

International Classification of Functioning, Disability and Health: A Model for Life Care Planners

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Abstract

The method life care planners use to evaluate the impact of a disability or injury is consistent with the theory behind the World Health Organization's International Classification of Functioning, Disability and Health (ICF). This highly accepted model has been advantageous to educators, clinicians, researchers, and policy makers who specialize in understanding the needs of individuals with chronic health care needs. As challenges to expert testimony continue to develop, life care planners must frequently demonstrate the validity of their approach to establishing future care and associated costs for individuals with disabilities. The purpose of this article is to describe the ICF model and elucidate its implications as a tool for life care planners to validate recommendations depicted in their life care plans.

Introduction

Since the term "life care plan" first appeared in print in Deutsch & Raffa's (1981) publication "Damages in Tort Actions," Life Care Planning has evolved to become a highly specialized "niche" area of practice. Today, evidence of that evolution is apparent, based on advances in a number of different areas. There are multiple training programs delivered through multiple formats that target both beginners and advanced practitioners (Berens, 2004). Increasing numbers of life care planners have become Certified Life Care Planners (May, 2002) and the credential is increasingly referenced in legal venues. There is now a section (International Academy of Life Care Planners/IALCP) within a major professional organization (International Association of Rehabilitation Professionals/IARP) that solely represents the needs and concerns of Life Care Planners (International Academy of Life Care Planners, 2007). Life care planning also has its own journal, the *Journal of Life Care Planning* (Weed, 2004), and its own Code of Ethics and Standards of Practice (McCollom & Weed, 2002; May, 2002; McCollom, 2006; IALCP, 2006). Four professional summits have helped to focus the professional development of the field (Weed & Berens, 2001; Riddick-Grisham, 2003; Deutsch & Allison, 2004; Riddick-

Grisham, 2006).

The field should feel justifiably proud of these accomplishments, and its success in these areas bodes well for the practice of life care planning. For any field to retain its dynamism and vitality, however, it is important not only to reflect on its accomplishments, but to engage in critical examination of its challenges and limitations, both in the present and projecting into the future. The decision of the U.S. Supreme Court in *Daubert v. Merrell Dow Pharmaceuticals, Inc.*, 509 U.S. 579 (1993) had a dramatic impact on life care planners as it created a yardstick against which the profession measured itself. The court in this case set out four criteria for the admissibility of expert testimony. These guidelines were summarized by Countiss and Deutsch (2002) as:

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; and 4) general acceptance within the relevant scientific community (p. 35).

Subsequent legal decisions further refined the requirements for admission of expert opinion testimony (Choppa, Johnson, Fountaine, Shafer, Jayne, Grimes & Field, 2004) and Countiss and Deutsch (2002) have aptly shown how the field of life care planning meets the tests of admissibility. While a number of articles and papers have documented the field's increased attention to issues of validity and reliability of the life care plan (McCollom & Crane, 2001; Deutsch, 1994; Sutton, Deutsch, Weed & Berens, 2004; Patterson, Murphy & Masterson, 2004). They do also, however, note that Life Care Planning is a relatively young profession, and judges may not understand the ways in which life care planning meets these admissibility criteria unless carefully educated. Consequently, it is important for life care planners not only to be knowledgeable about the way in which the profession meets these criteria, but they also need to be able to explain it to the court in language that is clearly understandable and using models that are acceptable and easily applied in this situation. Choppa and Deutsch (2002) rightly assert that Life Care Planning isn't a theory, in and of itself, but rather a tool of Case Management Practice. Nevertheless, to the extent that Life Care Planning can be shown to be a good "fit" with existing, accepted theory, and to the extent that theory can be shown to guide the process, the "tool" of Life Care Planning is likely to be much more readily accepted as a legitimate and relevant approach to establishing future care and associated costs.

