHCC should be accountable to NCCA.

*Priority Area #2: Advanced Training/Continuing Professional Education*

**Areas of Consensus:**

1. Training needs to be focused on disability specific courses.
  2. Programs covering advanced/complex issues are needed.
  3. Regionally based offerings are needed.
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**Areas of Discussion:**

1. Continuing education focused on clinical updates.
2. Continuing education focused on specialized areas of the life care plan.
3. Continuing education focused on changes in the legal field.
4. Continuing education focused on report writing.
5. Continuing education in non- traditional treatment of disease or disability states.
6. Need for new instructors.
7. Research-based continuing education.
8. Multiple forums to meet continuing education needs
9. Ethics continuing education as part of the CHCC re-certification requirements.
10. Education programs for life care planners in areas other than litigation.
11. Seminars with breakout sessions to give attendees more options.
12. Consider having certified instructors to provide on-going life care plan training.
13. Prep course for certification exam with study guide.

*Priority Area #3: Development of a Peer Review Process***Areas of Consensus:**

1. The field needs a formalized, blind peer review process that would be available to all life care planners.

**Areas of Discussion:**

1. Development of mentoring programs.
2. Availability of CEUs for individuals acting as mentors or peer reviewers.

*Priority Area #4: Centralized Data/Information Repository***Areas of Discussion:**

1. Development of a web site for life care planners.
2. Need to identify a way to communicate with all life care planners about national data.
3. Possible use of a listserv for life care planners.

*Priority Area #5: Research***Areas of Consensus:**

1. Life care planners must be involved in research.
2. Continuing education programs focused on demonstrating how to include research in the life care plan and how to present it.

**FOCUS AREA:**

Group Facilitators:

**Scope of Practice/Specialty Skills**

Ann Neulicht, Ph.D., CLCP, CRC, CVE, CDMS, LPC

Patricia McCollom, MS, RN, CRRN, CDMS, CCM, CLCP

Recorders: Patricia Costantini, RN, CRC, CCM, CLCP, LNCC  
Steve Shedlin, MS, CRC

The charge given this group was to explore the current requirements for becoming qualified and/or certified as a life care planner. Scope of discussion would include CHCC requirements for certification and Scope of Practice definitions published by CHCC and IALCP. Further, that the group, individually and collectively, establish priorities for these areas.

### **Overall Premises**

In light of the Scope of Practice definitions within the Standards of Practice published by the CHCC and IALCP, what do you believe are the qualifications to practice in the specialty area of life care planning? (question agreed upon by the facilitators, prior to the session)

### **Priority Areas**

*Priority Area #1: Qualifications/Education*

#### **Areas of Consensus:**

1. Professional licensure and/or certification (in good standing) in primary field of practice.
2. Advanced education and health care/rehabilitation background.

#### **Areas of Discussion:**

1. No consensus about the definition of advanced education and rehabilitation background.
2. No agreement regarding minimum college degree needed.
3. Four year college degree for registered nurses and Masters for other health disciplines was discussed.
4. **Active** participation in professional organizations.

*Priority Area #2: Qualifications/Work experience*

#### **Areas of Discussion:**

1. **Recent** experience in catastrophic health/case management.
2. Experience in collaborative teamwork (rehabilitation based).
3. Five to six years of clinical experience was considered a minimum by some.

*Priority Area #3: Certification by an Accredited Body*

#### **Areas of Discussion:**

1. Certification should flow from a core curriculum created by practicing professionals.
  2. Certifying body should not be proprietary.
  3. Certifying body should be made up of practicing life care plan practitioners.
  4. Re-evaluation of those "grandfathered" by CHCC. (Editor's Note: This has already
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- been acted upon by CHCC).
5. CHCC should be in compliance with NCCA.
  6. Additional research into the different life care planning certifications.
  7. Raise the standard of the CLCP certification.
  8. Should life care planners be certified in specialty areas?
  9. Mentoring (after course work) should be required for certification.

*Priority Area #4: Education and Training*

**Areas of Discussion:**

1. Structured training classes specific to life care planning (minimum of 120 hrs).
2. Training in elements of life care plan development including report writing, health care reimbursements, statistics and evidence-based methodology.
3. Peer review.
4. Ongoing continuing education specific to life care planning.

FOCUS AREA:           **Ethics**  
 Group Facilitators:   Chris Reid, Ph.D  
                                   Linda Shaw, Ph.D  
 Recorders:             Carol Hyland, CDMS, CLCP  
                                   Dawn St. Clair, RN, CRRN, CDMS, CCM

The charge given this group was to explore ethics involved in the practice of life care planning. Scope of discussion would include areas relating to framework for an ethical practice, rules of professional conduct, avenues to resolve ethical conflicts and resources

**Overall Premises**

All qualified life care planners seek to develop an ethical practice to ensure acceptable professional conduct. Certified life care planners are held to the Code of Professional Ethics as outline by the CHCC.

**Priority Areas**

*Priority Area #1: Framework for an Ethical Practice*

**Areas of Consensus:**

1. Stay within one's primary field of practice.
  2. Who is the actual client? Need to clearly define for whom the plan is being written and clearly communicate that to all parties involved.
  3. Dual (or multiple) relationships should be better defined in the CHCC Code.
  4. Conduct should be objective and unbiased regardless of who has hired you.
  5. Need to understand and apply the rules of confidentiality.
  6. Maintain current certifications and continuing education.
  7. Life care planning is not an "industry" as listed in the CHCC Code; it is an area of
-

- professional practice.
8. Need to maintain competency related to one's caseload.
  9. Need better definition in the CHCC Code about what creates a conflict of interest situation.

**Areas of Discussion:**

1. Need to ensure that all life care planners understand the ethical standards relevant to life care planning and the practitioner's own licensure/certification.
2. Need practice guidelines that are more specific regarding ethical rules.

*Priority Area #2: Rules of Professional Conduct*

**Areas of Consensus:**

1. Lack of CHCC accountability in determining management of ethical violations and complaints. Processes are not understood by individuals outside of CHCC and outcomes of the processes are not publicized.
2. Concern about AANLCP assertion that only nurses are qualified as life care planners.

**Areas of Discussion:**

1. There are many different professional disciplines practicing in life care planning, with separate ethical codes associated with each discipline. When practicing as a life care planner and there is a potential ethical code conflict, to which Code is one held? And does the Code consider the practice of life care planning?
  2. Is there anonymity in reporting unethical behavior?
  3. Can one be sued for reporting unethical behavior?
  4. Life care planning training needs to include ethics.
  5. Needs to be a clear definition of plagiarism in the field.
  6. The life care plan report should include a list of medical records reviewed and vendors contacted.
  7. Needs to be a way to unify life care planners.
  8. Medical recommendations need to have an appropriate foundation.
  9. What does a life care planner do when he/she disagrees with a physician recommendation?
  10. In Canada, the life care plan certifications are not honored. What is the impact on practice standards?
  11. To what ethical standard is someone who has not received life care planning training or certification held?
  12. Life care planners are held to the ethical standards of the CHCC yet many feel they did not participate in the development of those standards.
  13. How does one address an individual who is conducting himself or herself unethically?
  14. Are there individuals who have been improperly certified, and if so, what can be done about this?
  15. How do we develop plans for children without diminishing hope? Are we doing harm?
  16. What are the guidelines regarding use of interpreters when obtaining consent releases from bilingual clients?
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17. Are there mentors on ethical issues?

18. Do life care planners have a right to report unethical behavior to other certifying boards? Does this apply if the individual life care planner is not CHCC certified?

**FOCUS AREA:** **The Future of Life Care Planning**  
**Group Facilitators:** Horace Sawyer, Ph.D., CRC  
 Debbie Berens, MS, CRC, CCM, CLCP  
**Recorders:** Bill Goodrich, MA, CLCP, CRC, CCM, DABVE  
 Terry Arnold, RN, CDMS, CRRN, CLCP

The charge given to this group was to explore future developments, issues, and trends in life care planning. Scope of discussion would include areas relating to professionals, markets, services, resources, etc. Further, that the group, individually and collectively, establish priorities for these qualifications.

### **Overall Premises**

Qualified life care planners must demonstrate a level of competence combining education, professional preparation, and experience. Continuing education and professional training are essential. Future marketing will position life care planning at the next level of development. New markets and educating the public and other professionals are both important future dimensions. A mentoring process is needed, as well as an established peer review, with qualified professionals in life care planning.

Future research initiation and establishing a universal database will also be an important development for the successful future of life care planning. Accountability and compliance standards will facilitate a higher level of acceptance of life care plans in the future.

### **Priority Areas**

*Priority Area #1: Continuing Education and Professional Training in Life Care Planning*

#### **Areas of Discussion**

1. More cost effective and more geographically accessible training opportunities for potential life care planners in addition to what is now available.
2. Offer distance learning formats and regional learning opportunities for life care planners.
3. Continuing education is essential for maintaining qualified life care planners.
4. Broader scope of training opportunities, i.e., ergonomics, vocational, economic issues, etc., to better prepare and qualify life care planners.
5. More applied, hands-on training needed.

*Priority Area #2: Marketing Life Care Plans, Developing New Markets for Life Care Planning, and Educating the Public and Other Professionals*

#### **Areas of Discussion:**

1. Develop marketing to attorneys and the public regarding the benefit and utilization of
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life care plans as a case management tool in areas such as geriatric and elder care, Medicare trusts, individuals who are developmentally delayed, etc.

2. Develop new life care plan markets in patient advocacy to assist with planning for long term care, monitoring care on an ongoing basis, i.e. heart surgery or some acute illness, or long-term placement and/or finding alternatives for care, taking into consideration specific diseases or illnesses.
3. Explore new markets for life care plans outside the litigation arena.
4. Educate consumers on a national and international level.

*Priority Area #3: Mentoring Life Care Planners and Peer Review*

**Areas of Discussion:**

1. Develop and implement a formal mentoring program for development of new life care planners to include training of mentors, specifications/qualifications for mentors, determination of whether or not mentors could receive CEUs and development of a category for CEUs and establishment of fees for mentoring services.
2. Development of a list serve that would provide names of qualified and approved mentors.
3. Development of new leadership positions and recruit qualified life care planners to assume leadership roles and continue to promote the industry and ethical life care planning practices.
4. Initiate peer review/work product review to allow qualified life care planners to read and review life care plans, provide feedback and make comments/suggestions for improvements/enhancement.

*Priority Area #4: Initiate Research and Universal Data Base*

**Areas of Discussion:**

1. Continue research on reliability and validation of life care plans.
2. Initiate research on long term results of the life care plan, cost research, and consistency of life care plans.
3. Compile a universal database for resources and relevant life care planning articles with ability to have Internet availability to obtain actual articles.
4. Promote national organization specific to life care planning to serve as a national voice for life care planners to educate consumers, attorneys, legislators and professionals about life care planning and potentially serve as a universal database.

*Priority Area #5: Accountability and Standards for Compliance*

**Areas of Discussion:**

1. Develop more defined certification process including analysis of qualifications and experience as criteria for taking the certification test. Must have some experience in the field of life care planning prior to taking the certification exam.
  2. Promote published standards of practice and ethics for life care planners.
  3. Enforce standards of practice and ethics for life care planners.
-

4. Continually review standards of practice for development and implementation of higher standards and maintenance of standards.
5. Obtain national accreditation and oversight process for certification agency.

**Note:** Very little difference between Priorities 3, 4, and 5.

**Other Areas of Priority Discussed:**

1. National Organization for Life Care Planning (national voice for life care planners).
2. Collaboration and information-sharing between and among life care planners.

**Acknowledgements**

I would like to acknowledge colleagues who participated in the Summit 2002 and thank Roger Weed, Ph.D and Paul Deutsch, Ph.D. for their pioneering leadership in the field of life care planning and education for life care planners. Special thanks to Sheri Jasper for her skill and efforts to make the conference a success.

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March 14, 2003

Susan Grisham, RN, CCM, CLCP  
Chair, 2002 Life Care Planning Summit  
3126 West Cary Street, #137  
Richmond, Virginia 23221

Re: Proceedings

Dear Ms. Grisham:

As the Georgia State University representative, I am pleased to endorse the proceedings of the 2002 Summit. Having the opportunity to participate with *the* leaders within the life care planning field was a distinct honor.

In addition, the professionals' ability within this specialized industry to direct their own destiny by forging collaboration with a wide range of organizations and professionals from various disciplines is commendable. Your capabilities as Chair was paramount to its success and the results demonstrate your leadership. I look forward to future Summits.

Sincerely,

A handwritten signature in black ink, appearing to read "Roger Weed", enclosed in a hand-drawn oval.

Roger Weed, Ph.D., LPC, CRC, CDMS, CLCP, CCM, FIALCP  
Professor and Coordinator Graduate Rehabilitation Counselor Training



**INTELICUS**  
Knowledge That Earns

13 January 2003

Ms. Susan Riddick-Grisham  
Chair, Life Care Planning Summit 2002  
Life Care Manager, LLC  
3126 West Cary Street, #137  
Richmond, VA 23221

Dear Susan,

On behalf of Intellicus, I would like to fully endorse the Proceedings of the Life Care Planning Summit, held in Chicago on May 18-19, 2002. We are pleased and proud to have been a part of this important effort and hope that it will serve as a foundation document to guide the future development of Life Care Planning education, research and practice.

Sincerely,

Linda R. Shaw, Ph.D.  
Life Care Planning Faculty & Curriculum Chair



## International Association of Rehabilitation Professionals

January 22, 2003

Susan Riddick-Grisham  
3126 West Cary Street #137  
Richmond, VA 23221

Dear Susan:

On behalf of the International Association of Rehabilitation Professionals, I am pleased to endorse, without reservation, the results/proceedings of the Life Care Planning Summit 2002.

The focus of this Summit, *Standards of Practice and Certification*, is timely as is the goal of providing a forum to discuss relevant issues, identify areas of consensus as well as needs for further discussion regarding scope of practice, methodology, ethics and the future of life care planning.

The proceedings reflect issues that are of concern to Life Care Planners. We encourage efforts to develop an action plan to address the recommendations of the Summit and look forward to ongoing dialogue/future collaboration in this endeavor.

Susan, thank you for your innovative energy, dedication, and ongoing commitment to practitioners in the field of life care planning!!

Best Regards,

A handwritten signature in black ink, reading "Ann T. Neulicht". The signature is written in a cursive, flowing style with a prominent dot over the 'i' in "Neulicht".

Ann T. Neulicht, PhD, CLCP, CRC, CVE, CDMS, LPC, D-ABVE  
International Association of Rehabilitation Professionals Representative

3540 Soquel Ave., Suite A - Santa Cruz, CA 95062 - 831.464.4892 - fax 831.576.1417  
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January 30, 2003

Ms. Susan Riddick-Grisham  
Life Care Manager, L.L.C.  
3126 West Cary St., #137  
Richmond, Virginia 23221

Dear Ms. Riddick-Grisham,

On behalf of the University of Florida, we continue to fully support and endorse the efforts by professionals in life care planning to explore strategic focus areas and generate consensus outcomes. As these professionals represent various health care professions and areas of the country, the summits we have held are an important step in the future development of life care planning. I anticipate that these proceedings will facilitate a more positive and collaborative approach to the practice of life care planning.

Based on my experience at the Life Care Planning Summit held in Chicago on May 18-19, 2002, I would endorse the outcomes of this conference. It serves as a foundation for further direction of life care planning by professionals practicing this consultation specialty.

I would encourage other universities to become involved in curriculum and research development in life care planning and other areas of rehabilitation consultation. I appreciate your commitment and efforts in coordinating this important conference.

Sincerely,

A handwritten signature in cursive script that reads "Horace W. Sawyer".

Horace W. Sawyer, Ed.D.  
Professor and Chair

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## Commission on Health Care Certification

Peter B. Lubinskas  
Executive Director

### Commissioners

R. Brown, M.S.  
Kinesiology and Exercise  
Physiology

L. Carpenter, M.Ed.  
Case Management

P.B. Fitzgerald, D.C.  
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T. E. Forte, M.D.  
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Life Care Planning

Terry Winkler, M.D.  
Life Care Planning

M. Martelli, Ph.D.  
Psychology

Theodore Becker, Ph.D.  
Research and Statistics

Bill Mercer, P.T.  
Physical Therapy

R.D. Michaels, M.A.  
Vocational Evaluation

Horace Sawyer, Ed.D.  
Life Care Planning

Darrell Taylor, Ph.D.  
University Studies

Thursday, January 16, 2003

Susan Riddick-Grisham, RN, CCM, CLCP  
Life Care Manager, LLC  
3126 West Cary Street, Suite 317  
Richmond, VA 23221

Re: 2002 Life Care Planning Summit

Dear Ms. Riddick-Grisham:

I want to thank you for summarizing the results of the 2002 Life Care Planning Summit held in Chicago, Illinois. While I was unable to attend, I understand the discussions were very productive. The Commission on Health Care Certification (CHCC) supports your efforts to organize and to provide input to the Commission on a variety of issues.

We thank all those who participated and look forward to future participation in life care planning summits.

Sincerely,

Peter B. Lubinskas  
Director



February 25, 2003

Susan Riddick-Grisham  
Life Care Manager, L.L.C.  
3126 West Cary St., #137  
Richmond, VA 23221

Dear Susan:

The American Association of Nurse Life Care Planners, AANLCP, endorses the coming together of all Life Care Planners to address issues that impact the field. This opportunity affords Life Care Planners a voice in the future direction of Life Care Planning

Sincerely,

AANLCP Board

*498 East Golden Pheasant Drive*

*Draper, Utah 84020*

*Phone (801) 816-0908*

*888-575-4047*

*Fax (801) 553-9931*

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## **IALCP**

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International Academy of Life Care Planners  
114 N. W. Fifth Street, Suite 103, Ankeny, Iowa 50021

Tel: 800.531.5146  
Fax: 515.965.1286  
Email: [IALCP@aol.com](mailto:IALCP@aol.com)

January 29, 2003

Susan Riddick-Grisham  
Life Care Manager, L.L.C.  
3126 West Cary Street, #137  
Richmond, Virginia 23221

Dear Susan:

I have reviewed your summarization of the outcomes of the Life Care Planning Summit 2002. The responses from participants demonstrate a unified desire to promote quality life care planning practice through education, standards and communication. The International Academy of Life Care Planners endorses the results of the Summit 2002. Thank you for your diligent work on this project.

Sincerely,



Patricia McCollom, MS, RN, CRRN, CDSM, CCM, CLCP  
CEO

PM:sm

cc: Ann Neulicht

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**Participant List**  
**Oak Brook, IL**  
**LCP Summit 2002**  
**5/18/2002 - 5/19/2002**

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**5/18/2002 - 5/19/2002**

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# **Life Care Planning Summit 2004 The Progress Continues**

*Debbie Berens, CRC, CCM, CLCP*

## **Introduction**

The Life Care Planning Summit 2004 was held April 24-25, 2004 in Atlanta, Georgia with nearly 100 professionals in attendance. Although this year marked the third Summit for life care planning professionals, for the first time the Summit was held over a two day period, allowing for more dialogue and in-depth discussion of pertinent issues, with less need to hustle through the roundtable groups. With the overriding theme of "Competence," the Summit focused on five (5) topics:

- Certification Process
- CLCP Examination and CEUs
- Future Research in life care planning
- CLCP Mentoring Program
- Standards of Practice for life care planners

Chaired by Dr. Paul Deutsch and sponsored by MediPro Seminars, LLC and the University of Florida, the Summit again drew support and participation from key professional organizations in life care planning including the International Academy of Life Care Planners (IALCP), International Association of Rehabilitation Professionals (IARP), Care Planner Network, Foundation for Life Care Planning Research, American Association of Legal Nurse Consultants (AALNC) and Commission on Health Care Certification (CHCC). Other highly qualified and experienced life care planners donated their time and dedication to the Summit as organizers, speakers, facilitators and recorders for the roundtable discussions.

## **Process**

Following the structure of the previous two Summits, this year's Summit also utilized a modified nominal group technique in which a roundtable discussion group was held on each of the five topics listed above and attendees rotated through each of the roundtable discussions to provide input in the topic area. A group facilitator and recorder were assigned to each of the five discussion groups to assist the group through the process and record the comments and salient discussion points, with the goal of achieving consensus among the topics. Dr. Deutsch opened the session and Dr. Roger Weed provided an explanation of the modified nominal group technique to the entire audience. Introductory sessions were presented to the entire group to include a presentation by Dr. Weed and Susan Riddick-Grisham on Positive

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Outcomes from Summits 1 & 2, an Update on the CHCC from CEO Bob May and executive director Linda McKinley, overview of the Development of Standards of Practice by Karen Preston, and Life Care Planning Mentoring Program by Patti McCollom. The large group, having previously been assigned into five smaller groups that provided a cross-representation within each group of the various backgrounds, education, training, experience and knowledge of the life care planning professionals who were present, was ready to begin the process.

Following a lunch break, participants separated into the five smaller groups and rotated through roundtable discussions on each of the five (5) topic areas over the remainder of the day on Saturday and throughout the morning on Sunday. Every participant rotated through the five roundtables and each roundtable, with the exception of the first roundtable, provided approximately one hour 15 minutes for participants to discuss the specific topic and generate comments and consensus areas. (The first roundtable was scheduled for one and one half hours to allow sufficient time to become familiar with the process). With approximately 15 participants assigned to each of the small groups, the size enabled individual participation from each member. At the beginning of each roundtable discussion, 3x5 index cards were given to the group members and participants were asked to write 3-5 suggestions in order of priority relevant to the particular topic of that roundtable. The facilitator then went around the room and asked each participant to state his/her suggestions, while writing the suggestions/comments on a flip chart, combining suggestions when possible. After the suggestions were recorded from each participant, the participants were asked to "vote" on the top 3-5 suggestions and prioritize the most important issues pertaining to the topic area. Consensus among the roundtables was then determined based on the priority order of the issues. At the completion of all roundtable discussions (5 total), over the 2 day period, the facilitator and recorder within each topic area culled the data and determined those areas in which consensus was reached or a high level of agreement was obtained among the participants within the particular topic. This information was then presented back to the entire large group in the afternoon session on Sunday so that participants could learn of the consensus or priority areas which grew out of the roundtable discussions, as well as areas in which no consensus was reached. Unedited raw data from the five roundtable discussions were made available to the participants via PowerPoint presentation during the concluding session on Sunday and also via email shortly following completion of the Summit 2004.

### **Summary**

Although full proceedings and outcomes of the Life Care Planning Summit 2004, including consensus areas, will be published in the next few months, as well as presented at the International Conference on Life Care Planning on October 9 & 10, 2004 in New Orleans, Louisiana, some of the general consensus items identified by the participants and discussed in the large group session on Sunday, April 26, 2004, are summarized below:

- Terminology, including definition of "client," needs to be defined in the Standards of Practice and Standards of Practice should continue to delineate the qualifications to be a life care planner (endorsement of existing Statement 1.d), delineate educational requirements for entry into life care planning, and state the role and accountability of the life care planner.
  - Urge CHCC to pursue certification by a respected and nationally recognized
-

independent certifying agency that certifies certification bodies.

- Extend CLCP re-certification cycle to every 5 years consistent with many other certification renewals.
- Increase availability of advanced practice training in specialty areas.
- Ensure close monitoring of attendance at training programs that offer CLCP CEUs.
- The exam test body should be autonomous and separated from the training/educational group.
- Determine/verify need for mentoring program and agree on definition of mentoring program as applied to life care planning.
- Determine qualifications of a mentor and standardize the mentoring process and relationship before implementation of mentoring program.

Select common areas of concern or no consensus expressed by the group include:

- Key ethical issues in the Standards of Practice.
- Legitimacy/general acceptance for the Standards of Practice and what recourse should be taken when life care planners do not follow the Standards.
- Definition and meaning/purpose of a mentoring program for life care planners.

Full proceedings from the Summit 2004 will be published and a copy provided to each of the registered participants. Additional copies of the proceedings will be made available for sale to the general public.

### **Conclusion**

True to the specialty practice of life care planning, participants at the Life Care Planning Summit 2004 were intellectually and philosophically “charged up” for the task and fully participated in the modified nominal group process. The Summit 2004 consisted of practitioners from a wide variety of life care planning practices both within the US and Canada who hold an incredible amount of knowledge and experience. Mixed in with the “seasoned” life care planners were newer life care planning practitioners and, for the first time, the Summit welcomed some students from the Kaplan College distance learning certificate program in life care planning. From an historical perspective, it is obvious that much has been accomplished as a result of the previous Life Care Planning Summits 1 & 2 and life care planning professionals who have participated in any or all of the Summits can be proud of the contributions they have made. The life care planners and their contributions, in turn, have helped shape our practice and determine the direction for our industry based on the collective input. Consistent throughout all the Summits is the apparent general consensus for collaboration among professionals and organizations that represent life care planners. The

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Summits have offered and been successful in providing a proactive approach by life care planners to establish consistency and collaboration among and within the practice of life care planning.

