

International Academy of Life Care Planning: Yesterday and Today

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Abstract

This article highlights the vision and visionaries, milestones, and accomplishments of the International Academy of Life Care Planners from its inception through today. Important developments in life care planning are highlighted and individuals who have significantly contributed to the field of life care planning are noted.

It has been more than three decades since the first association for life care planners was established. The International Academy of Life Care Planners (the Academy) laid the foundation for the practice of life care planning through the development of standards of practice, a code of ethics, certification, research and more.

The Early Years

The International Academy of Life Care Planners (IALCP), originally known as the American Academy of Nurse Life Care Planners (AANLCP), was founded on October 16, 1996 by Patricia McCollom MS, RN, CRRN, CDMS, CCM, CLCP FIALCP (Field, 2017; IALCP, 2000). The goal was of the Academy was to become a non-profit professional association which would advance and promote the practice of life care planning through education and service to practitioners. The American Academy of Nurse Life Care Planners, which consisted of 60 founding members, was incorporated in Iowa with Ms. McCollom serving as chief executive officer (CEO). Between 1996 and 2005 time, office space and staff services for the AANLCP were donated by Patricia McCollom.

The AANLCP was governed by a five-member volunteer advisory panel, which was responsible for review of by-laws, development of educational programs, discussion of life care planning standards, and development of a fellowship designation in life care planning. Based upon a review of a 1997 AANLCP Newsletter, members of the advisory panel were:

- Doreen Casuto MRA, RN, CRRN
- Billie Kilpatrick RN, CRRN, CCM
- Linda Dierking BSN, RN, CRRN, CCM
- Sharon Reavis RN, MS, CRC
- Ann Lovegrove RN, BS, CDMS

The AANLCP held its first “inaugural” conference on April 4 and 5, 1997 in Des Moines, Iowa (AANLCP, 1997a). This was followed by a June 1997 pediatric training program held at the Mosby Medical Case Management Conference (MCMC) conference in Nashville, Tennessee. In September

1997, sessions were held at the Mosby Medical Case Management Conference (MCMC).

The AANLCP sought to expand its membership through reaching life care planners throughout the United States. They accomplished this by presenting at and collaborating with university and professional organizational conferences including MCMC, Case Management Society of America (CMSA), National Association of Rehabilitation Professionals in the Private Sector (NARPPS, now International Association of Rehabilitation Professionals or IARP), American Association of Legal Nurse Consultants (AALNC), Academy of Certified Case Managers (ACCM), Intelicus, and International Commission on Health Care Certification (ICHCC, formerly CHCC and Commission on Disability Examiner Certification or CDEC).

In 1997 the AANLCP developed three levels of membership: Member (requiring an active nursing license), Diplomate, and Fellow. The Diplomate and Fellow designations were based on varying degrees of education, expertise, contribution to life care planning, and number of peer reviewed life care plans (AANLCP, 1997b). The levels of membership were specifically defined by the AANLCP (1997b) as follows:

Fellow: A professional recognition for expertise, experience, and education constituting advanced practice in the field of life care planning.

Diplomate: A professional recognition for expertise and experience in the field of life care planning.

The Diplomate designation was discontinued in 1998 or 1999 (Field, 2017). Sharon Reavis was first to obtain Fellow status through AANLCP (S. Reavis, personal communication, August 8, 2019). *The Academy Letter* published by AANLCP in November 1999 reported that three professionals obtained Fellow status, but did not identify the members with the designation. As of 2019, there are 21 life care planning professionals (including some who are now retired or deceased) who have obtained Fellow status (IARP, 2019).

Under Ms. McCollom’s direction, the organization expanded to include individuals from all disciplines who were performing life care planning (Weed, 2018, p.6). As noted in historical documents (IALCP, 2000) Dr. Roger Weed hosted a meeting in Dallas in November 1997 with Commission on Disability Examiner Certification (CDEC), Intelicus, and the Academy to discuss avenues of collaboration. Attendees at this meeting were Roger Weed,

Linda Shaw, Robert May, Dan Devine COO Intelicus, Debbie Berens and Patricia McCollom (K. Preston, personal communication, February 21, 2018).

