Journal of Life Care Planning, Vol. 17, No. 3, (37-51)

A Historical Review of Life Care Planning Summits since 2000

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Abstract

In honor of the 25th anniversary of the International Symposium on Life Care Planning (ISLCP), we are providing historical perspectives on the various tentacles to our life care planning practice. Life care planning Summits are held by life care planners, about life care planning for life care planners. The goal of this article is to provide insight into all that goes into life care planning Summit proceedings and provide perspective on the importance of the Summits.

Whether one has been a life care planner for decades, or is new to the specialty practice, it is important to understand where we came from in order to be part of where we are going. Life Care Planning Summits have been an integral part of the development of the specialty practice of life care planning. We now have nearly two decades worth of work documented on 200 plus pages by over 700 participants over the course of 10 Summits in the specialty practice of life care planning. The goal of this paper is to understand our base and journey upward to reach the pinnacle of our practice.

Background on Summits

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).

The Life Care Planning Summit (Summit) is typically a biennial meeting of practitioners and interested parties in the specialty practice of life care planning. 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," who are quiet and less aggressive will have their voices heard. Summits use group dynamics and attempt to achieve consensus or near consensus. Most importantly, Summits typically set the foundation for the specialty practice and often are the source for agreed-upon standards of practice, standard of care, and ethics. Summit conferences are designed so that attendees give information to leaders. 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 of the Summits is the apparent general consensus for collaboration among professionals and organizations that represent life care planners. The 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. With each Summit, life care planners continue to reach consensus on a number of areas while also identifying 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.

The Summit explores important issues, provides opportunity to reach consensus on issues, provides opportunity to identify and define areas of controversy, and provides direction for future development and services. The Summit proceedings have been published after each meeting, and have twice been memorialized in the *Journal of Life Care Planning* (JLCP) in 2012, Volume 11:1 and in 2018, Volume 16:4. The International Academy of Life Care Planners (IALCP) currently the life care planning section of the International Association of Rehabilitation Professionals (IARP) 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 including the following:

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)

Methodology

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. A modified nominal group technique was used within each focus group of the Summit to gather information in an organized format and to reduce the influence of verbal or assertive participants on the outcome. Utilizing the methodology of Delbecq et al. (1975), the modified nominal group technique provided a comprehensive contribution.

The entire registered attendance was broken into smaller groups with approximately 15 participants assigned to each of the small groups. The smaller groups enabled individual participation from each member. The following process occurred:

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

Outcomes of Summit Proceedings

Over time, life care planning Summit results have been published and relied upon by practitioners in their daily practice. 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 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. The *Consensus and Majority Statements* serve as reinforcement for the work of the life care planner. Practitioners are on occasion asked about these statements during depositions as well, so familiarity with the statements is important

In 2010, the *Consensus and Majority Statements* were combined and reviewed with the attendees to ensure their relevance and continued applicability as a consensus statement. This was again reviewed in 2018 in a more formal manner with a delphi study completed by Cloie Johnson, MEd and Jamie Pomeranz, PhD. These results were then published in the *Journal of Life Care Planning* (Johnson, Pomeranz & Stetten, 2018). 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.

History of Summits

A brief time and location history of past Summits is noted below.

2000- Dallas, TX – April 12, 2000

The first life care planning Summit was held in Dallas, Texas on April 12, 2000 and was chaired by Dr. Roger Weed. The mission was to specifically address life care planning topics and issues with the goal of achieving consensus on five focus areas:

1. Professional preparation
2. Basic tenets and procedures for completing life care plans
3. Ethics:
4. Reliability and validity of the life care plan
5. Information dissemination

The Summit was sponsored by IARP, IALCP, Intelicus/University of Florida and the CDEC. In addition, the AALNC and the 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.

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.

Organizations and associations serving life care planners were invited to provide comments. The following representatives spoke:

- ICHCC/CLCP - Robert May, Rh.D., CRC (unable to attend due to weather)
- IALCP - Patricia McCollom, MS, RN, CRRN, CDMS, CCM, CLCP
- NARPPS (now IARP) - Ann Neulicht, Ph.D., CRC, CDMS, CVE, LPC, CLCP, DABVE
- AALNC - Patty Costantini, RN, M. Ed., CRC, CCM, CLCP, LNCC
- CMSA - 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 first Summit, with the goal of 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* (Neulicht et al., 2002). The results specifically described the current state of life care planning practice along with protocols/procedures used by life care planners.