If the Summit 2004 sounds like a monumental task to accomplish in one weekend, it was. Similar to the previous Summits, life care planning pioneers Paul Deutsch and Roger Weed were found discussing, strategizing, planning, and shaping for the future of life care planning with movers and shakers and future leaders in the industry. The “electricity” and intellectual discussion generated by all participants and facilitated by the roundtable facilitators was outstanding! Please also read the Editorial at the beginning of this issue for further commentary on the “flavor” of the Life Care Planning Summit 2004.

#### **About the Author**

Debbie Berens, MS, CRC, CCM, CLCP, has attended each of the Life Care Planning Summits in the role of participant, organizer, and/or facilitator. She has been active in the life care planning community for the past 15 years and has conducted various training seminars and presented at conferences as well as contributed over the years to writings and publications in the field of rehabilitation and life care planning. She currently serves as Associate Editor of the *Journal of Life Care Planning* in addition to her nationwide life care planning practice based in Atlanta, Georgia.

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# **Proceedings of the Life Care Planning Summit 2004 Atlanta, GA April 24-25, 2004**

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and  
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For an excellent overview of the *Life Care Planning Summit 2004* and description of the modified nominal group technique, refer to Debbie Berens' article which was published in the *Journal of Life Care Planning*, Volume 3, Number 2, (2004). All Summit attendees participated in all groups.

The theme of the Summit was "Competence" and included the following focus areas:

1. The Certification Process
2. CLCP Examination and CEU Credits
3. Future Research in Life Care Planning
4. CLCP Mentoring Program
5. Standards of Practice for Life Care Planners

In their group, Future Research in Life Care Planning, Ann Neulicht and Linda McKinley

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collected demographic information from Summit participants. Seventy five registrants for the 2004 Summit included individuals from all time zones (Eastern: 41, Central: 17; Mountain: 4; Pacific: 9) as well as Hawaii (1) and Canada (3). Fifty one individuals indicated that they were Certified Life Care Planners (CLCPs). There were 25 Certified Rehabilitation Counselors (CRCs), one Registered Nurse/Certified Rehabilitation Counselor (RN/CRC), one Occupational Therapist/Certified Rehabilitation Counselor (OT/CRC), one Occupational Therapist (OT), 2 Certified Case Managers (CCMs) and two Registered Rehabilitation Professionals (RRPs) listed on the registration list. As indicated by information provided by group participants (N=51), Nurses and Rehabilitation Counselors comprise a majority of the 2004 Summit. Details regarding educational status are found in Figure 1.

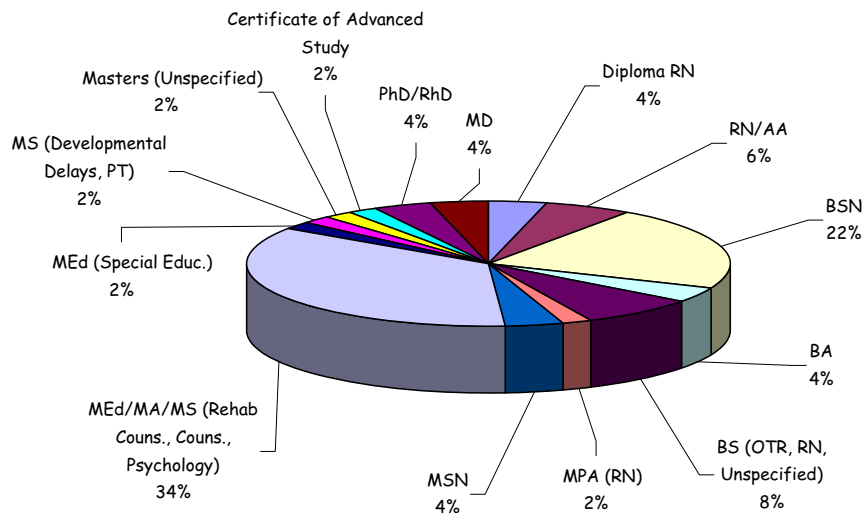


Figure 1: Educational Status of Summit 2004 Participants

Participants have practiced in their specialty area for 10 – 44 years, with an average of 25.52 (mean) to 26 (median) years. The most frequently cited number of years of experience is 18 (mode). Although one participant has been certified/practiced as a LCP for 4 months, experience as a LCP (following an established, standardized methodology for LCP) generally ranges from 1 – 29 years with a mean of 10 years, median of 8.75 years and mode of 8 years (i.e., 1996, the first year of formal certification). Forty-one participants are currently CLCPs, 2 had pending applications and one is a current student. This is a first summit for 33 individuals. Thirteen participants attended the 2000 Summit and 9 attended the 2002 Summit. Data is not available regarding individuals who have attended all three Summits.

### Focus Area 1: The Certification Process

Group Facilitator: Debbie Berens, MS, CRC, CCM, CLCP

Recorders: Steve Yuhas, CRC, CCM, CLCP, NCC, and Amy Sutton, RN, BSN, MA, CLCP

### General Purpose and Issues Contemplated by the Group

The charge given to this group was to analyze the following issues:

1. Examine the current certification and renewal requirements and provide suggestions for modification (i.e., maintain, revise, amend, add, remove.) Participants were referred to pages 9-10 of the CHCC Standards and Examination Guidelines reprinted in the Summit manual to review existing criteria to sit for certification and page 17 of the Guidelines for criteria for certification maintenance and renewal.
2. Consider whether or not CHCC should pursue certification by an independent certifying agency.

### Group Consensus Statements

1. Urge CHCC to pursue certification by a respected and nationally recognized independent certifying agency.\*
2. Refine experience requirements to sit for the CLCP exam.\*
3. Increase the required number of years of professional work experience within the primary discipline (Majority recommended five years of required experience).

*\*Denotes consensus across all groups.*

### Majority View

1. Pursue the non-profit status of CHCC.
2. Require a minimum of a Bachelor's degree as criteria to become certified (Discussion included instituting a "grandfather clause" for those who are already certified, but do not have a Bachelor's degree).
3. Increase the required number of onsite training hours, though the number of hours was unspecified.

### Minority View

1. Mandate certification in LCP in order to practice. This was a majority view represented by one (1) group. In the large group discussion, no consensus was reached.

### Areas of Discussion/Concern Unique to the Group

There was overwhelming consensus for CHCC to continue to pursue certification by NCCA or other respected and recognized independent certifying agency. Realizing that this will not be accomplished without assistance from certificants and other interested parties, there was discussion regarding the steps required to continue to pursue this option. Many attendees offered their administrative and financial support in order to achieve this goal.

The majority of participants supported increasing the number of onsite training hours required for certification. Participants noted that the current certification process requires significantly fewer onsite training hours when compared to the earlier process in which all 160 hours were onsite. Consensus regarding this issue was not achieved. Although a few participants suggested that the certification process should be revised to require that 100% of the certification hours occur exclusively onsite, the majority endorsed increasing the number (unspecified) of onsite training hours between what was previously required and what is currently required. Discussion clarified that the decision to reduce number of onsite training

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hours was in response to practitioners who are unable to attend a certification program that requires onsite training, exclusively.

**Focus Area 2: CLCP Examination and CEU Credits**

Group Facilitator: Linda Shaw, Ph.D., CRC

Recorder: Bob Gisclair, MS, CRC, CDMS, CCM, LPC, CLCP

General Purpose and Issues Contemplated by the Group

Participants were asked to focus on issues related to the:

1. CLCP Exam.
2. Acquisition of continuing education units (CEUs) for certification maintenance.

Group Consensus Statements

*Regarding the CLCP exam:*

1. Change the renewal period to 5 years and increase the CEU requirement (60 credits per 5 years).
2. Validity and reliability of exam items should be established before being used in scoring.
3. Develop the item writing process using experienced and trained LCPers.
4. Maintain an Advisory Group to evaluate and update the exam and to examine and publish information about the exam.

*Regarding CEUs:*

5. Increase the availability of more specific training in specialty areas such as burn injuries, complex trauma, collateral resources and expert testimony.
6. Increase the awareness of other professional associations of the existence of the CLCP credential in order to promote availability of their training programs for CLCP CEUs.
7. Establish a bulletin board with upcoming LCP training opportunities and hot topics.
8. Allow relevant training to be applied without pre-approval (consider reciprocity).
9. Ensure close monitoring of attendance.
10. The testing body should be autonomous and separated from training/educational group (i.e., CHCC should not provide training).

Majority View

*Regarding the CLCP exam:*

1. Require a minimum number of hours in basic LCP concepts (methodology) for initial certification.
  2. The passing cut-off score of the CLCP exam should be defined and made public.
  3. Develop a standardized scoring process for all exam takers; not normed to the group taking the exam during each testing session.
  4. Add an oral exam, in addition to the written exam, that consists of a presentation and defense of a LCP.
  5. CHCC should provide specific feedback on exam results by content area.
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*Regarding CEUs:*

6. Make CEUs available for mentoring, supervision, and LCP critiquing.

Minority View*Regarding the CLCP exam:*

1. Revisit the quantity and specificity of vocational content included in the exam, given that many nurses refer this analysis to vocational professionals.
2. Ensure that the preparatory course continues to be broad in content, rather than specific to the exam questions.
3. Increase the accessibility of the preparatory course by offering it in additional geographic areas and in distance and/or online formats.
4. Provide easier access to those taking the CLCP exam (consider multiple sites and/or computer administration).
5. Increase the number of items on the exam.
6. Establish regional representatives for critiques.
7. Allow only two opportunities to pass the exam and notify applicants that non-certified individuals should be discouraged from writing plans.
8. Include more questions about ethics and case law.
9. Utilize consultants with expertise in test development and validation in the CLCP exam development process.

*Regarding CEUs:*

10. Require a minimum number of CEUs to be in-person training.
11. Inform certificants, upon passing exam, of appropriate CEU providers.
12. Improve the availability of practicum/interactive learning opportunities.
13. Provide the accrediting body with requested data on the exam.
14. Consider raising the minimum number of CEUs required.
15. Ensure that links to CEU offerings on websites are focusing on training applicable to LCP.
16. Require submission of a LCP and provide feedback for renewal of certification.
17. Improve the process for obtaining CEU approval for inservice training.
18. Provide CEU training regarding how to be an effective mentor.
19. Stratify CEU requirements across topical areas.

Areas of Discussion/Concern Unique to the Group

Discussion generally focused more heavily on CEUs than the on the CLCP exam. There was significant discussion about the need to access quality advanced training that was specifically targeted to LCPs. Additionally, the group was concerned that training or professional activities that already exist and are relevant to LCP be easily utilized to meet their CLCP CEU requirements. For example, the group felt strongly that we need to increase awareness among related professional groups so that relevant training will be pre-approved for CLCP CEUs.

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Regarding the CLCP exam, there was great concern that the exam development and scoring process should be scrutinized for validity and reliability and that high standards should be maintained. The groups were divided with respect to the amount of vocational information that should be included in the exam, with nurses often preferring less content than other participants. There also was some acknowledgement that, although some items regarding the exam would be desirable, the costs and complexities of addressing the issues would make them difficult to implement. In some cases, such as the desire to extend the renewal period, participants were almost unanimous in asserting that they would be willing to pay more for their certification and renewals if necessary. In others, such as requiring an oral exam, there were quite a number of participants who felt that the logistics and expense would not make this course advisable.

### **Focus Area 3: Future Research in Life Care Planning**

Group Facilitator: Ann T. Neulicht, Ph.D, CLCP, CRC, CVE, CDMS, LPC, D-ABVE

Recorder: Linda McKinley, BSN, RN, CLCP, CDMS, CCM

#### General Purpose and Issues Contemplated by the Group

Each group was introduced to the topic by highlighting two primary purposes of research:

1. To identify what variables are related, how they are related, the nature of the specific mechanisms or processes that are involved, and the extent to which relationships can be generalized across populations.
2. To provide the best available approximation of the truth or falsity of propositions.

#### Majority View

1. Analyze LCP validity and reliability.
2. Study of the percentage of plans that are implemented.
3. Assess the accuracy and durability of LCPs.
4. Analyze whether cost projections are sufficient.
5. Conduct longitudinal studies (e.g., aging and disability).
6. Identify specific clinical research related to LCP recommendations (e.g., home supervision/DME).
7. Assess life expectancy accuracy.
8. Study the relationship of LCP implementation to quality of life.
9. Evaluate the cost effectiveness of LCPs.

#### Minority View

1. Analyze the comprehension and detail of LCPs.
  2. Conduct quality outcome comparisons between certified and non-certified providers.
  3. Specify "Top 5" reasons a certified LCP vs. non-certified LCP is/would be disqualified.
  4. Explore the relationship between geographic location and cultural diversity of LCPers and clients.
  5. Compare LCP projections, demand, award and actual cost.
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6. Assess patient compliance with a LCP.
7. Analyze the frequency of updates (especially pediatric plans).
8. Compare LCP and treatment provider recommendations.
9. Identify basic standards of care by diagnosis.
10. Assess the cost of care by diagnosis.
11. Evaluate referral reasons for LCP.
12. Explore the relationship between referral source, purpose of a LCP, and outcome.
13. Investigate the outcome of children with cerebral palsy as a function of school therapy vs. private care.
14. Analyze adherence to LCP standards.
15. Explore the relationship between date of injury, referral and discovery deadline (e.g., timeframe).
16. Identify LCP report formats (including research).
17. Assess the effect of case management on implementation and satisfaction with a LCP.
18. Explore the relationship/effect of certification on job satisfaction.
19. Development of a caregiver/family competency (patient understanding) assessment tool.
20. Study the effects of client characteristics on the LCP process.
21. Identify the effects of advancing technology on LCP.
22. Research the impact of LCP on case resolution.
23. Explore the impact of the LCP to decision making by the trier of fact; in other words, did the LCP assist in this process?
24. Assess the role of a LCPer.
25. Study unpaid caregiver services over time.
26. Define "least restrictive" research by state; in other words, how it is done and what it is called?
27. Explore the relationship between finances/support and return to work.

Areas of Discussion/Concern Unique to the Group

Research ideas that were proposed, and discussed, but did not receive a vote for inclusion in the top five priorities (by any group):

1. Impact of the funding source on LCP totals (e.g., Workers' Compensation vs. "other").
  2. Outcome of mentoring vs. non-mentoring on LCP quality.
  3. Use of urgent care vs. ER services in a LCP.
  4. Ethical dilemmas in LCP.
  5. Impact of case manager, court, and/or family coordination on LCP implementation.
  6. Impact/importance of family wishes (and cultural beliefs) on the LCP.
  7. Establishment of a clearinghouse for LCP research.
  8. Clarification of scope of practice.
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9. Comparison of plaintiff vs. defense LCP reviews.
10. Demographic information on LCP use (national and international).

**Focus Area 4: CLCP Mentoring Program**

Group Facilitator: Lori A. Allison, MA, CLCP

Recorder: Joseph R. Corcoran, MA, CRRN, CCM, CLCP

General Purpose and Issues Contemplated by the Group

Roundtable groups were asked to identify the primary considerations to be addressed prior to and/or during the process of developing a formal mentoring program.

Group Consensus Statements

1. First, arrive upon a definition of both the mentoring process and the mentoring relationship and then,
2. Consider the following issues:
  - The necessity of such a program
  - Minimum qualifications of the mentor
  - Assurance of access and equal opportunity for participation
  - Standardization of the mentoring process
  - Standardization of the mentoring relationship
  - Identification of incentives for participation in such a program
  - Legal and liability issues associated with the mentoring process
  - Administrative oversight of the mentoring program

Majority View

There were no majority view statements reached within this focus area.

Minority View

Small group discussions generated the following questions that should be resolved prior to and/or during the process of developing a formal mentoring program:

1. Who is qualified to be a mentor?
  2. Should mentors undergo a peer-review process?
  3. How can all interested parties participate?
  4. How does the mentoring process differ from other forms of collaboration and/or conferring with other practitioners in the field?
  5. Does the mentor become a co-author of the mentee's plans?
  6. What are the goals of the mentoring program? What is the expected end product?
  7. Should mentors undergo a formal training process?
  8. How can consistency among mentors be maintained?
  9. Should mentors be compensated?
  10. Can mentors and mentees earn CEU or "Points for Credit"?
  11. Does the mentor assume any liability for plans developed by the mentee?
  12. Can the anonymity of the patient/client be preserved?
  13. How can potential conflicts of interest be identified?
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### Areas of Discussion/Concern Unique to the Group

Although the development of a formal mentoring program was suggested during the Summit 2000 (Weed & Berens, 2001) and Summit 2002 (Riddick-Grisham, 2003) proceedings, there was considerable discussion regarding the nature of and necessity for such a program. For this reason, participants arrived upon only consensus and minority views.

### **Focus Area 5: Standards of Practice for Life Care Planners**

Group Facilitator: Karen Preston, PHN, MS, CRRN, FIALCP

Recorder: Susan Wirt, RN, CCM, CLCP, CRP, CRRN

### General Purpose and Issues Contemplated by the Group

Discussion focused upon issues related to the current Standards of Practice published in 2000. The development of the 2000 Standards was coordinated by a committee from the International Academy of Life Care Planners (IALCP) and reviewed by the LCP community at large through dissemination of drafts and discussions at national meetings. As the field of LCP has continued to evolve and mature, internal and external forces combine to influence the practice. The focus of discussion was examining what aspects of the Standards need to be retained and what aspects need to be revised to meet current state-of-the-art.

The discussion was very lively and thorough, revealing areas where LCPers share views regarding Standards of Practice and areas where there was considerable lack of clarity and consensus. Consensus and/or majority viewpoint was reached on several important points. We were also able to articulate critical areas that need further examination and discussion in an effort to eventually reach consensus.

### Group Consensus Statements

1. The term "client" shall be defined in Standards of Practice for LCPers.
2. Terminology used in the Standards of Practice needs to be defined.
3. Standards of Practice will continue to delineate the qualifications to be a LCPer (endorsement of existing Standard statement 1.d).
4. Standards of Practice state/delineate educational requirements for entry into LCP.
5. Standards of Practice shall state the role and accountability of the LCPer.
6. A study defining the role and accountability of the LCPer should be the basis for defining them in the Standards of Practice, when available.
7. Standards of Practice should be written in a way to allow the individual LCPer to utilize his/her professional judgment and experience (i.e., they should not be written to tie the hands of the LCPer).
8. Some aspects of the Standards of Practice are too detailed.

### Majority View

1. Standards should state that the client is the injured or disabled party. Dissenting minority opinion was that the client is the referral or payer source.
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### Minority View

1. There was disagreement regarding key ethical issues, including:
  - Whether dual roles/relationships can be appropriate (such as being the case manager and LCPer concurrently or sequentially, or whether a LCPer can also have any kind of relationship with the injured/disabled party).
  - The extent the LCPer can let the referral source or payer source influence the contents of the LCP to maintain satisfactory business relationships.
2. There needs to be an understanding of whether LCP Standards of Practice are different from, yet compatible with, Standards created for the various professions who are practicing LCPers.
3. There needs to be a way to reach a common set of LCP Standards of Practice so that LCPers are not held to Standards promulgated by multiple LCP entities, especially if the various Standards are not consistent. This includes understanding what creates legitimacy of the Standards and gaining acceptance throughout the industry.
4. LCPers are concerned about what should happen when LCPers do not follow Standards of Practice.

### Areas of Discussion/Concern Unique to the Group

Throughout the course of discussion, there was recognition that Standards of Practice create a powerful influence on the role of LCP and how LCPs are constructed and used. The discussion was positive in the desire to ensure that Standards are reasonable, provide protection for the LCPer and users of the plans, and contribute to the integrity of the LCP process. Clearly, there are critical areas that require further development as LCP continues to evolve.

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## **2006 Life Care Planning Summit/Town Hall Meeting: A Celebration of Life Care Planning ...10 Years Later**

*Debra E. Berens, CRC, CCM, CLCP*



The 2006 Life Care Planning Summit and Town Hall Meeting was held May 6-7, 2006 in Chicago, Illinois with over 170 professionals in attendance. Although this year marked the fourth Summit for life care planning professionals, the format for the program was different from years past. By using a “town hall” meeting approach, participants were encouraged to engage in open dialogue about issues, challenges, and opportunities relevant to life care planners. The meeting offered the ability for participants to get answers to their questions, raise topics for discussion, and share successes (and a few horror stories) in a comfortable, professional, and energized meeting space with peers. According to the Summit manual, the “Rules of Play” included: Speak up, listen and pay attention, acknowledge success, identify solutions, do not interrupt, and the now famous saying, “What Happens in Chicago, Stays in Chicago.”

The main format for the Summit were panel discussions, with a keynote address given by Dr. Jeffrey Kreutzer, Professor of Physical Medicine and Rehabilitation, Neurosurgery, and Psychiatry, at Virginia Commonwealth University Medical Center. Dr. Kreutzer’s presentation was titled “How to Use Published Research to Develop Intelligent, Empirically-Based Life Care Plans.” Over the course of two days, panel discussions covered such topics as:

Process and Methodology

Analysis of Future Needs  
Forensic/Trial Experiences  
Malpractice/Ethical Dilemmas  
New Markets/Referral Sources for the Life Care Planner  
Resources for the Life Care Planner  
Future Trends/Expectations

Also new to this year's Summit was a pre-Summit review by the participants of 22 actual life care plans provided anonymously and voluntarily by life care planners across the United States and Canada. The idea was to have participants perform a critical review of the plans prior to coming to the Summit, then discuss the process and review the comments at the Summit. General themes and pros/cons of the various anonymous life care plans were generated at the Summit and CEUs were provided to those participants who completed all 22 reviews.

Chaired and moderated by Susan Riddick-Grisham and organized by MediPro Seminars, LLC, the 2006 Life Care Planning Summit was sponsored by The Care Planner Network and co-sponsored by Virginia Commonwealth University, University of Florida, Foundation for Life Care Planning Research, Commission on Health Care Certification, and International Association of Rehabilitation Professionals/International Academy of Life Care Planners. Other highly qualified and experienced life care planners donated their time and dedication to the Summit as planning committee members, organizers, speakers, and panel moderators/facilitators.

Full proceedings and outcomes of the 2006 Life Care Planning Summit are expected to be published in the next issue of the *Journal of Life Care Planning* as well as presented at the International Conference on Life Care Planning in Atlanta, Georgia on October 14 & 15, 2006.



## 2006 Life Care Planning Summit Proceedings

*Susan Riddick-Grisham, BA, RN, CCM, CLCP*  
*Program Chair, 2006 Life Care Planning Summit*

*Editor's Note: The following proceedings were invited to be included in the Journal and represent the author's summary of the 2006 Life Care Planning Summit.*

### **Introduction and Background**

Networking with colleagues, celebrating individual and professional achievements, getting the latest on best practices, and hearing from panels of provocative, engaging and inspiring speakers, more than 150 life care planners gathered in Chicago, Illinois for the 2006 Life Care Planning Summit on May 6-7, 2006.

The organization of this year's Summit required some creative thinking on the part of the planning committee to be responsive to attendees' expectations while also be reflective of current life care planning practices and issues. Hopeful to step "outside the box" to view the complex situations and challenges faced by new and experienced life care planners, the 2006 meeting was, for the first time ever, conducted in a "town hall" style. Similar to previous Life Care Planning Summits, the purpose of this year's Summit was to demonstrate the continuation of the review of process and methodology for life care planning and the exploration of issues impacting the field. The town hall style was selected to provide an open forum for discussions in a relaxed, supportive environment. This style of meeting was in contrast to previous Summits where roundtable discussions about specific issues were focused on achievement of consensus from the field (Weed & Berens, 2001; Riddick-Grisham, 2003; Deutsch & Allison, 2004).

### **2006 Life Care Planning Summit Goals**

Titled, "A Celebration of Life Care Planning...10 Years Later," the 2006 Life Care Planning Summit had many purposes and goals. Billed as a "town hall" meeting, the following message was disseminated to life care planners prior to the Summit and captures the essence of the meeting:

Continuing education and professional development is part of the process of lifelong learning. Learning that occurs in the context of the daily workplace is far more likely to be relevant and reinforced, leading to better practice. As a profession we need to be self-confident enough to embrace a culture where continuing education and development, peer review, appraisal, and revalidation are not

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threatening concepts. Join us as we provide an open forum for experiential discussions about lessons learned by seasoned and new life care planners. Walk away with practical information that you can immediately apply to your practice setting (S. Grisham, personal communication, 2006).