As a result of this collaboration, it was determined that life care planning was transdisciplinary and “working toward the good of the whole was critical to successful practice for all” (IALCP, 2000, p. 2). The Academy became the International Academy of Life Care Planners (IALCP), a multidisciplinary association. This meeting also resulted in a mandate to work with the CDEC (now ICHCC) regarding certification, to collaborate with the University of Florida and others to present educational programs integrating advanced programming and research, and to develop a multi-page newsletter. The need for standards of practice was also identified.

The first life care planning and function research study was conducted by the Rehabilitation Institute of Southern Illinois University (AANLCP, 1997a). The CDEC began research and development for life care planning certification in 1994 with the first exam given in 1996 (McCollom & Weed, 2002)

In 1982, an initial definition of a life care plan was offered by Deutsch and Raffa in *Damages in Tort Action*. On April 3, 1998, the definition of the term life care plan was agreed upon after being generated by the IALCP, National Association of Rehabilitation Professionals in the Private Sector (NARPPS), and the University of Florida with Intelicus and being presented at the forensic section meeting at the NARPPS annual conference in Colorado Springs, Colorado. This definition remains in use today. The definition of life care plan is as follows:

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 who has chronic health care needs (IALCP, 1998, p. 3; Weed & Berens, 2018 p. 5).

The IALCP national advisory committee expanded to include two new committees, an education and an ethics committee in November 1999. Dr. Roger Weed was named chair of the ethics committee. By 2000, IALCP was also maintaining a website. Members of the IALCP advisory panel from 2000 – 2005 were Sharon Reavis, Karen Preston, Roger Weed, Doreen Casuto, Joseph Corcoran and Patricia McCollom (Field, 2017).

Life Care Planning Printed Materials

The AANLCP distributed their first quarterly newsletter entitled *Newsletter*, on January 28, 1997. These dissemination of these newsletters continued through AANLPC until January 28, 1998 when AANLCP transitioned to the International Academy of Life Care Planners (IALCP) and they assumed responsibility for disseminating these materials. On May 15, 1998, the first

quarterly newsletter of the IALCP was published. In the first issue of this publication, entitled the Academy Letter, there appeared a proposed set of life care planning standards of practice (IALCP, 1998, p. 4-5). This publication also announced that membership was open to “all persons involved in the production of life care plans” (IALCP, 1998, p. 6) and published the definition of a life care planning as accepted on April 3, 1998 (IALCP, 1998, p. 3).

The *Newsletters* and *Academy Letters* were the information and networking source for life care planners and included sections with product information in the “Product or Research Corner”. They addressed forensic questions in a section entitled “Legal Pad”. They informed readers about upcoming events in the “Calendar”. They also provided book reviews, editorials, guidelines and cost information on a variety of topics including cochlear implants, baclofen pumps, transplants, elder care, and aging and spinal cord injuries. Articles of interest were also adapted from other professional journals and printed in these documents.

By 2001, the *Academy Letter* contained the announcement that the first journal devoted to life care planning, *The Journal of Life Care Planning*, would be distributed starting in March 2002. The journal was being launched in collaboration with Dr. Tim Field, publisher and Elliot & Fitzpatrick. Patricia McCollom was the first editor, with Dr. Roger Weed serving as associate editor, and an editorial board consisting of Dr. Paul Deutsch, Doreen Casuto, and Sharon Reavis. In 2006, Dr. Tim Field graciously gifted the journal to the IALCP section of IARP (Field, 2006).

Life Care Planning Standards of Practice

The first set of proposed standards of practice were developed by Dr. Roger Weed with input from over 200 participants attending the 1997 Annual Life Care Planning Conference and other life care planning educational offerings. The first standards of practice committee members included: Chairperson Sharon Reavis RN, MS, CRC, CRRN, CCM; Ellen Barker MSN, RN, CNRN; Terry Blackwell EdD; Karen Preston MS, PHN, CRRN; and Roger Weed PhD, CRC (Field, 2017).

The first edition of the *Standards of Practice* was presented at the June 2000 life care planning conference (Field, 2017). Since then, standards of practice for life care planners have been field tested, revised and published as a second edition in 2006 and third edition in 2015 entitled *Standards of Practice for Life Care Planners* (IARP, 2015). Detailed historical information about life care planning standards of practice can be found a separate article in this same issue.

The IALCP participated in the first life care planning Summit, held April 12, 2000 in Dallas, Texas. The IALCP has co-sponsored and participated in all subsequent U.S. and Canadian Summits. Detailed historical information about life care planning Summits can be found in a separate article in this same issue.

