

# **Ethical Risks of Underestimating Life Expectancy in Life Care Planning Practice**

*Christine Reid, PhD CRC CLCP*

## **Abstract**

Ethical risks of underestimating life expectancy (LE) estimates for use in life care planning are analyzed. The effects of underestimated LE on the predictive validity of life care plans, the effects on individuals living with disability, and the overall ethical implications for professional practice are discussed. Limitations of current studies of mortality rates among people with different disabilities are addressed, including the lack of attention to economic status and the availability of appropriate health care. Evidence of the effect of poverty on LE estimates, as well as the prevalence of poverty among people living with disability, is presented.

*Keywords:* life expectancy, ethics, disability, rehabilitation, poverty, life care planning

According to DeVivo (2002), "Life expectancy is defined as the arithmetic average of remaining years of life for a group of comparable individuals" (p. 49). If a single total lifetime cost of all of the items detailed in a life care plan is needed, it is necessary to estimate how many years those costs will be incurred, through the predicted end of that individual's lifespan. Life expectancy estimates are commonly used to predict the end date when those services will no longer be needed in the life care plan. Reliable, valid methods to accurately predict life expectancy of people who have disabilities are also needed for the insurance industry, in order to reasonably forecast future payments on annuity products such as those purchased to fund structured settlements. Strauss, Shavelle, Pflaum, & Bruce (2008) emphasized the need for such insurance products, stating that "Without a market to bear the risk that the individual will live longer than expected, many disabled will outlive their life-care funding and become dependent on their families or the state" (p. 181). Looking more closely at the impact of these estimates on the person for whom a life care plan is developed, Krause & Saunders (2010) noted that life expectancy estimates ultimately affect "the extent to which services and goods will be provided in order to meet the lifetime needs of an individual with a catastrophic disability" (p. 15).

## **The Problem**

Why should life care planners be concerned about whether life expectancy estimates used in litigation are fair and accurate predictors of how long an individual will live if his or her life care plan recommendations are implemented? In addition to ethical or humanitarian concerns, life care planners should be concerned about how the accuracy of such estimation affects the validity of their life care plans. Deutsch, Allison, & Kendall (2003) include the following question in their discussion of how to evaluate the predictive validity of a life care plan (LCP):

---

“If projections of life expectancy are included in the LCP, are those projections accurate?” (p. 9B.05). The accuracy of a life expectancy estimate used to project total expenses associated with a life care plan very directly affects the validity of that life care plan when used to predict the costs necessary to maximize quality of life and minimize complications for the injured individual. Threats to the validity of life care plans directly affect the professional credibility of life care planners.

As professionals, life care planners also have an ethical responsibility to examine whether or not life expectancy (LE) estimates applied to their life care plans are likely to be accurate. Krause & Saunders (2010) pointed out that because goods and services listed in a life care plan, “such as attendant care, medications, and diagnostic tests, may be required to maintain life, underestimates of LE have the potential to undermine access to the very resources required for survival” (p. 15). If LE is underestimated, such underestimation can be dangerous to the survival (as well as quality of life) of the individual for whom a life care plan is developed. An underestimate of LE could become a self-fulfilling prophecy.

Overestimation of LE may carry different risks. For example, if an overestimation of LE is used to set pricing for an insurance product to provide an annual annuity to fund services identified in the life care plan, the costs for that product will be higher than they should be, leaving fewer resources for the individual living with disability to use for other important purposes. If overestimation of LE results in overpayment of damages to an individual who will not actually need to use the services in a life care plan for as long as projected, that may be considered a threat to the ethical principle of justice, if there are others in society who need those resources but do not have access to them.

Life care planners considering the ethical implications of underestimating or overestimating LE should consider three important questions. 1) Are currently used approaches to estimating life expectancy most likely to overestimate life expectancy or underestimate life expectancy? 2) What are the likely consequences of estimation error in that direction? 3) Do life care planners have a professional ethical obligation to do anything about such likely consequences? To begin the process of seeking answers to these questions, it is important to gain a better understanding of how LE is used in life care planning, what research has been conducted about factors expected to affect LE for people living with disability, and how principles outlined in relevant professional codes of ethics and standards of practice might be useful.

### **How life expectancy is estimated for litigation purposes**

In personal injury litigation resulting in a one-time settlement or award to compensate for damages projected through the end of an individual’s lifespan, a number is needed to estimate when that life is reasonably predicted to end. Three general approaches to setting that life expectancy estimate are currently used to produce the estimated end point for a life care plan. One method relies on data from published studies of mortality among people who have similar disabilities. Another method relies on using unreduced estimates of life expectancy based on population averages for individuals with similar demographic characteristics, regardless of disability. The third relies on physician prediction of an individual’s life expectancy. In some cases, a combination of methods is used, such as when general population estimates are reduced by a specified number of years because of a physician’s estimate of the number of years by which life expectancy will likely be reduced for his or her patient living with disability.