One goal of the Summit was to share in a celebration of the growth in the field, specifically over the past 10 years, and its multiple accomplishments including:

- Development of professional organizations for life care planners.
- Publication of peer reviewed Standards of Practice.
- Development of a national examination leading to certification of life care planners.
- Development of a Code of Ethics for life care planners.
- Development and quarterly publication of the *Journal of Life Care Planning*.
- Successful completion of four Life Care Planning Summits which have allowed life care planning professionals an opportunity to discuss and debate issues in the field.
- Development of an annual international life care planning conference.
- Ongoing presentation of quality continuing education programs directed at expanding the application of comprehensive, clinically-based life care plans.
- Multiple publications specific to life care planning.
- Implementation of listservs allowing for the sharing of resources and a discussion forum on a daily basis.
- Creation of the Foundation for Life Care Planning Research (FLCPR).
- Publication of research specific to life care planning including: Cimino-Ferguson, 2005; Deutsch et al., 2003; Deutsch et al., 2005; Deutsch et al., 2006; Kendall & Deutsch, 2002; Kendall & Casuto, 2005; Marini & Harper, 2006; Pomeranz, 2005; Sutton et al., 2002, and many others).

A second goal of the Summit was to create a forum for sharing experiences, questions and challenges among life care planners and in a relaxed and supportive environment. A third goal was to share useful tools, tips, and ideas among attendees as a way to enhance the efficiency and effectiveness of life care planners in providing quality and sound life care planning services. By all accounts, these goals and others were achieved!

Additional announcements leading up to the conference proclaimed that the 2006 Summit would provide life care planners a platform upon which they could discuss the changing market place, explore new business opportunities, and share success stories. The discussions were expected to be full of candor, humility, and, perhaps, some braggadocio. And indeed they were!

### **Sample of Participant Comments**

Evaluations completed by Summit participants have been received and reviewed. A sam-

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ple of some of the positive comments generated by the 2006 Life Care Planning Summit are included below. For privacy and confidentiality purposes, the names of those making the comments have been removed.

- “This Summit brought ‘real issues’ to discuss and promoted ‘fabulous’ discussions between seasoned and newer Life Care Planners.”
- “Best Summit yet! Good to see new faces in the presenters.”
- “Really enjoyed the networking opportunities and I learned much from each of the sessions.”
- “...lots of ‘newbies’...great!”

### **Something New to Try**

In advance of the 2006 Summit, attendees were offered the opportunity to participate in the first ever peer review of a sample of life care plans. According to the Standards of Practice for life care planners, “The Life Care Plan should be a working document that provides accurate and timely information which can be easily used by the client and interested parties. It should be a document that can be updated and serve as a lifelong guide to assist in the delivery of health care services in a managed format” (International Academy of Life Care Planners, Section II, 2006). What the Standards do not define is one single format for the presentation of the life care information. Instead, each life care planner decides on the report format that best allows him or her to relate pertinent information and the result has been a wide variety in report designs. The purpose of the Summit peer review process was to allow professionals who practice in the life care planning field a way to offer feedback regarding the strengths and weaknesses of the sample formats submitted by colleagues. The process also provided a framework for the reviewers to identify their own personal learning needs.

In total, twenty-two (22) sample life care plans were collected, sanitized, and sent to the registered program participants for review prior to the Summit. The samples showed wide variations in layout, organization, and the formatting of information. Summit participants were asked to review samples 1-11 using the “Comparison Matrix of Published Step-by-Step Procedures for Life Care Planning and Expert’s Procedures” (see Appendix A, as cited in Weed, 2004) and samples 12-22 were reviewed using the Deutsch & Associates Critique Form (see Appendix B). Participants also were asked to review the “Checklist for Review of Life Care Plans (see Appendix C, as cited in Weed, 2004). Additionally, as part of the overall peer review process, participants were asked to provide feedback regarding the strength of the two review tools.

In addition to the field reviews by registered participants of the 2006 Summit, each of the 22 life care plans was reviewed by a panel of workers’ compensation insurance professionals who offered feedback regarding the organization of the report form and the plan’s ability to provide relevant information in an organized easy-to-read format. This first ever “customer” review process was designed to give life care planning professionals feedback to allow for a better understanding of some customer needs as it pertains to the design format of the life care plan report. Insurance reviewers included:

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- Kim Griffiths- Pinnacol Assurance
- Tom Klasnick- Broadspire Services, Inc., a third party administrator
- Chris Lemon- Broadspire Services, Inc., a third party administrator
- Karen Wilbanks- CNA Insurance

The results of the peer review activity were mixed. While many reviewers stated they found it to be a valuable experience, others stated they found the activity to be overwhelming and time consuming. Below is a sampling of some of the comments made, with reviewers' names removed to preserve their privacy:

- "This exercise helped me to see other organizational approaches."
- "A very time intensive project, but what an eye opener."
- "Yes it was great to see how others approach their plans."
- "The diversity of the plans was education in and of itself. I appreciate the different styles; however, the exercise had some challenges and perhaps I did not understand the directions clearly."

Currently, the reviews of each sample life care plan are being summarized and prepared for distribution to the Summit attendees at a later date. The preliminary results suggest that the preferred life care plan report format should include a narrative report which includes a comprehensive review of medical and psychosocial information, inclusion of references regarding medical foundation for the basis of conclusions contained within the report, the use of charts which clearly delineate the start/stop dates of usage, frequency of recommendation, annual costs, and lifetime totals. The insurance reviewers emphasized the usefulness of including annual and lifetime totals as part of the life care plan.

#### **Overview of 2006 Summit Presentations**

Day One of the two day Summit began with a presentation by Ann Neulicht and Carol Walker titled, *The Life Care Plan RACE: Review, Analysis, Critique, Evaluation?* The presentation focused on issues to consider in writing, reviewing, analyzing, critiquing and/or evaluating a plan. (Editor's Note: See article by the same name beginning on page 91 of this issue). The presentation was followed by a panel discussion, *A Closer Look at Process/Methodology Issues*, moderated by Karen Preston who guided the discussions covering sources influencing methodology and highlighting some of the methodology conflicts. One example cited was the use of an in-person interview versus a telephone interview to gather information for consideration of life care plan opinions. Questions arose about the use of Standards of Practice as a methodology guide allowing for individualized decision making based on unique case characteristics rather than a tool to lock the process into an "only one way avenue." Attendees also were provided an opportunity at the Summit to conduct a peer review of the proposed revisions to the Standards of Practice and provide feedback into the revised Standards.

During this panel, a lengthy discussion was held regarding the importance of meeting the

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challenges of Daubert by utilizing a consistent methodology (Daubert, 1993). Dr. Paul Deutsch, long considered a leader in the field, offered his comments regarding the importance of creating a medical foundation for specific portions of the life care plan. He pointed out that the medical foundation can be created by collaboration with treating physicians or evaluators, and other clinical input. The use of evidenced-based Clinical Practice Guidelines such as those offered by the National Guideline Clearinghouse, <http://www.guideline.gov/>, can also offer the life care planner additional, relevant scientific literature on clinical and behavioral issues in a multitude of diagnostic conditions.

Two sessions of the Summit were devoted to interactive discussions regarding challenging issues faced by many life care planners, including the importance of obtaining reliable information. Opening the discussion, Ann Neulicht and Susan Riddick-Grisham explored the use of assessment tools as part of the information gathering phase of life care planning. Tools discussed included The Achenbach System for Empirically Based Assessment/ASEBA® (Achenbach, 2000), Behavior Rating Inventory of Executive Function/BRIEF™ (Gioia, Isquith, Guy, & Kenworthy, 1999), Judgment and Safety Screening Inventory (VCU/MCV, 2001), Disability Limitations Checklist (Reagles, 1997), Residential Accessibility Survey (Reagles, 2003), and the Community Integration Questionnaire/CIQ (Willer, 1993).

The speakers emphasized that many of these standardized assessment tools require specialized training and state licensure to administer and score, and the life care planner is advised to be aware of these requirements. The sessions resulted in an action plan to develop a comprehensive listing of assessment tools and instruments commonly used by life care planners when developing a life care plan. Summit participant and fellow life care planner, Joanne McDaniel, has offered and is in the process of compiling the list which will be available in the future on [www.careplanners.net](http://www.careplanners.net) and possibly published in a future issue of the *Journal of Life Care Planning*.

Continuing the discussion among participants, the group explored issues pertaining to ways to efficiently work with clinical teams and the establishment of medical foundation for the medical entries of a life care plan. Suggestions included:

- At the time of referral, confirm with referral source what and which physician(s) will be utilized to support the medical foundation for relevant aspects of the life care plan
  - Understand the limitations of each physician's specialty and area of expertise.
  - Understand the specialized knowledge of the life care planner and his or her ability to provide the needed foundation for select portions of the life care plan.
  - Acknowledge that there are differences in how life care planners approach the clinical teams
  - Acknowledge that life care planners come from a variety of professional and experiential backgrounds and typically will have varying credentials to offer the life care planning process.
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As a new learning tool, the 2006 Summit provided attendees an opportunity to hear a brief presentation from Mary Anne Ehlert, CFP (certified financial planner). Ms. Ehlert, Founder of Protected Tomorrows, a company focused on helping families with special needs plan for the future, has successfully built a national network of Protected Tomorrows expert advisors, or “Advocates,” who share her financial planning background and her dedication to serving the families of individuals with special needs. Ms. Ehlert reported that she has assisted over 3,000 families to develop financial plans. She shared her experiences in working with families as they make decisions in many of the areas that life care planners explore in the development of an individualized care plan. One excellent example that created a great deal of discussion was the issue of home care. It was noted that many life care planners may become challenged when trying to outline realistic home care scenarios. The shortage of nurses has resulted in many home care agencies refusing to guarantee the availability of services and life care planners are being forced to plan, consider or contemplate other options to meet the individual’s need. One idea that generated useful discussions was the provision to privately hire caregivers. Attendees explored ways to thoroughly assess the complex issues involved in a private hire situation, including how to complete background checks, bonding, costing and long term management. Attendees agreed that this is an area of great interest and suggested that additional educational programs addressing home care would be useful for the field.

The afternoon of Day One brought a lively discussion by keynote speaker, Dr. Jeffrey Kreutzer, a widely known neuropsychologist who has worked with life care planners across the country. Dr. Kreutzer’s presentation, *How to Use Research to Develop Intelligent, Empirically-Based Life Care Plans*, provided an overview of research regarding long-term neuropsychological problems following brain injury, post-brain injury driving, employment, productivity status and quality of life indicators. (Editor’s Note: See reprint of one of Dr. Kreutzer’s articles presented at the Summit beginning on page 99 in this issue.). The conclusion to Day One included three breakout sessions where each group was provided a sample life care plan for review and critique. The three sessions were led by three physicians experienced in life care planning: Dr. Terry Winkler, Dr. Richard Bonfiglio, and Dr. Robert Meier. The sessions allowed for group discussions regarding the assumptions and conclusions contained in each of the three sample life care plans.

Day Two of the Summit commenced with a panel discussion titled, “Best and Worst Trial Experiences” moderated by Bill Goodrich. This panel was designed to allow the participants to share real life deposition or trial experiences as a learning tool for future depositions or trials. Although this sometimes comical session was viewed by some as a “war story” session, many participants agreed that the power of interaction on this sensitive topic allowed for a great deal of individual learning and information exchange that helped to de-mystify the testimony experience.

The lively discussion continued into the next session, titled “Malpractice Concerns and Ethical Dilemmas” and moderated by Debbie Berens. Representing the Commission on Health Care Certification (CHCC), Evelyn Robert reviewed some ethical complaints submitted to the CHCC which included:

- Misrepresentation of credential.
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- Unqualified applicants with completed training from pre-approved training programs.
- Communication with opposing counsel who is counsel for retained certified life care planner (CLCP).
- Commissioner's review of life care plan of current seated commissioner.
- Certified life care planner's misrepresentation of employment status.
- File review of care plan to develop alternate care plan for opposing counsel
  - No injured party contact.
- Life care plan development without primary physician or rehabilitation team input.
- Development by CLCP of a Medicare Set Aside (MSA) document on a client whom the CLCP developed the life care plan.
- Disregard of conflicting file documents to life care plan goals.

Discussion focused on the possible perception of an ethical conflict involving a sole author of a life care plan and a MSA. The attendees requested additional feedback from the CHCC regarding future decisions pertaining to this dual role dilemma and requested an opportunity to offer field feedback before the CHCC made any final decision on the issue. Discussion also focused on the status of the CHCC's application for certification by a national certifying body. Questions on this topic were deferred to the CHCC chief executive officer.

Following the CHCC's report of ethical concerns brought before the Commission, Dr. Carol Walker initiated a lively discussion regarding professional licensure considerations when performing life care plan evaluations across state lines. Dr. Walker provided an overview of the mutual recognition model of nurse licensure that allows a nurse to have one license (in his or her state of residence) and to practice in other states (both physically and electronically), subject to each state's practice law and regulation. Under mutual recognition, a nurse may practice across state lines unless otherwise restricted. The attendees explored how this model applies to the other disciplines involved in the practice of life care planning.

Debbie Berens then presented an overview of actual ethics complaints submitted to the IALCP which included:

- Retaining attorney does not think life care plan is appropriate and refuses to pay for the life care planner's services leading up to and including development of the plan.
- Client/family disagrees with the life care plan and plan reportedly gives the appearance of inappropriate inclusion of some items and "over charging" of some items. Legal action reportedly is threatened against the life care planner.
- A life care planner retained by defense counsel contacts the client's treating physician without consent from the client or client's attorney.

Following the ethics session, the morning concluded with a panel discussion about "New Markets" in life care planning including trust case management or the implementation of life

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care plans as an expanding area of practice. Other new markets include life care planning/case management consultation to physicians and private life care planning consultation.

The afternoon session was opened by Leslie Watson and was titled "Work Smarter, Not Harder." Strategies to improve work productivity included the use of life care plan research assistants who can offer support by providing medical records review and summary and costing research. A comprehensive listing of research assistants can be found at [http://www.care-planners.net/lcp\\_tools.asp](http://www.care-planners.net/lcp_tools.asp). Resources for physician, lab, and medical facility fees were also outlined.

The 2006 Life Care Planning Summit concluded with a panel comprised of representatives of the IALCP, CHCC, and Foundation for Life Care Planning Research (FLCPR). The panel discussed trends and plans for the future of life care planning and each represented organization had an opportunity to offer suggestions. In addition to a membership drive, the IALCP offered the following plans:

- Complete transition to new organizational model, i.e., IARP.
- Increase IALCP visibility/awareness of our existence within the life care planning community.
- Increase membership in the Academy.
- Increase membership-driven services and programs.
- Increase education opportunities through a variety of venues/media/technologies.
- Develop long-range plans.

The CHCC proposed the following plans:

- Continued establishment of certifications:
  - Canadian Certified Life Care Planner (CCLCP)
  - Australia
  - Netherlands
  - China
  - Chinese Physical Therapists certified as Certified Disability Examiner (CDE)
- Additional development of certifications:
  - Certified Elder Care Specialist (CECS)
- Accreditation through National Commission for Certifying Agencies.
- Development of a review textbook for certification review course.
- Acceptance of CLCP qualifications by all pre-approved training programs.
- Continued academic research.

The Foundation for Life Care Planning Research proposed the following plans:

- Implementation of a Foundation fund raising project.
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- Continued support of research projects addressing the reliability and validity of the life care planning process.
- Development of a Foundation newsletter.
- Scholarship support to students pursuing life care planning education.

### **Conclusion**

In the opinion of this author, the 2006 Life Care Planning Summit was a great success and an enhancement to the field. As program chair, I was most pleased by the incredible amount of information sharing, professional support, and camaraderie that was displayed. There was an amazing amount of positive energy about where the practice is heading and what individual life care planners can contribute to the growth of the IALCP, FLCPR, and other entities focused on life care planning education and research. While the 2006 Life Care Planning Summit was not perfect (is that even possible?), much was learned from and about the process. Historically, each time a Life Care Planning Summit has been held, attempts are made to apply the lessons learned to the next Summit. Problems regarding the size and layout of the meeting room and technical problems with the microphones and audio-visual equipment will not be ignored as plans for the Summit 2008 get underway. Evaluations from the attendees have all been read and indicate that the “town hall” meeting format was an effective style. However, there were requests for a greater blend of panel presentations mixed with traditional lectures.

Looking forward to the 2008 Life Care Planning Summit, it is my hope that the specialty practice of life care planning will maintain the focus and energy generated thus far and that practitioners work together to build on all of the accomplishments of the past 25 years.

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Cindy Haseley	Randall Thomas
Ann Maniha	Steve Yuhas
Ann Neulicht	Carol Walker
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The Care Planner Network	Commission on Health Care
Virginia Commonwealth University	Certification (CHCC)
Medical Center	International Association of
University of Florida	Rehabilitation Professionals
The Foundation for Life Care	(IARP)/International Academy of
Planning Research (FLCPR)	Life Care Planners (IALCP)

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**Appendix A, Comparison Matrix of Published Step-by-Step Procedures for Life Care Planning and Expert's Procedures**

<p align="center"><b>Published Step-by-Step Procedures for Life Care Planning</b></p> <p><i>(Source: Step-by-Step Procedure for Life Care Planning, p. 624-625, in Weed, R. (Ed.). 2004. Life care planning and case management handbook. Boca Raton, FL: St. Lucie/CRC Press)</i></p>	<p align="center"><b>Comments Regarding Expert's Procedures (Based on records, report, deposition transcript, etc.)</b></p>
<p>Case Intake:</p> <ol style="list-style-type: none"> <li>1) When you talked with the referral source, did you record the basic referral information?</li> <li>2) Time frames discussed?</li> <li>3) Financial/billing agreement?</li> <li>4) Retainer received (if appropriate)?</li> <li>5) Arrange for information release?</li> </ol>	
<p>Medical Records:</p> <ol style="list-style-type: none"> <li>1) Did you request a <b>complete</b> copy of the medical records?</li> <li>2) Nurses' notes?</li> <li>3) Doctor's orders?</li> <li>4) Ambulance report?</li> <li>5) Emergency room records?</li> <li>6) Consultants' reports?</li> <li>7) Admission and discharge reports?</li> <li>8) Lab/x-ray/etc.?</li> </ol>	
<p>Supporting Documentation:</p> <ol style="list-style-type: none"> <li>1) Are there depositions of client, family or treatment team that may be useful?</li> <li>2) "Day in the life of" videotapes?</li> <li>3) And if vocational issues to be included in report – school records (including test scores)?</li> </ol>	

<p>4) Vocational and employment records? 5) Tax returns?</p>	
<p>Initial Interview Arrangements: 1) Is the interview to be held at the client's residence? 2) Have you arranged for all appropriate people to attend the initial interview (spouse, parents, siblings)?</p>	
<p>3) Did you allow 3-5 hours for the initial interview?</p>	
<p>Initial Interview Materials: 1) Do you have the initial interview form for each topic to be covered? 2) Supplemental form for pediatric cases, CP, TBI, SCI as needed? 3) Do you have a copy of the life care plan checklist? 4) Example plan to show the client? 5) Copy of appropriate Life Care Plan step-by-step booklet? 6) Camera or video camcorder to record living situation, medications, supplies, equipment, and other documentation useful for developing a plan?</p>	
<p>Consulting with Therapeutic Team Members: 1) Have you consulted with and solicited treatment recommendations from appropriate therapeutic team members?</p>	
<p>Preparing Preliminary Life Care Plan Opinions: 1) Do you have information that can be used to project future care costs? 2) Frequency of service or treatment?</p>	

<p>3) Duration? 4) Base cost? 5) Source of information? 6) Vendors?</p>	
<p>Filling in the holes: 1) Do you need additional medical or other evaluations to complete the plan? 2) Have you obtained the approval to retain services of additional sources from the referral source? 3) Have you composed a letter outlining the “right” questions to assure you are soliciting the needed information?</p>	
<p>Researching Costs and Sources: 1) Have you contacted local sources for costs of treatment, medications, supplies, equipment? 2) Or do you have catalogs or flyers? 3) For children, are there services that might be covered, in part, through the school system?</p>	
<p>Finalizing the Life Care Plan: 1) Did you confirm your projections with the client and/or family? 2) Treatment team members?</p>	
<p>3) Can the economist project the costs based on the plan? 4) Do you need to coordinate with a vocational expert?</p>	
<p>Last But Not Least: 1) Have you distributed the plan to all appropriate parties (client, referral source, attorney, economist, if there is one)?</p>	

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**Appendix B, Sample Life Care Plan Review Form****PAUL M. DEUTSCH & ASSOCIATES, P.A.****CRITIQUE CONSULTANT:**

Referred By:

Date Received:

Date Returned:

Type of Impairment:

**I. REVIEW OF AREAS COVERED**

- A. In relation to the type of disability involved, has the Life Care Planner analyzed all necessary areas?

**II. REVIEW OF TERMINOLOGY**

- A. Has the Life Care Planner used appropriate disability specific terminology?
- B. Does the use of this terminology reflect appropriately the Life Care Planner's knowledge of the disability?

**III. ANALYSIS OF OVERLAPS**

- A. Are the total number of hours involved in therapy within reasonable guidelines?
- B. Are the total number of weeks per year required to implement this plan within reasonable guidelines?
- C. Are the total number of days involved in implementing this plan per year within reasonable guidelines?
- D. Has the Life Care Planner avoided programmatic overlaps?
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**IV. ADDITIONAL RECOMMENDATIONS TO BE CONSIDERED BY THE LIFE CARE PLANNER**

A. Projected Evaluations:

- No Further Recommendations
- See Below For Recommendations

B. Projected Therapeutic Modalities:

- No Further Recommendations
- See Below For Recommendations

C. Diagnostic Testing/Educational Assessment:

- No Further Recommendations
- See Below For Recommendations

D. Wheelchair Needs:

- No Further Recommendations
- See Below For Recommendations

E. Wheelchair Accessories and Maintenance:

- No Further Recommendations
- See Below For Recommendations

F. Orthopedic Equipment Needs:

- No Further Recommendations
- See Below For Recommendations

G. Orthotics/Prosthetics:

- No Further Recommendations
- See Below For Recommendations

H. Aids For Independent Function:

- No Further Recommendations
  - See Below For Recommendations
-

I. Home Furnishings and Accessories (Durable Medical Items):

- No Further Recommendations
- See Below For Recommendations

J. Drug/Supply Needs:

- No Further Recommendations
- See Below For Recommendations

K. Home/Facility Care:

- No Further Recommendations
- See Below For Recommendations

L. Future Medical Care - Routine:

- No Further Recommendations
- See Below For Recommendations

M. Future Medical Care Surgical Intervention or Aggressive Treatment Plan:

- No Further Recommendations
- See Below For Recommendations

N. Potential Complications:

- No Further Recommendations
- See Below For Recommendations

O. Transportation:

- No Further Recommendations
- See Below For Recommendations

P. Architectural Renovations:

- No Further Recommendations
  - See Below For Recommendations
- 
-

Q. Leisure Time and/or Recreational Equipment:

- No Further Recommendations
- See Below For Recommendations

R. Vocational/Educational Plan:

- No Further Recommendations
- See Below For Recommendations

**V. IS THE PLAN EASY TO UNDERSTAND FOR ALL PARTIES CONCERNED  
(FAMILY, CLIENT, ATTORNEY, ECONOMIST, COUNSELOR)?**

**VI. OTHER COMMENTS**

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## Appendix C, Checklist for Review of Life Care Plans

### CHECKLIST FOR REVIEW OF LIFE CARE PLANS

**Was a complete set of medical and other relevant records provided with the referral?** Did narrative report accompany LCP? Deposition transcripts of client, family, and/or treatment team provided? “Day in Life of” or other videotapes of client? Photographs of client? Deposition of life care planning expert?

**Does LCP follow published standards and procedures?** Refer to IALCP website [www.ialcp.com](http://www.ialcp.com) for published standards. Use of published or standard checklists, forms, charts, etc.? Collaborative effort? Potential Complications referenced on appropriate page and not included in LCP?

**Are entries in LCP appropriate for disability/injury?** Input obtained from treatment team or consulting physician(s)? Medical, psychological and/or neurological foundation established? Life care planner’s recommendations within his/her area of expertise? Medical/therapeutic recommendations within respective providers’ area of expertise? Preventive and rehabilitative goals? All areas related to disability included? Costs related to disability only and not to general or routine care or pre-existing conditions? Costs based on geographic area or other appropriate database?

**Overlaps?** Are same or similar services listed more than once under different categories? Can one provider accomplish two recommendations and be more cost effective (e.g., qualified speech therapist or occupational therapist to also do assistive technology evaluation, primary care physician to also do urinalysis, etc.). Timeframes for services chronological or mutually exclusive?

