International Encyclopedia of Rehabilitation

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This publication of the Center for International Rehabilitation Research Information and Exchange is supported by funds received from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133A050008. The opinions contained in this publication are those of the authors and do not necessarily reflect those of CIRRIE or the Department of Education.

Social Participation

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Setting the context – From institutional exclusion to social participation

In the disability field, the concepts of 'participation' and 'social participation' have been made necessary since the 1990s in order to designate the terms and conditions of the performance of activities of daily living of an individual or a population within their life environment. The emergence of these concepts arose from the dynamics of various ideological changes. These concepts have justified a shift from the perspective of segregation, protection and special needs for people with body, function and behavior differences deemed deviant from normal standards or threatening for the surrounding community to one of exercise of fundamental human rights regardless of individual features.

Initiated in the Scandinavian countries at the beginning of the 1960s in direct response to the human rights infringements and the World War II concentration camps, the normalization movement questioned institutional settings excluding individuals with mental health problems or intellectual disabilities and also individuals with severe motor or sensory disabilities (Nirje, 1985; Wolfensberger, 1979). This new ideology developed by professionals working with these populations promoted the deinstitutionalization and implementation of organized services facilitating their community reintegration and the performance of activities and social roles that were the most similar to those valued in their social and cultural environment. Social integration policies for persons with disabilities began to be developed, which resulted in providing housing resources, educational services and sheltered or accommodating workplaces integrated to the community.

During the 1980s and 1990s, however, several criticisms led to the realization that physical integration in the life environment in educational or job settings was not sufficient and most often did not provide opportunities to these individuals to actually interact with the population within regular infrastructures and services and to perform the activities of their choice in environments attended by people of their age or sharing common interests (Flynn, 1994). As a result, the concept of community-based integration was developed, which made direct references to the active contribution of these persons as community members in activities normally valued by the overall population and in positive interactions with others (McColl, 2001; Thorn S. et al., 2009; Ware N.C, 2007).

Such a way of thinking is at the core of another complementary, parallel movement—the Movement for Independent Living (ILM). In contrast with movements of normalization and valorization of social roles supported by professionals and families for and on the behalf of managed individual with disabilities, the ILM was initiated by young people with motor or sensory disabilities who wished to emancipate beyond the control exerted

by professionals on their life. Therefore, this is a movement gathering the persons with disabilities themselves, aiming at the self-management of their support or transportation services, a kind of self-help based on peer expertise and experience and on promoting self-determination. The ILM is closely related to the social model of disability according to which environmental factors of physical nature such as architectural barriers in the urban environment, transportation infrastructures, as well as social factors such as the inadequacy of policies and services, and stigmatizing attitudes and beliefs are the primary sources of oppression and social exclusion for people with disabilities (Oliver, 1990, 1996). For the ILM, the presence and severity of the impairments and disabilities are secondary. The focus is rather put on the empowerment of each individual to control their life, on their involvement in decision-making processes as citizens, and the development of services and life settings giving opportunities for the true exercise of their human rights. The ILM is part of the more general disability advocacy movement, which chose to embrace the following slogan at the international level: "Nothing about us without us." (De Jong 1979; Ravaud, 2001)

Setting the socio-historical context shows that 'participation' or 'social participation' are concerned with people's actions and not with what we do to them or with a policy direction of organized services or environmental accommodation of individuals that are contributing to society. This is to be differentiated from social integration concerned with setting the context and what is done to these individuals.

Finally, the concept of social integration generally means that individuals with special features or differences are generally placed in a standard context without involving that this context is mandatorily transformed by this integration process. However, with the perspective of acknowledging equal human rights for all, including persons with disabilities, the notion of inclusion is increasingly used. Yet, it should be specified that inclusion as well as the former social integration are the expected features of the physical or social environment in which—in a more radical way with the concept of inclusion—persons with disabilities are considered in order to achieve the universal design giving everyone access to equal social participation. It is therefore appropriate to speak of an inclusive approach. 'Integration' and 'inclusion' are not synonyms of 'participation,' but these notions may be considered as quality indicators of the environmental factors determining the quality of social participation of populations with diversified personal features.

A construct deemed critical, yet not fully established at the international level

The concept of participation was introduced with the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) as a positive term substituting the term 'handicap' used in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (WHO 1980). Participation is defined in the ICF as "involvement in a life situation." As such, it is different from the concept of 'activity', which has replaced the concept of 'disability' and is defined as "the execution of a task or action by an individual." 'Activity and participation' refers to a unique taxonomy (see Appendix 1). The distinction is achieved by a qualifier and a type of specific environment. 'Activity'

designates the capacity of a person to accomplish a task in a standardized environment, and 'participation' refers to realization performance of the same task in real life environment. The ICF provides users with four options giving various opportunities of distinguishing, or not, between the taxonomic categories as pertaining to 'activity' or 'participation' fields (Rauch et al., 2010). The issue of lack of clarity in the concepts of 'activity and participation', which are not readily defined as mutually exclusive constructs, although this possibility is provided to users with the first option, is certainly one of the major criticisms against the ICF in the current scientific literature (Jette et al. 2003; Imrie, 2004; Institute of Medicine, (2007), Badley, 2008; Whiteneck and Djikers 2009).

