

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; Debbie 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 nation 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

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 Modify Delete	68.00 15.17 15.86	65.38 20.00 14.62	20.48 26.51 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 Modify Delete	68.28 17.24 14.48	68.46 17.69 13.85	33.73 18.07 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 Modify Delete	59.03 23.61 17.36	46.92 39.23 13.85	24.39 36.59 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 Modify Delete	69.72 16.90 13.38	61.54 21.54 16.92	13.41 12.20 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 Modify Delete	69.01 17.61 13.38	73.08 15.38 11.54	13.58 13.58 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 Modify Delete	59.44 16.08 24.48	45.38 20.77 33.85	12.35 2.47 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 Modify Delete	50.00 23.57 26.43	34.61 36.15 29.23	7.41 18.51 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 Modify Delete	52.78 21.53 25.69	49.23 29.23 21.54	13.58 25.93 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 Modify Delete	57.75 16.90 25.35	53.85 19.23 26.92	22.22 9.88 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 Modify Delete	67.36 18.06 14.58	68.46 18.46 13.08	20.99 14.81 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:

Cloie Johnson is a Rehabilitation Counselor and Case Manager providing Life Care Planning services at OSC Vocational Systems, Inc. in Bothell, WA. Cloie has chaired or co-chaired the Summits in 2010, 2011, 2012, 2015 and 17. She is also a past Chair of the IALCP the LCP Section of IARP and the recipient of the 2016 Lifetime Achievement Award in Life Care Planning.

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.