### **Complexity of factors interacting to affect life expectancy**

---

The appropriate norm group for estimating life expectancy in a life care plan would be a group of individuals with the same disabilities and the same pre-injury demographic characteristics who were then provided with the resources and tools needed to fully implement their life care plans, without risk of those funds running out at a specified end date. If such studies exist, they are rare indeed.

Life expectancy estimates are basically the result of generating regression equations that predict an outcome (age at which the individual is equally likely to be alive or not alive) from an available set of predictors among existing data from a given population. However, Wheelan (2013) cautioned that “Regression results will be misleading and inaccurate if the regression equation leaves out an important explanatory variable” (p. 218). To look for such explanatory variables, a review of relevant literature is appropriate.

### **Literature**

#### **Variability among studies of life expectancy**

There is considerable variation among published studies of life expectancy for people with specific disabilities. Differences in demographic characteristics, sampling frames, construct definitions, and variables included in the analyses all contribute to such variability. Slesnick & Thornton (1994) noted that “Studies concerning the mortality rate of those suffering spinal cord injuries vary as to the types of individuals in the study (age, sex, race, etc.), the date of the study, the type of care provided, and other factors” (p. 199). Changing the definition of a population to be included in the study, such as including all individuals admitted to an emergency room for spinal cord injuries versus including only those individuals who had already survived at least a year after injury, can make a great difference in the LE estimate. If most deaths from spinal cord injury occur shortly after the injury, including those deaths that occur within the first year will significantly reduce the LE estimate for the total population of individuals living with spinal cord injuries. However, a more appropriate comparison group for someone who has lived more than a year with a spinal cord injury is a group of people who have also survived at least a year with similar injuries. An even better comparison group would also be matched on additional variables, such as the presence or absence of secondary health conditions, which were identified as risk factors for mortality and diminished LE by Krause & Saunders (2011). Krause (2002) has identified “a host of important variables that impact life expectancy, including income, access to health care, health behaviors, and psychosocial adaptation” (p. 59). Krause and Saunders concluded in 2010 that “LE estimates in life care plans need to take into account economic factors in order to improve accuracy. It is important to allocate resources to meet all healthcare needs throughout the life cycle to ensure that LE is not compromised” (p. 15).

Some recent studies of life expectancy have resulted in higher estimates of LE than were predicted from previous studies. Strauss, Shavelle, & Ashwal (1999) reported updated estimates of life expectancy for people living in a “vegetative state” (VS), concluding that “On the basis of recent mortality rates, life expectancy in the VS is frequently higher than has generally been thought.” Pliplys (2012) discussed LE of people living with cerebral palsy, citing evidence that “if optimal medical care can be assured for these patients, their life expectancy, compared to published results, would be increased by an additional 10 years of age” (p. 31).

Even the statistical term used to define life expectancy can cause variability in estimates. Defining LE as the arithmetic average of remaining years of life for a comparable group may yield different results than defining it as the survival median, “50% survival time that is

defined as the time at which members of the group would be equally likely to be alive or deceased” (DeVivo, 2002). The arithmetic average of remaining years of life and the survival median may be significantly different from each other. Harrison-Felix, Hawley, Brown, & DeVivo (2013) discussed life expectancy of individuals with traumatic brain injuries (TBI), noting that “median survival following TBI will almost always be higher than life expectancy, just as it is in the general population” (p. 327).

### **Poverty and life expectancy**

Multiple studies have identified poverty as a risk factor for reduced life expectancy. Seeman, Merkin, Crimmins, Koretz, Charette, & Karlamangla (2008) highlighted the effect of insufficient education and low income variables as predictors of “biological risk profiles,” reporting that “Multivariable cumulative logistic regression models revealed that the education and income effects were each independently and negatively associated with cumulative biological risks, and that these effects remained significant independent of age, gender, ethnicity, and lifestyle factors such as smoking and physical activity” (p. 72). In California, Clarke, Miller, Chang, Yin, Cockburn, & Gomez (2011) studied race and socioeconomic status (SES) effects on life expectancy, finding that “Race/ethnicity and neighborhood SES had substantial and independent effects on life expectancy, underscoring the importance of monitoring health outcomes simultaneously by these factors” (p. 1373). Waldron (2007) found “a difference in both the level and the rate of change in mortality improvement over time by socioeconomic status for male Social Security-covered workers” (p.1). Specifically, “the top half of the average relative earnings distribution has experienced faster mortality improvement than the bottom half” (Waldron, 2007, p. 1). Crimmins, Kim, & Seeman (2009) “examined life table survivorship to clarify how mortality differentially removes those who are poor and those with high biological risk from the population” (p. 286). They concluded that “Poorer people ‘age’ earlier and this affects the age pattern of social differentials” (p. 286). Kalwij, Alessie, & Knoef (2013) examined the association between individual income and remaining life expectancy at the age of 65 (mandatory retirement age) in the Netherlands. They reported “remaining life expectancy at age 65 for low-income individuals as approximately 2.5 years less than that for high-income individuals” (p. 181).