Many suggestions were made to work according to option 1 of mutual exclusivity. Distinction is then made between what refers to the intrinsic ability of the individual to perform an action or simple activity and the performance of social, meaningful activity in given settings. These discussions are still extremely controversial, such as they also were at the end of the ICIDH revision process with the Beta 2 testing version (WHO 1999) when they justified the compromise that was worked out by the WHO with the ICF (Ravaud and Fougeyrollas, 2005; Levasseur et al. 2007).

Two current opportunities given to identify life situations pertaining to 'participation'

The first opportunity is closely related to the traditional knowledge of rehabilitation, which tends to consider activities of daily living (ADLs) and instrumental activities of daily living (IADLs), such as self-care, eating, dressing, and preparing meals as tasks performed by the individual independently and depending upon his functional capabilities. The activities requiring interaction with others and generally encompassed in the notion of social roles are also considered as being related to 'participation', as are the activities related to family, education, work, leisure and civic responsibility roles. (Whiteneck and Djikers, 2009; Mars G.M.J. et al., 2009).

The second opportunity is related to the concepts of the Quebec Classification: Disability Creation Process (QCDCP) (Fougeyrollas et al., 1998). This classification makes a mutually exclusive distinction in which capability is defined as "the potential of a person to accomplish physical or mental activities" and life habit as "a daily activity or social role valued by the person or his/her sociocultural context according to his/her characteristics (age, sex, sociocultural identity, values), which ensure his/her survival and well-being in his/her society throughout their lifetime."

Within this conceptualization, social participation reflects the performance of life habits. As such, it encompasses all the activities for which modalities of performance are socially constructed (see Appendix 2). Thus, they include both daily activities related to ADLs and IADLs and social roles. This highlights the fact that the activities related to nutrition, excretory hygiene or dressing are mandatorily of situational nature and defined by the social environment and its interaction with personal factors, including body systems, capabilities and personal identity factors at a given moment of life. Social participation components are then defined based on their social construct and no longer

based on a distinction between activities that can be performed independently and those that involve interaction with others (Plante et al. 2010; Mc Conachie et al., 2006; Anaby et al., 2008).

Qualifiers of participation or social participation

As previously mentioned, the ICF uses only performance to qualify the level of involvement of individuals in life situations. On the other hand, the QCDCP refers to the quality of performance of life habits that may be measured on a continuum ranging from full social participation to full disabling situations. The level of difficulty, level of human assistance, use of technical aids and need for physical or performance modality accommodation, such as allowed time and frequency, may be combined to these performance or achievement qualifiers. These can be operationalized quantitatively or qualitatively depending on the tool that is used. In addition, it is also possible to include in the assessment of the quality of social participation some specific qualifiers for the measurement of the subjective perceptions of concerned individuals, such as satisfaction, choice opportunity, and level of control, which all directly refer to notions of independence, empowerment and self-determination.

Virtually unavailable in the 1990s, there are currently a growing number of measurement tools assessing social participation that have either a general scope or aim at a specific population, with a perspective of quantitative or qualitative objectives as a result of the individual/environment interaction (Fougeyrollas et al., 1999; Desrosiers et al., 2004; Gray et al. 2006; Pinsonneault et al., 2007; Noonan et al., 2009; Brown et al., 2004; Anaby et al., 2008). There are also other tools related to these social participation measurements, such as tools for measuring community integration, which generally focus on active participation in three areas of living, that is independent living, social and recreational activities, as well as income-earning activities (McColl, 2001; Sander et al., 2010; Yasui and Berven, 2009).

Conclusion

The concepts of ‘participation’ and ‘social participation’ are increasingly acknowledged as the result of the individual/environment interaction. They refer to a historical and cultural life situation or series of life situations. They can be applied to both individuals or populations and share the conceptual dimensions of the system of human functioning (related to health conditions) (ICF) or human development (related to the anthropological perspective of non specific health conditions) (QCDCP). These concepts are universal and can be applied to any human being who is socially constructed as a person. In contrast with the anatomical, physiological and psychological dimensions, their conceptual boundaries between what intrinsically belongs to the potential of a person and life situations or habits are still not fully established at the international level.

Therefore, it is not too difficult to predict that the achievement of a mutually exclusive conceptualization, the inclusion of activities of daily living and instrumental activities of daily living as a dimension of personal or participation factors, and the standardization of quantitative and qualitative measurement tools will operate a true shift of paradigm in the field of disability studies, both in establishing and measuring the outcome of habilitation

and rehabilitation and measuring the outcomes of physical and social accommodations of the environment with respect to the implementation of the Convention on the Rights of Persons with Disabilities (2006).

Relating the quality of social participation with the quality of the exercise of human rights provides a promising perspective to definitely dismiss concepts that are still identifying personal features in standardized settings as being responsible for restrictions of participation in social activities.

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Appendices: Taxonomies of the International Classification of Functioning, Disability and Health (ICF) and Quebec Classification: Disability Creation Process (QCDCP)

Appendix 1: Taxonomy of Activities and Participation Included in the ICF (WHO, 2001)

1. Learning and applying knowledge
2. General tasks and demands
3. Communication
4. Mobility
5. Self-care
6. Domestic life
7. Interpersonal interactions and relationships
8. Major life areas
9. Community, social and civic life

Appendix 2 : Taxonomy of Life Habits Included in the QCDCP (Fougeyrollas et al., 1998)

Daily Activities

1. Nutrition
2. Fitness
3. Personal care
4. Communication
5. Housing
6. Mobility

Social Roles

1. Responsibility
2. Interpersonal relationships
3. Community life
4. Education
5. Employment
6. Recreation