**In-home/Facility Care?** For in-home pediatric care, are adjustments made for the time child at school and for time parents normally are expected to be available to parent the child? Adjustments made as child gets older and would normally require less assistance? Level of care appropriate to client’s needs (in general LPN for G-tube management, bowel/bladder program, trach care, medication administration, cut/clean nails; CNA/PCA/HHA for ADLs, meal preparation, laundry, housekeeping, driver, safety/supervision at home. Also refer to each State’s Nurse Practice act for specific requirements)? Do agencies surveyed provide CNA II or have special rules that allow trained CNAs to provide some “skilled” care under the supervision of RN/LPN? Consideration made to potential negotiated cost reduction with home health agency if long term contract? Parents/family expected to provide some of the care? Lawn/yard care and exterior/interior home maintenance included as adult? For residential community living program/facility, is average yearly cost of room and board deducted from per diem rate?

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**Appropriate cost reductions made or noted to economist with regard to general expenses incurred without disability?** For wheelchair accessible van, cost of average vehicle or trade-in value of family vehicle deducted? Accessible home, cost of average home in local area deducted? Dental/medical care, cost of routine care recommended for general population deducted? Adaptive clothing allowance, average yearly cost of clothing for general population deducted? Adaptive leisure equipment allowance, average yearly cost of recreation/leisure activities of general population deducted? Total enteral nutrition, average yearly cost of food consumption for general same-age population been deducted? Alternatively, is distinction made that the recommended services in plan are over and above that which is recommended for general population?

**Are cost calculated correctly?** Is the math correct? Source of cost information known or documented? If economic calculations are included, is life care planner qualified to make such calculations? Are costs of PRN or as needed services/items included in plan? Are costs of Potential Complications included?

**Vocationally relevant items?** Are vocational issues addressed or deferred to qualified vocational specialist for vocational considerations?

**Plan confirmation?** Plan reviewed/confirmed/endorsed by physician(s) and/or team, if access is available? Client/family, if access available? Future updates expected?

**Aesthetics?** Are plan entries easy to read, follow and understand? Does plan overall look professional and make sense? Minimal to no typographical errors or date errors? Is the information presented clearly, logically and with sufficient detail? Consistency between narrative report, records and plan entries?

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**About the Author**

Susan Riddick-Grisham has greater than 25 years of experience working with patients, families and clinical teams. Susan is the Founder of The Care Planner Network, an online community dedicated to improving the life care planning process by narrowing the variance in practice patterns, and by providing resources and networking opportunities to all practicing life care planners. She is also President of Life Care Manager, LLC which provides care manager and life care planning services on a national level.

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# LIFE CARE PLANNING SUMMIT 2008 PROCEEDINGS

*by Summit 2008 Co-Chairs*

*Karen Preston, PHN, MS, CRRN, FIALCP*

*Jamie Pomeranz, Ph.D., CRC, CLCP*

*Carol Walker, Ph.D., ABPP-CN, CLCP, CFE*

## **Introduction**

The Life Care Planning Summit is a biennial event made up and attended by 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 standards has been established, consensus and unity in the field is a developmental process. Through a series of round table discussions, 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 this specialty practice.

Consistent with previous Summits, the Life Care Planning Summit 2008 was designed to examine high priority issues in life care planning. At this point in time, a considerable amount of structure and process has been developed through training programs, professional associations, certifications, standards of practice, a professional literature base, and research programs. However, there are still differences in the methods by which individual life care planners practice, as well as varying opinions regarding continuing refinement of this practice area. Thus, the Life Care Planning Summit 2008 was intended to examine issues and provide direction at both the individual practitioner level and at the field level. Included at the end of this summary is a copy of the welcome letter to all attendees of the Summit.

In preparation for the Summit, discussion topics were selected by a planning committee who gathered ideas from life care planning practitioners in the field over a period of several months. The committee also reviewed topics discussed on various listservs relevant to life care planning. The process resulted in a lengthy list of topics that life care planners could address. The final selection was narrowed to cover topics that fit two categories:

1. Topics that were of the highest interest to individual practitioners, as demonstrated by frequency and duration of discussion.
2. Topics that were of priority to the field in terms of what would provide insight to organizations that support life care planners. This category included potential controversial topics that had not previously been discussed openly by practitioners and organizations.

The following six topics described below were selected as ones thought to be most relevant to the professional practice of life care planning. For each topic, questions were posed for discussion among the attendees. The topics, questions, and an explanation of the topic are discussed below. For each topic, dozens of ideas and comments were generated by the attendees. Using a group consensus technique outlined by Delbecq, Van de Ven, & Gustofson, (1975), the priority ideas for each topic were identified, and consensus statements were written. These proceedings represent the agreed concepts arising from the Life Care Planning Summit 2008 process.

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In addition to the agreed concepts, which are represented by consensus statements that were unanimously accepted by the attendees, there were several concepts where consensus was not reached. Many of these concepts are also included to illustrate topics where life care planners can continue dialog and field development. In particular, the areas where consensus was not reached provide a rich framework for future research, inclusion in education and training venues, and publication.

Note: Life care planners and professional organizations that provide support and services to life care planners are encouraged to use the results of the Summit to evaluate personal skills and practices, and to develop future services and programs for the life care planning community.

**Topic One:**

**Visions for LCP Future: Identifying Controversial Aspects of Plans Created by Various Professional Disciplines.**

**Questions and Explanation:**

1. What are the differences between life care plans created by practitioners of various backgrounds?
2. What are the strengths and challenges from these differences? Do they reflect “turf wars?”
3. What, if anything, do we need to do to address differences?

The rationale for these questions relate to the fact that life care plans are created by practitioners from many professional backgrounds. Differences in methodology among practitionerspractitioners from various backgrounds have been noted, such as performing independent testing and relying on personal opinions. There has been concern expressed about whether these “personalizations,” or differences in methodology, undermine the overall life care planning process, and whether all life care planners should be follow the same methodology. Discussing this topic provided an opportunity to explore problems and advantages related to differences among professional backgrounds. Moreover, participants had the opportunity to discuss solutions to identified problems.

**Discussion:**

There were seven different professional backgrounds represented by the Summit participants, with rehabilitation counselors and nurses predominating. Differences were acknowledged, but not viewed as necessarily being negative. Acceptance of key principles and practices can prevent the life care plan from being undermined. Areas of discussion included perceptions that:

- There are inconsistencies in methodology.
  - There are life care planners who seem to make recommendations outside their scope of practice.
  - There is a need to understand one’s own limitations and to end “turf wars.”
  - Some life care planners leave off recommendations and seem to have “tunnel vision,” giving more weight to recommendations within the scope of their own discipline.
  - There is a need for more consistent formatting across disciplines.
-

**Consensus Statements (Unanimous Agreement):**

1. Life care planners will follow generally accepted methodology.
2. Life care planners will adhere to relevant Codes of Ethics as applied to life care planning and based on their individual licensure, registration, and/or certification.
3. Life care planners will work within their scope of practice of their licensure, registration, and/or certification.
4. Life care planners will collaborate, as appropriate, between disciplines in plan preparation.
5. There is a need for life care planners across disciplines to utilize text, narrative, and rationales as a foundation for the process of life care planning.
6. There may be differences in clinical judgment that can result in different recommendations; this may be reasonable, but this difference may affect content and value.

**Topic Two:****Developing Unity in the Field: Standards of Practice Shaping the Role and Function of Life Care Planning****Questions and Explanation:**

1. For those who are Life Care Planners, is there anyone not familiar with the International Academy of Life Care Planning (IALCP) Standards of Practice?
2. Are the IALCP Standards of Practice still applicable today in your practice?

This topic was unique in that two purposes were established prior the Summit. The first purpose of this topic was to examine the evolution of life care planning practice role and function under the influence of standards of practice. The second purpose was to have participants review the first draft of an instrument developed to identify the roles and functions of life care planners.

**Discussion:**

All participants revealed that they were familiar with the Standards of Practice for Life Care Planners. All stated that they believed that the Standards are relevant. Discussion did not focus on any particular aspect of the Standards.

The purpose of a role and function study is to determine the status of what it means to be a life care planner and what a life care planner does. Comparison with prior studies shows the evolution of the professional practice of life care planning and provides opportunity for dialog about changes. The study is also important for education and certification programs to teach and measure relevant material. Summit participants were asked to review the role and function survey instrument developed for life care planners and provide written and verbal comments regarding the appropriateness and breadth of coverage of the items. Participants were asked to comment on the need for additional items as well as whether or not there were redundancies in the items listed on the instrument. Over 1000 written comments were provided by Summit the participants. The comments will be used to modify the instrument in preparation for the actual role and function study.

**Consensus Statements (Unanimous Agreement):**

1. All participants were familiar with the IALCP Standards of Practice.
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2. The IALCP Standards of Practice are applicable to today's life care planning practice.
3. The following themes represent the comments for role and function study instrument development. Note that some comments pertain to issues broader than the study instrument.
  - The instrument is comprehensive, relevant, and useful.
  - Some questions are duplicative and there is repetition in concepts; some questions can be combined.
  - Items need to be regrouped items and reorganized.
  - The instrument is lengthy; some individual questions are too long.
  - There is need for term clarification, i.e., definitions or glossary; be aware of vague terminology; avoid use of undefined acronyms.
  - The definition of client needs to be clarified.
  - Questions should ask what IS done not what SHOULD BE done.
  - Some questions need an example to provide a frame of reference.
  - The choices of answers needs modifying; need to be able to indicate that the answer varies with various situations.
  - The instrument needs to be applicable and worded for Canadian life care planners planners.
  - Consider obtaining CEU credit for completing the survey as part of the role and function study.
  - There needs to be a definition of when a practitioner becomes a life care planner (consistent understanding is lacking).

**Topic Three:****Best Practices: Methodology Issues in Data Collection****Questions and Explanation:**

1. What methods are you using in data collection, including processes followed and use of tools?
2. Do these constitute the best practices for methodology?

In some ways, this revisited a topic that was discussed at the Life Care Planning Summit in 2000. During the 2000 Summit, consensus was reached by attendees on the need to utilize an inclusive data collection process in order to obtain available and relevant records including those of the client, treating professionals, and other relevant appropriate providers. After this was done, Summit 2000 attendees then agreed on the need for conducting of a comprehensive interview with the client and his/her family or other collaterals, if possible. The need to communicate, where possible, with all relevant professionals/experts who were involved in the client's care was also a consensus decision.

The foundation for addressing these questions during the 2008 Summit was related to the fact that as a field develops and the body of relevant research increases, there are often changes in what constitutes best practices in the methodologies to be employed. The goal of this discussion was to determine the most consistent methodologies used by attendees and how

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these had either stood the test of time or evolved over time.

**Discussion:**

This was a very broad topic and many aspects were raised for discussion. There were many opinions about how data collection should be performed, yet consensus was only reached on a few broad statements, not on details. The areas discussed included:

- the reliability of telephone surveys for obtaining pricing.
- the use of checklists provided during the training sessions.
- the qualifications of research assistants.
- the lack of interview of plaintiff.
- the use of questionnaires for interview, establishment of a plan and standardized physician questionnaires.
- the use of discounted versus retail costs for items.
- the standardization of formats and what should be included in a standardized format.
- utilization of the actual provider of service to the injured person such as a primary care physician versus physicians from centers of excellence.
- use of historical data.
- differences between probable versus potential.
- contact with referral sources.
- the methodology of new treatments.
- contact with specialists in rehabilitation.
- equipment needs.
- accessibility needs.
- contact with other life care planners and clinicians.
- need for individualized case specific plans.
- understanding and researching the standards of practice of other disciplines as applicable to life care plan development.
- the use of research.
- diagnosis driven, evidence based practice utilizing clinical practice guidelines, and how to address life expectancy.

It is clear that there are also a number of areas where there are continuing questions regarding how the best practice for methodology might be achieved. These areas provide fertile territory not only for continued discussion in the field but also for developing research and educational projects to assess these areas.

**Consensus Statements (Unanimous Agreement):**

1. Life Care Planners will request and analyze relevant records, which may include, but are not limited to, medical, therapeutic, educational, vocational and billing records.
  2. Life Care Planners will interview evaluatees, seek input from family/caregivers, and conduct an onsite evaluation when available or appropriate.
-

3. Life Care Planners will gather geographically relevant and representative pricing.
4. Life Care Planners will collaborate with relevant parties, including but not limited to, treating or consulting healthcare professionals and other disciplines as available or appropriate.

The following statement represents a large majority view, but was not unanimous:

- Life Care Planners may request/obtain assessments or perform testing evaluations (within their scope of practice) in the process of data collection.

**Topic Four:**

**Best Practices: Methodology Issues in Creating Admissible Life Care Plans**

**Questions and Explanation:**

1. What practices increase or decrease the likelihood that a life care plan is vulnerable to exclusion by the courts?

This topic is covered in life care planning courses and has been a topic in articles and texts. However, the rules are different throughout the country and life care planners have had different experiences. This creates some complexity in adopting best practices for life care planners. The purpose of discussing this topic was to discover the experiences that life care planners have had, identify successes and areas of challenge, and identify strategies to prevent or salvage problem situations. There was opportunity to discuss how the “other side” finds ways to exclude a life care planner and a life care plan.

**Discussion:**

This topic generated much discussion and highlighted the regional differences experienced by life care planners. Issues discussed included:

- Whether life care planners should follow a particular training format.
- Whether there should be consistency in the format of the work product and in testimony.
- Whether the work product should be consistent regardless of the referral source and payment source.
- How to establish credibility and professional presence to communicate a strong presentation.
- How to determine adequate foundation for all areas.

The discussion overall showed the need for continued development in this area.

**Consensus Statements (Unanimous Agreement):**

1. Life care planners will educate all, including the trier of fact, about the life care planner’s training, education, experience, specialized knowledge, and credentials as well as plan methodology and rationale.
  2. Life care planners will use published methodology and standards of practice in developing the life care plan.
-

3. Life care planners will utilize adequate foundation for recommendations and opinions included in the life care plan.

**Topic Five:****Research: Priorities, Needs, and Practical Applications in Day-to-Day Practice****Questions and Explanation:**

1. List factors that make life care planners more or less likely to use research in life care planning.
2. What barriers are there to using research?
3. What is needed to make life care planners comfortable and competent using research?
4. What are the risks and benefits of using and citing research?

There is variability in actual practice about the use of research. The purpose of this topic was to gather information about current day-to-day practices and identify perceived needs related to research in life care planning.

**Discussion:**

Some participants responded that they do not conduct research by virtue of the fact that they develop life care plans in non-Daubert states and their life care plans are not challenged, or because they do not have a need to use research support. Identified advantages to using research were:

- Using research to clarify recommendations, treatment, patient history, etc.
- Using research as an educational tool.
- Using research to become familiar with the client's situation (diagnosis, population, culture, etc.), especially in rare and unusual cases.
- Using research to update current knowledge.

Barriers and concerns about using research included:

- Knowing how to ensure that research selected is valid and reliable.
- Determining if the research matches (or contradicts) the individual situation (diagnosis, needs, demographics, culture, etc.).
- Ability to conduct and bill for research time and resources.
- Determining whether the time and cost of doing research outweigh the usefulness to the case.
- Understanding research methodologies as applied to life care planning.
- Having the ability to appropriately analyze research studies.
- Ability to defend the use of research in a life care plan.
- Reluctance to use and rely on research that is outside the life care planners' scope of practice and/or level of expertise.

**Consensus Statements (Unanimous Agreement):**

1. Life care planners will be competent to understand and explain the research cited in the plan they authored.
-

2. Life care planners, when utilizing research to support the foundation for a life care plan recommendation, will endeavor to reference studies that are reasonable, relevant, and appropriate to the intended purpose.
3. As appropriate, life care planners may utilize literature to become familiar with and update current knowledge on the evaluatee's diagnosis, population, and cultural background.

**Topic Six:****Professional Business Issues: Risks and Benefits of Databases, Templates, and Software****Questions and Explanation:**

1. How do you evaluate a life care plan report in terms of readability, admissibility, consistency, standardization, accuracy, and the expense of preparation?

This topic was considered timely due to the increased use of technology in the development of life care plans. There are a number of databases available providing costs for services in life care plans (e.g. American Hospital Association and others) that are often used by life care planners. There are a number of software programs for use in creating life care plans. There are also checklists and forms (templates for gathering and organizing data) that have been utilized during the training programs in life care planning and continue to be used by life care planners.

The goals of the session were to acknowledge the growing availability of tools such as databases, templates, and software, and to explore whether these tools create benefits or challenges. Other goals were to examine issues related to individualized tailoring of a life care plan versus "cookie-cutter" plans in terms of efficiency, cost savings, and the credibility of the work product and ways to make work products easier for readers to understand and use. Also explored was the use of technology in terms of the potential erosion of the value of skilled life care planners through the utilization of more generic life care plans based on diagnosis and group data information.

**Discussion:**

Life care planners do use databases, software, and templates to create life care plans. There was acknowledgement that these tools vary in format and content, but there is not a desire to adopt standardized tools or to reject any particular tool. The impact of these tools creates efficiency, but tools are not viewed as a replacement for the professional judgment of the life care planner. Participants reinforced the need for appropriate foundation and methodology discussed during other topics, and that use of tools does not alter that need. Participants discussed these points:

- There is a place for databases, templates, and software; however, life care planning requires clinical knowledge and judgment as well as the ability to individualize the life care plan.
- The life care plan should be made cost efficient by reducing unnecessary information, educating the referral source regarding what services are needed, and preventing duplication of services.

**Consensus Statements (Unanimous Agreement):**

1. The life care plan is individualized, client specific, and should address issues associated
-

with aging.

2. The life care plan will be a clear, concise, user-friendly document.
3. The use of databases, templates, and software will have an appropriate foundation.
4. There should be transparency and consistency in the life care plan product and process.

### Summary

The 2008 Life Care Planning Summit 2008 provided life care planners with a valuable opportunity to address many important issues in the field of life care planning. With each Summit, life care planners continue to reach consensus on a number of areas as well as identify areas for continued growth. Consensus provides life care planners with information for comparing and improving their own practices. Areas where agreement is not achieved should cause life care planners to examine thoughtfully their practices, beliefs, and values. Life care planners need to determine whether differences of opinions are of consequence, and what efforts, if any, need to be made to reach consensus on an issue. In addition, the Summit provides organizations that provide services to life care planners with information that will enhance future programming. During the next two years, before Summit 2010, life care planners are encouraged to use this information to ensure that our field grows in relevance, credibility, marketability, and defensibility.

### 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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The Summit is co-sponsored by IARP, the Foundation for Life Care Planning Research (FLCPR), and the University of Florida



## **Welcome to the 2008 Summit for Life Care Planners**

The International Academy of Life Care Planners, a Section of IARP, is honored to host the 2008 Summit for Life Care Planners. This biennial event brings 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 have the opportunity to examine the hot issues in the field and contribute to the resolutions of these issues and to the continued evolution of the field. Representatives of life care planning training programs, certification programs, and professional associations will join with researchers, practitioners, and support service providers to explore the current state of the field and set future directions. The topics to be discussed at this Summit reflect the changes and maturation occurring in this dynamic field. Although the process of life care planning is not new, developing consensus and unity in the field in order to provide a credible, meaningful, marketable, and defensible service that reflects common principles and foundation among all life care planners is still a work in progress.

A unique feature of the 2008 Summit is that it is joined with the IARP Annual Conference. Attendees will meet on Thursday to participate in six round table discussions. On Friday, attendees will spend the morning attending the IARP Conference while the Summit leaders compile the data from Day One. On Friday afternoon, Summit attendees will reconvene to review, evaluate, and discuss the results. There will also be a discussion of how to apply the results to personal development and to guide organizations in providing relevant services. Summit attendees will then have an option to attend Saturday and Sunday of the IARP Conference at an attractive, reduced registration rate. This is an ideal opportunity for life care planners to attend both events and receive more continuing education units, all for little extra cost or time.

Open to life care planners at all levels of experience; this is your opportunity to participate in the future development of your field. Participants will be listed in the published proceedings following the Summit. We are pleased that you have chosen to join your colleagues in shaping your own destiny.

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**SUMMIT COMMITTEE**

KAREN PRESTON, Co-Chair, International Academy of Life Care Planners

CAROL WALKER, Co-Chair, Foundation for Life Care Planning Research

JAMIE POMERANZ, Co-Chair, University of Florida

CLOIE JOHNSON

JUDITH PARKER

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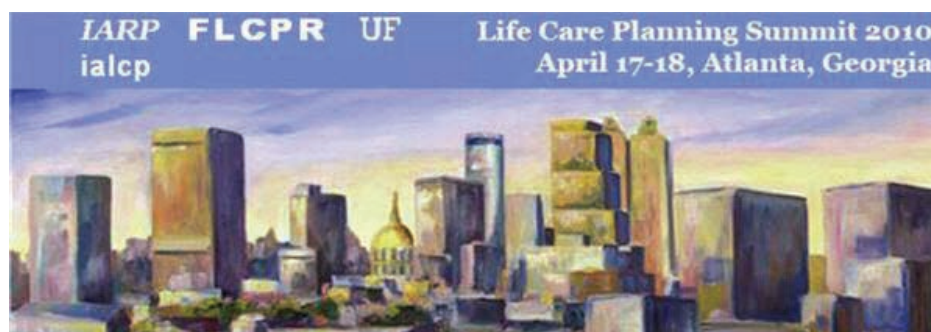
LINDA STEMPEL

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# LIFE CARE PLANNING SUMMIT 2010 PROCEEDINGS

*by Summit 2010 Co-Chairs*  
*Debbie Berens, Ph.D., CRC, CCM, CLCP*  
*Cloie Johnson, M.Ed., ABVE, CCM*  
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*Karen Preston, PHN, MS, CRRN, FIALCP*



## **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).

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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.

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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.

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**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 Miers, 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.
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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,

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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.
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- 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?

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**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.

**Life Care Planning Summit 2010 Attendees and Contributors:**

\*Denotes Summit Planning Committee Member

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Janice Landy	

## **Life Care Planning Canadian Summit 2011**

On June 3 and 4, 2011, the first Canadian Life Care Planning Summit was held in Toronto and sponsored by the International Academy of Life Care Planners (IALCP), International Association of Rehabilitation Professionals (IARP) Canadian Chapter, and the University of Western Ontario. This important event was attended by Canadian life care planners with an excellent representative sample of disciplines as well as leaders in the field of life care planning research, teaching, practice and policy-making. The event was initiated by the IARP Canadian Chapter in collaboration with the University of Western Ontario in an attempt to provide a forum for Canadian life care planners to develop consensus statements for the life care planning practice in Canada.

Multiple organizations provided invaluable support for this event including the following:

- The Foundation for Life Care Planning Research (FLCPR)
- The Care Planner Network
- International Commission on Health Care Certification (ICHCC)
- Canadian Society of Medical Evaluators (CSME)
- Vocational Rehabilitation Association (VRA) of Canada
- College of Vocational Rehabilitation Professionals (CVRP)
- University of Florida

Seventy-one participants representing a diversity of disciplines and backgrounds in life care planning, life care planning training, and professional associations met to explore the current state of the field and set future directions for life care planners in Canada. 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. The attendees reported backgrounds such as Occupational Therapist, Nurse, Vocational Rehabilitation Counselor, Rehabilitation Counselor, Physical Therapist, Speech Language Pathologist, Physician and Kinesiologist.

Cloie Johnson and Michel Lacerte were the co-chairs with Roger Weed providing both leadership and experience from previous summits in the use of the nominal group technique in developing consensus. Steve Yuhás, the upcoming chair for IALCP, Tony Choppa, past IALCP representative to IARP, Rick Robinson from the University of Florida, and Reg Gibbs served as Facilitators. Lynn Parker, Carol Bierbrier, Karen Rucas, Giovanna Boniface and Janice Ray were Recorders. Also present and assisting the IARP Canadian Chapter were Victoria Sweetman and Evie Cowitz. Evie has assisted in setting up a ListServ for Canadian

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life care planners and is the current president of VRA Ontario. Evie provided a VRA perspective and Victoria provided IARP Canadian Chapter perspective to this process. The proceedings of the event will be published in an upcoming issue of the *Journal of Life Care Planning*. In addition, a Legal Primer for Canadian Life Care Planners is also in the works.



From left: Michel Lacerte, Cloie Johnson and Roger Weed



From left: Cheryl Verbeek, Victoria Sweetman, Steve Yuhas, Reema Shafi and Giovanna Boniface

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# CANADIAN LIFE CARE PLANNING SUMMIT 2011 PROCEEDINGS

*by Summit 2011 Co-Chairs*  
*Cloie Johnson, MEd*  
*Michel Lacerte, MD*  
*With special contribution by Roger Weed, PhD*



## **Introduction**

On June 3 and 4, 2011, a conference was held specifically to address life care planning topics and issues in Canada with the goal of achieving consensus on five focus areas. This event was coordinated by the International Academy of Life Care Planners (IALCP), a section of the International Association of Rehabilitation Professionals (IARP), IARP Canadian Chapter, and the University of Western Ontario. The conference, held in Toronto, Ontario, was supported by the Foundation for Life Care Planning Research (FLCPR), the Care Planner Network, International Commission on Health Care Certification (ICHCC), Canadian Society of Medical Evaluators (CSME), Vocational Rehabilitation Association (VRA) of Canada, and the College of Vocational Rehabilitation Professionals (CVRP).

