

## **Organizational Viewpoints on Research in Life Care Planning**

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### **Abstract**

The field of rehabilitation has become increasingly reliant on evidence based practices to demonstrate efficacy and cost-effectiveness of service delivery. Life care planning, as a subspecialty of rehabilitation, is no exception. Life care planning as a multi-disciplinary profession is comprised of individuals with varying levels of educational background from differing fields of study. While most professionals coming to the specialty of life care planning have had experience reviewing and critiquing research articles as a component of their academic program (Deutsch & Allison, 2004), a comprehensive analysis of research requirements of various certifying bodies has not been conducted. This article provides research position ethics from certifying bodies and professional organizations commonly affiliated with life care planners, based upon prior role and function studies. This information is provided to clarify research requirements and standards for conducting and participating in research within the life care planning field. Kendall and Deutsch (2002) noted that lack of experience in doing research does not preclude professionals from entering into the realm of scientific research. This article will provide information both about the basic research process and provide suggestions for how life care planners can become involved in research.

### **Organizational Viewpoints on Research in Life Care Planning**

There continues to be an increasing trend in rehabilitation, healthcare and human service delivery for higher standards of accountability and evidence-based practice accounting for services delivered to individuals with disabilities (Saunders, Leahy, McGlynn, & Estrada-Hernandez, 2006). Historically, rehabilitation service provision was conceptualized within a medical model of disability and evaluation by individuals receiving services was not solicited. Today, however, individuals with disabilities are involved in service planning, and rehabilitation agencies have come under pressure to demonstrate accountability for their services due to budget cuts (Miller, Chan, Ferrin, Lin, & Chan, 2008). As stricter funding is present in most medical and rehabilitation programs, demonstrating that the rehabilitation services delivered are cost-effective and result in successful outcomes has become relevant to rehabilitation service delivery (Bellini & Rumrill, 2009; Saunders et al., 2006).

A 2009 National Council for the Dissemination of Disability Research (NCDDR) task force on best practices for disability and rehabilitation stated that evidence based practice (EBP) is quickly becoming the preferred approach for guiding disability and rehabilitation

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professionals in providing services to individuals with disabilities (Johnston et al., 2009). Evidence based practice is grounded in scientific research and empirical validation of procedures and methodology. As the field of rehabilitation becomes more concerned with the need for evidence based practices, there is a call for the integration of research and practice to provide the best possible services to individuals with disabilities. For life care planners, evidence based practice includes the grounding of plan recommendations in research literature pertinent to the specific individual for whom the plan is developed (Deutsch & Allison, 2004; Deutsch, Allison & Kendall, 2003).

In addition to the growing need for evidence based practice, the field of life care planning has been impacted by both state and federal judicial decisions, most notably *Daubert v. Merrell Dow Pharmaceuticals, Inc.* The 1993 United States Supreme Court decision in *Daubert v. Merrell Dow Pharmaceuticals, Inc.*, 43 F.3d 1311 set forth the criteria for the admissibility of expert testimony as follows:

1. whether the theory or technique can be or has been tested
2. whether the theory or technique has been subjected to peer review or publication
3. the known or potential rate of error
4. the general acceptance within the relevant scientific community (Countiss & Deutsch, 2002, p. 35).

Since the *Daubert* decision, life care planners have examined how life care planning can meet the above standard, as *Daubert* has been the yardstick by which life care planners measure their work (Pomeranz & Shaw, 2007). Issues arising from the *Daubert* decision have spurred research in life care planning, primarily to establish the reliability and validity of the life care planning process.

