The issue is—An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health—Some critical remarks

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The International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001) provides an international and interprofessional scientific basis for understanding and studying health. The concept of participation plays an important role in the classification and has become a central construct in health care, rehabilitation, and in occupational therapy. The aim of this paper is to provide a critical analysis of the concept of participation in the ICF. As background, the origins and current presentation of the ICF are presented. The use and function of the ICF and the contemporary discussions regarding the classification are reviewed. An occupational perspective on participation in the ICF reveals major shortcomings regarding the subjective experience of meaning and autonomy. Furthermore, the ICF has limitations in capturing different kinds of participation in a single life situation. Following these analyses we discuss the advantages and shortcomings of using the ICF, and how an occupational perspective can contribute to an ongoing discussion about the development of the ICF.


Introduction

In 2001, the World Health Organization (WHO) presented the International Classification of Functioning, Disability and Health, which is referred to as the ICF (World Health Organization [WHO], 2001). The ICF aims to provide an international and interprofessional scientific basis for understanding and studying health, outcomes, and determinations that can be used in the comparison of data across countries, for classification, in research, and for health policy. The current ICF, to a large extent, came about because of criticisms that were directed at its predecessor from disability studies. In particular, the ICF concept of participation has its origins in the disability studies literature and the related disability movement, which has emphasized the rights of disabled citizens to participate fully in society (Barnes, Mercer, & Shakespeare, 2000; Hurst, 2003; Swain, Finkelstein, French, & Oliver, 1994).

The concept of participation not only plays an important role in the ICF classification but also has become a central construct in health care, rehabilitation, and in occupational therapy. Participation might be seen as an external and multidisciplinary concept that provides support and recognition of the occupational perspective as the basis for occupational therapy (Gray, 2001). Not surprisingly, the term, participation, very quickly has become a part of the professional language in occupational therapy and incorporated by occupational therapy in literature, in theoretical models (Kielhofner, 2002), and in the field’s journals (e.g., OTJR: Occupation, Participation and Health). Although it is significant that occupational therapy has been able to incorporate the ICF concepts rapidly into the field’s perspectives, it will be equally important for the field to be aware of and contribute to critical analysis that will continue development of the ICF in the future.
Aim and Structure of the Paper

The aim of this conceptual paper is to provide a critical analysis of the concept of participation in the ICF. We begin by examining the origins and current presentation of the ICF followed by a review of the contemporary discussions about the classification, especially those emanating from disability studies. Then we will ask what might be done to further enhance the ICF concept of participation using an occupational therapy perspective on occupation.

The Development of the International Classification of Functioning, Disability and Health

The development of the ICF has engaged people worldwide over the past 3 decades. In 1973, WHO invited Dr. Philip Wood to create a classification of the outcomes of disease (Nordenfelt, 2003). The new classification aimed to be consistent with the International Classification of Diseases (ICD), an etiological framework classifying health conditions such as diseases, disorders, and injuries. For statistical purposes the ICD provided valuable information about patients with acute diseases, but was insufficient in describing the consequences of diseases in daily life. Such information was vital in order to enable better planning of services and provision of treatment and rehabilitation for persons with long-term disabilities or chronic conditions. In response to these shortcomings, WHO published the first edition of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980 (WHO, 1980).

ICIDH was the first systematic attempt to create an international nomenclature and classification of the consequences of diseases. In so doing it made a formidable breakthrough in the medical world at that time (Nordenfelt, 2003; Simeonsson et al., 2003). The consequences of diseases in the ICIDH were conceptualized in the form of three dimensions: Impairment–Disability–Handicap. Thus, a disease was hypothesized to cause impairment (defined as a loss or abnormality of bodily structures and functioning), that in turn would cause a disability (defined as a lack of ability to perform a normal activity), which in turn might be manifested as a handicap (defined as limitation with regard to fulfilling a role in life) (WHO, 1980). Although the ICIDH in general was well-received, it was also criticized for its linear and causal model, which linked impairment, disability, and handicap without accounting for the role of the environment (Imrie, 2004; Schneidert, Hurst, Miller, & Ustun, 2003; Simeonsson et al., 2003). Additionally, the disability rights movement has been especially critical that the ICIDH was based on the medical model placing the problem of disability within the individual rather than within the context of social, economical, and political domains. Thus, the ICIDH focused on the limitation of people’s abilities instead of barriers in the society (Barnes et al., 2000; Hurst, 2003; Simeonsson et al., 2003).