### **Poverty and disability**

If poverty reduces life expectancy, it is important to examine whether people with disabilities tend to have greater than average rates of poverty. If the rate of poverty is high, that is likely to have a negative effect on the life expectancy estimates generated from mortality tables for such people with disabilities.

She & Livermore (2009) reported that “Depending on the disability measure used, annual poverty rates are 2 to 5 times higher among people with disabilities compared to those without disabilities” (p. 244). Palmer (2011) carefully defined the constructs relevant to defining poverty among people with disabilities (PWDs), clarifying that “Relative to people without disabilities, PWDs are more likely to experience poverty of basic needs. The minimum needs required for a basic level of well-being are higher for PWDs than nondisabled people” (p. 212). Hughes (2013) addressed consequences of poverty for students with disabilities, stating that “Living in poverty increases the likelihood that students with disabilities will experience poor postschool outcomes” (p. 37). London, Heflin, & Wilmoth (2011) examined the effect of disability and veteran status on poverty rate, finding that “households with nondisabled veterans present have a lower likelihood of poverty, but that advantage is severely eroded when

---

the veteran or another family member has a work-limiting disability” (p.330). They also found that disabled nonveteran households “have the highest poverty rate (32.53%)” (London, Heflin, & Wilmoth, 2011, p. 330). Emerson, Shahtahmasebi, Lancaster, & Berridge (2010) reported that “When compared to families not supporting a child with a disability, families supporting a child with intellectual disability were (a) more likely to be poor, (b) more likely to become poor, (c) less likely to escape from being poor” (p. 224). Parish, Rose, & Swaine (2010) also identified “significant financial vulnerability among parents of children with developmental disabilities” (p. 235).

### **Effect of Poverty on Disability**

What happens when poverty and disability interact? As Palmer (2011) explained, the minimum needs for well-being of people who live with disability are greater than those for people who do not have disabilities. However, as identified in multiple studies, people with disabilities are more likely to be financially poor than are people who do not have disabilities. People living with disability tend to have fewer resources to meet greater needs, resulting in a multiplicative effect on poverty.

The litigation process itself can contribute to the risk of insufficient resources to meet the needs of people living with disability. If a settlement or award is based on the costs associated with implementing a life care plan and the loss of earnings (past and future), what happens when a part of that total (such as one third, for example) is taken out to pay legal fees? The resources available to meet the needs of that individual living with disability would then be reduced proportionally, resulting in greater poverty than would have been experienced if the individual were never injured.

### **Three Ways to Risk Underestimating Life Expectancy**

Each of the three general ways that are used to estimate life expectancy for use in implementing life care plans have the potential to underestimate LE for people living with disability.

#### **Using data from mortality studies of people with similar disabilities**

The tendency to underestimate life expectancy based on published mortality studies of people with disabilities or serious health challenges has been identified in a variety of professional journals. In the journal *Medical Decision Making*, Benbassat, Zajicek, Van Oortmarssen, Ben-Dov, & Eckman (1993) stated, “The assumption of constant excess mortality hazards over age and time from diagnosis is at odds with observed mortality in many diseases” (p. 237). In the *BC Medical Journal*, Anderson and Marion (2003) discussed “downward bias in the conventional methods of calculation” and reported that “Conventional estimates of life expectancy in elderly patients with life-shortening conditions are almost always lower than they should be” (p. 178). In the journal *Demography*, Yi, Danan, & Land (2004) explained that “disabled life expectancies that are based on conventional multistate life-table methods are significantly underestimated because of the assumption of no changes in functional status between age  $x$  and death” (p. 335).

#### **Health care provider estimates of life expectancy**

Leung, Hopman, & Kawakami (2012) studied the accuracy of patient life expectancy predictions made by physicians involved with prostate cancer management, concluding that “Physicians do poorly at predicting life expectancy and tend to underestimate how long patients have left to live” (p. 367). Wirth & Sieber (2012) studied health care professionals’

estimates of the mean life expectancy of older people, and reported that “health care professionals underestimated the mean remaining life expectancy of older persons by 10%, on average, with great variance (SD = 34%). Medical doctors, especially those not specialized in geriatrics, estimated worst” (p. 56).