Research analysis of data and evaluation of care recommendations are key elements in life care planning and development of a life care plan requires a commitment to a consistent and unbiased process and reliance on fact, research, and expertise (Weed & Berens, 2010). Research cannot only improve the life care planning process and raise standards in our field, but it can also assist in resolution of ethical dilemmas (Kendall & Deutsch, 2002). For a thorough discussion of dimensions of research including reliability, validity, the research process and study design and research ethics, see Kendall and Deutsch (2002). As life care planners come from diverse educational backgrounds, different orientations to research and research training may be held by practitioners within our field. A 2004 study of life care planners' research knowledge found that there was variability in the knowledge and application of research by life care planners, due to differences in obtained research education (Deutsch, Allison, & Kendall, 2003). Nevertheless, continuous use of research literature is an essential responsibility of life care planners. Below is a discussion of the basics of research pertinent to life care planners who desire to engage in research activities.

### **Research Basics**

With the need for ongoing research in the field of life care planning, a review of research protocol is provided. First, there are several levels of research. Primary research involves efforts that generate new knowledge and relates directly to the status/participation of people with disabilities in society (Bellini & Rumrill, 2009). Within life care planning research, examples of primary research include life care planning outcomes of individuals with disabilities. Secondary research measures the competencies, attitudes, and dispositions of service providers who work with people with disabilities. Examples of this research in life care planning include role and function studies of life care planners such as those conducted

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by Pomeranz, Yu and Reid (2010) as well as Neulicht, Riddick-Grisham and Goodrich (2010). Tertiary research efforts investigate knowledge about professional issues that are relevant to counselors and educators including ethical issues for practicing professionals (Bellini & Rumrill, 2009).

When engaging in research, a research protocol is typically submitted to an institutional review board (IRB) for review and approval. The purpose of all IRB review boards is to ensure protection of research participants which generally entail ensuring that risk of human harm is minimized, informed consent is obtained and documented, and data is stored safely and confidentially to protect participant identity. Informed consent is obtained from all participants (or their representatives) and an explanation of the research is provided in clear language. Institutional review board review may occur at different levels, based upon the human participant risk. Expedited IRB review occurs when the research involves no more than minimal risk and is reviewed by the IRB Chair without going through the full review board. At this level, implied or actual consent is obtained from all participants (or their representatives). Here, it is determined that there is no possibility that respondents can be identified or their responses could place them at risk and appropriate protections are implemented so that any risks related to invasion of privacy or breach of confidentiality are no greater than minimal. Expedited review in most instances can typically be approved in two or three weeks depending on the backlog of submissions, whereas full review may take 4 to 6 weeks, with the full board generally meeting monthly. Full IRB review is often, but not always, necessary if the researcher intends to use deception or involve certain populations (e.g., elderly, developmentally disabled). In all instances, full debriefing disclosure must occur following data collection. Finally, although universities are typically the entities most identified with the IRB process, hospitals, rehabilitation centers, and other such entities often have their own IRB process thereby requiring approval for multiple sources if the research is collaborative.

### **Multidisciplinary Field of Life Care Planning**

Recent role and function studies of life care planners have revealed a diversity of educational backgrounds and major fields of study (Neulicht, Riddick-Grisham & Goodrich, 2010; Neulicht et al., 2002; Pomeranz et al., 2010). A 2010 role and function study of 160 life care planners in the United States revealed the highest level of education obtained by life care planners included master's degree (48.9%), bachelor's degree (36.8%), associate's degree/ nursing degree (24.8%) and doctoral degree (12.8%) (Pomeranz et al., 2010). These findings were similar to a prior role and function study of life care planners conducted by Neulicht et al., (2002), where 44% of the respondents' highest level of education was a master's degree, for 29% a bachelor's degree and for 9% master's degrees. Turner (1997) also found that life care planners identified their highest levels of education as master's degree (44%), nursing diploma (34%), doctoral degree (13%) and bachelor's degree (7.5%). Information from recent role and function studies is found in Table 1. With these varying levels of educational attainment, there is significant variation in the level of academic preparation in research methodology.

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**Table 1.**

Highest Level of Education of Life Care Planners Reported in 2010

	Pomeranz et al. 2010	Neulicht et al. 2010
Doctoral Degree	12.8%	11%
Masters Degree	48.9%	47%
Bachelor's Degree	36.8%	27%
Nursing Diploma/ Associates of Nursing	24.8%	13.7%

In addition to having differing levels of education, life care planners also report having various professional areas of licensure and certification. A reflection of the areas of professional certification or licensure held by life care planners is reflected in the numerous certifications held by practicing life care planners. Table 2 reveals the most common certifications or designation held by life care planners. Since individuals could respond to multiple designations, so the total is greater than 100%.