2002- Chicago, IL – May 18 & 19, 2002

The next Summit was held on May 18 and 19, 2002 in Chicago, Illinois and was chaired by Susan Riddick-Grisham, RN. The topic areas included:

1. Scope of practice and skills
2. Ethics
3. Professional development
4. Methodology and functions
5. Future of life care planning

Building on the significant accomplishments of the April 2000 meeting, this Summit again created a forum for discussion among professionals about issues which impact the field of life care planning. In preparation for this professional meeting, an educational committee worked to identify five focus areas to be addressed in the roundtable discussions. 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* (IARP, 2015) and to determine if revisions are needed to better reflect changes in the field.
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.

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

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.

2004- Atlanta, GA – April 24-25, 2004

The Life Care Planning Summit 2004 was held April 24-25, 2004 in Atlanta, Georgia with nearly 100 professionals in attendance. Paul Deutsch, PhD chaired the Summit. 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 IALCP, IARP, Care Planner Network, FLCPR, AALNC and ICHCC. 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:

1. Certification Process
2. CLCP Examination and CEUs
3. Future Research in life care planning
4. CLCP Mentoring Program
5. Standards of Practice for life care planners

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 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.

2006-Chicago, IL – May 6 & 7, 2006

The May 6 and 7, 2006 Summit in Chicago, Illinois occurred with a panel comprised of representatives of the IALCP, CHCC, and the FLCPR. The panel discussed trends and plans for the future of life care planning and each represented organization had an opportunity to offer suggestions.

IALCP offered the following plans:

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

The CHCC proposed the following plans:

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

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

1. Implementation of a Foundation fundraising project.
2. Continued support of research projects addressing the reliability and validity of the life care planning process.
3. Development of a Foundation newsletter.
4. Scholarship support to students pursuing life care planning education.

2008- Los Angeles, CA – May 15 & 16, 2008

The 2008 Summit was held May 15 and 16, 2008 in Los Angeles, California. Co-Chairs for this event were Karen Preston, RN, Jamie Pomeranz, PhD and Carol Walker, PhD. This Summit was intended to examine issues and provide direction at both the individual practitioner level and at the field level. Specific areas included:

1. Visions for LCP Future: Identifying controversial aspects of plans created by various professional disciplines
2. Developing Unity in the Field: Standards of Practice shaping the role and function of life care planning
3. Best Practices: Methodology Issues in Data Collection
4. Best Practices: Methodology issues in creating admissible life care plans
5. Research: Priorities, needs, and practical applications in day-to-day practice
6. Professional business issues: Risks and benefits of databases, templates, software

2010- Atlanta, GA – April 17 & 18, 2010

On April 17 and 18, 2010 the Summit was held in Atlanta, Georgia. The Theme and Goals of Life Care Planning Summit 2010 were to:

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

The topics were narrowed to the following:

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

Topic 2: Best Practices for Determining Sources of Attendant Care in the Home

Topic 3: Review of Consensus Statements, Majority-View Statements and Results of Life Care Planning Summits 2000 – 2008

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 listserves 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.

Past *Consensus and Majority Statements* were reviewed by the attendees as homework and they were surveyed on the 2000, 2002, 2004, 2006 & 2008 *Consensus and Majority Statements* that had been compiled in 2010. Real-time voting was used with the participants for their feedback 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, the statement had to require substantive change to stay within the originally intended meaning. For deletion, it could not be modified without substantially altering the meaning, or if was now is irrelevant and was no longer required. It was not the intent of the Summit 2010 to rework previous statements for the sake of inconsequential wording.

Upon review of over 100 consensus statements from previous Summits, an analysis of the participants' voting was completed. Those items with 75% or greater consensus for "accept" were retained, and those with 75% or greater for "delete" were noted for deletion. Only one statement received 100% consensus, i.e., "Life Care Plans shall be individualized," and one statement had a majority of votes to recommend deletion, i.e., "Some aspects of Standards of Practice are too detailed."