In response, the disability rights movement put forward the social model of disability. This model concentrates on the environment as the true cause of disability; it stresses that disability is not a condition within the individual but instead is created in interaction with an oppressing social environment designed for nondisabled living (Barnes et al., 2000; Swain et al., 1994). As a result of this criticism, a revision process started in the 1990s, especially addressing the need to introduce environmental dimensions (Hurst, 2003). After several beta-versions, the current ICF was published in 2001 (WHO, 2001).

Compared to the earlier ICIDH, the current ICF is a significant step forward to a more integrative understanding of health. WHO proclaims: “ICF has moved away from being a ‘consequences of disease’ classification (1980 version) to become a ‘components of health’ classification” (WHO, 2001 p. 4).

Although the ICIDH emphasized the malfunctioning biological body in and of itself as the primary determinant of disability, the current ICF seeks to locate an understanding of disability at the intersection between the biological body and the social and institutional structures (Hurst, 2003; Imrie, 2004; Ueda & Okawa, 2003). This is in part evident by putting participation as one of the central components of the classification. Another major change emerging from the social model of disability is the emphasis within the ICF on environmental factors, organized in sequence from the individual’s most immediate environment to the general environment (Hurst, 2003; Nordenfelt, 2003; Schneidert et al., 2003). The recognition of the central role played by environmental factors has changed the locus of the problem and, by that focus of intervention, from the individual to the environment in which the individual lives (Hurst; Schneidert et al.). Thus, in the ICF, disability is a compound phenomena in which social and individual elements are both integral.

The Structure and Components of the International Classification of Functioning, Disability and Health

The ICF organizes information in two parts. The first part deals with functioning and disability and the second part covers contextual factors. It is emphasized that a person’s functioning and disability are conceived as dynamic interactions between health conditions and contextual factors.

Components of functioning and disability are divided in a Body functions and Body structures component and an Activity and Participation component. Body functions are defined as the physiological functions of body systems. Body structures are defined as the anatomical parts of the body such as organs, limbs, and their components. Activity is defined as the execution of a task or action by an individual. Participation is defined by involvement in life situations. Activity and Participation are classified within a single list but coded with two qualifiers: the capacity qualifier and the performance qualifier. The capacity qualifier describes an individual’s ability to execute a task or an action in a uniform or standard environment. The performance qualifier describes what an individual does in his or her current environment. The ICF states that performance can be understood as “involvement in a life situation” or “the lived experience” of persons in the actual context in which they live (i.e., participation), as the current environment brings in a societal context (WHO, 2001 p. 229).

Components of contextual factors are divided into Environmental factors and...
Personal factors. Environmental factors are defined as those factors that make up the physical, social, and attitudinal environment in which persons live and conduct their lives. These include factors involved in both immediate (e.g., products and technology for mobility) and more distant environments (e.g., social attitudes, system, and policies) that might have an impact on a person’s functioning. Environmental factors are said to have an impact (i.e., facilitating or hindering) on all components of functioning and disability. Personal factors are so far not classified in the ICF. The components of the classification are illustrated in Figure 1.

The Use and Function of the International Classification of Functioning, Disability and Health

The ICF is used for a variety of purposes such as health outcome research, population surveys, and as an organizational basis for social policy (Imrie, 2004). Professionals within health care and social welfare have also started to use the classification and incorporate the ICF’s view of health (Heerkens, Van der Brug, Napel, & Van Ravensberg, 2003; Stucki, Ewert, & Cieza, 2002). It provides a possibility of a common and shared understanding of disability as well as a language that is multidisciplinary. Moreover, the current ICF, unlike the former ICIDH, provides an understanding of disability that at least in part is in agreement with the views of persons in the disability rights movement (Hurst, 2003). This in turn may increase the opportunities for successful cooperation between client organizations, health care professionals, and other sectors.