In order to establish a consistent foundation, the Summit Proceedings from the first Life Care Planning Summit held in Dallas Texas in 2000, and Consensus Statements derived from the Summits subsequently held in 2002, 2004, 2006, 2008 and 2010 were supplied to the participants.

At the Canadian Life Care Planning Summit 2011, Canadian life care planners were invited to participate in the development of consensus statements for the practice of Life Care Planning in Canada. Leaders in the field of Life Care Planning research, teaching, practice and policy were in attendance at this first Canadian Summit.

This 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 issues in the field, while contributing to the continued evolution of life care planning.

Seventy-one participants representing a diversity of disciplines and backgrounds in life care planning, life care planning training, and professional associations met to explore the current state of the field and set future directions for life care planners in Canada. 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 is given to the following colleagues who participated as speakers, facilitators and recorders during this Summit: Carol Bierbrier, Talaal Bond, Giovanna Boniface, Deborah Carter, Evie Cowitz, Tony Choppa, Evelyn ten Cate, Pierre Côté, Reg Gibbs, Lynn Parker, Janice Ray, Rick Robinson, Karen Rucas, Victoria Sweetman, and Steve Yuhas.

We are also recognize with gratitude the generous sponsors: Invacare Canada - Vince Morelli, Theracare Marketing Network - Erica Regular, and IARP - Victoria Sweetman. Thank you very much!

### **Summit Focus Areas**

For purposes of the Canadian Summit, topics and issues were sorted into five focus areas which include:

1. Professional preparation:
  - i. Minimum Education qualifications
  - ii. Experience
  - iii. Certifications
  - iv. Other credentials
  - v. Continuing Education
  - vi. Mentoring
  - vii. Standards of Practice
  - viii. Resource Development
  - ix. Writing skills
2. Basic tenets and procedures for completing life care plans:
  - i. Records review
  - ii. Medical foundation
  - iii. Expert witness v. consultant
  - iv. Reports and content
  - v. Economic requirements
3. Ethics:
  - i. Relevancy of ethics from certifications or licenses not specific to life care planning
  - ii. Maintaining files
  - iii. Documenting contacts for Life Care Plan entries
  - iv. Staying within area of expertise
  - v. Confidentiality
  - vi. Objectivity
4. Reliability and validity of the life care plan:
  - i. Based on adequate foundation
  - ii. Opinions referenced in life care planning by credentialed professionals
  - iii. Based on the industry requirements (e.g., personal injury, workers' comp., etc.)
  - iv. Research data
5. Information dissemination:
  - i. How to disseminate the Summit proceedings

Summit participants attended the two day event in Toronto and utilized the same technology introduced in the 2010 Life Care Planning Summit in Atlanta, GA that tabulated participants' responses in real time by utilizing personal Audience Response Systems from Turning Technologies. Jason Eadie, whose assistance was invaluable, was the onsite technician

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who trained attendees and provided devices to record instant responses throughout the Summit.

### **Methodology**

The Canadian Life Care Planning Summit integrated technology with the Modified Nominal Group Techniques General Instructions provided by Roger O. Weed, Ph.D. and based on the group consensus techniques outlined by Delbecq, Van de Ven, and Gustofson (1975). As instructed, attendees were sorted into five groups and participated in 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, kinesiologists, and speech/language pathologists. One economist participated in one round on the topic of validity and reliability, and two lawyers participated in the Ethics and Tenets and Procedures topics, one of whom stayed for the entire conference.).

As with previous Summits, each group had a facilitator (leader) and recorder who used an easel and marker to summarize the data and assist in the group process. Every attendee participated in each round table session. 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 utilized to record each attendee's "vote" in an effort to achieve consensus statements among the full group.

All Facilitators and Recorders were provided the group technique general instructions prior to the Summit as well as two training sessions (one by conference call and another in person the morning of the conference). All participants were emailed written instructions prior to the conference and, as a prelude to the beginning of the groups, were given verbal directions as well as comments on the value of achieving consensus statements. The Facilitators who did not vote, were all Americans, had participated in at least one previous Summit, and were familiar with the process.

Following the Summit, a draft of the proceedings was sent to all attendees, speakers and participating organizations and their comments were solicited. Corrections and clarification were obtained from the participants and incorporated as appropriate into the proceedings.

Finally, a second "prepublication draft" incorporating the second edited version that represented consensus and majority views was distributed to participating organizations for endorsement and final comment. This document is a culmination of the efforts of many individuals and representative organizations that have contributed and endorsed the contents contained in this report.

### **Threshold for Acceptance**

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

1. Unanimous consensus statements were those agreed upon by 100% of participants.
  2. Majority view statements were those agreed upon by a majority of participants, thereby indicating a need for more discussion and consideration by the group in an effort to obtain consensus.
  3. Near consensus statements were those receiving 90 % or more votes.
  4. Minority view statements were those where a majority could not be reached, but where strong feeling/opinion was held by the minority.
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### Participants

The Canadian Life Care Planning Summit 2011 had 71 attendees; however, due to early flight departures and other legitimate reasons, the final session had slightly less numbers as noted below.

The large group attendees proceeded to attempt to reach consensus and ultimately achieved consensus on 33 statements. An additional 18 statements achieved majority view with a threshold of 90% or greater.

Demographics of the attendees in the large group session held on Day 2 indicated the group was comprised of 58 participants (n=58) through large group discussion of Topic 2, 51 participants through Topic 3, and 47 participants through review and discussion of Topic 5:

#### Gender

Male	7 %
Female	93 %

#### Age

Less than 30 years old	2%
Age 31 – 40	21%
Age 41 – 50	33%
Age 51 – 60	43%
Age 61 – 70	2%
Age 71 +	0

#### Practice Location

Ontario	91%
Quebec	0
PE, Nova Scotia, NB, NL	2%
Manitoba, Saskatchewan	0
Alberta, British Columbia	5%
Northeast USA	2%
(practicing Life Care Planning in Canada)	
NW, SE, SW USA	1%

#### Professional Background

Rehabilitation Counselor	31%
Nurse	7%
Occupational Therapist	47%
Physical Therapist	9%
Speech Language Pathologist	2%
Physician	2%
Kinesiologist	3%

Also in attendance were two lawyers and one economist, who commented when asked although they did not vote.

**Years Experience as Life Care Planner**

0 – 5 years	28%
6 – 10 years	34%
11 – 15 years	14%
16 – 20 years	21%
21 – 25 years	2%
25 years	2%

Note: The number of years in the attendee's respective professions was not asked.

**Association Memberships**

IARP	50%
IALCP	43%
VRA	33%
ICHCC – CLCP/CCLCP	33%

One half (50%) of the attendees held membership with the International Association of Rehabilitation Professionals (IARP), 43% were a member of the International Academy of Life Care Planners (IALCP), and 33% were a member of the Vocational Rehabilitation Association (VRA). One third (33%) of the attendees held the CCLCP/CLCP Certification from the ICHCC.

**RESULTS**

The following sections represent a summary of the results of each focus group. Observations were solicited from the facilitators and their input is noted before the actual round table consensus and majority view outcome statements.

**FOCUS TOPIC 1: PROFESSIONAL PREPARATION**

Group Facilitator: Tony Choppa

Recorder: Lynn Parker

**Overall Observations**

Qualified life care planners must demonstrate a level of competence combining education, professional preparation, and experience. The greatest strength and primary challenge of life care planning is the interdisciplinary nature of service delivery and qualified professionals preparing life care plans from different disciplines.

In life care planning, certification came before standards of practice and this is rare among service delivery strategies.

Life care planning is not a profession, but is comprised of different qualified professionals providing the same specific area of expertise and consultation (i.e., specialty within a profession). This is a strength of this specialty practice area.

Standards are needed that are professionally appropriate for life care planning without being exclusionary and that acknowledge the diversity of the practitioners' backgrounds.

**Results for Topic 1**

In the large group, the following statements were voted on using the audience response system.

**Total Group Consensus Statement:**

Similar to the 2000 Life Care Planning Summit in Dallas, TX, there were no statements that received consensus.

**Total Group Majority Statement:**

The following statements resulted in a majority view:

**Education:**

- Minimum bachelor's degree in a health or rehab field
- Minimum of 5 years clinical experience in health related field
- Bachelors and or licensure as a health care professional
- Beginning in 2011, minimum of bachelors degree in a health and allied health or rehab field

**Experience**

- 5 years in a vocational and/or health setting or clinical practice
- Minimum of 5 years clinical experience in a rehab and/or health related field

**Individual Group Outcomes****Group 1**

Critical issues in professional preparation:

Relevant Education  
Experience  
Certification  
Continuing Education  
Mentoring  
Standards of Practice  
Resource Development

**Consensus was reached on the following statement:****Education**

*Minimum bachelor's degree with the following specializations; Voc, SLP, OT, PT, Kin, RN*

**Group 2**

Critical issues in professional preparation:

Education  
Experience  
Formal training in life care planning  
Certification  
Mentoring

**Consensus was reached on the following statements:****Education**

Minimum bachelor's degree in a health or rehab field

**Experience**

Minimum of 5 years clinical experience in health related field

**Group 3**

Critical issues in professional preparation:

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Formal Education  
Experience  
Life care education  
Certification  
Continuing education  
Mentoring

**No Consensus was reached, however the following statements were developed.**

**Education**

Minimum bachelor's degree in an allied health or related field - Majority (8-3)

**Experience**

5 years clinical experience in a multi-disciplinary setting - Minority (6 against-5 for)

**Group 4**

Critical issues in professional preparation:

Education  
Experience  
Certification  
Mentor  
Writing skills

**Consensus was reached on the following statements:**

**Education**

Bachelors and/or licensure as a health care professional

**Experience**

5 years in a vocational and/or health setting or clinical practice

**Group 5**

Critical issues in professional preparation:

Education  
Experience  
Life care planning training  
Certification

**The following statements were developed.**

**Education – consensus**

Beginning in 2011, minimum of bachelors degree in a health and allied health or rehab field

**Experience – Majority (8 for and 1 against)**

Minimum of 5 years clinical experience in a rehab and/or health related field

**Experience – Minority (1 for and 8 against)**

Minimum of 2000 clinical hours over 5 years in a rehab and/or health related field

**FOCUS TOPIC 2: BASIC TENETS AND PROCEDURES**

Group Facilitator: Rick Robinson

Recorder: Karen Rucas

**Overall Observations**

Basic tenets and procedures of life care planning serve as the basic core beliefs and procedures upon which the life care plan is developed. Tenets and procedures directly impact the entire process of life care planning from initial referral to final consultation with parties involved in the matter.

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Overall, input from each of the five (5) groups was generally consistent. Following group input, each item was rated by the group according to importance, each item was then rank ordered by the facilitator. Although many items were identified as basic tenets and procedures, certain items received no “votes” in terms of the importance of the item as a basic tenet or procedure. Item input by the group is described below:

### **Results for Topic 2**

Following small group discussion, each item was brought to the large group for further consensus development.

#### **Total Group Consensus Statements:**

In the large group discussion, the following statements reached full consensus:

- The Life Care Plan should be objective.
- The Life Care Plan should be consistent in methodology.
- The Life Care Plan should be unbiased.
- The Life Care Plan should be based on peer-reviewed evidence.
- The Life Care Plan should be individualized to the person and his/her specific needs.

#### **Total Group Majority Statements:**

The following item was accepted as reaching majority view:

- The Life Care Plan should be client centered and one that restores maximum functioning and quality of life while considering individual needs.

### **Individual Group Outcomes**

#### **Group 1**

##### **TENETS**

Individualized to person  
Objective and consistent  
Flexible , dynamic and lifelong  
Comprehensive and based on multidisciplinary data  
Promote and/or maximize function  
Implementable

##### **PROCEDURES**

Comprehensive and objective assessment  
Maintain consistent system of data collection  
Research medical condition and resources  
Interview Individual and family  
Review, do analysis and synthesize data  
Request additional testing and/or medical documentation or consultation  
Consistent record keeping and recording

#### **Group 2**

##### **TENETS**

Client centered that restores maximum functioning and quality of life while considering individual needs  
Objective, consistent and unbiased  
A dynamic plan to optimize care including comprehensive medical, vocational, etc. information deemed appropriate, necessary and reasonable

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Evidence based practice and peer reviewed  
 Promotes maximum functioning and increased residual capacity  
 Dynamic tool related to both disability and development, and updated throughout the life cycle  
 Specific to the individual and geographic area  
 Information regarding medical, vocation, etc. is comprehensive  
 Recommendations are medically and vocationally reasonable, necessary and appropriate  
 Opinions are medical and professionally supported

### **PROCEDURES**

Communicate to/with the client, family and medical providers  
 Comprehensive data collection and review of records  
 Address gaps in records  
 Use standardized format  
 Research medical conditions or disability  
 Render opinions within scope of practice  
 Research items and costs in geographical area  
 Consistent system of data collection and records  
 Comprehensive file review  
 Ask appropriate questions of medical providers  
 Communicate with all relevant, reliable and credible professionals involved  
 Accept referral based on knowledge base

### **Group 3**

#### **TENETS**

Individualized to specific needs  
 Objectivity in the development of the plan  
 Comprehensive and based on multidisciplinary data  
 Includes future health related needs  
 Blueprint of lifetime rehab and medical needs  
 Includes costs for health related needs  
 Usable  
 Dynamic document  
 Has a consistent foundation  
 Restores quality of life  
 Inclusive data collection

### **PROCEDURES**

Conducting comprehensive assessment and interview with client and significant others  
 Comprehensive review of medical records and documentation  
 Consistent process of data collection and compilation  
 Based on medical, vocational and rehab needs with case specific data  
 Research of the medical condition  
 Request for medical information and/or assessments to fill in gaps  
 Standardized record keeping and recording  
 Verifiable, reliable and credible sources

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**Group 4****TENETS**

Individualized needs and promote optimal health, function and autonomy  
Plan is lifelong, flexible, dynamic and changes with the client's needs  
Restores as much as possible quality of life and lifestyle to person  
Defining rehabilitation as ability, autonomy and social reintegration  
Conclusions are based on relevant professional opinions from multi-disciplinary practitioners with appropriate expertise  
Plan is consistent with acceptable standards of care and research  
Plan is based on reliable data and data collection  
Plan is objective, unbiased and planner is not an advocate  
Integrates multiple sources of data  
Plan is all encompassing  
Plan is holistic and client centered  
Plan is clear, concise and reader-friendly

**PROCEDURES**

Do a comprehensive assessment and research of analysis  
Biomedical research to support recommendations  
Data must be reviewed and critically appraised  
Review medical records and fill in the gaps  
Consult with medical and rehab team, relevant to their practice  
Involve the client in the process including interview with client and family without a cultural context  
Reasonable recommendations  
Assumptions must be stated  
Research available programs and services within a geographical area  
Establish reasonable outcomes

**Group 5****TENETS**

Objectivity and consistency  
Individualized to reflect individual needs and maximum health functioning  
To return client to previous life to the extent possible  
Backed by research and relevant data to include medical, vocational and functional data and opinions  
Specific to whole person, disability and geographical region  
Recommendations are reasonable and logical  
Lifelong, flexible and dynamic tool  
Restore quality of life  
Holistic  
Comprehensive and multidisciplinary

**PROCEDURES**

Full and comprehensive assessment to include client interview  
Collaborative approach to reflect consultation with medical and rehab professionals where possible  
Follow consistent methodology

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Consider all data accepted and rejected and close the gap by requesting additional testing and data as required and when possible

Review medical records

Development of adequate and appropriate recommendations

Research medical condition

Research professional literature

Research appropriate and current costs

### **FOCUS TOPIC 3: ETHICS**

Group Facilitator: Steve Yuhas

Recorder: Janice Ray

#### **Overall Observations**

As the professional specialization of life care planning has evolved, the need to promote ethical practice among life care planners has taken on increasing prominence. Participants were grouped together and major themes were identified that encompass the majority of the comments. The consensus on these themes are described below

#### **Results for Topic 3**

##### **Total Group Consensus Statement:**

In the large group, the following became consensus statements:

- Life Care Planners must be impartial.
- Life Care Planners must be objective.
- Life Care Planners should be knowledgeable about the client's condition.
- Life Care Planners must exhibit integrity.
- Life Care Planners must maintain confidentiality.
- Life Care Planners must demonstrate integrity and honesty.
- The Life Care Plan must include professional disclosure.
- Life Care Planners must maintain Professional Boundaries.
- Life Care Planners must adhere to their relevant professional Code of Ethics and Rules of Conduct.
- Life Care Planners must comply with the Rules of Privacy regarding information and confidentiality.

##### **Total Group Majority Statement:**

- Life Care Planners must be competent.
- Life Care Planners must obtain Informed Consent when required.
- Life Care Planners must provide/demonstrate sound foundations for recommendations.
- The Life Care Plan must include a professional disclosure.

#### **Individual Group Outcomes**

##### **Group 1**

Impartial/Objective/Independent

Competency & knowledgeable about the client's condition – education/training

Intellectual Honesty and Integrity

Confidentiality – disclosure

Informed Consent – client education; information without consent; transparency

Accountability - disciplinary measures

Dual Relationships; professional boundaries; dual roles/conflict of interest

Ethics of conduct/empathy  
Consistency  
Business Practices – fees; referral fees; ‘who is the client’  
Reconcile client needs/wants  
Use of alternate non-traditional treatment  
Aware of inherent biases  
Constraints of system  
Research literature

**Consensus was reached on the following statements:**

Life Care Planners must be Impartial/Objective /Independent  
Life Care Planners demonstrate competency and are knowledgeable about the client’s condition – education/training  
Life Care Planners must exhibit intellectual honesty and integrity  
Life Care Planners must maintain confidentiality – disclosure of information  
Life Care Planners must execute Informed Consent – client education; refrain from obtaining information without consent; transparency

**Group 2:**

Objective  
Competency  
Foundations for recommendations  
Education  
Confidentiality  
Adhere to established procedures  
Certified/License in area of expertise  
Individualized Life Care Plan  
Scope of Practice  
Supervision/Mentoring new Life Care Plan  
Client’s Best Interest  
Association affiliation & CEU’s  
Life Care Plan is peer reviewed

**Consensus was reached on the following statements:**

Life Care Planners must be objective  
Life Care Planners must demonstrate competency  
Life Care Planners must provide/demonstrate sound foundations for recommendations  
Education  
Life Care Planners must maintain confidentiality

**Group 3:**

Competency  
Objectivity  
Confidentiality  
Individualized Life Care Plan  
Consistency  
Standards of Practice  
Certification Required

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Rules of Conduct  
Supervision/Mentoring  
Research  
Without Bias/Prejudice

**Consensus was reached on the following statements:**

Competency  
Objectivity  
Confidentiality  
Individualized Life Care Plan  
Consistency

**Group 4:**

Competency  
Objectivity – Equality  
Integrity and Honesty  
Transparency – Clarity of Role/Scope of Request  
Maintain Professional Boundaries  
Scope of practice  
Conflict of Interest  
Individualized to Client Needs – based on pre-existing status  
Valid basis for Recommendations – valid data  
Confidentiality  
Dual Roles

**Consensus was reached on the following statements:**

Life Care Planners must demonstrate competency  
Life Care Planners must demonstrate objectivity – equality  
Life Care Planners must demonstrate integrity and honesty  
Life Care Planners must exercise transparency – clarity of role/scope of request  
Life Care Planners must maintain professional boundaries

**Group 5:**

Objective unbiased assessment and development of Life Care Plans  
Life Care Plan Code of Ethics and Rules of Conduct  
Rules of Privacy re: information & confidentiality  
Expertise and experience in client's disability  
Transparency of Life Care Planner's role/referral source  
Consistent methodology and practices  
Respectful of individuals and families  
Responsibility to client  
Consider client's preference/lifestyle and cultural differences  
Obtain certification  
Practice within area of expertise  
Belong to a Professional Association

**Consensus was reached on the following statements:**

Life Care Planners must provide objective unbiased assessments for the development of

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Life Care Plan  
 Life Care Planners must adhere to the Life Care Plan Code of Ethics and Rules of Conduct  
 Life Care Planners must comply with the Rules of Privacy re: information & confidentiality  
 Life Care Planners must demonstrate expertise and experience in client's disability  
 Life Care Planners must be transparent in their Life Care Planning role to the referral source

#### **FOCUS TOPIC 4: RELIABILITY AND VALIDITY**

Group Facilitator: Reg Gibbs

Recorder: Giovanna Boniface

#### **Overall Observations**

What makes a life care plan reliable and valid? This is the challenge every life care planner faces each time a plan is written. In order for a life care plan to be reliable and valid, the author must use a standardized and dependable methodology, an approach that is consistent with the individual's injury/disability, and be based on current research and professional opinion.

#### **Results for Topic 4**

##### **Total Group Consensus Statement:**

In the large group discussion, the following statement reached full consensus:

- Life Care Planners must utilize a Consistent Methodology

##### **Total Group Majority Statement:**

- Life Care Planners should use reliable, consistent, dependable, standardized methods for drawing conclusions.
- Life Care Plans should include research/literature or medical foundation for recommendations.
- Life Care Plans should rely upon opinions of medical/rehabilitation professionals.

#### **Individual Group Outcomes**

##### **Group 1**

Consistent Methodology  
 Content Validity-use of reliable data, individualized to the client  
 Face Validity-include research to validate recommendations  
 Stay within scope of practice/expertise  
 Reasonable and Justifiable

##### **Consensus was reached on the following:**

Consistent Methodology

##### **Group 2**

Reliable, consistent, dependable, standardized method for drawing conclusions  
 Reliance on file review as well as pertinent medical and allied health professional opinion  
 Probability v. possibility  
 Individualized life care plan content  
 Standard methodology

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Maintenance of own file/records  
Knowledge of legal issues  
Review of entire records  
Sources of information referenced

**Consensus was reached on the following:**

Reliable, consistent, dependable, standardized method for drawing conclusions

**Group 3**

Standardized process of assessment  
Use of current research for foundation  
Awareness of medical foundation  
Accurate item costs and sources of information  
Individualized plan  
Probable v. possible  
Reasonableness  
Filling gaps for medical information  
Stay within Scope of practice  
Lack of medical opinion  
Consider pre-existing conditions  
Accounting for aging process  
Peer evaluation  
Consistent documentation/maintenance of file  
Conflicting medical opinions  
Evaluation of life care plan as a discipline  
Relying on treatment providers opinions for recommendations  
Life Care Planner knowledge of interpretation of research methods

**No consensus was reached within this group.**

**Group 4**

Consistent methodology  
Use of existing research  
Relevant professional opinion  
Accurate and standardized and sufficient data/documentation  
Foundational data/literature  
Method with predictive validity  
Stay in your field  
Plain language  
Stay within expertise area/stay in your field  
Appropriate opinions/discussion  
Absent data/ no validity  
Current resource database  
How function has impacted disability  
Standard report format  
Relevant purposeful plan  
Individualized plan  
Reliable data

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Template for cost table  
 Standard interview process (could be linked to consistent methodology)  
 Consistent with published standards/research  
 Supportive documentation for research  
 Validate recommendations

#### **Group 5**

Consistent methodology  
 Research/literature or medical foundation for recommendations  
 Reliance/use of opinions of medical/rehab professionals  
 Does Life Care Plan make sense  
 Individualized (lifestyle of client)  
 Effective Life Care Plan  
 Include relevant information; eliminate irrelevant  
 Content validity  
 Costs are referenced  
 Probability v. possibility  
 Life Care Planners and medical/health professionals stay within scope of practice

#### **Consensus was reached on the following:**

Consistent methodology  
 Research/literature or medical foundation for recommendations

#### **FOCUS TOPIC 5: INFORMATION DISSEMINATION**

Group Facilitator: Cloie Johnson

Recorder: Carol Bierbrier

#### **Overall Observations**

Each round table group was requested to identify means in which Summit proceedings should be disseminated; ways to distribute and disseminate Summit information and/or product. With great consistency, each group identified similar avenues.