Life Care Planning Research

The Foundation for Life Care Planning Research (FLCPR) was established in 2002 as a nonprofit research group focused on research of the life care planning process. In 2004 the Foundation joined in co-sponsoring and assumed the administrative responsibilities of the International Conference on Life Care Planning, later remained the International Symposium on of Life Care Planning (ISLCP). The FLCPR transitioned responsibility of the ISLCP to the IALCP section and IARP in 2016, with the understanding that IALCP / IARP would continue to support FLCPR's research mission. The first joint ISLCP / IARP conference was held in Pittsburgh in October 2016. Detailed historical information about the Foundation for Life Care Planning Research can be found in a separate article in this same issue.

Membership in IALCP

Membership in IALCP has grown from the original 60 members in 1997, to 157 members from the U.S. and Canada in 2000, 285 members by 2004, to a current IALCP membership of 495 (IARP, 2019).

As the IALCP grew in numbers, the operational responsibilities of the association were also growing. Membership dues were used to support postage, printing, website, membership, and collaborative efforts with other associations. In 2004, the advisory panel members began exploration to become a nonprofit association. Goals identified were to change to a nonprofit status, operate with funding not tied to the good will and donations of the members, have an elected board of directors, develop other revenue sources, increase membership, and promote a peer review program. Consideration was given to remaining independent by contracting with a professional association management company versus creating an affiliation with another professional association. Conversation with IARP began on December 8, 2004, developing a potential letter of agreement in January 2005, resulting in an in-person meeting on April 29, 2005 to reaffirm the framework of the agreement. Attendees at this meeting were Patricia McCollom, Lew Vierling, Doreen Casuto, Karen Preston, Glenn Zimmerman and Robert Taylor (Field, 2017).

The proposed framework of the agreement included:

- IALCP will continue relationships and co-sponsorships with other organizations for education conferences and coalitions
- The JLCP will remain a member benefit
- Standards of Practice will continue to be written
- The peer review program will remain intact with the sole accountability for revision, maintenance, and process by IALCP
- IARP is committed to embracing all disciplines
- Affirmed that rehabilitation refers to anyone helping others, not to a specific discipline
- IALCP could have marketing materials for the Section prominently displaying the IALCP name

- IALCP Section would determine member services
- IARP would modify IARP By-Laws to accommodate life care planners and a variety of disciplines as members (Field, 2017, p.136-137):

A press release entitled "International Academy of Life Care Planners and International Association of Rehabilitation Professionals Announce Merger" was published in the *Journal of Life Care Planning*. The release announced the joint venture between IALCP and IARP, with IALCP becoming a section of IARP. IARP President Robert Taylor noted:

The IALCP has established a positive reputation for support of members, quality practice and excellence in educational programming. IARP welcomes the opportunity to blend with this fine organization and share in the future and in the growth of our professional activities (IALCP, 2005, p. 147).

According to the press release, IALCP would retain its name, bylaws, procedures, peer-review program, *Standards of Practice*, would continue to offer the *Journal of Life Care Planning* as a member benefit, have a website with links to IARP groups, and IALCP members would have options within IARP for publications and educational programs. Glenn Zimmerman, executive director of IARP commented, "This merger represents a creative and innovative effort to promote specialty practice, while bringing groups with common goals together, to seek the best for their memberships" (IALCP, 2005, p. 147).

Patricia McCollom gifted IALCP to IARP as a new section, effective August 1, 2005. With the merger came a transfer of ownership and copyright of the *Journal of Life Care Planning* to IARP. The first elected board of directors of the IALCP section of IARP were Joe Corcoran, Jean Hope, Karen Preston, Sharon Reavis, and Tracy Wingate. The IALCP chairpersons to date include:

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|-----------|---------------------|-----------------------|
| 1996-2006 | Patricia McCollom | CEO, AANLCP/ IALCP |
| 2006-07 | Joe Corcoran | |
| 2007-09 | Karen Preston | |
| 2009-10 | Cloie Johnson | |
| 2010-11 | Heidi Fawber | |
| 2011-12 | Elizabeth Davis | |
| 2012-13 | Steve Yuhas | |
| 2013-14 | Gerri Pennachio | |
| 2014-15 | Patricia Costantini | |
| 2015-16 | Debbe Marcinko | |
| 2016-17 | Tracy Albee | |
| 2017-18 | Laura Woodard | |
| 2018-19 | Jody Masterson | |
| 2019-20 | Aaron Mertes | |
| 2020-21 | David Altman | – chair elect |