For occupational therapy, one value of the ICF is that it does call attention to the connection between health and occupation. The ICF’s definition of participation as involvement in life situations points to an understanding of health that incorporates a relationship between people’s daily life and health. On a conceptual level this perspective has similarities with assumptions in occupational therapy regarding how occupations influence people’s health (Kielhofner, 2002; Law, 2002; Wilcock, 2003; Wilcock & Townsend, 2000; Yerxa, 1998a).

Contemporary Discussions Regarding the International Classification of Functioning, Disability and Health

Disability researchers have also pointed out that the ICF is far from a finished product. They argue that parts of its theoretical and philosophical foundations require amplification and clarification (Imrie, 2004; Molin, 2004; Nordenfelt, 2003). Key critical discussions of the ICF are noted below.

The ICF continues to be subject to criticism within the disability studies and disability rights communities. For example, the labeling function of the ICF as a classification system has been widely criticized in the disability literature (Barnes et al., 2000). According to the disability studies perspective, the medical community's practice of classifying people has historically contributed to the stigmatization and oppression of persons with disabilities.

Imrie (2004) criticizes the theoretical and conceptual underpinnings of the ICF for a lack of clarity. For example, he argues that although “biopsychosocial” theory is at the heart of the ICF, this has not been made explicit. Moreover, little is known of its operational or practical utility. The lack of theoretical clarity in turn, he argues, may lead to different interpretations of the ICF’s theoretical and conceptual content by practitioners.

Several writers have noted that the subjective dimension of functioning is missing in the ICF (Ueda & Okawa, 2003; Wade & Halligan, 2003). Wade and Halligan recommended an additional subjective or internal part to include the personal (i.e., role satisfaction and happiness) as well as the environmental factors (i.e., salience and local culture). Ueda and Okawa argue that the understanding of the inner world of the client has proved a great asset in clinical practice and thus needs to be included in the ICF. They argue that several dimensions of life satisfaction should be integrated in the ICF.

Perenboom and Chorus (2003) have raised the issue whether participation can be assessed truthfully without taking into account person-perceived participation. According to these authors the best judge of participation is the respondent rather than the professional. Wade and Halligan (2003) note that the ICF still lacks a positive terminology in relation to impairment and disease. Furthermore, they argue that besides the social, physical, and personal context, as proposed by the ICF, a fourth context, time, is needed to complete a description of someone’s illness.

Nordenfelt (2003) argues that the notions of activities and participation in the

Figure 1. Interactions between the components of the International Classification of Functioning, Disability and Health (WHO, 2001, p. 18).
ICF partly rest on confusion between capacity for action and actual performance. He specifically highlights that every task is performed in an environment and cannot be anything peculiar to performance as interpreted in the ICF.

So far critical discussions in occupational therapy literature are rare. Haglund and Henriksson (2003) aimed to clarify similarities and differences between concepts in two commonly used occupational therapy assessments and the ICF. The conclusion made was that although the ICF can serve as a useful tool it is not sufficient as a professional language for occupational therapists (Haglund & Henriksson). A study concerning school assistants’ influence on participation for students with disabilities found several aspects of participation not captured in the ICF (Hemmingsson, Borell, & Gustavsson, 2003). The limitations of the concept of participation in relation to students with disabilities, and assessment problems related to participation have also been discussed by Hemmingsson (2002).

An Occupational Perspective on Participation in the International Classification of Functioning, Disability and Health

In this paper an occupational perspective refers to a body of knowledge developed in the literature of occupational therapy. The essence of the concept of occupation is people's doing, formulated in a position paper about occupation as “the ordinary and familiar things that people do every day” (Christiansen, Clark, Kielhofner, & Rogers, 1991; Yerxa, 1998b). Occupational form refers to the form and nature of the occupation, the conditions external to the person that are derived from the culture and the context in which the occupation is performed (Nelson, 1988, 1996).

The person goes into this occupational form with her or his capabilities and with a purpose (which refers to the goal of the occupational form) and a meaning (which refers to the broader existential aspect of the occupational form for the individual) (Nelson, 1988, 1996). A person’s motivation, interests, and habits also play an important role (Kielhofner, 2002). The output of this interaction between the occupational form and the person is occupational performance, what we commonly observe as a person doing something. In occupations people can develop a mastering and enabling experience that builds a base for self-determination and autonomy. Occupational performance is seen as a process that interacts not only with itself (i.e., people develop their skills by performing the occupation) but also with other performed occupations and the social, physical, and cultural contexts in which the occupation is performed (Kielhofner).