### **Underestimation of life expectancy of the general population**

Mitchell (2004) emphasized that the “life expectancy of all Americans, including people with disabilities, is increasing” (p. 93). White (2002) reported, “Life expectancy has increased by 40 years since 1840 and shows no sign of having peaked” (p. 1173). She then explains that “increases of just a few years can have an enormous impact on health and social services” (p. 1173). Oeppen & Vaupe (2002) focused on the rising rate of life expectancy for the general population, stating that “life expectancy has increased by 2.5 years per decade for a century and a half,” and “life expectancy will reach 100 in about six decades” (p. 1031). They also stated that “experts have repeatedly asserted that life expectancy is approaching a ceiling; these experts have repeatedly been proven wrong” (Oeppen & Vaupe, 2002, p. 1031).

Underestimation of life expectancy for the general population has implications for individuals planning for retirement, for pension systems, and for the health care system in general. Another implication of general underestimation of life expectancy may be that lay people (such as members of a jury) might erroneously think of an LE estimate as an upper limit on what should be expected, much like the “use by” date on a milk carton. In reality, LE is not an upper limit; it is the midpoint on a graph of cumulative mortality rates over time, in which the probability of being alive and that of not being alive are equal. The upper limit, or “use by” date, would be an asymptote (extreme) end of that graph. The LE is not the point where a person is expected to be dead; it is the point where, if the LE estimate is accurate, the person is as likely to be alive as to be dead. If the LE estimate provided is actually an underestimate of what life expectancy should be for such an individual, it is more likely than not that the individual will live past the given LE.

### **Risk of Systemic Bias**

In research, systemic bias occurs when uncontrolled factors systematically push a result in one direction or another. This is different from the concept of “bias” that is intended to favor one side or another in litigation. It is possible that either a plaintiff or defense attorney may make a strategic decision to maximize perception of reduced life expectancy for an injured individual. A zealous plaintiff attorney whose client has minimal life care plan expenses but a seven-figure income prior to injury could focus on loss of earnings capacity through reduced life expectancy as a way to maximize damages. On the other hand, a zealous defense attorney facing a very expensive life care plan could focus on reduced life expectancy in order to minimize the total costs of implementing the plan. In either of these cases, the attorney would emphasize the possibility of reduced life expectancy, in hopes of biasing a decision about damages in favor of her or his client.

Systemic bias in research could be either beneficial or problematic for a plaintiff or defense attorney. However, all life care planners should be concerned about systemic bias in research dealing with life expectancy estimates. Life care planners need to objectively and accurately project goods and services needed, and costs of those goods and services, over the lifetime of an individual living with disability; a systematic error in lifetime cost projection is a significant problem.

Combined, the problems with underestimating LE from existing mortality studies of

---

individuals with similar disabilities, evidence of the influence of poverty on reducing LE, evidence of the high rate of poverty among people living with disability, and a possible tendency of physicians to underestimate LE pose a significant risk of underestimating the life expectancy of people living with disability. Given this evidence, the answer to the question, “Are currently used approaches to estimating life expectancy most likely to overestimate life expectancy or underestimate life expectancy?” is clear: these approaches are most likely to underestimate life expectancy. The next question life care planners should then ask is, “What are the likely consequences of estimation error in that direction?”

### **Potential consequences of underestimation through systemic bias**

Basically, systemic bias that underestimates LE for people living with disability is expected to result in most people living beyond the estimated LE used to project expenses associate with the life care plan. It is therefore more likely than not that an individual will live past the estimated LE. If insufficient funding is provided for the services that individual will need after that date, reduced services can result in complications and decreased quality of life, as well as increased mortality risk because of insufficient health care. Given these likely consequences, the next question for life care planners to ask themselves is, “Do life care planners have a professional ethical obligation to do anything about such likely consequences?”

### **Ethical Implications**

What are the ethical implications for life care planners who become aware of this risk of underestimating life expectancy? Small (2002) asserted that because “life expectancy is really a representation of existing patterns of mortality, which in turn are determined by many influences, including the present allocation of health resources, it should not be taken as a prediction, and still less as a statement of entitlement” (p. 307). Brock recognized an argument that the “worst off” should receive priority in allocation of health care resources, “in order to reduce inequality, in order to increase equality of opportunity, because reducing greater deprivation has greater moral importance, because getting treatment will be subjectively most important to the sickest, or because the sickest have the greatest health needs” (2000, p. 12). Aside from these arguments, life care planners can evaluate the problem of underestimating life expectancy through application of an ethical decision-making model. Several relevant models are published in rehabilitation-related literature; one simple example was presented by Corey, Corey and Callahan, who outlined the following steps for addressing ethical concerns: (1) identify the problem or dilemma, (2) identify the potential issues involved, (3) review the relevant ethics codes, (4) know the applicable laws and regulations, (5) obtain consultation, (6) consider possible and probable courses of action, (7) enumerate the consequences of various decisions, and (8) decide on what appears to be the best course of action (p. 20 – 22).