Table 2

Common Professional Certifications and Licenses in 2010

Professional Certification	Pomeranz et al. 2010	Neulicht et al. 2010
CLCP	75.2%	74.3%
CCM	49.7%	41%
RN	43.9%	47.75%
CRC	32.5%	34.2%
ABDA, CEA, CEN, PHN, MSCC	28.7%	MSCC: 15.77%
CDMS	22.3%	19.82%
CRRN	12.7%	13.06%
CNLCP	11.5%	10.8%
LPC	9.6%	17.57%
ABVE	8.3%	9.46%

To add to their professional identity, life care planners reported membership in a variety of professional organizations. Table 3 reflects the most commonly affiliated professional organizations of life care planners.

Table 3  
Common Professional Organizations in 2010

Organization	Pomeranz et al. 2010	Neulicht et al. 2010
IARP	69.3%	63.5%
IALCP	60.7%	61.7%
CMSA	30.0%	25.7%
AALNC	24.7%	16.7%
AANLCP	18.7%	17.6%

### Organizational Research Positions

As life care planning is a multidisciplinary field comprised of medically trained and rehabilitation professionals, a review of research positions was made of organization publications to which life care planners commonly belong. Below are excerpts from the various organizational statements pertaining to research.

#### Certified Life Care Planner (CLCP)/ International Commission on Health Care Certification

Approximately two-thirds of life care planners in the United States hold a certification in life care planning, as a certified life care planner (CLCP). This credential is issued by the International Commission on Health Care Certification (ICHCC). The commission publishes a Standards and Examination Guidelines manual, including a Code of Professional Ethics, which addresses the role of research in life care planning. Principle eight addresses research activities, stating:

**Principle 8 - Research Activities: Disability examiners and life care planners shall assist in efforts to improve upon evaluation and life care plan protocols through participation in research programs or through literature reviews.**

The rules of professional conduct of the CHCC continues:

**R8.1** Disability examiners and life care planners will ensure that data for research meet rigid standards of validity, honesty, and protection of confidentiality.

**R8.2** Disability examiners and life care planners will be aware of and responsive to all pertinent guidelines on research with human subjects. When planning any research activity dealing with human subjects, disability examiners and life care planners will ensure that research problems, design, and execution are in full compliance with such guidelines.

**R8.3** Disability examiners and life care planners presenting case studies in class, professional meetings, or publications will confine the content to that which can be disguised to ensure full protection of the identify of patients.

**R8.4** Disability examiners and life care planners will assign credit to those who have contributed to publications in proportion to their contribution, or as agreed upon with the senior author if the senior author is other than the CHCC credential professional

(source: <http://ichcc.org/PDFs/chcc%20standards%20and%20guidelines%20manual%202008.pdf>) (p. 41)

### **International Association of Rehabilitation Professionals (IALCP)**

Approximately 60% of life care planners identify themselves as members of the International Association of Life Care Planners (IALCP). One of the core values of the IALCP is continuing education and research. Section IV, section b. of the IALCP Standards of Practice addresses research. Specifically, they state:

**b. The involvement of the Life Care Planner in the area of research should include, but not limited to, the following objectives:**

1. The Life Care Planner will strive to identify and participate in research independently or in collaboration with others, utilizing research tools and activities that will promote quality outcomes.
2. The Life Care Planner will critique literature for application to life care planning.
3. The Life Care Planner will use appropriate research findings in the development of Life Care Plans (source:

<http://www.rehabpro.org/sections/ialcp/focus/standards/IALCP%20-%20Standards%20of%20Practice.pdf>) (p.9)

### **Case Manager Certification (CCM)**

Over 40% of life care planners report being certified as a certified case manager (CCM). This credential is issued by the Commission for Case Manager Certification. Within the Code of Professional Conduct for Case Managers revised January 2009 research and research utilization is addressed in section six. These codes state specifically:

**S 27 - Research: Legal Compliance:** Certificants will plan, design, conduct, and report research in a manner consistent with ethical principles and federal and state laws and regulations, including those governing research with human subjects.