The International Classification of Functioning, Disability and Health (ICF)

Life care planners frequently evaluate the impact of a disability or injury utilizing a methodology that is consistent with the theory behind the International Classification of Functioning, Disability and Health (ICF). Developed by the World Health Organization (WHO), this model provides a unified and standard language and framework for the description of disability and health-related states (World Health Organization/WHO, 2001). The ICF was developed through international multi-disciplinary teams from 65 countries who collaborated to create a tool that serves different purposes and disciplines with high trans-cultural validity (Bilbao, Kennedy, Chatterji, Ustun, Barquero, & Barth, 2003). The intent of this model was to provide a mechanism for the development of international communication tools, especially with respect to rehabilitation. In addition, the ICF has been shown to be useful for identifying and measuring efficacy and effectiveness of rehabilitation services through functional profiling and intervention targeting (Peterson & Kosciulek, 2005). For example, the ICF framework can be used to systematically categorize intake, assessment, and outcome information collected for a

given group of rehabilitation service recipients (Bruyere, 2005).

The ICF model was created following two revisions of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which was developed in 1980. Revisions were developed in reaction to a paradigmatic shift of defining disability within a medical framework towards one reflecting social dimensions of disability (Simeonsson, Leonardi, Lollar, Bjorck-Akesson, Hollenweger, & Martinuzzi, 2003). The medical framework describes disability as a challenge imposed on an individual caused by disease, trauma, or health-related condition. Management of a disability based on the medical model is aimed at a cure or an individual's compensatory strategies, adjustment or behavioral change. Conversely, the social framework describes disability not as an attribute of the individual but rather as a complex collection of conditions, many of which are created by the social environment. Management of a disability (in addition to the individual's strategies) requires social action, environmental modification, attitudinal and ideological changes (World Health Organization/WHO, 2001).

The ICF is considered a biopsychosocial model which incorporates both medical and social perspectives. The ICF is made up of two parts (Figure 1). The first part includes components of functioning and disability. This part includes the body function and structures component, which can be further subdivided into two classifications. One classification is for functions of body systems, which involve physiological or psychological functions. The other classification is for body structures, which include anatomic parts of the body such as organs, limbs, and their components. The other component of functioning and disability, activities and participation consists of a wide range of different aspects of functioning from both an individual and societal perspective. Activities are defined as an execution of a task by an individual. Examples of activities depicted within the ICF model include: performing activities of daily living (ADL's), exercising, learning how to use a device, performing specific job duties, taking notes in class, and paying bills. Participation is described as in an execution of a task by an individual in society. Examples of participation include: parenting, interpersonal relationships, accessing public transportation, academic pursuits, and recreation (Scherer, Sax, & Glueckauf, 2005; WHO, 2001).

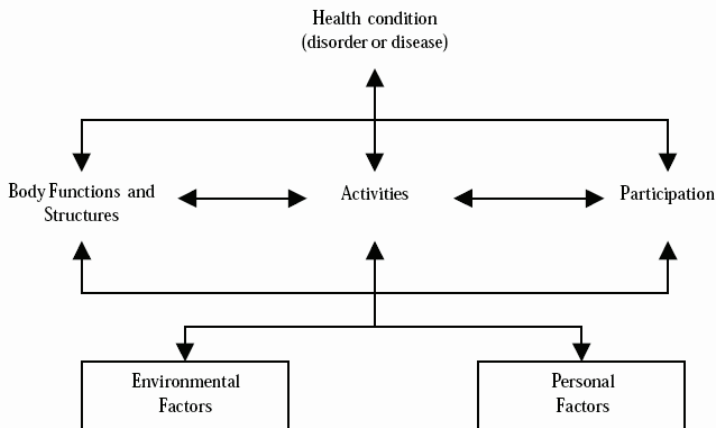


Figure 1. ICF Model. Reprinted with permission from the World Health Organization (WHO). Retrieved March 7, 2007 from <http://www.who.int/classifications/icf/site/intros/ICF-Eng-Intro.pdf>

The second part of the ICF model includes components of contextual factors (environmental and personal), which are external features of physical, social, and world attitudes, which can have an impact on the individual's performance in a given domain. Environmental factors can impact the functioning and disability part of the model. Although environmental factors are often overlooked by health care professionals (Macdonald-Wilson & Nemeo, 2005), such factors are critical for the development of life care plans. Examples of activities that would fall under this category are: assistive devices for accessibility and communication support from family, financial support, and systems and policies (Smiley, Threats, & Mowry, 2007).