2011- Toronto, ON – June 3 & 4, 2011

On June 3 and 4, 2011, the Canadian Life Care Planning Summit 2011 was held in Toronto, Ontario, Canada. This Summit was co-chaired by Cloie Johnson, MEd and Michel Lacerte, MD. The event brought together leaders in life care planning from a variety of organizations with a goal of promoting unity within Canada. Mimicking the first Summit, the goal was ensuring that those practicing in Canada were oriented to the Standards and identify any differences in life care planning practices outside of the United States. Multiple organizations provided invaluable support for this event including the FLCPR, The Care Planner Network, ICHCC, Canadian Society of Medical Evaluators (CSME), Vocational Rehabilitation Association (VRA) of Canada, College of Vocational Rehabilitation Professionals (CVRP), and the University of Florida.

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

1. Professional preparation
2. Basic tenets and procedures for completing life care plans
3. Ethics
4. Reliability and validity of the life care plan
5. Information dissemination

There was a consistent replication of results from the Summits of 2000, 2002, 2004, 2006, 2008 and 2010.

2012-Dallas, TX – May 5 & 6, 2012

The 2012 Life Care Planning Summit was held in Dallas, TX on May 5 & 6, 2012. The Summit was chaired by Cloie Johnson and hosted by the IALCP with co-sponsors including IARP, ICHCC, FLCPR and the University of Florida. The 2012 LCP Summit was benefitted by 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 took the typically inclusive approach even further by soliciting associations and organizations to participate in a round table discussion for the benefit of educating all life care planners on each association and organizations mission and progress. The 2012 Life Care Planning Summit was unique with an "outside the box" format. The committee put together a very ambitious agenda and 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. The open dialogue/town hall meeting had representatives from the associations and organizations involved in the multidisciplinary practice. Representatives included:

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

Each representative association/organization gave an introductory statement. They provided a brief statement of the current state of each 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 or 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 then gathered together in the evening after the first day and reported on the second day that they had agreed to create

liaison positions within their respective boards and continue to have interactive dialogue to ensure the members' needs are met.

As part of the 2012 Summit, there were 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 had passed since the original process occurred. Twenty-two 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* would be routinely reviewed for relevance, and all *Consensus and Majority Statements* will be reprinted and published. These were republished for reference at the end of the written proceedings. 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.

In follow-up, 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 Codes 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.

2015- Scottsdale, AZ – September 18, 2015

On September 18, 2015 the 2015 Life Care Planning Summit was held as a pre-conference to the International Symposium on Life Care Planning (ISLCP) in Scottsdale, Arizona. This Summit was sponsored by IARP and the Life Care Planning Section/International Academy of Life Care Planners (IALCP). This Summit was chaired by Cloie Johnson, MEd. Since the last Summit that was held in Dallas in 2012, Karen Preston, PhN had taken the lead on a task force to review and revise the life care planning 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* (IARP, 2015). Through this process new topics were identified which were focal to the 2015 Summit.

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 association and organization updates from the IALCP, FLCPR, AANLCP, CNLCP Certification Board and the ICHCC. Consensus Statements from the 2015 Life Care Planning Summit to be added to the prior 99 *Consensus and Majority Statements* from earlier Summits brought the total to 102.

2017- May 19 & 20, 2017 -Denver, Colorado

In 2017, the tenth life care planning Summit was held in Denver, Colorado. The summit was sponsored by IALCP and IARP with support and representation from the ICHCC, AANLCP and the FLCPR. The International Academy of Life Care Planners 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 co-chaired by Cloie B. Johnson and Susan Grisham.

Practicing life care planners in attendance actively participated in identifying venues where life care plans are utilized were developed. As a group, attendees compiled 29 venues or applications in which a life care plan may be developed. Additionally, the attendees reviewed the results of the 2017 Collateral Source Survey created by Dr. Jamie Pomeranz, which was sent to all known life care planners in March 2017. The results were enlightening, finding that 47% of the respondents were being asked to include collateral sources in life care plans, while 53% had not. Of the respondents, 59% had never included collateral sources in the development of a life care plan; 39% sometimes included collateral sources; and 2% reported always including collateral sources in their 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%).

A working lunch was held during the first day of the Summit proceedings. At this time, 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.

On day one of the life care planning Summit, an ethics workshop was again held. 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 1 below and was originally published by Field, Choppa, Johnson and Fountaine (2007), which was updated in Johnson, Lacerte and Fountaine (2015) and most recently updated in 2017 (Albee, Gamez & Johnson, 2017). It is illustrative of the historical nature, background and requirements of each credential.