**S 28 - Research: Subject Privacy:** Certificants who supply data, aid in the research of another person, report research results, or make original data available will protect the identity of the respective subjects unless an appropriate authorization from the subjects has been obtained or as required by law (source:

[http://www.gotomylist.com/eSystems/CCMC/CECenter/CCMC\\_CoC.pdf](http://www.gotomylist.com/eSystems/CCMC/CECenter/CCMC_CoC.pdf)) (p.7)

### **Commission for Rehabilitation Counselor Certification (CRC)**

Approximately 30% life care planners hold a certification as a rehabilitation counselor (CRC). The CRC certification is issued by the Commission on Rehabilitation Counselor Certification. The Code of Professional Ethics for Rehabilitation Counselors (2012) addresses research and publication in Section I. Extensive information is provided pertaining to rehabilitation research including research responsibilities (section I.1), informed consent and disclosure (section I.2), reporting results (section I.3), publication and presentations (section I.4) and confidentiality (section I.5). Below are excerpts from Section I.1 addressing research responsibilities with human participants:

- a. Use of human participants.** Rehabilitation counselors plan, design, conduct, and report research in a manner that reflects cultural sensitivity, is culturally appropriate, and is consistent with pertinent ethical principles, laws, host institutional regulations, and scientific standards governing research with human participants.
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**c. Precautions to avoid injury.** Rehabilitation counselors who conduct research with human participants are responsible for the welfare of participants throughout the research process and take reasonable precautions to avoid causing injurious psychological, emotional, physical, or social effects to participants.

Section I.2 addresses informed consent and disclosure. Excerpts from Section I.2 dealing with informed consent are below:

- a. Informed consent in research.** Individuals have the right to consent to become research participants. In seeking consent, rehabilitation counselors use language that: (1) accurately explains the purpose and procedures to be followed; (2) identifies any procedures that are experimental or relatively untried; (3) describes any attendant discomforts and risks; (4) describes any benefits or changes in individuals or organizations that might be reasonably expected; (5) discloses appropriate alternative procedures that would be advantageous for participants; (6) offers to answer any inquiries concerning the procedures; (7) describes any limitations on confidentiality; (8) describes formats and potential target audiences for the dissemination of research findings; and (9) instructs participants that they are free to withdraw their consent and to discontinue participation in the project at any time without penalty.
- c. Voluntary participation.** Participation in research is typically voluntary and without any penalty for refusal to participate. Involuntary participation is appropriate only when it can be demonstrated that participation has no harmful effects on participants and is essential to the research.
- d. Confidentiality of information.** Information obtained about participants during the course of research is confidential. When the possibility exists that others may obtain access to such information, ethical research practice requires that the possibility, together with the plans for protecting confidentiality, be explained to participants as part of the procedures for obtaining informed consent.
- e. Individuals not capable of giving informed consent.** When individuals are not capable of giving informed consent, rehabilitation counselors provide an appropriate explanation to and obtain agreement for participation and appropriate consent from a legally authorized person.

Section I.3 addresses reporting research results. This section states:

- a. Accurate results.** Rehabilitation counselors plan, conduct, and report research accurately. They provide thorough discussions of the limitations of their data and alternative hypotheses. Rehabilitation counselors do not engage in misleading or fraudulent research, distort data, misrepresent data, or deliberately bias their results. They explicitly mention all variables and conditions known to the investigator(s) that may have affected the outcome of studies or interpretations of data. They describe the extent to which results are applicable for diverse populations.
- b. Obligation to report unfavorable results.** Rehabilitation counselors report the results of any research of professional value. Results that reflect unfavorably on institutions, programs, services, prevailing opinions, or vested interests are not withheld.
- c. Identity of participants.** Rehabilitation counselors who supply data, aid in the research of another person, report research results, or make original data available, take due care

to disguise the identity of respective participants in the absence of specific authorization from the participants to do otherwise. In situations where participants self-identify their involvement in research studies, researchers take active steps to ensure that data is adapted/changed to protect the identities and welfare of all parties and that discussion of results does not cause harm to participants.