In addition to environmental factors, contextual factors include personal factors which refer to the particular background of an individual's life and living, and includes those features of the individual that are not part of the primary health condition or health state. These factors may include gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behavior pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level. All components within the two domains of the ICF contribute to a model of disablement (WHO, 2001).

The disablement scheme of the previous versions of the ICF conceptualized the cause and effect of disablement as a unidirectional pathway that emanated from the disease or active pathology to various types of functional consequences (Jette, 1994). As depicted in Figure 1, the arrows between each component in the ICF model are bi-directional, demonstrating that aspects of a disability can affect each other in either direction. For example, previous models suggested that a disease or health condition would lead to limitations in functional activities. There was previously no indication that limitation in activities could affect a health condition or disease. The ICF model, however, demonstrates that difficulties in activity could influence a health condition or disease. For example, an individual with a traumatic brain injury (health condition or disease) may be limited in effectively performing activities such as reading and writing. The bi-directional approach would suggest that not only does the alteration in brain functioning affect reading and writing performance, but if an individual does not work on skills such as reading and writing, that the individual's cognitive function may decline, thus exacerbating the health condition.

The accuracy of the bi-directional pathway depicted within the ICF-Model can also be observed by examining a chronic disease such as diabetes. The health condition would be referred to as the diabetes which affects the body's ability to produce insulin (body function and structure). Diabetes imposes limitations on an individual's activities with regards to eating and nutrition. If an individual does not adhere to activity limitations such as appropriate nutritional intake, damage can occur to body systems, thus exacerbating the negative effects of the disease.

Case Example

A case example can help to better illustrate how the ICF model can serve as a guide for understanding disability. The following example is based on an individual with a diagnosis of complete C6 tetraplegia. According to the ICF model, the health condition or disease would be the spinal cord injury. The individual could have significant functional limitations, which may lead to requiring assistance with activities of daily living (ADL's). The paralysis as a result of the level of spinal cord injury and physiological deficits would fall under bodily functions and

structures, while ADL's would make up the activities component of the model. The individual's participation would include the ability to execute tasks in society such as leisure, home/yard maintenance, vocational, and educational activities. Such participatory tasks may be limited due to other components of the model such as secondary health conditions, environmental factors, and personal factors. Secondary health conditions may be acute illnesses, respiratory problems, or conditions associated with spinal cord injuries. Environmental factors may include lack of family support or insufficient funding to support personal assistance services. Insufficient personal assistance will most likely lead to deficits in the functional, activities, participation, and possibly health conditions arenas.

Applications of the ICF Model

Since its inception, the ICF model has been advantageous to educators, clinicians, researchers, and policy makers who specialize in understanding the needs of individuals with chronic health care needs. This model has been used as a statistical tool for the collection and recoding of data, a research tool to measure outcomes, quality of life or environmental factors; a clinical tool for developing needs assessments and matching treatment with specific conditions; and a model for evaluating an individual's vocational potential, and developing rehabilitation outcomes evaluation (Dagfinrud, Kjekshus, Mowinckel, Hagen, & Kvien, 2005; Harris, MacDermid, & Roth, 2005; Ratzon, Jarus, & Catz, 2007; Simeonsson et al., 2003; Steiner, Ryser, Huber, Uebelhart, Aeschlimann, 2002; World Health Organization/WHO, 2001). In addition, over the past 20 years, the evolution of the ICF model has influenced policy decisions regarding the rights and functions of individuals with disabilities in society. Changes in both the model and public policy have influenced and been influenced by the shift from the medical model to a more social/environmental view of disability. The Americans with Disabilities Act (ADA) for example, which was established to bring people with disabilities into economic and social mainstream of American life, established functional definitions of disability and addressed environmental contexts which paralleled previous versions of the ICF (Peterson & Rosenthal, 2005). Finally, educators, who are responsible for disseminating information regarding the impact of a disability from both a medical and social perspective can utilize the ICF model to ensure that learners will have a clear understanding of all aspects of a disability (World Health Organization/WHO, 2001).