This article has provided some information relevant to the first two steps of such an ethical decision-making model. The next step, reviewing relevant ethics codes, depends in part on the primary profession of the life care planner applying this process. Each life care planner should carefully examine the ethical codes most relevant to his or her professional practice, and identify aspects of each of those codes that are relevant to this process. As a starting point, this article provides examples of how ethical principles may apply, and then cites specific elements of a variety of ethical codes to illustrate points that may be relevant to the ethical analysis by life care planners using those codes.

---

### **Ethical principles**

The following ethical principles permeate most professional codes of ethics. For example, they are defined in the preamble of the Code of Professional Ethics for Rehabilitation Counselors (Commission on Rehabilitation Counselor Certification, CRCC, 2009).

**Autonomy.** This principle focuses on the rights of clients to be self-governing, to make decisions for themselves. If reduced estimates of life expectancy reduce the funding available to people living with disability, what effect does that reduction have on their autonomy when trying to implement their life care plans?

**Beneficence.** This principle advocates for promoting the well-being of clients. It is the “do good” principle. Does this principle obligate life care planners to take some kind of action to promote the well-being of people with disabilities who are presented with an underestimated life expectancy?

**Nonmaleficence.** This principle is the foundation of the Hippocratic Oath in medicine: “Do no harm.” Does underestimating life expectancy risk harm to people living with disability?

**Fidelity.** This principle calls for faithfulness, keeping promises, and honoring the trust placed in us as professionals. Does underestimation of life expectancy violate the trust in professionals held by people living with disability?

**Justice.** This principle requires fair treatment of all clients, and appropriate services to all. Is it fair and just for an individual living with disability to end up without the services needed when he or she outlives an underestimate of life expectancy that is based on systemic bias?

**Veracity.** This principle requires honesty. Is it honest to use an estimate for life expectancy that is likely to be an underestimate of how long the individual will actually live?

### **Codes of ethics and standards of practice**

Life care planners who participated in the 2012 Life Care Planning Summit in Denver, Colorado noted that many codes of ethics and standards of practice are relevant to life care planning. Codes and standards associated with the International Academy of Life Care Planning, as well as the general certifying body for life care planners and discipline-specific codes relevant to practitioners with different professional backgrounds, were examined and discussed at that Summit. Examples of those codes and standards of practice, with excerpts relevant to the question of whether underestimating life expectancy is an ethical risk for life care planning practice, follow.

**International Academy of Life Care Planners (IALCP, 2006).** In the Standards of Practice for Life Care Planners, the “client” in life care planning is defined as “the person who is the subject of the life care plan” and a major goal of life care planning is “To assist the client in achieving optimal outcomes by developing an appropriate plan of prevention of complications and restoration” (p. 125).

**Commission on Health Care Certification (CHCC, 2007).** In the Standards and Examination Guidelines document for the Certified Life Care Planner credential, CHCC states that “The primary obligation of the disability examiner and life care planner is to the disabled person in question” (p. 34). In addition, “Life care planners shall serve as advocates for fair and balanced life care plans regardless of referral source, with the health, care, and safety of people with disabilities not to be compromised as a result of a submitted respective care plan” (p. 37).

**American Association of Legal Nurse Consultants (AANLC, 2009).** “The legal nurse consultant’s work is free from bias. The legal nurse consultant does not discriminate against

---

any person based on race, creed, color, age, sex, national origin, social status or disability” (p. 1).

**American Medical Association (AMA, 2001).** “A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights” (p. 1).

**American Nurses Association (ANA, 2001).** “The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient” (p. 6).

American Occupational Therapy Association (AOTA, 2010). “Occupational therapy personnel shall demonstrate a concern for the well-being and safety of the recipients of their services” (p. 3).

**American Osteopathic Association (AOA, 2012).** “A physician is never justified in abandoning a patient” (p. 1).

**American Physical Therapy Association (APTA, 2009).** “Physical therapists shall adhere to the core values of the profession and shall act in the best interests of patients/clients over the interests of the physical therapist” (p. 1).

**American Psychological Association (APA, 2010).** “Psychologists strive to benefit those with whom they work and take care to do no harm. In their professional actions, psychologists seek to safeguard the welfare and rights of those with whom they interact professionally and other affected persons” (p. 1).