Tribute to Patricia McCollom

The history and accomplishments of the IALCP cannot be discussed without acknowledging the contribution and

forward thinking vision of Patricia McCollom, and the advisory panel members. Patricia McCollom passed away in 2007. In 1996 Patricia McCollom, who had a background in nursing and case management, saw the need for an association responsive to the specialty area of life care planning. With her own initiative, she began the American Academy of Nurse Life Care Planners. The organization broadened to offer an inclusive, rather than exclusive, organization for life care planners, the International Academy of Life Care Planners. She was the primary force behind the committees that developed the Standards, Ethics, and Scope of Practice guidelines for life care planning, Fellow recognition, and the establishment of the *Journal of Life Care Planning*, serving as its editor for the first three years. Awareness of the practice of Life Care Planning was elevated through participation, co-sponsorship, and collaboration with other professional associations. To honor her, the Patricia McCollom/FLCPR Research Award was established to encourage individuals to perform research in life care planning.

Conclusion

As of 2019, we can celebrate three decades of accomplishments by the International Academy of Life Care Planners. They founded a professional organization for all life care planners, the International Academy of Life Care Planners (IALCP) which was merged as a section under the umbrella of the International Association of Rehabilitation Professionals (IARP). They developed the Fellow designation, issued through the College of Life Care Planning Excellence, which recognizes professionals who exemplify the profession through their expertise, experience and contribution to the field of life care planning. They identified the need and supported the development of a national exam leading to certification (CLCP) with a *Code of Ethics* (ICHCC, 2015). They field tested and published *Standards of Practice for Life Care Planners* (IARP, 2015). They launched quarterly publications as newsletters in 1997, leading to the *Journal of Life Care Planning*, the premier life care planning journal spanning from 2002 until present. They co-sponsored and participated in all life care planning Summits, allowing life care planning professionals an opportunity to discuss and debate issues in the field, contribute to development and revision of peer-reviewed standards of practice, prompt methodology standardization, and coordinate efforts of life care planning-related organizations toward common goals (with published results). They contributed to the presentation of an annual life care planning conference / symposium and continuing education events. They provided educational offerings as online webinars and conferences, publication of texts, chapters and articles specific to life care planning. They implemented listservs allowing for the sharing of resources and access to daily discussions. They supported the creation of the Foundation for Life Care Planning Research (FLCPR) which

has funded, provided assistance for research projects, and published articles contributing to the practice of life care planning (Deutsch, Weed, McCollom & Grisham, 2006.)

As of 2019, as life care planning has grown as a field, there are now two additional life care planning associations, The American Association of Nurse Life Care Planners, and the American Academy of Physician Life Care Planners.

The IALCP has provided a solid foundation for the practice of life care planning, an association that is inclusive, multidisciplinary, and collaborative. In conclusion, I cannot say better than Debra Berens said in her 2006 *Journal of Life Care Planning* Editorial entitled "Our Day Will Come":

Through these years, a tremendous amount of work has been done within the practice of life care planning that sets the foundation for future growth. I hope as you read this issue, you will focus on the history of our practice and gain a real sense of pride and ownership within this specialty practice. All life care planners must consider our past as we look to the future with an eye toward collaborative goals and directions needed to sustain the growth of our specialty practice.....The life care planners of yesterday and today continue to shape the destiny of this practice through individual successes and through support and collaboration with others in the field (Berens, 2006c, p. 49)

The IALCP section has its own unique challenges. The practice of life care planning is ever evolving and dynamic and will continue to be a journey. The IALCP must retain its unique identity within IARP, and continue to advance the practice, finding creative ways to fund projects, education, research and collaboration. Hopefully this article will inspire participation in the future growth of the practice. It is the goal of the IALCP to inspire life care planners to contribute in the best way that they can. The options are endless: Write an article, volunteer for a committee, serve on the section board, present at conferences, or collaborate with fellow life care planners. For each of us who have benefitted from the work of all of those life care planners who have gone before us, it is important that we contribute to our field so future members of the International Academy of Life Care Planners will benefit from all that we have learned.

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