- d. Reporting errors.** If rehabilitation counselors discover significant errors in their published research, they take reasonable steps to correct such errors in a correction erratum or through other appropriate publication means.
- e. Replication studies.** Rehabilitation counselors are obligated to make available sufficient original research data to qualified professionals who may wish to replicate the study.

Section I.4 addresses publication and presentations. It addresses the following areas:

- a. Recognizing contributions.** When conducting and reporting research, rehabilitation counselors are familiar with and give recognition to previous work on the topic, observe copyright laws, and give full credit to those to whom credit is due.
- b. Contributors.** Rehabilitation counselors give credit through joint authorship, acknowledgment, footnote statements, or other appropriate means to those who have contributed significantly to research or concept development in accordance with such contributions. Principal contributors are listed first and minor technical or professional contributions are acknowledged in notes or introductory statements.
- h. Nonprofessional relationships.** Rehabilitation counselors avoid nonprofessional relationships with research participants when research involves intensive or extensive interaction. When a nonprofessional interaction between researchers and research participants may be potentially beneficial, researchers must document, prior to the interaction (when feasible), the rationale for such interactions, the potential benefits, and anticipated consequences for research participants. Such interactions are initiated with appropriate consent of research participants. Where unintentional harm occurs to research participants due to nonprofessional interactions, researchers must show evidence of an attempt to remedy such harm.

Section I.5 addresses confidentiality involved in research activities. Excerpts from Section I.5 are below:

- a. Institutional approval.** When institutional review board approval is required, rehabilitation counselors provide accurate information about their research proposals and obtain approval prior to conducting their research. They conduct research in accordance with the approved research protocol.
  - b. Adherence to guidelines.** Rehabilitation counselors are responsible for understanding and adhering to national, local, agency, or institutional policies or applicable guidelines regarding confidentiality in their research practices.
  - c. Confidentiality of information obtained in research.** Violations of participants' privacy and confidentiality are risks of participation in research involving human participants. Investigators maintain all research records in a secure manner. They explain to participants the risks of violations of privacy and confidentiality and disclose to participants any limits of confidentiality that reasonably can be expected.
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- d. Disclosure of research information.** Rehabilitation counselors do not disclose confidential information that reasonably could lead to the identification of research participants unless they have obtained the prior consent of participants. Use of data derived from counseling relationships for purposes of training, research, or publication are confined to content that are disguised to ensure the anonymity of the individuals involved.
- e. Agreement for identification.** Rehabilitation counselors identify clients, students, or research participants in a presentation or publication only when it has been reviewed by those clients, students, or research participants and they have agreed to its presentation or publication (source: <http://www.crc certification.com/filebin/pdf/CRCCCodeOfEthics.pdf>) (p. 27)

### **Case Management Society of America**

Approximately 30% of life care planners in America belong to the Case Management Society of America (CMSA). According to CMSA's strategic mission, the organization advocates for patient well being, by providing evidence-based tools in resources in the practice of case management. Research is addressed in the bylaws of CMSA, Article II, section one, number six, which states:

Conduct and cooperate in research and courses of studies for the benefit of advancing the practice of case management (source:

<http://www.cmsa.org/CMSA/SocietyBylaws/tabid/228/Default.aspx>)

Within the Standards of Practice of CMSA, section VIII, subsection O addresses research encouraging the case manager to be familiar with current research findings and be able to apply them, as appropriate, to their practice. This familiarization will be demonstrated through:

- Compliance with legitimate and relevant research efforts, in order to quantify and define valid and reliable outcomes in case management.
- Incorporation of meaningful research findings into practice as appropriate (CMSA, 2010).