In summary, an occupational perspective focuses on the ordinary things that people do and occupational aspects of importance for health and development. Important aspects of an occupational perspective are:

- The subjective experience of meaning
- The subjective experience of autonomy and self-determination
- The complex interrelationships between different kinds of occupations

When scrutinizing the ICF’s concept of participation, these aspects of the occupational perspective will be addressed.

The International Classification of Functioning, Disability and Health’s Exclusion of the Subjective Experience of Meaning

The International Classification of Functioning, Disability and Health’s Exclusion of the Subjective Experience of Meaning

The first and probably most serious problem with the operationalization of participation in the ICF is the exclusion of the subjective experience of meaning. Conceptually, participation is first described in a promising way as “involvement in a life situation” or “the lived experience” of people in the actual context where they live (WHO, 2001 p. 229). As mentioned earlier, Activity and Participation are coded from the same list with two qualifiers: capacity and performance. Whereas capacity mainly refers to the individual’s ability to execute a task, the performance qualifier describes what an individual is observed to do in his or her current environment (the outsider’s view). It is noted in the ICF that the definition of participation brings in the concept of involvement and that some proposed definitions of involvement incorporate taking part, being included, or being engaged in an area of life (the insider’s view). Nevertheless, the ICF comes to the conclusion that the only possible indicator of participation is coding through performance. Thus, participation is operationalized as a person’s observed performance. The result in the classification of participation is that the person’s subjective experience of meaning is not included. This conclusion is supported in literature analyzing the ICF (Hemmingsson, 2002; Perenboom & Chorus, 2003; Ueda & Okawa, 2003; Wade & Halligan, 2003). Consequently, with this conceptualization it will only be possible to categorize and measure participation by examining the type of indicators that are observable from the outside and not by addressing the person's own subjective experience.

From an occupational therapy perspective, the ICF’s exclusion of the subjective experience of meaning is a major shortcoming. Over the last 20 years occupational therapy literature and theory has progressed from focusing on performance components to emphasizing the person’s subjective experience of participation in daily life. An example of this is the development of assessments that address the person’s subjective experiences of occupations such as the Canadian Occupational Performance Measure (COPM) (Law et al., 1994), the Occupational Performance History Interview (OPHI) (Kielhofner et al., 1997), and the School Setting Interview (SSI) (Hoffman, Hemmingsson, & Kielhofner, 2000). From an occupational perspective it could be argued that a person’s experience of meaning in an occupation is a key factor.
in the context of health. Results from observed performance do not automatically mean that a person experiences participation in an occupation. For example, by observing a person watching television we gain limited knowledge of this person's active involvement and engagement in the occupation. Research in occupational therapy has demonstrated that there is a risk of either underestimating or overestimating participation by taking into account only the outsider's view. For example, a study from a nursing home demonstrated that severely disabled elderly persons could experience participation in the absence of any observation of performance (Van't Leven & Jonsson, 2002). In the analyses it was concluded that being in the atmosphere of doing could be experienced as having the same quality as actually doing. This was obvious also for the participants themselves. For example, one expressed: "Yes, I think I do a lot and I do nothing" (Van't Leven & Jonsson, p. 151). An other ethnographic study regarding participation in school used several methods in data collection (Hemmingsson et al., 2003). Using observational methods, high-performance opportunities in the classroom for the student with disabilities were evaluated. When the student was asked about her subjective experience it was found that she experienced problems in participation due to the fact that the student prioritized social participation before optimal opportunities for participation in schoolwork.

Thus, the exclusion of the subjective experience of meaning in the ICF's operationalization of participation is a major shortcoming. In agreement with other literature (Molin, 2004; Perenboom & Chorus, 2003) it could be questioned if it is even possible to talk about participation without including the person's subjective meaning. The ICF's definition of participation might more correctly be named as observed performance in its natural context.