#### **Results of Topic 5**

##### **Total Group Consensus Statements:**

The large group reached consensus on the following statements:

- Life Care Planning Summit Proceedings should be disseminated through Peer Reviewed Journal
  - Life Care Planning Summit Proceedings should be disseminated through Journal of Life Care Planning
  - Life Care Planning Summit Proceedings should be disseminated through Professional Associations
  - Life Care Planning Summit Proceedings should be disseminated through Professional Association Websites
  - Life Care Planning Summit Proceedings should be disseminated through Professional Association Conferences
  - Life Care Planning Summit Proceedings should be disseminated through Webinars
  - Life Care Planning Summit Proceedings should be disseminated through CCLCP Course
  - Life Care Planning Summit Proceedings should be disseminated through ISLCP
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- Life Care Planning Summit Proceedings should be disseminated through LCP curriculum
- Life Care Planning Summit Proceedings should be disseminated through Manuals
- Life Care Planning Summit Proceedings should be disseminated through E-mail
- Life Care Planning Summit Proceedings should be disseminated through In Service
- Life Care Planning Summit Proceedings should be disseminated through Distance Learning
- Life Care Planning Summit Proceedings should be disseminated through Conference
- Life Care Planning Summit Proceedings should be disseminated through Websites on the Internet

**Total Group Majority Statements:**

They indicated the following as Majority Statements:

- Life Care Planning Summit Proceedings should be disseminated through Other Stakeholders Group Conferences-
- Life Care Planning Summit Proceedings should be disseminated through Newsletters
- Life Care Planning Summit Proceedings should be disseminated through the Regulatory College
- Life Care Planning Summit Proceedings should be disseminated through ICHCC Website
- Life Care Planning Summit Proceedings should be disseminated through a Canadian Website
- Life Care Planning Summit Proceedings should be disseminated through Stakeholders websites
- Life Care Planning Summit Proceedings should be disseminated through Manuals-Stand Alone
- Life Care Planning Summit Proceedings should be disseminated through Word of Mouth

**Individual Group Outcomes**

**Group 1**

Publication/journals  
 E-mail  
 Professional association's weblinks  
 Conferences  
 Website  
 Webinar  
 Professional Associations  
 Medical Legal Societies  
 Mailing  
 Universities/Training  
 Paper copy  
 Conferences for life care planning/IARP  
 E-mail to referral sources and colleagues  
 Journal of Life Care Planning  
 Word of mouth  
 In service  
 List Serves

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Manuals

**Consensus was reached on the following ways:**

Publication/Journal  
E-mail  
Websites  
Professional Association Web links  
Conferences  
Webinar  
University Training-majority

**Group 2**

Web  
Journal Peer Reviewed  
Professional Associations  
Newsletter  
Regulatory College  
Special Interest Groups  
CCLCP Course  
IBC/IIC  
Network of Educational Influential  
Webinar  
E-mail  
Meeting-Peer  
National Judicial Institutions  
Book-Printed  
Speakers Bureau  
Professional Assoc Web  
Library  
List Serves  
Monkey Survey Newspaper  
Newspaper

**Consensus was reached on the following ways:**

Web  
Journal Peer Review  
Professional Association  
Other Stakeholders Group Conferences-IBC/IIC/NJI/consumer/legal  
Newsletter  
Regulatory College  
Webinar  
CCLCP Course

**Group 3**

Website  
Journal of Life Care Planning  
Professional Associations members  
Journals (Professional)

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International Symposium of Life Care Planning  
Professional Colleges  
International Association of Rehabilitation Professionals/International Academy of Life  
Care Planners website  
ICHCC website  
Canadian Website  
Stakeholder Associations  
Life Care Planning curriculum  
List Serves  
One on One education  
In-service to professionals  
Google

**Consensus was reached on the following ways:**

Website  
Journal of Life Care Planning  
Professional Associations  
Professional Journals  
ISLCP  
Regulatory College/IALCP

**Majority was reached on the following ways:**

ICHCC Website  
A Canadian Website  
Life Care Planning curriculum

**Group 4**

Website-Professional Associations  
Professional Journals  
Internet  
Electronic Manual-Hardcopy  
E-mail  
In-service  
Distance Learning  
Conferences  
List Services

**Consensus was reached on the following ways:**

Website Professional Associations  
Professional Journals  
Electronic Manual-Hardcopy  
E-mail  
In Service  
Distance Learning  
Conferences  
Internet

**Group 5**

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Website  
Internet  
Journal (Peer reviewed)  
Webinar  
Professional Organizations  
List Serves  
Manuals-Hard copy/Electronic  
Word of Mouth  
Stakeholder's websites

**Consensus was reached on the following ways:**

Website/Internet/Search Optimized  
Journal  
Webinar  
Professional Organization  
List Serves  
Stakeholder's websites  
Manuals-Stand Alone  
Word of Mouth

**Summary**

The Canadian Life Care Planning Summit 2011 was on many levels a success and indicative of the diversity of the professionals in Canada, not unlike the diversity of Life Care Planners in the United States and elsewhere. There was a consistent replication of results from the Summits of 2000, 2002, 2004, 2006, 2008 and 2010. The initial work by the community in 2000 was mimicked by the attendees in Canada. The Summit proves once again to be an avenue of contribution by the practitioners to the field. We look forward to the work of the Canadians to utilize this process for ongoing success of Life Care Planners. Additionally, it is hoped that all Life Care Planners will take an active role in the growth and development of the field showing unity and collegiality.

**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.

**Canadian Life Care Planning Summit 2011 Attendees:**

Tanya Beattie  
Monique Besz  
Carol Bierbrier  
Martha Binstock  
Talaal Bond  
Giovanna Boniface  
Hazel Bowles  
Deborah Carter

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Jennifer Chladny  
Tony Choppa  
Deirdre Clayton  
Karen Collingwood  
Pierre Cote  
Beverly Cott  
Evie Cowitz  
Karyn Drewnowsky  
Judy Farrimond  
Laura Feldt  
Angela Fleming  
Connie Francoz  
Fred Geiger  
Vera Geiger  
Reg Gibbs  
Mary Hansen  
Joanne Hommik  
Belinda Humphrey  
Moirra Hunter  
Cloie Johnson  
Jennifer Johnston  
Robin Kadanoff  
Bonnie Koreen  
Ann Krause  
Tammy Kyle  
Michel Lacerte  
Ruth Leppard  
Galit Liffshiz  
Nancy Lok  
Paul Lukasik  
Sarah Macrae  
Ann McFarlane  
Mary Ellen Meyers  
Cindy Miller  
Dimple Mukherjee  
Barbara Nagy  
Elizabeth Parekunnel  
Lynn Parker  
Linda Petty  
Yvonne Pollard  
Elsa Poon  
Janice Ray  
Nancy Robinson  
Rick Robinson  
Joanne Romas  
Jordan Roovers  
Mathew Rose

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Karen Rucas  
Maria Scaringi  
Anne Schneiderman  
Susan Sereda  
Francois Sestier  
Reema Shafi  
Linda Simmons  
Lisa Simms  
Debra Stoch  
Susan Swanson  
Victoria Sweetman  
Evelyn ten Cate  
Edward Tenki  
Sandra Vellone  
Cheryl Verbeek  
Roger Weed  
Beverley Wilson  
Kim Wilson Wiles  
Steven Yuhás  
Samera Zoberi

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## SUMMARY OF TOTAL GROUP RESULTS FOR CANADIAN LIFE CARE PLANNING SUMMIT 2011

*Editor's Note: The following summary is intended to provide an "at-a-glance" summary of the Consensus and Majority View Statements reached during the inaugural Canadian Life Care Planning Summit held in June 2011 in Toronto, Canada in the five topic areas.*

### **Results for Topic 1**

In the large group, the following statements were voted on using the audience response system.

#### **Total Group Consensus statement:**

Similar to the 2000 Life Care Planning Summit in Dallas, TX, there were no statements that received consensus.

#### **Total Group Majority Statement:**

The following statements resulted in a majority view:

##### **Education:**

- Minimum bachelor's degree in a health or rehab field
- Minimum of 5 years clinical experience in health related field
- Bachelors and or licensure as a health care professional
- Beginning in 2011, minimum of bachelors degree in a health and allied health or rehab field

##### **Experience**

- 5 years in a vocational and/or health setting or clinical practice
- Minimum of 5 years clinical experience in a rehab and/or health related field

### **Results for Topic 2**

Following small group discussion, each item was brought to the large group for further consensus development.

#### **Total Group Consensus Statements:**

In the large group discussion, the following statements reached full consensus:

- The Life Care Plan should be objective
- The Life Care Plan should be consistent in methodology.
- The Life Care Plan should be unbiased.
- The Life Care Plan should be based on peer-reviewed evidence.
- The Life Care Plan should be individualized to the person and his/her specific needs.

#### **Total Group Majority Statements:**

The following item was accepted as reaching majority view:

- The Life Care Plan should be client centered and one that restores maximum functioning
-

and quality of life while considering individual needs.

### **Results for Topic 3**

#### **Total Group Consensus Statement:**

In the large group, the following became consensus statements:

- Life Care Planners must be impartial.
- Life Care Planners must be objective.
- Life Care Planners should be knowledgeable about the client's condition.
- Life Care Planners must exhibit integrity.
- Life Care Planners must maintain confidentiality.
- Life Care Planners must demonstrate integrity and honesty.
- The Life Care Plan must include professional disclosure.
- Life Care Planners must maintain Professional Boundaries.
- Life Care Planners must adhere to their relevant professional Code of Ethics and Rules of Conduct.
- Life Care Planners must comply with the Rules of Privacy regarding information and confidentiality.

#### **Total Group Majority Statement:**

- Life Care Planners must be competent.
- Life Care Planners must obtain Informed Consent when required.
- Life Care Planners must provide/demonstrate sound foundations for recommendations.
- The Life Care Plan must include a professional disclosure.

### **Results for Topic 4**

#### **Total Group Consensus Statement:**

In the large group discussion, the following statement reached full consensus:

- Life Care Planners must utilize a Consistent Methodology

#### **Total Group Majority Statement:**

- Life Care Planners should use reliable, consistent, dependable, standardized methods for drawing conclusions.
- Life Care Plans should include research/literature or medical foundation for recommendations.
- Life Care Plans should rely upon opinions of medical/rehabilitation professionals.

### **Results of Topic 5**

#### **Total Group Consensus Statements:**

The large group reached consensus on the following statements:

- LCP Summit Proceedings should be disseminated through Peer Reviewed Journal
  - Life Care Planning Summit Proceedings should be disseminated through Journal of Life Care Planning
  - Life Care Planning Summit Proceedings should be disseminated through Professional Associations
  - Life Care Planning Summit Proceedings should be disseminated through Professional Association Websites
  - Life Care Planning Summit Proceedings should be disseminated through Professional Association Conferences
-

- Life Care Planning Summit Proceedings should be disseminated through Webinars
- Life Care Planning Summit Proceedings should be disseminated through CCLCP Course
- Life Care Planning Summit Proceedings should be disseminated through ISLCP
- Life Care Planning Summit Proceedings should be disseminated through LCP curriculum
- Life Care Planning Summit Proceedings should be disseminated through Manuals
- Life Care Planning Summit Proceedings should be disseminated through E-mail
- Life Care Planning Summit Proceedings should be disseminated through In Service
- Life Care Planning Summit Proceedings should be disseminated through Distance Learning
- Life Care Planning Summit Proceedings should be disseminated through Conference
- Life Care Planning Summit Proceedings should be disseminated through Websites on the Internet

**Total Group Majority Statements:**

They indicated the following as Majority Statements:

- Life Care Planning Summit Proceedings should be disseminated through Other Stakeholders Group Conferences-
  - Life Care Planning Summit Proceedings should be disseminated through Newsletters
  - Life Care Planning Summit Proceedings should be disseminated through the Regulatory College
  - Life Care Planning Summit Proceedings should be disseminated through ICHCC Website
  - Life Care Planning Summit Proceedings should be disseminated through a Canadian Website
  - Life Care Planning Summit Proceedings should be disseminated through Stakeholders websites
  - Life Care Planning Summit Proceedings should be disseminated through Manuals-Stand Alone
  - Life Care Planning Summit Proceedings should be disseminated through Word of Mouth
- 
-



## SUMMARY OF TOTAL GROUP RESULTS FOR CANADIAN LIFE CARE PLANNING SUMMIT 2011

*Editor's Note: The following summary is intended to provide an "at-a-glance" summary of the Consensus and Majority View Statements reached during the inaugural Canadian Life Care Planning Summit held in June 2011 in Toronto, Canada in the five topic areas.*

### **Results for Topic 1**

In the large group, the following statements were voted on using the audience response system.

#### **Total Group Consensus statement:**

Similar to the 2000 Life Care Planning Summit in Dallas, TX, there were no statements that received consensus.

#### **Total Group Majority Statement:**

The following statements resulted in a majority view:

##### **Education:**

- Minimum bachelor's degree in a health or rehab field
- Minimum of 5 years clinical experience in health related field
- Bachelors and or licensure as a health care professional
- Beginning in 2011, minimum of bachelors degree in a health and allied health or rehab field

##### **Experience**

- 5 years in a vocational and/or health setting or clinical practice
- Minimum of 5 years clinical experience in a rehab and/or health related field

### **Results for Topic 2**

Following small group discussion, each item was brought to the large group for further consensus development.

#### **Total Group Consensus Statements:**

In the large group discussion, the following statements reached full consensus:

- The Life Care Plan should be objective
- The Life Care Plan should be consistent in methodology.
- The Life Care Plan should be unbiased.
- The Life Care Plan should be based on peer-reviewed evidence.
- The Life Care Plan should be individualized to the person and his/her specific needs.

#### **Total Group Majority Statements:**

The following item was accepted as reaching majority view:

- The Life Care Plan should be client centered and one that restores maximum functioning
-

and quality of life while considering individual needs.

### **Results for Topic 3**

#### **Total Group Consensus Statement:**

In the large group, the following became consensus statements:

- Life Care Planners must be impartial.
- Life Care Planners must be objective.
- Life Care Planners should be knowledgeable about the client's condition.
- Life Care Planners must exhibit integrity.
- Life Care Planners must maintain confidentiality.
- Life Care Planners must demonstrate integrity and honesty.
- The Life Care Plan must include professional disclosure.
- Life Care Planners must maintain Professional Boundaries.
- Life Care Planners must adhere to their relevant professional Code of Ethics and Rules of Conduct.
- Life Care Planners must comply with the Rules of Privacy regarding information and confidentiality.

#### **Total Group Majority Statement:**

- Life Care Planners must be competent.
- Life Care Planners must obtain Informed Consent when required.
- Life Care Planners must provide/demonstrate sound foundations for recommendations.
- The Life Care Plan must include a professional disclosure.

### **Results for Topic 4**

#### **Total Group Consensus Statement:**

In the large group discussion, the following statement reached full consensus:

- Life Care Planners must utilize a Consistent Methodology

#### **Total Group Majority Statement:**

- Life Care Planners should use reliable, consistent, dependable, standardized methods for drawing conclusions.
- Life Care Plans should include research/literature or medical foundation for recommendations.
- Life Care Plans should rely upon opinions of medical/rehabilitation professionals.

### **Results of Topic 5**

#### **Total Group Consensus Statements:**

The large group reached consensus on the following statements:

- LCP Summit Proceedings should be disseminated through Peer Reviewed Journal
  - Life Care Planning Summit Proceedings should be disseminated through Journal of Life Care Planning
  - Life Care Planning Summit Proceedings should be disseminated through Professional Associations
  - Life Care Planning Summit Proceedings should be disseminated through Professional Association Websites
  - Life Care Planning Summit Proceedings should be disseminated through Professional Association Conferences
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- Life Care Planning Summit Proceedings should be disseminated through Webinars
- Life Care Planning Summit Proceedings should be disseminated through CCLCP Course
- Life Care Planning Summit Proceedings should be disseminated through ISLCP
- Life Care Planning Summit Proceedings should be disseminated through LCP curriculum
- Life Care Planning Summit Proceedings should be disseminated through Manuals
- Life Care Planning Summit Proceedings should be disseminated through E-mail
- Life Care Planning Summit Proceedings should be disseminated through In Service
- Life Care Planning Summit Proceedings should be disseminated through Distance Learning
- Life Care Planning Summit Proceedings should be disseminated through Conference
- Life Care Planning Summit Proceedings should be disseminated through Websites on the Internet

**Total Group Majority Statements:**

They indicated the following as Majority Statements:

- Life Care Planning Summit Proceedings should be disseminated through Other Stakeholders Group Conferences-
  - Life Care Planning Summit Proceedings should be disseminated through Newsletters
  - Life Care Planning Summit Proceedings should be disseminated through the Regulatory College
  - Life Care Planning Summit Proceedings should be disseminated through ICHCC Website
  - Life Care Planning Summit Proceedings should be disseminated through a Canadian Website
  - Life Care Planning Summit Proceedings should be disseminated through Stakeholders websites
  - Life Care Planning Summit Proceedings should be disseminated through Manuals-Stand Alone
  - Life Care Planning Summit Proceedings should be disseminated through Word of Mouth
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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

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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

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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:

<b>Profession</b>	<b>Percentage*</b>
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

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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 evaluatee/family are recognized as best practice sources that provide foundation in Life Care Plans.

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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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## 2015 Life Care Planning Summit: Moving Forward and Looking Ahead

*Cloie B. Johnson, M.Ed.*

On September 18, 2015, the 2015 Life Care Planning Summit was held as a pre-conference to the International Symposium for Life Care Planners (ISLCP) conference in Scottsdale, Arizona. This Summit was sponsored by the International Association of Rehabilitation Professionals (IARP) and the Life Care Planning Section/International Academy of Life Care Planners (IALCP). I had the honor of chairing this Summit. My planning committee members were Patty Costantini, Jamie Gamez, and Debbe Marcinko. We also had a plethora of volunteers who were integral to the success of the Summit. On August 19, 2015, a Pre-Summit was held with the Facilitators and Recorders to allow them the opportunity to participate in both sessions and receive training on their duties during the Summit.

### Background

The Life Care Planning Summit is a biennial event attended by 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 resolution of these issues, and be involved in the continued evolution of the field.

Since 2000, over 500 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, 2011 (Canada) and 2012. Consensus and majority statements affecting the practitioner have been published.

Historically, Letters of Endorsement of the Summits and/or Proceedings beginning in 2000 have been received from a multitude of organizations involved with the multidisciplinary specialty practice 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)

Past Summit locations and dates include:

- 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
- Dallas, TX – May 5-6, 2012

Since the last Summit held in Dallas in 2012, Karen Preston took the lead on a task force to review and revise the Standards of Practice with the aid of the community of life care planners. This was completed and published in the *Standards of Practice for Life Care Planners*, Third Edition. Through this process, new topics were identified which were focal to the 2015 Summit.

The IALCP has taken the leadership role in chairing the Summit with the collegial relationships of the various associations and organizations within the life care planning community. Over time, the Summit results have been published and relied upon by practitioners in their daily practice. The Best Practices and Consensus and Majority Statements serve as reinforcement for the work of the life care planner. Practitioners are on occasion asked about these statements in the litigation arena. Summit proceedings are developed by life care planners for life care planners about life care planning. Being familiar and aware of these statements is very important. At the 2015 Summit, additional consensus statements were developed.

Facilitators and Recorders for the roundtable discussions were identified by the program Chair. They consisted of

qualified individuals from the supporting organizations as well as other experienced life care planning professionals. Due to the size of the number of participants, each topic area had two roundtables.

Professionals in various health care fields, including nursing, medicine, rehabilitation counseling, social work, physical and occupational therapy, are involved in developing life care plans. As this specialized field of practice continues to grow and develop, it is of specific purpose that a coordinated effort with standardized approaches be promoted. Education of new and experienced life care planners is an essential part of continuing professional development. The community of life care planners continues to look for more advanced educational opportunities along with ways to be involved in life care plan certification and research.

At the 2015 Summit, the group was assembled in a general session to explain the procedures and make brief opening statements that would serve to help focus attendees on the topics and issues.

Results of the *Life Care Plan Survey 2014: Business Practices and Protocols Survey*, conducted by Ann Neulicht and Susan Riddick-Grisham, with support from IARP, were presented as a precursor to the Best Practices in Business for Life Care Planners. The following are the results:

- A majority of respondents (55.6%) require a retainer before initiating work on a case. Retainer requests range from \$500 to \$10,000 (average, \$2,500).
- Over 87% of respondents indicate that they routinely (greater than 75% of the time) include interview notes/forms and case-generated documents in their file.
- Over 90% of respondents include cost research, written correspondence to/from other professionals, a narrative report, and Life Care Plan in their case file.
- Respondents overwhelmingly bill by the hour (86.6%), although a majority (51.1%) do not charge a different fee for “rush” services (defined as 1 week or less to 12 weeks or less, with an average of 4 weeks or less).
- A range of 10 to 80 hours is reported for Life Care Plan completion (mean of 38.9 hours; median, 40 hours; mode, 50 hours).
- A majority of respondents (61.3%) charge a different rate for court/deposition appearance.
- While a majority of respondents also charge for court/deposition appearance travel (61.3%), a different rate is not charged for travel (79.3%), professional services when retained as a non-testifying consultant (96.5%), research assistance (80.5%), or administrative services (77.4%).
- Contacting the referral source is the most prevalent means for resolving non-payment of bills (58.5%).
- A majority of respondents (64.2%) keep closed case files in both paper and paperless formats, including generated work products (93.6%), interview notes (78%), expert’s (own) deposition (59.6%), other expert reports (50.4%), and research notes (70.2%).
- Most of the respondents (40.1%) maintain closed files for 7 years.
- The primary health care-related professions of respondents are Rehabilitation Counseling (40.1%) and Nursing (34.5%).
- The primary certification is a CLCP (73.9%). A majority of respondents (60.6%) are owners of an independent practice with employees/subcontractors (75.8% rely on others to assist with cost research and 50.8% to assist with medical records review). Life Care Planning has been a part of most (58.87%) respondents’ practices for 11 to 30 years.
- Respondents have completed 1 to 3,883 Life Care Plans; the mean number of plans completed by respondents is 334 (median/mode: 100).
- At least 144 respondents participated in the survey.

After the general session, numbers were assigned randomly to obtain an integrated mix of experience, training and knowledge. Every attendee rotated through both topic focus groups and participated in discussions on all topics.

The modified nominal group technique was used within each group to gather information in an organized format and to reduce the influence of verbal or assertive participants on the outcome. A summary of the modified nominal group technique follows:

1. Ask the group members to write down their top 3 to 5 suggestions in order of priority.
2. Use a flip chart to go around the group and write down suggestions.
3. Combine suggestions when possible.
4. After the issues are recorded, ask the attendees to “vote” on 3 to 5 of the suggestions listed.
5. After the vote, the group facilitator assigns 1 to the highest, 2 to the second highest, etc.
6. Facilitator adds up the score for each and the top scoring 3 to 5 recommendations represent the decisions for that group.
7. When the large group reconvened, each small group contributed 3 to 5 recommendations.

Theoretically, several overlapping recommendations should be made. Time was reserved at the end of the day for additional discussion with the participants.

A working lunch then was held to include an Ethics Presentation by Dr. Christine Reid. She provided the following for this Summit write-up:

Goals of the working lunch focused on ethics included:

- 1) *learning about developments related to the consensus statement focused on ethics from the last Summit, calling for organizations relevant to life care planning to come together and develop a unified code of ethics for life care planning practice, and*
- 2) *discussing (in small groups) ethical dilemmas that Summit participants have encountered in life care planning practice, framing the discussion in terms of the ethical*

principles of Autonomy, Beneficence, Fidelity, Justice, and Nonmaleficence.

In the previous (2012) Summit, participants agreed on a consensus statement related to ethical practice in life care planning:

“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.” Since that time, there have been some conference calls among leaders of these organizations, but there has not been a commitment to collaborate on a unified code of ethics for life care planners. When committee members revising the Standards of Practice for Life Care Planners (3rd edition) engaged in an empirically-supported process of Standards revision, they determined that it was most appropriate to separate the Standards from the ethical guidelines portion of the previous Standards version, and to defer decisions focused on revisions of the ethical guidelines to a separate committee charged with developing an appropriate code of ethics. IARP has now begun the process of appointing a committee responsible for revising its code of ethics in a manner that could be applicable to all life care planners.

2015 Summit participants reviewed basic ethical principles that serve as the foundation for most professional codes of ethics. Descriptions of the principles of Autonomy, Beneficence, Fidelity, Justice, and Nonmaleficence were reviewed from the CDMS Code of Professional Conduct Preamble ([http://www.cdms.org/uploads/files/CDMS\\_Code\\_of\\_Professional\\_Conduct.pdf](http://www.cdms.org/uploads/files/CDMS_Code_of_Professional_Conduct.pdf)) and the CRCC Code of Professional Ethics for Rehabilitation Counselors Preamble <http://www.crccertification.com/filebin/pdf/CRCCCodeOfEthics.pdf>.