**American Speech-Language-Hearing Association (ASHA, 2010).** “Individuals shall honor their responsibility to hold paramount the welfare of persons they serve professionally” (p. 1).

**Association of Rehabilitation Nurses (ARN, 2003).** “All people have the right to receive rehabilitation services regardless of their age, race, gender, ethnicity, religion, or economic status” (p. 2).

**Certification of Disability Management Specialists Commission (CDMSC, 2009).** “Certificants shall respect the integrity and protect the welfare of those persons or groups with whom they are working” (p. 3).

**Commission on Case Manager Certification (CCMC, 2009).** “Certificants will respect the rights and inherent dignity of all of their clients” (p. 1).

**Commission on Rehabilitation Counselor Certification (CRCC, 2009).** In the section on Forensic and Indirect Services, “Rehabilitation counselors produce unbiased, objective opinions and findings that can be substantiated by information and methodologies appropriate to the evaluation” (p. 15).

**International Association of Rehabilitation Professionals (IARP, 2007).** “IARP members are to respect the integrity and protect the welfare of the individuals or groups to whom their work pertains” (p. 1). Within the Forensic section of this document, IARP states, “So that justice is served by accurate determination of the facts involved, Forensic Rehabilitation Experts/Consultants use their abilities in an objective, unbiased, nonpartisan, impartial, and fair manner in arriving at findings, conclusions, and/or opinions” (p. 4).

### **Putting it all together**

Three important questions were asked earlier in this article. 1) Are currently used approaches to estimating life expectancy most likely to overestimate life expectancy or underestimate life expectancy? 2) What are the likely consequences of estimation error in that direction? 3) Do life care planners have a professional ethical obligation to do anything about such likely consequences?

---

An answer to the first question can be deduced from empirical evidence outlined in this article. There is strong evidence of the risk of systemic bias and underestimation of life expectancy for people living with disability when expectancy estimates are based on currently published mortality studies of individuals with similar disabilities, especially if those studies do not control for the effects of variables such as poverty. There is also evidence for the risk of underestimation of life expectancy by physicians. There is even some risk of underestimating life expectancy when using general population estimates (disregarding disability), given evidence of the sustained trend for increasing life expectancy over time.

Given that 1) published studies of LE among people living with specific disabilities are highly variable and do not tend to examine relevant factors such as poverty or access to health care resources, 2) factors such as poverty have been identified as strong predictors of reduced life expectancy, and 3) there is substantial empirical evidence that people living with disability have a higher rate of poverty than does the general population, it is highly likely that current LE estimates for people living with disability are underestimates. Therefore, most LE estimates used in life care plans are likely to be underestimates, and it is more likely than not that the individuals for whom those plans were developed will live longer than the predicted LE.

What are the likely consequences of estimation error that underestimates LE? If life expectancy estimates are underestimated, funding provided in a settlement or award to fund the life care plan will likely be insufficient to provide the needed services. If needed services are not provided, quality of life may be reduced, and preventable complications may result, potentially hastening the individual's death. An underestimated life expectancy may very well become a self-fulfilling prophecy.

Do life care planners have a professional ethical obligation to do anything about such likely consequences? Analysis of ethical principles, as well as relevant ethical codes and standards of practice, suggests that life care planners have some ethical responsibility to take action if we conclude that underestimating life expectancy is dangerous to the people for whom we develop life care plans. We also have a responsibility to ensure the reliability and validity of our life care planning process, and to address validity threats. Each life care planner should consult her or his relevant ethical codes, review applicable laws and regulations (such as which definition of life expectancy is used within the relevant jurisdiction), consult with another professional who is familiar with ethical decision-making processes, consider possible courses of action and the likely consequences of such action from the perspective of relevant stakeholders, and then select and implement the best course of action.

When considering a course of action, life care planners should not limit themselves to thinking solely about implications for their current evaluatees. For example, in addition to educating a variety of stakeholders about the risks of underestimating life expectancy, life care planners could contribute to research to improve the literature examining mortality among people living with disability who were provided with life care plans. If we study mortality and quality of life outcomes while taking into account factors such as the sufficiency of funding and actual provision of services specified in life care plans, more sophisticated and appropriate predictions of life expectancy could be made for individuals with similar disabilities in the future.