Life Care Planning and the ICF Model

The enormous impact that the ICF model has had, not only in the US but throughout the world, warrants attention from life care planning experts who frequently analyze the medical, psychosocial, and economic impact of disability. The ICF can provide a very useful framework for conceptualizing and explaining the process of life care planning. To better understand the relationship between life care planning and the ICF model, these authors have pictorially "placed" the components of a life care plan within the ICF model (Figure 2). As depicted in Figure 2 below, all elements of the life care plan can be captured within various components of the ICF model. Furthermore, a life care planner could substantiate his/her recommendations by referencing this model. Considering the case example discussed previously, an individual with a spinal cord injury (health condition), would likely require numerous medically-related evaluations and medical care. Such medical care may include specialty evaluations and routine follow-up and future surgeries. In addition, an individual's condition can be further exacerbated following potential complications. For example, if an individual develops decubitus ulcers and they go untreated, an individual's health status could decline considerably.

The participation component incorporates essential aspects of a life care plan that allow an individual with a catastrophic injury to function in society. These activities include: personal assistance/attendant care, vocational/education plans, and aids for independent living. In order for an individual with a spinal cord injury to have full participation, every effort must be made by the life care planner to ensure that an individual can maintain a functional level to execute basic life activities. Such activities include ambulation and mobility, ability to use equipment such as wheelchair, automobile, and orthopedic equipment. Without the ability to perform these functions, the ability to participate in activities in society becomes challenging.

In order to maintain body structure and function life care planners must project therapeutic modalities for an individual which often include but are not limited to: physical therapy, occupational therapy, individual/family counseling, and speech therapy. Effective and critical functioning of individuals with disabilities is often based on the ability to maintain medications and obtain the necessary disability-related supplies. As depicted in Figure 2, lack of medications and supplies to maintain body function can impact an individual's ability to engage in activities and participate in society, which can negatively effecting that person's health condition.

Contextual factors are frequently considered by life care planners for determining whether an individual can execute individual activities and participate in society. For example, an individual with a spinal cord injury who utilizes a wheelchair would most likely require an accessible bathroom to navigate for bowel and bladder management and bathing/showering activities. Without this accessibility, the individual would not be able to perform ADL's relating to hygiene. This inability to maintain such basic self-care activities would prevent an individual from interacting in society (working, going to school, socializing, etc.). Education and vocational training recommendations within a life care plan coincide with the contextual factors depicted within the ICF model. Following the occurrence of a spinal cord injury, an individual may need to examine other vocational options due to physical and possibly cognitive limitations. These contextual factors clearly facilitate an individual's ability to adapt to his/her disability, thus promoting active participation. Furthermore, the model clearly illustrates the way in which addressing participation can directly impact the health condition (e.g. inability to recreate may lead to inactivity, which in turn increases the probability of secondary or exacerbated health conditions). The model provides a clear and well-accepted justification for considering the individual's comprehensive functional needs, including needs related to participation.