The Exclusion of the Subjective Experience of Autonomy

The second issue related to the ICF's definition of participation regards the lack of emphasis on people's opportunities to influence their daily lives and make decisions about personal questions (here labeled as autonomy). This is an aspect of participation that often is put forward in the disability literature and by client organizations as well as from individual persons with disabilities (Barnes et al., 2000; Duncan & Brown, 1993; Swain et al., 1994). It is also emphasized in legal documents in order to increase equal opportunities for persons with disabilities (Asheim, 1999; Brownlea, 1987; Lewin, 1998). The aspect of autonomy and self-determination could also be seen as having an objective and a subjective side. The objective side regards the society and its legislation and organization. Persons with disabilities do not always have the legal rights or formal opportunities to participate in daily occupations. For example, a disabled student might not have the same opportunities to choose schooling as a student without disabilities. The lack of legal rights to assistance may also decrease the autonomy of persons with disabilities significantly and also decrease opportunities to participate in social life (Duncan & Brown, 1993). Regarding these objective aspects, the ICF is suitable to address and classify different aspects with the use of the environmental factors. The subjective aspect regards the person's experience of autonomy and self-determination. Like a person's subjective meaning of an occupation, this aspect of participation is not easily observed. This issue is not addressed in the ICF and the classification of these issues will therefore be focused exclusively on the objective parts of autonomy.

From an occupational perspective this is another shortcoming in understanding participation. The point is that what people are observed to do in life (operationalized as participation in the ICF) is not necessarily what people wish to do or choose to do. They may be under pressure or they may do things because no other options are available for persons with disabilities. Self-determination and autonomy are stressed as important factors for experiencing participation in occupation. For example, the turn to a more client-centered practice in occupational therapy (Law, 1998; Law, Baptiste, & Mills, 1995; Pollock, 1993) has its basis in the recognition of the importance of the subjective experience of autonomy and partnership in an effective therapeutic relationship. Human rights for persons with disabilities include autonomy and self-determination. If this aspect of participation is ignored, the risk is obvious that the meaning of participation is different for persons without disabilities than it is for persons with disabilities. Thus, the exclusion of the subjective experience of autonomy in the ICF is a shortcoming that ignores the importance of autonomy as an important part of the participation concept.

Limitations in Capturing Different Kinds of Participation in a Single Person's Life Situation

The third problem we want to address concerns the complex relationship between different kinds of participation in a single life situation. With the ICF it is possible to classify the degree of participation in different areas such as mobility, self-care, and major life areas. For each component of functioning, environmental factors shall be considered and coded accordingly. Environmental factors are said to be either facilitators or barriers for participation. It is noted that an environmental factor may be a barrier either because of its presence or its absence and that an environmental factor may be a barrier for one person but at the same time a facilitator for another (WHO, 2001). These statements are important and in line with the occupational therapy literature, although somewhat limited. In current discussions in occupational therapy as well as in other literature about the environment (Cutchin, 2004), emphasis is placed on the environment being closely integrated within the individual as well as within the occupation. However, the most important shortcoming in the ICF is the one-dimensional view on environmental factors as either facilitators or barriers for participation that in turn will decrease or increase the person's participation in a certain life situation.

An occupational perspective addresses parts of the environment as complex phenomena that play several and sometimes-incongruous roles (Kielhofner, 2002). An environmental factor may be a facilitator and a barrier at the same time for the same person. For example, research has demonstrated that a school assistant may facilitate academic participation and at the same time be a hindrance for social participation.
(Hemmingsson et al., 2003). This points to the importance of recognizing that a single life situation may involve different kinds of participation. For example, it may emphasize academic participation versus social participation in school. With this limitation the ICF’s conceptualization tends to be unidimensional with limited possibilities to capture the dynamics in the concept of participation. The ICF’s concept regarding environmental facilitators or barriers in a life situation may simplify an often complex and incongruous relationship where several types of participation might be involved in a single life situation.