Table 1

Credential Analysis

Credential	Independent Accreditation	Year Est.	Minimum Education Required	Minimum Experience Required	Code of Ethics/ Standards of Practice	Exam Required	CEUs Required	Non-Profit
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 these ethical dilemmas.

After the working lunch, two panel presentations filled the remainder of Summit day one. The first panel was made up of four speakers: Lan Lievense of Healthcare Financial Consultants; Robert Meier, MD of Amputee Services of America; Cassandra Smith of Yavapai Professional Medical Billing and Coding; and Ray Agostinelli of FairHealth. The goal was to gain insight into the issues of charges and costs.

The second panel of the day included Tony Choppa, Joan Schofield, Amy Sutton, Ray Agostinelli and Lan Lievense. 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."

The second day of the Summit began with a review of the group nominal process and roundtable discussions. Interestingly, it was noted that there was consensus that the attendees did not want statements that were specifically focused on the litigation aspect of life care planning work included. It was also consensus that a comprehensive and systematic review be undertaken of the existing 102 statements from the life care planning summits since 2000, through a multi-association process to determine if they were still appropriate and relevant is needed. Additionally after review of the 102 statements, life care planners agreed that a position statement (white paper) would be prepared regarding the presentation of charges and/or costs in life care plans to provide guidance to life care planners for the variety of uses and jurisdictional requirements encountered. 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 in the life care plan.

Additionally, the group reaffirmed prior *Consensus and Majority Statements* including #98, #86, #82 and #79 and a recommendation was made 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".

Summary

Summits remain an important barometer for the specialty practice of life care planning. It is through these events that our community of multidisciplinary professionals can unite and direct the continued success of life care planners. Taking a vested interest in the past and working towards a better tomorrow serves every life care planner. The outcomes of the Summits reveal issues for life care planning associations and organizations to shape and reinforce the standards of practice, ethics and day-to-day work. The *Consensus and Majority Statements* reinforce these activities. Because these statements are so important, the most recent *Consensus and Majority Statements* are outlined below in Table 2 so that once again history makes its mark and all readers can benefit. Additionally, all resources used in the development of the Summits are provided for reference in Table 3.

Consensus and Majority Statements
Table 2

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 modified Delphi Study in 2018

The following statements were created by Life Care Planners at various Summits between 2000 and 2017, and 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 explore markets for Life Care Planning outside litigation.
7. Life Care Planners shall have knowledge of relevant laws and regulations as well as local and national care standards.
8. Life Care Planners shall understand optimal outcomes achievable for particular injuries.
9. Revised: 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.
10. Life Care Planners shall complete 120 hours of training including courses that focus on disability issues and is specific to Life Care Planning.

11. Life Care Planning programs shall be based on the latest knowledge and practices.
12. Life Care Planning programs shall cover certification-preparation as well as advanced topics and complex issues.
13. Life Care Planning programs shall be offered in accessible geographic locations and electronically.
14. Life Care Planning continuing education units shall be available at an increasing number of forums.
15. Life Care Planning continuing education units shall be available at forums that may not focus solely on Life Care Planning.
16. 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.
17. Life Care Planner certification shall render its holder a qualified Life Care Planner, provided that certification is maintained.
18. Life Care Planner certification shall be renewed every five years with the accumulation of 60 continuing education units.
19. Life Care Planners shall be licensed and/or certified in their professional discipline before being certified as a Life Care Planner.
20. Life Care Planner certification standards shall be augmented.
21. The International Commission on Health Care Certification shall apply for National Commission for Certifying Agencies accreditation.
22. Life Care Planners shall hold a certification that has mechanism for complaints and resolution.
23. Life Care Planning certification shall flow from a practitioner-created core curriculum.
24. The Life Care Planning certifying body shall not be proprietary.
25. The Life Care Planning certifying body shall manage and disclose ethical complaints and violations.
26. Life Care Planning certification exams shall be developed and maintained by an advisory group.
27. 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.
28. Standards of Practice terminology shall be reviewed
29. Standards of Practice terminology shall be defined.
30. Standards of Practice shall delineate educational requirements for entry into the practice of Life Care Planning.
31. Standards of Practice shall assert the role and accountability of Life Care Planners
32. Standards of Practice shall be based on a study defining the role and accountability of Life Care Planners.
33. Standards of Practice shall allow for individual judgment and expertise.
34. Standards of Practice shall be utilized in the development of the practice of Life Care Planning.
35. Standards of Practice shall be applicable to current practices.
36. Life Care Planners shall accept referrals only in their area of expertise.
37. Life Care Planners shall draft Life Care Plans under supervision for one year.
38. Life Care Planners shall maintain objectivity.
39. Life Care Planners shall maintain strict adherence to confidentiality practices.
40. Life Care Planners shall renounce inappropriate, distorted or untrue comments about peers.
41. Life Care Planners shall renounce inappropriate processes and training.
42. Life Care Planners shall disclose and differentiate between the roles in which they may be called upon to act.
43. Life Care Planners shall avoid dual relationships when objectivity may be challenged.
44. Life Care Planners shall better define dual relationships.
45. Life Care Planners shall establish themselves within their primary field of practice.
46. Life Care Planners shall objectively place their client's interests before any personal or professional consideration.
47. Life Care Planners shall adhere to relevant Codes of Ethics.
48. Life Care Planners shall have access to recourse/corrective action process for Ethical violations.
49. Life Care Plans shall be individualized.
50. Life Care Plans shall be objective and consistent.
51. Life Care Plans shall be lifelong and flexible.
52. Life Care Plans shall be a clear, concise and user-friendly document.
53. Life Care Plans shall be comprehensive and based on multidisciplinary data.
54. 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.
55. Life Care Planners shall consider the integrity of data.
56. Life Care Planning shall depend on data collection, analysis and synthesis.
57. Life Care Planners may request additional data, testing and evaluation if required.
58. Life Care Planners shall research condition, resources, services and costs.
59. Life Care Plans shall utilize established procedures.
60. 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.