Participants reviewed how ethical dilemmas differ from clear ethical violations, because dilemmas have an element of “on the one hand..., but on the other hand . . .” when looking at what would be the “best” ethical decision. Participants then discussed how ethical dilemmas can often be described in terms of conflict between ethical principles. For example, if an evaluatee desires one approach to service delivery, but the treating healthcare providers recommend another approach as “best” for this individual, that can be considered a conflict between the client’s Autonomy (making one’s own choices) and the healthcare providers’ desire for Beneficence (what is likely to be “best” for the evaluatee). Discussing the ethical principles related to an ethical dilemma can be a useful tool in ethical consultation.

Organizations and associations involved with life care planning were invited to present to the attendees. They provided a brief synopsis of their presentation for the purposes of these proceedings.

### **2015 Summit Remarks by Victoria Powell on behalf of the AANLCP**

1. AANLCP is in the process of publishing our scope and standards of practice. Purchase of the nearly 300 page books will be available in January 2016.

2. AANLCP will hold its annual conference in San Antonio at the Hilton Palacio del Rio on February 5-8, 2016 (pre-conferences are on the 4th). The annual conference dates will be flexible, but the conference has officially moved from fall to late winter/early spring. The theme for this next conference is Blazin’ the Trail: Addressing Sensory Disorders Across the Ages. Presentations will include topics such as cochlear implants, visual disturbances, Language Acquisition through Motor Planning, sexual dysfunction, the ACA, service animals, CRPS, and much more.

3. Our membership offerings have changed and we now offer tiered memberships which allow members to pick and choose from the benefits they most value. The membership levels are Basic, Deluxe, and Premier. Each tier includes different products, services, and discounts.

4. Membership is open to nurses as well as non-nurses. Non-nurses are encouraged to join as associate members. Associate members are now offered the option to select tiered memberships in order to take advantage of our purchasing power resulting in greater member discounts.

5. Member benefits now include coding and costing resources and more. EBSCO Nursing Reference Center, Find-A-Code, ASA Crosswalk, ODG, Medical Fees are offered as well as discounts to PMIC, AHD, and Word Rake. NANDA discounts are in the works.

6. We also offer a resource repository called Crash Cart. This platform allows members to search various topics to find forms, templates, letters, websites, databases, costing spreadsheets, and other useful information.

7. We have a mentorship program called Lifeline. This is free to our members and works to pair members together for mentoring in both situational and ongoing needs. Lifeline includes mentorship for business-related topics as well as life care planning practice-related topics.

8. AANLCP is now working at the policy level. We have joined National Quality Forums which is a non-profit, nonpartisan organization, whose members work to improve healthcare in both public and private sectors by developing consensus statements and convening various stakeholders to spur action and improvement.

9. AANLCP is also a member of the Nursing Organizations Alliance. This partnership allows us to identify, educate and collaborate with other nursing organizations to build on issues of common interest in order to advance the nursing profession. The focus is to address current and emerging nursing and health care issues.

10. The Journal of Nurse Life Care Planners has gotten a new facelift and layout. It is currently being indexed and full text articles are available on our website.

11. Our Core Curriculum is undergoing a revision. Lori

Dickson is the editor for the second edition. Expected publication date is late 2017/early 2018.

12. AANLCP offers several webinar educational series. We have a potpourri of topics available in our monthly #WebinarWednesday series. We also launched our Mastermind series this year which consists of four-week courses each made up of a webinar, weekly discussion groups, and an exam. Mastermind covers a variety of business-related topics such as strategic planning, financial health, marketing, testimony, subcontracting, report writing, and more. Mastermind 2016 will begin in February.

#### **2015 Summit Remarks by Jan Roughan from the CNLCP**

American Association of Nurse Life Care Planners (AANLCP) was founded in 1997.

The Association established the Certified Nurse Life Care Planning (CNLCP®) Certification Board as a separate non-profit entity in 2008.

The Certification Board develops criteria for, and oversees specialty nursing certification within the practice of nurse life care planning.

The Board, in an effort to be inclusive, has created several “pathways” to afford nurses practicing within the field of life care planning the opportunity to obtain specialty certification.

Of particular relevance to those nurses who already have their CLCP is a “reciprocity” pathway that allows an individual to apply for, and obtain the CNLCP®, without having to sit for the exam. The reciprocity criteria, along with the criteria for other expanded pathways that were created recently by the CNLCP® Certification Board, is contained in the CNLCP® Handbook published on AANLCP’s website.

Two of the many goals of the CNLCP® Certification Board are:

- establishment of a level of professionalism in life care planning that is backed by evidence-based determination of the treatment needs of the individual affected by illness/injury
- securing accreditation by the American Board of Nursing Specialties (ABNS), thereby recognizing nurse life care planning as an advanced practice within the nursing profession

#### **2015 Summit Remarks by Susan Grisham from the FLCPR**

The Foundation for Life Care Planning Research was established in 2002 as a nonprofit research group, with a primary focus on research on the reliability and validity of the Life Care Planning process. Although that remains an important consideration for the Foundation, the Board has broadened the scope of the mission to consider any well-developed research design in Life Care Planning that advances the field and makes a significant contribution to the population of disabled individuals Life Care Planners seek to serve.

Publications are supported by research grant funding from FLCPR. The most recent research grant was awarded to Noel Ysasi, Ph.D., in 2014. His research involved the empirical analysis of 123 Psychiatrists and 120 Life Care Planners (LCPs) regarding their professional opinions as to the prevalence and frequency of secondary complications (SCs) among persons with spinal cord injuries. Opinions were then compared with the empirical literature. Participants described how decisions were made and whether to include the costs of future SCs or not based on the possibility (less than 50%) versus probability (greater than 51%) of such complications occurring. Furthermore, this researcher surveyed both groups to assess for potential ethical concerns among persons operating as a LCP (provides expert testimony). This study was intended to provide LCPs with a guide as to whether or not particular SCs should be included within the life care plan, while gathering additional support from psychiatrists as to whether the inclusion of a cost should be added for specific SCs. Publications will be forthcoming.

#### **2015 Summit Remarks by Patricia Costantini from the IALCP**

Patty Costantini, Life Care Planning Section – IALCP (International Academy of Life Care Planners) Past Chair, provided an update on IALCP’s activities, which have included the items listed below.

- The Journal of Life Care Planning was revived in 2015 under the leadership of Editor Dianne Simmons Grab. JLCPP is on course to publish four issues by the end of the year.
- IALCP convened a meeting of life care planning industry leaders, which was held earlier that day (9/18/15). In attendance were representatives and staff from IALCP and IARP, the Foundation for Life Care Planning Research, the American Association of Nurse Life Care Planners (AANLCP), and the International Commission on Health Care Certification (ICHCC). The industry leaders agreed to identify common goals and interests and to continue to meet (preferably at life care planning conferences) intermittently to maintain open communication and collegiality.
- IALCP members have participated in IARP’s educational endeavors by providing webinars relevant to life care planning practice. Additional webinars will be available in upcoming months.
- IALCP section is excited and well prepared to assist in the transition of the ISLCP (International Symposium for Life Care Planning) from the FLCPR to IARP. Current IALCP Chair, Debbe Marcinko, will be Co-Chair of the 2016 IARP conference, to be held in Pittsburgh, Pennsylvania.
- The IALCP board of directors continues to direct its efforts on updating and streamlining its strategic plan. Goals are focused on the overall advancement of the

practice of life care planning.

### **2015 Summit Remarks by Evelyn Robert from the ICHCC**

We submitted the application for accreditation and will know something by the end of the year and that we were very optimistic. The other announcement was that effective January 2016 the exam will be a two-prong exam which will include a life care plan written and based on a sample provided by the commission and the multiple choice exam.

Robert May also spoke. He went more into the accreditation and his thanks to Dr. Reid for all of her help with the application process.

### **2015 Summit Remarks by IARP Chief Staff Officer**

IARP Executive Director Carl Wangman addressed the opening session of the 2015 Summit by quipping any association executive would welcome the opportunity to address more than 80% of the members of his or her association.

He paid tribute to the leadership of the Foundation for Life Planning Research Board and its decision to refocus on vitally needed original research for the community. He said IARP and its staff look forward to the opportunity to bring together the highly rated symposium and IARP annual meeting. The first joint meeting for the two organizations will be held in Pittsburgh, Pennsylvania, October 20-23, 2016. Evidence of the importance of life care planners to the Pittsburgh event is the choice of Debbie Marcinko, the current chair of the IARP Life Care Planning IALCP section, as the co-chair of the combined venture. The other chair is veteran IARP member Steve Shedlin, a past president of the international organization.

Mr. Wangman emphasized IARP's focus on the development of its ever-increasing student membership. There are currently over 700 student members in North America. He admitted a mistake had been made when the IARP staff and board assumed that graduates would shortly be employed after receiving their master's degree. He said the original steppingstone to professional individual members in the association is called professional candidate. The initial thinking was that professional candidate status would be available for one year. Now, the IARP board has determined a minimum of two years is more logical for a student to graduate, seek a job, and be employed. After the two-year period, the student is more likely to qualify as a regular member of the association. All students will be contacted with this new longer probationary period.

Another major change in IARP is this focus on the total career opportunities that exist for association members. Before July 1 of this year, members who were interested in more than one of the special interest sections were required to pay additional dues. As of July 1, all sections are now available to all members, with the only exception being that members of the Social Security Vocational Experts section must have a blanket purchase agreement number from the

Social Security Administration as a prerequisite of their membership in that section. He said the association would create a separate discussion group for those interested in SSVE work, but have not yet received training.

IARP continues its outreach to new service areas. The new Vocational Rehabilitation Transition Services Section is an outgrowth of a special program conducted last spring as a part of the IARP Advanced Training Series. Highlighting federal action opening new practice opportunities, the pioneer IARP program conducted in Chicago over two and a half days featured Jim Boyd, Judy Drew, and Liz Watson as the faculty. The 40 attendees extolled the virtues of the program, and a companion discussion group for the attendees has been effective for the last six months. Liz Watson, who has been selected to the IARP Board of Directors to represent the new Vocational Rehabilitation Transition Services Section, will shortly establish a discussion group and outline of the objectives of the section.

The IARP executive also paid special tribute to Heidi Fawber, Patty Costantini, and Debbie Marcinko for their aggressive promotion of the Pittsburgh venue. He also saluted Susan Riddick-Grisham and her program committee for program excellence of the Symposium. He promised that IARP, in its management role for the 2016 event, would ensure the quality of the Symposium is maintained at its current high level.

After the working lunch with presentations on Ethics, and by the various organizations and associations affiliated with life care planning, attendees were re-assembled into one large group and the breakout group results were presented and summarized. Overall, a significant amount of consensus was reached on multiple topics. In other areas, there was a majority view. The entire group then participated in exploring whether or not these statements were in fact a Majority or Consensus view. Interestingly enough, despite great efforts by the facilitators and volunteers to identify and avoid already established majority and consensus statements, and/or already established Standards of Practice, some statements were found to be duplicative and therefore were rejected due to their redundancy.

Following the Summit, a draft of the proceedings was sent to all attendees. Corrections and clarification were obtained from the participants and incorporated as appropriate into these proceedings. This document is a culmination of the efforts of many individuals and representative organizations that have contributed and endorsed the contents contained in this report.

Best Practices for Business and Best Practices for Transparency were the main topics for the 2015 Summit. This one-day Summit was a full day with a working lunch, including an Ethics Presentation by Dr. Christine Reid, followed by updates from the IALCP, Foundation of Life Care Planning Research (FLCPR), American Association of Nurse Life Care Planners (AANLCP), Certified Nurse Life

Care Planners (CNLCP) Certification Board, and the International Commission on Health Care Certification (ICHCC).

Topics discussed in the breakout sessions were: Best Practice in Business of Life Care Planners and Best Practice in Transparency for Life Care Planners.

Consensus Statements from the 2015 Life Care Planning Summit to be added to the prior 99 Consensus and Majority Statements from earlier Summits include:

100. Life Care Planners have the option to use support staff under their direction and guidance in completing life care plans.

101. Life Care Planners shall identify conflicts of interest.

102. Life Care Planners shall identify the sources of their recommendations.

The attendees were an integral part in the development and outcome for the field. Attendees are listed below:

Michele Albers  
 Dorajane Apuna  
 Mary Barros-Bailey  
 Debbie Berens  
 Harold Bialsky  
 Santo Steven Bifulco  
 Stephanie Birely  
 Marianne Boeing  
 Nancy Bond  
 Giovanna Boniface (Recorder)  
 Penelope Carragone  
 Anthony Choppa (Facilitator)  
 Nick Choppa  
 Lisa Clapp (Facilitator)  
 Michelle Clarence  
 Maryanne Cline  
 Denise Colingnon  
 Mariann Cosby  
 Patricia Costantini  
 Brian Daly  
 Kelly Dawson  
 Heidi Fawber  
 Brook Feerick (Recorder)  
 Nancy Forest  
 John Fountaine\* (Recorder)  
 Cynthia Fricke  
 Jamie Gamez\* (Recorder)  
 Reg Gibbs (Facilitator)  
 Shelene Giles (Recorder)  
 Bob Gisclair  
 Cathy Gragg  
 Gary Michael Graham  
 Cathy Gross  
 Susan Guth  
 Janice Haris  
 Camie Hawkins

Lois Hawkins  
 Stacey Helvin  
 Carolyn Higdon  
 Shanna Huber  
 Carol Hyland  
 Harvey Jacobs  
 Vicky Jensen (Recorder)  
 Amy Johnson Mackenzie  
 Alex Karras  
 Elizabeth Kattman  
 Anita Kelly  
 Charles Kincaid  
 Trudy Koslow (Recorder)  
 Susan LaFollette  
 Stony Landry  
 Joanne Latham  
 Sherry Latham\* (Recorder)  
 Dirk Leverant  
 Ashley Literski  
 Paul Lukasik  
 Lisa Mancuso  
 Ann Maniha  
 Stephen Mann  
 Debbie Marcinko  
 Irmo Marini  
 Michael Martinez  
 Francine Mazone  
 Hector Miranda  
 Nancy Mitchell  
 Ann Neulicht  
 Michele Nielsen  
 Jodie Nolf  
 Erin O'Callaghan  
 Judith Parker (Recorder)  
 Gerri Pennachio  
 Regina Pepin  
 Kellie Poliseno  
 Victoria Powell  
 Karen Preston (Facilitator)  
 Edmond Provder  
 Christine Reid  
 Rhonda Renteria  
 Mary Sue Richards  
 Susan Riddick-Grisham  
 Evelyn Robert  
 Mary Rohrig  
 Jan Roughan  
 Anne Savage Veh\* (Recorder)  
 Carla Seyler (Recorder)  
 Lisa Simeoni  
 Dianne Simmons Grab  
 Ron Smolarski  
 Geri Springston  
 Diane Steffy  
 Linda Stempel

Larry Stokes  
Robert Taylor  
Wendy Thomason  
Karen Tobie Shearer  
Kacy Turner  
Carol Upman  
Liz Vinton  
Hope Wade  
Heidee White  
Lora White  
Candace Winter  
Daniel Wolstain  
Helen Woodard  
Laura Woodard  
Steven Yuhas  
Nancy Zangmeister

\*Participated in Pre-Summit process which was included in general discussion.

**About the Author**

**Cloie B. Johnson**, M.Ed., is a Rehabilitation Counselor and Case Manager providing life care planning service at OSC Vocational Systems, Inc. in Bothell, Washington. Cloie has chaired or co-chaired the Summits in 2010, 2011, 2012 and 2015. She is also a past Chair of the IALCP.



## 2017 Life Care Planning Summit Proceedings

*Tracy Albee, RN*

*Jamie N. Gamez, MA*

*Cloie B. Johnson, MEd*

Life care planning is an advanced specialty practice performed by a diverse community of professionals in various health care fields. Due to the diversity of professional backgrounds in life care planning and because this specialized practice continues to grow and develop, it is vital that a coordinated effort with standardized approaches be promoted. Education of emerging and experienced practicing professionals is a key aspect of fostering the advancement of the field. While process and standards of practice for life care planning have been established and published, consensus and unity in this diverse field is an evolving process. Through life care planning Summits, life care planners have the opportunity to examine relevant issues, contribute to the resolution of these issues, and be involved in the evolution of the specialty practice, (Johnson, 2012; Johnson and Gamez, 2015; Johnson and Gamez, 2017).

Life care planning Summits are historically biennial events attended by life care planning practitioners with the goal of exploring the current state and future direction of life care planning. Since 2000, over 600 life care planners have participated in Summits, demonstrating a commitment to addressing cutting-edge issues affecting the life care planning community.

Published Summit results are generally accepted and relied upon by life care planning practitioners. The Best Practices and Consensus and Majority Statements derived from past Summits (Johnson 2015; Preston and Johnson, 2012) serve as reinforcement for the work of the life care planner. Summits are unique, in that their proceedings are developed by practicing life care planners, for life care planners and about life care planning. At the 2017 Summit, consensus was achieved in several key areas.

### **2017 Life Care Planning Summit**

On May 19-20, 2017, the tenth life care planning Summit was held in Denver, Colorado. The summit was attended by 102 life care planners from diverse backgrounds and geographic locations. Past Summit locations and dates include:

- 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
- Dallas, TX – May 5-6, 2012
- Scottsdale, AZ – September 18, 2015

This article includes 2017 Summit proceedings, including submissions by organizational representatives and panelists from IALCP, AANLCP, ICHCC and FLCPR. The content was reviewed by the Summit committee and presented to attendees for their review to ensure that the contents accurately reflect the events of the 2017 Summit proceedings.

The 2017 Summit was sponsored by the International Association of Rehabilitation Professionals (IARP) and the Life Care Planning Section/International Academy of Life Care Planners (IALCP) with support and representation from the International Commission on Health Care Certification (ICHCC), the American Association of Nurse Life Care Planners (AANLCP) and the Foundation for Life Care Planning Research (FLCPR). The IALCP took the leadership role in chairing the Summit, with collaboration and support from various associations and organizations within the life care planning community. The 2017 summit was chaired by Cloie B. Johnson and Susan Grisham. The planning committee included Tracy Albee, Debbie Berens, Jamie Gamez, Sherry Latham, Karen Preston, Patricia Rapson, Evelyn Roberts and Denise Wrenn. There were also numerous volunteers who contributed to the success of the Summit. Practicing life care planning professionals in attendance included nurses, rehabilitation counselors, physicians, social workers, physical therapists, occupational therapists and speech language therapists.

### **Pre-Summit Workshop: May 12, 2017**

Prior to the Summit, twelve facilitators and recorders of the nominal group process were identified by the program chairpersons to assist in the coordination of Summit activities. Facilitators were Tracy Albee, Reg Gibbs, Karen Preston and Steve Yuhas and recorders were Debbie Berens, Brook Feerick, Carol Hyland, Jody Masterson, Linda Olzack, Dana Penilton, Patricia Rapson and Laura Woodard. These individuals were qualified practicing life care planning professionals. On May 12, 2017, a Pre-Summit workshop was held via video conference call with the facilitators and recorders to allow them the opportunity to participate in Summit sessions. During this Pre-Summit, Cloie Johnson served as facilitator and John Cary and Laura Stajduhar served as recorders. Participant responses collected during the workshop were incorporated into the second day of Summit proceedings. During this workshop, these individuals also received training on their Summit duties from Cloie Johnson.

### Summit Day One Proceedings: Friday May 19, 2017

On the first day of the Summit, all event attendees were assembled in a general session for presentations and panels explaining the purpose of the 2017 Summit. The goal of the 2017 summit, to further define “associated costs”, was presented. Topics included how costs are derived and methods to determine and utilize collateral sources. A presentation covering a review of past Summits and a specific look at where “associated costs” were already referenced within the current Consensus and Majority Statements (Johnson, 2015; Preston & Johnson, 2012) and the Standards of Practice for Life Care Planners (IARP, 2015) was conducted.

Practicing life care planning professionals in attendance actively participated in this review, which set the stage for the remainder of the Summit. During the general session on May 19th, the focus was on providing a foundation of knowledge for the nominal group process, which would unfold during the second day of the Summit in the breakout sessions and the large group discussion.

### Life Care Plan Venues

A closer look into venues where life care plans are utilized was undertaken. As a group, attendees generated 29 venues or applications in which a life care plan may be developed by a qualified professional. These are outlined in Table 1 below.

**Table 1**

#### ***Life Care Planning Venues***

Civil litigation to include personal injury, general liability and medical malpractice  
Trust funds  
Wealth management  
Setting reserves  
Vaccine cases  
Worker’s compensation cases  
Structured settlements  
Private hire  
Medicare Set-Asides (MSA)  
Marital dissolution proceedings  
Discharge planning  
Business dissolution  
Specialized injury compensation funds  
Veteran’s disability  
Veteran’s independent living assessments  
Estate planning  
Pre-litigation settlement  
Deceased/replacement costs  
Conservatorships/guardianships  
Victim’s assistance programs  
American Civil Liberty Union (ACLU) matters  
Pre-nuptial agreements  
Fundraising support  
Case management

Elder advocacy

Adoption

Clinical trial adverse results

Special education planning

Embezzlement/fraudulent use of funds

### Collateral Sources

Day one also provided a review of results from the 2017 Collateral Source Survey (Pomeranz, N.d.) which was sent to all known life care planners in March 2017, prior to the 2017 Summit. A total of 187 life care planners from 26 states responded to the survey. A total of 47% of the respondents reported being asked to include collateral sources in life care plans, while 53% had not. Of the respondents, 59% reported never having included collateral sources in the development of a life care plan, 39% sometimes include collateral sources and 2% reported always including collateral sources in life care plans. When asked who instructs them to include collateral sources in the development of a life care plan, respondents answered: The referral source (57%), federal rulings (4%), state rulings (6%) or done at my discretion (34%). When asked what specific collateral sources they had included in the development of life care plans, the following were reported: Medicaid (35%), Medicare (41%), Tricare (16%), VA Benefits (22%), Medicaid Waivers (13%), Federal/State mandated Vocational Rehabilitation Services (20%), Federal/State mandated Blind Services (14%), Federal/State mandated Deaf Services (8%), ACA or other private health insurance (35%) and Other (47%). Respondents included collateral sources in the following types of cases: Litigated Plaintiff Cases (38%), Litigated Defense Cases (59%), Trusts (17%), Vaccine Cases (16%), Dissolution Cases (8%), Direct Hire from Family (18%) and Other (25%).

The following survey question was posed: *When including collateral sources in the development of life care plans, do you verify and document the limitations? (Examples: Waiting lists for Medicaid Waivers or if Medicaid is a payer source, one can only go to physicians who accept Medicaid).* The following answers were given: Always (49%), Sometimes (21%) and Never (29%). Regarding knowledge of collateral sources, respondents noted: I am aware of all of the them and everything they pay for (11%); I know some information about some of them and/or some of what they pay for (68%); I know little about them and what they pay for (14%); I know nothing about them and what they pay for (4%); and I don't care (3%).

### Professional Organization Input

A working lunch was held during the first day of the Summit proceedings. During this lunch, updates were provided by organizations which offer support, certification, education and/or guidance to life care planners. Presentations were made by representatives of the ICHCC, IARP, IALCP, FLCPR and AANLCP. The American Academy of Physician

Life Care Planners (AAPLCP) was invited, however, declined attendance. Below is a summary of remarks made by representatives of each involved organization.

***International Commission on Health Care Certification.***

Ms. Sherry Latham provided an update for the International Commission on Health Care Certification. The International Commission on Health Care Certification assumed the responsibility to provide the first specialty certification for life care planners, the Certified Life Care Planner (CLCP) credential, in 1996. The CLCP was developed out of a growing need for professionals to demonstrate competency, qualifications, and professional expertise in the role as a life care planner.

Ms. Latham stressed that all representatives of the ICHCC are available to assist life care planners with questions about the certification itself, approved educational programs as preparation for the Certified Life Care Planner (CLCP) certification, the standards of the CLCP, ethical dilemmas, approved continuing educational programs or any other matters associated with the field of life care planning.

The ICHCC has been actively pursuing accreditation for the CLCP through the National Commission for Certifying Agencies (NCCA), and continues to strive to fulfill the stringent requirements. An important factor in obtaining accreditation is the need for statistical information demonstrating a comprehensive analysis of the certification practices providing valid and reliable information. The ICHCC currently has surveys available to life care planners to address those needs. There are two surveys, the role and function study and a report writing survey, which can be located on their website, [www.ichcc.org](http://www.ichcc.org). It is vital that the Commission collect as much information for the best representation of statistical information. Four CLCP CEU's can be obtained for completing each survey. Another component of accreditation is the statistical information involving a Beta test, which will be posted soon on the ICHCC website. A post will be sent out on the list-serves when available and the ICHCC encourages everyone to participate in this vital component of the accreditation process.