### **American Association of Nurse Life Care Planners**

Approximately 18% of life care planners belong to the American Association of Nurse Life Care Planners. This organization encourages life care planners to participate in the advancement of the profession through mentorship, collegiality, education, and ongoing knowledge development and contribute to the dissemination of materials and information to advance the nursing and life care planning practice (AALCP, 2011). At the time of this article going to press, the association's standards of practice were in the process of revision based upon the American Nurse Association's Standards of Practice. The revised standards will include language pertaining to research. The standards can be found at [http://www.aanlcp.org/Code\\_ofProfessionalEthicsandConduct11-11.pdf](http://www.aanlcp.org/Code_ofProfessionalEthicsandConduct11-11.pdf).

### **American Association of Legal Nurse Consultants**

Approximately 20% of life care planners belong to the American Association of Legal Nurse Consultants (AALNC). The mission statement of AALNC is to provide a forum education and research. The AALNC's Specialty Practice of Legal Nurse Consulting (2005) stresses the use of knowledge learned through research to educate and advocate for patients and improve healthcare outcomes. This organization, in their specialty Practice of Legal

Nurse Consulting Position Statement (2005) addresses the role of research in the practice of legal nurse consultants. It states:

As knowledge based professionals, Legal Nurse Consultants use information learned in the research and development of a case to improve future health care for patients, to advocate for remedies for patients who have received inadequate care, and to provide education to clients, patients, health care providers, and the public as appropriate. Legal Nurse Consultants seek adequate protection of patients and the public and promote accepted standards of care that will serve to prevent injury and alleviate suffering.

Similar to other registered nurses working in research settings, informatics, administrative positions, and other role settings, Legal Nurse Consultants engage in specialty nursing practice that covers many roles, some including direct patient care and others influencing patient care indirectly. For example, the nurse Case Manager or Life Care Planner directly influence patient outcome by assessing patient needs and making appropriate recommendations (source:

[http://www.aalnc.org/resource/resmgr/position\\_statements/positionstatement.pdf](http://www.aalnc.org/resource/resmgr/position_statements/positionstatement.pdf)) (p2)

### **Conclusions**

As life care planners, we are both members of the field of rehabilitation, which is investing heavily in the production of evidence based research and participants in a judicial system that increasingly exacts rigorous standards for admitting expert witness testimony. As such, the expectations of our credentialing bodies and our professional organizations reflect a commitment to ongoing research. However, the field continues to need increased participation in research endeavors to validate and improve service provision to individuals with disabilities. As life care planning is a multidisciplinary field comprised of nurses, case managers, rehabilitation counselors, and other healthcare related professionals, our field encompasses professionals with varying levels of research training. Lack of familiarity with research may limit a life care planner's willingness to design, conduct or participate in research projects.

Admittedly, life care planners may not have time to dedicate to designing and implementing a solo research project. However, rehabilitation counseling programs seek ideas from practicing professionals to assist graduate students in completing their curriculum based research. As private rehabilitation is a relatively recent addition to the rehabilitation counseling curricula, many graduate students lack the valuable "real world" experience helpful in generating research projects in private rehabilitation areas including life care planning. Serving as a student mentor or providing research ideas to rehabilitation counseling programs is another avenue for life care planners to contribute to the growing body of empirically based life care planning research.

It is clear that the professional organizations and certifying bodies involved in the field of life care planning each encourage knowledge of and participation in ongoing professional research. Life care planners should continue to look for opportunities to participate in research that will improve the field of life care planning. Research involvement may include conducting individual research or participation in research conducted by professionals in the field of life care planning. Such efforts may receive support from the Foundation for Life Care Planning Research (<http://www.flcpr.org/>). To encourage participation, researchers often obtain continuing education credits for participating life care planners. At a minimum,

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all professionals involved in life care planning should both understand their ethical obligation to participate in research and stay abreast of research based literature published in professional journals to inform their practice.

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