61. Revised: Life Care Plans shall be developed in the client's/evaluee's best interest.
62. Life Care Plans shall include a basis for recommendations.
63. Life Care Planners shall utilize a reliable, consistent method for reaching conclusions.
64. Life Care Planners shall utilize adequate medical and other data for opinions.
65. Life Care Plans shall include an annotated list of requested and reviewed data/sources.
66. Revised: Life Care Planners shall utilize standardized procedures and tools for gathering and reporting information and feature standardized forms and formats.
67. Revised: Life Care Planners will use consistent methodologies to evaluate similar cases.
68. Life Care Plans shall rely on medical/allied health professional opinions.
69. Life Care Plans shall be limited to the planner's expertise and scope of practice.
70. Life Care Planners shall methodically handle divergent opinions.
71. Revised: Life Care Planners shall properly inject professional expertise.
72. Life Care Planners shall utilize credible, evidence-based guidelines.
73. Life Care Planners shall conduct an in-person interview whenever permitted.
74. Life Care Planners shall utilize protocols for cost research.
75. Life Care Planners shall gather geographically relevant & representative prices.
76. Life Care Planners shall utilize protocols for using local versus national resources.
77. Life Care Planners shall follow generally accepted methodology.
78. Differences in clinical judgment can result in different recommendations
79. Life Care Planning databases, templates and software shall have appropriate foundation.
80. Life Care Planning products and processes shall be transparent and consistent.
81. Life Care Planners shall be involved in research.
82. Life Care Planners shall study the reliability, validity and accuracy of Life Care Plans.
83. 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.
84. 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.
85. Life Care Planners shall study the impact of Life Care Plans upon quality-of-life.
86. Life Care Planners shall understand and explain research used in a Life Care Plan.
87. Life Care Planners may independently make recommendations for care items/services that are within their scope of practice.
88. 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
89. When the Life Care Planner includes home care, both private-hire and agency-procured services are options to be considered.
90. The cost of private hire home care includes care giver compensation and associated expenses.
91. Life Care Planners shall consider the impact of aging.
92. Review of evidence based research, review of clinical practice guidelines, medical records, medical and multidisciplinary consultation, and evaluation/assessment of evaluee/family are recognized as best practice sources that provide foundation in Life Care Plans.
93. 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.
94. Life Care Planners will define terminology of our work product(s).
95. Life Care Planners have the option to use support staff under their direction and guidance in completing Life Care Plans.
96. Life Care Planners shall identify conflicts of interest.
97. Life Care Planners shall identify the sources of their recommendations.

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Table 3

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Author's note:

It has been an honor and privilege to be an attendee, a planning committee member, a facilitator, a recorder and a chair multiple times over through the years. My appreciation is extended to the many professionals who have piloted our course and those who have continually served this specialty practice.