---

---

**References**

- American Association of Legal Nurse Consultants (AANLC). (2009). *Code of ethics and conduct with interpretive discussion*. Chicago, IL: Author.
- American Medical Association (AMA). (2001). *Code of medical ethics of the American Medical Association*. Chicago, IL: Author.
- American Nurses Association (ANA). (2001). *Code of ethics for nurses with interpretive statements*. Silver Spring, MD: Author.
- American Occupational Therapy Association (AOTA). (2010). *Occupational therapy Code of ethics and ethics standards*. Bethesda, MD: Author.
- American Osteopathic Association (AOA). (2012). *Osteopathic code of ethics*. Chicago, IL: Author.
- American Physical Therapy Association (APTA). (2010). *Code of ethics for the physical therapist*. Baltimore, MD: Author.
- American Psychological Association (APA). (2010). *Ethical principles of psychologists and code of conduct*. Washington, DC: Author.
- American Speech-Language-Hearing Association (ASHA). (2010). *Code of ethics*. Rockville, MD: Author. doi:10.1044/policy.ET2010-00309
- Anderson, T. W. & Marion, S. A. (2003). Underestimation of life expectancy in Elderly patients: The example of paraplegia. *BC Medical Journal*, 45(5), 178-182.
- Association of Rehabilitation Nurses (ARN). (2003). *Position statement: Ethical issues*. Glenview, IL: Author. Retrieved from <http://www.rehabnurse.org/advocacy/content/Position-Statement-Ethical.html>
- Benbassat, J., Zajicek, G., Van Oortmarssen, G. J., Ben-Dov, I., & Eckman, M. H. (1993). Inaccuracies in estimates of life expectancies of patients with bronchial cancer in clinical decision making. *Medical Decision Making*, 13, 237-244. doi: 10.1177/0272989X9301300310
- Brock, D. W. (2000). Health care resource prioritization and discrimination against persons with disabilities. In L. P. Francis & A. Sivers (Eds.), *Americans with disabilities: Exploring implications of the law for individuals and institutions* (pp. 223-235). New York: Routledge.
- Certification of Disability Management Specialists Commission (CDMSC). (2009). *The CDMS code of professional conduct*. Schaumburg, IL: Author.
- Clark, C. A., Miller, T., Chang, E. T., Yin, D., Cockburn, M., & Gomez, S. L. (2010). Racial and social class gradients in life expectancy in contemporary California. *Social Science & Medicine*, 70(9), 1372-1380. doi: 10.1016/j.socscimed.2010.01.003
- Commission for Case Manager Certification (CCMC). (2009). *Code of professional conduct for case managers with standards, rules, procedures, and penalties*. Mt. Laurel, NJ: Author.
- Commission on Health Care Certification (CHCC). (2007). *Standards and examination guidelines*. Midlothian, VA: Author.
- Commission on Rehabilitation Counselor Certification (CRCC). (2009). *Code of professional ethics for rehabilitation counselors*. Schaumburg, IL: Author.
- Corey, G., Corey, M. S., & Callahan, P. (2003). *Issues and ethics in the helping professions*. (6th ed.). Pacific Grove, CA: Brooks/Cole.
- Crimmins, E. M., Kim, J. K., & Seeman, T. E. (2009). Poverty and biological risk: The earlier "aging" of the poor. *The Journals of Gerontology, Series A: Biological Sciences and Medical Sciences*, 64A(2), 286-292. Doi: 10.1093/Gerona/gln010
-