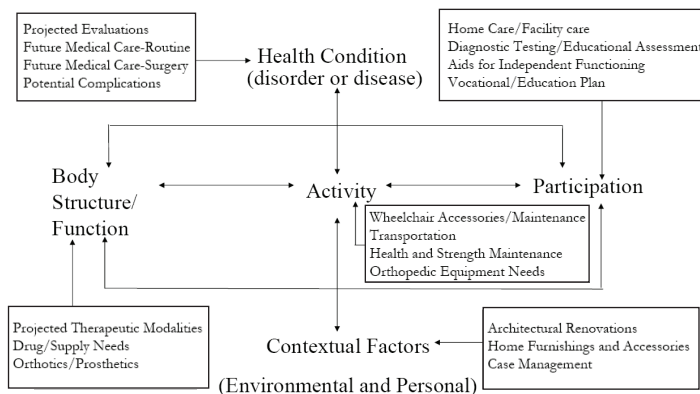


Figure 2. The Life Care Planning-ICF Model

Implications for Life Care Planners

The consistency between the methodology utilized by life care planners with the theory behind the ICF model opens the door to a plethora of opportunities for the field of life care planning. Life care planners can take advantage of the fact that their specialization demonstrates a “good fit” with an existing well established, frequently published, international model of disability. Just as life care planners regularly rely on published research, clinical practice guidelines, and professional standards, the ICF can serve as a valuable source for substantiating recommendations included within a life care plan. The ICF model is being utilized by a number of rehabilitation professionals demonstrating its broad range applicability to injuries and disabilities. In fact, a review of the current literature revealed a number of conceptual and empirically-based articles that were developed based on the ICF model. Table 1 includes examples of published articles that may be beneficial to life care planners seeking validation for recommendations. Included within the table is a description of each article and topics useful to life care planners.

Table 1. Recent ICF literature

<u>Citation</u>	<u>Description</u>	<u>LCP Area(s)</u>
(Scherer et al., 2005) Activities and participation: The need to include assistive technology in rehabilitation education. <i>Rehabilitation Education</i>	Describes how assistive technology can improve the functioning of individuals with disabilities from the perspective of the <i>environmental</i> component of the ICF	Architectural renovations, home furnishings and accessories, aids for independent living.
(Wang et al., 2006) Exploring the role of contextual factors in disability models. <i>Disability and Rehabilitation</i>	Defines contextual factors within the ICF, which include interpretation of environmental and personal factors in the context of disability	Therapeutic modalities (individual/family counseling), case management, vocational considerations.
(Simeonsson et al., 2003). Applying the ICF model to measure childhood disability. <i>Disability and Rehabilitation</i>	Identifies issues related to application of the ICF to measure disability in childhood and reviews approaches and tools to assess childhood disability	Pediatric life care planning, therapeutic modalities, projected evaluations,
(Biering-Sorensen et al., 2006) Developing core sets for persons with spinal cord injuries based on the ICF as a way to specify functioning. <i>Spinal Cord</i>	The development of a comprehensive ICF core set for spinal cord injury to be used as a checklist to assess patient's needs, formulate rehabilitation goals and evaluate progress.	Life care planning for individuals with spinal cord injuries.
(Pierce & Hanks, 2006) Life Satisfaction After Traumatic Brain Injury and the World Health Organization Model of Disability. <i>American Journal of Physical Medicine and Rehabilitation</i> .	Determine which components of the (ICF) are most predictive of global life satisfaction after traumatic brain injury.	Life care planning for individuals with traumatic brain injury. Changes in recommendations over time (e.g. aging and rehabilitation).

As the table indicates, a variety of scientific peer-reviewed journals have published ICF-related articles related to numerous disabilities, illustrating its comprehensive application.

In addition to providing research validity to life care planning recommendations, the ICF model can connect rehabilitation professionals internationally through a common disability language that is accepted world-wide. This can be especially advantageous to life care planners seeking to market their services at an international level. In addition, increased interest in the field of life care planning creates opportunities for individuals from other countries to provide similar services within their own countries. There already exists a Canadian certification in life care planning and other countries may develop professional certifications as well.

There is a precedent for this level of international communication in the widespread, transnational use of the International Classification of Diseases (ICD-10), which has become the international standard diagnostic classification for all general epidemiological and many health management purposes. Interestingly enough, the ICF compliments the ICD-10, allowing professionals to communicate disability-related issues beyond mortality and disease. Life care planners who are involved in the development of Medicare Set-Asides (MSA) are already relying on this coding system.

Conclusion

It may be surprising that a recent model of disability has been developed and relied upon that mirrors a theory developed by life care planners who have been evaluating the impact of disability from a biopsychosocial perspective for over 25 years. As such, life care planners should be applauded for advancing a profession prior to the national and international community implementing a comprehensive model and universal language of disability. With such attention being placed on this model of disability, life care planners can use the ICF as a platform for illuminating the appropriateness of life care plan recommendations, market the field of life care planning at an international level, educate future life care planners regarding the appropriateness of evaluating a disability from a biopsychosocial perspective, and seek federal funding to research and validate life care planning methodologies.

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