To summarize the occupational perspective on participation in the ICF, it has been argued that the operationalization of participation, as observed performance, is too limited to fully understand participation. The performance aspect is one relevant aspect but not enough to give a comprehensive picture of participation defined in the ICF as involvement in life situations. The subjective experience has to be added, especially in the following two dimensions:

- The experience of meaning in connection to participation in a life situation
- The experience of autonomy and self-determination

Furthermore, the ICF’s view fails to recognize that one life situation may involve different kinds of participation and fails to acknowledge the complex aspect of environmental influences on participation. A comprehensive view of environmental influence has to recognize that different kinds of participation can appear in a single life situation and that environmental factors at the same time can be both barriers and facilitators for participation.

Discussion

The current version of the ICF represents an important step forward to a more integrated view on health. The progression from a disease orientation focused on the body to a health orientation where the person is placed in an environment and involved in life situations represents a major shift in the view on health. The ICF’s definition of participation as involvement in life situations points to an understanding of health that incorporates a relationship between people’s daily life and health. On a conceptual level this perspective has similarities with assumptions in occupational therapy regarding how occupations influence people’s health (Kielhofner, 2002; Law, 2002; Wilcock, 2003; Wilcock & Townsend, 2000; Yerxa, 1998a).

The ICF is an internationally recognized model that aims to have influence on the health care systems and social policies in different countries. Occupational therapy should use this model to get support for an occupational perspective. Participation in the ICF, defined as involvement in a life situation, connects very closely to the relationship between occupation and health. In community and government health planning these aspects have to be addressed. In rehabilitation, systems of care must include the concrete life situations in which a client is involved. The strong emphasis on the environmental influences in the ICF gives support to occupational therapy interventions focused on environmental change (Kielhofner, 2002; Law, 1991). This focus of intervention also corresponds to demands from the disability rights movement of environmental change to create an inclusive society (Barnes et al., 2000; Bickenbach, Chatterji, Badley, & Ustun, 1999; Swain et al., 1994).

One of the ICF’s strengths is that is has both the micro- and macroperspective on the environmental influences on health. This suggests that occupational therapy might consider broadening its conceptualization of the environment. Many occupational therapy models and theories have a tendency to be too focused on the individual’s immediate environment without enough consideration for the macro levels of the environment such as social policies, structural organization, etc. For example, the emerging debate about occupational justice (Whiteford, 2000; Wilcock & Townsend, 2000) is consistent with the macro perspective of the ICF.

As pointed out in the analysis, a major shortcoming in the ICF is the exclusion of the subjective experience regarding participation. This could have serious consequences in terms of how to assess participation. Measurements and evaluations might become only objectively focused, and by that they miss an important aspect of participation. Occupational therapy has to have a principal and critical standpoint on this issue and argue that, for example, our concept of occupation and the assessment we develop are not equivalent with the concept of participation as defined by the ICF. Referring to the contemporary debate about the ICF, this critique is also shared by others (Perenboom & Chorus, 2003; Ueda & Okawa, 2003). Additionally, disability theorists have long criticized the health professions for defining the needs of persons with disabilities without taking into account their experiences (Barnes et al., 2000; Swain et al., 1994).

From a historical perspective we can see that the ICF is an international document in development. It is and will be discussed and criticized from different points of views for years to come. These discussions will be valued and eventually incorporated into new versions. It is essential that an occupational perspective is visible in this discussion. We would argue that occupational therapy has a special responsibility to take an active part in the development of knowledge with special emphasis on people’s participation in daily life. Occupational therapy has been studying the relation between people’s health and daily occupations, including environmental influences, for many years and is therefore a valuable partner in the international discussion. We thus have an obligation to contribute to the development of the classification.

It is interesting to draw a parallel with occupational therapy’s own paradigmatic development and the critique we have presented regarding participation in the ICF. Only a few decades ago occupational therapy was dominated by a medical perspective that focused on objective measurable performance components. In the discussion that followed, the field recognized that this perspective was insufficient to effectively support clients to regain health in their daily occupations. We had to listen to their experiences and understand their daily living contexts. We had to build partnerships with our clients that allowed them to experience mastery and self-determination. Interestingly, similar arguments are part of the discussion of the ICF (Perenboom & Chorus, 2003; Ueda & Okawa, 2003).
Wade & Halligan, 2003). Occupational therapy will do well to reflect on its own historical journey when we take part in discussions driving the future development of the ICF.

References


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