***Foundation for Life Care Planning Research.***

Dr. Debbie Berens provided an update for the Foundation for Life Care Planning Research. First, appreciation was extended for allowing the Foundation for Life Care Planning Research to provide an update on the organization. Dr. Paul Deutsch, who typically provides the update, was instrumental in forming the FLCPR in 2002 and continues to champion its mission. Unfortunately, Dr. Deutsch has had some medical issues that have resulted in his retirement from his practice and his primary Foundation leadership responsibilities. Dr. Deutsch sounds well and he wants everyone to know that even though he has retired from

his active life care planning practice, he continues to follow what is going on in life care planning and remains very interested in the progress, leadership, and future direction of our specialty practice. Susan Riddick-Grisham who led the Foundation for many years as Chair of the Board, rolled off the Board over the summer and appreciation of her tremendous work for the Foundation was expressed. In 2016, Dr. Debbie Berens was named co-President with Dr. Deutsch and since his retirement, she has served as President of the Foundation.

The Foundation is a nonprofit research group with the primary mission of supporting research on the process of life care planning, including research on the reliability and validity of the life care planning process. Several years ago, the Foundation made the decision to shift away from sponsoring or co-sponsoring educational conferences (mainly the International Symposium on Life Care Planning/ISLCP) to focus on the Foundation's primary mission of supporting research related to life care planning. Over the past 15 years of funding research, the Board has broadened the scope of its mission to consider any well-developed research design in life care planning that advances the field and/or makes a significant contribution to the population of individuals with disabilities who life care planners seek to serve.

The Foundation reported that it is currently funding a research project designed to replicate and expand a study published in 2006 regarding replacement values of durable medical equipment (DME). Results of the current study are expected to enhance and advance the field in the area of recommended replacement schedules, frequency and maintenance costs of some of the most commonly recommended DME included in life care plans. While other studies relevant to life care planning also are currently being conducted, all are invited to consider submitting a proposal to the FLCPR for a research grant. One suggested project is to update the Bibliography of Life Care Planning and Related Publications, originally published in the inaugural issue of the *Journal of Life Care Planning* in 2002. The bibliography has not been updated since that time and it is believed there are life care planning and related publications over the past 15 years that could be added to it. For anyone interested in conducting research and how the FLCPR may be able to help, please go to the Foundation's website, [www.flcpr.org](http://www.flcpr.org).

***International Association of Rehabilitation Professionals.***

Mr. Steven A. Yuhus, IARP President-Elect, provided an updated on IARP activities. Appreciation was given of everyone's attendance at the IARP 2017 Summit and of the 2017 Summit conference committee, Cloie Johnson, Susan Riddick Grisham, and Tracy Albee. Appreciation was noted of IARP/ IALCP Section leadership, its members and ongoing contributions with recognition given the past and present IALCP Board members in attendance.

An overview of IARP was provided noting they were comprehensively striving to serve life care planners and the rehabilitation community. Kim Bailey was announced as IARP's new Executive Director. The ISLCP/ IARP Conference will be held in St. Louis in October 2017. Noted appreciation was also given to Susan Riddick Grisham for her more than 20 years contribution with ISLCP. The ISLCP 2017 RFP's received to date were also shared with Summit attendees.

#### ***International Academy of Life Care Planners (IALCP).***

Debbe Marcinko, IALCP Immediate Past Chair provided an updated of IALCP. The IALCP (formerly the American Academy of Life Care Planners) became a section of the International Association of Rehabilitation Professionals (IARP) in 2006. The association with IARP has afforded greater networking and sharing of resources of the various professional disciplines and experts in rehabilitation. They have chaired and co-sponsored the Life Care Planning Summits since 2000, and the annual Symposium of Life Care Planning (since 1994) including the Symposium of Life Care Planning conference combined with the IARP annual conference in 2016. Their first Standards of Practice were published in 2000 and are now in the 3rd Edition (IARP, 2015). The *Journal of Life Care Planning* was introduced in April 2002. As a member of the IALCP Life Care Planning IARP Section, members receive a subscription to the *Journal of Life Care Planning* and the *Rehabilitation Professional*, access to live and pre-recorded webinars, the annual conference, access to networking and discussion groups of all IARP sections, and access to affinity programs such as FairHealth, American Hospital Agreement, AAACEUs, and liability insurance coverage.

The Fellow designation (FIALCP) was established in 1996 (through the IALCP) and continues under IARP. The purpose of the fellow program is to recognize expertise, experience and contribution to the field of life care planning. The program recognizes those life care planners who have achieved a high level of skill and who use their skills and knowledge to promote the advancement of life care planning. IALCP promotes relationships with other organizations for education, coalition, and collaboration in the promotion of life care planning.

#### ***American Association of Nurse Life Care Planners (AANLCP).***

Denise Wrenn provided an update of activities in AANLCP. On January 2, 2017, Denise Wrenn assumed the role of president of AANLCP®. In 2017, the AANLCP® executive board held their annual strategic planning meeting in Reno, Nevada. The association selected Annie Wiest, KAMO Management Company as Executive Director and Mariann F. Cosby, accepted the position as the new journal editor. During the 2017 conference, Colleen Manzetti Research Committee Chair presented the findings from a

research project completed in 2016.

The Association continues to offer tier memberships, which allow not only registered nurses interested in nurse life care planning, but an associate membership to individuals in other health care professions. The association is on schedule to complete an update to *A Core Curriculum for Nurse Life Care Planning*, an essential knowledge resource for the practice. The 2018 release date has yet to be determined.

The association mission in 2017 continues to focus on supporting the nursing community's efforts to achieve excellence in the practice of nurse life care planning. During the planning sessions, the board identified five drivers of organizational performance with goals designed as a strategic alignment to move the association closer to the vision, mission, and values of the association over the next three to five years. The five strategic domains are: Membership, finance, education, research and practice management and these domains are to become the pillars of the association in 2017 and beyond. The domains support the organization's mission and the focus on action and define the specific strategies to attain crucial goals.

In March 2017, the annual education conference was held in Scottsdale, Arizona. The association hosted keynote speaker JR Martinez, 'Dancing with the Stars' 2011 Season 12 winner, and a world-renowned motivational speaker, actor, best-selling author and U.S. Army veteran. The conference committee put together a rock-star line-up of speakers who motivated, informed, and inspired all who attended. The 2018 education conference, The Art of Life Care Planning will be held in St. Petersburg, Florida on March 16-19. They are expecting to repeat the excitement experienced in Scottsdale.

#### ***Ethics Workshop.***

On day one of the life care planning Summit, an Ethics Workshop was held. During the workshop, a review of the various credentials for those who prepare life care plans was shared. It is well-known that life care planning is a specialty practice, in which a variety of professionals, holding various licensures and certifications, participate. A review of the various credentials for those who prepare life care plans was shared with historical background for each. The credentials explored include American Board of Vocational Experts (ABVE), Certified Case Manager (CCM), Certified Disability Management Specialist (CDMS), Certified Life Care Planner (CLCP), Certified Nurse life care planner (CNLCP), Certified Physician Life Care Planner (CPLCP) and Certified Rehabilitation Counselor (CRC). The analysis of each credential included identifying if there was independent accreditation, the year established, minimum education and experience requirements, code of ethics/standards of practice, requirement for examination and continuing education units (CEU) as well as non-profit status. This information is presented in Table 2 below and was originally published in Field, Choppa, Johnson,

Fountaine & Jayne (2007), which was updated in Johnson, Lacerte and Fountaine (2015) and most recently updated in 2017. It is illustrative of the historical nature, background and requirements of each credential.

Table 2

*Credential Analysis*

Credential	<u>Independent Accreditation</u>	<u>Year Est.</u>	<u>Minimum Education Required</u>	<u>Minimum Experience Required</u>	<u>Code of Ethics/ Standards of Practice</u>	<u>Exam Required</u>	<u>CEUs Required</u>	<u>Non-Profit</u>
ABVE	No	1980	Yes	Yes	Yes	Yes	Yes	Yes
CCM	Yes	1993	Yes	Yes	Yes	Yes	Yes	Yes
CDMS	Yes	1984	Yes	Yes	Yes	Yes	Yes	Yes
CLCP	No	1996	Yes	Yes	Yes	Yes	Yes	No
CNLCP	No	1999	Yes	Yes	Yes	Yes	Yes	Yes
CPLCP	No	2014	Yes	Yes	Yes	Yes	Yes	Yes
CRC	Yes	1975	Yes	Yes	Yes	Yes	Yes	Yes

The presentation included aspects of various credential codes of ethics, followed by small and large group discussion surrounding a variety of applicable ethical dilemmas. Participants were asked to contemplate and propose resolutions to various ethical dilemmas.

***Panel Presentation – Charges.***

After the working lunch, two panel presentations filled the remainder of Summit day one. The first panel was made up of four speakers: Lan Lievens of Healthcare Financial Consultants; Dr. Robert Meier of Amputee Services of America; Cassandra Smith of Yavapai Professional Medical Billing and Coding; and Ray Agostinelli of FairHealth. The following questions were posed to panel participants:

- How do providers set their charges?
- Is there a commonly accepted definition of “usual and customary”? What other terms are used? What do these terms really mean? Do providers ever expect to get paid their full billed amount?
- Do providers have a single charge for each CPT code or do they have a variety of charges for a variety of circumstances? For example, self or private pay v. insurance v. lien rates
- What can you tell us about providers that do not accept any insurance or have a concierge practice?
- What is the best terminology to use when we call to get cost information?
- Is there an accepted concept that charges/contracts for cash

payers or large insurance companies must be higher in order to cover their losses that occur by accepting Medicaid/Medicare?

- Does a quoted charge fully reflect what a provider will receive and might there be other “incentives” within the contracts?

The following is a summary of the panel presentation. The statements are the product of each panelist and not an endorsement by the attendees of the Summit, planning committee or any organization involved in the Summit. The summary statements below were developed from the presentations given and were reviewed by each individual panel participant.

***Lan Lievens of Healthcare Financial Consultants***

Usual, Customary and Reasonable Fee (UCR) is the charge or range of charges evaluated against another provider for similar services in a geographical area. Usual, Customary and Reasonable Fees are not set for the healthcare industry, by Medicare, or any third-party payer, although payers may choose to define how much they will pay. Databases can show the range of charges for the same or similar services by the same or similar medical provider in a comparable geographic area. Usual, Customary and Reasonable Fee (UCR) calculations must include the geographical location. There is a difference between the amount charged and the amount that will be paid, with payments ranging from 0 to 140% of the gross charges. The amount providers are paid

change every day, therefore, trying to estimate what will be paid is completely speculative.

Charges are determined by the provider identifying the cost to provide a service and dividing it by the number of those services they are expected to deliver. There are direct costs and indirect costs. This process is simply a budget. The goal of the insurance company is to set premiums high and buy services low. There are patients who would rather pay 100% of a medical bill than to run it through their insurance, which happens frequently in affluent areas of the country (e.g. famous people who do not want their insurance charged, as it opens them up to lack of confidentiality).

An explanation of capitation contracts was undertaken. A provider may get more than 100% of their billed charges if the insurance pays a flat amount monthly, regardless of the charges incurred. If the patient is not seen at all in the hospital in any given month, the provider is still paid the contracted amount.

Databases are absolutely needed to look at historical charges within a geographical area. These databases prove whether charges are falling within the UCR range. When doing a past cost analysis, Mr. Lievens typically uses two or three (or more) databases. Mr. Lievens does not change the databases but does ask the database vendors how each program handles charge outliers. He agrees that a provider can charge anything that they want and the provider can accept any payment that they want; however, there is legislation coming soon that may change that. A properly managed medical office/provider will have only one fee schedule and the amount of payment they accept may vary depending on business situations, contracts and social considerations (i.e. many medical offices write off copay amounts for clergy.) Payments from insurance companies include more than what is on a bill. For example, a provider may receive 80% of the bill on paper, but then receive a balloon payment at the end of the contract. This will not show up on a patient invoice or explanation of benefits. Providers with a concierge practice may charge a flat fee or they may have a charge structure. For example, the provider may charge an application fee, an enrollment fee, an annual charge for being a member of their practice, and a published fee schedule for the services provided. Concierge practices do not accept insurance or do third party billing. Concierge practices are not required to release their financial information, unless to a potential client who needs to know this before deciding to join the practice. There is a current trend for providers to move towards a concierge practice and these charges are not included in the standard databases. It is unknown how the industry will handle these new practice concepts.

Mr. Lievens recommends looking up “cost shifting” to find a remarkable amount of information on how providers make money. Cost shifting is a methodology used in all businesses, including healthcare. When Medicare or Medicaid decreases their payments, the provider generally

needs to increase their charges. In order to stay in business, a provider must get 100% of their operating costs through billed charges. This does not happen by the entire patient population, but rather by the case-mix. If a provider only considers one payer source as a valuation of their medical services, then they are only considering a small portion of what their cost of service really is.

***Dr. Robert Meier of Amputee Services of America.***

Usual, Customary and Reasonable Fee (UCR) is most consistently defined by the “Medicare allowable” and represents the profit beyond the cost to provide the service. A physician group can charge whatever they please, but that does not mean that is what they will be paid. Payments are very much regionally based. Life care planners need to go to an authoritative source to get the charges for certain services. For example, if you have a patient with a spinal cord injury, should you go to a local provider or should you go to a place like Craig Hospital? Life care planners need to get their costs from the experts in any particular field. This is a reason not to use databases in some circumstances.

***Cassandra Smith of Yavapai Professional Medical Billing and Coding***

Ms. Smith shared that she agrees with Mr. Lievens regarding the definition of UCR; however, in reality the UCR varies based upon zip codes, formularies of the insurance companies, and the payments based on any given contract. Every insurance plan pays a different amount with hundreds of factors involved in each contract. The UCR really means nothing and it is often just a way for insurance companies to get out of paying a bill. Providers know that when they accept a particular insurance contract, they will get what they get and it is a “take it or leave it” system. She noted prices are typically set around any given provider’s current contracts and the provider may also determine a non-insurance pricing model. Insurance, whether a provider takes it or not, typically guides the billing practices. Retail pricing is, more likely than not, a multiplication of the Medicare allowable fee schedule. For example, the industry standard is to set the charges at 300 to 400% of the Medicare fee schedule. Providers do not expect to be paid their retail price, but this is the base pricing. Providers are lucky if they receive 50% of their billed amount, with average payment being 30% to 50% of the charge, when the patient is out-of-network. However, they may receive 0 payments for out-of-network patients as well. If the patient is in-network, the provider may get 90% to 100% of the billed amount, as defined by the contract. A provider could bill for the same services for 20 patients, all with the same contract, and could receive 20 different reimbursements.

Physicians who work for corporations have no control over their charges, so if a life care planner is trying to obtain the charge for a service, they must get to the practice manager. Most physicians do not have any understanding of

how their own charges are determined. Often it is the biller who decides what to bill, not the providers themselves. There are different rates for different payers, such as self-pay, liens and insurance

A provider must be careful how they disclose their different rates for different payers due to antitrust laws that may apply. If a provider is caught giving out different rates to different payers, they risk losing their insurance company contracts. Ms. Smith's company advises providers to have one charged rate for everybody, but that it is okay to accept the insurance payment and then to bill the balance to the patient, if this is allowed by the contract. When asked about the concept of providers charging some patients more to make up for those payers who pay too little, this is not allowed. There are three types of payers: In-network, out-of-network, and private pay. A provider must take a balanced approach and look at what percentage of their patients are Medicare, Medicaid, insurance and private pay. That is the only way to offset losses.

#### **Ray Agostinelli of FairHealth.**

FairHealth was founded in 2009. They have 60+ contributors, including private payers, TPAs and self-insured employer plans. There are now 23 billion claims included in their data, reflecting over 150 million covered lives. It is geographically specific with over 500 geographical zip codes. FairHealth's benchmark products array billed charges across a range of percentiles (50th to 95th) reflecting the distribution of market rates for healthcare services in specific geographic areas. Many payers use the benchmark products in developing fee schedules, including plans that reimburse out-of-network providers based on a percent of usual and customary rates. When asked about whether a life care planner should ask for charges or expected payments, he agreed with other panelists that the actual paid amount can vary greatly based on a variety of factors and opined that a database based on billed charges will provide less variability in those numbers. Providers who do not accept insurance must set their fee schedule, which they do by using a database or they may set their charges on a percentage of the Medicare fee schedule. If providers will not disclose their fees, this is a practice management issue.

#### **Panel Presentation – Collateral Sources**

The second panel of the day included Tony Choppa, Joan Schofield, Amy Sutton, Ray Agostinelli and Lan Lievens. The theme of this panel was "Associated Costs and Collateral Sources – Understanding the various payer sources which impact life care plans combined with court rulings that also direct the inclusion or exclusion of payer sources or billed versus paid amounts in various jurisdictions." A summary of the panel presentation is found below. The statements are the product of each panelist and not an endorsement by the attendees of the Summit, planning committee or any organization involved in the Summit.

#### **Panelist 1: Tony Choppa.**

Mr. Choppa provided a brief review of the presentation by himself, Dr. Timothy Field, and Cloie Johnson who authored *The Collateral Source Rule and the ACA: Implications for life Care Planning*, originally presented at the 2015 International Symposium on Life Care Planning (ISLCP). There is an increasing friction among life care planners and attorneys about how to handle collateral sources. This is a state-by-state issue, but life care planning standards are not based on case law.

Mr. Choppa referred to the Matlock Chart, used in a prior presentation, which was based on 2013 data. The Matlock Chart has not been updated, despite the case law that has evolved, since its publication. There are three categories of statutes: Those that reduce the verdict solely on the collateral sources; those that eliminate collateral sources altogether; and those that require consideration of collateral sources. Case law is the driving force.

Prior Life Care Planning Consensus Statements (Johnson, 2015; Preston & Johnson, 2012) require the life care plan to be objective and consistent (#51); life-long and flexible (#52); transparent and reproducible (#82) and use non-discounted and market rates (#98). Standards and Consensus Statements must allow the flexibility for life care planner to meet the legal precedents of a specific jurisdiction. There is nothing that prohibits the providing of a variety of information, but how this is done while staying within standards and ethics is the challenge. Footnotes to the life care plan can be added to the life care plan for accuracy and ensuring compliance with standards of practice.

Motions-in-limine are usually about the methodology of how a life care planner arrives at the opinion they hold, not the opinion itself. The trier of fact, not life care planners, decides what the right cost is or who should pay.

#### **Panelist 2: Joan Schofield.**

Ms. Schofield uses Medicaid Waiver collateral sources within her practice when pricing support services are not generally available. In her area (New Mexico), up to 50% of the population qualifies for government benefits / healthcare. She uses the Waiver programs within her state and can find fee schedules on the government websites. The providers who accept government funding may provide care to a person who does not have government funding and ask for same amount in reimbursement that they would have collected from the government (i.e. they do not mark up the care for cash payers). This provides value of these services based upon the public agency fee schedule.

**Panelist 3: Amy Sutton.**

Ms. Sutton provides a choice of prices. Her goal is to assure that the individual will have funds to purchase the services, but if asked to consider a different scenario (such as what the Medicare or Medicaid reimbursement would be), she will do so. She takes case law into consideration. The definition of "non-discounted rates" does not imply that cash rates are "discounted". Discounted rates are ones that have been negotiated for an entity and are not available to the general public.

**Panelist 4: Ray Agostinelli.**

Mr. Agostinelli expressed his opinion that it is important for life care planners to understand the rules and statutes of the states where they work. FairHealth's data includes worker's compensation fee schedules. Because FairHealth is used for dispute resolution (in New York), they often must defend their methodology. The level of their consistency makes their database defensible. FairHealth updates their benchmarks two to four times per year and they are released within one to two months of the data becoming available. FairHealth database was not developed for life care planners; however, the repository of the data is an asset to life care planners. FairHealth is a window into the market.

**Panelist 5: Lan Lievens.**

Mr. Lievens emphasizes that he is not attorney and no statement may be regarded as legal advice. The only valid test to predict the future costs of care is today's charges. Collateral sources are speculative because: There is no guarantee that the plaintiff will be eligible for an insurance; that the insurance will cover the services; or that there will be medical providers in the plaintiff's geographic area accepting a specific insurance. There are two pending litigated cases where the plaintiff received an award based on collateral sources and now that collateral source is not available and the plaintiff does not have enough money to purchase the care.

Discussion of *Howell v. Hamilton* (2011) and *Corenbaum v. Lampkin* (2013) was undertaken. In *Howell*, the California Supreme Court ruled that an individual was entitled only to the economic damages in the amount that they or their insurers paid/will pay for medical services, not the difference in what is billed and what is paid. The *Howell* case did not affect the reality of the healthcare financial industry because the underlying direct and indirect costs of healthcare services remained unchanged but resulted in an increase in attorneys encouraging plaintiffs to get their healthcare on a lien instead of using their insurance or applying for insurance(s) for which the plaintiff may be eligible. The healthcare industry cannot force a patient to use existing insurance if the patient wishes to pay in other ways including cash or lien arrangements.

This is part of what generated *Corenbaum v. Lampkin* (2013) where the court held that billed amounts were irrelevant and inadmissible if treatment was covered by

insurance and that non-economic damages and expert testimony could use unadjusted bills when determining damages. These rulings resulted in defense attorneys arguing that a plaintiff has the responsibility to mitigate their own damages.

**Summit Day Two Proceedings**

The second day of the Summit began with a review of the group nominal process. Each participant was assigned to one of four groups comprised of life care planners with a mix of experience, training and knowledge. Each attendee rotated through all focus groups and participated in discussions of all topics. The modified nominal group technique was used within each group, gathering information in an organized format, aimed to reduce the influence of any overly verbal or assertive participants, on the outcome. The nominal group technique is described below.

First, group members write down their top three to five suggestions in order of priority and facilitators use flip charts to go around the group and write down suggestions, combining suggestions when possible. After the issues are recorded, the attendees are asked to "vote" on their top five of the suggestions listed. After the vote, the group facilitator assigns five points to the responses with the highest count, four points to the second highest, three points to the third choice, two points to the fourth choice and one point to the fifth choice. The facilitator adds up the score for each and the top scoring three to five recommendations represent the decisions for the group. When the large group reconvened, each small group contributed three to five recommendations for consideration by all participants. Theoretically, several overlapping recommendations should be made. The 2017 Summit, like previous Summits, utilized two recorders per facilitator, to allow one to record responses on the easel for all to review and one on a laptop computer to record the data in a formatted spreadsheet for verification and transport of data. Following the rotating group nominal process, results were collated and participants were reconvened into a general session where the results were discussed to determine consensus. On topics or recommendations where everyone agreed, consensus is achieved. If a majority agreed, the statement is considered "support by the majority" but not consensus. If fewer than one-half of attendees agreed, the decision reflects "minority viewpoint" or is removed from the list. Consensus is the goal. After lively discussion, the following results were obtained:

**Consensus:** A comprehensive and systematic review of the existing 102 statements from the life care planning Summits since 2000 through a multi-association process to determine if they are still appropriate and relevant is needed.

**Consensus:** Life care planners shall develop a position statement (white paper) regarding the presentation of charges and/or costs presented in the life care plan that provides guidance to life care planners for the variety of uses and jurisdictional requirements encountered by life care planners.

The paper:

- a. Must take into consideration that “associated costs” are referenced in the definition of a life care plan and
- b. Ensure the current geographically relevant monetary charges for a good and service are in the life care plan.

Consensus: There was a consensus to reaffirm prior Consensus and Majority Statements including #98, #86, #82 and #79, which were reaffirmed during the 2017 Summit proceedings. For reference, these items are outlined in Table 3 below.

**Table 3**  
**2017 Consensus Statements**

#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.

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

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

#79 Life Care Planners shall follow generally accepted methodology

Consensus: In the future review of the statements, it will be necessary to look closely at #56 (applicability, relevance and the obligation of life care planner to know the integrity of our data versus only the sources of data) to consider the definition of “integrity”. It is noted that there was a consensus that the group did not want any statements specifically focused on the litigation aspect of the life care planning work.

**Conclusion**

In May 2017, the tenth biennial life care planning Summit was conducted as a cooperative effort with major life care planning organizations including the International Association of Rehabilitation Professionals, the American Association of Nurse Life Care Planners, the International Academy of Life Care Planners, the Foundation for Life Care Planning Research and the International Commission on Health Care Certification. This year’s topic focused primarily on the subject of pricing items contained in a life care plan. With over 100 Summit attendees from diverse healthcare backgrounds, a rich dialogue was held among seasoned life care planning professionals. As a result of the process, four consensus statements were issued. These

statements, along with topics discussed during the 2017 Summit are designed to enhance the practice of all life care planners and serve as a guide for best practices in the field.

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**Author Acknowledgement**

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