- Deutsch, P. M., Allison, L., & Kendall, S. L. (2003). Research design and statistics: A practical guide to reading research literature and practice guidelines. In P. M. Deutsch & H. W. Sawyer (Eds.), *A guide to rehabilitation* (pp. 9B1-9B88). White Plains, NY: AHAB.
- DeVivo, M. J. (2002). Estimating life expectancy for use in determining lifetime costs of care. *Topics in Spinal Cord Injury Rehabilitation*, 7(4), 49-58.
- Emerson, E., Shahtahmasebi, S., Lancaster, G., & Berridge, D. (2010). Poverty transitions among families supporting a child with intellectual disability. *Journal of Intellectual & Developmental Disability*, 35(4), 224-234. doi: 10.3109/13668250.2010.518562
- Harrison-Felix, C. L., Hawley, L. A., Brown, A. W., & Devivo, M. J. (2013). Life expectancy and wellness. In N. D. Zazler, D. I. Katz, & R. D. Zafonte (Eds.), *Brain injury medicine* (pp. 319 – 331). New York: Demos Medical.
- Hughes, C. (2013). Poverty and disability: Addressing the challenge of inequality. *Career Development and Transition for Exceptional Individuals*, 36(1), 37-42. doi: 10.1177/2165143413476735
- International Academy of Life Care Planners (IALCP). (2006). Standards of practice for life care planners. *Journal of Life Care Planning*, 5(3), 123-129.
- International Association of Rehabilitation Professionals (IARP). (2007). *Code of ethics, standards of practice and competencies*. Glenview, IL: Author.
- Kalwij, A. S., Alessie, R. J. M., & Knoef, M. G. (2013). The association between individual income and remaining life expectancy at the age of 65 in the Netherlands. *Demography*, 50, 181-206. doi: 10.1007/s13524-012-0139-3
- Krauss, J. S. (2002). Accuracy of life expectancy estimates in life care plans: Consideration of nonbiographical and noninjury factors. *Topics in Spinal Cord Injury Rehabilitation*, 7(4), 59-68.
- Krause, J. S. & Saunders, L. L. (2010). Life expectancy estimates in the life care plan: Accounting for economic factors. *Journal of Life Care Planning*, 9(2), 15-28.
- Krause, J. S. & Saunders, L. L. (2011). Health, secondary conditions, and life expectancy after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 92, 1770-1775. doi: 10.1016/j.apmr.2011.05.024
- Leung, K.M.Y.B., Hopman, W. M., & Kawakami, J. (2012). Challenging the 10-year rule: The accuracy of patient life expectancy predications by physicians in relation to prostate cancer management. *Canadian Urological Association Journal*, 6(5), 367-373.
- London, A. S., Heflin, C. M., & Wilmoth, J. M. (2013). Work-related disability, veteran status, and poverty: Implications for family well-being. *Journal of Poverty*, 15(3), 330-349. doi: 10.1080/10875549.2011.589259
- Mitchell, M. (2004). Aging with cerebral palsy, spinal cord injury and amputation: Implications for life care planners. *Journal of Life Care Planning*, 3(2), 93-104.
- Oeppen, J. & Vaupe, J. W. (2002). Broken limits to life expectancy. *Science*, 296(5570), 1029-1031. doi: 10.1126/science.1069675
- Palmer, M. (2011). Disability and poverty: A conceptual review. *Journal of Disability Policy Studies*, 21, 210-218. doi: 10.1177/1044207310389333
- Parish, S. L., Rose, R. A., & Swaine, J. G. (2010). Financial well-being of US parents caring for coresident children and adults with developmental disabilities: An age cohort analysis. *Journal of Intellectual and Developmental Disability*, 35(4), 235-243. doi: 10.3109/13668250.2010.519331
- Pliophly, A. V. (2012). Life expectancy determinations: Cerebral palsy, traumatic brain
-

- injury, and spinal cord injury analysis and comparison. *Journal of Life Care Planning*, 11(3), 25-38.
- Seeman, T., Merkin, S. S., Crimmins, E., Koretz, B., Charette, S., & Karlamangla, A. (2008). Education, income, and ethnic differences in cumulative biological risk profiles in a national sample of US adults: NHANES III (1988 – 1994). *Social Science & Medicine*, 66, 72-87. doi: 10.1016/j.socscimed.2007.08.027
- She, P. & Livermore, G. A. (2009). Long-term poverty and disability among working-age adults. *Journal of Disability Policy Studies*, 19, 244-256. doi: 10.1177/1044207308314954
- Slesnick, F. & Thornton, R. (1994). Life expectancies for persons with medical risks. *Journal of Forensic Economics*, 7(2), 197-207.
- Small, R. (2002). The ethics of life expectancy. *Bioethics*, 16(4), 307-334.
- Strauss, D. J., Shavelle, R. M., & Ashwal, S. (1999). Life expectancy and median survival time in the permanent vegetative state. *Pediatric Neurology*, 21(3), 626-631.
- Strauss, D., Shavelle, R., Pflaum, C., & Bruce, C. (2001). Discounting the cost of future care for persons with disabilities. *Journal of Forensic Economics*, 14(1), 79-87.
- Waldron, H. (2007). Trends in mortality differentials and life expectancy for male Social Security-covered workers, by socioeconomic status. *Social Security Bulletin*, 67(3), 1-28.
- Wheelan, C. (2013). *Naked statistics: Stripping the dread from the data*. New York: W. W. Norton & Company.
- White, C. (2002). Life expectancy is consistently underestimated, say researchers. *British Medical Journal*, 324(7347), 1173.
- Wirth, R. & Sieber, C. C. (2012). Health care professionals underestimate the mean life expectancy of older people. *Gerontology*, 58(1), 56-59.
- Yi, Z., Danan, G., & Land, K. C. (2004). A new method for correcting underestimation of disabled life expectancy and application to the Chinese oldest old. *Demography*, 41(2), 335-361. doi: 10.1353.dem.2004.0018

#### Author Bio

Christine Reid, Ph.D., CRC, CLCP, Rehabilitation Counseling Professor at Virginia Commonwealth University, serves on the Foundation for Life Care Planning Research Board of Directors.